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Cancer distress coach: Pilot study of a mobile app for managing posttraumatic stress

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Keywords

Cancer survivorship; Feasibility study; mHealth; posttraumatic stress; PTSD

1 | BACKGROUND

Posttraumatic stress disorder (PTSD) symptoms are common following a cancer diagnosis and treatment; incidence rates range from 20% (early stage) to 80% (recurrent cancer).[1] Persisting symptoms affect 37% of lymphoma survivors more than 7 years after diagnosis and correlate with low quality of life. Non-White and low-income survivors are at highest risk but often lack access to traditional treatments such as office-based cognitive behavioral therapy because of cost and other barriers.[2,3]

Mobile technology may be a cost-effective strategy to address cancer survivors' psychosocial needs. Its use is widespread with 68% of Americans owning smartphones in 2015.[4] Among low-income and African American individuals, 50% and 70% own smartphones, respectively, offering a new platform to reach these populations who experience health care disparities. In recognition of this technology bridge, there is a growing portfolio of psychiatric and behavioral mobile apps that are improving access to solutions for people in need.[5]

Unfortunately, there are no cancer distress mobile apps available for download; this prompted us to expand our search. One of the US Department of Veterans Affairs (VA) apps, PTSD Coach, reinforces cognitive behavioral therapy messages and is available at no

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cost via iTunes (iOS) and Google Play (Android).[6] Significant research demonstrates its feasibility, acceptability, and preliminary efficacy among VA patients and community trauma survivors.[6–8] Given this, we partnered with the VA to modify PTSD Coach into Cancer Distress Coach (CDC) and revised it following usability testing with 30 cancer survivors.

This pilot study aims to evaluate the acceptability, feasibility, and potential efficacy of CDC in improved PTSD, distress symptoms, and self-efficacy to manage symptoms to inform further app development and design of a more rigorous efficacy trial.

2 | METHODS

2.1 | Participants and procedures

The Duke University Health System Institutional Review Board approved this study. Eligible patients were approved for contact by their treating physician; examined with lymphoma, breast, or prostate cancer; ≥19 years of age; and had active PTSD symptoms (ie, scored ≥30 on the PTSD Checklist—Specific [PCL-S]).[9] Patients provided informed consent and completed electronic questionnaires. During the initial meeting, CDC was downloaded onto the participant's or study-provided iOS device and participants were shown how to use the app and device (if borrowed). Qualtrics survey links were emailed 4 and 8 weeks later to assess PTSD symptoms, distress, self-efficacy, and perceived helpfulness, satisfaction, and acceptability of CDC. Objective app usage data were captured by Heap, Inc. (heapanalytics.com).

2.2 | Cancer distress coach

Cancer Distress Coach can be used as a stand-alone education and symptom management tool and contains 4 modules: (1) "Learn about PTSD" provides 8th grade reading level content derived from the National Cancer Institute PDQ resource; (2) "Self-assessment" administers the PTSD Checklist and provides interpretive feedback including symptom severity; (3) "Manage Symptoms" routes the user to a number of helpful mind-body exercises; and (4) "Find Support" contains links to cancer and noncancer-related professional care.

2.3 | Instruments

Demographic and clinical data were self-reported at baseline. Outcomes were collected at baseline, week 4 and week 8. Posttraumatic stress disorder symptoms were measured with the PCL-S, a 17-item self-report instrument that maps to the diagnostic criteria.[9] Items were keyed on the cancer diagnosis and treatment. It had good internal consistency at baseline (α = 0.86). The National Comprehensive Cancer Network distress thermometer (DT) assessed overall distress. The Self-efficacy for Managing Chronic Disease Scale (SEMCD) is a 6-item measure of self-efficacy for coping with chronic disease.[10] Its internal consistency was α = 0.94 at baseline. We also included 10 items measuring PTSD symptom coping self-efficacy developed specifically for use with PTSD Coach. It had an internal consistency of 0.92 at baseline and was correlated with the SEMCD (r = .68; P < .0001). Finally, at week 8, 15 items were used to assess perceived helpfulness, satisfaction, and acceptability[6] and had an internal consistency of 0.97.

2.4 | Data analysis plan

Analyses were conducted using SAS 9.4 (Cary, North Carolina). Descriptive statistics summarized participant characteristics and survey data. Paired *t* tests were used to assess change in the PCL-S (primary outcome), distress, and self-efficacy measures. If <50% of the items were missing, instrument scores were adjusted by calculating the average score for the completed items in that area and then assigning the missed item(s) that average score. *P* values were adjusted on the basis of Bonferroni procedure to control family-wise error rate in the context of multiple paired *t* tests for each outcome.

3 | RESULTS

Thirty-one adults consented to participate and completed baseline and and 2.7 years postdiagnosis (SD = 2.9), mostly female (82.8%), 22.6% with a mean income < $30,000 per year, and over a quarter non-White (37.9%). Participants used the app an average of 2.8 times per week (SD = 3.2).

As shown in Table 1, a large majority (89.7%) of participants endorsed at least moderate satisfaction with CDC and 86.2% that it provided practical solutions to experienced problems. Also, 79.3% endorsed that CDC was helpful in learning about and enhancing knowledge of posttraumatic stress. Most participants (72.4%) reported that CDC helped to overcome the stigma of seeking mental health services.

The mean PCL-S reduction of 5.8 (SD = 8.7) from baseline to week 4 ($t = 3.28$, df = 23, unadjusted $P = .003$, and Bonferroni adjusted $P = .01$) and 6.1 (SD = 11.1) from baseline to week 8 ($t = 3.05$, df = 30, unadjusted $P = .005$, and Bonferroni adjusted $P = .01$) were both significant. At week 8, 48.4% reported a PCL-S reduction of ≥5 points from baseline (ie, a minimum threshold for response) and 32.3% experienced a clinically significant reduction (ie, ≥10 points).

The mean DT reduction of 1.6 (SD = 2.8) from baseline to week 4 ($t = 2.44$, df = 19, unadjusted $P = .02$, and Bonferroni adjusted $P = .07$) and 1.3 ($SD = 3.1$) from baseline to week 8 ($t = 2.08$, df = 25, unadjusted $P = .048$, and Bonferroni adjusted $P = .15$) were also significant. Distress thermometer scores were correlated with PCL-S scores at week 8 ($r = .54$, $P = .003$). The mean improvement in the SEMCD from baseline to week 4 (mean = .19, SD = 2.06, $t = 0.45$, df = 23, unadjusted $P = .33$, and Bonferroni adjusted $P = 0.99$) and week 8 (mean = .46, SD = 1.96, $t = 1.27$, df = 28, unadjusted $P = .11$, and Bonferroni adjusted $P = .33$) were nonsignificant as were changes in the PTSD symptom coping self-efficacy measure (mean = 2.68, SD = 15.88, $t = 0.83$, unadjusted $P = .21$, and Bonferroni adjusted $P = .63$ for baseline to week-4 change; mean = 3.44, SD = 16.46, $t = 1.13$, df = 28, unadjusted $P = .14$, and Bonferroni adjusted $P = .41$ for baseline to week-8 change). There is no significant difference in both self-efficacy measures between the participants who use their own device and who use the study-provided device at baseline, week 4, and week 8 (all unadjusted $P > .05$).

4 | CONCLUSIONS

We found support for the acceptability and preliminary efficacy of CDC as a self-management tool for cancer-related PTSD symptoms. Nearly 90% of participants endorsed being at least moderately satisfied with the app and most also reported it was helpful in learning about, assessing for, and finding resources and effective ways of managing PTSD symptoms. Participants also reported reductions in PTSD symptoms after 4 and 8 weeks of app usage with close to half (48.4%) showing reliable improvement in symptoms at 8 weeks. While unadjusted distress scores improved, significant improvements in adjusted distress and self-efficacy scores were not evidenced.

Our findings are consistent with those found among users of PTSD Coach. For example, 89.7% and 88.9% of cancer survivors and veterans receiving PTSD treatment, respectively, were at least moderately satisfied with the CDC and PTSD Coach apps.[6] Mean days per week of usage was similar between cancer (2.8) and community trauma (2.7) survivors.[8] Furthermore, 32% of cancer survivors and 39% of community trauma survivors reported clinically significant change following use.[7]

Although the results of this pilot study are encouraging and inform a full-scale trial, they are subject to several limitations. First, the lack of a control group prevents determination of causality. Second, demand characteristics may be responsible for the favorable ratings. Third, the small (and mostly female) sample may limit the generalizability of findings and result in insufficient power to detect actual improvements in self-efficacy.

These findings suggest that CDC may be a cost-effective tool that if added to clinical care, cancer survivors would find it helpful in managing their symptoms of PTSD. Future research should use a randomized clinical trial to determine efficacy of CDC. Today, many distressed cancer patients fall through the cracks because of miscommunication and lack of resources following a positive distress screen.[11] Aided by the significant correlation between the DT and PCL-S, it is easy to envision implementing the app within distress management protocols at cancer clinics nationally if positive findings emerge from future controlled research.

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Key points

- Our team re-versioned the mobile app developed primarily for war veterans, PTSD Coach, for cancer survivors who are suffering from posttraumatic stress disorder (PTSD) symptoms.
- The acceptability and potential efficacy of the Cancer Distress Coach (CDC) app was achieved through 8 weeks of feasibility testing on iOS devices.
- Most of the 31participants (86%) reported that CDC provided practical solutions to their problems and almost half (48%) reported a PTSD Checklist—Specific reduction of ≥5 points (ie, a minimum threshold for response).
- The mean reduction in PTSD Checklist—Specific scores from baseline to week 4 and baseline to week 8 was 5.8 (SD = 8.7; unadjusted $P = .003$, and Bonferroni adjusted $P = .01$) and 6.1 (SD = 11.1; unadjusted $P = .004$, and Bonferroni adjusted $P = .01$), respectively.
- The CDC was well received, and use of it was associated with significant reductions in PTSD and distress symptoms (all unadjusted $P < .05$). A randomized clinical trial is being planned to examine causality.

TABLE 1

Mean ratings of perceived helpfulness of and satisfaction with Cancer Distress Coach (N = 31)

Item	M (SD)	Endorsed moderately or greater, %
Overall, how satisfied are you with the Cancer Distress Coach app?	2.45 (0.95)	89.7
Providing practical solutions to the problems I experience	2.38 (1.05)	86.2
Helping me learn about symptoms of posttraumatic stress	2.41 (1.21)	82.8
Helping me find effective ways of managing my symptoms	2.28 (1.28)	79.3
Helping me feel that there is something I can do about my posttraumatic stress	2.45 (1.18)	79.3
Increasing my access to additional resources	2.07 (1.03)	79.3
Enhancing my knowledge of posttraumatic stress	2.24 (1.24)	79.3
Helping me learn about treatments for posttraumatic stress	2.21 (1.29)	75.9
Helping me better understand what I have been experiencing	2.17 (1.23)	75.9
Helping clarify some of the myths about posttraumatic stress	2.07 (1.36)	75.0
Helping me overcome the stigma of seeking mental health services	2.03 (1.32)	72.4
Helping me feel more comfortable in seeking support	2.21 (1.26)	69.0
Providing a way for me to talk about what I have been experiencing	2.00 (1.31)	65.5
Helping me track my symptoms	1.68 (1.09)	53.6
Helping me know when I am doing better or when I am doing worse	1.69 (1.17)	51.7

Ratings: 0 = Not at all; 1 = slightly; 2 = moderately; 3 = very; 4 = extremely.