Implementing a Low-Literacy, Multimedia Information Technology System to Enhance Patient-Centered Cancer Care

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Organization: Northwestern University
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Summary: Information about cancer, if delivered in a user-friendly way, can reach people with limited literacy skills. This research team, led by Elizabeth Hahn, hypothesizes that promoting patient understanding of disease and treatment through innovative information delivery methods will lead to better communication; treatment adherence; and outcomes including patient satisfaction with health care, cancer-related knowledge, self-efficacy, treatment, and health-related quality of life (HRQL).

This project modified a widely-used talking touchscreen multimedia information and assessment system for patients being treated for breast and colorectal cancer to be more accessible for patients across the spectrum of literacy skills. The CancerHelp® Talking Touchscreen (TT), developed by the CancerHelp Institute and investigators on this grant, is available at participating clinics during office hours via a kiosk at the site. The software provides patient education on diagnoses, treatment, support, side effects, prevention, and screening. It contains easy access to cancer information from the National Cancer Institute, user statistics, and customizable features. Strategies to enhance the ease of understanding of the material and navigating through the program will be implemented. For example, the amount of text on each screen will be shortened; patients will have the option to choose between text-based or audio presentation of education materials, communication tools, and assessment questions; and videos will be developed for certain modules.

The intervention is being evaluated through a randomized controlled trial (RCT) with a targeted enrollment of 200 patients with breast or colorectal cancer at three ambulatory cancer care centers. Patients in both the intervention group and control group will use the TT to complete surveys on knowledge, satisfaction, HRQL, and other study measures, as many as three times during treatment and once afterwards. Both groups will receive diagnosis- and treatment-specific brochures; however, only patients randomized to the intervention arm will have access to the intervention-adapted software. The Behavioral Model for Vulnerable Populations, which assesses patient characteristics, resources, needs, health behaviors, and health outcomes, will also be used to assess study outcomes.

During regular visits to cancer care centers for treatment, participants interact with the adapted CancerHelp® TT that enables patients to print information and generate a visit-specific checklist of their top priorities to discuss with their providers. At the conclusion of their in-clinic cancer treatments, participants in the intervention arm also receive a post-treatment cancer survivorship care plan, modeled on templates from the Institute of Medicine (IOM). The survivorship care plan summarizes the cancer treatments they have received and provides appropriate aftercare recommendations, including detailed
contact information for future appointments. Participants’ oncologists review the care plan with the participants and instruct the participants to provide a copy to their primary care physicians (PCPs). This survivorship care planning is designed to minimize the interruptions in care that can occur when patients complete their cancer treatments.

**Specific Aims:**

- Test whether a low-literacy-friendly multimedia information and assessment information technology system used in daily clinical practice improves patient outcomes during treatment in 200 recently-diagnosed breast and colorectal cancer patients based on the primary endpoints: satisfaction with health care communication, knowledge of cancer and treatment, self-efficacy, adherence to recommended treatment, and HRQL. *(Ongoing)*

- Evaluate the relationships between patient characteristics, resources, needs, health behaviors, and health outcomes using the Behavioral Model for Vulnerable Populations. *(Ongoing)*

- Test whether use of the multimedia information technology system improves adherence to recommended post-treatment surveillance care and HRQL during the early post-treatment surveillance period (3 months after treatment). *(Upcoming)*

**2011 Activities:** The research team continued to recruit and enroll patients into the RCT. The team held regular onsite meetings with the directors of the three participating sites to review procedures for identifying and enrolling patients. These meetings facilitate communication, organization of patient data, and identification of the physician responsible for presenting the survivorship plan to the patient. The project has now recruited 129 of 200 patients. Due to lower-than-expected patient volume, it may not be possible to reach the recruitment goal. However, because the power calculations were based on a modest improvement in the outcome, Ms. Hahn expects that there will be enough statistical power to detect a strong impact, even with lower enrollment.

Survivorship plans continue to be developed for intervention arm patients. Clinician compliance with developing and distributing the plans continues to be a challenge, as clinicians do not always have enough time. As a result, research assistants complete as much of the plan as possible and the plans are given to study participants who are encouraged to share them with their PCPs for discussion of ongoing care.

As last self-reported in the AHRQ Research Reporting System, project progress and activities are mostly on track with the revised timeline and project budget spending is roughly on target. The project team is using two 1-year no-cost extensions to provide extra time to for study recruitment and data analysis.

**Preliminary Impact and Findings:** Thirteen patients were enrolled in field testing that was completed toward the end of 2009. Patient feedback was largely positive and was used to improve the software.

Ms. Hahn reports that this study has been extremely informative regarding the feasibility, acceptability, and implementation of survivorship care plans. While the IOM recommends that every cancer patient receives a survivorship plan, providers often do not have the time to develop the plan. Ms. Hahn reports that an automated mechanism for developing survivorship care plans could facilitate the process.

**Target Population:** Adults, Cancer: Breast and Colorectal, Low Literacy, Low SES/Low Income*, Medically Underserved, Safety Net

**Strategic Goal:** Develop and disseminate health IT evidence and evidence-based tools to support patient-centered care, the coordination of care across transitions in care settings, and the use of electronic
exchange of health information to improve quality of care.

**Business Goal:** Implementation and Use

* This target population is one of AHRQ’s priority populations.