

Abstract

A Patient-Centered Approach to Tailoring a Mobile-Based Mindfulness and Social Support Intervention for Adolescents and Young Adults With Cancer

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Abstract

Background: There is an emerging interest in identifying and meeting the unique needs of adolescents and young adults (AYA) with cancer. Roughly 700,000 AYA are diagnosed with cancer each year in the United States, and the incidence in this cohort has increased steadily over the past 30 years. Nevertheless, improvements in cancer outcomes for AYA lag far behind the advances that have been made for young children and older adults. Recent work has documented significant levels of unmet needs among AYA with cancer, particularly psychosocial challenges during the transition to adulthood—e.g., abrupt disruption to school and social life, fears for an uncertain future, and body image concerns. A mobile-based intervention for youth is an ideal way to complement treatment by delivering a psychosocial intervention which is developmentally appropriate and derived from evidence-based approaches to fostering resilience through mindfulness-based coping strategies and social support.

Objective: To use a patient-centered approach to design, and evaluate the feasibility of a mobile-based psychosocial intervention for adolescent and young adult cancer patients.

Methods: Formative research involved three steps: (1) In-depth interviews were conducted with ten AYA with sarcoma, with parents of the five adolescents, and six healthcare providers (N=21). Families were recruited from UCLA Pediatric Bone and Soft Tissue Sarcoma Program. Interview guides were based on the Resilience in Illness Model (RIM), which describes four health protective factors for resilience (social integration, family environment, courageous coping and derived meaning), and two risk factors (illness-related distress and defensive coping). Interview guides also included questions about preferences for a mobile intervention. Coding and analysis was inductive, also based on the RIM theory. (2) Adaptations were made to an existing mindfulness app (Whil Concepts, Inc.), which offers a program for youth called “Grow,” with over 500 audio relaxations. Modifications included creating a 4-week “Mindfulness for Resilience in Illness” program, with 28 relaxation exercises, and the addition of videos featuring two sarcoma survivors as program hosts. A patient advisory board was created to review drafts of content. (3) A one-month pilot study was conducted with 20 AYA cancer patients, which included using the app and engaging in a private Facebook usability group to (a) elicit beliefs about the mindfulness app and potential future enhancements, and (b) promote social support. Pre- and post-measures of mindfulness, social support, body image and quality of life were collected as well as post-intervention satisfaction data.

Results: Themes derived from the in-depth interviews were incorporated into a demonstration version of the mobile app specifically for AYA cancer patients. Quantitative and qualitative evaluation data will be presented.

Conclusions: A patient-centered approach may be a useful way to inform development of a mobile-based intervention for AYA with cancer. The intervention may be a feasible complement of medical and psychological treatment.

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KEYWORDS

adolescent; app; cancer; young adult

Multimedia Appendix 1

Full poster.

[\[PDF File \(Adobe PDF File\), 937KB-Multimedia Appendix 1\]](#)

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