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## Do Breast Cancer Survivorship Care Plans Improve Health Outcomes?

Steven S. Coughlin<sup>1,2,\*</sup>, Lee Caplan<sup>3</sup>, Jessica Lynn Stewart<sup>4</sup>, and Lufei Young<sup>5</sup>

<sup>1</sup>Department of Population Health Sciences, Medical College of Georgia, Augusta University, Augusta, GA

<sup>2</sup>Research Service, Charlie Norwood Veterans Administration Medical Center, Augusta, GA

<sup>3</sup>Morehouse College of Medicine, Department of Community Health and Preventive Medicine, Atlanta, GA

<sup>4</sup>College of Allied Health Sciences, Augusta University, Augusta, GA

<sup>5</sup>College of Nursing, Augusta University, Augusta, GA

### Abstract

Although they have been widely studied, important questions remain about the impact of breast cancer survivorship care plans on improving health outcomes. The goal of this article was to review published studies on the impact of cancer survivorship care plans on health outcomes and health care delivery among breast cancer survivors. A total of 111 article citations were identified in PubMed and non-duplicates in CINAHL. After screening the abstracts or full texts of these articles and reviewing the references of previous review articles, 7 studies met the eligibility criteria. All of the studies had a randomized controlled design. Early trials of the efficacy of breast cancer survivorship care plans generally showed little or no improvement in health outcomes. The positive findings of recent studies suggest that survivorship care interventions that empower and activate patients to self-manage their follow-up care and improve patient-provider communication may be especially promising.

### Keywords

Breast Cancer Survivors; Cancer Survivorship Care Plans

### Introduction

Since the Institute of Medicine report “From Cancer Patient to Cancer Survivor: Lost in Transition” was published in 2006<sup>1</sup>, cancer survivorship care plans have been widely

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\*Correspondence: Dr. Steven S. Coughlin, Professor, Division of Epidemiology, Department of Population Health Sciences, Medical College of Georgia, Augusta University, 1120 15th Street, AE-1042, Augusta, GA 30912, USA; scoughlin@augusta.edu.

Ethical Statement

This article does not contain any studies with human participants performed by any of the authors. The authors do not have control over any full data.

introduced in oncology. Previous follow-up guidelines for cancer survivors had been mainly restricted to surveillance for recurrence of the primary cancer<sup>2</sup>. An important point of the Institute of Medicine report was that survivorship care plans must be more comprehensive than those and address the chronic effects of cancer, monitor for late effects, and promote healthy lifestyles. The purpose of these plans is to help the growing number of cancer survivors deal with the challenges associated with cancer survivorship<sup>3</sup>. Survivorship care plans include a treatment summary and follow-up care plans. The treatment summary consists of details of the cancer diagnosis, including date of diagnosis and type, location, stage, and histology of the cancer, and a listing of the treatments that have been administered, including the names and contact information of the treatment providers and facilities as well as information about the treatments administered<sup>4</sup>. The follow-up plan contains specific recommendations, which should be based on published guidelines when available, for ongoing care and health promotional strategies. In 2015, the American College of Surgeon's Commission on Cancer's accreditation criteria for survivorship care were introduced<sup>5</sup>. The CoC criteria require that cancer centers provide survivorship care plans to patients completing primary cancer treatment with curative intent<sup>6</sup>. Nevertheless, important questions remain about the impact of cancer survivorship care plans on improving health outcomes<sup>7</sup>.

The goal of this article was to review published studies on the impact of cancer survivorship care plans on health outcomes and health care delivery among breast cancer survivors. Although there have been previous systematic reviews on cancer survivorship care plans<sup>7-10</sup>, none has focused specifically on breast cancer, and additional studies with positive findings have recently appeared in the literature.

## Methods

The present review is based upon bibliographic searches in PubMed and CINAHL and relevant search terms. Articles published in English from 1985 through October 1, 2018 were identified using the following MeSH search terms and Boolean algebra commands: breast cancer AND survivorship care plans. The searches were not limited to words appearing in the title of an article nor to studies in a particular country or geographic region of the world. The references of review articles were also reviewed<sup>7-10</sup>. Information obtained from bibliographic searches (title and topic of article, information in abstract, study design, and key words) was used to determine whether to retain each article identified in this way. Only studies written in English that examined the impact of breast cancer survivorship care plans on health outcomes were eligible for inclusion.

## Results

A total of 111 article citations were identified in PubMed and non-duplicates in CINAHL. After screening the abstracts or full texts of these articles and reviewing the references of previous review articles, we were left with 7 studies that met the eligibility criteria. All of the studies had a randomized controlled design. The main health outcomes included 1) disease progress outcomes (e.g., cancer recurrence rate); 2) patient outcomes (e.g., quality of life [QOL] or health related quality of life [HRQoL], activity limitation, self-efficacy, patient

activation, cancer-specific distress, level of depression and anxiety, and 3) health service measures (e.g., guideline adherence, patient satisfaction, continuity and coordination of care, etc).

Grunfield et al.<sup>11</sup> conducted an 18-month randomized controlled trial (RCT) comparing routine follow-up either in the hospital or in general practice. A total of 296 women with stage I-III breast cancer in remission were enrolled in the trial. The median time to hospital confirmation of recurrence was 21 days in the hospital group and 22 days in the general practice group. No significant differences were observed across groups in quality of life (QOL) or mean anxiety score. The change from baseline in mean depression score was higher in the general practice group.

Grunfeld et al.<sup>12</sup> conducted a RCT comparing follow-up in a cancer center according to usual practice with follow-up by the patients' own family physician. A total of 968 women with early-stage breast cancer who had completed adjuvant treatment, were disease free, and were between 9 and 15 months after diagnosis were enrolled in the trial. In the family physician group, there were 54 recurrences of breast cancer (11.2%) and 29 deaths (6.0%). In the cancer center group, there were 64 recurrences (13.2%) and 30 deaths (6.2%). In the family physician group, 17 patients (3.5%) experienced a serious cancer-related clinical event compared with 18 patients (3.7%) in the cancer group. There were no significant differences across groups in health-related QOL.

Grunfield et al.<sup>13</sup> conducted a 12-month RCT comparing two groups: 1) those who received a survivorship care plan which was reviewed during a 30-minute educational session with a nurse, and 2) those who received guidelines on follow-up by the patient's primary care physician. The primary outcome of interest was cancer-related distress. Secondary outcomes included QOL, patient satisfaction, continuity/coordination of care, and health service measures. A total of 408 women with early-stage breast cancer who had completed primary treatment at least 3 months previously were enrolled in the trial. There were no significant differences between groups in cancer-related distress or any of the patient-reported secondary outcomes. More patients in the nurse-led educational session intervention group than the control group correctly identified their primary care physician as primarily responsible for follow-up (98.7% vs. 89.1%,  $P=0.005$ ).

Hershman et al.<sup>14</sup> conducted a 6-month RCT comparing a survivorship intervention (receipt of NCI publication "Facing Forward: Life after Cancer Treatment", meeting with a nurse/nutritionist, and receipt of a treatment summary and surveillance and lifestyle recommendations) with a control group. A total of 126 women with early-stage breast cancer were enrolled in the trial. There were no significant differences between groups in patient satisfaction or impact of cancer scale. However, the intervention group had lower scores on cancer worry ( $P=0.02$ ).

In a 24-month RCT comparing an intervention group which received a survivorship care plan with a control group that included a total of 408 patients with early-stage breast cancer, Boekhout et al.<sup>15</sup> found no differences between groups in health service and patient-reported outcomes. This is the same study as Gruenfeld et al. (13) but the follow-up was longer. The

outcomes included cancer-specific distress, health-related QOL, patient satisfaction, continuity and coordination of care, and health service outcomes such as adherence to guidelines.

Kvale et al.<sup>16</sup> conducted a RCT comparing the Patient-owned Survivorship Transition Care for Activated, Empowered survivors (POSTCARE) intervention to usual care. The POSTCARE intervention included a single motivational interviewing encounter in which the coach assisted patients with completion of their treatment summary and identification of health goals (cancer follow-up, other health issues, healthy habits, symptom improvement). Compared with those receiving usual care, participants in the intervention group had significantly higher self-reported health ( $p=0.017$ ) and lower social role limitations ( $P=0.014$ ) and a trend towards greater self-efficacy ( $P=0.07$ ). Three QOL domains (physical role, bodily pain, and emotional role) showed improvement and significant between group differences at the 3-month follow-up.

Maly et al.<sup>17</sup> conducted a RCT comparing usual care with a survivorship care nurse counseling session combined with the provision of individualized treatment summaries and survivorship care plans to patients and their health care providers. A total of 212 low-income, predominantly Latina breast cancer patients with stage 0-III disease were enrolled in the trial. Participants in the intervention group reported greater physician implementation of recommended breast cancer survivorship care (e.g., treatment of depression or hot flashes) than did those in the control group.

## Discussion

This comprehensive review of the impact of survivorship care plans (SCPs) has focused on breast cancer survivors with a broader scope than previous reviews. The outcomes focused on three domains: cancer progress, patients' health outcomes and health services outcomes.

There are inconsistent results about the impact of SCPs among 7 randomized control trials, which could be caused by the following issues with respect to study design and intervention delivery. First, the selected outcomes (e.g., patient reported health state and perceptions of health services) are not likely to be affected by SCPs alone over a short time period. Therefore, these studies produced statistically non-significant findings. The studies reporting significant findings used the outcomes what are sensitive and responsive to care management type of interventions, such as depressive symptoms, cancer worry, and quality of life. However, for any specific outcomes, there was only one study with significant findings. In addition, there was little consistency in outcomes being assessed and the measurements used to assess the same outcome. All studies except one study reported the significant effect of SCPs on health services outcomes. Again, the outcomes selected to evaluate health services (e.g., guideline adherence, continuity and coordination of care) require system level of intervention over a long period of time. It is less likely that short term impact of SCPs will be seen on these health services outcomes. As a result, the lack of consistent significant findings across studies limits generating strong evidence about the effects SCPs on cancer progression, patient-reported outcomes and health service outcomes. For future research in this field, we recommend selecting the appropriate outcome measures

that are likely to be sensitive and responsive to SCP interventions. Jacobsen suggested using more proximal outcomes, such as patient and provider knowledge, patient-provider communication quality, understanding of care provider roles in follow-up care<sup>7</sup>. Adopting these proximal and process measures will help future studies capture the impact of SCPs.

Second, there was great variation across studies in the design and delivery of SCP interventions. There was great inconsistency regarding intervention dosing, duration, delivery frequency, deliver mode and format. Compared to previous negative studies, recent RCTs conducted by Kyale et al.<sup>16</sup> and Maly et al.<sup>17</sup> added new strategies to maximize the impact of SCPs, therefore, generating significant results and improved health outcomes in breast cancer survivors. In the study by Kyale et al.<sup>16</sup>, the POSTCARE intervention, which was informed by the Chronic Care Model of Wagner, included a single motivational interviewing encounter in which the coach- assisted patients with the completion of their treatment summary and identification of health goals. Survivorship care interventions that empower and activate patients to self-manage their follow-up care and improve patient-provider communication may be especially promising. The study by Maly et al.<sup>17</sup> included a 1-hour one-on-one counseling session with a survivorship care nurse combined with the provision of individualized treatment summaries and survivorship care plans to patients and their health care providers. The survivorship care plan was also adapted for low-literacy and Spanish-speaking populations. Participants were coached to write down their three most important questions for their physicians as a way of increasing patient empowerment. The women practiced role playing discussions with their physician and asking for implementation of survivorship care recommendations with their physicians. From Kyale and Maly's studies, we learned that SCPs alone are unlikely to be effective if there are no additional mechanisms to ensure adequate follow up care. Furthermore, we noticed significant difference in terms of the follow-up data collection on intervention effects across studies. Given the limited evidence drawn from existing studies, we recommend that the future focus should focus on improving the methodology quality of randomized control trials, developing guideline in conducting experimental studies in this field, and utilizing common measures and instruments to assess SCP effects in cancer patients. A further issue is that the study by Grunfield et al.<sup>13</sup> was conducted more than 20 years ago and the results may not be comparable to those of more recent studies.

Our review found limited evidence about the impact of SCP on patients' outcomes or health service outcomes. However, it is premature to conclude that SCPs are ineffective considering small numbers of studies with great heterogeneity in study design, intervention mechanism and deliver, and outcome measures. The IOM report recommends the use of SCPs to improve patient's cancer treatment experience and provide guidelines for the patient and provider<sup>18</sup>. Calls for the development and wide-spread dissemination of survivorship care plans have been accompanied by expectations that there will be improvements in the understanding of survivors of their cancer treatment, potential late effects, and follow-up care recommendations<sup>19</sup>. However, practitioners increasingly recognize that there are remaining challenges, for example, the optimization of the survivorship care planning process and the adoption of more tailored and coordinated care<sup>19</sup>.

Salz et al.<sup>20</sup> surveyed National Cancer Institute (NCI)designated cancer centers about the extent to which survivorship care plans were in use. About 43% of NCI-designated cancer centers delivered survivorship care plans to their breast or colorectal cancer survivors. The percentage is likely higher today due to the CoC accreditation criteria. Klabunde et al.<sup>21</sup> examined physician roles in providing cancer-related follow-up care to cancer survivors using data from a national survey of primary care physicians. Over half of primary care physicians reported providing follow-up care for survivors and co-managing the care with oncologists. Far fewer oncologists reported co-managing follow-up care for survivors with primary care providers.

In conclusion, early trials of the efficacy of breast cancer survivorship care plans generally showed little or no improvement in health outcomes<sup>11, 13, 14, 15</sup>. Studies by Grunfeld et al. showed that outcomes were comparable when breast cancer patients received follow-up care by primary care physicians rather than specialists. Recent studies by Kvale et al.<sup>16</sup> and Maly et al.<sup>17</sup> suggest that survivorship care interventions that empower and activate patients to self-manage their follow-up care and improve patient-provider communication may be especially promising.

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**Table 1.**  
Studies of the impact of breast cancer survivorship care plans on health outcomes

| Author               | Design  | Outcomes   | Sample Size  | Results   |
|----------------------|---|--|--|---|
| Grunfeld et al. 1996 | 18-month randomized controlled trial (RCT) comparing routine follow-up either in hospital or in general practice  | Time to hospital confirmation of breast cancer recurrence; quality of life (QOL), depression score, anxiety score  | 296 women with stage I-III breast cancer in remission  | The median time to hospital confirmation of recurrence was 21 days in the hospital group and 22 days in the general practice group. No significant differences were observed across groups in QOL or mean anxiety score. The change from baseline in mean depression score was higher in the general practice group.  |
| Grunfeld et al. 2006 | RCT comparing follow-up in the cancer center according to usual practice vs. follow-up by their own family physician  | Rate of breast cancer recurrence-related serious clinical events. The secondary outcome was health-related QOL   | 968 women with early-stage breast cancer who had completed adjuvant treatment, were disease free, and were between 9 and 15 months after diagnosis | In the family physician group, there were 54 recurrences (11.2%) and 29 deaths (6.0). In the cancer center group, there were 64 recurrences (13.2%) and 30 deaths (6.2%). In the family physician group, 17 patients (3.5%) experienced a serious clinical event compared with 18 patients (3.7%) in the cancer group. There were no significant differences across groups in health-related QOL. |
| Grunfeld et al. 2011 | 12-month RCT comparing two groups: 1) receipt of a survivorship care plan which was reviewed during a 30-minute educational session with a nurse, and 2) receipt of the survivorship care plan and guidelines on follow-up by the patient's primary care physician  | The primary outcome was cancer-related distress. Secondary outcomes included QOL, patient satisfaction, continuity/coordination of care, and health service measures   | 408 women with early-stage breast cancer who completed primary treatment at least 3 months previously  | There were no significant differences between groups in cancer-related distress or any of the patient-reported secondary outcomes. More patients in the intervention group than the control group correctly identified their primary care physician as primarily responsible for follow-up (98.7% vs. 89.1%, $P=0.005$ ).   |
| Hershman et al. 2013 | 6-month RCT comparing survivorship intervention (receipt of NCI publication "Facing Forward: Life after Cancer Treatment", meeting with a nurse/nutritionist, and receipt of a treatment summary and surveillance and lifestyle recommendations) with control group   | Impact of cancer, patient satisfaction, and assessment of survivor concerns  | 126 women with early-stage breast cancer   | There were no significant differences between groups in patient satisfaction or impact of cancer scale. The intervention group had lower scores on cancer worry ( $P=0.02$ ).   |
| Boekhout et al. 2015 | 24-month RCT comparing receipt of survivorship care plan with control group   | The primary outcome was cancer-specific distress. Secondary outcomes included health-related QOL, patient satisfaction, continuity and coordination of care, and health service outcomes such as adherence with guidelines.                                  | 408 patients with early-stage breast cancer  | No differences were observed between groups in health service and patient-reported outcomes.  |
| Kvale et al. 2016    | RCT comparing Patient-owned Survivorship Transition Care for Activated, Empowered Survivors (POSTCARE) to usual care. The POSTCARE intervention included a single motivational interviewing encounter in which the coach assisted them with completion of their treatment summary and identification of health goals (cancer follow-up, other health issues, healthy habits, symptom improvement) | Patient outcomes (QOL, social/role activities limitations, self-efficacy for managing chronic disease, patient activation, and depression scale) and care coordination (primary care physician visits and reported discussion of the survivorship care plan) | 79 patients with stage 0-IIIB breast cancer  | Participants in the intervention group vs. those receiving usual care had significantly higher self-reported health ( $p=0.017$ ) and lower social role limitations ( $P=0.014$ ) and a trend towards greater self-efficacy ( $P=0.07$ ). Three QOL domains (physical role, bodily pain, and emotional role) showed improvement at the 3-month follow-up  |
| Maly et al. 2017     | RCT comparing usual care vs. survivorship care nurse counseling session combined with the provision of individualized treatment summaries   | Physician implementation of recommended breast cancer survivorship care  | 212 low-income, predominantly Latina   | Participants in the intervention group reported greater physician implementation of recommended breast cancer   |



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|--------------------|--|--|--|--|
| <b>Author</b>      |  |  |  |  |
| <b>Design</b>      | and survivorship care plans to patients and their health care providers                              |  |  |  |
| <b>Outcomes</b>    |  |  |  |  |
| <b>Sample Size</b> | breast cancer patients with stage 0-III disease  |  |  |  |
| <b>Results</b>     | survivorship care (e.g., treatment of depression or hot flashes) than did those in the control group |  |  |  |