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Alberta CancerBridges development of a care plan evaluation measure

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ABSTRACT

Background No standardized measures specifically assess cancer survivors' and healthcare providers' experience of Survivor Care Plans (SCPs). We sought to develop two care plan evaluation (CPE) measures, one for survivors (CPE-S) and one for healthcare providers (CPE-P), examine initial psychometric qualities in Alberta, and assess generalizability in Manitoba, Canada.

Methods We developed the initial measures using convenience samples of breast (n = 35) and head and neck (n = 18) survivors who received SCPs at the end of active cancer-centre treatment. After assessing Alberta's SCP concordance with Institute of Medicine (IOM) recommendations using a published coding scheme, we examined psychometric qualities for the CPE-S and CPE-P. We examined generalizability in Manitoba, Canada, with colorectal survivors discharged to primary care providers for follow-up (n = 75).

Results We demonstrated acceptable internal consistency for the CPE-S and CPE-P subscales and total score after eliminating one item per subscale for CPE-S, two for CPE-P, resulting in revised scales with four 7-item and 6-item subscales, respectively. Subscale scores correlated highly indicating that for each measure the total score may be the most reliable and valid. We provide initial CPE-S discriminant, convergent, and predictive validity using the total score. Using the Manitoba sample, initial psychometrics similarly indicated good generalizability across differences in tumour groups, SCP, and location.

Conclusions We recommend the revised CPE-S and CPE-P for further use and development. Studies documenting the creation and standardization of SCP evaluations are few, and we recommend further development of patient experience measures to improve both clinical practice and the specificity of research questions.

Key Words Care plans, survivorship, distress screening, breast cancer, head and neck cancer, oncology

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INTRODUCTION

For many cancer survivors, ending active treatment leads to uncertainty about their risk of recurrence and the organization of their care moving forward[1,2]. To address these concerns, oncology providers in the United States are mandated at the end of curative-intent treatment to clarify for patients what comes next through the provision of survivor care plans (SCPs)[3]. The Institute of Medicine (IOM) report on cancer survivorship[2] strongly encouraged post-treatment individualized SCPs to enhance coordinated and quality care while addressing survivors' and primary care providers' (PCPs') transition concerns. An SCP contains individualized diagnostic and treatment details, follow-up and surveillance guidelines, symptoms of recurrence to monitor, information on health behaviour, coping, and resources[1,2,4], and some include specific tools supporting health-behaviour-change planning or self-management[1]. Although no jurisdiction or accreditor mandates delivery, Canadian provincial oncology centres are beginning to offer and evaluate SCPs[1,5,6]. While SCP research has grown, best practices for patient and provider assessment and SCP delivery post-treatment remain unclear or not broadly instituted[2,7,8]. A developing literature supports the use of SCPs[9-14], and describes optimal content, formats[4,15-22], and key-stakeholders' views[1,23,24], but methods of evaluating SCPs and their impact on stakeholders are just emerging[4,25-30].

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Due to the absence of a common validated measure[4,31-35], researchers often generate study-specific measures of patients' and providers' SCP experiences, including satisfaction, usefulness, emotional reaction, or communication value[4,25-30]. Some studies measure how closely SCPs adhere to recommended IOM standards[4,36] so that the thoroughness of SCP format can be linked with outcomes. Our study, perhaps uniquely, offers scales appropriate across types of SCPs, health systems, and perspectives, providing psychometric attributes of two SCP evaluation measures: Care Plan Evaluation-survivors or CPE-S and Care Plan Evaluation-Healthcare Providers or CPE-P. We used convenience data from delivery of three Canadian SCPs for cancer survivors: two given in Alberta at active treatment completion, one for breast (BCA), another for head and neck (HN); one in Manitoba, (colorectal [CRC]), at transfer-of-care to PCPs for follow-up. Our aim was to document initial steps so that this measure can be used and improved in future research and practice. We assessed Alberta's SCP-coherence with IOM recommendations, followed by item and subscale analysis for CPE-S and CPE-P, CPE-S stability over six months, and CPE-S convergent, divergent, and predictive validity comparing to scales measuring similar or different constructs, and testing associations with outcomes over time. In Manitoba, we assessed CPE-S generalizability to a different setting and SCP.

We hypothesized (H) the following:

(H1) Alberta's SCPs will have high concordance with IOM recommendations.
(H2.a) CPE-S and CPE-P will have acceptable internal consistency, skewness, and kurtosis. (H2.b) Subscales will correlate moderately.
(H3) CPE-S ratings will be relatively stable (reliable) over six months.
(H4.a) CPE-S will have moderate to high correlations with theoretically related, and low to small correlations with theoretically unrelated measures, demonstrating initial convergent and discriminant validity.
(H4.b) Higher baseline CPE-S will correlate moderately with more positive ratings of PCP consultations one month later, and with improvement in distress over six months, providing initial predictive validity. Ratings of the same consultation on the CPE-S and CPE-P will correlate highly.
(H5.a) CPE-S will generalize to another province, patient population, and SCP delivery method, showing similar item internal consistency, subscale correlations, and
(H5.b) discriminant and convergent validity.

METHODS

Care Plan Evaluation (CPE) Development

Because no published scale evaluated survivors' and providers' SCP experiences, the CancerBridges multi-disciplinary team created the CPE, comprising four face-valid, 8-item (Likert-type scales [1-do not agree to 5-completely agree]) subscales (Satisfaction; Usefulness; Emotional Reaction; Communication Value). We selected domains based on SCP delivery goals for survivors and PCPs outlined in the IOM report[2]: that they feel *satisfied* that their questions are addressed; that the SCP was *useful* in the transition following treatment; that receiving the SCP would *reduce negative emotional reactions,* including distress and abandonment fears, and instead *provide relief*; and that SCPs would *improve communication among health professionals* and survivors helping them to navigate health issues. To reduce response bias, we reverse-coded 14 (43.7%) items. We evaluated two SCP demonstration projects, funded by the Canadian Partnership Against Cancer (CPAC), differing by SCP delivery methods, tumour groups, and provinces. Goals for the CPE-S were to examine initial psychometric qualities and generalizability, and, for the CPE-P, to examine initial psychometric qualities in Alberta.

Participants

In accordance with the Declaration of Helsinki, this study received ethics and data sharing approval through respective research ethics boards (The Conjoint Health Research Ethics Board at the University of Calgary; Research Ethics Board Faculty of Medicine, University of Manitoba, and Research Resource Impact Committee of CancerCare Manitoba). All participants signed informed consent.

Breast Cancer and Head and Neck Cancer Survivors, Nurses, Primary Care Providers

In Alberta, nurses identified consecutive survivors in their cancer clinic/community/and navigator roles (see Collie *et al.*[1] for details). Survivors' eligibility criteria included over age 18, English literate, stages I–III, and within 2 weeks (+/-) of end of active treatment regardless of formal oncology discharge status. For BCA (n = 36), the study was provincial, including two urban (Calgary and Edmonton) and two rural (Drumheller and Lloydminster) Alberta Health Services (AHS) cancer-centre sites, and one community-based organization (CBO). For HN survivors (n = 21) we included one urban location (Calgary). The CancerBridges multidisciplinary team developed SCPs for BCA and HN survivors differing only in tumour-specific details. Trained nurses delivered SCPs during consultations with survivors who then completed the CPE-S[1]. Nurses who delivered SCPs (N = 8 of 8) and PCPs who received them by fax after consultations (N = 22 of 57), completed the CPE-P after consultations.

Colorectal Cancer Survivors

Manitoba's nurse-oncologist teams delivered SCPs during standard clinical consultations to consecutive colorectal cancer (CRC) survivors at the time of medical-responsibility-for-care transfer to community family physicians or nurse-practitioners (PCPs). We approached survivors in CancerCare, Manitoba cancer clinics (Winnipeg) or Winnipeg Regional Health Authority, with those consenting receiving mailed surveys that included the CPE-S and other measures. Eligibility criteria included patients discharged to PCP care, over age 18, English literate, Stage I–III CRC, minimum 12-months post-diagnosis, with CT scan demonstrating no evidence of recurrence.

Survivor Care Plan Development

Both provinces' care plans included CPAC- and IOM-recommended features[2]: diagnosis and treatment

summaries (TS); follow-up and surveillance plans; coping, adjustment, and healthy-living recommendations/survivor priorities and goals; resources and activities for survivors; care-team contact information, and distress screening (SCPS). In Alberta, nurses hand-entered TS information prior to consultations. To empower survivors to set their own priorities and plans, survivors and nurses interactively completed remaining SCP items during consultations. In Alberta, in addition to post-consultation surveys that included the CPE-S, we retained SCP elements as data.

Breast and Head and Neck

After a full-day group nurse training to assess distress and deliver SCPS, nurses personalized survivors' TSs using medical records. Nurses scheduled face-to-face or phone consultations to deliver SCPS, answer questions, and clarify needs and goals[1]. One breast nurse (of 7) delivered individualized SCPS during group classes. Following delivery, we scanned SCPS into medical records, provided survivors copies, and faxed them to PCPS. We encouraged survivors to schedule SCP consultations with PCPS within the month. Following consultations, nurses, patients, and participating PCPS completed respective CPE measures. Survivors completed the minimum dataset for distress screening across Canada[37] during SCP delivery (T1), as part of surveys following SCP delivery (T2), and at 6-months (T3).

Colorectal

CancerCare Manitoba's electronic record populated SCPS with printed copies including three sections: a patient-specific TS, a CRC-specific guide to survivorship, and a general survivorship information booklet for all cancers. After staff education, the nurse-physician team that had cared for patients during their chemotherapy prepared their SCPS with project-manager support. Physicians were medical oncologists or family physicians in oncology, specially trained family physicians overseeing chemotherapy in smaller hospitals in a shared-care arrangement with medical oncologists. Nurse-physician teams presented and discussed patient SCPS at their final, 20-minute transitional appointment, where patients completed and staff reviewed with them the minimum data set for distress screening across Canada[37]. Nurse-physician teams faxed completed SCPS to participants' PCPS, with whom they were encouraged to meet within the month. Participants completed surveys once after PCP consultation, usually one to three months later.

Measures

Demographics and Cancer History

Alberta and Manitoba survivors completed separate demographic and medical questionnaires (Table I).

H1: SCP Concordance with IOM Recommendations

In Alberta, the CPE-S and CPE-P development site, we ensured that our SCPS matched closely with IOM recommendations[4] so these evaluations were based on fulsome SCP experiences. To ensure comparability with standardized SCP templates, we used a coding scheme that matches aspects of actual-use TSS and SCPS with the guidelines, yielding a concordance score[4]. Coding-scheme authors developed these for BCA TSS and SCPS in the United States, so several items were irrelevant to Alberta's public healthcare system. Coding-scheme authors developed no coding guidelines for HN SCPS, so we copied BCA coding-scheme guidelines applicable to both and added criteria through consultation with a HN nurse specialist. Two independent coders rated our BCA and HN SCPS separately against these criteria with kappa (κ) statistics of agreement calculated. They then consensus-coded their work to resolve conflicts (BCA: TS $\kappa = 0.733$, SCP $\kappa = 0.500$; HN: TS $\kappa = 0.808$, SCP $\kappa = 0.455$).

Edmonton Symptom Assessment System (ESAS)

In Alberta, to reduce multiple testing when examining discriminant and predictive validity, we used the mean (of 9 items) ESAS[37-39]. The ESAS is a valid and reliable part of the Canadian minimum dataset for distress screening. Patients rate current experience of nine symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and shortness of breath) on 10-point Likert-type scales (0-symptom is absent to 10-most severe).

Contact Sheets

In Alberta, we used survivors' ratings of topic-discussion frequencies (5-point Likert-type scales: 1-not at all to 5-a lot) following nurse SCP consultations to assess CPE-S convergent validity[40] because each topic theoretically relates to pieces of an ideal SCP consultation. Interactive consultations led by survivors' priorities determined whether survivors discussed these nine topics: Information about cancer, Resources for cancer patients, Coping with cancer, Feelings, Work issues, Sexuality, Life-style changes, Taking control of life, and Follow-up tests and appointments. For predictive validity, we used survivor ratings of five positive and four negative affect words (Likert-type scale: 0-not applicable to 5-a lot) describing their PCP consultations, predicting that better SCP nurse consultations (higher CPE-S) at baseline would prepare them to feel more positively about PCP consultations one month later.

Patient Continuity of Care Questionnaire (PCCQ)

In Manitoba, we examined convergent validity with the PCCQ[41,42] consisting of 41 Likert-type items identifying continuity-of-care issues post-discharge from a hospital setting. This is a reliable and valid short questionnaire developed in Canada that Manitoba investigators modified for use at the time of discharge to PCP follow-up[43]. Delivering more highly evaluated SCPS should improve survivors' continuity of care[44-46].

Data Analysis

We conducted the following tests of our hypotheses:

(H1) reported percentage concordant reports when evaluating Alberta's match with IOM SCP templates using Stricker *et al.*'s 2012 coding rules[4].

(H2.a) counted missing answers, and analyzed skewness and kurtosis of items and subscales to evaluate CPE-S and CPE-P usability and psychometrics, and used Cronbach's alphas and item-to-total correlations to evaluate CPE-S and CPE-P internal consistency.

TABLE I Demographic, medical, and study variables by tumour group

	Alberta		Alberta		Manitoba	
	Breast cancer		Head and neck cancer		Colorectal cancer	
	N	M (*SD*) or %	*N*	M (*SD*) or %	*N*	M (*SD*) or %
Age at diagnosis (years)	36	53.58 (9.29)	18	55.51 (11.90)	83	62.22 (8.68)
Age at study entry (years)	36	54.12 (9.20)	18	56.25 (11.70)	83	63.94 (8.79)
Diagnosis to SCP delivery (months)	36	6.85 (3.05)	18	3.66 (1.30)	83	20.97 (12.64)
Gender						
Male	0	0.0	17	80.9	54	65.1
Female	36	100.0	4	19.1	29	34.9
Site of recruitment						
Urban	19	52.8	21	100.0	—	—
Rural	6	16.6	0	0.0	—	—
Community-based organization	11	28.6	0	0.0	—	—
Size of town (population)						
>100,000	—	—	—	—	54	65.1
10,000–100,000	—	—	—	—	6	7.2
1000–10,000	—	—	—	—	7	8.4
<1000	—	—	—	—	9	10.8
Unknown	—	—	—	—	7	8.4
Distance: home to cancer centre, km		52.2 (61.3)		66.1 (74.9)	—	—
Ethnicity						
Caucasian	32	88.9	14	66.7	68	83.1
Chinese	1	2.8	2	9.5	0	0.0
Multiple ethnicities	1	2.8	2	9.5	0	0.0
Latin American/Hispanic	0	0.0	1	4.8	0	0.0
First Nation/Metis/Inuit	0	0.0	1	4.8	4	4.8
Other	1	2.8	0	0.0	5	6.0
Did not answer	1	2.8	1	4.8	5	6.0
Marital status						
Married or Living as married	28	77.8	14	66.7	66	79.5
Single/Never married	2	5.6	1	4.8	3	3.6
Divorced/Separated	3	8.4	4	19.2	7	8.4
Widowed	2	5.6	1	4.8	4	4.8
Did not answer	1	2.8	1	4.8	3	3.6
Education						
Less than high school	0	0.0	0	0.0	17	24.1
Graduated high school	13	36.1	13	61.9	22	27.7
Some college	8	22.2	5	23.8	18	21.7
Bachelor's degree	5	13.9	2	9.5	16	19.3
Some graduate school	4	11.1	0	0.0	0	0
Master's degree or above	5	13.9	0	0.0	4	4.8
Did not answer	1	2.8	1	4.8	2	2.4
Household income						
< $59,999	5	13.9	11	52.4	—	—
$60,000 to $99,999	8	22.2	2	9.5	—	—
$100,000 or above	15	421.7	5	23.8	—	—
Did not answer	8	22.2	3	14.3	—	—

TABLE I Continued

	Alberta		Alberta		Manitoba	
	Breast cancer		Head and neck cancer		Colorectal cancer	
	N	M (*SD*) or %	*N*	M (*SD*) or %	*N*	M (*SD*) or %
Employment status						
Not employed or Retired	10	27.8	9	42.9	44	53.0
Part time (< 30 hours)	7	19.4	2	9.5	10	12.0
Full time (≥ 30 hours)	18	50.0	9	42.9	26	31.3
Did not answer or Other	1	2.8	1	4.8	3	3.6
English first language						
Yes	30	83.3	15	71.4	—	—
No	5	13.9	5	23.8	—	—
Did not answer	1	2.8	1	4.8	—	—
Treatment						
Surgery	36	100.0	8	38.1	77	92.7
Ostomy	—	—	—	—	22	26.5
Chemotherapy	18	50.0	16	76.2	74	89.1
Radiation	20	55.6	20	95.2	42	50.6
Hormone	29	80.6	—	—	—	—
Stage						
0	2	5.6	—	—	0	0.0
I, II	33	91.6	—	—	20	24.1
III	1	2.8	—	—	62	74.7
Unknown	0	0.0	—	—	1	1.2
Type of breast cancer						
Invasive ductal carcinoma	34	94.4	—	—	—	—
Ductal carcinoma *in situ*	2	5.6	—	—	—	—
Type of surgery						
Lumpectomy/Segmental resection	19	52.8	—	—	—	—
Mastectomy	15	41.7	—	—	—	—
Bilateral mastectomy	2	5.6	—	—	—	—
Estrogen receptor status						
Positive	33	91.7	—	—	—	—
Negative	2	5.6	—	—	—	—
Unknown	1	2.8	—	—	—	—
Type of head and neck cancer						
Tongue	—	—	4	19.1	—	—
Nasopharynx	—	—	4	19.1	—	—
Oropharynx	—	—	5	23.8	—	—
Hypopharynx	—	—	2	9.5	—	—
Other	—	—	4	19.1	—	—
Nodes with squamous cell cancer but primary unknown	—	—	2	9.5	—	—
Type of colorectal cancer						
Cancer site						
Colon	—	—	—	—	36	43.4
Rectum	—	—	—	—	47	56.6

TABLE I Continued

	Alberta		Alberta		Manitoba	
	Breast cancer		Head and neck cancer		Colorectal cancer	
	N	M (*SD*) or %	*N*	M (*SD*) or %	*N*	M (*SD*) or %
Study variables						
CPE-S total baseline	35	116.49 (15.98)	18	105.67 (21.70)	76	117.86 (18.36)
Satisfaction	35	29.29 (4.32)	18	27.39 (5.38)	75	29.72 (4.79)
Usefulness	35	28.77 (4.74)	18	24.56 (5.32)	75	28.89 (4.59)
Emotional reaction	35	28.80 (4.52)	18	26.39 (5.61)	74	29.27 (4.91)
Communication value	35	29.60 (3.91)	18	27.39 (7.11)	77	29.81 (5.46)
CPE-S total 6 months	28	112.57 (15.83)	11	102.18 (19.92)	—	—
Satisfaction	28	28.50 (4.83)	11	26.91 (5.11)	—	—
Usefulness	28	27.54 (4.52)	11	23.45 (4.87)	—	—
Emotional reaction	28	28.32 (4.71)	11	25.27 (6.25)	—	—
Communication value	28	28.25 (4.22)	11	26.55 (5.94)	—	—
Nurse CPE-P total baseline	36	87.97 (12.29)	21	90.14 (5.94)	—	—
Satisfaction	36	23.69 (3.06)	20	22.50 (1.50)	—	—
Usefulness	33	22.18 (3.52)	20	22.45 (2.28)	—	—
Emotional reaction	36	21.69 (4.06)	21	22.29 (1.95)	—	—
Communication value	36	20.61 (3.37)	21	22.33 (2.90)	—	—
PCP CPE-P total baseline	16	95.25 (13.11)	6	94.50 (12.50)	—	—
Satisfaction	16	24.56 (3.86)	6	22.83 (3.87)	—	—
Usefulness	16	24.69 (3.20)	6	24.50 (4.85)	—	—
Emotional reaction	16	23.50 (3.83)	6	21.67 (4.23)	—	—
Communication value	16	22.56 (4.13)	6	25.50 (2.26)	—	—

SCP = survivor care plan; CPE-S = care plan evaluation-survivor; CPE-P = care plan evaluation-provider; PCP = primary care provider; — = no data provided.

(H2.b) examined CPE-S and CPE-P subscale-score interrelationships, predicting moderate correlations, using Spearman's *rho* (as effect size estimates, 0.20 as small, 0.50 moderate, and 0.70 large) by tumour group for CPE-S (BCA, HN), and by provider for CPE-P (Nurses, PCPs).

(H3) used an intra-class correlation to test CPE-S Total Score stability from baseline to 6 months, and evaluated CPE-S change over time, using Hierarchical Linear Model (HLM) analysis with a random-effect co-variance structure on Total Score (Proc Mixed SAS) with effects due to Group (BCA or HN), Time (over 6 months), and Group × Time.

(H4.a) used Spearman's *rho* to evaluate discriminant/convergent/predictive validity, predicting small correlations with CPE-S for Alberta's discriminant measures (baseline demographic and medical variables, and baseline ESAS measuring symptom distress as a construct quite different from SCP evaluations); predicted moderate to large CPE-S correlations with convergent measures (survivors' ratings of Topic discussions during SCP consultations); and examined convergent validity using an intra-class correlation between survivors' CPE-S and nurses' CPE-P of the same consultation.

(H4.b) examined predictive validity expecting higher baseline CPE-S ratings to predict 1) moderate correlations with higher positive and lower negative affect during PCP consultations a month later, and 2) moderate correlations with Total ESAS Distress improvement using slopes across three time-points.

(H5.a) repeated item analysis for internal consistency and subscale correlations to assess generalizability to another province (Manitoba), tumour group (colorectal), and type of SCP.

(H5.b) expected small correlations between CPE-S and theoretically unrelated demographic and medical variables for discriminant and moderate to large correlations for convergent validity with continuity-of-care (PCCQ), a measure theoretically related to the CPE-S.

We present descriptive CPE-S statistics and box plots of tumour groups' total scores to explore distributions. For all analyses, due to the large number of tests, we used $p \leq 0.01$.

RESULTS

Participants

Alberta's BCA and HN survivors were similar in age, distance to cancer centre, race, marital status, education, employment status, majority English first language, but differed in expected ways by sex, time to SCP delivery (differing treatment lengths), medical details, and household incomes

(Table I). Breast cancer SCP delivery time was 33 days (6–63 days) and for HN -2 days (-32–100 days). Colorectal cancer survivors in Manitoba were older with longer time from diagnosis to SCP meetings (consistent with recruitment at discharge).

(H1) IOM-Recommendation Concordance

For Alberta's BCA SCP, consensus-coded total scores based on Stricker *et al.*'s[4] scoring were 40/54 (74%) for TS, and 21/30 (70%) for SCP. Total scores for HN SCPS were 25/42 (60%) for TS and 20/27 (74%) for SCP. Compared with Stricker *et al.*'s[4] BCA survivors (in LIVESTRONG™ Network of Survivorship Centers of Excellence), our TSs and SCPS looked more concordant with IOM recommendations (TS: theirs $M = 46\%$, ours $M = 67\%$; SCPS: theirs $M = 59\%$, ours $M = 72\%$). Within TSS, our discordant categories were supportive treatment (0/3, 0%) and chemotherapy details (3/7, 43%). Within SCPS, our discordant categories were cancer surveillance (0/3, 0%) and non-cancer surveillance (0/3, 0%). In our HN TS, chemotherapy details (2/8, 25%), and radiation details (1/3, 33%) were most discordant, but for HN SCPS, cancer surveillance (0/3, 0%) and signs of cancer (recurrent and second; 1/2, 50%) were most discordant.

(H2.a) CPE-S Item and Subscale Analysis

In Alberta, four people completed too few items to score subscales (2 BCA, 2 HN), but few items were missed (missing: BCA mean = 0.31, standard deviation [SD] = 0.80, median = 0.0, range = 0.0 to 3.0; HN mean = 0.39, SD = 0.85, median = 0.0, range = 0.0 to 3.0).

Based on Cronbach's alphas and item-to-total correlations, we eliminated one item per subscale. The removal of these four items (three reverse-scored) improved alphas: (Satisfaction, 0.70 to 0.72; Usefulness, 0.78 to 0.84; Emotional reaction, 0.78 to 0.79; Communication value, 0.78 to 0.82; Total score, 0.93 to 0.94). The revised, shortened CPE has four 7-item subscales (Table II). We found that items had acceptable skewness (-1.84 to -0.25, median = -0.96) and kurtosis (-1.01 to 2.95, median = 0.24) (2 greater than ±2), indicating that they met normality assumptions. Subscales and total scores had acceptable skewness (-0.99 to -0.40, median = -0.52) and kurtosis (-0.95 to 0.68, median = -0.20).

The revised CPE-S has acceptable baseline and six-month internal consistency, with Total score the strongest: (baseline, six-month) $\alpha = 0.94, 0.93$; Satisfaction $\alpha = 0.72, 0.77$; Usefulness $\alpha = 0.84, 0.74$; Emotional reaction $\alpha = 0.79, 0.79$; Communication value $\alpha = 0.82, 0.79$ (Table II).

(H2.b) Subscale Inter-Relationships

Table III shows moderate to large Spearman correlations among subscales in each tumour group. To eliminate redundancy, analyses below use Total scores as providing the best CPE measure. Tumour-group correlation patterns were similar, showing a high degree of generalizability.

(H3) Stability

Total score intra-class correlation demonstrated stability between baseline and six months (0.651). We examined change over time and could demonstrate no significant Time ($F = 3.8(36)$, $p = 0.06$) or Group × Time ($F = 0.83(36)$, $p = 0.78$) changes. Out of a possible total score of 140, BCA

TABLE II Means, internal consistency, and subscale and total score correlations for the Care Plan Evaluation-Survivors (CPE-S)

CPE	Alberta Breast Cancer						Alberta Head and Neck Cancer						Manitoba Colorectal Cancer					
	Mean (SD), rho, and α (*n*=35)						Mean (SD), rho, and α (*n*=18)						Mean (SD), rho, and α (n=75)					
	Mean (SD)	1	2	3	4	5	Mean (SD)	1	2	3	4	5	Mean (SD)	1	2	3	4	5
1. Satisfaction	29.29 (4.32)	**0.67**					27.39 (5.38)	**0.79**					29.72 (4.79)	**0.78**				
2. Usefulness	28.77 (4.74)	0.75[b]	**0.83**				24.56 (5.32)	0.89[b]	**0.80**				28.89 (4.59)	0.78[b]	**0.75**			
3. Emotional reaction	28.80 (4.52)	0.87[b]	0.78[b]	**0.75**			26.39 (5.61)	0.87[b]	0.77[b]	**0.84**			29.27 (4.91)	0.84[b]	0.79[b]	**0.80**		
4. Communication value	29.60 (3.91)	0.81[b]	0.71[b]	0.75[b]	**0.67**		27.39 (7.11)	0.71[b]	0.72[b]	0.71[b]	**0.91**		29.81 (5.46)	0.77[b]	0.78[b]	0.81[b]	**0.83**	
5. Total Score	116.49 (15.98)	0.94[b]	0.89[b]	0.92[b]	0.89[b]	**0.92**	105.67 (21.70)	0.94[b]	0.87[b]	0.94[b]	0.83[b]	**0.92**	117.86 (18.33)	0.91[b]	0.91[b]	0.93[b]	0.91[b]	**0.94**

[a] $p \leq 0.05$
[b] $p \leq 0.01$. Cronbach's alpha for each subscale and total score are bolded and in the diagonals. Spearman's *rho* correlations.

TABLE III Discriminant and convergent validity with cpe-S total scores for Alberta and Manitoba

	Alberta	Alberta	Manitoba
	Breast cancer	Head and neck cancer	Colorectal cancer
	CPE-S total score Spearman *rho*		
Discriminant validity			
Age at diagnosis	0.05	-0.14	0.06
Age at study entry	0.01	-0.14	0.08
Time from diagnosis to SCP	-0.09	-0.16	0.15
Surgery	-0.12	0.00	0.01
Chemotherapy	-0.11	-0.05	-0.05
Radiation	0.16	0.15	-0.05
ESAS total score	-0.05	-0.41	
Convergent validity			
Topic discussions			
1. Information about cancer	0.35[a]	0.76[b]	
2. Resources for survivors	0.28	0.57[a]	
3. Coping with cancer	0.46[b]	0.53[a]	
4. Feelings	0.54[b]	0.66[b]	
5. Work issues	0.44[b]	0.40	
6. Sexuality	0.31	0.29	
7. Lifestyle changes	0.31	0.39	
8. Taking control of life	0.29	0.45	
9. Follow-up tests and appoint.	0.29	0.75[b]	
PCCQ			
1. Information transfer			0.50[b]
2. Management of forms			0.57[b]
3. Management of communication			0.54[b]
4. Relationships in community			0.56[b]
5. Management of follow-up			0.51[b]

[a] $p \leq 0.05$
[b] $p \leq 0.01$.
CPE-S = Care Plan Evaluation-Survivors; SCP = survivor care plan; ESAS = Edmonton symptom assessment system; PCCQ = patient continuity of care questionnaire.

(mean = 116.49, SD = 15.98) and HN (mean = 105.67, SD = 21.70) survivors evaluated the SCP positively; however, HN survivors rated it somewhat lower ($F = 5.8(51)$, $p = 0.02$).

(H4) Discriminant/Convergent Validity

(H4.a) Discriminant

As hypothesized, the CPE-S Total score correlations with demographic and medical variables were small, demonstrating that it is not measuring age, time, or treatment-related issues. As predicted, correlations between CPE-S Total score and ESAS total were small and non-significant for BCA ($r = -0.05$, $p = 0.77$); however, HN was moderate though non-significant ($r = -0.41$, $p = 0.10$). Care plan evaluation-survivors is related to distress at a low level, but does not measure symptom distress (Table III).

(H4.a) Convergent

As expected, CPE-S correlations with relevant SCP-consultation topic discussions were moderate to large (BCA: median = 0.31; SD = 0.09; range 0.28–0.54; HN: median = 0.53; SD = 0.17; Range 0.29–0.76) (6 correlations significant at $p \leq 0.01$). Breast cancer and HN differed on significant correlations: BCA – Coping with cancer, Feelings, and Work issues; HN – Information about cancer, Feelings, and Follow-up tests and appointments (Table III). Intra-class correlations between nurses' CPE-P and survivors' CPE-S indicated similar SCP-consultation ratings (0.75), providing evidence of convergent validity from multiple perspectives. Survivors did not complete a CPE-S rating for their SCP consultation with PCPS.

(H4.b) Predictive Validity

As predicted, we found moderate CPE-S correlations with survivors' affect during PCP consultations about one month (1.33, SD = 1.30) later (BCA, HN: Negative Affect: $r = -0.39$, $p = 0.03$, $r = -0.34$, $p = 0.28$; Positive Affect: $r = 0.32$, $p = 0.08$, $r = 0.51$, $p = 0.09$). We found partial support for higher CPE-S baseline ratings predicting steeper declines in ESAS Total Symptom Distress over six months with BCA more related than HN (BCA: $r = -0.49$, $p = 0.003$; HN: $r = -0.13$, $p = 0.61$).

(H5.a) Generalizability

Manitoba's CPE-S for CRC survivors (Table II) had similar internal consistency (Total Score α = 0.94; Satisfaction α = 0.78; Usefulness α = 0.75; Emotional reaction α = 0.80; Communication value α = 0.83). Subscale scores also correlated with similarly large effect sizes (0.77 to 0.93). Figure 1 shows that the 3 tumour groups reported similar CPE-S levels despite SCP-delivery differences.

(H5.b) Likewise as predicted, the CPE-S correlated at a low level with demographic and medical variables, but significantly with PCCQ scores, indicating a strong relationship with continuity of care (Table III).

(H2.a) CPE-P Item and Subscale Analysis

We used CPE-S psychometric analysis processes to evaluate CPE-P. In Alberta, nurses rated the CPE-P after SCP deliveries (57 total), and PCPs rated it after SCP consultations (returning 16 BCA, 6 HN CPE-Ps). Nurses failed to complete more items than PCPs (nurse mean missing = 1.30, SD = 1.55, median = 1.0, range = 0.0 to 8.0; PCPs mean missing = 0.36, SD = 0.73, median = 0.0, range = 0.0 to 2.0), so that we could not score one nurse Satisfaction (HN) and four nurse Usefulness subscales (3 BCA, 1 HN).

We randomly selected one CPE-P per nurse for alpha calculations so nurses who filled these out for multiple patients were not represented more than once. Based on item-to-total correlations, missing items, and comments, we eliminated two items per subscale. The removal of these eight items (6 reverse-scored) improved some alphas, eliminated confusing items, and provided a shortened measure (Satisfaction, 0.73, to 0.70; Usefulness, 0.62, to 0.69; Emotional reaction, 0.57, to 0.74; Communication value, 0.51, to 0.71; Total score, 0.89, to 0.90). The shortened CPE-P demonstrated acceptable internal consistency, particularly the Total Score, and has four 6-item subscales (Table IV). Most items, subscales, and total scores had acceptable skewness (Items: -2.15 to -0.05, median = -0.92; 2 greater than ±2; Subscales and total scores: -0.09 to 0.44, median = -0.22) and kurtosis (Items: -1.34 to 7.64, median = 0.44; 7 greater than ±2; Subscales and Total scores: -0.15 to 0.30, median = 0.05).

(H2.b) Subscale Inter-Relationships

For nurses and PCPs, most subscales were highly correlated, indicating that Total Score best represents the CPE-P (Table IV). Nurses reported somewhat lower total scores than PCPs (Table IV).

DISCUSSION

We report first steps in SCP-evaluation-measure creation for survivors (CPE-S) and healthcare providers (CPE-P). Each measures satisfaction, usefulness, emotional reaction, and communication value for the specific SCP delivered. For initial psychometrics, we used SCP-delivery data from BCA and HN survivors in Alberta. To ensure the SCPs we evaluated matched closely with IOM recommendations[47], we applied a published coding system[4], demonstrating close concordance with guidelines at or above levels reported by LIVESTRONG™ Survivorship Centers in the United States. We demonstrated acceptable internal consistency for CPE-S and CPE-P after eliminating one and two items per subscale, respectively. We recommend revised scales with four 7-item, and 6-item subscales respectively (Appendix 1, 2). Subscale constructs overlap with moderate to large effect sizes. Therefore, total scores best represent the two measures. We found survivors' CPE-S ratings reliable over six months, and that higher CPE-S at baseline predicted

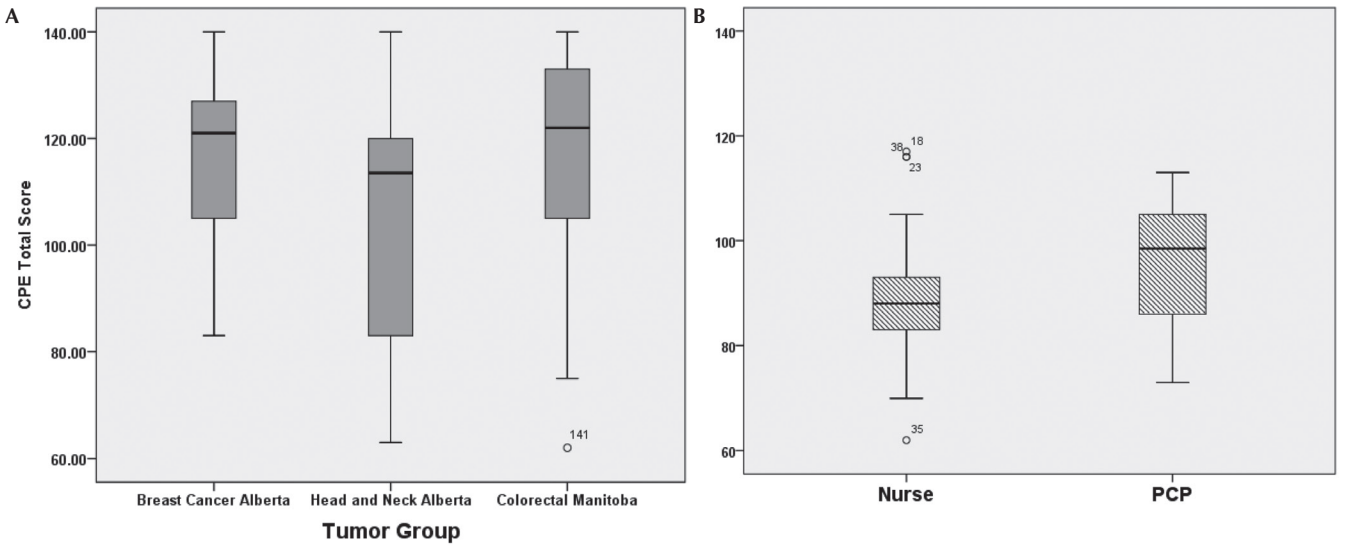

FIGURE 1 CPE-S and CPE-P Distributions across Survivor and Provider Samples. Graphed are box-and-whisker plots. A) Care Plan Evaluation-Survivor (CPE-S) distributions for three tumour groups, two in Alberta and one in Manitoba. B) Care Plan Evaluation-Provider (CPE-P) distributions for two providers, nurses who delivered care plans and primary care physicians (PCPs) who received them. Bottom line on whisker = the smallest observation; bottom line on box = lower quartile; middle line on box = median; top line on box = upper quartile; top line on whisker = largest observation; circles = mild outlier.

TABLE IV Means, internal consistency, and subscale and total score correlations for the Care Plan Evaluation-Healthcare providers (cpe-P)

CPE-P	Alberta nurses							Alberta primary care providers					
	Mean, *rho* and α							Mean, *rho* and α					
	Mean (*SD*) Random 1 Nurse	Mean (*SD*) All Nurses	1	2	3	4	5	Mean (*SD*)	1	2	3	4	5
1. Satisfaction	24.56 (3.54)	23.27 (2.66)	**0.71**					24.09 (3.85)	**0.70**				
2. Usefulness	23.22 (4.21)	22.28 (3.09)	0.53[b]	**0.64**				24.64 (3.59)	0.50[a]	**0.73**			
3. Emotional reaction	21.89 (4.43)	21.91 (3.42)	0.46[b]	0.54[b]	**0.69**			23.00 (3.93)	0.86[b]	0.51[a]	**0.77**		
4. Communication value	21.44 (4.45)	21.25 (3.29)	0.30[a]	0.40[b]	0.57[b]	**0.79**		23.36 (3.90)	0.60[b]	0.65[b]	0.55[b]	**0.70**	
5. Total score	91.00 (15.02)	88.77 (10.40)	0.70[b]	0.74[b]	0.83[b]	0.78[b]	**0.92**	95.05 (12.65)	0.91[b]	0.72[b]	0.89[b]	0.81[b]	**0.91**

[a] $p \leq 0.05$
[b] $p \leq 0.01$. Cronbach's alpha for each subscale and total score are bolded and in the diagonals. Spearman's *rho* correlations, and means (SD) in the tables.

distress-symptom improvement over six months. Better survivor ratings at baseline also predicted a more positive PCP SCP-discussion experience a month later.

We found that CPE-S generalized to another province, tumour group, and an independently developed SCP. We found evidence for discriminant/convergent validity in both provinces. For convergent validity, CPE-S correlated moderately with their ratings of SCP-delivery topic discussions in Alberta, and better continuity-of-care in Manitoba. Discriminant correlations were low for CPE-S with demographic and medical variables, and with distress symptoms.

These indicators further SCP-evaluation development from multiple perspectives. We encourage clinicians to use these SCP-implementation tools for patients and healthcare providers. Measuring patient perceptions of SCPs and healthcare consultations as they leave oncology-centre treatment can facilitate clinical understanding of unmet needs and clarify empowerment strategies for self-managing survivorship tasks. Through CPE-S correlations, we found that tumour groups valued aspects of SCP conversations differently: BCA ratings correlated highly with coping, feelings, and work-issue discussions, whereas HN correlations highlighted cancer information, tests and appointments, and feelings. These correlations offer evidence that patients valued discussing feelings and coping as much as receiving cancer information. For CRC patients, the CPE-S strongly correlated with management of continuity of care. The CPE-S thus captures an aspect of continuity of care as patients enter survivorship, an important patient-related outcome at discharge.

Interestingly, higher end-of-treatment CPE-S scores also correlated with future improvements in symptoms over six months. This indicates the potential for comprehensive care planning consultations to facilitate better prospective symptom management during survivorship transition, a time-period associated with many difficulties for survivors.

These measures also facilitate clearer examination of where and how patients benefit from transition consultations at discharge, and might improve the types of conversations we have and processes we engage as healthcare providers. Primary care providers could utilize their CPE-P for guidance to improve communication with survivors in their practices. If they or their survivors gave low ratings on communication value following an SCP discussion, for instance, they might seek to provide better guidance, information, or referrals to the survivor that would improve communication with other providers.

Patient and provider SCP-experience evaluations could also facilitate research, for instance, moderator or mediator analyses when examining medical, psychosocial, healthy lifestyle, and survival outcomes. If survivors are given one SCP at discharge, then their CPE-S could correlate with or moderate their longitudinal outcomes. If survivors' SCP conversations with PCPS evolve over time, with multiple opportunities to update and enhance their SCP and provide multiple CPE-S ratings over time, researchers could examine whether those changes mediated outcomes. Sharpening our understanding of the links between patients' evaluations of the SCPS we deliver and their outcomes might allow researchers to understand whether and how SCPS improve patient experience, allowing deeper insight if randomized trials have null outcomes[35,48,49].

Limitations

This study used convenience data from two Canadian provinces during funded demonstration projects. These two CPE measures would benefit from further development and psychometric evaluations using larger survivor samples. Questions that ask providers about integrating SCPS into their practices may be welcome additions and improve the CPE-P[26,35]. Small sample sizes, predominantly Caucasian and urban participants, and many exploratory tests (despite $p \leq 0.01$ criterion) may limit generalizability. However, studies documenting the creation and implementation of SCP evaluations are few, and this work may be a valuable starting point to facilitate further development of patient-experience measures to improve clinical practice and the specificity of SCP research questions.

CONCLUSION

Cancer survivors, nurses, and PCPS valued our SCPS, and initial psychometrics of our evaluation measures are promising even though groups' post-treatment symptoms, prognoses, and trajectories widely diverged. We recommend

our revised CPE-S and CPE-P with four 7-item, and 6-item subscales, respectively, comprising each total score. We hope this initial work allows researchers and clinicians to improve the specificity of their research questions and individualized SCP consultations. We also hope others will continue to improve these SCP measures.

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The Care Plan Evaluation results reported here have not been published elsewhere, although portions of these studies have been presented at the Canadian Association of Psychosocial Oncology conference, Toronto, Ontario, May 4–6, 2011; the Alberta Cancer Foundation Research Conference, Banff, Alberta, November 8–10, 2010; the Care About Cancer Conference, Edmonton, Alberta, June 16–18, 2011; the Canadian Cancer Research Conference, Toronto, Ontario, November 27–30, 2011; and the American Society of Clinical Oncology/American Society for Radiation Oncology Multidisciplinary Head and Neck Cancer Symposium, Phoenix, Arizona, January 26–28, 2012; as well as at a number of local continuing education forums. We published a qualitative analysis that utilized demographic and medical data reported here[1].

CONFLICT OF INTEREST DISCLOSURES

We have read and understood *Current Oncology*'s policy on disclosing conflicts of interest, and we declare that we have none.

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APPENDIX 1. CPE-S

DATE _____ ____ ____
Month Day Year

Instructions: For each of the statements below, circle the number that shows how much you agree, using the scale listed below.

1	2	3	4	5
I do not agree		**I agree but have some reservations**		**I completely agree**

1. I feel satisfied with the information in this care plan.	1	2	3	4	5
2. I think this care plan will be useful to me over time.	1	2	3	4	5
3. I am unhappy that some of the issues I know I will face in the future are not included in this care plan.	1	2	3	4	5
4. This care plans feels overwhelming.	1	2	3	4	5
5. I am confused by this care plan.	1	2	3	4	5
6. I feel committed to following through with the recommendations on this care plan.	1	2	3	4	5
7. By looking at this care plan, I feel that my doctors and nurses understand my experience.	1	2	3	4	5
8. I am concerned that I cannot follow through on the recommendations in this care plan.	1	2	3	4	5
9. I want to change some of this care plan to suit my needs.	1	2	3	4	5
10. It is clear from my plan who to go to for each cancer need in the future.	1	2	3	4	5
11. I feel encouraged to try some of the options listed in the care plan for making changes to my lifestyle.	1	2	3	4	5
12. Having this care plan, I have hope that I can navigate this cancer experience.	1	2	3	4	5
13. I do not know who to contact when I have a question.	1	2	3	4	5
14. Having this medical information makes it easier to co-ordinate and to communicate with my family doctor.	1	2	3	4	5
15. I do not feel there is a need for this care plan.	1	2	3	4	5
16. This plan has made it clear who to turn to for help with distress.	1	2	3	4	5
17. Seeing this care plan, I feel less worried than I did before.	1	2	3	4	5
18. I don't know if my family doctor will agree with this care plan.	1	2	3	4	5
19. I am relieved to see such a detailed care plan for my future cancer needs.	1	2	3	4	5
20. I feel I can now talk clearly with my nurse about my post-treatment needs.	1	2	3	4	5
21. Access to this information has improved my quality of life.	1	2	3	4	5
22. This care plan is easy to use.	1	2	3	4	5
23. There is too much information in this care plan.	1	2	3	4	5
24. This plan was tailored well to my specific needs during this transition from treatment.	1	2	3	4	5
25. I am not clear about how to move forward with the recommendations in this care plan.	1	2	3	4	5
26. I am happy with how this care plan was delivered to me.	1	2	3	4	5
27. Having this information has decreased my distress.	1	2	3	4	5
28. I do not know how to follow through on some of these recommendations.	1	2	3	4	5

THANK YOU

APPENDIX 2. CPE-P

DATE _____ ____ ____
Month Day Year

Instructions: For each of the statements below, circle the number that shows how much you agree, using the scale listed below.

1 **I do not agree**	**2**	**3** **I agree but have some reservations**	**4**	**5** **I completely agree**

1. I feel satisfied with the information in this care plan.	1	2	3	4	5
2. I think this care plan will be useful to the survivor over time.	1	2	3	4	5
3. This care plans feels overwhelming to deliver.	1	2	3	4	5
4. I am confused by this care plan.	1	2	3	4	5
5. I am committed to following through with the recommendations on this care plan that pertain to me.	1	2	3	4	5
6. By delivering this care plan, I communicated that I can understand the survivor's experience.	1	2	3	4	5
7. It is clear from their plan who to go to for each cancer need in the future.	1	2	3	4	5
8. I felt encouraged to suggest some of the options listed in the care plan for making changes to the survivor's lifestyle.	1	2	3	4	5
9. Having this care plan, I have hope that I can help the survivor navigate this cancer experience.	1	2	3	4	5
10. I do not know who to contact when I have a question about this care plan.	1	2	3	4	5
11. Having this medical information makes it easier for me to co-ordinate and to communicate with other members of this survivor's medical team.	1	2	3	4	5
12. I do not feel there is a need for this care plan.	1	2	3	4	5
13. This plan has made it clear who to turn to for help with the survivor's distress.	1	2	3	4	5
14. Seeing this care plan, I feel less worried about the survivor than I did before.	1	2	3	4	5
15. I am not interested in this care plan.	1	2	3	4	5
16. I am relieved to see such a detailed care plan for the survivor's future cancer needs.	1	2	3	4	5
17. I feel I can now talk clearly with the survivor about their post-treatment needs.	1	2	3	4	5
18. Access to this information has the potential to improve the survivor's quality of life.	1	2	3	4	5
19. This care plan is easy to use.	1	2	3	4	5
20. There is too much information in this care plan.	1	2	3	4	5
21. This plan was tailored well to the survivor's specific needs during this transition from treatment.	1	2	3	4	5
22. I am not clear about how to move forward with the recommendations in this care plan.	1	2	3	4	5
23. I am happy with how this care plan was delivered to the survivor.	1	2	3	4	5
24. I do not know how to follow through on some of these recommendations.	1	2	3	4	5

THANK YOU