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Evaluation of the efficacy and usability of NCI's *Facing Forward* booklet in the cancer community setting

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Abstract
Introduction The NCI developed the print-based educational brochure, *Facing Forward*, to fill a gap in helping cancer patients meet the challenges of transitioning from active treatment to survivorship; however, little research has been conducted on its efficacy.

Purpose The aims of this study were to evaluate the efficacy of *Facing Forward* in promoting the uptake of recommended behaviors (e.g., ways to manage physical changes) and to explore its usability.

Methods At the last treatment appointment, early-stage breast, prostate, colorectal, and thoracic cancer patients ($N=340$) recruited from community clinical oncology practices and an academic medical center completed a baseline assessment and were randomized to receive either *Facing Forward* ($n=175$) or an attention control booklet about the NCI's Cancer Information Service ($n=165$). Patients completed follow-up assessments at 8 weeks and 6 months post-baseline.

Results The reported uptake of recommended stress management behaviors was greater among intervention than control participants at both 8 weeks post-baseline ($p=0.016$) and 6 months post-baseline ($p=0.017$). At 8 weeks post-baseline, the intervention control group difference was greater among African-American than Caucasian participants ($p<0.03$) and significant only among the former ($p<0.003$); attendance at a cancer support group was also greater

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among the intervention than control group participants ($p < 0.02$). There were no significant intervention control group differences in the reported uptake of recommended behaviors in three other categories ($p > 0.025$). Intervention participants rated *Facing Forward* as understandable and helpful and indicated a high level of intention to try the behaviors recommended.

Conclusions Facing Forward can enhance early-stage survivors' reported ability to manage stress and increase support group use during the reentry period.

Implications for Cancer Survivors Facing Forward can help survivors meet the challenges of the reentry period.

Keywords Survivorship · Cancer control · Psychosocial interventions · Facing Forward

Introduction

Given breakthrough advances in cancer screening and treatment, over 12 million people in the USA are currently living with a personal history of cancer [1–3]. Indeed, the 5-year survival rates for cancer have improved dramatically over the last 20 years, increasing from an average of 50 % across all cancer sites and stages between 1975 and 1977 to 68 % between 1999 and 2006 [1]. For localized breast, prostate, and colorectal cancer diagnoses, the 5-year survival rates are even more striking: 98, 100, and 90 %, respectively [4]. Thus, cancer patients are increasingly likely to be confronted with a range of survivorship challenges, including living with the possibility of recurrence or diagnosis with a second cancer as well as the need to cope with the often adverse physical and psychosocial side effects of the disease and its treatment [5].

Challenges of the reentry period

A critical period for cancer survivors is the year following completion of primary treatment, referred to as the reentry phase [6–11]. Despite the fact that treatment completion is generally viewed as a positive event, a growing literature documents the life disruption that cancer patients can experience during this period [5, 12–16]. Challenges of reentry span all of the major domains of quality of life, including physical, psychological, social, and existential [11]. In the physical domain, persistent symptoms are common and vary as a function of both the type of cancer and the treatment. For example, breast cancer survivors who have had chemotherapy can experience fatigue, sexual problems, difficulty with memory, musculoskeletal problems, and/or weight problems [17]. Prostate cancer patients who have had radical prostatectomy or radiotherapy can experience urinary, sexual, and/or bowel dysfunction [18]. With regard to psychological difficulties, it is estimated that 16–34 % of survivors experience at least one of the three symptoms of posttraumatic stress (i.e., high levels of intrusive thoughts, avoidance, and hypervigilance) [19]. In the social sphere, survivors often experience social stigma and other more subtle issues related to their social relationships, as well as socioeconomic barriers to employment and insurance [11, 20]. In the existential arena, survivors report changes related to the meaning of life, self-identity, autonomy, dignity, and spirituality [21–23].

Not surprisingly, many survivors feel ill-equipped to deal effectively with the range of challenges they face at this transitional juncture, as well as the need to adjust to a "new" normal, suggesting a lack of available informational and other resources to assist them in their coping efforts [11, 22, 24]. Notably, 34 % of survivors report having more than five moderate or severe unmet needs at the beginning of the post-treatment phase; for two thirds of these individuals, these unmet needs continue to be reported 6 months later [25]. A recent systematic review of 57 studies quantified the unmet needs of survivors and found that as many as 83 % of survivors have experienced unmet informational needs during the post-treatment period; unmet needs also arise with respect to physical concerns (52 %), activities of daily living (41–47 %), supportive care (38–53 %), sexuality (33–34 %), communication (30 %), psychosocial matters (8–17 %), and finances (5–13 %) [26]. Yet, healthcare practitioners are generally not well-equipped to provide systematic guidance to survivors about securing needed resources [27].

NCI resource for the reentry period: *Facing Forward*

To help bridge the gap in available resources for cancer survivors during the reentry period, the National Cancer Institute developed Facing Forward: Life after Cancer Treatment. It was first published in 1990 [28] and underwent extensive revision in 2002. In 2006, the Office of Cancer Survivorship of the NCI, in collaboration with the Office of Communication and Education, published a another major revision based on current evidence pertaining to the reentry phase and adapted from materials developed for a psychoeducational trial for women with breast cancer during reentry, NCI grant no. CA63018) [29, 30]. The revised booklet was developed with input from both cancer experts and patients. Patient input was solicited through focus groups and on assembled versions of the text prior to publication.

Facing Forward is directed toward adults of diverse ages and cancer types. It addresses five major domains of informational needs experienced by survivors after active treatment: physical functioning, emotional functioning, interpersonal relationships, life perspectives, and practical concerns. It includes information related to each of these domains and provides associated behavioral recommendations [9, 31–33]. It is available at no cost through the National Cancer Institute in English and Spanish (for a description of the translational process, see [34]) in print, pdf, and online versions (http://www.cancer.gov/cancertopics/coping/life-after-treatment).

While *Facing Forward* materials are provided at all NCI-designated clinical and comprehensive cancer centers, as well as the NCI Community Cancer Centers Program sites, it is difficult to know how widespread use of these booklets may be more generally. However, NCI warehouse data indicate that an average of 55,000 print copies are ordered per year, which does not include the number of copies printed individually online or printed by cancer centers using NCI print files. Delivery route can be very variable depending on the setting of care and clinical practice (e.g., provided by physician or other healthcare team member, picked up in waiting room, accessed by phone or online). Although *Facing Forward* has far-reaching potential for widespread dissemination, the efficacy and the usability of this material have yet to be systemically evaluated, particularly in the context of the community setting where the majority (85 %) of cancer survivors receive care and where patient educational and social resources often are not readily available [35].

Study objectives

To fill this empirical void, we conducted an evaluation of *Facing Forward*, predominantly within the community clinical oncology setting. Guided by the Cognitive Social Health Information Processing (C-SHIP) model [28, 29], which emphasizes the interplay among behavioral intentions and actions with underlying cognitions and affects, we conducted a randomized controlled trial comparing a group that received *Facing Forward* to an attention control group. The study focused on early-stage breast, prostate, colorectal, and thoracic cancer patients because these are the diagnoses with the greatest prevalence and overall high survivorship rates [1]. The primary aims of the study were to evaluate the efficacy of *Facing Forward* in promoting the self-reported uptake of behavioral recommendations, including cancer support group use, as well as to evaluate the moderating role of ethnicity with respect to intervention efficacy [30, 31]. Guided by the C-SHIP model, we postulated that *Facing Forward* would help patients to emotionally and cognitively process their personal perceptions of vulnerability and by providing them with actionable recommendations (i.e., stress management techniques, side effects management, and participation in support groups) at a time of heightened awareness and vulnerability at reentry. Thus, our primary outcomes of interest were selected to reflect the self-reported uptake of action-oriented behaviors that are recommended in *Facing Forward*. A secondary aim was to examine the usability of the booklet for survivors in the *Facing Forward* arm in terms of the extent to which they reported reading it, perceived it to be understandable and helpful, and felt knowledgeable and confident about engaging in the recommended management actions.

Methods

The trial is registered at ClinicalTrials.gov, no. NCT01440855.

Participants

Participants (N=340) were adult cancer patients (>18 years) who were finishing chemotherapy and/or radiation therapy for stage I, II, or III breast, colorectal, prostate, or thoracic cancer. These cancer diagnoses were chosen because they are common in the survivorship population and to allow for generalizability of the study findings to both genders. In addition, the sample was limited to English speakers and people with their first primary cancer. Survivors were excluded from the study if they had received surgery only with no adjuvant therapy or had a second primary cancer or recurrent disease.

Procedure

Recruitment was conducted between February 23, 2005 and May 30, 2009, following approval from the Fox Chase Cancer Center's (FCCC) institutional review board as well as by the local institutional review boards. Participants were recruited from community clinical oncology practices (CCOP) as well as from FCCC and research centers affiliated with the FCCC CCOP Research Base. Participants were recruited by the site nurse either on the patient's last day of treatment or at his or her first follow-up appointment if it was within 28 days after the last treatment visit. After completing the consent form and a baseline survey, participants were stratified by type of cancer, recruitment site, gender, and whether or not they had received chemotherapy in light of the evidence of more severe lingering symptoms associated with chemotherapy than with other treatments [32]. The site nurse, who was not informed about the study hypotheses, then employed a simple randomization strategy, developed by the FCCC Data Management group and implemented through the use of a computerized algorithm, to allocate participants to receive either the print version of *Facing Forward* or the print version of the Cancer Information System (CIS) Fact Sheet.

Follow-up surveys were mailed at 8 weeks and 6 months post-baseline. The 8-week follow-up assessment time point was selected because cancer patients frequently report sustained or increased concerns and needs in the time period between their treatment and the 3-month follow-up visit [9, 33]. The 6-month follow-up point was selected to assess the more distal effects of the intervention [30]. Reminder phone calls were made by the FCCC research staff to non-responders 2 weeks after survey mailings.

Intervention and control arms

Intervention arm participants received the NCI's *Facing Forward*, a 61-page booklet that describes common feelings and reactions that cancer survivors experience during the reentry phase and offers behavioral recommendations to help them through this period, i.e., ways of dealing with common problems and brief guidelines for managing physical, emotional, social, and practical concerns [34]. The booklet contains the following sections, in sequence: Congratulations on Finishing Your Cancer Treatment, Getting Follow-up Medical Care, Ways to Manage Physical Changes, Body Changes and Intimacy, Your Feelings, Social and Work Relationships, and Reflection. There is also a six-page appendix which provides information on Financial and Legal Matters and Resource Organizations. Most notably, the appendix also contains detailed instructions on "Learning to Relax," which includes two relaxation exercises with step-by-step instructions designed to help survivors manage stress; these are the most fine-grained and formalized action-oriented behavioral recommendations in the booklet. To increase the salience of the booklet and facilitate its use, the study nurse at each site provided intervention arm participants with a brief scripted verbal introduction to the booklet, accompanied by a one-page printed orientation that informed them about its purpose and described its sections.

To control for increased attention and the written intervention format, control arm participants received the print version of the CIS Fact Sheet, which is available on the Cancer Information Service web site [35]. This five-page document provides information about the Cancer Information Service, organized as follows: "What is the NCI's Cancer Information Service," "How can the NCI's CIS information specialists help me," and "How can I use the CIS's services." It also includes definitions of glossary terms and a table of e-mail and web site addresses. Intervention arm participants also received a copy of this booklet. To equate for the procedure used in distributing *Facing Forward* to the intervention arm participants and to increase the salience of the control booklet, the study nurse at each site provided a brief scripted verbal introduction to the material, accompanied by a one-page printed orientation that provided information about the purpose of the Cancer Information Service, how to contact it, and its hours of operation.

Measures

Socio-demographic and medical variables

Age, gender, race, education, marital status, cancer type, and cancer treatment were assessed at baseline.

Reported uptake of behavioral actions

The extent to which participants in both trial arms reported engaging in the recommended behaviors contained in *Facing Forward* was the trial's primary outcome. The behaviors were organized into four subscales: use of follow-up medical care (six items, e.g., "Have you developed a wellness plan?"); side effects management (seven items, e.g., "Have you used any tips for regaining your appetite?"); stress management (eight items, e.g., "Have you used relaxation techniques?"); and social and financial matters management (seven items, e.g., "Have you used any suggested tips for dealing with family issues?"). Assessments asked whether the respondent engaged in each behavior (0 = "no", 1 = "yes"); "yes" responses were summed to create the subscale scores. Questions were administered at baseline and at 8 weeks and 6 months post-baseline. Cronbach's alpha values in the present sample for baseline, 8-week, and 6-month subscale scores were, respectively: use of follow-up medical care, 0.57, 0.55, and 0.62; side effects management, 0.64, 0.63, and 0.60; stress management, 0.82, 0.85, and 0.84; social and financial matters management, 0.75, 0.74, and 0.75.

Reported attendance at a cancer support group

One item assessed reported attendance at a cancer support group: "Have you attended a cancer support group?" 0 = "no", 1 = "yes." This item was administered to participants in both trial arms at baseline and at 8 weeks and 6 months post-baseline.

Usability of Facing Forward

To measure the usability of *Facing Forward*, we developed original items and also used adapted versions of items developed by the NCI Cancer Survivorship Education and Promotion Program. Items required a rating scale response and were administered to participants in the *Facing Forward* arm at 8 weeks and 6 months post-baseline. Assessments fell into the following seven categories, each of which was measured as an unweighted item sum score: (1) *Read* (nine items)—whether patients read each of the six booklet sections and three appendices, e.g., "Did you read the [e.g.] the Medical Care Section of the *Facing Forward* guide?" (0 = "no", 1 = "yes"); (2) *Extent read* (13 items)—the extent to which patients read each of the six booklet sections, three appendices, and the tips or exercises included in them, e.g., "To what extent did you read [e.g.] the information about getting follow-up medical care after cancer treatment" (1 = "not at all" to 5 = "completely"); (3) *Understandability* of the booklet (15 items), e.g., "In general, how understandable did you find the information contained in this publication? (1 = "not at all understandable" to 4 = "very understandable"); (4) *Informativeness* (eight items)—how informative the booklet was with respect to eight post-treatment challenges, e.g., "After reading the *Facing Forward* booklet, I felt I knew more about communicating with my doctor to get the most out of my visits" (1 = "strongly disagree" to 4 = "strongly agree"); (5) *Confidence* (eight items)—how confident patients were in their ability to deal with the same eight post-treatment challenges, e.g., "After reading the *Facing Forward* booklet, how confident are you about your ability to communicate with your doctor to get the most out of your visits" (1 = "extremely confident" to 5 = "not at all confident"); and (6) *Helpfulness* (15 items) of the booklet, e.g., "In general, how helpful did you find this publication? (1 = "not at all helpful" to 4 = "very helpful"). Cronbach's alpha values in the present sample for the 8-week and 6-month item category scores are as follows, respectively: *Read*, 0.85 and 0.86; *Extent read*, 0.97 and 0.96; *Understandability*, 0.96 and 0.87; *Informativeness*, 0.94 and 0.94; *Confidence*, 0.92 and 0.93; and *Helpfulness*, 0.97 and 0.94.

Center for Epidemiologic Studies—Depression Scale

This is a 20-item self-report scale designed for use in the general population [36] that has excellent concurrent validity [37]. Scores range from 0 to 60; higher scores indicate more symptoms of depression. Generally, a cutoff score of 16 indicates a need for further assessment [36]. The scale was administered at baseline and at 8 weeks and 6 months post-baseline. Cronbach's alpha values in the present sample for baseline, 8-week, and 6-month scores were, respectively, 0.81, 0.78, and 0.80.

Statistical analysis

All analyses were conducted using SAS, version 9.2. The primary outcome was reported usage of behaviors in the four categories as well as reported attendance at a cancer support group. Chi-square analysis for categorical variables and *t* tests and ANOVA for continuous variables were employed (at α= 0.05, two-tailed) to conduct comparisons to determine whether there were potential confounder variables, i.e., demographic and medical variables and baseline scores on the outcome variables. Analysis of covariance (ANCOVA) was used to evaluate the efficacy of *Facing Forward* (aim 1), controlling for the baseline values of reported usage of behaviors; two-tailed tests were conducted at α=0.05/2=0.025 to control the family-wise type I error, i.e., the probability of rejecting one or more of the hypotheses erroneously when performing multiple hypothesis tests [38]. Linear regression was used to evaluate the moderating status of ethnicity; socio-demographic variables (age, gender, education, marital status); and medical variables (disease site, disease stage, chemotherapy, radiation therapy). Linear regression was used to evaluate the moderating status of ethnicity; socio-demographic variables (age, gender, education, marital status); and medical variables (disease site, disease stage, chemotherapy, radiation therapy). Whenever a significant moderator was found, we computed the intervention effect at 8 weeks or 6 months by the moderator status from the ANCOVA model to make sense how this variable moderates the intervention effect. To characterize the usability of *Facing Forward* (aim 2), means, standard deviations, and percentages were computed. All analyses were performed on an intent-to-treat basis and missing data values were censored.

Results

Participant flow

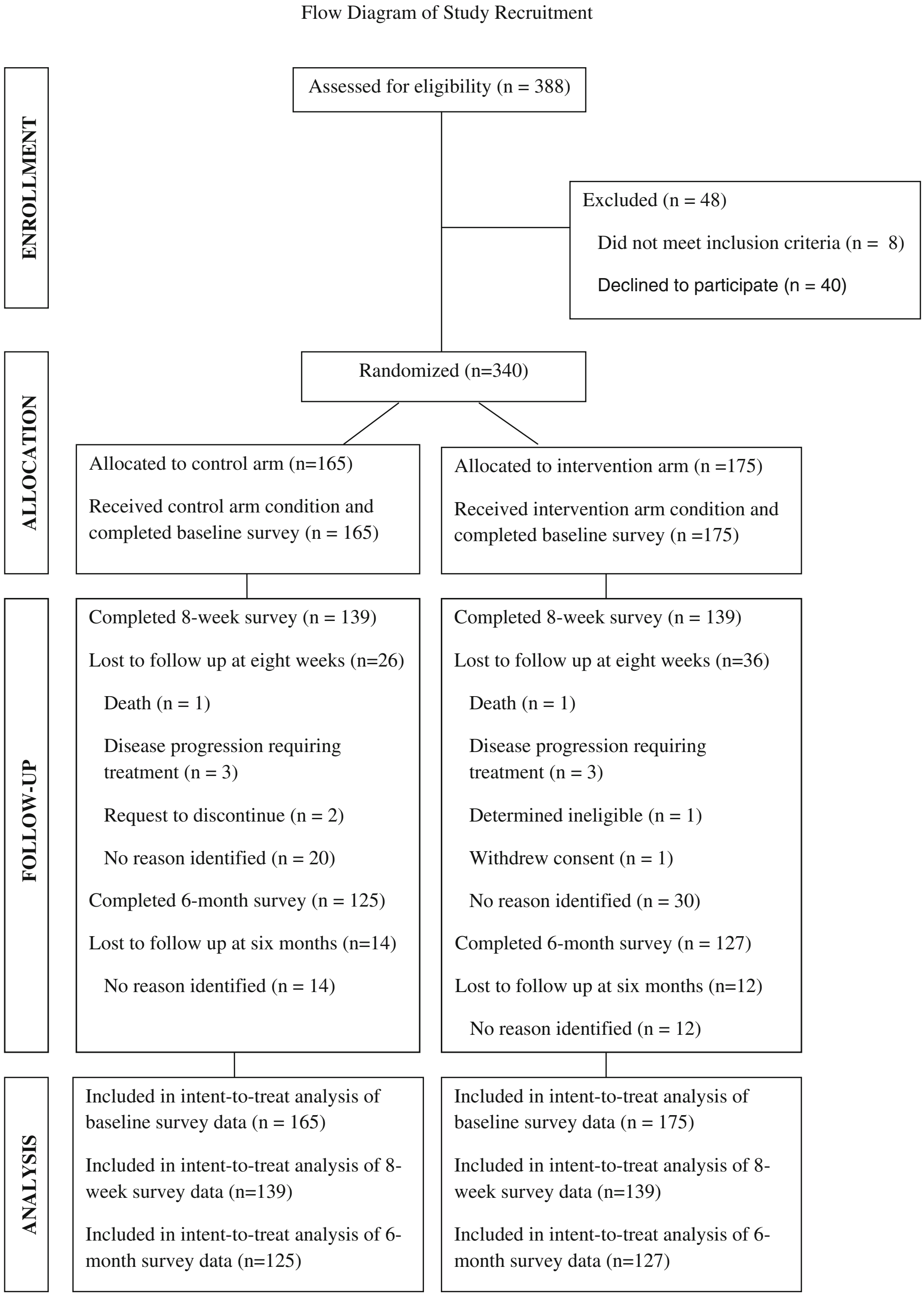
Participants (N=340) were recruited from the following sites: Hematology-Oncology Associates of Central New York (n=75), Geisinger Hospital (n=74), Main Line Health (n=72), Christiana Hospital (n=43), North Shore University Hospital (n=48), The State University of New York Downstate Medical Center (n=12), Medical College of Georgia (n=9), Fox Chase Cancer Center (n=5), and Meharry Medical College (n=2). Of the 340 participants, 277 (81.47 %) completed the 8-week assessment and 251 (73.82 %) completed the 6-month assessment. Retention did not vary as a function of the trial arm (p>0.05; Fig. 1). With respect to differences between completers and noncompleters, at 8 weeks, completers were older (completers: mean age=58.7 years, SD=12.2; noncompleters: mean age=55 years, SD=11.29; mean difference=3.7 years, p<0.02) and at, 6 months, completers had lower Center for Epidemiologic Studies—Depression Scale (CES-D) scores (completers: mean CES-D score=11.3, SD=8.01; noncompleters: mean CES-D score=15.2, SD=10.44; mean difference=−3.9, p<0.001).

Participants had a mean age at baseline of 58 years, were predominantly female (76.2 %), Caucasian (84.1 %), and married (69.6 %) and had at least a high school education (65.7 %; Table 1). Cancer diagnoses included stage I, II, and III breast (67 %), prostate (16.2 %), colorectal (13.2 %), and thoracic cancers (3.5 %). Stage of diagnosis did not significantly differ between the intervention and control arms. Participants had received radiation therapy (72.35 %), chemotherapy (28.53 %), and/or biological therapy (1.47 %). At baseline, the mean CES-D score was 12.04 (SD=8.63). There were no significant differences at baseline between the intervention and control groups with respect to socio-demographic (age, gender, race, education, marital status) and medical variables (cancer type, cancer stage, cancer treatment).

Efficacy of *Facing Forward*

Table 2 highlights the differences between the intervention and control groups in the uptake of behaviors recommended in

Fig. 1 Flow diagram of study recruitment



Facing Forward, adjusted by baseline uptake of recommended behaviors. The reported uptake of recommended stress management behaviors among the intervention participants was greater than among the control participants at both 8 weeks post-baseline ($p=0.016$, effect size=0.299) and 6 months post-baseline ($p=0.017$, effect size=0.310), adjusting for baseline levels of reported uptake (Table 2). The reported uptake of recommended behaviors in the other behavior categories (follow-up medical care, side effects management, and social and financial matters management) did not differ between the intervention and control groups at either time point ($p>0.025$), adjusting for baseline levels of reported uptake. The difference in uptake of stress management behaviors between the intervention and control groups at 8 weeks was greater among African-American than among Caucasian participants ($p<0.03$; Fig. 2) and significant only among African-American participants ($p<0.003$, effect size=0.982; difference among Caucasian participants, $p=0.144$), adjusting for the baseline levels of reported uptake. We also examined the moderating effects of age, gender, marital status, education, cancer diagnosis, cancer stage, chemotherapy,

Table 1 Characteristics of the study sample at baseline

	All (*N*=340)	Control (*n*=165)	Intervention (*n*=175)	*p* value[a]
Age (years)	58 (12.1)[b]	57.1 (11.86)	58.9 (12.3)	0.19
Gender				
Male	81 (23.82)	38 (23.03)	43 (24.57)	0.74
Female	259 (76.18)	127 (76.97)	132 (75.43)	
Race				
Caucasian	286 (84.12)	143 (86.67)	143 (81.71)	0.21
African American	54 (15.88)	22 (13.33)	32 (18.29)	
Diagnosis				
Breast cancer	228 (67.06)	112 (67.88)	116 (66.29)	0.73
Colorectal cancer	45 (13.24)	23 (13.94)	22 (12.57)	
Prostate cancer	55 (16.18)	26 (15.76)	29 (16.57)	
Thoracic cancer	12 (3.53)	4 (2.42)	8 (4.57)	
Stage				
Stage I	109 (32.06)	50 (30.30)	59 (33.71)	0.96
Stage II	146 (42.94)	73 (44.24)	73 (41.71)	
Stage III	54 (15.88)	27 (16.36)	27 (15.43)	
Stage IIIA	24 (7.06)	12 (7.27)	12 (6.86)	
Limited stage disease (small cell lung cancer only)	7 (2.06)	3 (1.82)	4 (2.29)	
Chemotherapy				
No	243 (71.47)	117 (70.91)	126 (72)	0.82
Yes	97 (28.53)	48 (29.09)	49 (28)	
Radiation therapy				
No	94 (27.65)	46 (27.88)	48 (27.43)	0.93
Yes	246 (72.35)	119 (72.12)	127 (72.57)	
Biological therapy				
No	335 (98.53)	162 (98.18)	173 (98.86)	0.61
Yes	5 (1.47)	3 (1.82)	2 (1.14)	
Highest schooling				
High school	117 (34.93)	60 (36.59)	57 (33.33)	0.92
Some college	68 (20.3)	32 (19.51)	36 (21.05)	
College graduate	81 (24.18)	38 (23.17)	43 (25.15)	
Post-college (graduate or higher)	69 (20.6)	34 (20.73)	35 (20.47)	
Marital status				
Widowed	28 (8.36)	16 (9.76)	12 (7.02)	0.37
Divorced or separated	44 (13.13)	24 (14.63)	20 (11.7)	
Married/living as married	233 (69.55)	113 (68.9)	120 (70.18)	
Single	30 (8.96)	11 (6.71)	19 (11.11)	
Psychological measure				
CES-D	12.04 (8.63)	12.57 (9.41)	11.54 (7.81)	0.27

[a] *p* values compare the intervention and control arms

[b] Mean (standard deviation)

radiation therapy, and stress level (i.e., CES-D score) at baseline. None of these potential moderators was found to be was significant.

At the 8-week follow-up, intervention participants were more likely than control participants to have attended a cancer support group within the two preceding months, controlling for baseline reports of participation in a cancer support group (p=0.02). Specifically, 14.5 % of the intervention participants had attended a cancer support group compared to 7.6 % of the control group participants. At the 6-month follow-up, this difference was no longer significant, with support group participation rates dropping to 8.5 and 6.4 %, respectively.

Usability of *Facing Forward*

At the 8-week and 6-month follow-up time points, 84 and 76 % of intervention participants, respectively, reported having read *Facing Forward* and on average having read it mostly to completely (Table 3). On average at both follow-up time points, participants rated the booklet as understandable to very

Table 2 Differences between the intervention and control groups in the uptake of behaviors recommended in *Facing Forward*, adjusted by baseline score

Questionnaire subscales	Follow-up assessment	Race	Mean difference between groups	Standard error	*t* value	*p* value	Control group, *n*	Intervention group, *n*	Effect size
Follow-up medical care	8 weeks	–	0.180	0.154	1.16	0.25	139	139	0.143
	6 months	–	0.360	0.176	2.05	0.05	125	127	0.264
Side effects management	8 weeks	–	0.004	0.149	0.03	0.98	139	139	0.004
	6 months	–	−0.065	0.153	−0.42	0.67	125	127	−0.054
Stress management	8 weeks	Total sample	0.627	0.258	2.43	0.016[a]	137	128	0.299
		Caucasian	0.408	0.278	1.47	0.144	120	106	0.196
		African American	2.043	0.673	3.04	0.003[a]	17	22	0.982
	6 months	Total sample	0.630	0.261	2.41	0.017[a]	120	121	0.310
		Caucasian	0.560	0.281	1.99	0.048	104	104	0.276
		African American	1.072	0.708	1.51	0.132	16	17	0.526
Social and financial matters management	8 weeks	–	0.152	0.169	0.90	0.37	139	139	0.106
	6 months	–	0.042	0.172	0.25	0.80	125	127	0.035

Baseline uptake of behaviors were controlled

[a] Statistically significant at the 0.025 level (two-tailed)

understandable and as helpful to very helpful. At both follow-up time points, participants on average agreed strongly that they knew more about dealing with post-treatment challenges after reading *Facing Forward* and that they were moderately confident in their ability to deal with these challenges.

Discussion

Efficacy of *Facing Forward*

The primary purpose of this study was to evaluate the efficacy of *Facing Forward* in promoting the adoption of recommended behaviors for addressing the challenges associated with the reentry phase of cancer survivorship. In comparison with the attention control group, participants who received *Facing Forward* reported greater uptake of stress management behaviors at both 8 weeks and 6 months post-baseline. At 8 weeks post-baseline, the efficacy of *Facing Forward* in promoting reported uptake of stress management behaviors was greater among African-American than Caucasian participants and significant only among African-American participants. These findings suggest that the specific recommendations contained in *Facing Forward* can be effective in promoting the uptake of stress management behaviors in both the short term (8 weeks) and longer term (6 months) in the population of survivors at large. They also demonstrate that in the short term, *Facing Forward* is efficacious specifically among African Americans. The results are important given that stress reduction programs have been shown to reduce anxiety and diminish pain and fatigue [39].

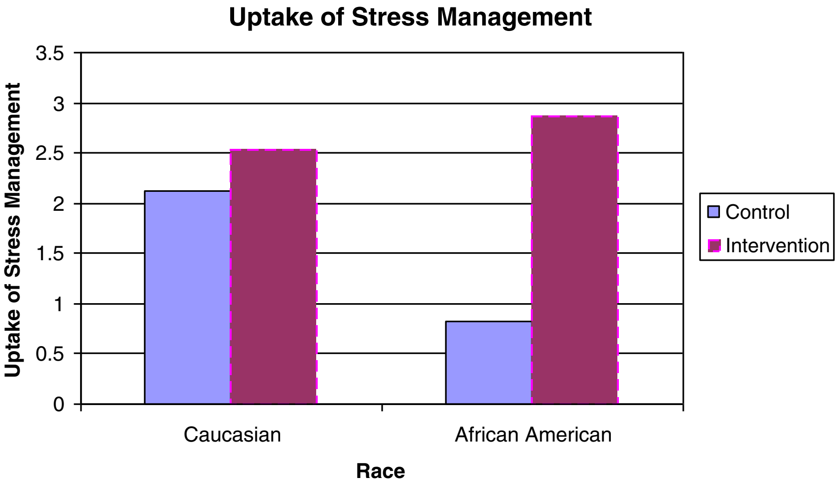


Fig. 2 Uptake of stress management behaviors at baseline and 8 weeks post-baseline among Caucasian and African-American participants

Table 3 Usability of *Facing Forward* at 8-week and 6-month follow-up

Question categories	8-week follow-up			6-month follow-up		
	No. of questions	*N*	Mean rating (SD)	No. of questions	*N*	Mean rating (SD)
Read (booklet section or appendix; yes, no)	9	115	0.84 (0.26)	9	110	0.76 (0.36)
Extent read (booklet section or appendix; 1–5 scale, not at all–completely)	13	112	4.06 (0.94)	13	96	4.06 (0.88)
Understandability (of booklet, booklet sections, or tips; 1–4 scale, not at all understandable–very understandable)	15	115	3.72 (0.50)	15	102	3.73 (0.48)
Informativeness (about how to deal with specific post-treatment challenges; 1–4 scale, strongly disagree–strongly agree)	8	113	3.05 (0.52)	8	96	3.06 (0.50)
Confidence (in ability to deal with specific post-treatment challenges; 1–5 scale, not at all confident–extremely confident)	8	111	3.98 (0.68)	8	95	4.01 (0.73)
Helpfulness (of booklet, booklet sections, or tips; 1–4 scale, not at all helpful–very helpful)	15	116	3.38 (0.55)	15	99	3.45 (0.47)

Although this study did not directly address the efficacy of the behaviors recommended in *Facing Forward* in reducing distress, many of these behaviors (e.g., relaxation and meditation) have evidence-based support [40–43]. To the extent that survivors adopt behaviors such as these based on reading *Facing Forward*, the booklet can serve as an important resource for survivors who lack access to or are not interested in engaging in more intense, time-consuming, and costly interventions for promoting adaptive coping, such as individual cognitive–behavioral therapy, desensitization therapy, and various forms of group therapy [40, 44, 45].

The impact of the intervention in the domain of stress management behaviors may be due in part to the fact that the *Facing Forward* appendix includes step-by-step instructions for two relaxation exercises, one that involves progressive muscle relaxation with imagery and the other a meditative relaxation exercise. These types of detailed instructions were not provided for other recommended health behaviors. Thus, the component on stress management provides not only education (as is the case for the other *Facing Forward* domains) but also detailed self-regulatory action strategies. The provision of such strategies, in turn, may increase the relevance and assimilation of the stress management section [46]. In addition, it is possible that physicians and other healthcare providers are less inclined and equipped to assess and address strategies for improved coping, and therefore patients are particularly in need of ancillary relaxation materials.

The greater impact of the intervention at 8 weeks for African Americans is consistent with findings suggesting that African Americans tend to utilize online cancer support groups and health resources less than Caucasians do [47]. They also have been found to seek information about psychosocial support more than Caucasians do [48, 49]. Indeed, among callers to the NCI Cancer Information Service, the majority of contacts by African Americans were focused on coping with the disease, e.g., seeking medical and support services rather than on prevention information [50], suggesting that they have a greater need for the stress management components of *Facing Forward*.

It should be noted that *Facing Forward* did not demonstrate efficacy for uptake of three other sets of behaviors (i.e., follow-up medical care, side effects management, or management of social and financial matters). Perhaps more intensive or tailored approaches are required for adoption of effective behaviors in these realms.

Support group use

A second finding of the study is the association of the receipt of *Facing Forward* with reported attendance at a cancer support group at the 8-week follow-up time point. *Facing Forward* contains two pages of text within the section “Your Feelings,” which specifically addresses and recommends support group use. At reentry, patients frequently report feeling abandoned by their medical team and vulnerable because they do not know how to manage the uncertainty, distress, and challenges associated with life after treatment [11, 27, 33, 51]. Support groups may help fill this gap in care at the end of treatment. Support has been shown to have beneficial effects by helping patients cope with the challenges of cancer survivorship [37, 40] as well as by encouraging them to develop a new attitude toward their illness experience, make important changes in their lives, communicate better with their physician and family, and more effectively access cancer-related information and resources [41]. This benefit may be particularly useful within the first 2 months of survivorship, when the support of the medical team, as well as the availability of family resources, is typically less accessible and would help explain why at the 6-months follow-up the difference between the two study groups would disappear.

Usability of *Facing Forward*

The study results with regard to the usability of *Facing Forward* are highly encouraging. The mean ratings of the booklet with respect to its usability indicate that intervention participants: (1) read most of the booklet within 8 weeks of receiving it; (2) judged the booklet to be understandable and helpful; (3) believed strongly that as a result of reading the booklet they knew more about the behavioral strategies that it recommends; and (4) felt highly confident in their ability to carry out those strategies. These findings indicate that *Facing Forward* contains content that is of interest to survivors and perceived to be relevant to their needs and that survivors find *Facing Forward* clearly written and comprehensible. The findings also suggest that *Facing Forward* provides behavioral strategies that survivors believe they can utilize.

Study limitations

Although the findings are promising, there are certain limitations. First, our study sample included predominantly female Caucasians with breast cancer. Second, those who completed assessments at 8 weeks were significantly older than noncompleters by almost 4 years, and at the 6-month time point, completers had significantly lower CES-D scores than noncompleters, thereby potentially affecting the generalizability of the results. Third, despite the fact that patients reported being more knowledgeable as a result of receiving *Facing Forward*, we did not verify whether they actually read the booklet, nor did we verify their uptake of behavioral strategies. Fourth, because there was no evaluation of literacy levels, we were unable to determine the extent to which literacy levels affected the use and impact of *Facing Forward*. This variable should be further explored in future studies. Finally, social desirability may have influenced the reported levels of uptake, although the findings were specific to uptake of stress management behaviors.

Implications of study findings

Because the study was conducted mainly in the context of the CCOP, the results allow for generalizability to the community setting, where the majority of cancer patients are treated. The findings are also relevant to intervention studies that use *Facing Forward* as a control arm when evaluating novel survivorship materials or interventions.

This study potentially has major implications given the current 12 million adult cancer survivors and the projected steady growth of this population over the coming decades, in particular of older survivors, as well as the nationwide circulation of *Facing Forward* and its credibility as an NCI-produced informational resource. To further enhance the utility of study findings, future studies should explore how *Facing Forward* can be more effectively integrated into routine service delivery. For example, it would be useful to know how the impact of the booklet varies depending on the mode of delivery (e.g., whether a healthcare professional provides *Facing Forward* to patients with a recommendation to read it or patients independently select the booklet), timing of delivery (e.g., before or after treatment completion), type, stage, and personal and familial history of cancer, as well as demographic and individual characteristics of the target population.

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