Feasibility and Acceptability of an iPad Application to Explore Symptom Clusters in Adolescents with Cancer

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Objectives

- Discuss the feasibility and acceptability of a newly developed iPad application to explore symptom clusters in adolescents with cancer

- Describe adolescents’ perspectives of using an iPad application to communicate their symptom experience
Cancer in Adolescents in the United States

- Approximately 10,500 individuals 10 – 19 years of age diagnosed with cancer each year in the United States (National Cancer Institute, 2012)
  - Cure rates approximately 83%
  - Cancer is the leading cause of disease-related death among adolescents in the United States

- Adolescent cancers distinct from those of younger children or adults
  - Lymphoma, leukemia, germ cell tumors, CNS tumors, and melanoma

- Treatment frequently involves combination chemotherapy given over months to years
Developmental Characteristics of Adolescents

- Shift from concrete to abstract thinking
  - Able to consider possibilities and outcomes

- Development of a sense of identity
  - Achieving independence from parents

- Difficulty with decision-making under stress
  - Maturing brain function related to emotional and impulse control
  - Increase in risky behaviors

- Technology “natives”
  - Access to electronic media
  - Prefer computers vs. paper for health surveys
Adolescents with cancer report up to 12 concurrent symptoms (Baggott et al., 2010; Collins et al., 2000; Enskar & von Essen, 2008; Hedstrom et al., 2006; Hedstrom et al., 2004; Yeh et al., 2009; Zhukovsky et al., 2009)

Number of symptoms and associated symptom distress greatest while receiving treatment (Collins et al., 2000; Enskar & von Essen, 2007; Hinds et al., 2009)

Severity of symptoms influences decision-making related to treatment (Docherty, Sandelowski, & Preisser, 2006; Woodgate, Degner, & Yanofsky, 2003)
What is a Symptom Cluster?

- Two or more symptoms that are related to each other and that occur together (Kim et al., 2005)
- Relationships between the symptoms are associative and not necessarily causal
- May share a common etiology or underlying mechanism (Barsevick, 2007)

Hockenberry & Hooke, 2007
Why Study Symptom Clusters vs. Individual Symptoms?

- Identifying and understanding symptom clusters…
  - Informs effective symptom management interventions (Kim et al., 2005; Miaskowski, Dodd, & Lee, 2004)
  - May lead to prevention and relief of the complex and/or synergistic effects of multiple symptoms on patient outcomes (Kim et al., 2005; Miaskowski, Dodd, & Lee, 2004)
Investigating Symptom Clusters in Adolescents and with Cancer

- Dominant approaches for studying symptom clusters include multivariate statistical methods to identify clusters from patient-reported symptoms (Baggott et al., 2012; Hockenberry et al., 2011; Miaskowski et al., 2006; Yeh et al., 2008)

- No studies have explored whether and how adolescents cluster their symptoms or the meaning they attach to their symptoms and symptom clusters

- Symptom cluster heuristics is an alternate methodological approach that explores patients' interpretation and meaning of the symptom cluster experience
Study Aim

- Explore the feasibility and acceptability of using a computer-based symptom cluster heuristics tool (the C-SCAT) to explore symptom clusters experienced by adolescents with cancer
Participant Criteria

Inclusion criteria
- 13 – 18 years of age
- Primary, relapsed, or secondary cancer
- Previous receipt of at least one cycle of myelosuppressive chemotherapy
- Within 24 to 96 hours of first dose of chemotherapy dose for the current chemotherapy cycle
- Ability to read, write, and understand English
- Physical and cognitive ability to complete the tool

Exclusion criteria
- Illness deemed by the study team as impeding the capacity to understand the consent/assent process
Goals of the C-SCAT

- Integrate innovative and developmentally meaningful technology in a novel approach to study symptoms and symptom clusters in adolescents with cancer

- Elicit interpretive guidance from adolescents as to the meaning of their symptoms and symptom clusters by allowing the adolescents to identify:
  - Symptoms, possible causes, alleviating/exacerbating factors, attempted self-management strategies, and the effects of the symptom on daily activities
  - Causal and temporal relationships among symptoms they perceive to be related
  - Names for identified symptom clusters and key symptoms within clusters
Select Symptoms
Drag the symptoms you have experienced in the past 24 hours into the main portion of the screen

- Lack of energy
- Pain
- Feeling sad
- Feeling drowsy
- Nausea
- Feeling irritable
- Difficulty sleeping
- Difficulty concentrating
- Difficulty swallowing
- Dizziness
- Lack of appetite
- Don’t look like myself

St. Baldrick's Foundation - Participant #901
"Tap" on each Symptom to answer questions about each symptom

Lack of energy

What do you think causes it?

What do you think helps make it better?

What do you think makes it worse?

Have YOU (not your doctors or nurses) tried anything that made it better? If yes, what was it?

Have YOU (not your doctors or nurses) tried anything that made it worse? If yes, what was it?

What effect does this symptom have on your day-to-day life?
Cause?
Do you think that some of the symptoms cause other symptoms?

If you think some of the symptoms cause other symptoms “Tap” on a line to indicate which symptom causes the other.

To change the direction of the arrow, tap on the line again.

To show a two-way arrow, tap on the line a third time.
Study Procedure

- Participants completed the C-SCAT app with a study team member present
- Participants completed a questionnaire delivered via the iPad addressing the app’s acceptability
- Ethical considerations
  - IRB approval granted from the three data collection sites
  - Parental permission and participant assent obtained from participants 13 – 17 years
  - Informed consent obtained from participants 18 years
Sample Characteristics

Gender
- Males: 65%
- Females: 35%

Race/Ethnicity
- White/Non-Hispanic: 80%
- Hispanic: 10%
- Asian/Pacific Islander: 7%
- African American: 3%

n = 40; median age 15 years
Sample Characteristics

- Acute lymphoblastic lymphoma: 20%
- Acute myelogenous leukemia: 7%
- Hodgkin lymphoma: 25%
- Non-Hodgkin lymphoma: 5%
- Sarcoma: 32%
- Other solid tumor: 8%
- Brain tumor: 3%
- Acute myelogenous leukemia: 7%
- Other solid tumor: 8%
Feasibility

- 100% of participants completed the app in a single setting
  - Mean time to completion 26 minutes (range 2 - 83 minutes)
- 67% of participants indicated that the final picture was an accurate or very accurate depiction of their symptoms
- 3 cases of technical difficulties resulting in lost/missing data
- Participants able to complete app with minimal questions for clarification
Acceptability

Percent of respondents in agreement

- Questions on the app were clear or very clear
- Instructions in the app were easy to follow
- Easy to type or draw in the app
- App asked important questions
- Bored while completing the app
- Acceptable amount of time to complete the app
Acceptability

How did it feel to think about your symptoms while completing the app?

- “It made me understand my own symptoms a little better, actually”
- “It was fine. It certainly didn’t make my symptoms worse.”
- “It was kind of hard because I’ve had so many different symptoms that I can’t remember if they happened within the time period you asked about.”
- “Not good to [be] reminded [of] all [the] bad things.”
- “Painful”
- “Sucky”
Acceptability

- 94% expressed a preference for the app vs a paper-and-pencil version
  - “Doing it on paper would be boring and a lot more work to do. And most people my age are lazy and wouldn't want to do it.”
  - “It's incredible technology, there's nothing exciting about paper”
  - “No erasing, and the iPad had autocorrect, and also I’m used to typing on touchscreens.”
  - “Because of my hands and neuropathy easier to do on iPad”
Conclusions

- The C-SCAT demonstrated initial feasibility and acceptability among adolescents with cancer receiving chemotherapy

- Opportunities for future refinements
  - Minimizing risk of technical difficulties
  - Limiting the number of questions in the app
Clinical Implications

- Use the C-SCAT to facilitate a personalized approach to symptom management as a mobile health resource
  - Enhance adolescent-healthcare provider communication
  - Prioritize symptom management interventions

- Integrate the C-SCAT with electronic medical record systems, including telehealth systems
Directions for Future Research

- Include the C-SCAT as a component of an intervention across the cancer continuum
- Evaluate or revise the C-SCAT for use with other health/illness states
- Evaluate the C-SCAT in other age groups
  - School-age children
  - Young adults
  - Parents
  - Adults
  - Older adults
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Sample Characteristics

- 40 participants
  - 14 female; 26 male
  - Median 15 years
- Race/ethnicity
  - White/non-Hispanic 80%
  - Hispanic 10%
  - Asian/Pacific Islander 7.5%
  - African American 2.5%
- Cancer diagnoses
  - Acute lymphoblastic leukemia 20%
  - Acute myelogenous leukemia 7.5%
  - Hodgkin lymphoma 25%
  - Non-Hodgkin lymphoma 5%
  - Sarcoma 32.5%
  - Brain tumor 2.5%
  - Other solid tumor 7.5%