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First Descents, an adventure program for young adults with cancer: who benefits?

Brad Zebrack[1] · Minyoung Kwak[2] · Laura Sundstrom[1]

Abstract

Background Participation in camps, adventure programs, retreats, and other social events offers experiences that can promote self-efficacy and quality of life.
Purpose The purpose of the study was to examine whether participation in a 1-week outdoor adventure program resulted in improvements in psychological distress, self-efficacy, and/ or social support for young adult cancer patients (AYAs) aged 18–40 years. The study examined the differential effect of participation for AYAs who indicated moderate to severe symptoms of psychological distress prior to their trip.
Methods Standardized measures of distress, self-efficacy, and social support were administered pre-trip, post-trip, and 1 month after program completion (follow-up). Univariate and multivariate models examined baseline scores for non-distressed participants compared to distressed participants, changes in outcomes from pre-trip to post-trip and follow-up for the entire sample, and the extent to which change rates for each outcome differed for distressed versus non-distressed participants.
Results All participants demonstrated significant improvement in self-efficacy over time. Distressed participants reported a significantly greater decrease in distress symptoms and greater increase in self-efficacy and social support at post-trip and 1 month later when compared to non-distressed participants.

Conclusions Findings suggest that participation in an outdoor recreational activity designed specifically for AYAs with cancer contributes to significant reductions in distress and improvements in self-efficacy and social support, and particularly for AYAs reporting clinically significant distress symptoms prior to the initiation of their activity.

Keywords Intervention · Young adult · Quality of life · Depression · Anxiety · Self-efficacy

Introduction

Grounded in theories of human development, Rowland describes a universal impact of cancer in terms of its disruptions across various domains of life and then argues that these impacts are experienced differently depending upon the time in life at which cancer is diagnosed [1]. For example, young people diagnosed with and treated for cancer between the ages of 15 and 39 years are more likely than younger children and older adults to experience social isolation and psychological distress associated with the life disruptions caused by cancer and its treatment [2]. To minimize these life disruptions and simultaneously promote healthy growth and development, adolescents and young adults with cancer (AYAs) benefit from opportunities that facilitate their engagement in physical and social activities with peers [3].

Quality of life for AYAs is largely a function of social involvement and support; therefore, improving social support can be a useful strategy for mitigating the adverse influences of cancer on a body image, identity formation, emotional development, coping skills, and occupational goals [4]. Peer support programs designed specifically for AYAs offer opportunities to build interpersonal and problem-solving skills, important developmental challenges that are often compromised by a cancer diagnosis

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[4, 5]. Group interactions and sharing of life experiences create a sense of community among group members and provide AYAs with opportunities to address mutual concerns, thus reducing feelings of social isolation, depression, and anxiety [6, 7].

Self-efficacy—defined as "beliefs in one's capabilities to organize and execute the courses of action required to produce given levels of attainments" (p. 3) [8]—is another key element of quality of life for AYAs [9]. Self-efficacy refers to confidence that one can competently perform a given task, or perform within a given domain, such as managing the effects of cancer and its treatment. Studies suggest that supportive care resources, including peer support programs, promote self-efficacy and link improved self-efficacy with improved quality of life [10–13]. Oncology camps, adventure programs, and retreats offer experiences that promote self-efficacy, boost self-image, raise confidence, increase physical activity, and improve independence [14–18].

Patients with poor support networks, low self-esteem, and low self-efficacy may have the most to gain from participating in peer support programs, in that they have been reported to experience significantly greater improvements attributable to their participation when compared to patients with higher levels of self-esteem and self-efficacy [19]. For example, among adolescents who participated in a therapeutic recreation camp, statistically significant improvements in coping capability were observed only for those with low coping capability prior to camp [20]. Yet, cancer patients with the least social support, lowest levels of cancer literacy, highest levels of depression and anxiety, and most avoidant coping styles have the lowest reported interest in psychosocial care despite having the most to gain [21, 22].

The purpose of this study was to examine the effects of participating in a 1-week outdoor adventure program for AYA cancer patients and survivors. Specifically, the study aims were to examine the short-term effect of program participation on psychological distress, self-efficacy, and social support, and to see whether there was a differential effect of participation for AYAs who indicated moderate to severe (clinically significant) symptoms of psychological distress prior to their trip. We hypothesized that improvements in distress, self-efficacy, and social support would be greater and more likely to be sustained for 1 month following program completion for those who were moderately to severely distressed prior to program participation, when compared to participants who were not clinically distressed.

Methods

Data were collected as part of a comprehensive program evaluation of *First Descents (FD)*, a Colorado-based organization that offers week-long outdoor recreation programs for young adult cancer patients and survivors aged 18–40 years at the time of application (firstdescents.org).

Participants

The study involved all AYA cancer patients and off-treatment survivors aged 18–40 years and diagnosed with any form of invasive cancer, who self-selected for participation in a week-long outdoor adventure program (FD1) in 2015.

Data collection

An electronic survey was developed by the University of Michigan School of Social Work Curtis Center Program Evaluation Group in collaboration with FD staff to measure three outcomes of interest for 2015 program participants. The survey was administered via email and as part of FD's established administrative procedures for communicating with and collecting data from participants before and after trips. Surveys were administered at three time points: 2 weeks before their program initiation (pre-trip), 2 days after program completion (post-trip), and 1 month later (follow-up).

Measures

Standardized scales were administered at each time point to measure psychological distress, self-efficacy, and social support.

Psychological distress was measured using the *Patient Health Questionnaire—4 (PHQ-4)*, a four-item brief screening instrument for anxiety and depression with demonstrated validity and reliability in population-based research studies and clinical samples of adult cancer patients [23]. For each item, subjects endorse the frequency at which they experience a symptom, from 0 ("not at all") to 3 ("every day"). Categorical responses for each item are summed to derive a total continuous distress score ranging from zero (0) to 12. Lower scores indicate lower levels of distress. A score of six (6) or greater distinguishes respondents with moderate-to-severe distress from those reporting mild to no symptoms. This cut-point is used to subdivide the study sample in analyses, described below.

Self-Efficacy was measured using the *Cancer Behavior Inventory—Brief (CBI-B)*, a measure of behavioral coping responses to cancer with demonstrated reliability and validity in clinical research studies with adult cancer patients [9, 24, 25]. The CBI-B is a 14-item measure that assesses respondents' competence and confidence with regard to six behavioral coping responses: (1) maintenance of activity and independence, (2) coping with treatment-related side effects, (3) accepting cancer/maintaining a positive attitude, (4) seeking and understanding medical information, (5) affect regulation, and (6) support seeking. Item responses ranged across a 5-point Likert scale, from 1 ("not at all confident") to 5 ("totally confident"). For each participant, all item responses were

summed to derive a single continuous outcome score ranging from 14 to 70. Higher scores indicated greater self-efficacy.

Social support was measured using the *Duke-UNC Functional Social Support Questionnaire (DUFSS)*, an eight-item multi-dimensional, functional social support questionnaire that measures perceived support [26]. The measure has demonstrated levels of internal consistency and test-retest reliability, as well as significant correlations with other measures of social functioning in studies with medically ill patients, including adult cancer patients [27, 28]. Item responses ranged across a 5-point Likert scale, from 1 ("much less than I would like") to 5 ("as much as I would like"). Item responses were averaged to derive a single outcome score of one (1) to five (5), with higher scores indicating higher levels of social support.

As part of the trip application process, participants provided descriptive data, including current age, sex, race, marital/relationship status, work/school status, cancer diagnosis, and date of diagnosis.

Data analytic plan

Included in analyses were participants who completed at least one survey. Descriptive analyses summarized the demographic and clinical characteristics of the participants. A linear mixed model with random intercept and slope examined longitudinal changes in distress, self-efficacy, and social support. Repeated observations of outcome measures were nested within individuals; therefore, the linear mixed model consisted of two levels: a model of individual changes in outcomes at the observation level, which specified within-person parameters (i.e., time since the pre-trip survey), and a model specifying between-person parameters at the person level (i.e., sociodemographic characteristics, cancer type, and mild versus moderate-severely distressed sub-group prior to the initiation of their FD activity).

We first analyzed changes of outcome measures at pre-trip, post-trip, and follow-up for the entire sample. We also examined the differential effects of distress on program participation. Among participants who completed the baseline survey, we identified respondents with moderate-to-severe psychological distress and then compared changes in their distress, self-efficacy, and social support scores with those who had mild or no distress symptoms (non-distressed). Multivariate analyses compared rates of change for distressed and non-distressed participants, while controlling for sociodemographic characteristics and cancer diagnosis type. Analysis was performed using STATA.

Linear mixed models account for common analytic challenges in longitudinal data, such as correlations among multiple observations for individuals, and missing data. Linear mixed models utilize all data, including repeated observations at unequal intervals and data for subjects with missing observations assuming that these data are missing at random

[29, 30]. To determine whether data were missing at random and possibly contributing to response bias, we compared demographic characteristics and cancer types among (1) participants who completed surveys at three time points, (2) those who answered at least one survey, and (3) those who did not respond to any survey, and then plotted the means of the outcome measures for these three groups of respondents [31]. An observational evaluation of these mean plots did not suggest any detectable pattern for missing data (plots not shown). In addition, we tested the distributional assumptions for the residuals after fitting the linear mixed model and confirmed the residuals were normally distributed and thus not violating assumptions for linear mixed models.

Results

Five hundred twenty-six young adults applied for an FD1 trip in 2015. Of these, 347 actually attended an FD1 trip and were administered pre-trip, post-trip, and follow-up surveys. Two hundred forty-seven young adults completed the initial pre-trip survey (71.2%), 196 completed the post-trip survey (56.5%), and 159 completed the 1-month follow-up survey (45.8%). Table 1 summarizes the demographic characteristics and cancer types for 304 participants who completed at least one of the three surveys

Table 1 FD1 participant characteristics (*n* = 304)

	N (%)
Age	
18–29 years	113 (37.2)
30–39 years	168 (55.3)
40 years[a]	17 (5.6)
Gender	
Male	49 (16.1)
Female	249 (81.9)
Race	
White	239 (78.6)
Non-white	53 (17.4)
Marital/relationship status	
Not married/in relationship	202 (66.4)
Currently married/in relationship	94 (30.9)
Working or in school	
No	73 (24.0)
Yes	227 (74.7)
Cancer diagnosis	
Brain tumor/Central Nervous System	21 (6.9)
Hematological	89 (29.3)
Solid tumor/soft tissue	180 (59.2)

Totals do not equal 100% due to missing data

[a] These participants were 39–40 years old when they applied and turned 40–41 years by time of data collection
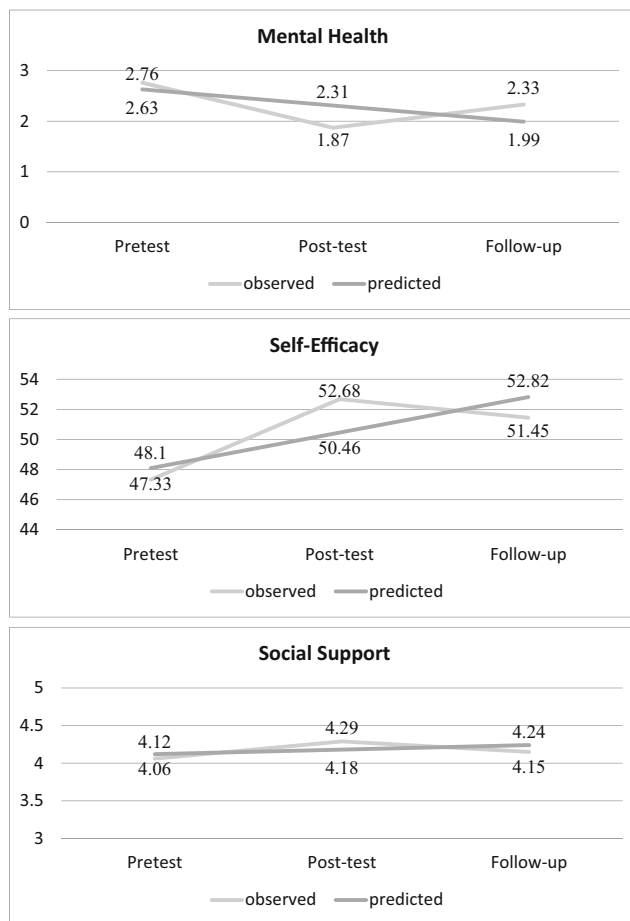
Fig. 1 Predicted and observed mean changes in mental health, self-efficacy, and social support

(response rate 87.6%). Contingency tables and χ^2 tests of statistical significance (not shown) were used to compare descriptive characteristics of 93 FD1 participants who completed surveys at all three time points to 211 who completed at least one but not all three surveys, and also to the 43 young adults who did not complete any survey. No statistically significant differences in age, sex, race, marital/relationship status, work/school status,

and cancer diagnostic category were observed for these three groups (at $p < 0.05$).

Longitudinal results

Observed and estimated mean scores for distress, self-efficacy, and social support at each time point are depicted in Fig. 1. These results indicate that pre-trip (baseline) scores were statistically significant predictors of post-trip and follow-up scores (Table 2). Specifically, the rates of change over time in mental health and self-efficacy scores were statistically significant ($\beta = -0.322$, $p < 0.001$; $\beta = 2.361$, and $p < 0.001$, respectively). Distress symptoms were significantly fewer at post-trip and follow-up when compared to baseline. Self-efficacy scores for post-trip and follow-up assessments were significantly greater when compared to pre-trip scores. A statistically significant increase in social support scores was seen from baseline to post-trip; however, social support scores decreased from post-trip to follow-up. Thus, the overall rate of change in social support over time was only marginally significant ($\beta = 0.064$, $p = 0.053$).

Comparisons for distressed versus non-distressed participants

Based on PHQ-4 scores, 30 respondents (12.3%) were identified as experiencing moderate-severe distress prior to their trip. When comparing mean distress, self-efficacy, and social support scores for distressed (moderate-severe) and non-distressed (mild to none) participants at each of the three time points, distressed participants reported a greater decrease in their distress scores and greater increases in self-efficacy and social support scores at post-trip and follow-up when compared to non-distressed participants (Table 3, Fig. 2). The effect sizes given a sub-sample of 30 participants identified as distressed were $\delta = 2.30$ for mental health, $\delta = 0.81$ for self-efficacy, and $\delta = 0.74$ for social support. Assuming a statistical

Table 2 Longitudinal changes in mental health, self-efficacy, and social support

	Mean (SD)			Mean differences (p value)			Model predicting longitudinal changes[b]					
							Intercept			Slope		
	Pre-trip $n = 247$	Post-trip $n = 196$	Follow-up $n = 159$	Pre vs. post	Pre vs. follow-up	Post vs. follow-up	Estimate	SE	p	Estimate	SE	p
Distress[a]	2.76 (2.46)	1.87 (2.10)	2.33 (2.34)	<0.001	0.009	0.03	2.626	0.145	0.001	−0.322	0.1	<0.001
Self-efficacy	47.33 (7.31)	52.68 (5.71)	51.45 (6.19)	<0.001	<0.001	0.003	48.11	0.429	<0.001	2.361	0.28	<0.001
Social support	4.06 (0.81)	4.29 (0.77)	4.15 (0.84)	<0.001	0.182	0.022	4.115	0.048	<0.001	0.064	0.03	0.053

[a] The number of participants who responded for pre-trip, post-trip, and follow-up of distress is 244, 195, and 158, respectively. These figures are different from those for self-efficacy and social support because there were missing values of items measuring distress

[b] For this model predicting longitudinal changes in distress, self-efficacy, and social support, $n = 304$ participants who responded to at least one survey at any time point. The number of total observations across time points is 597, 602, and 602 for distress, self-efficacy, and social support, respectively

Table 3 Comparison of distressed versus non-distressed participants for mental health, self-efficacy, and social support (mean scores and standard deviation)

	Distressed at pre-trip			Non-distressed at pre-trip		
	Pre-trip $n = 30$ (12.3%)	Post-trip $n = 22$ (14.4%)	Follow-up $n = 20$ (16%)	Pre-trip $n = 214$ (87.7%)	Post-trip $n = 131$ (85.6%)	Follow-up $n = 105$ (84.0%)
Mental health	7.73 (1.89)	3.36 (2.80)	3.85 (2.76)	2.07 (1.57)	1.51 (1.82)	1.98 (2.20)
Self-efficacy	42.1 (7.66)	51.84 (6.52)	50.97 (5.44)	48.01 (6.96)	53.34 (5.24)	51.78 (6.10)
Social support	3.53 (0.89)	4.11 (0.98)	3.91 (1.03)	4.13 (0.78)	4.29 (0.78)	4.20 (0.85)

power of 0.8 and significance level of 0.5 (two-tailed), the minimum number of required subjects was 3 for mental health, 24 for self-efficacy, and 29 for social support, respectively. Thus, these analyses were adequately powered to detect statistically significant differences.
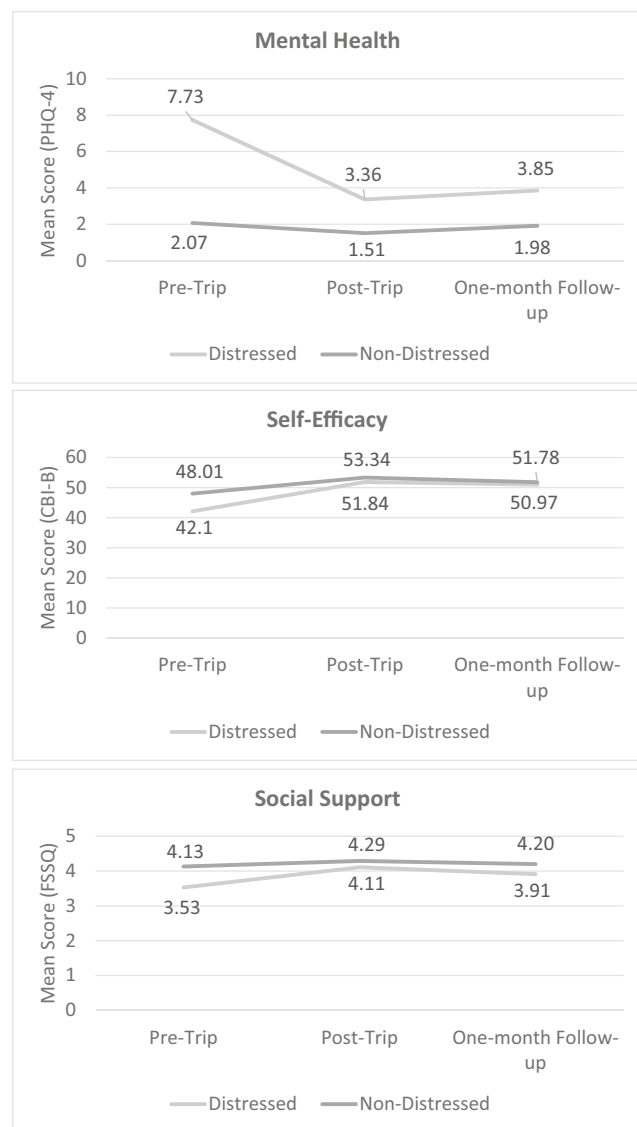
Fig. 2 Comparison of distressed versus non-distressed participants for mental health, self-efficacy, and social support (mean scores)

Factors associated with changes in mental health, self-efficacy, and social support over time

After controlling for sociodemographic characteristics and cancer diagnoses, multivariate models examined (1) baseline distress, self-efficacy, and social support scores for non-distressed participants compared to distressed participants; (2) rates of change in each outcome over time; and (3) the extent to which change rates for each outcome differed for distressed versus non-distressed participants (Table 4).

Prior to their trip, distress scores for distressed participants were, by definition, significantly higher than those of non-distressed participants ($\beta = 5.24$, $p < 0.001$). After accounting for control variables, the change rate for distress scores for the non-distressed participants over time was not significant: distress scores for the entire group at 1-month follow-up were no different than they were prior to the trip. However, the interaction term estimating differences in change rates for distressed versus non-distressed participants indicates that the change rate for distressed participants was significantly greater than the rate of change for non-distressed participants ($\beta = -2.29$, $p < 0.001$). Post hoc analysis (not included in the model) indicated that the reduction in distress scores over time for distressed participants was statistically significant ($\beta = -2.40$, $p < 0.001$).

Distressed participants reported significantly lower self-efficacy scores than non-distressed participants prior to their trip ($\beta = -5.12$, $p < 0.001$). In addition, respondents who were married or in a relationship reported significantly higher levels of self-efficacy at baseline than did single participants ($\beta = 1.66$, $p = 0.043$). The observed increase in self-efficacy for non-distressed participants over time also was statistically significant ($\beta = 2.30$, $p < 0.001$), and the interaction term indicates that the improvement in self-efficacy over time for distressed participants was significantly greater than it was for

Table 4 Multivariate models of changes in mental health, self-efficacy, and social support

Mental health (n = 224; observations = 481)	Estimate	SE	p value
Intercept[a]	1.39	0.45	0.002
Distressed at pre-trip (1 = distressed)	5.24	0.34	<0.001
Slope (change rate): time[b]	−0.11	0.11	0.32
Time × distressed at pre-trip	−2.29	0.29	<0.001
Control variables			
Age at diagnosis			
18–29 years (ref)	Ref		
30–39 years	0.05	0.22	0.806
40+ years	−0.33	0.50	0.509
Gender (1 = female)	0.30	0.28	0.286
Race (1 = non-white)	0.09	0.28	0.745
Marital/relationship status (1 = married)	0.19	0.23	0.417
Occupational status (1 = occupied in school/work)	0.05	0.23	0.814
Cancer diagnosis			
Brain tumor/CNS (ref)	Ref		
Hematological	0.11	0.41	0.798
Solid tumor/soft tissue	0.28	0.39	0.474
Self-efficacy (n = 224; observations = 482)	**Estimate**	**SE**	**p value**
Intercept[a]	48.51	1.62	<0.001
Distressed at pre-trip (1 = distressed)	−5.12	1.30	<0.001
Slope (change rate): time[b]	2.30	0.32	<0.001
Time × distressed at pre-trip	2.01	0.86	0.019
Control variables			
Age at diagnosis			
18–29 years	Ref		
30–39 years	0.68	0.80	0.394
40+ years	1.62	1.80	0.368
Gender (1 = female)	−1.07	1.02	0.296
Race (1 = non-white)	1.39	1.01	0.167
Marital/relationship status (1 = married)	1.66	0.82	0.043
Occupational status (1 = occupied in school/work)	1.04	0.83	0.209
Cancer diagnosis			
Brain tumor/CNS (ref)	Ref		
Hematological	−0.51	1.48	0.730
Solid tumor/soft tissue	−0.92	1.39	0.509
Social support (n = 224; observations = 482)	**Estimate**	**SE**	**p value**
Intercept[a]	4.03	0.21	<0.001
Distressed at pre-trip (1 = distressed)	−0.54	0.16	0.001
Slope (change rate): time[b]	0.07	0.04	0.084
Time × distressed at pre-trip	0.13	0.11	0.207
Control variables			
Age at diagnosis			
18–29 years (ref)	Ref		
30–39 years	−0.27	0.10	0.009
40+ years	0.07	0.23	0.760
Gender (1 = female)	0.21	0.13	0.105
Race (1 = non-white)	0.01	0.13	0.910
Marital/relationship status (1 = married)	0.18	0.10	0.079
Occupational status (1 = occupied in school/work)	0.34	0.11	0.001

Table 4 (continued)

Cancer diagnosis			
Brain tumor/CNS (ref)	Ref		
Hematological	−0.20	0.19	0.280
Solid tumor/soft tissue	−0.22	0.18	0.216

[a] Intercept scores represent mean mental health, self-efficacy, and social support scores at baseline for the reference group (i.e., participants who are not distressed at pre-trip, 18–29 years old, male, white race, not married, not occupied, brain tumor survivor)

[b] The slopes represent the changes in mean mental health, self-efficacy, and social support scores from pre- to post-trip and from post-trip to follow-up for the reference group (i.e., participants who are not distressed at pre-trip, 18–29 years old, male, white race, not married, not occupied, brain tumor survivor)

non-distressed respondents ($\beta = 2.01$, $p = 0.019$). Post hoc analysis (not included in the model) indicated that self-efficacy scores for distressed participants significantly increased over time ($\beta = 4.31$, $p < 0.001$).

Finally, distressed respondents reported significantly lower levels of social support at pre-trip compared to non-distressed respondents ($\beta = -0.54$, $p = 0.001$), as did participants aged 30 to 39 years when compared to younger respondents ($\beta = -0.27$, $p = 0.009$). Those who were currently employed or in school at the pre-trip time point reported higher levels of social support than did those who were not employed or in school ($\beta = 0.34$, $p = 0.001$). The change rate for non-distressed participants over time was not significant ($\beta = 0.07$, $p = 0.084$). The change rates for distressed and non-distressed respondents were not significantly different ($\beta = 0.13$, $p = 0.207$), although post hoc analysis (not included in the model) indicated that the change rate was significant for distressed respondents ($\beta = 0.20$, $p = 0.039$).

Discussion

The findings reported here suggest that participation in an outdoor recreational activity designed specifically for AYAs with cancer contributes to reductions in psychological distress and improvements in self-efficacy and social support, and particularly for AYAs reporting moderate-to-severe symptoms of distress prior to the initiation of their FD activity. Because distress levels were relatively low for most FD participants, we did not observe a statistically significant change in distress for the sample as a whole. However, approximately one of every five participants in an FD activity reported clinically significant levels of distress upon initiation of their trip. For them, the effect of participation observed here is notable although a longer follow-up period is probably needed to allow for a more robust assessment of any sustained effects of program participation. Indeed, the observed slight worsening of scores from post-trip to 1-month follow-up suggests that AYAs may also benefit from a "bolus" of support to re-stimulate the positive effects of program participation.

Research is needed to further evaluate the efficacy of peer support programs as a social intervention for managing depression or anxiety among young adults with cancer, particularly given that medications for treating mental health and adjustment disorders have deleterious side effects, and their efficacy is often compromised by poor adherence [32, 33]. No similar disabling psychopharmacological or behavioral effects have been reported as a result of participation in an outdoor adventure program.

The self-efficacy instrument administered in this study was designed specifically to assess cancer patients' beliefs or confidence in their abilities to maintain activity and independence, manage treatment side effects, maintain emotional well-being, and seek support [9]. Results indicated that participation in FD programming contributed to levels of self-efficacy at 1-month follow-up that were a significant improvement over levels reported prior to program participation. Furthermore, the differential impact of FD participation for distressed participants was greater to the extent that their levels of self-efficacy, while lower than those of non-distressed participants at pre-trip baseline, eventually matched that of non-distressed participants at 1-month follow-up.

Psychosocial oncology research suggests that social support resources promote coping capabilities and self-efficacy [11, 12]. Participation in programs like *First Descents* promotes social connection and support: AYAs meet on these trips, form quick bonds of friendship, and retain those friendships over time. Whereas social support was reportedly worse for distressed participants prior to their trip, it improved over time. These observed improvements derived from the peer support experience on FD programs may contribute to other important behavioral outcomes, such as return to school or work or improved treatment adherence, both of which are particularly challenging behavioral issues for psychologically at-risk AYA cancer patients [4, 34].

The relatively small response rate, self-selection of participants, and disproportionate representation of participants by race, gender, and cancer type when compared to the US

population limit the generalizability of the findings, as does the single cohort design lacking a comparison group. The sample's demographic composition suggests that the program activities, or perhaps its marketing, may only appeal to a narrow and self-selected group of AYAs. Further efforts are needed to understand how or why AYAs of a certain demographic (e.g., female) are more or less likely to be interested in these types of programmatic activities.

Conclusion

For more than 10 years, *First Descents* has refined an outdoor adventure peer support program that offers safety and encouragement not usually available to young people suffering with cancer. Their tag line "*Out Living It*" inspires AYAs to retain or regain a sense of hope and normalcy after a cancer diagnosis. Whether kayaking, surfing, or rock climbing, these opportunities to push oneself beyond one's limits, meet inspiring people, and experience stunningly beautiful settings may be critical contributors to cancer patients' well-being, recovery, and survival.

Compliance with ethical standards

Conflict of interest B.Z. is a member of the Medical Advisory Board for First Descents but receives no compensation. No other authors have disclosures. B.Z. has full control of all primary data and agrees to allow the journal to review their data if requested.

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