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# Standardized versus personalized survivorship care plans for breast cancer survivors: A program evaluation

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## ABSTRACT

The Wellness Beyond Cancer Program provides survivorship care plans (SCPs) to cancer survivors, as they transition from cancer centres back to their primary care provider (PCP) upon treatment completion. A program evaluation examined whether standardized SCPs resulted in comparable outcomes on perceived knowledge and patient activation as personalized SCPs. Breast cancer survivors who received either standardized or personalized SCPs completed pre- and post-surveys during their discharge appointment, which included an in-house measure on perceived knowledge, The Perceived Efficacy in Patient-Physician Interactions, and The Patient Activation Measure. Eighty-seven breast cancer survivors completed the surveys (personalized SCP  $n = 43$ ; standardized SCP  $n = 44$ ). Standardized SCPs resulted in comparable knowledge and activation outcomes as personalized SCPs. Cost-efficient

standardized SCPs may help alleviate human resource constraints and may be considered for further evaluation and implementation in cancer centres.

## METHODS

Advances in treatment and an ageing population have contributed to an increasing number of cancer survivors. In order to address the growing demand, survivorship care has transitioned from oncology in tertiary care settings to primary care settings (Dawes et al., 2015). In 2006, the Institute of Medicine (IOM) released a pivotal report, which found that many patients felt 'lost in transition' to primary care (Institute of Medicine & National Research Council, 2006). At present, many barriers continue to exist: preliminary findings from a citizen brief show that between 22–67% of adult cancer survivors had trouble finding help for their health concerns (Mattison et al., 2018). To aid in the coordination of care and improve communication between healthcare providers (HCPs) in tertiary care and primary care settings, survivorship care plans (SCPs) have been recommended (Cancer Journey Portfolio, 2012; Institute of Medicine & National Research Council, 2006). The IOM identified two central components to SCPs: firstly, follow-up care instructions in line with surveillance guidelines; and secondly, a treatment summary (Institute of Medicine & National Research Council, 2006). However, adoption of SCPs has been limited, likely due to lack of institutional and human resources and inconsistent evidence on their effectiveness (Dulko et al., 2013; Jacobsen et al., 2018).

Inconsistencies in the content and delivery of SCPs, as well as a focus on distal outcomes, such as long-term health status rather than proximal outcomes, such as survivor's knowledge of follow-up surveillance, may be contributing to conflicting findings in SCP literature (Jacobsen et al., 2018). Among proximal outcomes, previous research suggests that SCPs can increase satisfaction with information received, decrease health worry and depression, increase ability to identify family physicians as the primary care provider (PCP), and increase adherence to surveillance guidelines (i.e., attending medical appointments and engaging in preventative screening) (Grunfeld et al., 2020; Jabson, 2015; Jacobsen et al., 2018). Another potential benefit of SCPs is patient activation (Jeppesen et al., 2018). Patient activation refers to a patient's knowledge and understanding of their active role in the self-management of their health and their level of confidence in their ability to fulfill this role (Hibbard & Mahoney, 2010; Hibbard, et al., 2007). Patient activation has been shown to have a positive impact on survivors' health outcomes,

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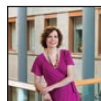
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self-management behaviours, and healthcare utilization (Hibbard & Mahoney, 2010; Hibbard et al., 2007).

The Wellness Beyond Cancer Program (WBCP) at The Ottawa Hospital in Ottawa, Ontario, provides breast cancer survivors with personalized SCPs, as part of a comprehensive transition to primary care (Rushton et al., 2015). The purpose of the WBCP is to meet the individual physical and psychosocial needs of cancer survivors and to increase their intent to self-manage their follow-up care through empowering them to be active agents in their long-term care (Rushton et al., 2015; Liska, et al., 2018). For more information about the WBCP see Rushton et al., 2015. Survivors referred to the WBCP are asked to complete a needs assessment upon referral. Personalized SCPs are completed by an oncology nurse and take an average of 45 minutes to prepare. Survivors self-identified physical and psychosocial needs are populated to the SCP by the WBCP clerk. Survivors who are discharged from the WBCP to the care of their PCP meet with a nurse to review their personalized SCP. Discharge sessions take place with a WBCP nurse either in person one-on-one or in a group format of approximately 8 to 12 survivors (Rushton et al., 2015). Due to increasing human resource constraints, a standardized SCP was developed by the WBCP to reduce completion time for each SCP.

In the present climate of limited healthcare resources, time-intensive personalized SCPs pose a challenge to the long-term implementation and sustainability of SCPs (Dulko et al., 2013). The purpose of this evaluation was to determine if use of a standardized SCP results in comparable outcomes, in terms of perceived knowledge and patient activation, with breast cancer survivors to those achieved using a personalized SCP. To our knowledge, no studies have previously compared a personalized SCP to a standardized version of a SCP.

### **Content of the Personalized Survivorship Care Plan and the Standardized Survivorship Care Plan**

The personalized survivorship care plan was previously developed by the WBCP team (Rushton et al., 2015) and took approximately 45 minutes to complete per survivor. The standardized SCP was developed by one author (C.M-L) and the WBCP manager to be more cost-effective by reducing the time of completion to approximately 15 minutes. The personalized SCP included a treatment summary (i.e., diagnosis, medications received, surgeries, etcetera.), and follow-up surveillance guidelines specific to breast cancer survivors (e.g., mammogram, breast self-check) with the next follow-up test due date indicated. The standardized SCP included the same follow-up surveillance guidelines. Outstanding self-identified needs reported at the time of completion of the needs assessment continued to be populated to both documents. The principal difference between the SCPs was the absence of the treatment summary and recommended next follow-up test due dates. A standardized or personalized SCP was electronically sent to the survivors' primary care provider following discharge and care plan review appointments, as per usual practice.

### **Evaluation**

This project received ethics exemption from the Ottawa Health Science Network Research Ethics Board. Breast cancer

survivors were recruited consecutively during their individual or group discharge sessions from the WBCP. The following inclusion criteria were applied: (a) survivor of primary breast cancer; (b) discharged from the WBCP and received either a standardized or personalized SCP; (c) attended a discharge appointment in person (either one-on-one or group format); and (d) agreed to participate in the program evaluation.

Patients were recruited at the time of their discharge and care plan review appointments. Appointments were held either at the General Campus or the Irving Greenberg Family Cancer Centre Campus of The Ottawa Hospital Cancer Centre. For individual sessions, patients were asked by the reception clerk to complete a numerically identified pre-discharge questionnaire in the waiting room prior to their discharge appointment. After the discharge appointment, the nurse provided patients with the post-discharge questionnaire, which were completed in the waiting room and returned to the clerk upon completion. For group discharge sessions, the nurse leading the session provided a numerically identified pre- and post-discharge questionnaire package at the beginning of the session to those agreeing to participate. Participants completed the pre-discharge questionnaire prior to the start of session and completed the post-discharge questionnaire at the conclusion of the session. Both questionnaires were returned to the nurse via the numerically identified package.

Patients who received personalized SCPs were recruited from February to April 2019, followed by patients who received the standardized SCP from April to June 2019. Patients were recruited sequentially and were not randomized into personalized SCP or standardized SCP groups.

### **Instruments**

Based on a recent systematic review (Jacobsen et al., 2018), the following relevant SCP outcomes for the WBCP were chosen with stakeholders (the WBCP nurses, a program manager, and a clinical psychologist working with oncology patients): patient activation and knowledge acquisition. A brief demographic form that collected information on age, education, marital status, and ethnicity was included with the pre-discharge questionnaire.

*Perceived Knowledge Questionnaire.* We adapted the Perceptions of Care Coordination measure, which had been previously used to evaluate health literacy and SCPs in breast cancer patients (Brennan et al., 2015; Hawley et al., 2010). Questions selected assessed perceived knowledge around care; however questions were modified to inquire about future follow-up care rather than present care. The eight items were rated on a five-point Likert scale from "Strongly Disagree" to "Strongly Agree". Internal consistency of this measure was  $\alpha = 0.88$  in the present study. The post questionnaire additionally asked whether the SCP met patients' needs.

*Perceived Efficacy in Patient-Physician Interactions (PEPPI).* The PEPPI measures patients' self-efficacy in obtaining medical information and expressing chief medical concerns to their physicians (Maly et al., 1998). The PEPPI has been validated with geriatric populations. However, it has previously been used to assess SCPs with success (Maly et al., 2017). The

shorter five-item scale was selected, which rates items on a five-point Likert scale ranging from “Little Confidence” to “Very Confident”. In the present sample the alpha of Cronbach was  $\alpha = 0.90$ .

*Patient Activation Measure (PAM)*. This 13-item questionnaire assesses patient activation on a four-point Likert scale, ranging from ‘totally disagree’ to ‘totally agree’ with an option of ‘non-applicable’. This questionnaire has been validated with several chronic conditions (Hibbard et al., 2004; Rademakers et al., 2012). In the present sample the alpha of Cronbach was  $\alpha = 0.92$ .

### Statistical Analysis

The data was analyzed using IBM SPSS version 25. Baseline characteristics of patients were reported using means ( $\pm$  standard deviation) for continuous and percentages for categorical variables. T-tests and Chi-square were used to test for differences between those who received a personalized versus standardized SCP.

## RESULTS

### Participants

A total of 87 breast cancer survivors were recruited. The sample was predominantly white (85%), married (68%), with a mean age of 64. Survivors’ education varied: completed high school (26%), some college (16%) or trade training (16%), and a bachelor’s degree (24%). Forty-three survivors received a personalized SCP and 44 survivors received a standardized SCP. Most received their SCP during a group discharge and care plan review session (60%). There were no sociodemographic differences between the groups, and no differences were found based on the modality of the discharge session during which they received their SCP (one-on-one versus group). See Table 1 for a full description of the sample.

### Descriptive statistics

See Table 2 for pre- and post-reception of SCP total scores on perceived knowledge, PEPPI, and PAM, comparing survivors who received a personalized SCP to those who received a standardized SCP. Univariate analyses revealed that survivors who received a personalized SCP reported greater perceived knowledge post-reception of their SCP compared to those who received a standardized SCP. There were no differences in perceived efficacy in patient-physician interactions and patient activation between the types of SCP. On the additional perceived knowledge questionnaire item asking whether SCP met patients’ needs, both groups of survivors indicated that their SCP met many or all their needs and no differences between the groups were found.

### Pre- to post-reception of SCP differences by format (personalized versus standardized SCP)

Three separate 2X2 mixed ANOVAs were conducted to examine changes in pre- and post-scores on perceived knowledge, PEPPI, and PAM with a Between Factor of SCP type (personalized versus standardized). Both SCPs resulted in significant increases in all areas measured. For perceived knowledge, we found a significant effect of Time ( $F_{(1,71)} = 110.1$ ,

**Table 1**

#### Patient Demographics

	Personalized SCP N=43	Standardized SCP N=44
Age Range	44-81	40-83
Mean Age	65.7 (8.5)	62.8 (10.5)
Ethnicity	N (%)	N (%)
White	39 (90.7%)	35 (79.5%)
Asian	1 (2.3%)	6 (13.6%)
Hispanic	1 (2.3%)	1 (2.3%)
Black	1 (2.3%)	1 (2.3%)
Native American	1 (2.3%)	-
Other	-	1 (2.3%)
Education		
No schooling	-	1 (2.3%)
Nursery-8 <sup>th</sup> grade	1 (2.3%)	-
Some high school	1 (2.3%)	1 (2.3%)
High school	12 (27.9%)	11 (25%)
Some college	8 (18.6%)	6 (13.6%)
Trade Training	6 (14%)	8 (18.2%)
Bachelor’s degree	11 (25.6%)	10 (22.7%)
Master’s degree	3 (7%)	2 (4.5%)
Professional degree	-	3 (6.8%)
Ph.D	1 (2.3%)	-
Marital Status		
Single	5 (12%)	1 (2.3%)
Married	26 (60.5%)	33 (75%)
Divorced	6 (14%)	4 (9.1%)
Separated	1 (2.3%)	-
Widowed	4 (9.3%)	4 (9.1%)
Missing	1 (2.3%)	2 (2.4%)
Mode of delivery of the SCP		
One-on-one	20 (46.5%)	15 (34.1%)
Group	23 (53.5%)	29 (65.9%)

**Table 2**

*Descriptive data (mean and standard deviation) for pre- and post-reception of SCP total scores on perceived knowledge, perceived efficacy in patient-physician interactions, and patient activation for breast cancer survivors who received a personalized SCP versus a standardized SCP*

Measure and time point (possible range)	Personalized SCP N=43	Standardized SCP N=44	<i>p</i>
Pre-SCP perceived knowledge (8–40)	27.3 (6.5)	26.1 (6.8)	.46
Post-SCP perceived knowledge (8–40)	36.4 (3.6)	33.9 (5.7)	.03
Post-SCP perceived knowledge additional item about SCP meeting needs (1–5)	4.5 (0.6)	4.3 (0.8)	.15
Pre-SCP PEPPI (5–25)	20.7 (3.1)	19.6 (4.7)	.21
Post-SCP PEPPI (5–25)	23.0 (2.5)	22.3 (3.7)	.25
Pre-SCP PAM (13–52)	43.5 (6.0)	40.6 (7.7)	.07
Post-SCP PAM (13–52)	46.1 (5.6)	45.6 (6.7)	.73

Note. Perceived knowledge: Perceived Knowledge Questionnaire; PEPPI: Perceived Efficacy in Patient-Physician Interactions; PAM: Patient Activation Measure

$p < .001$ , partial eta-squared = 0.61) but no significant TimeXSCP type interaction ( $F_{(1,71)} = 1.2$ ,  $p = .28$ , partial eta-squared = .02). For PEPPI, we found a significant effect of Time ( $F_{(1,82)} = 56.5$ ,  $p < .001$ , partial eta-squared = 0.41) but no significant TimeXSCP type interaction ( $F_{(1,82)} = 0.2$ ,  $p = .70$ , partial eta-squared = 0.00). For PAM, we found a significant effect of Time ( $F_{(1,78)} = 24.0$ ,  $p < .001$ , partial eta-squared = 0.24) but no significant TimeXSCP type interaction ( $F_{(1,78)} = 1.8$ ,  $p = .19$ , partial eta-squared = 0.02). These results suggest that survivors report greater perceived knowledge and self-efficacy in patient-physician interactions and reported feeling more activated to be agents in their follow-up care, regardless of the type of SCP they received.

#### **Pre- to post-reception of SCP differences by delivery (one-on-one versus group)**

We compared changes in outcomes (perceived knowledge, perceived efficacy in patient-physician interactions, and patient activation) by mode of delivery of SCP (one-on-one versus group) using three separate 2X2 mixed ANOVAs and found no significant TimeXMode of delivery interaction. We also tested three separate 3X2 mixed ANOVAs to test for the possibility of an interaction of type of SCPXMode of deliveryXTime. Again, we found no significant three-way interactions. These results suggest that there were no differences between group and individual discharge sessions on our measured outcomes, regardless of whether survivors received a personalized or standardized SCP.

#### **Discussion**

This program evaluation assessed whether standardized SCPs could result in comparable perceived knowledge acquisition and patient activation outcomes as personalized SCPs. The overall analysis does suggest that standardized SCPs offer comparable outcomes on self-efficacy in patient-physician interactions and patient activation to those of personalized SCPs. Survivors who received a personalized SCP reported greater perceived knowledge, however the standardized SCP

resulted in a significant increase in perceived knowledge from pre to post. Further, both SCPs met many or all the needs of survivors with no differences between the two groups. These are promising results as standardized SCPs can greatly reduce barriers to the implementation and sustainability of SCPs given that they expedite the process of SCP preparation. These findings led us to discuss the following clinical implications for providing and evaluating standardized SCPs in breast cancer populations.

Contrary to other studies that have found inconclusive evidence on the effectiveness of SCPs, our findings suggest SCPs may have an impact on perceived knowledge, self-efficacy, and patient activation. This may be attributable to concentrating on stakeholder-identified and proximal outcomes of SCPs, which has been emphasized in the literature (Birken et al., 2018; Chahine & Urquhart, 2019; Hill et al., 2019). Indeed, Birken and colleagues (2018) found that many randomized control trials assessing SCPs focused on distal outcomes such as health-related quality of life which stakeholders did not believe SCPs influenced and stressed the importance of stakeholder-identified proximal outcomes in the assessment of SCPs (e.g., knowledge, self-efficacy) (Birken et al., 2018). SCPs have been developed as communication and educational tools; therefore, they are unlikely to impact distal outcomes like quality of life and long-term health-status which are compounded by other social and clinical factors (Birken et al., 2018). Therefore, collaboration with stakeholders on the evaluation of SCPs may be an important component in accurately capturing the effectiveness of SCPs as transition tools in other survivorship programs.

Treatment summaries have been reported as an important and central component of SCPs for patients (Smith et al., 2011) and Primary Care Providers (O'Brien et al., 2015), and have been recommended by organizations such as the IOM and Canadian Partnership Against Cancer. The personalized SCPs align with present recommendations for the inclusion



of treatment summaries in SCPs. Regrettably, the treatment summary is the time-intensive defining feature of the personalized SCP. The absence of the treatment summary is a shortcoming of the standardized SCP and this loss of information may be particularly impactful for PCPs. O'Brien and colleagues (2015) reported that PCPs found the treatment summary to be the most valuable aspect of the SCP (O'Brien et al., 2015). Exploring PCPs' perspectives on a standardized SCP may be a worthy area of future exploration. However, this may be mitigated if treatment summaries could be automatically populated into standardized SCPs in the future or electronically accessed independently by survivors (i.e., MyChart).

Presently, SCPs are varied in content and delivery as no universally accepted template of a SCP exists, which has resulted in discrepancies across the literature. A standardized SCP can provide consistency across settings and research studies, which would allow a greater understanding of the impact SCPs have on patients and HCPs. Survivorship care plans can be costly to implement, particularly personalized SCPs, which require dedicated time for a nurse to complete. Standardized SCPs may prove more feasible for other cancer centers to implement than personalized SCPs, fostering greater adaption and adherence to guidelines recommending SCPs for every cancer survivor. For example, standardized SCPs can be created for different cancer populations by tailoring the surveillance guidelines to a specific population (i.e., colorectal cancer). However, it is possible that the content of a SCP is not as critical for patients as the nurse-led discharge session which may be the active ingredient driving patient outcomes. The discharge session provides an opportunity to connect with patients and emphasize their role as active agents in their follow-up care, as well as the role of their PCP (Singh-Carlson et al., 2018). Moreover, the effectiveness of SCPs may

be related to an expert oncology nurse's proficiency in delivering the information to cancer survivors (e.g., motivational interviewing techniques). However, this was not evaluated in the present study and may be an area of future exploration. Lastly, no differences were found between receiving a SCP in a group or one-on-one setting; therefore, a group discharge may be a more cost-effective method of SCP provision while maintaining comparable outcomes to individual sessions.

### Limitations

This study has several limitations. Firstly, participants were not randomized into groups, though no baseline differences were found between groups. Secondly, this evaluation was completed exclusively with breast cancer survivors. Therefore, the results may not be generalizable to other cancer survivor populations. Thirdly, as survivors were asked to complete questionnaires by the nurse during a group discharge appointment, this may have caused patients to feel pressured to complete surveys to appear favourably to nurses, leading to inflated or bias results. Further, the adapted perceived knowledge measure was not pilot tested with patients prior to implementation nor validated, however it was reviewed by stakeholders. Lastly, the results should be interpreted with caution as this study was slightly underpowered (0.75).

### CONCLUSIONS

Standardized SCPs show promisingly similar results to personalized SCPs for selected proximal outcomes: perceived knowledge, self-efficacy and activation. Based on our findings, standardized SCPs may be a more cost-effective alternative to personalized SCPs, while continuing to increase perceived knowledge acquisition, self-efficacy, and activation in breast cancer survivors.

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