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### **Publication Date**

2015

### **DOI**

10.1002/pon.3939

Peer reviewed

**Clinical Correspondence**

# Developing a treatment summary and survivorship care plan responsive to African-American breast cancer survivors

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Received: 18 December 2014

Revised: 18 May 2015

Accepted: 15 July 2015

Dear Editor,

## Background

African-American breast cancer survivors (AABCS) are understudied in the emerging survivorship care planning (treatment summary and survivorship care plan, TSSCP) literature. This article presents our TSSCP-African-American breast cancer (AABC) template, initially informed by a consensus review panel of survivor-advocates [1], and now in a format that is available for clinical application

## Methods

### Methodological framework

This project to develop a TSSCP-AABC template employed a two-phase, mixed-methods [2] design with an informative consensus panel to inform the initial TSSCP-AABC template. In this second phase, our stepwise approach towards the TSSCP template creation used a shared care model [3]. This model includes activated patients who joined oncology and primary care providers who provided input and evaluation to make available this current TSSCP-AABC template.

### Development of treatment summary and survivorship care plan

The preliminary informative phase of the development of the TSSCP is described in detail elsewhere [1]; AABCS ( $N=25$ ) and community health advocates ( $N=3$ ) participated in three facilitated, structured, and informative forums to review and provide input on relevant

cultural, clinical, and socioecological modifications to the American Society of Clinical Oncology (ASCO) [4] Breast Cancer Adjuvant Treatment Plan and Summary and Survivorship Care Plan (v3 10/09) [5]. These advocates challenged the one-size-fits-all approach to TSSCPs and put forth recommendations towards the creation of a more patient-centered TSSCP that considers disease, clinical, and cultural characteristics for African-Americans. Based on this process, the TSSCP-AABC template was developed.

### TSSCP-AABCS evaluation

#### Participants

Sixty healthcare professionals from research-based medical centers, community oncology and general medical practices, and nurses associations were identified by the advocates and members of the first phase informative consensus team and recruited via mail or e-mail to be evaluators of the TSSCP-AABC template. Forty-two healthcare professional evaluators including oncology physicians ( $N=5$ ), primary care physicians ( $N=2$ ) psycho-oncology professionals ( $N=3$ ), oncology nurses ( $N=5$ ), and primarily care setting nurse practitioners ( $N=27$ ); and 12 survivor-advocates participated in this review and evaluation of the TSSCP-AABC ( $N=54$ ). The response rate for professionals was about 78%; the response for the advocates was about 92%. Each evaluator gave their informed consent prior to the inclusion in this study. All professional evaluators had at least 4 years experience serving diverse populations of cancer survivors with a focus on underserved and ethnic minority patients including AABCS.

## Procedure

The evaluation form and copies of the TSSCP-AABC and TSSCP-ASCO with a description of the evaluation project were e-mailed to the evaluators. The evaluators were asked to rate both templates using the 20-item evaluation form. Each item on the evaluation form (e.g., 'How well does the TSSCP present information relevant to AABCS?') was rated on a 4-point scale (1=poor to 4=excellent). The evaluation form provided space for written comments and critique of the TSSCP-AABC template. The completed evaluations were returned via e-mail, fax, or courier. Study staff conducted a phone debriefing session once the evaluation form was returned to obtain any further suggestions and feedback from the evaluators.

## Data analyses

*Quantitative analysis:* All quantitative evaluative data were entered into SPSS v.20 (SPSS Inc., Chicago, IL, USA) [6]. Evaluation items were summed to generate overall scores for each of the five evaluative domains: (1) content; (2) clarity; (3) utility; (4) cultural responsiveness; and (5) socioecological responsiveness. Wilcoxon-signed rank tests were used to compare ratings on each evaluative domain for the TSSCP-AABC template and the TSSCP-ASCO template. Additionally, Mann-Whitney tests were used to explore potential variances between the review scores of the oncology and primary care health professionals and the survivor evaluators.

## Results

Data were analyzed using IBM SPSS v.20 [2]. Evaluation items were summed to generate overall scores for each of the evaluative domains. Wilcoxon-signed rank tests compared ratings on each domain for the TSSCP-AABC and TSSCP-ASCO templates. Mann-Whitney tests examined potential variances between review scores of the oncology and primary care health professionals and survivor-advocate evaluators.

The TSSCP-AABC template was rated more favorably than the TSSCP-ASCO by health professionals on all domains. Specifically, the TSSCP-AABC had higher mean ratings on content ( $Z = -5.14, p < 0.01$ ), clarity ( $Z = -5.23, p < 0.01$ ), utility ( $Z = -5.23, p < 0.01$ ), cultural responsiveness ( $Z = -5.02, p < 0.01$ ), and socioecological responsiveness ( $Z = -5.15, p < 0.01$ ). These results suggested that the TSSCP-AABC enhanced clinical (e.g., cancer-related and co-occurring chronic conditions), cultural (e.g., images and spirituality), and socioecological (e.g., community resources, activating AABCS to engage in their care) responsiveness relevant to the AABCS population.

Primary care health professionals rated the clarity of the TSSCP-AABC more highly than did the oncology health professionals ( $U = 50.0, p < 0.01$ ). This difference may be

influenced by oncology professionals' extensive experience with the complexities of cancer, from patients' perspectives, and practical understanding that documentation is not equivalent to patient education. Thus, the oncology professionals were somewhat less enthusiastic about the clarity of the TSSCP-AABC to fully inform patients. There were no significant differences between the health professionals' ratings and the survivors-advocates' ratings.

## Discussion

Our findings indicate that the TSSCP-AABC template enhanced the content, clarity and utility, and the clinical, cultural, and socioecological responsiveness of the TSSCP. The evaluators emphasized that the added inclusion of the following: (1) primary care providers and attention to co-occurring chronic conditions and their medications; (2) the presentation of health advisories that include aspects relevant to younger survivors; and (3) the list of potential health-related quality of life concerns with supportive care strategies that include spirituality and culturally embedded informal support networks are significant clinical and cultural enhancements to TSSCP templates. It must be noted that these added domains may be relevant to all survivors and not AABCS, only. However, the cultural tailoring of the presentation of the first page, in particular, enhances acceptability and patient activation.

Some limitations exist. One issue is that our TSSCP-AABC is fairly comprehensive, and this may limit uptake in already time-strapped clinical settings. Our TSSCP-AABC is designed to meet all the Institute of Medicine standards for quality survivorship care; however, this template is designed to allow for ongoing evaluation, refinement, and tailoring for practical use. Additionally, the current evaluators are a convenience sample; therefore, their evaluation may tend to be more favorable.

Overall, our findings are timely and make available a TSSCP-AABC template that can be readily used in clinical practice in its entirety or modified to inform quality, integrated follow-up care, and surveillance by attending to multiple chronic conditions and health advisories. The actual implementation of this TSSCP-AABC template for each patient may require completion by a nurse or clinical social worker as the most cost-effective (considering patient safety and professional knowledge) and practical implementation at the end of surgical (and radiation and chemotherapy, if given) treatment. Integration with electronic medical record is necessary to facilitate the rapid completion of the treatment summary and providers' components, and many of the health advisories and resources can be pre-populated, while the quality of life components should be individually tailored. It may be clinically appropriate for the oncologist or advanced practice oncology nurse to review the treatment summary and surveillance components, and a nurse or

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social worker to review the health advisories and quality of life aspects of the TSSCP with each patient.

The findings of this study are particularly important at this juncture in the implementation of the Commission on Cancer recommendation to provide survivorship care plan and the roll-out of the Affordable Care Act—as both focus on improving patient-centered care.

### Acknowledgements

This research is supported by a grant from California Breast Cancer Research Program and the City of Hope Excellence Program.

### Conflict of interest

The authors declare that they have no conflict of interest.

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### Ethics approval

This study was approved by the appropriate ethics committee and has therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

### Financial disclosures

The authors have no financial disclosures to report.