Evolution of the Cancer Distress Coach App to Manage Stress in Cancer Survivors

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Agenda

I. Survivorship Landscape
II. Coping with Cancer-related Trauma
III. Lymphoma Cohort Study
IV. Responding to Trauma Symptoms
V. mHealth Research Initiatives
Self-introduction
Why is this topic important?

I. SURVIVORSHIP LANDSCAPE
Who is a Cancer Survivor?

- “The term cancer survivor includes anyone who has been diagnosed with cancer, from the time of diagnosis through the rest of his or her life.” – NCCS, 1986

- Historically, a subset of survivors who completed active treatment and are five years post-diagnosis
Estimated Number of US Cancer Survivors

Estimated US Prevalence by Current Age

US Persons Alive Diagnosed with Cancer, By Site

American Cancer Society, 2014
Cancer diagnosis and treatment are traumatic events.

II. COPING WITH CANCER & ASSOCIATED TRAUMA
Impacts of Lymphoma Treatment

American Cancer Society, 2016. Available at:
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index
Cancer Survivor Needs

American Cancer Society, 2016. Available at:
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index

*Posttraumatic stress*
What is Posttraumatic Stress Disorder (PTSD)?

• Results from exposure to a traumatic event
  – Motor vehicle accidents
  – Physical or sexual assault
  – Military combat
  – A life threatening illness (e.g., Cancer)

• Symptoms
  – Intrusion (e.g., nightmares, flashbacks)
  – Avoidance (e.g., medical appointments)
  – Negative changes in mood, thoughts (e.g., guilt, blame)
  – Arousal (e.g., difficulty sleeping and concentrating)

PTSD Prevalence

• General population
  – About 7% over a lifetime
  – Twice as high in military (14%)

• Cancer population
  – Full PTSD, about 10%
  – Posttraumatic stress symptoms range from 20 - 80%
  – Early studies:
    ➢ Childhood cancer survivors and their parents (Kazak, 1998)
    ➢ Adolescent and young adult survivors (Pelcovitz, 1998)
    ➢ Breast cancer (Cordova, 1995)

http://www.ptsd.va.gov/professional/ptsd-overview/epidemiological-facts-ptsd.asp

PTSD Risk Factors

At risk for cancer-related PTSD:

- Younger age
- Lower income and/or education
- Prior trauma
- Less social support
- More intense treatment (e.g., transplant)
- More advanced stage or recurrence of disease

Coping with Trauma

Post-traumatic Growth

• New opportunities and possibilities
• Improved relationships
• Increased inner strength
• Greater appreciation for life
• Deepening spirituality

What does this mean for cancer survivors?

III. LYMPHOMA COHORT STUDY
Lymphoma Cohort Study

• 2005 Initial Survey
  – Survivors identified through Tumor Registry
  – Duke Cancer Center and UNC Lineberger
  – Diagnosed with non-Hodgkin lymphoma >2 years ago

• 2010 Follow-up Survey
  – Repeated most of the same measures

Follow-up Survey Procedures

- Surveys mailed to 682 lymphoma survivors who participated in initial survey
- Survivors ≥7 years post-diagnosis
- Linear regression used to identify predictors of PTSD over 5 year period
## Cross-tabulation of PCL-S Symptom Scores at Initial and Follow-up Surveys

<table>
<thead>
<tr>
<th>Post-traumatic stress symptoms at initial survey</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>51 (14.6)</td>
<td>11 (3.1)</td>
<td>7 (2.0)</td>
<td>281 (80.3)</td>
<td>350 (62.8)</td>
</tr>
<tr>
<td>1</td>
<td>46 (34.8)</td>
<td>20 (15.2)</td>
<td>13 (9.8)</td>
<td>53 (40.2)</td>
<td>132 (23.7)</td>
</tr>
<tr>
<td>2</td>
<td>11 (26.2)</td>
<td>15 (35.7)</td>
<td>4 (9.5)</td>
<td>12 (28.6)</td>
<td>42 (7.5)</td>
</tr>
<tr>
<td>3</td>
<td>9 (27.3)</td>
<td>3 (9.1)</td>
<td>18 (54.5)</td>
<td>3 (9.1)</td>
<td>33 (5.9)</td>
</tr>
<tr>
<td><strong>Total (%)</strong></td>
<td>349 (62.7)</td>
<td>117 (21.0)</td>
<td>49 (8.8)</td>
<td>42 (7.5)</td>
<td>557 (100)</td>
</tr>
</tbody>
</table>
PTSD Risk Factors in Lymphoma Sample (n=566)

Independent associations w/persistent PTSD:

- Low income (< $30,000 / year)
- Currently receiving lymphoma treatment
- More/increasing negative perceptions of lymphoma
- Less positive perceptions of lymphoma
Lymphoma Cohort Conclusions

• More than 1/3 of lymphoma survivors report persisting or worsening PTSD symptoms
• Providers should be aware of enduring risk
• Early identification of those at risk can be accomplished using standardized measures
• Treatments that target perceptions of the cancer experience might improve outcomes
Recommendations for clinical care.

IV. WHAT WE CAN DO
Screening for PTSD

- Cancer experience is >1 stressful event
  - During treatment, recurrence, follow-ups
- Individuals require monitoring over time
  - Usually begin within 3 months, yet may persist
- Many potential triggers
  - Diagnosis, treatment, test anxiety, recurrence
- PTSD symptoms similar to other disorders
  - Depression, anxiety, phobias, panic disorder

PTSD Assessment

• Interview
  – Clinician-administered PTSD Scale (CAPS-5)

• Self-report
  – PTSD Checklist (PCL-5)
  – Primary Care PTSD Screen (PC-PTSD-5)

National Center for PTSD. Assessment Overview (2017).
https://www ptsd.va.gov/professional/assessment/overview/index.asp
PTSD Treatment

• Treat early in survivorship trajectory
• Crisis intervention techniques are helpful
• Behavioral therapy
  – Cognitive behavioral & processing therapies
  – Prolonged exposure
  – Eye Movement Desensitization & Reprocessing (EMDR)
• Pharmacotherapies
  – SSRIs, SNRIs

National Center for PTSD: http://www ptsd va gov/professional/treatment/overview/clinicians-guide-to-medications-for-ptsd asp
NCI PDQ: http://www cancer gov/about-cancer/coping/survivorship/new-normal/
PTSD Resources

• National Center for PTSD
  http://www.ptsd.va.gov/professional/

• National Cancer Institute PDQ

• American Society for Clinical Oncology
Cancer Survivorship
Clinical Practice Guidelines

American Cancer Society, 2016. Available at:
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/toolsforhealthcareprofessionals/index
How we are addressing needs through mobile technology.

V. MHEALTH RESEARCH
Project Summary

2005 & 2010: Cancer-related PTSD Duke/UNC Cohort Study

2014-15: Original 1.0 app Pilot Study

2016-17: DIHI-redesigned 2.0 app Randomized Control Trial
Cancer Distress Coach 1.0

Symptom Management

Assessment

Tools

Duke University School of Nursing

National Center for PTSD

Duke Clinical Research Institute
Step 1: Usability testing (n=30)

- 1 hour interviews with cancer survivors
- 95% felt app was “easy to use”
- 80% felt app would be helpful daily
Step 2: Pilot Study Aims

- Acceptability
- Feasibility
- Preliminary Efficacy
Cancer Distress Coach 1.0

Pilot Study Methods

• Duke Cancer Center recruitment
• 8 weeks app usage
• Data collected baseline, Week-4, Week-8
  o Demographics
  o PTSD symptoms (PCL-S)
  o User satisfaction
  o App usage
## Pilot Study Results - Sample

<table>
<thead>
<tr>
<th>Characteristics (n=31)</th>
<th>% or Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>82.8</td>
</tr>
<tr>
<td>Non-White Race</td>
<td>37.9</td>
</tr>
<tr>
<td>Income &lt; $30,000</td>
<td>22.6</td>
</tr>
<tr>
<td>Mean age</td>
<td>55.9 (9.2)</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>2.7 (2.9)</td>
</tr>
</tbody>
</table>
Cancer Distress Coach 1.0

Acceptability

Percent who endorsed as moderately or greater (n=31)

- Overall, how satisfied are you with the app?
- Providing practical solutions to my problems…
- Helping me learn about PTSD symptoms…
- Enhancing my knowledge of posttraumatic stress…
- Increasing my access to additional resources…
- Helping me feel that there’s something I can do…
- Helping me manage my PTSD symptoms…

[Bar chart showing percent endorsed as moderately or greater for each statement]
Cancer Distress Coach 1.0

Feasibility – App Usage

<table>
<thead>
<tr>
<th>Usage</th>
<th>Range</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weeks</td>
<td>1 - 8</td>
<td>4.8 (3.2)</td>
</tr>
<tr>
<td>Sessions per week</td>
<td>1 - 13</td>
<td>2.8 (3.2)</td>
</tr>
</tbody>
</table>
## Preliminary Efficacy

Change in PCL-S Scores

<table>
<thead>
<tr>
<th>Timeframe</th>
<th>N</th>
<th>Mean (SD) Change</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline to Week4</td>
<td>24</td>
<td>-5.8 (1.8)</td>
<td>.003</td>
</tr>
<tr>
<td>Baseline to Week8</td>
<td>31</td>
<td>-6.1 (2.0)</td>
<td>.005</td>
</tr>
<tr>
<td>Week4 to Week8</td>
<td>24</td>
<td>-1.3 (0.9)</td>
<td>.18</td>
</tr>
</tbody>
</table>
Conclusions

• Participation was associated with significant improvements in PTSD symptoms

• Clinically significant reductions in PTSD symptoms observed in 48% of sample

• A DIHI-sponsored clinical trial is underway to assess causality
Trial Methods

- National recruitment via AppStore & GooglePlay
- Block randomization (patient or caregiver; low or high distress)
- Data collected baseline, Week-4, Week-8
  - Demographics
  - PTSD symptoms (PCL-5)
  - Self-efficacy
  - User satisfaction
Cancer Distress Coach 2.0

• **Available NOW (U.S. ONLY)**
  – Free download (AppStore & GooglePlay)
  – iOS ResearchKit & Android ResearchStack

• **Contact:** CancerDistressCoachApp@duke.edu

• **Learn:** http://dukecancerinstitute.org/distresscoach

• **Watch:** WRAL Interview 7/6/2017
  YouTube Patient Video

_Funded by the Duke Institute for Health Innovation
Supported by the Duke Cancer Institute_
Cancer Distress Coach 2.0
Teamwork!

1. Mobile App Development
   - Jamie Daniel
   - Mike Revoir
   - iOS and Android: Duke Institute for Health Innovation
   - Backend Development: Ephori, LLC

2. Protocol Development & Security
   - Sophia Smith, PhD, MSW, Principal Investigator
   - Cristy Van Sant, Clinical Research Coordinator
   - Approved
   - Trial registered at ClinicalTrials.gov

3. Project Management
   - Videos produced by Duke University School of Nursing
   - Informational webpage hosting by Duke Cancer Institute
Final Thoughts

- Posttraumatic stress symptoms can be prevalent and persistent among the cancer population
- It’s important to validate and normalize experience
- Refer to mental health provider for diagnosis and treatment if symptoms are bothersome
- Please help to spread the word about the Cancer Distress Coach trial!