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Bridging the transition from cancer patient to survivor: Pilot study results of the Cancer Survivor Telephone Education and Personal Support (C-STEPS) program

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Abstract

Objective—To develop a feasibility study of a theory-driven telephone counseling program to enhance psychosocial and physical well-being for cancer survivors after treatment.

Methods—Participants (n = 66) were recruited from two Colorado hospitals with self-administered questionnaires at baseline and two weeks post-intervention. The one group, intervention only design included up to six thematic telephone counseling sessions over three months. Topics included nutrition, physical activity, stress management, and medical follow-up. Primary outcomes were cancer-specific distress, self-reported fruit and vegetable consumption and physical activity.

Results—Of 66 subjects, 46 completed at least one counseling module and the follow-up assessment (70% retention rate). Mean satisfaction was 9 out of 10, and all participants would recommend C-STEPS to other survivors. Cancer-specific distress (Impact of Event Scale – Intrusion subscale) decreased for entire study population ($p < 0.001$) and stress management session participants ($p < 0.001$). Fruit and vegetable consumption increased for nutrition and exercise session participants ($p = 0.02$) and the entire sample (p = NS). Physical activity increased in the entire group ($p = 0.006$) and for nutrition and exercise session participants ($p = 0.01$).

Conclusion and practice implications—C-STEPS is a feasible telephone counseling program that transcends geographic barriers, demonstrating the potential to decrease distress and promote coping and healthy lifestyles among cancer survivors.

Keywords

Cancer Survivorship; Transactional Model of Stress and Coping; Motivational interviewing; Telephone counseling

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1. Introduction

The transition from active cancer patient to survivor involves a fundamental transition in self-perception and the coordination of ongoing medical care, an important issue for the 13.7 million cancer survivors in the United States today [1]. The Institute of Medicine (IOM) released the groundbreaking report, From Cancer Patient to Cancer Survivor: Lost in Transition [2] trumpeting the need for comprehensive, evidence-based survivorship care to bridge this chasm.

Previous research has shown that cancer survivors post-treatment can suffer from clinically significant psychosocial sequelae that may compromise health related quality of life [3], as well as low adherence to established guidelines for healthy diet, nutrition and physical activity practices among survivors [4–6]. This compelling need to provide both psychosocial and health promotion services to survivors captures a fundamental premise of this research: the plausibility of developing and delivering a convenient and exportable intervention incorporating psychosocial well-being and health promotion behaviors that reduces a serious access barrier by eliminating the need for return visits to the treatment institution [7,8].

For over 20 years, telephone counseling has been recommended to provide psycho-educational support to cancer patients and survivors [9–12]. Numerous randomized trials have tested such interventions among cancer patients post-treatment [13–26], many of which have reported significant effects for psychosocial outcomes [21–26]. However, we are not aware of any published studies utilizing telephone counseling to simultaneously address psychosocial and health behavior outcomes among cancer survivors post-treatment. This paper reports results from the Cancer Survivor Telephone Education and Personal Support (C-STEPS) program, one such study conducted as a small-scale feasibility project.

2. Methods

All research procedures, intervention protocols and materials were reviewed and approved by the Colorado Multiple Institutional Review Board (COMIRB).

2.1. Research design, patient eligibility and sample size

2.1.1. Research design—C-STEPS was evaluated as a small-scale feasibility study using a single-arm (intervention-only) research design with participants serving as their own controls. A convenience sample of participants was recruited from the Cutaneous Oncology and Urologic Oncology Programs at the University of Colorado Cancer Center (UCCC), and from a rural community based cancer center (St. Mary Corwin Medical Center). Patients were approached on-site by a study coordinator for enrollment, where written informed consent was obtained. Baseline self-administered questionnaires were completed on-site at the time of enrollment or completed off-site and returned by mail. After completion of the three-month C-STEPS program, follow-up self-administered questionnaires were completed by mail.

2.1.2. Eligibility criteria and sample size—Eligibility criteria for C-STEPS included (1) diagnosis of stage I, II, or III disease, (2) attending the last treatment visit or any follow-

up visit up to one year; (3) not in active treatment or with signs of recurrent cancer; (4) at least twenty-one years of age; (5) English speaking; (6) able to read and write; and (7) able to give informed consent. Based on these eligibility criteria, 66 patients were initially enrolled in C-STEPS (UCCC = 37, St. Mary Corwin = 29), of which 46 (70%) completed the three-month follow-up questionnaire (UCCC = 26, St. Mary Corwin = 20).

2.2. Theoretical underpinnings of the intervention

2.2.1. Transactional Model of Stress and Coping—Reflecting its distinctive, dual focus on stress and coping and behavior change, the theoretical foundations of C-STEPS draw from the Transactional Model of Stress and Coping (TMSC) [27–29], and Motivational interviewing (MI) [30–32]. TMSC posits that responses to potentially stressful events or situations depend on primary appraisal, secondary appraisal and coping efforts. Empirical evidence supports the complex effects of appraisal on coping efforts and coping outcomes, with important motivational, behavioral, and affective consequences for the coping process [33–39]. Subjective appraisals of stressors [39–41] and coping efficacy [38] appear to serve as more significant predictors of physical, emotional and social well-being than presence of the stressors themselves. Several studies provide support for various components of the appraisal-coping model [41–44]. In general, the model points to teaching individuals to evaluate their primary appraisals of stressful situations achieve accurate primary appraisals, evaluate coping resources, and enhancing these resources as necessary by increasing functional and tempering less functional coping efforts [45]. Strategies to mobilize individuals to modify their sources of stress and enhance emotional and tangible social support are also important coping efforts [46]. Applications of the TMSC have been shown to improve coping and functional adaptation to cancer [47,48], critically ill patients [49–51], and HIV patients and their caregivers [52–54].

2.2.2. Motivational interviewing—MI is a conversational style intended to elicit the motivation required to move individuals through the stages of behavioral change, and is particularly effective with individuals at early stages of readiness [32]. Brief MI consists of a menu of techniques that help elicit the client's own argument for change and activation of healthy behaviors and has been used successfully in health behavior interventions [30,32]. Classic exemplars of brief MI techniques include agenda setting circles menus, readiness rulers and decisional balance sheets, which were standardized in the C-STEPS program. Non-judgmental reflective responses and well-timed summaries mirror and reinforce the benefits of behavior change and the client's self-efficacy. Discussion of barriers to change is contained, specific and solutions focused. MI has been proven effective across a variety of behavioral outcomes [30,55].

2.3. Intervention overview

The telephone counseling program was delivered by two masters-level psychosocial oncology counselors affiliated with the nationally recognized UCCC Cancer Information and Counseling Line (CICL) [9]. C-STEPS was a three to six session program delivered in two modules over a three month period. The specific modules and thematic domains include: (1) *Meet the Challenge*, a three-session intervention dealing with uncertainty and stress management after cancer and (2) *Healthy Options*, a three-session intervention

focused on healthy diet and physical activity practices. Thematic materials were used to structure and augment the C-STEPS telephone counseling. These materials included a stress management guide, stress management worksheets, a LIVESTRONG ™ Survivorship Guide, American Institute for Cancer Research (AICR) diet and physical activity booklets and additional MI worksheets.

The counseling process began with a brief orientation call, during which participants were introduced to the program and given an overview of the counseling materials and themes. At this time, participants were invited to choose one or both modules, with the latter prioritized based on preference. Those participants who chose only one of the two thematic modules received three sessions over a six week period while those who chose both received six sessions over a twelve week period. During the thematic sessions, counseling unfolded in a uniform fashion. The counselor opened the session by taking time to establish or deepen rapport, followed by a review of the thematic materials. For the *Meet the Challenge* module, the participant and counselor explored common survivorship issues as highlighted in the LIVESTRONG Survivorship Guide and utilized the C-STEPS Stress Management Guide to prioritize and learn strategies to cope with salient survivorship stressors. For the *Healthy Options* module, the participant and counselor reviewed the AICR booklets: *The New American Plate* and *Move More to Prevent Cancer*. Also highlighted in each *Healthy Options* session were the American Cancer Society (ACS) recommendations for healthy portion sizes, plate composition, eating at least five servings of fruits and vegetables daily, and exercising for at least 150 min per week. Using MI strategies developed specifically for C-STEPS, the counselor actively elicited the participant's intrinsic values and desires for engagement in the targeted diet and physical activity behaviors. Additionally, all participants were encouraged to obtain a written treatment summary and follow-up care plan from their oncology medical providers. Homework was assigned between sessions and each session included a review of previous goals and a plan for next steps toward reaching the targeted stress and coping or behavioral goals. The final session provided a synthesis and integration of topics and goals from previous calls.

2.3.1. Counselor training, supervision, and quality assurance—The four-week counselor training included assigned reading, group discussion, and role play exercises. The training program assumed a level of counselor competency and telephone counseling experience provided by the CICL standard service training program. All intervention counseling sessions were tape-recorded. For internal quality control review, 10% of tapes were randomly selected and coded using standardized forms for intervention fidelity, with counselor feedback provided weekly.

2.4. Baseline and follow-up self-administered questionnaires

The baseline questionnaire included standardized sociodemographic questions (e.g., age, gender, education, income, marital status, and race/ethnicity) from the Behavioral Risk Factor Surveillance System [4]. Both the baseline and follow-up questionnaires included assessments of cancer-specific distress, fruit and vegetable consumption and physical activity, reflecting the main psychosocial and behavioral endpoints for program evaluation.

2.4.1. Cancer-specific distress—Cancer-specific distress was assessed using the Impact of Event Scale (IES), a 15-item self-report scale assessing two psychological responses to stressful life events: intrusion (IES-I) and avoidance (IES-A) [56–59]. The respondent reports the frequency of experiencing either avoidance or intrusion of specified thoughts during the past 7 days. Subscale scores are calculated for Intrusion (7 items; alpha = .78) and Avoidance (8 items; alpha = .82). Internal reliabilities range from 0.72 to 0.92, with test–retest reliabilities (1–6 weeks) ranging from 0.87 to 0.94 [56]. In this study, the adverse life event refers to the cancer experience. Low distress on either scale was scored as 0–8, moderate was 9–19, and high was 20+ [55,57].

2.4.2. Fruit and vegetable consumption—Daily fruit and vegetable servings were assessed from a question used in previous research [60–65] derived from two summary questions included in the Block food frequency questionnaire [64]. Research has shown that this question yields highly consistent estimates compared to the two summary questions [5]. The question stem defines a serving size (i.e., "…a serving is about a medium size apple or ½ cup of chopped vegetables or fruit or about 6 oz. of 100% fruit or vegetable juice"), then assesses daily intake ("About how many servings of fruits and vegetables do you usually eat or drink on an average day? Please include fruits, vegetables and 100% fruit or vegetable juices in your number.")

2.4.3. Physical activity—Moderate and vigorous physical activities were assessed by standardized questions from the Behavioral Risk Factor Surveillance System [5]. Separate questions ask respondents whether they do moderate physical activity for at least 10 min at a time that causes "some increase in breathing or heart rate" (e.g., brisk walking, bicycling, vacuuming, gardening, etc.), and vigorous physical activity for at least 10 min at a time that causes "large increases in breathing or heart rate" (e.g., running, aerobics, heavy yard work, etc.) If yes to either or both questions, respondents are asked how many days per week they do moderate and vigorous physical activity for at least 10 min, and how many total minutes per day are spent doing moderate or vigorous physical activity. The answers to both questions were summed to provide an estimate of total minutes per week of moderate and vigorous physical activity.

2.4.4. Process evaluation—The three month follow-up questionnaire included process evaluation questions, assessing satisfaction and helpfulness of C-STEPS with a 10-point scale, where 1 = lowest and 10 = highest, and whether the participant would recommend C-STEPS to other cancer survivors (yes/no).

2.5. Statistical analyses

Study data were collected and managed using REDCap (Research Electronic Data Capture) hosted at the University of Colorado Denver [66]. REDCap is a secure, web-based application designed to support data capture for research studies. Preliminary analysis included descriptive statistics (means, standard deviations and frequencies). Preliminary analysis included descriptive statistics (means, standard deviations and frequencies). To assess differences between means for the outcome variables (continuous IES scores, servings of fruits and vegetables per day, minutes of physical activity per week) at baseline

and 3-months follow-up, dependent *t*-tests were used. A *p*-value of 0.05 was considered significant. All statistical analyses were conducted as two-tailed tests using STATA, version 11 (College Station, TX: StataCorp LP).

3. Results

3.1. Sociodemographic characteristics of participants at baseline

As indicated in Table 1, participants enrolled in this study covered a wide age range: 22–80+, with a mean age of 59.5. Men and women were represented equally. The majority of participants were non-Hispanic White, married, well educated, and currently employed or retired. Nearly all participants had health insurance. Over half of the sample earned $50,000 or less per year, and approximately a third earned less than $25,000 annually.

3.2. Disease characteristics at baseline

As shown in Table 2, the most prevalent cancer sites among participants were melanoma, prostate and breast, respectively. Consistent with eligibility criteria for this study, the dominant stage of cancer across types and gender was stage 2.

3.3. Implementation and process evaluation

3.3.1. Implementation evaluation—Of the 66 participants initially enrolled, 13 (20%) declined to participate before selecting their preferred intervention modules. Seven additional participants (10%) dropped from the program (typically after the first counseling session) or failed to return the three-month follow-up questionnaire. Reasons for dropping from the program included being too busy, having other serious medical conditions, not interested in making lifestyle changes and/or feeling that the program was not a good fit. Of the remaining 46, 21 (46%) selected both modules, 13 (28%) selected stress and coping, while another 12 (26%) selected healthy behaviors. Counseling sessions were scheduled up to 60 min and on average lasted 45 min. For those participants who chose only one module (Healthy Options or Meet the Challenge) (n = 23) 78.2% completed all three sessions (mean = 2.7 sessions). For those who chose both modules (n = 23), 65.7% completed all six sessions (mean = 5.4 sessions). Reasons for not completing all sessions included personal illness, competing life demands such as caring for others, and travel. Missed appointments due to the participant forgetting about the appointment were rare. This may be attributed in large part to the implementation of regularly scheduled reminder calls and easy access to the counselor through voicemail and email. Also, counselors scheduled sessions at the convenience of the participant including during evening and weekend hours.

3.3.2. Process evaluation—Participants were highly satisfied with the program, with a mean overall satisfaction rating of 9.0 on a scale of 1–10. Participants rated the usefulness of the telephone counseling program highly with a mean of 8.8, and all participants who completed the follow-up questionnaire said they would recommend the C-STEPS program to other survivors.

3.4. Outcome evaluation

3.4.1. IES-I—On the IES Intrusion subscale, 67% of participants at baseline reported moderate distress or above. Among all participants (n = 46), a significant decrease in mean cancer specific intrusive thoughts was observed (from 10.2 to 6.5, $p < 0.001$). Among participants receiving the stress and coping module (n = 34), improvement in distress was even more pronounced (from 11.9 to 7.0, $p < 0.001$). This change effectively decreased distress levels from moderate to mild. Among melanoma patients at baseline (n = 18), IES-I scores were higher when compared to all participants (14.8 vs. 10.2, $p = 0.005$) and demonstrated the greatest improvement (from 14.8 to 8.6, $p < 0.001$).

3.4.2. IES-A—On the IES-A subscale, 59% of participants at baseline reported moderate levels of distress as indicated by cancer specific avoidant behavior. As with the IES-I, all participants (n = 46) showed a significant decrease in cancer specific avoidance (from 11.5 to 9.1, $p = 0.046$). This improvement was more pronounced among participants receiving the *Meet the Challenge* module (from 13.6 to 10.2, $p = 0.02$). Once again, greatest improvement was seen among melanoma patients (from 14.3 to 10.2, $p = 0.025$) (Table 3).

3.4.3. Fruit and vegetable consumption—Although not statistically significant, an increase in daily fruit and vegetable servings was observed among all participants, from an average of 4.1 daily servings at baseline to 4.6 at follow-up. However, among participants who received the *Healthy Options* module (n = 33), a statistically significant increase in daily consumption of fruits and vegetables was found, from 3.8 to 4.6 daily servings (p = 0.02).

3.4.4. Physical activity—For physical activity, the mean moderate or vigorous activity at baseline for the entire sample was 166.8 min per week, slightly above the standard recommendation of 150 min. For all participants (n = 46), minutes of physical activity increased to 242.0 ($p = 0.006$). This increase was more pronounced for the *Healthy Options* participants (from 146.7 to 236.0 ($p = 0.01$) (Table 4).

3.4.5. Replication costs—The replication costs for the C-STEPS intervention include the unit cost for the print materials (estimated at $10 per client, and 90 min of counselor time per session for six sessions, where each counseling session would be approximately 45 min duration, with 15 additional minutes devoted to preparation time, another 15 min for preparing counselor notes post counseling session, and 15 min for callbacks and record-keeping. These costs also include one hour of supervision time budgeted per client. For this study the annual counselor salary was budgeted at $50,000 or about $25 per hour (37.00 per session) × 6 sessions = $225, with supervisor time budgeted at $35 per hour. Thus the study-specific replication costs are estimated at $270 per client or about $45 per counseling session for the six session program.

4. Discussion and conclusion

4.1. Discussion

The main objective of this study was to test the feasibility of a theory-driven telephone counseling program to enhance psychosocial and physical well-being for cancer survivors after treatment. The findings from this study suggest that C-STEPS is a feasible telephone counseling program that transcends geographic barriers, demonstrating the potential to decrease cancer specific distress and promote healthy lifestyles among cancer survivors. Especially noteworthy, with a 70% completion rate, C-STEPS appealed to a broad range of survivors in terms of age, gender, income, and cancer diagnosis. Of recruited participants who dropped from the program, 20% did so before or at the start of the first counseling session. Only seven (10%) dropped from the program after having interacted with the C-STEPS counselor. Also noteworthy is that program satisfaction ratings were exceptionally high, and all participants indicated that they would recommend C-STEPS to other cancer survivors.

Regarding improvements in psychosocial functioning, all participants demonstrated significant decreases in cancer specific distress (both intrusion and avoidance) from baseline to follow-up. These decreases were more pronounced for participants who chose the *Meet the Challenge* (stress and coping) module alone or in combination with *Healthy Options*. Additionally, melanoma patients, who had the highest levels of distress at baseline, showed the largest relative decrease in distress, compared to all study participants. This finding is not surprising given that melanoma survivors may have exceptional need for psychosocial intervention. They tend to be younger than most adult cancer survivors, with younger age being a well-established risk factor for cancer-specific distress [66–68]. Melanoma survivors also have a less predictable prognosis compared to many other cancer survivors, which can exacerbate feelings of uncertainty and distress.

Regarding healthy lifestyles, among all participants, this pilot study also found positive (but non-significant) trends in improved diet (fruit and vegetable servings). However, among *Healthy Options* participants, fruit and vegetable consumption increased by 0.8 servings per day. This result is striking because most participants received only one diet-related session. Physical activity findings were even stronger, with an increase in moderate or vigorous physical activity among all participants from 167 min per week at baseline to 242 at follow-up. Among *Healthy Options* participants, the relative increase was greater, from 147 to 236 min per week.

Finally, several key limitations of this small-scale feasibility study should be noted. Resource limitations precluded the addition of a control or comparison group. Thus, it is conceivable that the significant changes observed in the primary outcomes may reflect secular trends that would have occurred independently of C-STEPS. While the single-arm research design cannot conclude that improvements are necessarily due to treatment, the magnitude of change observed in this study over a short (3 month) time period would seem to argue against this singular, competing interpretation of program efficacy. Similarly, resource limitations precluded the opportunity to conduct longer-term follow-up to ascertain whether observed changes from baseline will attenuate over time. Finally, all of the

behavioral endpoints examined in this pilot study were based on self-report, which are potentially susceptible to reporting bias. These limitations highlight the need for additional larger-scale randomized trials. Such research should be pursued, based on the feasibility demonstrated by this pilot study, and because of the pressing need to develop survivorship programs that will be exportable, sustainable, and effective while maximizing reach to all in need of such programs.

4.2. Conclusion

To our knowledge, C-STEPS is the first telephone counseling program to include intervention components and primary outcomes in both psychosocial well-being and health behaviors. By demonstrating the feasibility of adding a health behavior component to a more traditional psychosocial program for cancer survivors, programs like C-STEPS may introduce new opportunities for programmatic synergism. For example, promoting healthy behaviors by evoking intrinsic motivation and self-efficacy support, two key tenets of MI, may actually enhance and synergize the effectiveness of stress and coping interventions. As a case in point, consider the common re-entry survivor emotional states such as uncertainty and fear of recurrence within the context of TMSC. For many survivors, the post-treatment emotional terrain is nuanced by the distressing sense that life is uncontrollable. Classic TMSC interventions are aimed at enhancing perceptions of control through the application of approach-focused coping strategies that promote problem-solving, emotional regulation and finding meaning. Within this context, efforts to promote healthy behavior change could be viewed as one viable coping strategy to enhance perceptions of control among survivors reporting elevated levels of cancer-specific distress.

Another innovative aspect of this study was allowing participants to choose the modules they received. Approximately one half of participants chose both modules and one quarter chose one or the other. Although preliminary, these data suggest value and feasibility of cancer patients to tailor program content based on their perceived need.

Virtually all previous studies of psychosocial telephone counseling programs have targeted a single or very limited number of cancer diagnoses [16,21,23], presumably reflecting the belief that such targeting enhances program effectiveness. However, the counterpoint to this argument is that no cancer program has sufficient resources to develop individualized and highly targeted psychosocial programs to accommodate all or most cancer diagnoses that require intervention. From this perspective, extreme “audience segmentation” may be counterproductive to the presumptive goal of developing exportable, sustainable and cost-efficient psychosocial programs. C-STEPS, a general cancer survivorship program, provides an exemplar of how one such program could maximize reach and benefit to all survivors with demonstrable need.

Finally, while C-STEPS was designed as a general survivorship program, tailoring of this program to individual survivors was not sacrificed, but instead reflects a signature characteristic of this program. The program is standardized to process rather than content. Counseling processes that define both the TMSC and MI provide the ultimate examples of highly tailored, patient-centered communication, where tailoring is fundamentally linked to individual stressors (TMSC) or sources of ambivalence for behavior change (MI). This form

of tailoring allows programs such as C-STEPS to be highly individualized and patient-centered, while also providing service as a more general, exportable and sustainable cancer survivorship program.

4.3. Practice implications

Beginning in 2015, all cancer programs in the United States that will seek accreditation from the American College of Surgeons (ACoS) must implement mandatory distress screening and provision of services for all cancer patients with moderate distress and above [69,70]. This mandate presents a monumental challenge which could also affect cancer programs internationally that may soon implement a similar protocol for distress screening and follow-up: providing psychosocial services to numerous cancer patients and survivors who will be identified as having demonstrable need. By integrating psychosocial telephone counseling within the broader context of a comprehensive standard service program for cancer survivors post-treatment, programs like C-STEPS could help cancer programs respond to this challenge in a rational and cost-efficient manner.

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Table 1

Sociodemographic characteristics of sample at baseline.

	N	%
Age		
20–29	1	2.2
30–39	2	4.3
40–49	7	15.2
50–59	12	26.1
60–69	14	30.4
70–79	8	17.4
>80	2	4.3
Gender		
Male	22	47.8
Female	24	52.2
Education		
High school graduate	6	13.0
Some college	18	39.1
College graduate	13	28.3
Post-graduate	9	19.6
Race/ethnicity		
White	41	89.1
Other	4	8.7
Missing/did not report	1	2.2
Marital status		
Married/living with a partner	32	69.6
Not married	14	30.4
Employment		
Employed for wages	21	45.7
Retired	18	39.1
Other	7	15.2
Income		
≤$25K	16	34.8
$25K–$50K	9	19.6
$51K–$75K	9	19.6
$76K+	10	21.7
Missing	2	4.3

Table 2

Disease and treatment characteristics of sample at baseline.

	N	%
Cancer type		
Melanoma	18	39.1
Prostate	11	23.9
Breast	10	21.7
Head and neck	2	4.3
Other	5	10.9
Stage		
I	9	19.6
II	15	32.6
III	8	17.4
Unknown	11	23.9
Missing	3	6.5
Surgery		
Yes	36	78.3
No	10	21.7
Chemotherapy		
Yes	16	34.8
No	27	58.7
Missing	3	6.5
Radiation		
Yes	18	39.1
No	25	54.4
Missing	3	6.5

Table 3

IES I and IESA – change from baseline to follow-up.

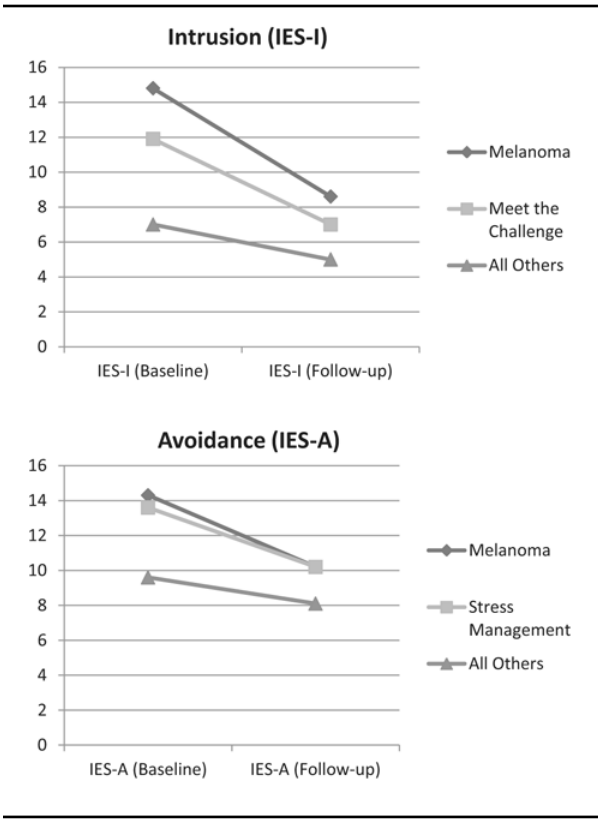

Table 4

Fruit and vegetable consumption and physical activity change from baseline to follow-up.