

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

Principal Investigator:	Hahn, Elizabeth, M.A.
Organization:	Northwestern University
Mechanism:	RFA: HS07-007: Ambulatory Safety and Quality Program: Enabling Patient-Centered Care Through Health Information Technology (PCC)
Grant Number:	R18 HS 017300
Project Period:	September 2007 – September 2012
AHRQ Funding Amount:	\$1,198,839

Summary: Information about cancer, if delivered in a user-friendly way, can reach individuals with limited literacy skills. This project hypothesized that promoting patient understanding of disease and treatment through innovative information delivery methods would 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 onsite kiosk. The software provides patient education on diagnoses, treatment, support, side effects, prevention, and screening. It contains easy-to-access cancer information from the National Cancer Institute, user statistics, and customizable features. Strategies to increase understanding of the material and program navigation were implemented. For example, the amount of text on each screen was shortened; patients had the option to listen to an audio presentation of education materials, communication tools, and assessment questions; and videos were developed for certain modules.

The intervention was 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 and control groups used 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 received diagnosis- and treatment-specific brochures; however, only patients randomized to the intervention arm had access to the intervention-adapted software. The Behavioral Model for Vulnerable Populations, which assesses patient characteristics, resources, needs, health behaviors, and health outcomes, was also used to assess study outcomes.

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. **(Achieved)**

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

2012 Activities: The research team continued to recruit and enroll patients into the RCT. During regular visits to cancer care centers for treatment, participants interacted with the adapted CancerHelp® TT that enabled 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 received a post-treatment cancer survivorship care plan, modeled on templates from the Institute of Medicine (IOM). The survivorship care plan summarized the cancer treatments they had received and provided appropriate aftercare recommendations, including detailed contact information for future appointments. Oncologists were asked to review care plans with participants and instruct them to provide a copy to their primary care physicians (PCPs). This survivorship care plan was designed to minimize the interruptions in care that can occur when patients complete their cancer treatments. To complete the study, the study team conducted an analysis to evaluate the impact of the modified CancerHelp® TT.

Due to challenges with patient recruitment, Ms. Hahn used two 1-year no-cost extensions to complete the trial and data collection. As last self-reported in the AHRQ Research Reporting System, project progress was on track in some respects but not others, and project budget spending was on track. At the end of the project, all aims and milestones were achieved. This project was completed in September 2012.

Impact and Findings: Thirteen patients were enrolled in field testing that was completed near the end of 2009. Patient feedback was largely positive and was used to improve the software. Newly-diagnosed breast and colorectal cancer patients (n=129) self administered the questionnaires using the TT kiosk in clinic waiting rooms. Patients—even those who were computer-naïve—completed questionnaires on their own or with minimal assistance. Clinician compliance with developing and distributing the survivorship plans was a challenge because clinicians were frequently pressed for time. As a result, research assistants completed as much of the plans as possible, gave them to study participants, and encouraged them to share the plans with their PCPs for discussion of ongoing care.

Data analysis indicated that participants in the TT intervention group trended toward a larger increase in satisfaction with communication, HRQL, health beliefs, and cancer knowledge compared to the control group, although differences were not statistically significant. Health literacy was moderately associated with better HRQL, higher cancer knowledge, and more adaptive health beliefs. Ms. Hahn reported that this study was extremely informative regarding the feasibility, acceptability, and implementation of survivorship care plans. While the IOM recommends that every cancer patient receive a survivorship plan, providers often do not have the time to develop them. Ms. Hahn reported that an automated mechanism for developing survivorship care plans could facilitate the process. The CancerHelp® TT kiosk and software continues to be used at one of the clinical sites as part of regular educational initiatives.

Target Population: Adults, Cancer: Breast and Colorectal, Low Literacy, Low SES/Low Income*, Medically Underserved, Racial or Ethnic Minorities*, Safety Net, Women*

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.*