Testing the Impact of a Cancer Survivorship **Patient Engagement Toolkit** on Selected Health Outcomes

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OBJECTIVES: To evaluate an interactive electronic Cancer Survivorship Patient Engagement Toolkit (CaS-PET) using a single-group pre-/post-test design.

SAMPLE & SETTING: 30 cancer survivors with a mean age of 56.5 years (SD = 13.6) were recruited from the University of Maryland Medical Center in Baltimore.

METHODS & VARIABLES: CaS-PET was designed to deliver survivorship care plans (SCPs) with multifactorial support and comprised of SCPs, biweekly follow-up using patient portal e-messages, and online resources. Outcomes included healthrelated quality of life, symptom burden, impact of cancer, fear of recurrence, physical activities, dietary behavior, patient-provider communication, adherence to treatment, and e-health literacy.

RESULTS: At three months, there was a significant improvement in quality of life, physical symptom burden, and total symptom burden.

IMPLICATIONS FOR NURSING: Findings suggest an excellent potential for using CaS-PET for survivors who are in transition from treatment to survivorship.

KEYWORDS cancer; survivorship care plan; patient portal: online resource: discussion board ONF, 46(5), 572-584.

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eeting the care needs of cancer survivors is a population health issue because unmet needs result in poor health outcomes and increased healthcare use (Rajotte, Heron, Syrjala, & Baker, 2017). Cancer survivors who complete active treatments with curative intent and transition to long-term survivorship develop a new set of care needs as they adapt to a new normal while still managing difficult symptoms associated with treatment, such as fatigue and pain (Gosain & Miller, 2013; Mayer, Nasso, & Earp, 2017; National Cancer Institute [NCI], 2018a). Most survivors are not well prepared to manage these issues at home (National Academies of Sciences, Engineering, and Medicine [NASEM], 2018). Addressing these care needs, the Institute of Medicine recommended that every patient with cancer receive a survivorship care plan (SCP), which is a comprehensive document that includes a treatment summary and a follow-up care plan (Institute of Medicine & National Research Council, 2006). The American College of Surgeons Commission on Cancer (2016) requires its accredited programs to provide SCPs to at least 50% of eligible patients.

Prior findings consistently showed that patients and providers perceive SCPs as important health information for cancer care (Birken et al., 2018; LaGrandeur, Armin, Howe, & Ali-Akbarian, 2018; Mayer, Birken, Check, & Chen, 2015). Many descriptive studies have shown positive relationships between SCPs and health outcomes (Jacobsen et al., 2018; Mayer et al., 2015). However, overall adoption rates for SCPs have been low, and there is a lack of randomized controlled trials that show the effectiveness of SCPs (Brennan, Gormally, Butow, Boyle, & Spillane, 2014; Mayer et al., 2015; NASEM, 2018). The current survivorship care planning practice that only requires provision of an SCP at one point is insufficient for survivors who are in transition because they often need continued support (Gosain & Miller, 2013; Mayer et al., 2017; NCI, 2018a). In an effort to fill this gap, the current authors developed an interactive electronic Cancer Survivorship Patient Engagement Toolkit (CaS-PET) as an alternative strategy to the current SCP practice. CaS-PET was designed to deliver SCPs with proactive support and continued follow-up, leveraging health information technology (IT) tools commonly used in cancer centers. The toolkit includes SCPs, biweekly follow-up with patients using patient portal e-messages, and online resources specific to survivors in the transition phase. The aim of this study was to test the preliminary effects of CaS-PET using a pilot sample of 30 patients. The authors hypothesized that, at the end of the CaS-PET intervention, participants would demonstrate significant improvement in health-related quality of life, symptom burden, impact of cancer, fear of recurrence, level of physical activity, dietary behavior, patient-provider communication, adherence to treatment, and e-health literacy.

Survivorship Care Plans

Background and Gaps in Current Practice

Overall adoption rates of SCPs are low (12%-43%) (Birken & Mayer, 2017; NASEM, 2018; National Institutes of Health, 2015). A publication by NASEM (formerly Institute of Medicine) on survivorship care addressed some of the challenges to SCP implementation, including a lack of evidence showing SCPs' effect on survivors' health outcomes and resources needed to develop SCPs (NASEM, 2018). Prior findings consistently showed that patients and providers perceived SCPs as important health information needed for quality cancer care (Birken et al., 2018; Jacobsen et al., 2018; LaGrandeur et al., 2018; Mayer et al., 2015). Many descriptive studies have also shown positive relationships between SCPs and survivors' perceived health outcomes (Mayer et al., 2015). However, the number of randomized controlled trials that have tested the effectiveness of SCPs is limited, and the results are inconsistent (Brennan et al., 2014; Jacobsen et al., 2018; LaGrandeur et al., 2018; Mayer et al., 2015). Jacobsen et al. (2018) reviewed 13 randomized controlled trials that examined the effectiveness of SCPs. The authors found positive findings in single studies for outcomes, such as depressive symptoms and satisfaction with care; however, general findings

on commonly assessed outcomes (e.g., physical, functional, and psychological well-being) were not significant. The authors also reported that, when SCPs were delivered with additional support, findings tended to be more positive.

Many other studies have also reported excess staff time and insufficient resources needed to develop SCPs (Birken, Mayer, & Weiner, 2013; Dulko et al., 2013; Isaacson et al., 2017). Building SCPs requires multiple healthcare providers' involvement, and it takes time and effort to pull accurate data from multiple sources (Viswanathan et al., 2014). These high levels of effort needed to develop SCPs can be justified if SCPs yield tangible outcomes; however, reinforcing a survivorship practice guideline without demonstrated effectiveness is concerning.

Provision of SCPs is a standard of care, and cancer survivors and providers perceive that SCPs are important to cancer care. However, the development of SCPs is a resource-intensive process, and there has been a lack of evidence that shows effectiveness of SCPs. Further efforts must be made to develop more effective SCP delivery approaches and to test their effects on survivors' health outcomes using randomized controlled trials.

Cancer Survivorship Patient Engagement Toolkit

As shown in previous studies, SCPs may yield better outcomes when delivered with the necessary support (Jacobsen et al., 2018). Despite the plethora of resources available online, few cancer support sites offer structured resources focused on survivors who are in transition. As a first step to fill this gap, a threemonth CaS-PET program was developed for survivors to deliver SCPs with supportive resources and a continued communication mechanism between the patient and healthcare team. The program included SCPs, biweekly follow-up using patient portal e-messages, and online survivorship resources (Well Beyond Cancer [WBC]). CaS-PET is designed to make SCPs living documents that continue to evolve through survivorship. SCPs are delivered to patients toward the end of treatment and then are rarely revisited by patients and providers; most survivors do not even review SCPs at home (Faul et al., 2012). In the current fragmented U.S. healthcare system, cancer survivors are often lost to follow-up once treatment ends (Institute of Medicine, 2013; Institute of Medicine & National Research Council, 2006). In-person follow-up of survivors for a prolonged time after treatment ends is a resource-intensive process. CaS-PET, which uniquely packages SCPs with necessary resources using frequently used health IT tools, can be an alternative approach to provide necessary care to this group.

CaS-PET e-messages can be an excellent alternative to face-to-face appointments because they give

FIGURE 1. Overview of Cancer Survivorship **Patient Engagement Toolkit Content**

Session 1: Weeks 1-2

- Introduction to patient portal and Well Beyond Cancer
- Module 1: Transition to Survivorship
 - □ Cancer survivorship
 - □ Survivorship care plans
 - Managing your health
- Discussion board and virtual library

Session 2: Weeks 3-4

- Module 2: Nutrition
 - □ What food should I eat?
 - □ Tips on preparing foods
 - Special considerations
- Goal setting, discussion board, and virtual library

Session 3: Weeks 5-6

- Module 3: Exercise
 - □ Benefits of exercise
 - Guidelines to follow
 - □ Considerations for survivorship
- Goal setting, discussion board, and virtual library

Session 4: Weeks 7-8

- Module 4: Cancer and Relationships
 - Sexuality and intimacy
 - Work after treatment
 - Fertility and pregnancy
 - □ Parenting
- Goal setting, discussion board, and virtual library

Session 5: Weeks 9-10

- Module 5: Fear and Mental Health
 - □ Fear of recurrence
 - Depression and anxiety
 - Concerns about body image
 - How to deal with difficult emotions
- Goal setting, discussion board, and virtual library

Session 6: Weeks 11-12

- Module 6: Stress Management Using Mindfulness
 - How to manage stress
 - What is mindfulness?
 - Practicing mindfulness and loving kindness
- Goal setting, discussion board, and virtual library
- Oncology nurse coordinator performs overall evaluation of goal accomplishments, identifies further care needs, and revises the survivorship care plan as needed.

a bidirectional communication mechanism between patients and the healthcare team while serving as a vehicle to provide proactive, cost-effective support. For example, oncology nurse navigators or nurse coordinators send out prescheduled e-messages asking survivors about their general condition and support needs. Each e-message includes a hyperlink to helpful resources (i.e., a new WBC learning session) (see Figure 1).

The WBC is an online resource program (optimized for mobile devices) with six sessions, including learning modules using videos with accompanying moderated discussion forums and optional virtual libraries. WBC was specifically developed for survivors who are about to complete treatment or who recently completed treatment. The program was developed through collaboration between clinicians in cancer centers and the research team. The content of the WBC program was guided by a conceptual quality-of-life model for survivors (Mayer et al., 2017). The model identified the following four areas of need that affect quality of life for cancer survivors:

- Physical well-being and symptoms (e.g., overall physical health, strength or fatigue, sleep or rest, pain, appetite)
- Psychological well-being (e.g., anxiety or depression, fear of recurrence, cognition or attention, distress of diagnosis and treatment)
- Social well-being (e.g., family distress, roles and relationships, intimacy and sexual function, appearance, employment, isolation, finances)
- Spiritual well-being (e.g., mindfulness, meaning of illness, hope)

All videos were developed by clinicians who provide direct care in cancer centers and survivors. At the end of each WBC module, participants could join the anonymous discussion board to discuss topics related to the modules focusing on health goals, challenges experienced by survivors, and strategies to overcome them. Discussions were moderated by a nurse coordinator.

Methods

Design and Participants

This was a one-group pre-/post-test design study with participants recruited from the University of Maryland Marlene and Stewart Greenebaum Comprehensive Cancer Center in Baltimore. Individuals were eligible if they were aged 18 years or older, diagnosed with cancer, and treated with curative intent within six months from enrollment. Participants could use the Internet and email independently, had access to the Internet and email, and either had an existing patient portal account or signed up for one prior to the start of the study. Upon approval by the University of Maryland, Baltimore Human Research Protections Office, potential participants were identified by the study oncology nurse navigators because their main roles included working with patients who were in active treatment and completing SCPs. If they showed interest, the research nurse approached the patient for full screening and consent. The recruitment period was from January 19, 2018, through June 13, 2018. If the patient did not have a patient portal account, the research nurse assisted the patient in signing up.

In this pilot study, the sample size (N = 30) was determined based on the availability of participants during the data collection period. With this sample, the authors would have sufficient power (p > 0.8) to detect a medium effect size of changes (d = 0.5) in the outcomes pre- and postintervention, assuming the correlation between repeated measures is o.6.

Measures

Demographic variables included age, sex, education level, general health conditions (e.g., chronic illnesses), and cancer-related characteristics (i.e., cancer types, cancer stage, and treatment types). Internet and patient portal experiences were assessed by years of use. At the end of the intervention, participants were asked about their perceptions of the usefulness of SCPs and WBC. The former was assessed using one item with a yes/no response option; the latter was assessed using a three-item usefulness subscale of the Health Web Site Usability Questionnaire on a seven-point Likert-type scale from 1 (strongly disagree) to 7 (strongly agree) (alpha = 0.94) (Nahm, Resnick, & Mills, 2006). In addition, participants' experiences with using the WBC program and SCPs were assessed using open-ended questions.

Outcome Measures

Health-related quality of life was assessed using the 12-item SF-12® that asks about a person's physical and mental health (Gandek et al., 1998; Ware, Kosinski, & Keller, 1996). The measure includes two summary scales: physical composite summary (PCS) and mental composite summary (MCS). It has been used widely in cancer research, and validity of the measure (i.e., convergent and discriminant validity) has been established in previous studies (Bhandari, Kathe, Hayes, & Payakachat, 2018; Horick et al., 2017; Neuner et al., 2014). The calculated alpha ranged from 0.94 to 0.97 (Gandek et al., 1998).

Symptom burden was assessed using the Memorial Symptom Assessment Scale (Portenoy et al., 1994). The scale includes 32 items on either a four- or five-point Likert-type scale from 1 (rarely) to 4 (almost constantly) for frequency, 1 (slight) to 4 (very severe) for severity, and o (not at all) to 4 (very much) for distress. The scale assesses various symptoms across three dimensions: frequency, severity, and distress. Validity of the measure was assessed using criteria measures (e.g., distress), and calculated alpha coefficients ranged from 0.58 to 0.88 (Portenoy et al., 1994).

Impact of cancer on the lives of survivors was assessed by the 47-item Impact of Cancer scale, version 2, on a five-point Likert-type scale from 1 (strongly disagree) to 5 (strongly agree) (Bouskill & Kramer, 2016; Chopra & Kamal, 2012; Crespi, Ganz, Petersen, Castillo, & Caan, 2008; Zebrack, Yi, Petersen, & Ganz, 2008). The scale consists of two higher-order summary scales, a positive impact scale and negative impact scale, as well as three additional subscales measuring employment and relationship effects. The scale has established construct validity and acceptable internal consistency (alpha = 0.76-0.89) (Bouskill & Kramer, 2016; Chopra & Kamal, 2012; Crespi et al., 2008; Zebrack et al., 2008).

Fear of recurrence was assessed by the six-item Assessment of Survivor Concerns scale on a four-point Likert-type scale from 1 (not at all) to 4 (very much) (Gotay & Muraoka, 1998; Gotay & Pagano, 2007). Convergent and discriminant validity of the scale was examined through comparisons with the Positive and Negative Affect Schedule scale and the Center for Epidemiologic Studies-Depression scale. The calculated alpha ranged from 0.63 to 0.93 (Gotay & Muraoka, 1998; Gotay & Pagano, 2007).

Levels of physical activity were assessed using the International Physical Activity Questionnaire-Short Form (Ainsworth et al., 2006). The seven-item measure assesses the amount of time spent on vigorous- and moderate-intensity activities, walking, and sitting (Lee, Macfarlane, Lam, & Stewart, 2011). Validity of the measure was assessed using objective measures, and the calculated alpha ranged from 0.48 to 0.8 (Lee et al., 2011).

Levels of dietary behaviors were assessed using the Combined Fat/Fruit-Vegetable Screener (17-item Block Fat Screener and 7-item Block Fruit-Vegetable Screener) (Block, Gillespie, Rosenbaum, & Jenson, 2000; NutritionQuest, 2014). Higher scores on the fat subscale indicate a diet high in fat, and higher scores on the fruit-vegetable subscale indicate a diet high in fruits and vegetables. Validity of the measure

was assessed using the full-length Food Frequency Questionnaire (King, Vidourek, & Schwiebert, 2009). Repeated measure assessments have shown the stability of the measure.

Patient-provider communication was assessed using the three areas of the Components of Primary Care Index (Flocke, 1997; Flocke, Stange, & Zyzanski, 1998): interpersonal communication, provider's knowledge about the patient, and care coordination. The provider is defined as the oncology nurse navigators/nurse practitioner who delivers the SCP to patients. The measure includes 12 items on a fivepoint Likert-type scale from 1 (strongly disagree) to 5 (strongly agree). The original scale assesses four areas, including patient preference to see the usual doctor. These three areas were chosen because they are associated with communication between the patient and provider. The validity of the measure was examined using factor analysis (Flocke et al., 1998). This tool has been tested in prior studies, and its calculated alpha was 0.88 (Nahm et al., 2017).

Adherence to treatment was assessed using the five-item Medical Outcomes Study General Adherence Scale on a six-point Likert-type scale from 1 (none of the time) to 6 (all of the time). It assesses a person's tendency to adhere to medical recommendations (Hays, 1994). The validity of the measure was assessed using criterion validity, and the calculated alpha was 0.81 (Eisermann, Haase, & Kladny, 2004).

E-health literacy was assessed by the eHealth Literacy Scale, an eight-item tool assessing a person's knowledge, comfort, and perceived skills for locating, evaluating, and applying e-health information for health issues on a Likert-type scale from 1 (strongly disagree) to 5 (strongly agree) (Norman & Skinner, 2006). Validity of the scale has been evaluated using construct validity, and its calculated alpha in a prior study was 0.94 (Chung & Nahm, 2015; Norman & Skinner, 2006).

Procedures

Once a patient agreed to participate and signed the consent form, he or she completed an online baseline survey and met with the oncology nurse navigators to go over the SCP. Then, the first e-message was sent to the participant using the pre-scripted message, followed by biweekly e-messages. Each message asked about participants' general health condition and additional support needs and included a hyperlink to a WBC learning session comprised of a learning module and a discussion board. The navigators developed six biweekly scripted messages, and those messages were

TABLE 1. Sample Chara	cteristics (N = 30)
Characteristic	n
Gender	
Female	23
Male Race	7
Black	18
White	10
Other	2
Ethnicity Not Hispania and ating	20
Not Hispanic or Latino Hispanic or Latino	29 1
Marital status	
Married	16
Not married Education	14
Some college or college degr	ree 22
Graduate degree	6
High school diploma or less	2
Monthly income (\$)	40
3,000 or greater Less than 3,000	18 11
Missing data	1
Employment	
Employed Retired	17 9
Other	4
Chronic disease ^a	
High blood pressure	15
Arthritis Depression	7 6
Diabetes	6
Kidney issues Osteoporosis	3
Heart issues	2
Other	7
Hospitalized in the past 3 m	
No Yes	22 8
Years with main healthcare p	
Less than 1	13
1-3 7-9	7 1
10 or greater	7
Missing data	2
	Continued on the next page

TABLE 1. Sample Characteristics (N = 30) (Continued)

(Continuou)	
Characteristic	n
Computer competency	
Beginner	4
Competent	11
Proficient	10
Expert	5
Used Internet for health information	
Yes	28
No	2
Patient portal experience prior to study	
Yes	24
No	6
Patient portal use in the past 12 months	
0 (none)	1
1-2 times	1
3-9 times	5
Monthly	4
More than monthly	13
Missing data	6

^a Participants could indicate that they had more than one chronic disease.

sent out by the research nurse. A virtual library was also available for additional resources. Participants' response to e-messages was optional. The oncology nurse navigators and the research nurse monitored e-message responses and discussion board posts and provided additional support as needed. If participants' responses were a simple acknowledgment of the receipt (e.g., "I received the email."), then the research nurses responded. If the messages required additional support, the oncology nurse navigators followed up with the participants.

Regarding fidelity monitoring of the intervention, barriers and facilitators for CaS-PET implementation were captured by open-ended questions in patient surveys and clinicians' comments throughout the project. Participants' use of the learning modules and discussion board was monitored weekly via the usage reports generated from the Epic patient portal program and web analytics reports.

Data Analysis

Descriptive statistics (mean, standard deviation [SD], range, frequency, and proportion) were computed for each variable to summarize the data and check

the distribution, outliers, and missing values. Skewed variables (e.g., physical activities) were corrected via logarithm transformation. Linear mixed models were used to test whether changes in outcome measures from baseline to the end of intervention were statistically significant. Mixed models allowed inclusion of all data even if an individual dropped out and was not assessed postintervention. For each outcome, linear mixed models included a random intercept to account for correlation between the repeated measurements. The fixed effects included time indicator variable (baseline and postintervention) and the covariates. Because this study was a one-group pre-/post-test design, the authors controlled the covariates of age, gender, number of chronic diseases, and hospitalization in the past three months in the model to reduce the potential confounding effects from these variables. These covariates are known to affect the outcome measures assessed in this study, such as quality of life, health behaviors, and symptom burden (Cataldo et al., 2013; Salvatore, Ahn, Jiang, Lorig, & Ory, 2015). Effect size (ES) was calculated as the model-based difference of the outcome from pre- to postintervention divided by its baseline SD. The authors also assessed the CaS-PET usage using descriptive statistics (mean, median, mode, and frequency).

The qualitative data were analyzed using a combination of a content analysis method suggested by Krippendorff (2013) and an inductive coding approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Three coders analyzed the qualitative data separately. One coder was a doctoral-prepared researcher who had conducted and published several qualitative studies. The other two coders were research associates who had completed doctoral-level qualitative research courses and had experience in qualitative data analysis. In the initial phase of the coding process, the coders reviewed comments and identified potential themes (or categories). They then coded each comment separately using those themes. As coding progressed, themes were also refined. Upon completion of initial coding, three coders reviewed the results together. Although the results of the initial coding between coders were similar, some discrepancies were noted. The coders discussed those discrepancies, and a consensus was reached for final coding.

Results

A total 39 patients were approached by oncology nurse navigators, and 9 patients declined for various reasons, such as lack of interest (n = 3), no follow-up communication (n = 2), and others (e.g., relocation, did not feel like she belonged to the cohort). Thirty participants agreed to participate in the study; among those, 27 completed the three-month follow-up survey. Three participants did not submit the follow-up survey, and no reason was provided.

Participant Characteristics

The mean age of participants was 56.5 years (SD = 13.6, range = 29-81), and the majority were women (see Table 1). More than half of participants were Black, with about one-third being White. Half of participants were breast cancer survivors. The average years of Internet experience was 16.6 (SD = 6.6, range = 4-31). The majority had experience in using patient portals, with the average being 14.9 months of use (SD = 15.7, range = 1-49). Among those, about half used patient portals more than monthly. Average e-health literacy was 30.3 (SD = 5.1, range = 8-40), as measured by the survey.

Table 2 shows the group means and the SDs of each outcome at baseline and after the three-month intervention. Overall, mental health and physical health

TABLE 2. Outcome Means and Standard Deviations at Baseline and 3 Months Post-Treatment							
	Scale	Baseline (N = 30)		3 Months (N = 27)			
Outcome	Range	$\overline{\mathbf{X}}$	SD	$\overline{\mathbf{X}}$	SD		
Health-related quality of life							
Physical component summary Mental component summary	0-100 0-100	42.2 45.4	7.81 10.55	46.1 44.8	7.48 10.15		
Symptom burden							
Physical symptom ^a Psychological symptom ^a Global distress index ^a Total symptom ^a	0-4 0-4 0-4	0.7 0.9 1 0.6	0.53 0.84 0.74 0.4	0.5 0.7 0.8 0.5	0.28 0.82 0.6 0.3		
Impact of cancer							
Positive impact ^b Negative impact ^a Employment concern ^a Relationship concern (not partnered) ^a Relationship concern (partnered) ^a	1-5 1-5 1-5 1-5 1-5	3.9 2.9 2.9 2 1.6	0.65 0.9 1.32 1.17 0.57	3.9 2.8 3.3 2.3 1.6	0.56 0.82 1.35 1.13 0.58		
Physical activity MET ^c							
Total activity Vigorous activity Moderate activity Walking activity	- - -	6 2.3 4.7 4.9	2.6 3.33 2.75 2.42	6.8 4 5.3 5.4	0.94 3.28 2.07 1.33		
Dietary behavior							
Fat intake Fruit and vegetable intake	0-68 0-28	19.6 11.1	6.01 4.84	20.3 11.8	9.13 5.01		
Health care-related variable							
Adherence Patient-provider communication E-health literacy	5-30 12-60 8-40	25.2 48.3 30.3	4.57 6.02 5.11	24.1 48.8 31.8	3.63 5.23 4.3		
Fear of recurrence	6-24	15.9	15.19	15.9	14.73		

^a Higher scores indicate more negative results.

^b Higher scores indicate more positive results.

[°] Log transformation was used to correct skewness.

MET—amount of energy expended

of the sample participants were 45.4 and 42.2, respectively. Among various physical and mental cancer symptoms, frequently experienced cancer symptoms included lack of energy and pain, followed by worrying about cancer coming back, difficulty sleeping, feeling sad, and constipation. The average scores for fat and fruit/vegetable consumption indicated a diet high in fat and low in fruit and vegetables. For physical activities, about half of the participants reported a low level of activity followed.

Hypothesis Testing

Table 3 presents the results of linear mixed models examining the differences of changes in outcomes from baseline to three months. At the end of the intervention, participants improved physical health and reduced symptom burden significantly. Although the mean scores for all different types of physical activities increased, no statistical significance was achieved. The e-health literacy outcome also showed improvement, but the increase was not statistically significant.

Participants' experience with using SCPs and WBC resource program: The majority of participants (n = 22) found the SCP helpful. For the optional openended question—What do you like most about having the SCP?—20 participants responded. More than half of them (n = 11) commented that the SCP provided helpful information on treatment and future plans. Six participants commented that SCPs helped them stay healthy. One participant stated the following:

The plan helped me move from treatment to living in the present. I was stuck in the cancer mode and the plan enabled me to see a future in survivorship. It helped me plan and set realistic goals.

Regarding the question on suggestions, most (n = 17) responded that they had no further suggestions. Overall, participants reported that the WBC program helped them better manage their health (\overline{X} = 18.07, SD = 4.56, range = 3-21). For the optional open-ended question-What do you like most about having the WBC online resource program?—the majority (n = 16)mentioned helpful information, such as "It gave me a better understanding of the importance of obtaining knowledge pertaining to my treatment and proper questions to ask." Two participants specifically appreciated the videos, and another two mentioned the online access. Two participants appreciated learning from others. Most other comments on the WBC were positive.

Fidelity monitoring: Nineteen of 27 participants completed all six modules, and seven completed less than 50% of modules. Usage of each module ranged from 60% to 80%. The most frequently used modules were Transition to Survivorship (80%) and Nutrition (73%). The mean time for module review throughout the intervention period was 155 minutes (SD = 153.4, median = 111, range = 0.55-706.8). Findings from the usability assessment showed that the program was user friendly (\overline{X} = 72.5, SD = 17, range = 12–84). Throughout the project period, the help desk received only a few calls (two for forgotten usernames, two for missed survey items, and one for a web browser issue).

Discussion

The demographic and descriptive findings from this pilot sample provide helpful information for further survivorship studies with Black cancer survivors. Compared to the overall cancer population (incidence rates of 448.8 for White people versus 453.4 for Black people per 100,000 people; census rate of 72.3% White people versus 12.7% Black people [NCI, 2018b; U.S. Census Bureau, n.d.]), the selected sample included a high proportion of Black cancer survivors. Participants were recruited from a cancer center that treated largely underserved inner-city patients, 11 of whom had an income of less than \$3,000 per month (the median monthly income in the United States was about \$3,900 in the second quarter of 2019 [U.S. Department of Labor, 2019]). Findings suggest an opportunity to improve healthy behaviors in this group. At baseline, when asked about their habits during the past 12 months, participants reported consuming a diet high in fat and low in fruit and vegetables. For physical activities, about half of the participants (n = 16) reported a low level of activity. At the end of the intervention, both behaviors improved somewhat, but the improvements were not statistically significant. Combined with a high prevalence of chronic conditions in this age group, unhealthy diet and activity behaviors placed this group of cancer survivors at high risk for worse outcomes. Therefore, it is particularly important to provide resources that can help these survivors improve their diet and exercise.

Immediately after treatment, survivors need continued support for physiologic and psychological health. For example, the majority of participants in the current study experienced lack of energy and pain, and about half reported fear of cancer recurrence and feeling sad. In addition, the overall average mental health status in this sample was lower than typical for individuals with a history of cancer. The untoward baseline health habits combined with lingering symptoms from cancer and its treatment may have negatively affected the physical and mental health of this sample. SCPs can be helpful tools to address these issues; however, appropriate support will need to be provided.

At the end of the intervention, there was a significant improvement in the physical health dimensions of quality of life and symptom burden. Most other variables also showed some improvement in mean scores, but the changes were not significant. In general, cancer survivors who complete active treatment with curative intent and transition to a new normal seem to have significant mental and emotional support needs. In the current study, despite improvement in physical health, mental health areas (e.g., fear of recurrent, concerns with job) did not show much improvement (either staying the same or slightly decreasing). Individuals with cancer who are in active treatment receive a great deal of encouragement and support from healthcare teams, peer patients, and family members. However,

TABLE 3. Results of Hypotheses Testing From Linear Mixed Models From Baseline to 3 Months Post-Treatment

Outcome	Scale Range	Estimate	95% CI	р	ES
Health-related quality of life					
Physical component summary Mental component summary	0-100 0-100	3.38 -0.51	[0.02, 6.75] [-3.42, 2.4]	0.049 0.722	0.43 -0.05
Symptom burden					
Physical symptom ^b Psychological symptom ^b Global distress index ^b Total symptom ^b	0-4 0-4 0-4 0-4	-0.24 -0.1 -0.14 -0.14	[-0.43, -0.04] [-0.33, 0.12] [-0.31, 0.04] [-0.27, -0.01]	0.018 0.351 0.13 0.038	-0.45 -0.12 -0.18 -0.34
Impact of cancer					
Positive impact ⁶ Negative impact ^b Employment concern ^b Relationship concern (not partnered) ^b Relationship concern (partnered) ^b	1-5 1-5 1-5 1-5 1-5	-0.005 -0.16 0.43 0.19 0.05	[-0.18, 0.17] [-0.37, 0.04] [0.12, 0.74] [-0.34, 0.72] [-0.23, 0.33]	0.956 0.114 0.01 0.45 0.688	-0.01 -0.18 0.33 0.16 0.09
Physical activity MET ^d					
Total activity Vigorous activity Moderate activity Walking activity	- - -	0.63 1.47 0.55 0.22	[-0.14, 1.4] [-0.09, 3.04] [-0.72, 1.81] [-0.39, 0.82]	0.104 0.064 0.382 0.464	0.24 0.44 0.2 0.09
Dietary behavior					
Fat intake Fruit and vegetable intake	0-68 0-28	0.42 0.13	[-2.63, 3.48] [-1.43, 1.68]	0.78 0.869	0.07 0.03
Health care-related variable					
Adherence Patient-provider communication E-health literacy	5-30 12-60 8-40	-0.94 0.75 1.43	[-2.4, 0.52] [-1.57, 3.08] [-0.46, 3.33]	0.196 0.509 0.133	-0.21 0.12 0.28
Fear of recurrence	6-24	-0.3	[-1.81, 1.21]	0.689	-0.06

^a Beta coefficient estimation of the time term in linear mixed models including covariates (e.g., age, number of chronic illness, gender, hospitalization)

^b Higher scores indicate more negative results.

^c Higher scores indicate more positive results.

^d Log transformation was used to correct skewness.

CI-confidence interval; ES-estimated effect size; MET-amount of energy expended

when they finish treatment, they feel lost and worry about the future (Institute of Medicine & National Research Council, 2006; Philip & Merluzzi, 2016). Although the importance of psychosocial support needs in cancer survivors has been addressed in other studies (Martínez Arroyo, Andreu Vaíllo, Martínez López, & Galdón Garrido, 2019; Naughton & Weaver, 2014; Weaver et al., 2012), these mental health issues are less recognized by healthcare providers compared to physical symptoms (Naughton & Weaver, 2014). Emerging health IT tools, such as patient portals and e-messages, can empower and engage patients in their care and allow the healthcare team to provide necessary support to meet their care needs, including their mental and emotional needs, beyond the active treatment phase (Badr, Carmack, & Diefenbach, 2015; Fleisher et al., 2015).

Findings showed that survivors who are in transition from the active treatment phase to survivorship may benefit from proactive provision of resource materials. These findings are consistent with other findings (Ganz et al., 2013; NASEM, 2018). For example, in a Breast Health Global Initiative 2013 consensus statement, Ganz et al. (2013) emphasized that patient education could help survivors better transition from a provider-intense active treatment program to a post-treatment self-management program.

The SCP components and WBC were favorably reviewed by the participants. The most frequently used modules were Transition to Survivorship and Nutrition. Considering the diet habits of this sample, these findings suggest a meaningful potential for using CaS-PET to improve health behaviors in this group. Based on the authors' experience with other online studies, embedding hyperlinks to modules in patient portal e-messages seems to be an effective way to get participants to open the web modules. In addition, the low attrition rate of 10% was encouraging for a threemonth intervention study. The majority of the sample had a low socioeconomic background; however, they owned smartphones (many used CaS-PET on their smartphones). Therefore, online support can be an effective alternative to face-to-face clinic visits for this group.

A major limitation of this pilot study is its small sample size and lack of a control group. In addition, the selected sample included a high proportion of Black and underserved cancer survivors. Therefore, generalizability of the findings needs to be limited accordingly. The setting of the study included only one large cancer center, and the data collection mainly relied on self-reported surveys. The next phase of the

KNOWLEDGE TRANSLATION

- Most cancer survivors who have completed treatment with curative intent need continued support, such as survivorship care plans, to manage their care.
- E-health programs can be effectively used to deliver supportive follow-up care to the rapidly growing number of cancer survivors who transition from the active cancer treatment phase into
- Patient portals, such as e-messages for continued follow-up, can be an excellent tool to empower and engage cancer survivors in

study will be conducting a randomized controlled trial with larger samples recruited from multiple settings with a refined CaS-PET based on the findings from this pilot study. The data collection method will also include chart reviews and objective measures, such as body mass index and step counts.

Implications for Nursing

There has been a growing emphasis on the roles of oncology specialty nurses in the provision of survivorship care (Mayer et al., 2017; Mendelsohn et al., 2017; Rosenzweig, Kota, & van Londen, 2017). Often, oncology nurse navigators are those who are responsible for developing and providing SCPs and coordinating survivorship care. CaS-PET may be an approach to assist oncology nurse navigators' efforts in providing evidence-based and customized resources to survivors. Using health IT tools, such as patient portals, CaS-PET also helps coordinate better care because it can facilitate interprofessional team care. Nurses have track records of providing survivorship care to individuals with cancer, and it is time to standardize their efforts and assess the impact of the care. The current study's findings can provide clinicians and researchers with important preliminary data that can propel further studies.

Conclusion

Cancer survivors who complete treatment and transition to long-term survivorship need continued support from care providers. The findings suggest that CaS-PET can be an effective strategy to meet care needs of survivors. Considering the rapidly increasing number of cancer survivors and expected shortage of oncology specialists, the impact of this type of resource will soon be higher. Through successfully incorporating the CaS-PET protocol into the selected cancer center's workflow, this study demonstrated that cancer centers could leverage the existing health IT tools to deliver SCPs with resources. In particular, provision of proactive support can empower and engage survivors in their care, ultimately resulting in improved patient outcomes and higher satisfaction with care. Additional larger-scale randomized controlled trials are needed to test the effectiveness of the CaS-PET with survivors with diverse cancer types.

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