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Cancer survivorship care for young adults: a risk-stratified, multicenter randomized controlled trial to improve symptoms

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Abstract

Purpose—Young adult (YA) cancer survivors have high rates of adverse health and psychosocial outcomes. This risk-stratified, multicenter, randomized controlled trial (RCT) compared a self-management survivorship intervention to usual care in YA survivors with symptoms of cancer-related distress, insomnia, fatigue, pain, and/or depression.

Methods—Eligibility included age 18–39 at diagnosis with an invasive malignancy in the previous 1–5 years. Baseline assessment determined “high need” participants, with 2–5 elevated targeted symptoms. We randomized high need participants to intervention or usual care and offered intervention participants a survivorship clinic visit, which included mutually decided action plans for symptoms. Follow-up calls at 1 and 3 months after the clinic visit reviewed action

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Ethics approval The protocol was approved by the Institutional Review Boards of the Coordinating Center, Fred Hutchinson Cancer Research Center, and of each of the other participating sites.

Consents Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare no competing interests.

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plan progress. Outcomes compared rates of improved symptoms for intervention vs usual care at 6 months and 12 months.

Results—*N* = 344 completed baseline assessment, with *n* = 147 (43%) categorized as high need and randomized. Of *n* = 73 randomized to the intervention, *n* = 42 (58%) did not attend their survivorship clinic visit. In intent-to-treat analyses, aggregate symptom scores did not differ between arms, though distress improved for 46% in the intervention arm at 6 months compared to 18% in usual care (*p* = 0.03) among those with elevated distress at baseline.

Conclusions—Distress improved for YAs who received self-management survivorship care. However, the study demonstrates a need for alternative strategies for providing YA survivorship care.

Trial registration— NCT02192333

Implications for Cancer Survivors—While YA survivors demonstrate some improved distress when provided survivorship care, to make care accessible and effective, they require options such as remote delivery of care.

Keywords

Young adult; Cancer survivor; Survivorship care plan; Randomized controlled trial; Risk-stratified; AYA

Introduction

After cancer treatment, young adult (YA, aged 18–39 at diagnosis) survivors have higher rates of adverse health and psychosocial outcomes than most other cancer survivor groups, as highlighted in National Academy of Medicine (NAM) and National Cancer Institute (NCI) reports [1–6]. YAs will spend most of their lives as cancer survivors with physical, social, and emotional needs not only that differ from their peers, but also that differ from the needs of younger or older cancer survivors. They have significant risks for long-term complications including subsequent malignant neoplasms (SMNs) and accelerated development of usual age-related comorbid conditions [7–21]. Nonetheless, more than 50% of YA cancer survivors do not receive recommended cancer-related follow-up care [22]. In addition, YAs have significantly greater psychological distress and fewer positive health beliefs than older adult survivors [23].

Survivorship care plans (SCPs) may help YAs with their healthcare surveillance and symptom management needs [24]. SCPs are recommended for all cancer survivors including YAs, and should include the following information: (1) cancer type, treatments, and their potential long-term effects, (2) information about screening and preventive evaluations and their timing, and (3) recommendations about lifestyle practices [6, 25]. To date, research testing the delivery of a printed SCP with a single clinic visit has not found improved symptoms or health outcomes, although survivors may report feeling positive about having received SCPs [26–40]. Personalizing an action plan for the individual and following up to address barriers to completing the action plan may be necessary to make SCPs more effective [41, 42]. However, a review found that health promotion and psychological

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interventions have not yet improved healthcare adherence in YA survivors, again pointing to the need for improved methods [43].

In 2012, the LIVESTRONG Foundation convened 150 community leaders, stakeholders, cancer survivors, and cancer survivor advocates to define what the key *Essential Elements* of *survivorship care* (EESC) were. The panel determined that there were five essential elements of survivorship care that all cancer survivors require: (1) SCP, psychosocial care plan, and treatment summary; (2) screening for new cancers and surveillance for recurrence; (3) care coordination strategy, which addresses care coordination with primary care physicians and primary oncologists; (4) health promotion education; (5) symptom management and palliative care [44]. The LIVESTRONG Foundation also provided grants to seven National Comprehensive Cancer Centers as the "Survivorship Centers of Excellence Network" to develop successful strategies to implement these EESC.

Using the EESC, and recognizing the need for risk-stratified survivorship interventions in which those with elevated needs receive a higher level of care, we designed a clinical trial based on the principles of self-management and shared decision-making [45]. Self-management has been used to help patients cope with their chronic diseases (e.g., diabetes) and more recently their cancer survivorship care [46–49], including for increasing physical activity, improving diet, and reducing distress [50]. While definitions of self-management vary, all descriptions include the provision of education and interventions that increase patient skills and confidence in managing their own health, life roles, and psychological needs [47, 51, 52]. Skills training includes problem-solving, decision-making, training in the use of available resources, goal setting, taking action, and sharing in health decisions that understand and include patients' own personal values and priorities [47, 51, 52]. Improvement in emotional health, or reduction of distress, is a cornerstone of self-management both in the focus on psychological health as a priority and through the improvement in self-efficacy as reflected in confidence in managing one's own health needs. When used in shared decision-making as a cornerstone of self-management, SCPs also may increase communication between oncologists and primary care providers [53].

In this paper we report the outcomes of a risk-stratified, multicenter, randomized controlled trial (RCT) comparing a self-management focused survivorship care intervention to usual care (control) in YA cancer survivors defined as "high need" based on having at least two elevated symptoms of pain, fatigue, sleep disturbance, depression, and/or distress, using standardized cut-points as published for each symptom measure. The intervention included a survivorship-focused in-person clinic visit to deliver the EESC using a self-management approach, which included delivery of a treatment summary and survivorship care plan, mutual decision-making to agree on an action plan addressing the five targeted symptoms, and two follow-up telehealth booster calls. We hypothesized that, among high need YA survivors, those randomized to the intervention would report aggregate symptom scores that were improved at 6 months when compared with controls. Additionally, among survivors with a specific elevated symptom at baseline, we hypothesized a higher proportion of those in the intervention vs control arm would meet criteria for being not elevated on that symptom at 6 months. Secondary hypotheses predicted similar improvements at the 12-month time point. We also hypothesized that, for those with a baseline low level of

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confidence in their survivorship knowledge, a higher proportion of those receiving the intervention would report improved scores compared with the controls at 6 and 12 months. Additional exploration considered the differences between participants randomized to the intervention who did or did not complete their intervention clinic visit and follow-up calls.

Methods

Design

The study was a multicenter, risk-stratified, RCT conducted at four of the national Survivorship Centers of Excellence Network (SCOEN) sites. Risk stratification for elevated symptoms, and therefore eligibility for randomization, required a minimum of 2 of 5 symptoms scored above established cut-points for the measures used. Participants without elevated scores (not randomized) were assessed at the same time points as randomized participants.

Participants

All participants received their most recent cancer treatment at the SCOEN site that approached the survivor for consent. Participants were 18–39 at time of diagnosis with an invasive malignancy that included breast, gastrointestinal, female or male genitourinary system, sarcoma of bone or soft-tissue, leukemia, and lymphoma. Eligible participants must have received surgery, cytotoxic chemotherapy, biological or targeted agents, or radiation therapy in the previous 1.0 to 4.99 years. Eligible patients must have been seen for a follow-up visit at the participating center at least once in the 3 years prior to enrollment and/or were scheduled to be seen for follow-up in the next 6 months (i.e., in active follow-up). The study was limited to those able to read and speak English adequately to complete the patient-reported outcomes (PRO) assessment. Survivors who had a prior visit at a survivorship clinic or had already received a treatment summary and SCP were excluded.

Procedures

All procedures were reviewed and approved by the Institutional Review Board (IRB) at the coordinating center, Fred Hutchinson Cancer Research Center, and each IRB at the other enrolling clinical sites and performed in accordance with the 1964 Declaration of Helsinki. Informed consent was obtained prior to participation in the study. The study targeted enrollment for high need arm randomization was $n = 152$. Lists of potentially eligible survivors were identified from SCOEN site tumor registries and randomly ordered by the study biostatistician for order of approach. The lists were checked with medical records to confirm inclusion criteria and verify vital status and current mailing addresses. Potentially eligible survivors were sent a letter of approach and a study brochure from their SCOEN site via postal mail describing the study and requesting that they either visit the study website to register for the study or return the response form requesting follow-up from the study coordinator or opting out of the study. Initial mail contacts were followed with one more letter to those who did not respond and up to five phone calls until the participant was reached and indicated interest or declined participation.

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At time of enrollment, all participants were directed to a secure online portal where they provided acknowledgement of informed consent and then completed the online baseline PRO. Responses to their PRO were scored in real time by an automated algorithm. Based on standard clinical cut-points for elevated symptoms and their response scores to 5 symptom scales (depression, distress, insomnia, fatigue, pain), participants were categorized as either (1) “low need” if scores were not above cut-points on two or more symptoms or (2) “high need” if scores were above cut-points on two or more symptoms. Survivors in the high need category were randomized to one of two treatment arms: (1) the EESC Intervention arm which included an in-person clinic visit, additional survivorship resource materials, and two “booster” telehealth calls or (2) usual care (UC) control arm that followed the institutional standard of care for survivors but that did not include providing a treatment summary and SCP for the duration of the study. The low need group also received UC. Data on diagnosis, stage and cancer treatment were abstracted from medical records for all participants, and they were asked to complete a baseline and 6- and 12-month PRO. The 6- and 12-month follow-up PRO were abbreviated but similar in content to the baseline PRO. Participants received a $50 gift card of their choice (Amazon, Starbucks, or iTunes) for completing the baseline survey.

EESC intervention arm—Participants designated “high need” based on survey responses and randomized to the intervention were contacted by phone or email (as preferred) to schedule an in-person survivorship clinic visit. (Telemedicine visits were not available at the time of the study.) Participants were contacted up to six times or until they declined to have a clinic visit or until the visit was completed. Missed visits were rescheduled and attempts were made to overcome barriers to the visit through adaptation of scheduling, assistance with insurance coverage questions, and facilitating resolution of other identified barriers. For survivors randomized to the intervention, the survivorship clinic visit contained all tier 1 elements of the EESC [44]. These included the following: a treatment summary and SCP, recommendations for screening for new cancers, care coordination strategies with primary care physicians and primary oncologists, health promotion education, and symptom management. In addition, they were provided with late effects education, feedback on their psychosocial and medical assessment, and as needed, a referral for nutrition services, physical activity services, weight management, and psychosocial care. Using a self-management approach with shared decision-making, the clinician and patient mutually determined an action plan with goals to be accomplished in the next 6 months specific to the patient’s elevated symptoms as well as other patient priorities [47].

Survivor action plan: Using a pre-printed carbonless copy form, the clinician and patient wrote down the plan, including the symptoms, defined actions, who was responsible for completing the action (patient or clinician), and by what date. The survivor action plan was completed during the clinic visit, a copy given to the patient, and a copy maintained in the participant’s study file. An additional copy was mailed to the patient prior to the scheduled booster calls.

Booster calls: At 4–6 weeks and 12–14 weeks after the survivorship clinic visit, the patient received a call from a trained, supervised survivorship team member at the

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coordinating center to check on the patient's progress on goals set in the survivor action plan. They reviewed the plan, acknowledged goals achieved and, for goals not achieved or for remaining symptoms, identified barriers and revised actions to reach the mutually determined goals. If the team member and patient determined that further follow-up was needed by the survivorship clinician, the team member notified the clinician who contacted the patient.

Usual care control arm—*S*urvivors randomized to the control arm or in the low need group received the standard of care/UC that patients who were not seen in the survivorship clinic would receive at the cancer center, including routine oncology follow-ups including management of symptoms, cancer screening, referrals other than to survivorship clinic, or resources that their treating oncology team would usually provide to patients. They completed assessments at the same time points as the EESC intervention arm. At the time of the study, standard of care at all participating cancer centers required referral to be seen in a survivorship clinic, and based on eligibility criteria, no study participants had been seen in a survivorship clinic or received a treatment summary and SCP. Although they were not referred to the survivorship clinics during the year of the study, they were given the option of a survivorship clinic visit after their 12-month assessment.

Measures

Study coordinators abstracted participants' medical records for details of diagnosis, histopathology, treatment exposures, related dates of events, and to confirm demographic information. These data were entered into a centralized single point of entry Survivorship Informatics Management System (SIMS) program at the coordinating center and were used to describe the sample. The patient-reported outcomes (PRO) utilized in this study included measures which have had extensive reliability and validity testing in cancer survivors. The primary outcomes each have a psychometrically defined cut-point indicative of elevated symptoms.

Primary outcomes

CTXD: The CTXD is a 23-item inventory of distress or worry related to stressful events for cancer survivors, with mean score calculated and an established cut-point of > 1.10 indicating elevated distress [54, 55]. The measure was developed from structured interviews with cancer patients, nurses, and physicians and has been used with thousands of long-term survivors. It has six subscales: uncertainty, family strain, health burden, identity, managing medical systems, and finances. Testing supports its value as a predictor of health outcomes [56, 57]. Internal reliability for cancer survivors is alpha = 0.93.

ISQ: Insomnia is measured with 5 items indicating frequency of sleep problems from 0 = "never" to 5 = "always, 5–7 times per week" [58]. A continuous scoring is the sum of the 5 items and the measure's established cut-point for elevated insomnia is a rating of 4 (frequently, 4–5 times per week) or higher on one or more of the three items for difficulty falling asleep, staying asleep, or sleep is unrefreshing. This is a version of the Pittsburgh Sleep Symptoms Questionnaires and has been extensively tested with the US population.

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BPI: The Brief Pain Inventory (BPI) is extensively used for all types of pain, including cancer. It is widely tested for reliability and validity [59, 60]. The BPI rates the severity of pain and the degree to which their pain interferes with common dimensions of mood and function. Two scores are calculated: a mean of 3 intensity items (worst, average, now) on scale from a 0 = 'no pain' to 10 = 'pain as bad as you can imagine,' and a mean of 5 interference items on a scale from 0 = 'does not interfere' to 10 = 'completely interferes.' The established cut-point for elevated pain is an intensity score > 4.

FSI: The Fatigue Symptom Inventory (FSI) is a widely used measure of fatigue for cancer survivors [61]. It has a total mean score of 13 items that assess the duration, intensity and disruptiveness of fatigue and its impact on quality of life. The measure was designed for use in the cancer population and evidence supports its strong reliability and validity [61, 62]. The established cut-point for the FSI is ≥ 3.

PHQ-8: The PHQ system is designed to briefly assess clinical symptoms of mood disorders as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV for psychiatric diagnoses [63, 64]. The depression measure has two screening items, followed by 6 additional symptoms if either of the screening responses are endorsed. This measure is one of the most widely used tools for screening depression across medical and psychiatric diseases and has strong reliability and validity [65, 66]. As is acceptable per the measure developers, we did not ask the suicide-related question, so scores were prorated for 8 instead of 9 items. The cut-point for moderate or greater depression symptoms is one of the two screening items scored 2 = "at least half the days" and a total score ≥ 10.

Secondary outcome

Confidence in survivorship information: This measure asks about confidence in knowledge of topics related to cancer and follow up care that are included in survivorship education and in SCPs, with response options ranging from 0 = "not at all confident" to 2 = "very confident." Item examples include the following: "The long-term physical effects you may experience from cancer and its treatment," or "Which screening tests you should have to detect health problems other than cancer (such as heart disease, diabetes, high cholesterol)." The measure has been tested with $N = 209$ cancer survivors with internal consistency reliability of 0.95, mean 2.4 (SD 0.48) and two factors [67]. In analyses, we used a cut-point of < 2.88 to indicate low confidence (the mean minus 1 SD).

Covariates

Sociodemographics: These items asked about race, ethnicity, income, education, marital status, work status, insurance, and living situation.

Comorbidity index: The self-report comorbidity index parallels the Charlson comorbidity index which is scored from medical records [68]. It includes a screening review of systems to which survivors respond with a yes or no for each major comorbidity. The measure has strong kappa agreement with the Charlson index, has documented validity and test–retest reliability and has been used in our previous survivorship studies [68]. Studies document the accuracy of cancer survivor self-report of medical diseases when compared with medical

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records [69, 70]. SF12: The SF12 is a widely used measure of QOL, with two subscales calculated as *t* scores, a mental component, and a physical component [71, 72].

Statistical analysis

The primary analytic component of this study was a 2-arm RCT among the group of "high need" YA survivors. The original primary endpoint of the study was described as the mean of the two *z*-scores of the two highest scores for the symptoms that determined the participant's eligibility as "high need" for randomization to the study. In practice, this outcome was not tenable as definitions of impairment did not necessarily align with highest magnitude *z*-scores for each person, and because subjects who had more than 2 criteria for which they qualified as "high need" would not contribute all relevant information about change in outcomes. Therefore, we slightly modified the primary endpoint by (1) for each participant, generating a difference between their *z*-score at 6-month follow-up and their *z*-score at the baseline for each of the five primary outcome measure and (2) generating an average of those differences for each person across the five symptoms, generating a primary endpoint that was a continuous measure at the 6-month post-randomization PRO assessment that summarized the change in scores since baseline. Mean scores for the primary outcome measure were compared between the study using *t*-tests. Two-sided significance levels were set at an α level of 0.05. Balance between study arms was evaluated with respect to key factors that could influence the outcomes such as sex, age, race, education, income, diagnosis, and type of treatment (surgery only, chemotherapy in the regimen, radiation with or without surgery) and, it was determined that adjusted comparisons were not needed. Post-hoc planned analyses compared binary versions of each symptom outcome measure (elevated vs notelevated symptom) at the 6-month and 12-month follow-up times among the subgroup of individuals who had a specific elevated symptom at baseline. This effectively compared the proportion of individuals who changed from elevated to nonelevated for each measure between study arms. Similar analyses compared the study arms for binary scores (elevated vs not elevated) on the confidence in survivorship information score. These analyses utilized chi-squared or Fisher's exact tests (where applicable) for comparisons. Additional secondary analyses compared these outcomes between the high need control arm and those members of the high need intervention arm who attended a clinic visit.

Results

We identified 1098 YA survivors who were eligible for approach after initial screening and were approached for enrollment (Fig. 1), with a protocol-designated, targeted enrollment of $N = 455$ and target for randomization to the high need group of $N = 152$. Of the 1098 potentially eligible, 451 (41.1%) registered and were sent links to the online consent and survey, with 344 completing the baseline survey. Another 35 were lost to follow-up and 612 declined actively or passively to participate. Age range at time of diagnosis was 18 to 39 years (mean 31.7, SD 5.8), and age at time of study participation was 20 to 45 years (mean 35.4, SD 5.7) (Table 1). Because we enrolled breast cancer survivors, 70% ($n = 242$) of participants were female; among participants with non-breast cancer diagnoses, 49.5% ($n = 102$) were male. While a majority were White and non-Hispanic/Latinx, 17.3% ($n = 58$) were Asian, Black, or Native American race and 8.8% ($n = 30$) were Hispanic/Latinx

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ethnicity. In comparing high need and low need groups, a higher proportion of high need participants had less than a 4-year college degree, were more likely to be unpartnered, had annual income levels < $81,000, and had Medicare or other public forms of health coverage (all $p < 0.01$).

At baseline assessment, 147 (42.7%) participants were categorized as “high need” and 197 (57.3%) as “low need.” Of the high need cases, 73 were randomized to the intervention and 74 to the usual care control arm. By design, participants in the high need group were more likely to endorse the targeted symptoms (Table 1), with the three symptoms of distress, insomnia, and fatigue co-occurring in 49.0% ($n = 72$). While pain and depression were less prevalent (31.3% and 29.3% respectively), for those with pain, 91.3% ($n = 42$) reported insomnia, 87.0% ($n = 40$) reported fatigue, and 84.8% ($n = 37$) reported distress. For those with depression, 93.0% ($n = 40$) also reported insomnia, 83.7% ($n = 36$) also reported distress, and 79.1% ($n = 34$) also reported fatigue.

Survivors in the high need group reported a lower level of confidence in survivorship information with 53.1% ($n = 78$) below the cut-point for confidence in survivorship knowledge compared with 29.6% ($n = 58$) of those in the low need group being below the cut-point for confidence.

For those randomized to the intervention, 42 (57.5%) did not attend the survivorship clinic visit, citing reasons related to cost ($n = 7$, 16.7%) or travel distance ($n = 7$, 16.7%) as primary reasons, although $n = 24$ (57.1%) simply never made or kept their appointment without providing a reason. Of note, $n = 40$ (95.2%) of those who completed their clinic visit also completed their booster calls. In comparing high need participants randomized to the intervention who did or did not complete their clinic visit (Online Resource: Supplementary Table), those who completed the in-person clinic visit were more likely to have at least a 4-year college degree ($n = 25$, 80.6%, for completers versus $n = 22$, 52.4%, for non-completers, $p = 0.02$). Otherwise, we identified no clinical, sociodemographic, or targeted symptom factors that distinguished those who did or did not complete their clinic visit.

Six-month outcomes

The intent to treat planned analyses compared mean *z*-score changes from baseline to follow-up between the high need intervention arm and the high need control arm at 6-months follow-up. Mean change in *z*-scores were − 0.038 (SD 0.487) and 0.049 (SD 0.542) for the intervention and control arms, respectively, resulting in the mean difference between study arms (intervention – control) of − 0.087 (95% CI − 0.38, 0.20) and $p = 0.54$.

Secondary planned analyses carried out among those elevated on a symptom at baseline compared the rate of improvement to being not elevated by 6 months in the high need intervention arm vs the high need control arm (Table 2). Of the 5 symptoms, only distress demonstrated a greater rate of improvement among those in the intervention arm. Of those with elevated distress at baseline in the high need intervention arm, 46.2% ($n = 12$) no longer reported elevated distress compared to 18.2% ($n = 6$) of those in the high need control arm ($p = 0.03$). Confidence in survivorship information did not differ by arm.

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Twelve-month outcomes

At 12 months, the mean difference between study arms in *z*-score changes was somewhat larger though non-significant, at − 0.21 (95% CI −0.47, 0.05) and $p = 0.10$, with mean change in *z*-score for the intervention of − 0.137 (SD 0.384) and for the control of 0.072 (SD 0.621). In binary 12-month analyses, no targeted symptoms improved at a higher rate in the intervention vs control arms in the intent to treat analysis for those elevated at baseline on that symptom (Table 3). There was a non-significant, descriptively higher rate of improvement for those with depressive symptoms in the intervention arm at 12 months with 77.8% ($n = 7$) of those elevated at baseline demonstrating improvement at the 12-month assessment compared to 33.3% ($n = 4$) of controls ($p = 0.08$), but with very small numbers of individuals in this analysis. We found a similar non-significant result for fatigue, with 37% ($n = 10$) of the intervention arm improved at 12 months versus 17.9% ($n = 7$) of the control arm ($p = 0.09$).

Comparing intervention participants who completed their clinic visit vs controls

Given the large proportion of participants in the high need intervention arm who did not complete their clinic visit, to further explore intervention outcomes, we examined improvement rates in targeted symptoms from baseline to 6 or 12 months among only those who completed their clinic visit compared to those in the high need control arm (Table 4). Parallel to the intent to treat analysis, those in the intervention arm who were distressed at baseline and completed their clinic visit were more likely than controls to have improved distress (53.3%, $n = 8$, versus 18.2%, $n = 6$, in the control arm, $p = 0.02$). In addition, those with low confidence in survivorship information in the intervention arm who completed their clinic visit were more likely to no longer have low confidence at 6 months compared to controls (87.5%, $n = 7$, for those with the clinic visit vs 37.5%, $n = 12$, for controls, $p = 0.03$). The rates of elevated scores for other targeted symptoms did not differ between those in the intervention who received their clinic visit and the controls at 6-months. Although a small sample size, of those in the intervention arm who completed the in-person clinic visit and were elevated in depressive symptoms at baseline, 100% ($n = 5$) improved in depressive symptoms at 12 months compared to 33.3% ($n = 4$) of those in the control arm ($p = 0.03$).

Finally, we compared those in the usual care to those in the Intervention for completion rates of 6- and 12-month assessments and found that the usual care group was somewhat more likely to complete their follow-up assessments than the Intervention group (63.5% vs 45.2% at 6 months, $p = 0.026$; 63.5% vs 47.9% at 12 months, $p = 0.057$, respectively). Furthermore, we tested the likelihood of completing the 6- and 12-month assessments within the Intervention group for those who did or did not attend their clinic visit and found similar, though non-significant, differences at 6 and 12 months ($p > 0.13$). For example, 58.1% of those who attended their clinic visit completed the 12-month assessment while 40.5% of those who did not attend their clinic visit completed the 12-month assessment.

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Discussion

Although YAs are widely documented to have elevated survivorship needs relative to older cancer survivor age groups, randomized controlled trials that test personalized interventions to improve outcomes and manage late effects in YA survivors are uncommon [73]. This study demonstrates the potential for such interventions as well as several of the major challenges in meeting the healthcare and symptom needs of YA survivors including implementing RCTs in this population. We found that when unmet symptom needs were addressed in self-management focused survivorship clinic visits and follow-up calls, YA survivors improved in cancer-related distress in the intent to treat analysis at 6 months, though other symptoms did not improve. Furthermore, in the analysis of those with symptom needs who were randomized to the intervention and who completed their clinic visits, both distress and confidence in survivorship knowledge improved at 6 months. This finding stands in contrast to other RCTs with adult survivors and meta-analyses that demonstrate no improved outcomes between SCP recipients and controls for distress, anxiety, depression, confidence in survivorship knowledge, physical functioning, self-efficacy, or with satisfaction with follow-up care and information provision [26, 74]. Equally notable, however, over half of the YA survivors with multiple elevated symptoms, who consented to the study, completed the baseline assessment, and were then assigned to the intervention, did not complete their clinic visit to receive the intervention. These findings demonstrate the need for alternative strategies to meet YA survivorship needs including improved strategies to recruit and retain this population.

This study identified several gaps in reaching YAs with unmet symptom needs and in standard clinical strategies to provide healthcare to YA survivors. Among participants, over 40% had 2 or more elevated symptoms, most commonly insomnia, distress, and fatigue, as well as 40% reporting lack of confidence in their survivorship knowledge. The frequency of these symptoms confirms the need for interventions to improve these outcomes. Unrelieved pain, reported by 14%, and depression reported by 13%, were less common symptoms. Clinical factors including diagnosis and extent of treatment did not distinguish those with high versus low unmet symptom needs, nor did numerous demographic factors. However, as often seen, socioeconomic disparities did impact health outcomes with those receiving publicly funded healthcare more likely to be in the high need group along with those with lower incomes, those who had not completed college, and unmarried survivors. Surprisingly, among the clinical and sociodemographic factors tested within the high need intervention arm, only a college degree predicted a greater likelihood of completing the clinic visit. These results reconfirm the well-documented findings that lack of access to resources and support such as among those with low socioeconomic status and less education, are driving factors in sustaining unmet healthcare and symptom needs. We also note the possibly counterintuitive finding that clinical factors such as intensity of clinical treatment, type of diagnosis, and time since diagnosis were unrelated to extent of unmet symptom needs. We thought that financial strains, travel distance or lack of insurance would explain why participants declined their clinic visits. While all of these were reasons expressed by some participants, none were dominant reasons given, and the most likely response was to delay the visit or not respond to requests to schedule a visit after their initial participation. As

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a signal for strategies that might more effectively reach these YAs, nearly all (95%) of those who completed their visits completed their booster phone calls. The non-participation rate, along with the high levels of unmet needs, demonstrates the importance of finding alternative strategies to reach YAs, understand and overcome barriers, and provide their survivorship care.

YA cancer survivors face practical issues, healthcare system related barriers, and psychosocial challenges related to receiving appropriate follow-up medical care, likely helping to explain the low rates of in-person clinic visits completed during this trial [75]. With the expanding availability and acceptability of telehealth and digital modalities for providing healthcare, these approaches are particularly suited to meet needs of YA survivors. YAs are *digital natives* and continued exposure to and integration of digital interventions is the norm [76]. However, there is insufficient evidence to state conclusively which digital health delivery mode or intervention feature has the largest impact on outcome, engagement, or adherence among YAs [77]. Both contextual factors (e.g., uninterrupted app access, receiving the intervention in summer months) and population characteristics (e.g., lower depression, higher motivation to change) appear to play a role in YA digital health engagement [78]. However, this circles back to the problem of reaching those with greatest need who may well be less motivated or have more depression or distress. Embedding a SCP in an app, which can be introduced during routine care, with ongoing access post-treatment, may be a useful implementation strategy for disseminating SCPs to an YA survivor population [78]. To develop a digital health intervention that engages YA survivors and recognizes their diversity of needs and responses, it is necessary to investigate methods to overcome barriers to care and to include YAs in the design of survivorship care using qualitative research and patient-centered approaches and conduct usability testing prior to RCT implementation [79, 80].

This study has several strengths including being one of few YA survivor RCTs addressing survivorship care and symptom needs with a personalized survivorship plan and telehealth follow-up calls. The study used a risk-stratified randomization as recommended by National Cancer Institute expert panels to improve the cost-effectiveness, resource preservation, and effect sizes of interventions by focusing on treating those with meaningfully elevated symptoms or healthcare needs [81]. The enrollment at four large cancer centers in the USA, where survivorship is a referral service rather than a standard of care, similar to survivorship services at most cancer centers in the USA, adds to the potential generalizability of the findings. The two main distinctions between this clinical trial intervention and standard survivorship care were the additions of a specific action plan focused on symptoms and the two follow-up booster calls.

Limitations also need to be noted. Approximately 58% of those eligible for participation declined, and for those who participated, retention was low both for completing their survivorship clinic visits and for completing follow-up assessments. These findings emphasize the importance of further exploring barriers, facilitators, and motivators to participation for YAs and the need to design intervention, recruitment and retention strategies specific to their needs. Although the study was powered for the number of survivors enrolled, the low participation rate limits the generalizability and argues for

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innovative intervention modalities as described above. In addition, low participation in the intervention clinic visits compromised confidence in the intent to treat findings of the RCT, potentially biasing our results and underscoring the need for replication or adaptation of the methods. The multiple analyses also highlight the need for replication of the intervention findings. Although the directions of reduced symptom rates were as predicted at 6 and 12 months, in the intervention participants who received clinic visits versus controls we had inadequate power to be confident of those results. Since the usual care arm was a delayed treatment rather than attention control arm, we cannot rule out that the intervention findings could be an impact of attention rather than specific to the intervention effect. While 25% of the sample was Hispanic/Latinx and/or non-white, and we found no differences in the ratios of high and low need designations between races or ethnicity, the sample size was not large enough to examine subgroup responses to the intervention within races, ethnicity, or other diversity factors. Although lack of power to examine racial and ethnic disparity in intervention participation or response is not uncommon in cancer research[82], further research is needed with specific subgroups to address their survivorship needs directly. While the survivors were enrolled at large cancer centers in the USA, some YAs are treated at pediatric programs or in community oncology settings and their needs and responses to interventions remain to be defined. Another point to consider in future intervention designs was the lack of previous relationship the participant had with the booster call team member. There may be improved outcomes if the clinician providing the survivorship visit is able to continue following survivors through their booster sessions.

While this survivorship clinical trial demonstrated the unmet symptom and survivorship care needs of YAs, it also found that traditional clinical models for meeting those survivorship needs are not adequate for YAs and need to be adapted to their preferences as well as the realities of their lives. Distress improved for YAs who received self-management survivorship care with a clinic visit and two follow-up calls. However, to make care more accessible and effective, YAs require flexible options for participation such as remote delivery of care with ongoing follow-up.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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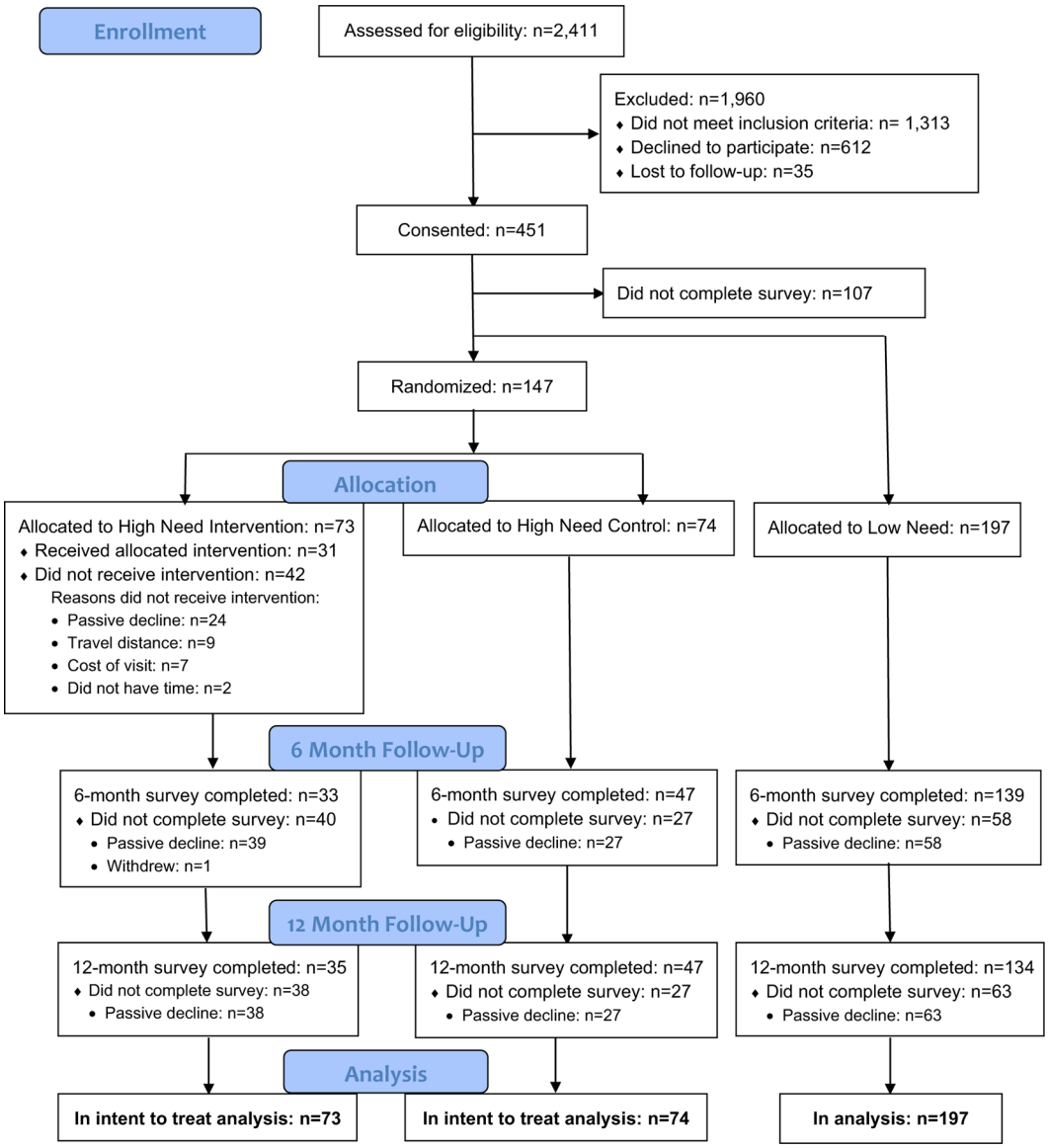

Fig. 1.
Flow diagram of study participation

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Table 1

Clinical, sociodemographic, and baseline symptom characteristics of participants by group and randomized arm, with *p*-value for comparison of (A) high need total to (B) low need total

	High need			B. Low need total (*N* = 197)	All need levels (*N* = 344)	*p* value A vs B
	Control (*N* = 74)	Intervention (*N* = 73)	A. High need total (*N* = 147)			
Age study entry						0.79
20–29	10 (13.5%)	18 (24.7%)	28 (19.0%)	34 (17.3%)	62 (18.0%)	
30–39	38 (51.4%)	35 (47.9%)	73 (49.7%)	105 (53.3%)	178 (51.7%)	
40 +	26 (35.1%)	20 (27.4%)	46 (31.3%)	58 (29.4%)	104 (30.2%)	
Sex						0.27
Female	57 (77.0%)	51 (69.9%)	108 (73.5%)	134 (68.0%)	242 (70.3%)	
Male	17 (23.0%)	22 (30.1%)	39 (26.5%)	63 (32.0%)	102 (29.7%)	
Race						0.62
American Indian or Alaska Native	1 (1.4%)	0 (0.0%)	1 (0.7%)	1 (0.5%)	2 (0.6%)	
Asian	8 (10.8%)	6 (8.2%)	14 (9.5%)	27 (14.2%)	41 (12.2%)	
Black	4 (5.4%)	3 (4.1%)	7 (4.8%)	8 (4.2%)	15 (4.5%)	
White	61 (82.4%)	64 (87.7%)	125 (85.0%)	154 (81.1%)	279 (82.8%)	
Missing	0	0	0	7	7	
Ethnicity						0.72
Hispanic/Latinx	7 (9.5%)	5 (6.8%)	12 (8.2%)	18 (9.3%)	30 (8.8%)	
Not Hispanic/Latinx	67 (90.5%)	68 (93.2%)	135 (91.8%)	176 (90.7%)	311 (91.2%)	
Missing	0	0	0	3	3	
Marital status						**< 0.01**
Married/living with partner	42 (56.8%)	47 (64.4%)	89 (60.5%)	150 (76.1%)	239 (69.5%)	
Single/divorced/widowed	32 (43.2%)	26 (35.6%)	58 (39.5%)	47 (23.9%)	105 (30.5%)	
Education						**< 0.01**
High school or GED	4 (5.4%)	6 (8.2%)	10 (6.8%)	11 (5.6%)	21 (6.1%)	
Some college/2-yr vocational	21 (28.4%)	20 (27.4%)	41 (27.9%)	26 (13.2%)	67 (19.5%)	
4-yr college/post-graduate	49 (66.2%)	47 (64.4%)	96 (65.3%)	160 (81.2%)	256 (74.4%)	
Income						**< 0.01**
$0–40K	18 (24.7%)	19 (26.8%)	37 (25.7%)	25 (13.0%)	62 (18.4%)	

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	High need			B. Low need total (*N* = 197)	All need levels (*N* = 344)	*p* value A vs B
	Control (*N* = 74)	Intervention (*N* = 73)	A. High need total (*N* = 147)			
$41–80K	27 (37.0%)	17 (23.9%)	44 (30.6%)	39 (20.2%)	83 (24.6%)	
$81 K +	28 (38.4%)	35 (49.3%)	63 (43.8%)	129 (66.8%)	192 (57.0%)	
Missing	1	2	3	4	7	
Insurance						**< 0.01**
Medicare	8 (10.8%)	8 (11.0%)	16 (10.9%)	4 (2.0%)	20 (5.8%)	
No insurance	0 (0.0%)	3 (4.1%)	3 (2.0%)	9 (4.6%)	12 (3.5%)	
Private	51 (68.9%)	53 (72.6%)	104 (70.7%)	164 (83.2%)	268 (77.9%)	
Public	8 (10.8%)	8 (11.0%)	16 (10.9%)	11 (5.6%)	27 (7.8%)	
Self-pay	7 (9.5%)	1 (1.4%)	8 (5.4%)	9 (4.6%)	17 (4.9%)	
Diagnosis						0.32
Breast	26 (35.1%)	29 (39.7%)	55 (37.4%)	85 (43.1%)	140 (40.7%)	
Leukemia/lymphoma	21 (28.4%)	24 (32.9%)	45 (30.6%)	63 (32.0%)	108 (31.4%)	
Other solid tumors	27 (36.5%)	20 (27.4%)	47 (32.0%)	49 (24.9%)	96 (27.9%)	
Treatment						0.70
Radiation/chemo + / − surgery	29 (39.2%)	25 (34.2%)	54 (36.7%)	73 (37.1%)	127 (36.9%)	
Surgery/chemo	20 (27.0%)	32 (43.8%)	52 (35.4%)	79 (40.1%)	131 (38.1%)	
Transplant	5 (6.8%)	10 (13.7%)	15 (10.2%)	15 (7.6%)	30 (8.7%)	
Surgery/radiation or surgery	19 (25.7%)	4 (5.5%)	23 (15.6%)	24 (12.2%)	47 (13.7%)	
No treatment info	1 (1.4%)	2 (2.7%)	3 (2.0%)	6 (3.0%)	9 (2.6%)	
Age diagnosis						0.34
18–24	9 (12.2%)	17 (23.3%)	26 (17.7%)	29 (14.7%)	55 (16.0%)	
25–34	30 (40.5%)	30 (41.1%)	60 (40.8%)	96 (48.7%)	156 (45.3%)	
35–39	35 (47.3%)	26 (35.6%)	61 (41.5%)	72 (36.5%)	133 (38.7%)	
Time from diagnosis						0.45
Mean (SD)	3.9 (1.3)	3.8 (1.2)	3.8 (1.3)	3.7 (1.5)	3.8 (1.4)	
Participating cancer center						0.67
1	21 (28.4%)	22 (30.1%)	43 (29.3%)	65 (33.0%)	108 (31.4%)	
2	29 (39.2%)	29 (39.7%)	58 (39.5%)	65 (33.0%)	123 (35.8%)	
3	13 (17.6%)	11 (15.1%)	24 (16.3%)	36 (18.3%)	60 (17.4%)	
4	11 (14.9%)	11 (15.1%)	22 (15.0%)	31 (15.7%)	53 (15.4%)	

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	High need			B. Low need total (*N* = 197)	All need levels (*N* = 344)	*p* value A vs B
	Control (*N* = 74)	Intervention (*N* = 73)	A. High need total (*N* = 147)			
Distress (CTXD)						**< 0.01**
Not elevated	21 (28.4%)	18 (24.7%)	39 (26.5%)	162 (82.7%)	201 (58.6%)	
Elevated	53 (71.6%)	55 (75.3%)	108 (73.5%)	34 (17.3%)	142 (41.4%)	
Insomnia (ISQ)						**< 0.01**
Not elevated	7 (9.5%)	10 (13.7%)	17 (11.6%)	156 (79.2%)	173 (50.3%)	
Elevated	67 (90.5%)	63 (86.3%)	130 (88.4%)	41 (20.8%)	171 (49.7%)	
Fatigue (FSI)						**< 0.01**
Not elevated	13 (17.6%)	15 (20.5%)	28 (19.0%)	176 (89.3%)	204 (59.3%)	
Elevated	61 (82.4%)	58 (79.5%)	119 (81.0%)	21 (10.7%)	140 (40.7%)	
Pain (BPI)						**< 0.01**
Not elevated	50 (67.6%)	51 (69.9%)	101 (68.7%)	194 (98.5%)	295 (85.8%)	
Elevated	24 (32.4%)	22 (30.1%)	46 (31.3%)	3 (1.5%)	49 (14.2%)	
Depression (PHQ)						**< 0.01**
Not elevated	54 (73.0%)	50 (68.5%)	104 (70.7%)	195 (99.5%)	299 (87.2%)	
Elevated	20 (27.0%)	23 (31.5%)	43 (29.3%)	1 (0.5%)	44 (12.8%)	
Confidence (CSI)						**< 0.01**
Not elevated	27 (36.5%)	42 (57.5%)	69 (46.9%)	138 (70.4%)	207 (60.3%)	
Elevated	47 (63.5%)	31 (42.5%)	78 (53.1%)	58 (29.6%)	136 (39.7%)	

CTXD Cancer and Treatment Distress, *ISQ* Insomnia Sleep Questionnaire, *BPI* Brief Pain Inventory, *FSI* Fatigue Symptom Inventory, *PHQ* Patient Health Questionnaire Depression, *CSI* Confidence in Survivorship Information

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Table 2

Among those elevated on a symptom at baseline within the high need group, comparison of the control and intervention arms for rates of elevated symptoms at 6 months (intent to treat analysis)

	High need control*	High need intervention*	Total	*p* value
Distress (CTXD)	(*N* = 33)	(*N* = 26)	(*N* = 59)	**0.03**
6-month not elevated	6 (18.2%)	12 (46.2%)	18 (30.5%)	
6-month still elevated	27 (81.8%)	14 (53.8%)	41 (69.5%)	
Insomnia (ISQ)	(*N* = 42)	(*N* = 26)	(*N* = 68)	0.57
6-month not elevated	11 (26.2%)	5 (19.2%)	16 (23.5%)	
6-month still elevated	31 (73.8%)	21 (80.8%)	52 (76.5%)	
Fatigue (FSI)	(*N* = 38)	(*N* = 26)	(*N* = 64)	0.75
6-month not elevated	8 (21.1%)	4 (15.4%)	12 (18.8%)	
6-month still elevated	30 (78.9%)	22 (84.6%)	52 (81.2%)	
Pain (BPI)	(*N* = 13)	(*N* = 6)	(*N* = 19)	1.00
6-month not elevated	4 (30.8%)	2 (33.3%)	6 (31.6%)	
6-month still elevated	9 (69.2%)	4 (66.7%)	13 (68.4%)	
Depression (PHQ)	(*N* = 9)	(*N* = 8)	(*N* = 17)	0.33
6-month not elevated	7 (77.8%)	4 (50.0%)	11 (64.7%)	
6-month still elevated	2 (22.2%)	4 (50.0%)	6 (35.3%)	
Confidence (CSI)	(*N* = 32)	(*N* = 16)	(*N* = 48)	0.54
6-month not elevated	12 (37.5%)	8 (50.0%)	20 (41.7%)	
6-month still elevated	20 (62.5%)	8 (50.0%)	28 (58.3%)	

CTXD Cancer and Treatment Distress, *ISQ* Insomnia Sleep Questionnaire, *BPI* Brief Pain Inventory, *FSI* Fatigue Symptom Inventory, *PHQ* Patient Health Questionnaire Depression, *CSI* Confidence in Survivorship Information

*Ns reflect number of subjects who were elevated on a symptom at baseline and therefore differ for each symptom type

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Table 3

Among those elevated on a symptom at baseline within the high need group, comparison of the control and intervention arms for rates of elevated symptoms at 12 months (intent to treat analysis)

	High need control*	High need intervention *	Total	*p* value
Distress (CTXD)	(*N* = 33)	(*N* = 24)	(*N* = 57)	0.74
12-month not elevated	6 (18.2%)	6 (25.0%)	12 (21.1%)	
12-month still elevated	27 (81.8%)	18 (75.0%)	45 (78.9%)	
Insomnia (IsQ)	(*N* = 43)	(*N* = 31)	(*N* = 74)	0.25
12-month not elevated	11 (25.6%)	4 (12.9%)	15 (20.3%)	
12-month still elevated	32 (74.4%)	27 (87.1%)	59 (79.7%)	
Fatigue (FsI)	(*N* = 39)	(*N* = 27)	(*N* = 66)	0.09
12-month not elevated	7 (17.9%)	10 (37.0%)	17 (25.8%)	
12-month still elevated	32 (82.1%)	17 (63.0%)	49 (74.2%)	
Pain (BPI)	(*N* = 14)	(*N* = 9)	(*N* = 23)	1.00
12-month not elevated	6 (42.9%)	4 (44.4%)	10 (43.5%)	
12-month still elevated	8 (57.1%)	5 (55.6%)	13 (56.5%)	
Depression (PHQ)	(*N* = 12)	(*N* = 9)	(*N* = 21)	0.08
12-month not elevated	4 (33.3%)	7 (77.8%)	11 (52.4%)	
12-month still elevated	8 (66.7%)	2 (22.2%)	10 (47.6%)	
Confidence (CsI)	(*N* = 34)	(*N* = 18)	(*N* = 52)	0.36
12-month not elevated	10 (29.4%)	8 (44.4%)	18 (34.6%)	
12-month still elevated	24 (70.6%)	10 (55.6%)	34 (65.4%)	

CTXD Cancer and Treatment Distress, *ISQ* Insomnia Sleep Questionnaire, *BPI* Brief Pain Inventory, *FSI* Fatigue Symptom Inventory, *PHQ* Patient Health Questionnaire Depression, *CSI* Confidence in Survivorship Information

*Ns reflect number of subjects who were elevated on a symptom at baseline and therefore differ for each symptom type

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Table 4

Comparison of symptoms at 6 months and 12 months among survivors who were elevated on a symptom at baseline for the control arm vs the intervention arm survivors who completed their clinic visit

	High need control	High need intervention, completed clinic visit	Total	*p* value
6-month outcomes				
Distress (CTXD)	(*N* = 33)	(*N* = 15)	(*N* = 48)	**0.02**
6-month not elevated	6 (18.2%)	8 (53.3%)	14 (29.2%)	
6-month still elevated	27 (81.8%)	7 (46.7%)	34 (70.8%)	
Insomnia (ISQ)	(*N* = 42)	(*N* = 13)	(*N* = 55)	1.00
6-month not elevated	11 (26.2%)	3 (23.1%)	14 (25.5%)	
6-month still elevated	31 (73.8%)	10 (76.9%)	41 (74.5%)	
Fatigue (FSI)	(*N* = 38)	(*N* = 12)	(*N* = 50)	0.43
6-month not elevated	8 (21.1%)	1 (8.3%)	9 (18.0%)	
6-month still elevated	30 (78.9%)	11 (91.7%)	41 (82.0%)	
Pain (BPI)	(*N* = 13)	(*N* = 4)	(*N* = 17)	0.58
6-month not elevated	4 (30.8%)	2 (50.0%)	6 (35.3%)	
6-month still elevated	9 (69.2%)	2 (50.0%)	11 (64.7%)	
Depression (PHQ)	(*N* = 9)	(*N* = 5)	(*N* = 14)	0.58
6-month not elevated	7 (77.8%)	3 (60.0%)	10 (71.4%)	
6-month still elevated	2 (22.2%)	2 (40.0%)	4 (28.6%)	
Confidence (CSI)	(*N* = 32)	(*N* = 8)	(*N* = 40)	**0.02**
6-month not elevated	12 (37.5%)	7 (87.5%)	19 (47.5%)	
6-month still elevated	20 (62.5%)	1 (12.5%)	21 (52.5%)	
12-month outcomes				
Distress (CTXD)	(*N* = 33)	(*N* = 15)	(*N* = 48)	0.28
12-month not elevated	6 (18.2%)	5 (33.3%)	11 (22.9%)	
12-month still elevated	27 (81.8%)	10 (66.7%)	37 (77.1%)	
Insomnia (ISQ)	(*N* = 43)	(*N* = 15)	(*N* = 58)	0.48
12-month not elevated	11 (25.6%)	2 (13.3%)	13 (22.4%)	
12-month still elevated	32 (74.4%)	13 (86.7%)	45 (77.6%)	
Fatigue (FSI)	(*N* = 39)	(*N* = 11)	(*N* = 50	0.67
12-month not elevated	7 (17.9%)	3 (27.3%)	10 (20.0%)	
12-month still elevated	32 (82.1%)	8 (72.7%)	40 (80.0%)	
Pain (BPI)	(*N* = 14)	(*N* = 5)	(*N* = 19)	0.63
12-month not elevated	6 (42.9%)	3 (60.0%)	9 (47.4%)	
12-month still elevated	8 (57.1%)	2 (40.0%)	10 (52.6%)	
Depression (PHQ)	(*N* = 12)	(*N* = 5)	(*N* = 17)	**0.03**
12-month not elevated	4 (33.3%)	5 (100.0%)	9 (52.9%)	
12-month still elevated	8 (66.7%)	0 (0.0%)	8 (47.1%)	
Confidence (CSI)	(*N* = 34)	(*N* = 11)	(*N* = 45)	0.46
12-month not elevated	10 (29.4%)	5 (45.5%)	15 (33.3%)	
12-month still elevated	24 (70.6%)	6 (54.5%)	30 (66.7%)	

CTXD Cancer and Treatment Distress, *ISQ* Insomnia Sleep Questionnaire, *BPI* Brief Pain Inventory, *FSI* Fatigue Symptom Inventory, *PHQ* Patient Health Questionnaire Depression, *CSI* Confidence in Survivorship Information

*Ns reflect number of subjects who were elevated on a symptom at baseline and therefore differ for each symptom type

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