Developing Clinical Decision Support for Direct Use by Patients: Challenges and Lessons Learned from Symptom Management in Cancer Patients

David F. Lobach, MD, PhD, MS1; Janet L. Abraham, MD2; Donna L. Berry, RN, PhD2; Michael S. Rabin, MD2; Ilana Braun, MD2; Manan Nayak, MA2; Mary E. Cooley, RN, PhD2

1Religious Health and Duke University Medical Center, Durham, NC; and
2Dana-Farber Cancer Institute, Boston, MA

Abstract
One approach for engaging and empowering patients is through the development of clinical decision support (CDS) tools designed for direct use by patients. In this project we assessed the feasibility of creating CDS tools for the self-management of symptoms in cancer patients. Patient safety and health literacy issues were addressed. Additionally, in order to provide suggestions for symptom relief, recommendations for medication therapy were structured to reference existing clinical management practices of the overseeing clinician.

Introduction
Relatively little is known regarding CDS for patients with cancer and few studies have described CDS tools for direct use by cancer patients1-2. In these studies, the focus of the CDS was to identify the presence or absence of a specific symptom through an algorithm with a single decision node followed by general recommendations for managing that symptom3 or through heavy reliance on interactions with clinical personnel2. The literature provides no precedents for developing more complex self-management algorithms for cancer patients. The goal of this project was to understand the needs of patients with regard to CDS, along with identifying effective mechanisms for delivering patient guidance for self management of their symptoms and direction for when to call their clinicians.

Methods
The first phase of the project was to understand patient and clinician perspectives regarding symptoms and quality of life experiences during cancer treatment and the second phase was to develop resources such as CDS tools for direct use by patients. In phase 1, patient and clinician perspectives were ascertained through focus groups and semi-structured interviews. Participants included a total of 57 adult patients who had received cancer treatment within the past six months and 51 clinicians who provided care in ambulatory oncology settings. For phase 2, oncologists, palliative care specialists, and nurse scientists drew from evidence-based resources and worked with CDS experts to develop computable algorithms that would enable patient self-management for pain, constipation, and nausea and vomiting. The clinical algorithms were converted to patient friendly language and an interactive format in order to assess usability and comprehensibility through focus groups, interviews, and patient-directed think aloud sessions.

Results: Challenges and Lessons Learned
Significant challenges were identified in developing CDS tools for symptom management in cancer patients. A primary concern was maintaining patient safety by identifying potential serious or life-threatening causes for symptoms and directing patients to seek contact with their clinicians. Accordingly, all three patient CDS algorithms began with the identification of “red flags” that would necessitate that the patient exit the CDS tool to seek clinician guidance. A second challenge was to support users across a wide breadth of health literacy. To address this challenge, we developed content at a fifth grade reading level and provided descriptions and educational information that users could elect to review or skip based on perceived information needs.

In order to provide medication-related advice, we sought to ensure that recommendations were evidence-based and grounded in therapies approved by the clinician overseeing a patient’s care. Accordingly, we inquired whether a patient was using a particular therapy or if he had been prescribed that particular therapy. If he was not using the therapy, he was advised to use it. If he had not been prescribed the recommended therapy, he was advised to contact his clinician and inquire if this therapy could be appropriate.

Conclusion
Through this project, we have shown an approach for providing CDS for patient self-management in cancer care including provisions for patient safety and recommendations for medication use for symptom control.

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References