

Grant Final Report

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Implementing a low-literacy, multimedia IT system to enhance patient-centered cancer care

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Abstract

Purpose: To test whether a low-literacy-friendly, multimedia information and assessment system used in daily clinical practice enhances patient-centered care and improves patient outcomes.

Scope: Ambulatory English-speaking adult patients with Stage I-III breast or colorectal cancer, and receiving chemotherapy and/or radiation therapy.

Methods: The CancerHelp-Talking Touchscreen (TT) multimedia software collects patient self-report data and provides access to cancer education information. Patients were randomized to one of two arms: CancerHelp-TT intervention or control, stratified by clinic. They participated in the study through the end of treatment and into early survivorship.

Results: A total of 129 patients participated in the study (65 intervention and 64 control). The majority were female (82%), non-Hispanic African Americans (57%), with a high school or lower education (57%); mean age was 52 years. The CancerHelp-TT software was favorably rated by intervention participants. There were no statistically significant ($p < 0.05$) differences between randomized groups in satisfaction with communication, health-related quality of life, health beliefs and cancer knowledge. There is a consistent trend that participants in the intervention group showed a larger increase over time in all four endpoints, compared to the control group. Health literacy was moderately associated with better health-related quality of life, higher cancer knowledge and more adaptive health beliefs. Survivorship Care Plans were completed for several patients, but few received it from their oncologist.

Key Words: health information technology; underserved populations; health literacy; cancer

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Final Report

Purpose

The overall objective of this demonstration project was to test whether a low-literacy-friendly, multimedia information and assessment system used in daily clinical practice enhances patient-centered care and improves patient outcomes. The intervention combined two existing assessment and education systems to provide a multimedia information technology (IT) resource: CancerHelp-Talking Touchscreen (TT). This user-friendly IT resource delivers comprehensive, state-of-the-art patient education information, allows patients to “personalize” the information at each session, enables low literacy patients to self-administer patient-reported outcomes questionnaires, allows patients to create an individually tailored list of needs and concerns to share with their health care providers, and assists patients in preparing for the transition between active cancer treatment and follow-up care.

We conducted a prospective randomized trial of 129 patients with breast or colorectal cancer at three ambulatory cancer care centers serving vulnerable populations in Chicago. Patients were randomized to CancerHelp-TT or control/standard education and followed through the end of treatment and into the early survivorship period (first follow-up visit).

Primary Aim. To test whether a low-literacy-friendly multimedia information and assessment IT system used in daily clinical practice improves patient outcomes during treatment in 200 recently diagnosed breast and colorectal cancer patients.

Primary Endpoints

Satisfaction with healthcare communication
Knowledge of cancer and treatment
Self-efficacy
Adherence to recommended treatment

Secondary Endpoints

Health-related quality of life

Secondary Aim 1. To evaluate the relationships between patient characteristics, resources, needs, health behaviors and health outcomes using the Behavioral Model for Vulnerable Populations (Andersen, 1968; Andersen, 1995; Gelberg et al., 2000).

Secondary Aim 2. To test whether use of the multimedia IT system improves the following patient outcomes regarding the early post-treatment surveillance period (three months after treatment):

Adherence to recommended post-treatment surveillance care

Health-related quality of life

Scope

Background

We focused on cancer for three reasons: 1) its large prevalence, making it the second-most common disease in the U.S. (American Cancer Society, 2003); 2) the multifactorial issues inherent in the current management of the disease(s); and 3) our extensive experience in this area. Cancer is an excellent model for understanding the impact of chronic, life-threatening illness upon patient-reported outcomes and preferences for treatment over time. Early efforts to promote electronic information sharing between patients and providers should focus on people with chronic conditions (Working Group, 2004). This is because of the potential for improvements in the coordination, effectiveness, safety and efficiency of clinical care as well as self-care and self-management (Working Group, 2004).

Context

We enrolled ambulatory cancer patients at the clinic where they were receiving their primary treatment course (chemotherapy and/or radiation therapy).

Settings

This project met the qualifications for the “vulnerable populations” funding preference. A description of the three cancer care centers that participated in the project is provided below:

- John H. Stroger Hospital (JSH) of Cook County: The racial/ethnic composition of the patient population at JSH is 60% African-American, 17% Hispanic, 7% Asian, and 16% White. The service area is mainly defined by poverty, lack of insurance or inability to pay for health care, and such patients are sent to JSH since it provides health care regardless of the ability to pay. The mission statement of JSH is: “To provide a Comprehensive Program of Quality Health Care with Respect and Dignity, to the residents of Cook County, regardless of their ability to pay.” JSH has been designated by the Illinois Department of Healthcare and Family Services (IDHFS) as a disproportionate share hospital (DSH).
- Mt. Sinai Hospital (MSH): The racial/ethnic composition of the patient population at MSH is 53% African-American, 36% Hispanic, 4% White and 7% unknown. MSH serves the populations located on the Near West and South Sides of the City of Chicago. These communities are primarily comprised of African-American and Hispanic residents, and are considered to be some of the most disadvantaged from an economic point of view. The mission statement of MSH includes the following: “Beyond the public health needs of the community, Sinai is committed to serving all those who require health care services, regardless of their ability to pay, as evidenced by our charity care policy and cost of government-sponsored indigent health care.” Mt. Sinai is a market leader in caring for the City of Chicago’s uninsured population. MSH is designated as a DSH.

- Advocate Illinois Masonic Medical Center (AIMMC): The racial/ethnic composition of the patient population at AIMMC is 14% African-American, 38% Hispanic, 4% Asian, 40% White, and 4% other or unknown. Approximately 15% are Medicaid patients. The mission statement includes the following: “For patients with whom the cancer center has established a relationship (for example, started treatment in the hospital), we will continue their care for free.”

None of the participating cancer care centers has a system for direct patient access to personal health information.

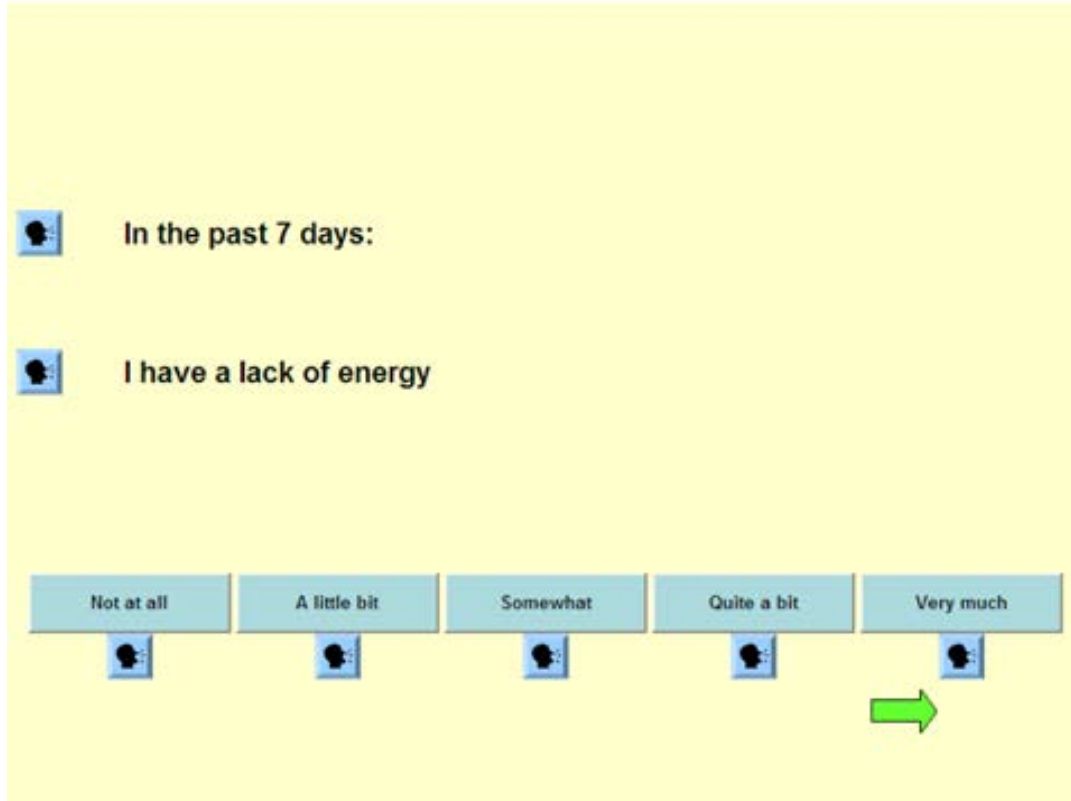
Methods

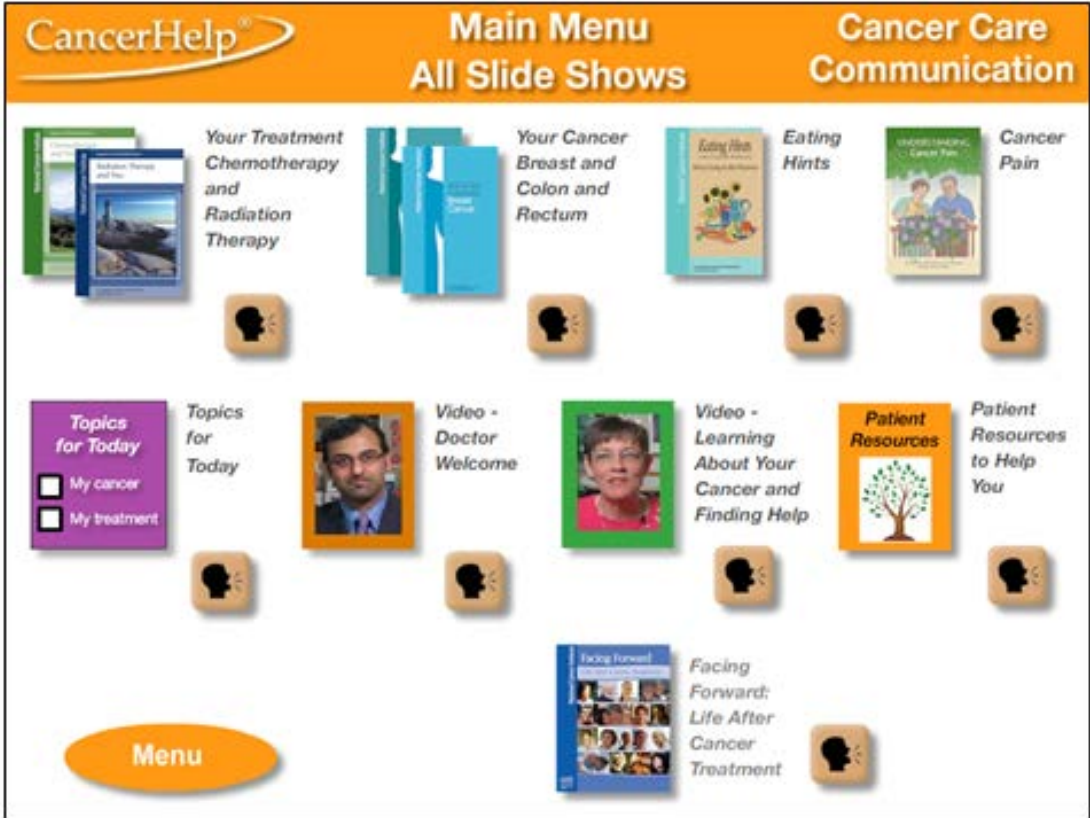
Development of the CancerHelp-Talking Touchscreen (CancerHelp-TT)

The CancerHelp-TT software consists of two separate but integrated programs to collect patient self-report data and to provide cancer education information. It employs an interactive design with audio and visual tools and user-friendly features to enhance accessibility for patients with low literacy (see screen images in Figure 1). Audio is available on the data collection component as well as the education component. An ID and password were assigned to each study participant to ensure that patients in the control arm accessed only the data collection module while the intervention arm accessed both modules. Patients also received a wallet-size card with their ID, password and study contact information. The research assistant’s phone number was also posted on the kiosks as well as on the CancerHelp-TT login screen.

The full version of the CancerHelp-TT software was installed on several hardware platforms including tablet PCs and the on-site kiosks (see Figure 2). Tablet PCs were in the possession of the research assistants (RAs) at all times. Stand-alone kiosks were set up in a private room at each recruiting cancer care center. Study assessment activities occurred only when the study RA was present, whereas the educational material was accessible at any time. Study RAs were a regular presence in the clinics and were available as needed for assistance. We observed high standards of data security practices. Our approach to security consists of a collection of policies, procedures and practices that are designed to maximize the following three characteristics for critical resources: confidentiality, integrity and availability. Our infrastructure for confidential data management includes the sophisticated use of firewall technologies, dedicated database servers and related technological capabilities. A small amount of protected health information (PHI) was gathered by the RAs for purposes of tracking study participants over time. None of the PHI elements were stored on the kiosk computers. These elements were stored on each RA’s tablet laptop in a separate database with password protection. Other data associated with an individual was indexed only by a generic study ID. Encryption was used wherever data were transferred. Implementation strategies for data management take full consideration of regulations directing confidentiality and security of electronic data transmission and storage. Upon completion of this study and exhaustion of the data retention period, all patient identifiers will be deleted in compliance with HIPAA regulations. The software was installed on the kiosks and laptops as a stand-alone application, i.e., none of the data collection activities were done online. No certification was requested from the following organizations: www.hitsp.org and www.cchit.org.

Figure 1. CancerHelp-Talking Touchscreen (CancerHelp-TT) Screen Images





How is chemotherapy given?

Chemotherapy may be given in many ways.

- **Injection.** The chemotherapy is given by a shot in a muscle in your arm, thigh, or hip or right under the skin in the fatty part of your arm, leg, or belly.



Figure 2. Kiosk



CancerHelp[®] Patient Education Software has been used in cancer care centers since 1991. The touchscreen interface was designed to reach users of all levels of computer literacy, including novices. Information comes from NCI sources and is updated monthly via CD-ROMs. Although it is extremely user-friendly, the original version of the software is not fully accessible to those with low literacy skills. We adapted the software to shorten the amount of text on each screen, added more multicultural images, and added sound files so that text can be read aloud (see screen images in Figure 1). These adaptations were implemented to make the software more user-friendly for patients across the spectrum of literacy skills.

Strategies were implemented to enhance the ease of understanding the material and navigating through the program. These include the use of simple and familiar words, and providing definitions for technical or unfamiliar words. Another strategy relates to the visual message, including reinforcement of written messages and enhancement of the learning process. Visual materials incorporated a variety of contemporary visual representations of the target population. A list of national and local organizations and support groups was added to the program, thereby providing an integral resource to support patients and families where they live.

Study Design

Study participants were randomized to one of two arms: CancerHelp-TT intervention or control (usual education), stratified by clinic. They participated in the study through the end of treatment and into the early survivorship period. Participants in both arms used the TT to complete knowledge, satisfaction, health-related quality of life and other study measures up to three times during treatment, and once after treatment. Both groups received NCI diagnosis- and treatment-specific brochures to standardize usual education across sites (What You Need to

Know Series/Patient Summary; and Chemotherapy and You and/or Radiation Therapy and You) (<https://pubs.cancer.gov/ncipl/home.aspx?js=1>). Participants randomized to the intervention arm had access to the CancerHelp-TT patient education software, which includes the option to generate personally relevant consultation checklists of issues they may wish to discuss during medical visits. The software also includes a video module based on the NCI Facing Forward booklet (<https://pubs.cancer.gov/ncipl/detail.aspx?prodid=P119>). CancerHelp-TT was available on a kiosk in a private room at any time during clinic hours.

To measure patient satisfaction with communication, we created a 6-item composite index using items from the Commonwealth 2006 Quality of Health Care Survey (www.commonwealthfund.org) and the FACIT-TS (www.facit.org). We considered using the 6-item Provider Communication scale from the CAHPS[®] Group & Clinician core questionnaire. We ultimately decided to not use this scale for two reasons. First, the time frame for the item is the “Past 12 months.” We enrolled recently diagnosed cancer patients and were interested in provider communications during their cancer care. Thus, the “past 12 months” is an inappropriate time frame. Second, we did not aggregate at the Group or Clinician level, which is the purpose of the CAHPS Group & Clinician survey. Furthermore, we did not collect any information on individual clinicians or clinician groups. For these reasons (time frame and level of data aggregation) we used a different measure of satisfaction with communication.

Other patient-reported outcome measures included health beliefs, cancer knowledge, health literacy (Health Literacy Assessment Using Talking Touchscreen Technology: Health LiTT; Hahn et al., 2011), self-efficacy (Communication and Attitudinal Self-Efficacy scale for cancer: CASE-cancer; Wolf et al., 2005), one item adapted from the Control Preferences Scale (Degner et al., 1998), the Functional Assessment of Cancer Therapy-General (FACT-G; Cella et al., 1993; www.facit.org), the Eastern Cooperative Oncology Group Performance Status Rating (ECOG PSR), and several evaluation questions (both self- and interviewer-administered).

We designed a Survivorship Care Plan, modeled on the IOM and ASCO recommendations that all patients should be given a summary of their treatment and a comprehensive plan for follow-up. Such a plan would inform patients (and their providers) of the long-term effects of cancer and its treatment, identify psychosocial support resources in their communities, and provide guidance on follow-up care, prevention, and health maintenance. Our research assistants filled out most of the Care Plan with information they obtained from chart review and then gave it to physicians to finalize and deliver to patients.

Statistical analysis

The primary analysis strategy for the longitudinal data (satisfaction, health-related quality of life, knowledge, health beliefs) was based on a covariance pattern mixed effects model for repeated measures. Intervention group, visit and group-by-visit interaction were entered as fixed effects. An event-driven analytic strategy was used, rather than a time-driven strategy, because the assessments occurred during clinically relevant phases of cancer treatment, e.g., beginning, during and end of treatment, and post-treatment (Fairclough, 2002). This strategy is especially advantageous for different treatment regimens.

Prior to performing analyses, we evaluated the amount, reasons and patterns of missing data to determine if missing data were missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR) (Troxel et al., 1998; Little, 2002). If missing data can be considered to be MCAR or MAR, then a mixed model is advantageous because all available

data can be used; in other words, the analyses are not restricted to only those participants with complete data over time.

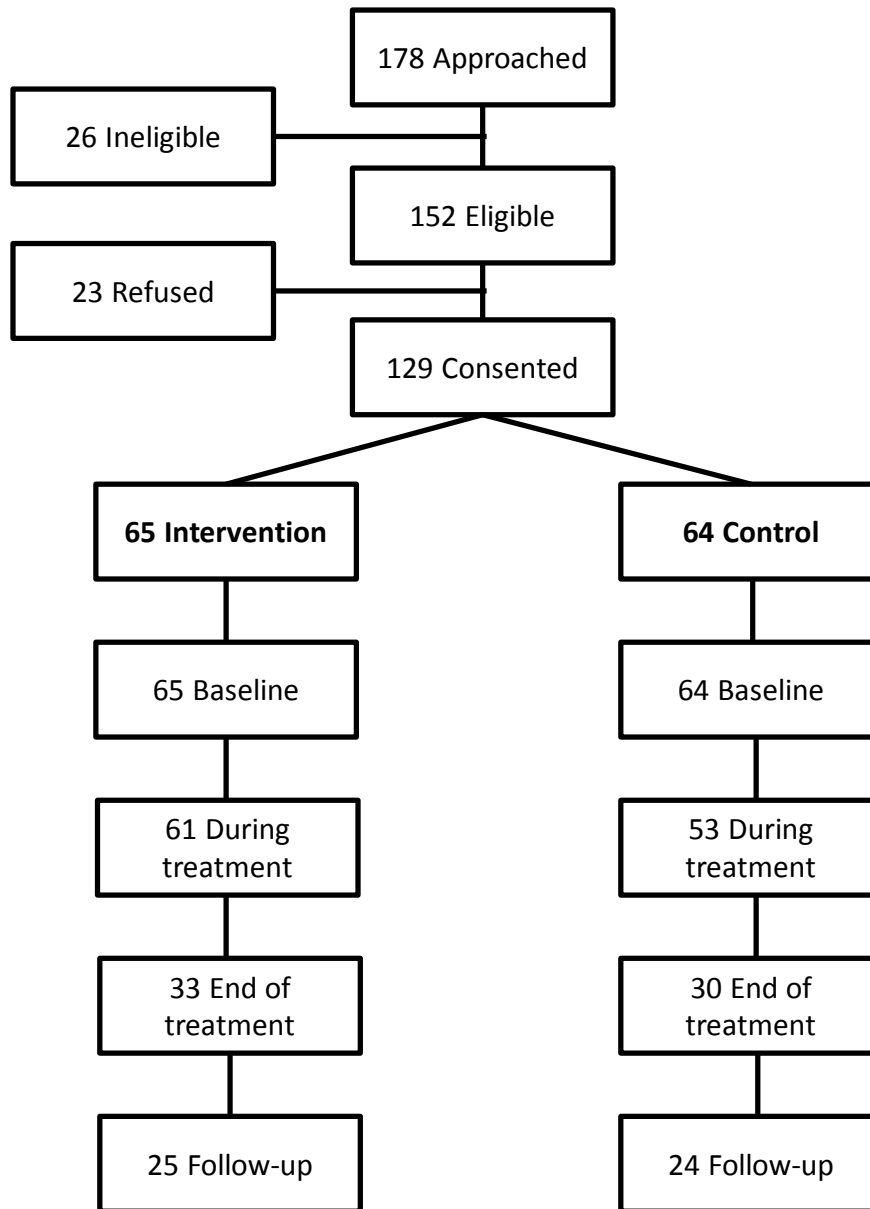
Results

Primary Aim

To test whether a low-literacy-friendly multimedia information and assessment IT system used in daily clinical practice improves patient outcomes during treatment in recently diagnosed breast and colorectal cancer patients.

Our goal was to enroll and randomize 200 patients. We approached a total of 178 patients (see Figure 3). Among 152 who met study inclusion criteria, the majority ($n=129$) consented to participate (85%). The main reason for refusal was that the study seemed to be too time-consuming.

Figure 3. Study Accrual Flowchart



Our actual accrual was 129 patients, with 65 randomized to the intervention arm and 64 randomized to the control arm (see Figure 1). Of the 129 total ambulatory patients enrolled in the study, 73 (57%) were non-Hispanic African Americans and 29 (22%) were Hispanics (see Table 1). Patients were primarily female (82%) with a mean age of 52 (range, 26-70). The highest educational attainment was high school or less for 57% of participants, and the mean Health LiTT score was 52.

Table 1. Patient Characteristics by Study Arm (n=129)

	Intervention (n=65)	Control (n=64)	p-value^a
Race/Ethnicity	n (%)	n (%)	0.19
Hispanic, any race	16 (24.6)	13 (20.3)	
African American, non-Hispanic	32 (49.2)	41 (64.1)	
White, non-Hispanic	14 (21.5)	6 (9.4)	
Other, non-Hispanic	3 (4.7)	4 (6.3)	
Sex			0.97
Female	54 (83.1)	53 (82.8)	
Male	11 (16.9)	11 (17.2)	
Cancer Type			0.51
Breast	48 (73.8)	47 (73.4)	
Colon	11 (16.9)	14 (21.9)	
Rectal	6 (9.2)	3 (4.7)	
Education			0.25
Less than high school grad/GED	19 (29.2)	12 (18.8)	
High school grad/GED	16 (24.6)	26 (40.6)	
Some college or more	29 (44.6)	25 (39.1)	
Missing	1 (1.5)	1 (1.6)	
Has your physical condition or medical treatment caused you financial difficulties?			0.48
Not at all	18 (27.7)	13 (20.3)	
A little bit	12 (18.5)	7 (10.9)	
Somewhat	10 (15.4)	13 (20.3)	
Quite a bit	6 (9.2)	7 (10.9)	
Very much	17 (26.2)	23 (35.9)	
Don't know	1 (1.5)	0 (0)	
Missing	1 (1.5)	1 (1.6)	
Do you have any form of health insurance or health plan, including any private health insurance plan or a government program such as Medicare or Medicaid, or do you not have any health insurance at this time?			0.71
Yes (covered/some covered)	40 (61.5)	38 (59.4)	
No (not covered)	23 (35.4)	25 (39.1)	
Missing	2 (3.1)	1 (1.6)	
Patient-Reported ECOG PSR			0.04
Normal activity, without symptoms	16 (24.6)	23 (35.9)	
Some symptoms, but do not require bed rest during waking day	34 (52.3)	18 (28.1)	
Require bed rest for less than 50% of waking day	9 (13.8)	16 (25.0)	
Require bed rest for more than 50% of waking day	5 (7.7)	4 (6.3)	
Unable to get out of bed	0 (0)	2 (3.1)	
Missing	1 (1.5)	1 (1.6)	
Control Preferences			0.42
I prefer to make decisions about my health care.	1 (1.5)	0 (0)	
I prefer to make decisions about my health care after seriously considering my doctor's opinion.	8 (12.3)	6 (9.4)	
I prefer that my doctor and I share responsibility for making decisions about my health care.	26 (40.0)	35 (54.7)	
I prefer that my doctor make decisions about my health care, but seriously considers my opinion.	22 (33.8)	16 (25.0)	

	Intervention (n=65)	Control (n=64)	p-value^a
I prefer to leave decisions about my health care to my doctor.	6 (9.2)	4 (6.3)	
Missing	2 (3.1)	3 (4.7)	
How much have you looked at booklets or pamphlets for information about your health or cancer?	n (%)	n (%)	0.59
Not at all	5 (7.7)	4 (6.3)	
A little bit	10 (15.4)	11 (17.2)	
Somewhat	28 (43.1)	21 (32.8)	
A lot	21 (32.3)	27 (42.2)	
Missing	1 (1.5)	1 (1.6)	
How much have you looked on the Internet for information about your health or cancer?			0.25
Not at all	24 (36.9)	34 (53.1)	
A little bit	15 (23.1)	8 (12.5)	
Somewhat	6 (9.2)	5 (7.8)	
A lot	18 (27.7)	16 (25.0)	
Missing	2 (3.1)	1 (1.6)	
How much have you talked to a doctor for information about your health or cancer?			0.48
Not at all	0 (0)	1 (1.6)	
A little bit	7 (10.8)	7 (10.9)	
Somewhat	17 (26.2)	11 (17.2)	
A lot	40 (61.5)	44 (68.8)	
Missing	1 (1.5)	1 (1.6)	
How much have you talked to a nurse for information about your health or cancer?			0.16
Not at all	8 (12.3)	11 (17.2)	
A little bit	6 (9.2)	9 (14.1)	
Somewhat	26 (40.0)	14 (21.9)	
A lot	24 (36.9)	29 (45.3)	
Missing	1 (1.5)	1 (1.6)	
	Mean (SD)	Mean (SD)	
Age	52.6 (10.3)	51.1 (10.5)	0.39
Health Beliefs^b	31.2 (3.9)	31.4 (3.6)	0.43
Cancer Knowledge Scale^c	7.8 (2.4)	8.0 (2.4)	0.56
FACT-G^d	75.5 (17.0)	75.4 (17.5)	0.98
CASE: Understand & Participate in Care^e	13.1 (1.7)	13.0 (2.0)	0.67
CASE: Maintain Positive Attitude^f	13.4 (2.3)	12.7 (2.5)	0.11
CASE: Seek & Obtain Information^g	13.2 (2.1)	13.3 (2.0)	0.82
Satisfaction with Communication Scale^h	14.8 (4.2)	15.8 (3.1)	0.09
Health LiTTⁱ	51.8 (7.7)	51.3 (8.2)	0.72

^aFor categorical variables, chi-square or Fisher's exact tests were used to test for differences between treatments, and for continuous variables, t-tests were used.

^bThe Health Beliefs scale is the sum of 10 items with a theoretical range of 10-40.

^cThe Cancer Knowledge scale is the sum of 11 items with a theoretical range of 0-11.

^dThe FACT-G is the sum of 27 items with a theoretical range of 0-108.

^eThe Understand & Participate in Care subscale is the sum of 4 items with a theoretical range of 4-16.

^fThe Maintain Positive Attitude subscale is the sum of 4 items with a theoretical range of 4-16.

^gThe Seek & Obtain Information subscale is the sum of 4 items with a theoretical range of 4-16.

^hThe Satisfaction with Communication scale is the sum of 6 items with a theoretical range of 0-18.

ⁱThe Health LiTT score is a t-score calculated from 10 items with a scale mean of 50, SD of 10.

The majority of study participants met the definition of AHRQ’s “priority populations;” specifically, we enrolled patients from the following groups: inner-city, low income, minorities and women. All of the study participants met the criteria of needing chronic care.

Three factors contributed to the lower than expected number of enrolled study participants. First, the numbers of potentially eligible patients were much lower than originally estimated at each institution. Our study was focused only on early stage disease (Stage I-III); however, many patients being treated at the cancer care centers had advanced disease (Stage IV). Second, there were some changes in clinical staff at two of our enrolling sites, which required additional meetings and training sessions. Third, our entire research group moved from one institution to another, which resulted in some study delays.

Two factors contributed to the lower than expected numbers of study participants with an assessment at the end of treatment ($n=63$; 49%) and at follow-up ($n=49$; 38%) (see Figure 3). First, the length of treatment for each patient was expected to last about six months; however, the mean length of treatment for our study participants was over nine months, with some patients being treated for up to two years. This extended the study period and increased the amount of research staff effort. Second, due to all of the unanticipated challenges described here, it was necessary to end the study early without completing assessments for all study participants.

Longitudinal analyses were performed for four study endpoints to date: satisfaction with communication, health-related quality of life, health beliefs and cancer knowledge. After evaluating reasons and patterns of missing data, it is reasonable to assume that data are missing completely at random (MCAR) or missing at random (MAR). This permitted implementation of mixed models that used all available data; in other words, the analyses were not restricted to only those participants with complete data over time. Least-squares means at each scheduled assessment time and p -values from the mixed models are shown in Tables 2a-2d. Overall, there were no statistically significant ($p<0.05$) differences between randomized groups at any assessment timepoints. In general, participants in both groups exhibited an increase over time in satisfaction and health-related quality of life. The control group showed no change in health beliefs and a small decrease in cancer knowledge over time, whereas the intervention group showed an increase in both beliefs and knowledge. There is a consistent trend that participants in the intervention group showed a larger increase over time in all four endpoints, compared to the control group. For example, the mean increase in satisfaction in the intervention group was 2.5 (Baseline: 14.8 to Follow-up:17.3) whereas the mean increase in the control group was 1.8 (Baseline: 15.9 to Follow-up:17.7). Analyses are continuing for these and other endpoints.

The tables below show the least-squares means and p -values from the mixed effects models.

Table 2. Primary Aim: Results of Mixed Effects Models for Repeated Measures

Table 2a. Satisfaction with Communication

	Control	Intervention	p-value
Visit	<i>mean</i>	<i>mean</i>	
Baseline	15.9	14.8	0.087
During treatment	16.5	16.3	0.755
End of treatment	16.5	15.8	0.425
Follow-up	17.7	17.3	0.418

Table 2b. FACT-G (health-related quality of life)

	Control	Intervention	p-value
Visit	<i>mean</i>	<i>mean</i>	
Baseline	75.4	75.5	0.979
End of treatment	76.2	79.0	0.464
Follow-up	84.4	86.6	0.516

Table 2c. Health Beliefs

	Control	Intervention	p-value
Visit	<i>mean</i>	<i>mean</i>	
Baseline	31.5	31.2	0.699
End of treatment	31.5	32.1	0.456

Table 2d. Cancer Knowledge

	Control	Intervention	p-value
Visit	<i>mean</i>	<i>mean</i>	
Baseline	8.0	7.8	0.564
End of treatment	7.6	8.5	0.099

Secondary Aim 1

To evaluate the relationships between patient characteristics, resources, needs, health behaviors and health outcomes using the Behavioral Model for Vulnerable Populations (Andersen, 1968; Andersen, 1995; Gelberg et al., 2000).

To date, we have conducted a series of mediation analyses (using multivariable linear regression models) to evaluate whether Health Literacy may be a mediator of the effects of patient characteristics on selected outcomes. This multi-step process is described below (Holmbeck, 1997; Evans, 1997).

First, the independent variable must be significantly associated ($p < 0.10$) with Health Literacy. Second, the independent variable must be significantly associated ($p < 0.10$) with the dependent variable. Third, Health Literacy must be significantly associated ($p < 0.10$) with the dependent variable. Fourth, there cannot be a statistically significant interaction between the independent variable and Health Literacy [note: we did not yet evaluate interaction]. Fifth, the effect of the independent variable on the dependent variable must be less after controlling for Health Literacy.

After adjustment for other covariates, the final models (see Table 3) suggested that Health LiTT was moderately associated with better health-related quality of life ($p = 0.10$), higher cancer knowledge ($p = 0.03$) and more adaptive health beliefs ($p = 0.11$). Health LiTT was not a mediator of the effects of covariates on the outcomes.

Table 3. Secondary Aim 1: Mediation Analyses

3a. Multiple linear regression

- separate sets of analysis for each outcome
- bivariate & multivariate models
- evaluation of health literacy as a mediator

Outcome measure	# items (response scale)	Mean (SD)	Score Range	Internal Consistency Reliability
Functional Assessment of Cancer Therapy-General (FACT-G)	27 (Likert)	75.2 (17.1)	0-108	0.73
Health Beliefs	10 (Likert)	28.4 (3.4)	10-40	0.65
Cancer Knowledge	11 (True/False/DK)	7.9 (2.5)	0-11	0.75
Satisfaction with Communication	6 (Likert)	15.3 (3.8)	0-18	0.93

Independent variables: Diagnosis, gender, race/ethnicity, insurance, age, education, financial difficulties, self-efficacy, clinic, information sources, decision-making preferences, health literacy

3b. Outcome: FACT-G

Independent variables	Parameter estimate Bivariate	Parameter estimate Multi-variable
Financial difficulties		
Not at all	8.78 ***	10.31 ***
Little bit	11.96 ***	10.64 ***
Somewhat	8.80 ***	9.68 ***
Quite a bit	1.88	8.10 **
Very much	----	----
CASE: positive attitude	3.56 ***	3.49 ***
Health LiTT	0.42 ***	0.28 **

* $p < 0.25$, ** $p < 0.10$, *** $p < 0.05$

Mediation analysis:

- CASE is significantly associated ($p < 0.10$) with Health LiTT
- Effect of CASE is not meaningfully lower after controlling for Health LiTT

3c. Outcome: Health Beliefs

Independent variables	Parameter estimate Bivariate	Parameter estimate Multi-variable
Education		
> H.S.	2.19 ***	1.81 ***
H.S./GED	1.76 ***	1.55 **
< H.S.	----	----
Health LiTT	0.09 ***	0.06 **

* $p < 0.25$, ** $p < 0.10$, *** $p < 0.05$

Mediation analysis:

- Education is significantly associated ($p < 0.05$) with Health LiTT
- Effect of Education is not meaningfully lower after controlling for Health LiTT

3d. Outcome: Satisfaction with Communication

Independent variables	Parameter estimate Bivariate	Parameter estimate Multi-variable
Cancer care center		
Traditional	2.62 ***	1.76 ***
Small safety net	0.82 ***	0.08
Large safety net	----	----
CASE: seek & obtain information	0.98 ***	0.82 ***
Talked to doctor for information		
A lot	2.88 ***	2.69 ***
Somewhat	0.59	1.11 *
Not at all, a little bit	----	----
Decision-making preference		
Self (consider doctor's opinion)	0.91	0.91
Shared	-1.47 ***	-1.80 ***
Doctor (doctor consider my opinion)	----	----

* $p < 0.25$, ** $p < 0.10$, *** $p < 0.05$

3e. Outcome: Cancer Knowledge

Independent variables	Parameter estimate Bivariate	Parameter estimate Multi-variable
Education		
> H.S.	1.79 ***	1.42 ***
H.S./GED	0.92 *	0.71 *
< H.S.	----	----
Health LiTT	0.08 ***	0.06 ***

* $p < 0.25$, ** $p < 0.10$, *** $p < 0.05$

Mediation analysis:

- Education is significantly associated ($p < 0.05$) with Health LiTT
- Effect of Education is not meaningfully lower after controlling for Health LiTT

Secondary Aim 2

To test whether use of the multimedia IT system improves patient outcomes regarding the early post-treatment surveillance period (three months after treatment).

The longitudinal analyses described in the section above included assessment data obtained during follow-up (the early post-treatment surveillance period). We developed software tools designed to help intervention arm participants in the transition between active treatment and follow-up care. The software includes a video module based on the NCI Facing Forward booklet (<https://pubs.cancer.gov/ncipl/detail.aspx?prodid=P119>). We are in the process of compiling usage statistics regarding how often patients viewed this video module.

Our research assistants completed the Survivorship Care Plans for several patients, using information they were able to obtain from chart review. It was not always possible for the research assistants to access the chart and to compile this information. The Care Plans were then given to the patient's treating oncologist, who had responsibility for finalizing the information and delivering it to the patient. Unfortunately, what we learned from our study is that physicians told us they did not have sufficient time to go over this plan with their patients. They all agreed on the importance of this component of care, but underestimated the amount of time that would be needed to deliver it to each patient.

Evaluation and Use of CancerHelp-TT

We administered several evaluation questionnaires to participants, by self- or interviewer-administration. We are continuing to compile and analyze these data. Table 4 shows that the CancerHelp-TT software was favorably rated by participants randomized to the intervention arm. In addition, most patients had no difficulty navigating CancerHelp-TT software, and most provided favorable ratings and comments:

"Great! It was easy to find the information I needed."

"It is easy to use. I don't need help. I can do it at my own pace."

"Great, it was so easy to use, you can move from one screen to the other without a problem."

"It was great. You have helpful information and it's easy to access the information I need."

"Educational, informational, and best of all easy to read and understand."

Usage data were collected by the software and we are in the process of fully analyzing these data. A total of 154 patient sessions occurred in the clinic; 59 of these sessions (38%) occurred at times other than scheduled study visits. This means that some patients returned to the kiosk to access the educational information on their own.

Table 4. Evaluation of CancerHelp Software (*n*=65 intervention arm)

	Bsln. (<i>n</i>=57)	During trt (<i>n</i>=61)	End trt (<i>n</i>=29)	F-up (<i>n</i>=23)
I found the information I wanted				
No/not as much as I wanted	---	16%	3%	4%
Yes, almost as much as I wanted	39%	42%	45%	39%
Yes, and as much as I wanted	61%	42%	52%	57%
CancerHelp was useful				
Not at all/a little bit	---	16%	14%	4%
Somewhat	37%	36%	28%	39%
A lot	63%	51%	59%	57%
Helped me better understand my disease and treatment				
Not at all/a little bit	2%	6%	14%	---
Somewhat	47%	38%	24%	43%
A lot	51%	56%	62%	57%
I will use CancerHelp again				
No	2%	---	---	---
Maybe	42%	49%	45%	70%
Definitely	56%	51%	55%	31%

Discussion

To our knowledge, this is the first study to integrate a novel multimedia system for self-administration of patient-reported outcomes and access to patient education information for patients with diverse literacy and computer skills in safety net facilities. The multimedia software

reduced reading level demands and was rated favorably by patients. Its usefulness was endorsed by clinicians, some of whom continue to make the software available to patients on the kiosk in their clinic. This study successfully integrated research activities into daily clinical practice at three cancer care centers for underserved patients.

Most patients who receive care in these safety net facilities do not have computers at home, and some of them requested a DVD. A CD-ROM was available and was provided to them, but a DVD had not been developed for this study. Although the software was available on a kiosk in the clinic at any time, cancer patients who are undergoing chemotherapy and/or radiation therapy may not always have additional time or energy to spend in the clinic.

Survivorship Care Plans were completed by research assistants and then given to the patient's treating oncologist, who had responsibility for finalizing the information and delivering it to the patient. Unfortunately, what we learned from our study is that physicians told us they did not have sufficient time to go over this plan with their patients. They all agreed on the importance of this component of care, but underestimated the amount of time that would be needed to deliver it to each patient. One of our co-investigators (Sofia Garcia, PhD) just received a grant from the American Cancer Society-Illinois Division to develop and implement a patient-centered Treatment Summary and Survivorship Care Plan intervention tailored to women completing in-clinic treatment for breast cancer in one of the safety net cancer care centers that participated in our C3 study (Mt. Sinai). This new grant will provide funding for a clinician to deliver the care plan to patients. The results and lessons learned in our AHRQ-funded C3 study will be very useful for this new project.

Longitudinal analyses were performed for four study endpoints to date: satisfaction with communication, health-related quality of life, health beliefs and cancer knowledge. Overall, there were no statistically significant differences between randomized groups at any assessments. In general, participants in both groups exhibited an increase over time in satisfaction and health-related quality of life. The control group showed no change in health beliefs and a small decrease in cancer knowledge over time, whereas the intervention group showed an increase in both beliefs and knowledge. There is a consistent trend that participants in the intervention group showed a larger increase over time in all four endpoints, compared to the control group. Analyses are continuing for these and other endpoints. For example, we plan to stratify patients by those who used the software only at a scheduled study assessment visit vs. those who also used it at other times. We hypothesize that more exposure to the educational software may be associated with better outcomes.

After adjustment for other covariates, we found that health literacy was moderately associated with better health-related quality of life, higher cancer knowledge and more adaptive health beliefs; it was not a mediator of the effects of covariates on the outcomes. The next steps will be to explore effects of health literacy to determine whether tailoring of the intervention is needed.

We are continuing to analyze the data for this study, and will continue dissemination activities. Several manuscripts are being developed, and we have two upcoming conference presentations (see below).

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List of Publications and Products

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Conference presentations

Hahn EA. Cancer Care Communication (C3): Enhancing patient-centered cancer care for vulnerable populations through the use of a low-literacy, multimedia IT system (AHRQ R18-HS017300). Agency for Healthcare Research and Quality 2008 Annual Conference: Promoting Quality...Partnering for Change, Bethesda, Maryland, September 9, 2008.

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Hahn EA. Enhancing patient-centered care for underserved populations through the use of a novel multimedia Health IT system. Agency for Healthcare Research and Quality 2011 Annual Conference: Leading Through Innovation & Collaboration, Bethesda, Maryland, September 19, 2011.

Hahn EA. The Talking Touchscreen (La Pantalla Parlanchina): Innovative Multimedia Methods for Health Outcomes Assessment and Patient Education in Underserved Populations. International Conference on Methods for Surveying and Enumerating Hard to Reach Populations, New Orleans, LA, November 3, 2012.

Conference presentations (upcoming)

Garcia SF. Cancer Care Communication (C3): A Low Literacy-friendly, Multimedia Information Technology System to Enhance Patient-centered Care. American Psychosocial Oncology Society (APOS) 10th Annual Conference, Huntington Beach, CA, February 14-16, 2013.

Garcia SF. Satisfaction with Cancer Care Communication in a Study of a Multimedia Patient Assessment and Education System. 34th Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine, San Francisco, CA, March 20-23, 2013.

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Electronic resources

Talking Touchscreen for assessment of patient-reported outcomes. Web-based questionnaire administration tool available through Assessment CenterSM.
<http://www.assessmentcenter.net/>

CancerHelp[®] Learning Program. Multimedia patient education modules available from the CancerHelp[®] Institute. <http://www.cancerhelp.org>