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CLINICAL TRIAL

# Randomized controlled trial of a clinic-based survivorship intervention following adjuvant therapy in breast cancer survivors

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**Abstract** In 2006, the IOM released a report citing the importance of "survivorship plans" to improve quality of life and care coordination for cancer survivors, but little has been done to evaluate their efficacy. Women with early-stage breast cancer were randomized within 6 weeks of completing adjuvant therapy to a survivorship intervention group (SI) or control group (CG). All subjects were given the NCI publication, "Facing Forward: Life after Cancer Treatment." The SI also met with a nurse/nutritionist to receive a treatment summary, surveillance, and lifestyle recommendations. Both groups completed questionnaires on the impact of cancer (IOC), patient satisfaction (FACIT-TS-PS), and assessment of survivor concerns (ASC) at baseline, 3 and 6 months. Within and between group *t* tests and linear regression analyses were performed. Among 126 women (60 CG, 66 SI), mean age was 54 years, 48 % were Hispanic, and the groups were well-balanced by baseline characteristics. No significant differences between the CG and SI on the FACIT-TS-PS or IOC at 3 and 6 months were seen. The ASC health worry subscale was lower (less worry) in the SI compared to CG ($p = 0.02$). At all time-points, Hispanic women had higher (worse) health worry ($p = 0.0008$), social-life interference ($p = 0.009$), and meaning of cancer scales ($p = 0.0004$), and more trust in medical professionals ($p = 0.03$) compared to non-Hispanic women. While the SI did not lead to significant improvements in most patient-reported outcomes, it was associated with decreased health worry. Future interventions should determine the most efficient and effective method for delivering survivorship care plans.

**Keywords** Survivorship · Care plans · Randomized trial

## Introduction

More than 2 million women living in the United States today are breast cancer survivors. However, limited data exist on the experiences of women during the critical transitional period following the end of primary treatment. This period is marked by high levels of stress [1] and patients report being ill-prepared for the lingering side-effects of cancer therapy, such as fatigue, weight gain, and persistent neuropathy [2]. In a sample of 233 women treated for breast cancer within the prior year, the most frequent concerns were fear of cancer recurrence, pain, death, late effects, and medical bills [3]. Furthermore, little information exists on the survivorship experience of minority populations. Minorities are typically underrepresented in most studies examining the quality of life and psychosocial functioning of cancer survivors, and this is especially true of non-English speaking minority populations.

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The Institute of Medicine (IOM) released a report in 2006, *From Cancer Patient to Cancer Survivor: Lost in Transition*, describing the importance of comprehensive treatment summaries that outline the plans for surveillance, detail the late effects of treatment, and promote healthy lifestyles to modify risk factors for the late effects of treatment [4]. Subsequently, the Commission on Cancer added a survivorship care plan to its accreditation standards to "improve quality of life" [5]. Little is known about the impact of these interventions on patients' well-being or how they should be implemented.

A randomized clinical trial of several psycho-educational interventions geared to aid patients during the transition period following primary treatment found that a videotape designed to increase active, approach-oriented coping skills improved vitality, specifically in patients who reported feeling unprepared for "re-entry" [6]. In contrast, a Canadian study of cancer survivors randomized patients at the point of referral to their primary care physician, several years after completing primary therapy (median 35 months), to a survivorship care plan (30 min educational session with a nurse) or not. No differences between arms were observed in cancer-related distress, patient satisfaction, or psychological distress [7].

In a single-blinded randomized trial, we evaluated the effect of an in-person survivorship intervention following adjuvant breast cancer therapy on health worry, treatment satisfaction, and the impact of cancer. Secondary objectives were to determine if differences exist between Hispanic and non-Hispanic ethnic groups.

## Methods

### Participants

Women who had a history of stage 0–III breast cancer and were within 6 weeks of completion of initial adjuvant treatment (radiation or chemotherapy) were recruited from Columbia University Medical Center (CUMC). Patients were excluded if they received surgery alone without adjuvant therapy or had a significant psychiatric illness that precluded completion of questionnaire. Hispanic women were over-sampled to achieve a roughly equal number of Hispanic and non-Hispanic participants. All trial participants provided written informed consent in English or Spanish. The trial was approved by the local Institutional Review Board (NCT00821288).

### Randomization

Women were randomized to the survivorship intervention group (SI) or control group (CG). The randomization was stratified by Hispanic ethnicity. A block randomization list was created via a computer generated sequence for each of the stratification groups, and consent forms corresponding to the randomization arms were placed in sealed sequential envelopes. The research staff was unaware of the randomization sequence. Because the study posed minimal risk, subjects were told that they were in a study of cancer survivors and were unaware they were being randomized. Patients who were interested in participating were given the next sequential envelope containing the corresponding randomized consent form.

### Interventions

Both groups were given the National Cancer Institute (NCI) publication, *Facing Forward: Life after Cancer Treatment*, by the research staff [8]. *Facing Forward* is a guide for people who were treated for cancer. It is a 24-page manual, available in English and Spanish, that summarizes many key issues of interest to cancer survivors during the re-entry phase, and contains sections on a number of issues after cancer treatment, including medical care, potential symptoms, emotions, social relationships, and dealing with practical matters, such as insurance and employment.

In addition to the NCI publication *Facing Forward*, the SI group also met in person for about 1 h with a nurse practitioner and a nutritionist (in English or Spanish) to receive a personalized treatment summary, surveillance recommendations, discussion of risk for late effects and toxicities, and screening and lifestyle recommendations. The content of the visit was based on guidelines from the American Society of Clinical Oncology (http://www.cancer.net/survivorship/asco-cancer-treatment-summaries, http://preventcancer.aicr.org).

### Outcome measures

At baseline, all subjects completed a questionnaire to obtain information on demographics, medical history, and health habits.

At baseline, 3 and 6 months, patients completed a series of questionnaires. Treatment satisfaction was measured using the functional assessment of chronic illness therapy-treatment satisfaction patient-satisfaction (FACIT-TS-PS) questionnaire [9]. Satisfaction is measured by the instrument through 32 questions regarding explanations by doctors, personal interactions with doctors, comprehensive care by the treatment staff, technical quality of the cancer care, decision-making, satisfaction with nursing care, and trust of the treatment staff. Questionnaire items were combined into an overall measure of satisfaction. The 81-item Impact of Cancer (IOC) scale was used to measure unique and multidimensional aspects of long-term cancer

survivorship [10]. This instrument focuses almost exclusively on problems, issues, and changes that long-term survivors ascribe to their cancer experience. The assessment of survivor concerns (ASC) questionnaire is a 5-item instrument comprising two subscales: cancer worry subscale (includes fear of future tests, new cancer, and recurrence) and health worry subscale (includes concerns about death and health) with responses on a 4-point Likert scale ("not at all", "a little bit", "somewhat", or "very much") [11]. The ASC has excellent internal consistency and validity, and is appropriate in both short-term and long-term survivor populations [11].

In addition, patients completed the physical and functional well-being sub-scales of the Functional Assessment of Cancer Therapy (FACT) [12], the Center for Epidemiologic Studies Depression (CES-D) scale [13], a 3-item health literacy assessment [14], and the Memorial Symptoms Assessment Scale to capture treatment-related side effects [15]. Understanding about recommendations on breast cancer surveillance and follow-up care were also assessed.

## Statistical analysis

We described demographic, clinical, and outcome variables by using means and standard deviations for continuous variables and percentages for categorical variables, by treatment group and by ethnicity. Intention-to-treat analysis was performed. The a priori primary endpoint was between-group difference in the ASC cancer worry subscale at 3 months. The secondary objectives were to compare the IOC, ASC, and FACIT-TS-PS between the two groups. Two-sample *t* tests and paired *t* tests were used to compare between-group and within-group differences, respectively. Similar analyses were performed to compare the differences between and within ethnic groups. There was no pre-determined plan to adjust for multiple comparisons.

Linear regression analysis was performed to investigate the effects of the intervention on domains of the FACIT-TS-PS, IOC, ASC, FACT-B, and CES-D controlling for Hispanic ethnicity. Additional exploratory linear regression analysis was performed evaluating predictors of the ASC health worry item, controlling for age, stage, ethnicity, education, marital status, employment, income, and health literacy score. Multiple predictive models were checked for goodness of fit and their residuals were plotted to check for normality. The most parsimonious model was ultimately selected.

Lacking historical data, in the a priori analysis plan, we estimated that we had 81 % power with 120 patients to detect a 0.6 mean standard deviation between groups with a

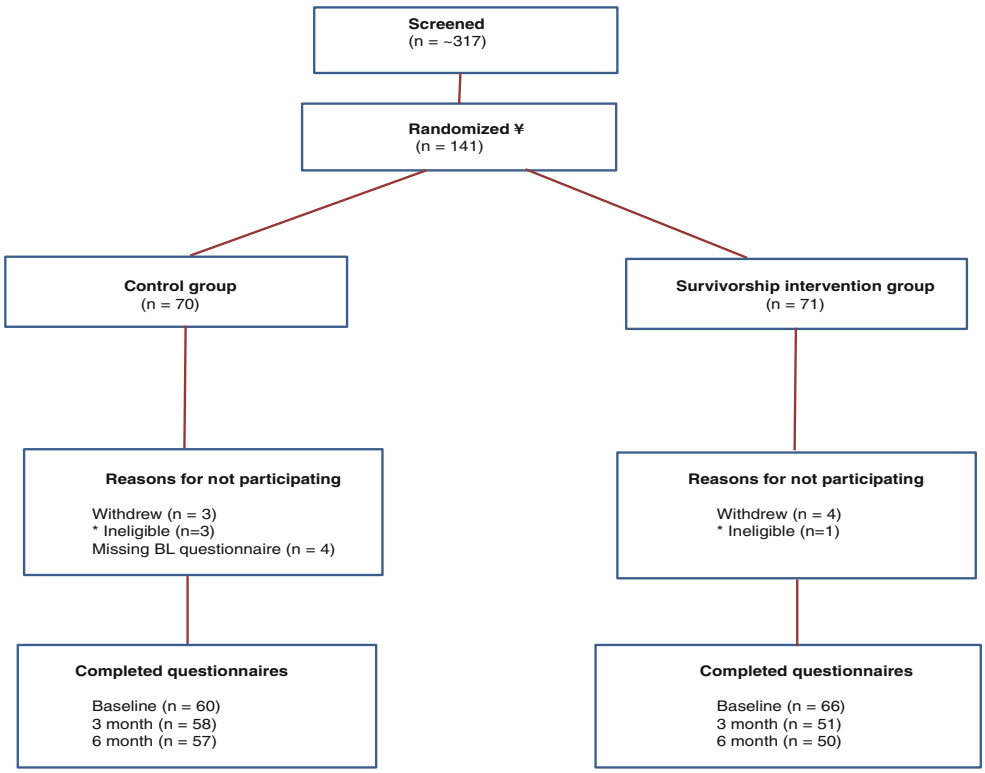


**Fig. 1** Consort diagram. *Subjects ineligible due to progression (CG group n = 1, SI group n= 1); randomized but not consented (CG group n = 2). ¥Patients unaware they were being randomized therfore randomized to one of two consent forms after non-specific discription of study

**Table 1** Baseline demographics and clinical characteristics by intervention group and ethnic group

| Baseline characteristic | Control group | | Survivorship intervention | | *p* value | Hispanic ethnicity | | Non-Hispanic ethnicity | | *p* value |
|---|---|---|---|---|---|---|---|---|---|---|
| | No | % | No | % | | No | % | No | % | |
| Age (years) | | | | | 0.54 | | | | | 0.35 |
| Mean | 54.9 | | 53.7 | | | 53.2 | | 55.1 | | |
| SD | 10.9 | | 12.1 | | | 11.3 | | 11.8 | | |
| Race | | | | | 0.38 | | | | | |
| Caucasian | 35 | 58.3 | 38 | 59.4 | | | | | | |
| Black, African American or Caribbean | 18 | 30.0 | 15 | 23.4 | | | | | | |
| Asian | 3 | 5.0 | 1 | 1.6 | | | | | | |
| American Indian | 0 | 0 | 1 | 1.6 | | | | | | |
| Other | 4 | 6.7 | 9 | 14.1 | | | | | | |
| Ethnicity | | | | | 0.46 | | | | | |
| Non-Hispanic | 33 | 55.0 | 32 | 48.5 | | | | | | |
| Hispanic | 27 | 45.0 | 34 | 51.5 | | | | | | |
| Primary language | | | | | 0.50 | | | | | |
| English | 36 | 60 | 43 | 65.1 | | | | | | |
| Spanish | 24 | 40 | 23 | 34.9 | | | | | | |
| Education | | | | | 0.89 | | | | | <0.0001 |
| Grade school | 11 | 18.6 | 10 | 15.1 | | 20 | 33.3 | 1 | 1.5 | |
| High school | 15 | 25.4 | 17 | 25.8 | | 21 | 35.0 | 11 | 16.9 | |
| College | 19 | 32.2 | 25 | 37.9 | | 16 | 26.7 | 28 | 43.1 | |
| Graduate school | 14 | 23.7 | 14 | 21.2 | | 3 | 5.0 | 25 | 38.5 | |
| Marital status | | | | | 0.37 | | | | | <0.01 |
| Single | 12 | 20.3 | 17 | 25.8 | | 18 | 29.5 | 11 | 17.2 | |
| Married/living with partner | 31 | 52.5 | 38 | 57.5 | | 25 | 40.9 | 44 | 68.7 | |
| Divorced/separated | 13 | 22.0 | 7 | 10.6 | | 12 | 19.7 | 8 | 12.5 | |
| Widowed | 3 | 5.1 | 4 | 6.1 | | 6 | 9.8 | 1 | 1.6 | |
| Employment | | | | | 0.87 | | | | | <0.01 |
| Full-time | 21 | 35.6 | 22 | 33.3 | | 13 | 21.7 | 30 | 46.1 | |
| Part-time/self-employed | 11 | 18.6 | 9 | 13.6 | | 7 | 11.7 | 13 | 20.0 | |
| Unemployed | 7 | 11.9 | 9 | 13.6 | | 12 | 20.0 | 4 | 6.1 | |
| Other[a] | 20 | 33.9 | 26 | 39.4 | | 28 | 46.7 | 18 | 27.7 | |
| Income | | | | | 0.78 | | | | | |
| 0–$30,000 | 22 | 42.3 | 22 | 38.6 | | 33 | 70.2 | 11 | 17.7 | <0.0001 |
| $30,001–60,000 | 5 | 9.6 | 9 | 15.8 | | 7 | 14.9 | 7 | 11.3 | |
| $60,000–100,000 | 12 | 23.1 | 11 | 19.3 | | 4 | 8.5 | 19 | 30.6 | |
| Greater than $100,000 | 13 | 25.0 | 15 | 26.3 | | 3 | 6.4 | 25 | 40.3 | |
| Religion | | | | | 0.42 | | | | | <0.0001 |
| Catholic | 33 | 56.9 | 38 | 58.5 | | 48 | 78.7 | 23 | 37.1 | |
| Protestant/Christian | 12 | 20.7 | 7 | 10.8 | | 8 | 13.1 | 11 | 17.7 | |
| Jewish | 7 | 12.1 | 10 | 15.4 | | 0 | 0 | 17 | 27.4 | |
| Other | 6 | 10.3 | 10 | 15.4 | | 5 | 8.2 | 11 | 17.7 | |
| Menopausal status | | | | | 0.97 | | | | | 0.11 |
| Pre-menopausal | 9 | 15.0 | 9 | 13.6 | | 9 | 14.7 | 9 | 13.8 | |
| Post-menopausal | 44 | 73.3 | 49 | 74.2 | | 41 | 67.2 | 52 | 80.0 | |
| Not sure | 7 | 11.7 | 8 | 12.1 | | 11 | 18.0 | 4 | 6.1 | |

**Table 1** continued

| Baseline characteristic | Control group | | Survivorship intervention | | *p* value | Hispanic ethnicity | | Non-Hispanic ethnicity | | *p* value |
|---|---|---|---|---|---|---|---|---|---|---|
| | No | % | No | % | | No | % | No | % | |
| Ever/current smoker | | | | | | | | | | |
| Yes | 4 | 6.7 | 0 | 0 | 0.05 | 2 | 3.3 | 2 | 3.1 | 1.0 |
| No | 56 | 93.3 | 66 | 100.0 | | 59 | 96.7 | 63 | 96.9 | |
| Drink alcohol | | | | | 0.72 | | | | | <0.0001 |
| Yes | 29 | 48.3 | 34 | 51.5 | | 17 | 27.9 | 46 | 70.8 | |
| No | 31 | 51.7 | 32 | 48.5 | | 44 | 72.1 | 19 | 29.2 | |
| Stage | | | | | 0.97 | | | | | 0.07 |
| 0 | 1 | 1.4 | 2 | 2.8 | | 3 | 4.9 | 0 | 0 | |
| I | 35 | 50.0 | 33 | 46.5 | | 24 | 39.3 | 36 | 55.4 | |
| II | 25 | 35.7 | 27 | 38.0 | | 24 | 39.3 | 24 | 36.9 | |
| III | 9 | 12.9 | 9 | 12.7 | | 10 | 16.4 | 5 | 7.7 | |
| Tumor grade | | | | | 0.17 | | | | | 0.16 |
| 1 | 12 | 16.9 | 8 | 11.3 | | 8 | 13.1 | 8 | 12.3 | |
| 2 | 31 | 43.7 | 25 | 35.2 | | 19 | 31.1 | 31 | 47.7 | |
| 3 | 26 | 38.0 | 38 | 53.5 | | 33 | 54.1 | 26 | 40.0 | |
| Unknown | 1 | 1.4 | 0 | 0 | | 1 | 1.6 | 0 | 0 | |
| Tumor size (cm) | | | | | 0.62 | | | | | 0.09 |
| ≤2 | 45 | 64.3 | 40 | 56.3 | | 31 | 50.8 | 45 | 69.2 | |
| 2.1–5 | 23 | 32.9 | 29 | 40.8 | | 27 | 44.3 | 19 | 29.2 | |
| >5 | 2 | 2.9 | 2 | 2.8 | | 3 | 4.9 | 1 | 1.5 | |
| Type of surgery | | | | | 0.68 | | | | | 0.74 |
| Lumpectomy | 37 | 52.9 | 40 | 56.3 | | 33 | 54.1 | 37 | 56.9 | |
| Mastectomy | 33 | 47.1 | 31 | 43.7 | | 28 | 45.9 | 28 | 43.1 | |
| Chemotherapy | | | | | | | | | | 0.53 |
| Yes | 50 | 71.4 | 55 | 77.5 | 0.41 | 45 | 73.8 | 51 | 78.5 | |
| No | 20 | 28.6 | 16 | 22.5 | | 16 | 26.2 | 14 | 21.5 | |
| Radiation | | | | | 0.74 | | | | | 0.24 |
| Yes | 51 | 72.9 | 50 | 70.4 | | 47 | 77.0 | 44 | 67.7 | |
| No | 19 | 27.1 | 21 | 29.6 | | 14 | 22.9 | 21 | 32.3 | |
| Hormonal therapy | | | | | 0.20 | | | | | 0.06 |
| Yes | 52 | 74.3 | 59 | 83.1 | | 43 | 70.5 | 55 | 84.6 | |
| No | 18 | 25.7 | 12 | 16.9 | | 18 | 29.5 | 10 | 15.4 | |

[a] Employment other includes retired, full-time student, homemaker, disabled or other

5 % type I error rate. All statistical analyses were two-sided and performed using SAS version 9.2 (SAS Institute, Inc., Cary, NC).

## Results

### Accrual, eligibility, and evaluability

From February 2008 to June 2011, approximately 317 patients were pre-screened. Of those who did not participate, about 3/4 were not eligible and the majority of the others could not return for an additional visit. A total of 141 patients were randomized to receive one of two consent forms. Seven patients withdrew, four were subsequently found to be ineligible (two subjects progressed while on study and two subjects did not sign consent after randomization), and four did not complete baseline questionnaires. This left 126 patients who were evaluable at baseline, of whom 60 received the CG and 66 received the SI (Fig. 1).

### Patient characteristics

Patient characteristics by intervention assignment are shown in Table 1. The mean age was 54 years in the SI and 55 in the CG; 41 % of the subjects were Hispanic, 37 % spoke Spanish, a little over one half were married, about

**Table 2** Outcome measures by intervention group

| | Baseline | | | | | 3 months | | | | | 6 months | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Control | | Intervention | | *p* value | Control | | Intervention | | *p* value | Control | | Intervention | | *p* value |
| Variable | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | |
| FACIT-TS-PS[a] | | | | | | | | | | | | | | | |
| Explanations | 87.71 | 17.87 | 88.01 | 17.49 | 0.93 | 85.63 | 19.98 | 86.83 | 19.20 | 0.75 | 86.71 | 20.90 | 87.50 | 15.91 | 0.83 |
| Interpersonal | 84.81 | 18.52 | 84.85 | 20.31 | 0.99 | 83.82 | 19.37 | 86.44 | 20.36 | 0.50 | 86.90 | 21.20 | 87.11 | 18.42 | 0.96 |
| Comprehensive care | 76.87 | 21.96 | 79.86 | 23.10 | 0.46 | 75.88 | 23.78 | 82.91 | 20.30 | 0.10 | 77.78 | 22.72 | 83.60 | 20.28 | 0.17 |
| Technical quality | 95.37 | 10.08 | 92.93 | 13.02 | 0.24 | 88.70 | 17.96 | 91.11 | 13.28 | 0.42 | 94.75 | 14.95 | 92.22 | 13.33 | 0.36 |
| Decision making | 77.86 | 21.54 | 78.79 | 22.79 | 0.82 | 75.95 | 23.11 | 76.10 | 23.12 | 0.97 | 77.56 | 22.23 | 80.57 | 23.61 | 0.50 |
| Nurses | 90.40 | 20.99 | 90.74 | 17.93 | 0.92 | 87.50 | 20.33 | 89.78 | 16.16 | 0.53 | 89.09 | 18.41 | 90.89 | 15.98 | 0.59 |
| Trust | 92.96 | 12.27 | 92.55 | 13.00 | 0.86 | 90.50 | 16.25 | 92.00 | 13.78 | 0.61 | 91.82 | 15.28 | 91.33 | 14.08 | 0.87 |
| Overall | 97.03 | 11.45 | 99.22 | 6.25 | 0.20 | 96.55 | 15.14 | 97.55 | 10.31 | 0.69 | 97.73 | 9.95 | 97.50 | 10.41 | 0.91 |
| Impact of cancer[b] | | | | | | | | | | | | | | | |
| Physical health awareness | 4.11 | 0.85 | 3.79 | 0.90 | 0.04 | 4.02 | 0.81 | 3.90 | 0.97 | 0.50 | 4.06 | 0.79 | 4.09 | 0.73 | 0.86 |
| Physical body changes | 2.87 | 1.10 | 2.78 | 1.05 | 0.61 | 2.93 | 1.23 | 2.81 | 1.15 | 0.62 | 2.78 | 1.15 | 2.78 | 1.04 | 0.99 |
| Psychological positive self-evaluation | 3.77 | 0.85 | 3.88 | 0.69 | 0.41 | 3.80 | 0.77 | 3.90 | 0.69 | 0.51 | 3.88 | 0.78 | 3.92 | 0.69 | 0.82 |
| Psychological negative self-evaluation | 2.39 | 0.89 | 2.17 | 0.70 | 0.13 | 2.39 | 0.86 | 2.20 | 0.86 | 0.27 | 2.37 | 0.83 | 2.14 | 0.80 | 0.15 |
| Existential positive outlook | 3.93 | 1.00 | 4.04 | 0.87 | 0.52 | 4.05 | 0.92 | 4.06 | 0.75 | 0.93 | 3.96 | 0.97 | 4.14 | 0.90 | 0.32 |
| Existential negative outlook | 3.02 | 1.11 | 2.89 | 0.99 | 0.50 | 3.10 | 1.02 | 2.67 | 1.10 | 0.04* | 2.86 | 1.04 | 2.90 | 0.94 | 0.84 |
| Social life interferences | 2.71 | 1.13 | 2.54 | 0.96 | 0.35 | 2.68 | 1.24 | 2.31 | 0.84 | 0.07 | 2.45 | 1.12 | 2.55 | 0.99 | 0.66 |
| Social value of relationships | 3.84 | 0.95 | 3.89 | 0.91 | 0.79 | 3.79 | 0.97 | 3.83 | 0.90 | 0.84 | 4.00 | 0.98 | 3.80 | 0.90 | 0.28 |
| Meaning of cancer | 3.60 | 0.91 | 3.51 | 0.80 | 0.54 | 3.51 | 0.90 | 3.50 | 0.89 | 0.98 | 3.47 | 0.95 | 3.42 | 0.76 | 0.76 |
| Health worry | 3.64 | 0.99 | 3.45 | 1.04 | 0.30 | 3.57 | 0.94 | 3.45 | 1.17 | 0.55 | 3.58 | 0.96 | 3.66 | 1.01 | 0.65 |
| Higher order positive scales | 3.84 | 0.76 | 3.82 | 0.65 | 0.89 | 3.83 | 0.71 | 3.82 | 0.71 | 0.94 | 3.86 | 0.73 | 3.87 | 0.62 | 0.93 |
| Higher order negative scales | 2.93 | 0.75 | 2.77 | 0.75 | 0.23 | 2.93 | 0.84 | 2.69 | 0.83 | 0.13 | 2.80 | 0.80 | 2.80 | 0.75 | 0.97 |
| Assessment of survivor concerns[c] | | | | | | | | | | | | | | | |
| Future tests | 2.57 | 1.13 | 2.33 | 1.04 | 0.66 | 2.65 | 0.98 | 2.33 | 0.95 | 0.09 | 2.33 | 1.04 | 2.43 | 0.98 | 0.61 |
| New cancer | 2.60 | 1.13 | 2.76 | 0.99 | 0.40 | 2.60 | 1.02 | 2.46 | 1.05 | 0.48 | 2.48 | 0.99 | 2.43 | 0.98 | 0.79 |
| Recurrence | 2.77 | 1.10 | 2.98 | 0.96 | 0.27 | 2.81 | 1.01 | 2.57 | 1.00 | 0.22 | 2.65 | 0.99 | 2.52 | 0.97 | 0.51 |
| Cancer worry subscale | 2.64 | 1.03 | 2.80 | 0.93 | 0.39 | 2.69 | 0.88 | 2.45 | 0.92 | 0.18 | 2.48 | 0.94 | 2.46 | 0.92 | 0.90 |
| Death worry | 2.18 | 1.11 | 2.14 | 1.12 | 0.84 | 2.19 | 1.18 | 1.84 | 1.04 | 0.11 | 1.98 | 1.05 | 1.79 | 0.82 | 0.32 |
| Health worry | 2.88 | 1.03 | 2.85 | 0.96 | 0.88 | 3.19 | 0.94 | 2.69 | 1.03 | 0.01* | 2.73 | 1.01 | 2.51 | 0.96 | 0.27 |
| Health worry subscale | 2.51 | 0.94 | 2.49 | 0.90 | 0.92 | 2.69 | 0.87 | 2.28 | 0.90 | 0.02* | 2.39 | 0.91 | 2.16 | 0.82 | 0.18 |
| FACT-B[d] | | | | | | | | | | | | | | | |
| Physical well-being | 7.00 | 6.11 | 7.18 | 6.93 | 0.88 | 6.43 | 6.47 | 6.12 | 6.27 | 0.80 | 5.04 | 5.39 | 5.13 | 5.34 | 0.93 |
| Functional well-being | 11.12 | 7.33 | 10.03 | 6.80 | 0.39 | 11.90 | 7.49 | 9.46 | 6.79 | 0.08 | 9.89 | 6.84 | 10.17 | 6.61 | 0.83 |
| CES-D[e] | | | | | | | | | | | | | | | |
| Depression score | 16.91 | 12.76 | 15.58 | 10.33 | 0.54 | 17.12 | 12.56 | 13.96 | 10.58 | 0.16 | 14.66 | 10.59 | 14.22 | 10.26 | 0.83 |
| MMAS (N, %)[f] | | | | | | | | | | | | | | | |
| Severe/very severe symptoms | 54 | 94.7 | 64 | 96.9 | 0.66 | 535 | 96.4 | 49 | 96.1 | 1.0 | 51 | 94.4 | 46 | 92 | 0.71 |
| Literacy[g] | | | | | | | | | | | | | | | |
| Literacy score | 1.47 | 0.57 | 1.59 | 0.65 | 0.28 | 1.57 | 0.74 | 1.39 | 0.64 | 0.19 | 1.37 | 0.73 | 1.32 | 0.67 | 0.71 |

* $p < 0.05$ between groups

[a] FACIT-TS-PS: higher score indicates greater satisfaction in each domain; score range (0–100)

[b] Impact of Cancer: higher score indicates greater positive or negative feeling depending on domain; Positive domains: physical health awareness, psychological positive self-evaluation, existential positive outlook, social value of relationships, meaning of cancer; Negative domains: physical body changes, psychological negative self-evaluation, existential negative outlook, social life interferences, health worry

[c] Assessment of survivor concerns: higher scores indicate greater worry; score range (1–4)

[d] FACT-B: Higher score indicates greater quality of life; physical well-being score range 0–28; functional well-being score range 0–28

[e] CES-D depression score <16 = not depressed; 16–26 = mild depression; 27–60 = major depression

[f] MMAS (memorial symptoms assessment (mean of total number with severe scores defined as 3/4)

[g] Literacy score: higher score indicates lower literacy; score range 0–4

**Table 3** Outcome measures by ethnic group

| Variable | Baseline | | | | | 3 months | | | | | 6 months | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Non-Hispanic | | Hispanic | | *p* value | Non-Hispanic | | Hispanic | | *p* value | Non-Hispanic | | Hispanic | | *p* value |
| | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | |
| FACIT-TS-PS[a] | | | | | | | | | | | | | | | |
| Explanations | 88.9 | 16.9 | 86.9 | 18.4 | 0.47 | 87.0 | 17.8 | 85.3 | 21.6 | 0.66 | 89.1 | 16.3 | 85.3 | 19.3 | 0.28 |
| Interpersonal | 85.5 | 20.7 | 84.1 | 18.1 | 0.71 | 86.4 | 18.3 | 83.4 | 21.5 | 0.45 | 89.5 | 16.8 | 84.6 | 21.7 | 0.20 |
| Comprehensive care | 75.9 | 24.9 | 81.1 | 19.5 | 0.20 | 78.0 | 22.9 | 81.3 | 20.4 | 0.44 | 80.4 | 22.7 | 80.7 | 19.4 | 0.94 |
| Technical quality | 92.9 | 13.1 | 95.3 | 10.0 | 0.28 | 90.6 | 16.1 | 90.2 | 15.5 | 0.90 | 95.4 | 11.2 | 91.7 | 16.8 | 0.20 |
| Decision making | 77.9 | 23.2 | 78.8 | 21.0 | 0.82 | 76.1 | 21.8 | 75.7 | 24.0 | 0.93 | 81.9 | 19.4 | 75.7 | 25.7 | 0.17 |
| Nurses | 88.3 | 22.9 | 93.0 | 14.3 | 0.18 | 88.5 | 18.7 | 88.4 | 18.6 | 1.00 | 92.0 | 15.2 | 88.4 | 18.0 | 0.28 |
| Trust | 91.7 | 14.4 | 93.9 | 10.4 | 0.31 | 88.5 | 16.0 | 94.6 | 11.4 | 0.03* | 92.3 | 13.4 | 90.6 | 16.3 | 0.58 |
| Overall | 96.8 | 12.4 | 99.6 | 3.2 | 0.09 | 94.9 | 17.1 | 99.0 | 7.0 | 0.11 | 97.6 | 10.1 | 97.9 | 10.1 | 0.89 |
| Impact of cancer[b] | | | | | | | | | | | | | | | |
| Physical health awareness | 3.9 | 0.8 | 4.0 | 0.9 | 0.48 | 3.8 | 0.9 | 4.1 | 0.9 | 0.15 | 4.0 | 0.7 | 4.1 | 0.8 | 0.90 |
| Physical body changes | 2.8 | 0.9 | 2.9 | 1.2 | 0.57 | 2.7 | 1.2 | 3.1 | 1.2 | 0.10 | 2.6 | 1.0 | 2.8 | 1.1 | 0.30 |
| Psychological positive self-evaluation | 3.6 | 0.8 | 4.1 | 0.6 | <0.01* | 3.6 | 0.7 | 4.1 | 0.7 | <0.01* | 3.7 | 0.7 | 4.1 | 0.7 | <0.01* |
| Psychological negative self-evaluation | 2.3 | 0.8 | 2.2 | 0.8 | 0.66 | 2.3 | 0.8 | 2.3 | 0.9 | 0.66 | 2.3 | 0.8 | 2.2 | 0.8 | 0.73 |
| Existential positive outlook | 3.8 | 1.0 | 4.2 | 0.9 | 0.03* | 3.8 | 0.9 | 4.3 | 0.7 | <0.01* | 3.8 | 1.0 | 4.3 | 0.8 | 0.02* |
| Existential negative outlook | 2.9 | 1.0 | 2.9 | 1.1 | 0.71 | 2.8 | 1.0 | 3.0 | 1.1 | 0.49 | 2.8 | 0.9 | 3.0 | 1.1 | 0.20 |
| Social life interferences | 2.4 | 1.0 | 2.9 | 1.1 | <0.01* | 2.2 | 1.0 | 2.7 | 1.0 | 0.02* | 2.2 | 0.9 | 2.7 | 1.0 | <0.01* |
| Social value of relationships | 3.6 | 0.9 | 4.1 | 0.9 | <0.01* | 3.6 | 0.9 | 4.0 | 0.9 | <0.01* | 3.7 | 0.9 | 4.1 | 0.9 | 0.04* |
| Meaning of cancer | 3.3 | 0.9 | 3.8 | 0.7 | <0.01* | 3.2 | 0.8 | 3.8 | 0.9 | <0.01* | 3.2 | 0.8 | 3.7 | 0.8 | <0.01* |
| Health worry | 3.4 | 0.9 | 3.7 | 1.1 | 0.03* | 3.2 | 1.0 | 3.8 | 1.0 | <0.01* | 3.4 | 1.0 | 3.8 | 0.9 | 0.02* |
| Higher order positive scales | 3.6 | 0.7 | 4.0 | 0.6 | <0.01* | 3.6 | 0.7 | 4.1 | 0.6 | <0.01* | 3.7 | 0.7 | 4.0 | 0.6 | 0.02* |
| Higher order negative scales | 2.8 | 0.7 | 2.9 | 0.8 | 0.21 | 2.6 | 0.8 | 3.0 | 0.8 | 0.05* | 2.7 | 0.7 | 2.9 | 0.8 | 0.07 |
| Assessment of survivor concerns[c] | | | | | | | | | | | | | | | |
| Future tests | 2.6 | 1.1 | 2.6 | 1.1 | 0.79 | 2.5 | 1.0 | 2.5 | 1.0 | 0.96 | 2.3 | 0.9 | 2.4 | 1.0 | 0.50 |
| New cancer | 2.6 | 1.0 | 2.7 | 1.1 | 0.71 | 2.6 | 1.0 | 2.4 | 1.1 | 0.35 | 2.4 | 0.9 | 2.5 | 1.0 | 0.89 |
| Recurrence | 2.9 | 1.0 | 2.9 | 1.1 | 0.82 | 2.6 | 1.0 | 2.7 | 1.0 | 0.58 | 2.5 | 0.9 | 2.6 | 1.0 | 0.58 |
| Cancer worry subscale | 2.7 | 0.9 | 2.7 | 1.0 | 0.77 | 2.6 | 0.9 | 2.5 | 1.0 | 0.90 | 2.4 | 0.8 | 2.5 | 1.0 | 0.67 |
| Death worry | 2.1 | 1.0 | 2.2 | 1.2 | 0.77 | 2.0 | 1.2 | 2.0 | 1.2 | 1.00 | 1.9 | 0.9 | 1.9 | 1.0 | 0.95 |
| Health worry | 2.6 | 0.9 | 3.1 | 1.0 | 0.02* | 2.6 | 1.0 | 3.2 | 0.9 | <0.01* | 2.4 | 0.8 | 2.8 | 1.1 | 0.06 |
| Health worry subscale | 2.4 | 0.9 | 2.6 | 0.9 | 0.19 | 2.3 | 0.9 | 2.6 | 0.9 | 0.058 | 2.2 | 0.8 | 2.4 | 1.0 | 0.17 |
| FACT-B[d] | | | | | | | | | | | | | | | |
| Physical well-being | 5.9 | 3.1 | 8.3 | 6.8 | 0.05* | 4.2 | 5.4 | 8.1 | 6.2 | <0.01* | 3.2 | 3.5 | 6.8 | 5.8 | <0.01* |
| Functional well-being | 8.2 | 6.3 | 13.1 | 7.0 | <0.01* | 7.9 | 6.1 | 13.4 | 7.2 | <0.01* | 7.9 | 5.7 | 12.4 | 6.8 | <0.01* |

**Table 3** continued

| Variable | Baseline | | | | | 3 months | | | | | 6 months | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Non-Hispanic | | Hispanic | | *p* value | Non-Hispanic | | Hispanic | | *p* value | Non-Hispanic | | Hispanic | | *p* value |
| | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | | Mean | SD | Mean | SD | |
| CES-D[e] | | | | | | | | | | | | | | | |
| Depression score | 11.6 | 8.5 | 20.5 | 12.3 | <0.01* | 11.4 | 9.7 | 19.6 | 12.4 | <0.01* | 11.3 | 9.1 | 18.0 | 10.7 | <0.01* |
| MMAS (*N*, %)[f] | | | | | | | | | | | | | | | |
| Severe/verysevere symptoms | 60 | 95.2 | 58 | 96.7 | 1.0 | 50 | 94.3 | 50 | 98 | 0.62 | 49 | 94.2 | 46 | 92.0 | 0.71 |
| Literacy[g] | | | | | | | | | | | | | | | |
| Literacy score | 1.5 | 0.6 | 1.6 | 0.6 | 0.24 | 1.4 | 0.5 | 1.6 | 0.8 | 0.15 | 1.5 | 0.6 | 1.3 | 0.7 | 0.20 |

* $p < 0.05$ between groups

[a] FACIT-TS-PS: higher score indicates greater satisfaction in each domain; score range (0–100)

[b] Impact of cancer: higher score indicates greater positive or negative feeling depending on domain; Positive domains: physical health awareness, psychological positive self-evaluation, existential positive outlook, social value of relationships, meaning of cancer; Negative domains: physical body changes, psychological negative self-evaluation, existential negative outlook, social life interferences, health worry

[c] Assessment of survivor concerns: higher scores indicate greater worry; score range (1–4)

[d] FACT-B: Higher score indicates greater quality of life; physical well-being score range 0–28; functional well-being score range 0–28

[e] CES-D depression score <16 = not depressed; 16–26 = mild depression; 27–60 = major depression

[f] MMAS (memorial symptoms assessment (mean of total number with severe scores defined as 3/4)

[g] Literacy score: higher score indicates lower literacy; score range 0–4

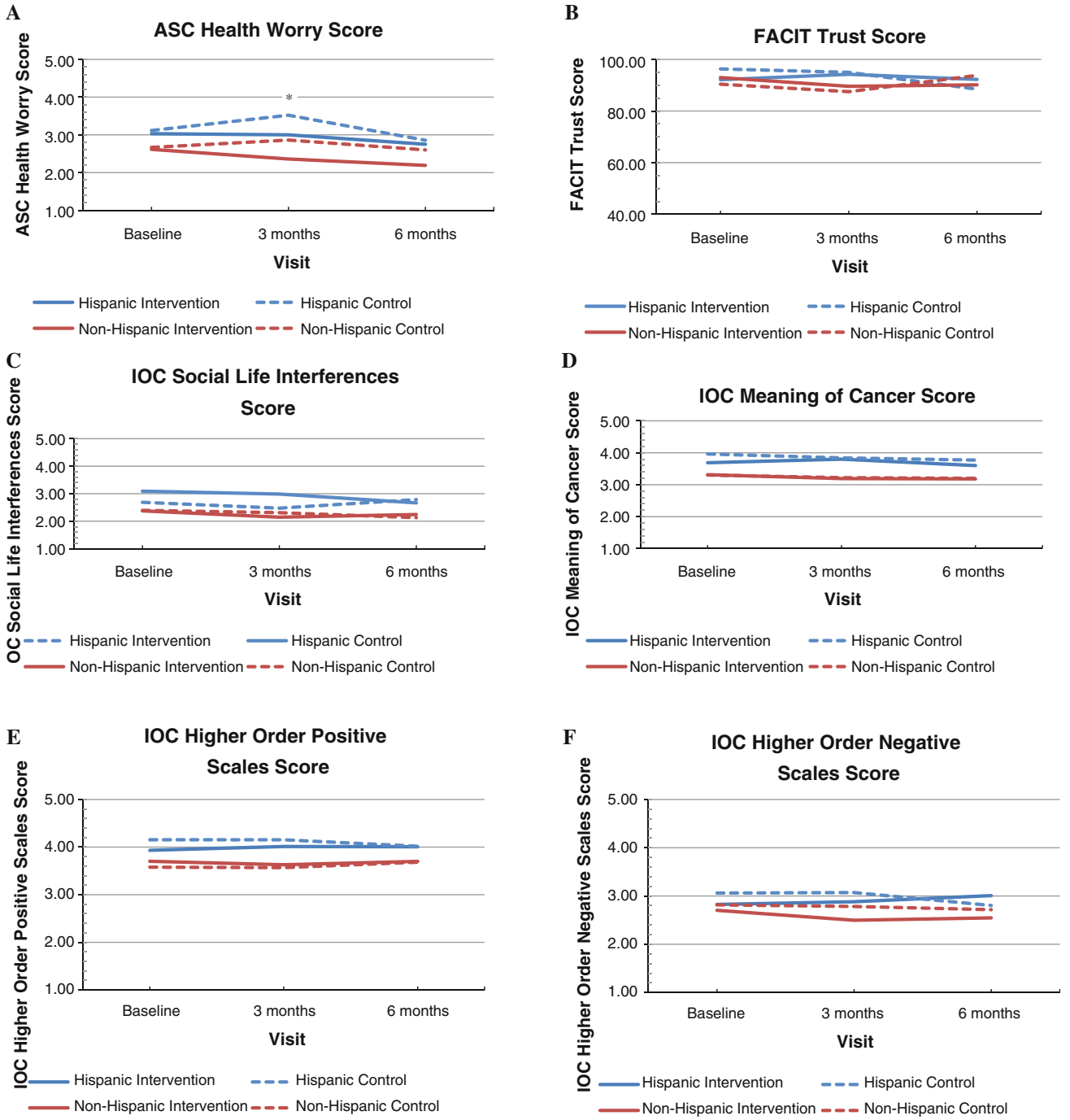


**Fig. 2** Change in scores over time by intervention group and ethnicity. ASC = Assessment of survivor concerns, IOC = Impact of Cancer, FACIT TS PS = functional assessment of chronic illness therapy-treatment satisfaction patient-satisfaction (*$p < 0.05$ compared by ethnicity and by treatment group)

73 % were post-menopausal, and about 75 % had received chemotherapy in both groups. No notable imbalances by arm were observed for demographic, clinical, or treatment characteristics. Table 1 also compares Hispanic to non-Hispanic women. Hispanic women were significantly less educated, less likely to be married or living with a partner, less likely to have full time employment, had lower household income, and were less likely to report drinking alcohol compared to non-Hispanic women.

## Patient outcomes by intervention group

At baseline, the CG had a higher score on the physical health awareness scale (more health awareness) of the IOC. At

3 months, there was no statistically significant between-group difference on the ASC cancer worry subscale. In addition, no difference was seen in total scores or subscale scores between the CG and SI groups on the FACIT-TS-PS, FACT (physical/functional), or CES-D scores (Table 2). The mean existential negative outlook subscale of the IOC was higher in the CG compared to SI (3.10 vs. 2.67, $p = 0.04$) at 3 months; however, change from baseline was not significant between groups. The health worry subscale of the ASC increased (more worry) significantly in the CG and decreased significantly in the SI ($p = 0.05$) (Appendix in supplementary material). At 3 months, the health worry subscale was significantly higher for the CG compared to SI (2.69 vs. 2.28, $p = 0.02$) although at 6 months, this difference did not persist. Patients with higher physical awareness had higher health worry ($p = 0.008$).

### Patient outcomes by ethnicity

At baseline, 3 and 6 months, there were statistically significant differences ($p < 0.05$) between Hispanic women and non-Hispanic women, although these differences did not change over time (Table 3). Hispanic women had higher scores (better quality-of-life) on the Physical and Functional Well-Being subscales of the FACT, higher (worse) scores on the CES-D Depression scale, higher health worry scores on both the ASC and IOC, and higher (worse) scores in the social life interferences and higher order negative subscales of the IOC. However, Hispanic women also reported more medical trust in the FACIT-PS-TS, a higher value of social relationships, meaning of cancer and higher order positive scales on the IOC, compared to non-Hispanics. Figure 2 is the mean change over time between intervention groups, stratified by ethnicity, of some of the key outcome measures. There was no significant interaction between treatment and ethnicity.

### Multivariate analysis

A multivariable exploratory linear regression analysis was performed to evaluate the association between the individual ASC health worry item at 3 months and the intervention, controlling for age, stage, ethnicity, education, marital status, employment, income, and health literacy.

The relationship between SI and less health worry remained significant ($p = 0.04$); however, the relationship between Hispanic ethnicity and health worry was no longer significant ($p = 0.12$) (Table 4).

## Discussion

In this randomized, single-blinded study of a survivorship intervention, we did not observe a difference in the cancer worry subscale of the ASC or most of the other patient-reported outcomes assessing treatment satisfaction, cancer survivor concerns, depression, or the impact of cancer. While we observed a significant improvement in health worry subscale scores among women in the SI group at 3 months, this difference did not persist at the 6-month time-point. While we found no interaction between treatment and ethnicity, we did find, overall, that Hispanic women had significantly different scores at all time-points on many of the measurements, including depression, health worry, and social life interferences.

Our study is unique in that patients were randomized shortly after completing their adjuvant therapy for early-stage breast cancer, a period of time that is known to be associated with heightened levels of stress [1] and concerns about fear of cancer recurrence, pain, death, late effects, and medical bills [3]. Guidelines following the IOM report suggested that this point in breast cancer treatment would be an appropriate point to intervene [16]. In addition, the IOM acknowledged that there was a lack of evidence to support survivorship care plans, but that it made sense to pursue use of these plans while data about the efficacy and costs were being evaluated [16, 17]. While we did not find a large difference between groups in cancer worry, treatment satisfaction, or quality of life, it should be noted that the control group did receive the NCI publication, which is not often the standard of care. We also do not know if the SI could have been delivered in a more effective manner.

In some ways, our results are similar to those found in a study of a survivorship intervention targeting a point

**Table 4** Multivariable Linear Regression model for the Assessment of Survivors Concerns (ASC) individual health worry item at 3-months

| Variable | Parameter estimate | $p$ value |
|---|---|---|
| Survivorship intervention | −0.43 | 0.04 |
| Stage 2 | −0.26 | 0.91 |
| Stage 3 | 0.28 | 0.41 |
| Age | −0.02 | 0.07 |
| Hispanic ethnicity | 0.39 | 0.12 |
| Education-grade school | 0.50 | 0.23 |
| Education-high school | −0.41 | 0.17 |
| Marital status: single/divorced/widowed | 0.38 | 0.12 |
| Employment: part-time/self-employed | −0.02 | 0.96 |
| Unemployed | −0.19 | 0.62 |
| Employment-other | −0.19 | 0.49 |
| Income $0–30,000 | 0.35 | 0.34 |
| Income $30–60,000 | 0.80 | 0.07 |
| Income $60–100,000 | 0.29 | 0.31 |
| Baseline literacy score | −0.04 | 0.84 |

several years later in patients' care following cancer diagnosis. In the study by Grunfeld et al. [7]., 408 long-term breast cancer survivors transitioning from their oncologist to their primary care physicians were randomized to a discharge visit with and without a survivorship care plan. They observed no differences with regard to cancer-related distress, psychological distress, or patient satisfaction. While our study is very different in nature, the patient-reported outcome measures used in both studies were similar. It is possible that these measures do not capture other health benefits or improvements in long-term outcomes or quality and coordination of patient care. It is also worth noting that our sample's individual item health worry score for both groups were both higher (more worry) than were reported in the short and long-term cancer survivor data from Gotay et al. [11]. This may be due to differences in the study population as that sample was more heterogeneous with regard to cancer type and stage. In addition, while baseline differences between groups may have influenced the results, significant differences were still seen in change in health worry over time between the groups.

Since the IOM report, several studies have examined the uptake of survivorship care plans, but unlike ours, most have evaluated them with regard to coordination of care. In a recent survey of all NCI-designated cancer centers focusing on concordance with the IOM recommendations, 43 % delivered survivorship care plans to breast and colorectal cancer survivors [18]. In this survey, oncology providers expressed concern about the feasibility and cost associated with implementation. Furthermore, in a study among Massachusetts physicians, 56 % reported preparing plans; however, only 14 % of primary care physicians reported receiving them [19]. In addition, primary care physicians report that these plans are valuable in increasing their knowledge and influencing patient care [20]. With increasing use of the electronic health record, access to this information is likely to increase among primary care physicians.

We were interested to see substantial differences in the survivorship experience of Hispanic and non-Hispanic women. Hispanic patients are currently the largest ethnic minority in the United States (12.5 % of the population) [21]. Hispanic cancer patients are considered vulnerable for adverse outcomes. Focus groups that compared the experiences of breast cancer survivors from four ethnic groups reported that Hispanic participants expressed greater concerns about pain, survival, and sexuality, as well as financial hardships and employment status, than other minority patients [22]. We found that Hispanic women had more extremes in scores than the non-Hispanic women. It is unclear if this represents true differences or may be more related to cultural differences in answering questionnaires or socioeconomic differences. It could also be a finding introduced by differential item functioning [23]. These biases result when ethnic/racial groups have different probabilities of answering a questionnaire based on different cultural beliefs. However, in the regression analysis, after controlling for confounding variables, such as education, health literacy, and employment, ethnicity was no longer a predictor of health worry.

This study had several strengths. First, both groups received an intervention and did not know that they were being randomized. We felt that knowledge of the study design would influence the patient-reported outcome measures used in this study. The patient population was ethnically, educationally, and economically diverse, and therefore, the results have a higher likelihood of being generalizable to similar populations. Finally, we used outcome measures that have been well validated and represent concerns faced by cancer survivors.

The study also had several important limitations. This was a single institution trial where patients were seen in a breast cancer-specific clinic, and it is possible that physicians' behaviors change as a result of knowledge that the trial was ongoing, otherwise known as the "Hawthorne effect." We also limited the study to breast cancer survivors. It is possible that due to the abundance of breast cancer information provided by the media, patients may have less of a need for an in-person intervention similar to ours. Less is known about survivors of other cancers, and these results may not be generalizable to those populations. In addition, while all of the questionnaires were translated into Spanish by a certified translator who was approved by the local IRB, several of them were not officially "validated". However, they were reviewed by several experienced bilingual research personnel, and because we evaluated change over time, we think this would have had little impact on the main findings. It is possible that cultural differences may have influenced how the questions were interpreted. Due to the short-term follow up, we were unable to assess how the intervention influenced long-term concerns or coordination of care. Finally, it is possible that other outcome measures may have been more sensitive to the short-term benefits of the survivorship intervention.

In summary, we did not find a short-term benefit of an in-person personalized survivorship intervention as opposed to providing a publication that addresses survivors' concerns in terms of patient-reported measures of well-being and treatment satisfaction. We did find that the intervention reduced health worry, and future studies should confirm this finding. It should be noted that there were significant costs associated with the intervention, as it utilized more health care resources. Future trials evaluating interventions should be multicentered, focus on evaluating the most efficient and effective methods of delivering survivorship care plans, and should determine their

influence on coordination of care and utilization of health care resources.

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