

The Talking Touchscreen: A New Approach to Outcomes Assessment in Low Literacy

Short title: **The Talking Touchscreen**

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ABSTRACT

Purpose: Cancer patients who are deficient in literacy skills are particularly vulnerable to experiencing different outcomes due to disparities in care or barriers to care. Outcomes measurement in low literacy patients may provide new insight into problems previously undetected due to the challenges of completing paper-and-pencil forms.

Description of Study: A multimedia program was developed to provide a quality of life assessment platform that would be acceptable to patients with varying literacy skills and computer experience. One item at a time is presented on the computer touchscreen, accompanied by a recorded reading of the question. Various colors, fonts and graphic images are used to enhance visibility, and a small picture icon appears near each text element allowing patients to replay the sound as many times as they wish. Evaluation questions are presented to assess patient burden and preferences.

Results: An ethnically diverse group of 126 cancer patients with a range of literacy skills and computer experience reported that the “talking touchscreen” (TT) was easy to use, and commented on the usefulness of the multimedia approach.

Clinical Implications: The TT is a practical, user-friendly data acquisition method that provides greater opportunities to measure self-reported outcomes in patients with a range of literacy skills.

Key Words: low literacy; vulnerable populations; quality of life; touchscreen computer; cancer

INTRODUCTION

As patient-reported outcomes play an increasing role in medical decision-making and evaluation of healthcare, effective methods for measuring those outcomes among vulnerable populations must be developed and validated. Patients with a chronic or terminal illness, those with limited literacy or English language skills, and ethnic minorities are particularly vulnerable to receiving sub-optimal care and may experience different health outcomes due to disparities in care or due to barriers to care (1,2). Outcome measurement in these patients may provide new insight into disease or treatment problems that may have gone undetected simply because many studies have not been able to accommodate the special needs of such patients. This article briefly summarizes the literature available on the association between literacy and health outcomes, identifies the need for innovative approaches to outcomes assessment in vulnerable populations, describes the development and testing of a new multimedia program for quality of life assessment, and offers suggestions for using innovative technologies to enhance communication with diverse patient populations.

BACKGROUND

Low Literacy and Health Outcomes

Low literacy is a widespread but neglected problem in the United States. The 1992 National Adult Literacy Survey (NALS) measured common literacy tasks that adults encounter in daily life (3). Results from the NALS suggest that approximately 44 million Americans are functionally illiterate in the English language, e.g., unable to locate information in brief sample text and documents, and another 50 million have marginal literacy skills, e.g., unable to

synthesize information from complex or lengthy texts, or perform quantitative tasks involving two or more sequential operations (3). This means that almost half of the adult population experiences difficulty in using reading, speaking, writing and computational skills in everyday life situations. "Health literacy," the constellation of skills required to function in the healthcare environment, may be significantly worse than functional literacy because of the unfamiliar context and vocabulary of the healthcare system (4).

In 1992, the National Cancer Institute established the National Work Group on Literacy and Health (5) to focus attention on communication difficulties associated with limited literacy skills. Low literacy has been shown to be associated with poorer physical health (6,7) and with advanced stage prostate cancer at presentation (8); these associations persist even after adjustment for demographic and socioeconomic indicators, including years of education. The NALS found that 75% of American adults with a physical or mental health condition scored in the two lowest literacy levels (3). Low literacy may also result in higher healthcare costs due to ineffective healthcare, poorer health status or higher hospitalization rates (6).

Years of education have been weakly associated with poor health, including cancer mortality (9). However, literacy and years of formal education are only modestly correlated (3, 10,11) and the association between education and health may disappear after adjusting for literacy (6,8). Years of education reflect the educational level attempted, but literacy is an indicator of the educational level attained. Literacy is thus a better indicator of the ability to acquire new knowledge and cope with societal demands (6).

Although the majority of adults with poor literacy are white, native-born Americans, ethnic minorities are disproportionately represented (6,10). Using a multilingual test of functional health literacy, Williams and colleagues (11) reported that over one-third of English-

speaking patients and nearly two-thirds of Spanish-speaking patients at two public hospitals had inadequate or marginal health literacy. For example, some were unable to understand information regarding medication directions, appointments and informed consent. Barriers to healthcare and poorer health outcomes have been consistently reported for Latino patients with poor English language skills (12-15).

One of the key outcome measures being evaluated in current research is perceived health status, or quality of life (QOL), a recognized and highly-valued endpoint of care (16).

Administration of QOL questionnaires is usually performed with paper-and-pencil instruments, and multilingual versions of questionnaires often are not available. Interviewer administration is labor-intensive and cost-prohibitive in most healthcare settings. Therefore, patients with low literacy or those who do not speak English are typically excluded from any outcome evaluation where patient-reported data are collected on forms. Although a number of QOL studies in cancer survivors have been conducted, inadequate attention has been devoted to the specific needs of cancer survivors in ethnic minority and medically underserved communities (17,18). Our knowledge about QOL in these individuals is subsequently limited.

Computer Technology and Its Application to Healthcare

Computerized assessment of patient-reported outcomes provides an innovative method for gathering and using self-report data (19,20) and may be feasible for individuals with limited literacy skills. Computer-based testing has been successfully implemented in clinical settings, and debriefing interviews have revealed a high level of acceptability by patients, even by those who are very ill or inexperienced in the use of computers (21-28). All of these applications,

however, have been accessible only to respondents who can read the text on the screen, or who have someone to read it aloud to them.

Recently, audio components have been added to computer-based assessment to administer survey questions about sensitive behaviors in an audio format and record responses without an interviewer (29). Respondents across the range of literacy can thus answer questions in complete privacy, even if their reading ability is limited (30). In light of research findings that many low literate patients are ashamed of their reading deficiencies and would prefer not to disclose them (31,32), a standardized approach across levels of literacy has the added advantage of reducing the stigma of low literacy. There is also anecdotal evidence that adding an audio component enhances the concentration of respondents with good reading skills (33). This article describes the development and testing of the Talking Touchscreen: a multimedia program that makes QOL assessment more accessible to patients with low literacy skills, including those who are functionally illiterate. We sought to provide a simple and efficient administration method that can be incorporated into a busy clinical setting with minimal burden on staff and patients.

METHODS

Instruments

Patient-rated QOL is typically assessed in one of two ways: 1) health status questionnaires that evaluate multiple dimensions of health and well-being from the patient's perspective; and 2) health utility measures that are used for decision analysis and cost-utility studies. While there are a number of reliable and valid QOL questionnaires, there is no gold standard, and selection of the most appropriate one depends on the characteristics of the

population and the purpose for measurement. We selected two widely used health status instruments for this study: the Functional Assessment of Cancer Therapy-General (FACT-G; 34,35) and the Short Form-36 Health Survey (SF-36; 36). All of the FACT-G items and most of the SF-36 items were written at or below the sixth-grade reading level (37). We also selected a preference-based measure of QOL. These three instruments are briefly described below.

The FACT-G is the cornerstone of the Functional Assessment of Chronic Illness Therapy (FACIT; 35) measurement system which is a multi-item compilation of a generic chronic illness questionnaire (now 27 items) and many specific subscales which reflect issues or problems associated with different diseases. There are over 300 items in the FACIT system and each is in the form of a statement, e.g., "I have pain", "I get emotional support from my family", "I worry that my condition will get worse", "I am able to enjoy life." The rating scale for all items is comprised of five Likert-type response categories: "not at all", "a little bit", "somewhat", "quite a bit" and "very much." The FACIT instruments have established reliability and validity, including sensitivity to change (34,38-41). Scores are available for total QOL and the dimensions of physical well-being, social/family well-being, emotional well-being, functional well-being, and disease-specific concerns.

The SF-36 Health Survey is a 36-item measure of eight health concepts and two higher order dimensions (36). The questions ask about limitations in physical activities, social activities and usual role activities ("Does your health now limit you in...lifting or carrying groceries...?"), or general health concerns ("How much bodily pain have you had during the past 4 weeks?"). Some questions use yes/no response categories, others have Likert-type responses ("yes, limited a lot", "yes, limited a little", "no, not limited at all"), and some are phrased as true/false

statements. Numerous studies have been published documenting its reliability and validity (42,43).

Utilities are preference-based measures of QOL that are designed to reflect the patient's value for her/his current health state, and are most typically used to adjust the life years saved by a treatment in cost-utility analyses. The standard gamble (SG) method is often preferred because it is the only approach that directly conforms to vonNeumann Morgenstern expected utility theory (44,45). Mortality risk inherent in medical decision-making is an integral part of the SG utility interview. Assessment of SG utilities is generally conducted with paper forms and visual aids, usually by interview but occasionally by self-administration (44,46). We adapted a Standard Gamble Utility Questionnaire (SGUQ) for this project. Patients are asked up to ten questions regarding their preference for their current state of health or an imaginary treatment that carries with it a stated risk of immediate death. The probability of immediate death is increased in increments of ten percent each time a respondent indicates a preference for the imaginary treatment. The assessment stops when the patient is unwilling to accept additional risk, or is indifferent to the alternatives.

Development of the Talking Touchscreen

A multimedia program developed by Assist Technologies (Scottsdale, AZ) was modified to create a user-friendly QOL assessment that would be acceptable to patients with varying literacy levels and computer experience. The program was installed on a portable touchscreen computer with a 12-inch monitor (Javelin LCP) and audio headset. Patients interact only with the touchscreen, rather than a keyboard, which may be intimidating for computer novices. As each question is displayed on the touchscreen, it is automatically read out loud. To answer,

respondents touch a "button" on the touchscreen monitor and their response is automatically highlighted which provides visual confirmation of their choice. Figure 1 shows screen images from different parts of the program. The first screen (Figure 1A) has a brief set of instructions describing the sound and touchscreen features of the program. Figure 1B shows one item from the FACT-G and Figure 1C shows one of the SGUQ screens. The text for each questionnaire element (instructions, items, response categories) appears on the screen in different colors and boxes, and a small picture icon (a picture of an ear) appears near each text element. Patients may touch the screen icons as many times as they wish in order to replay the sound for each element and can adjust the volume on the headset as needed. They may also remove the headset and respond to the visual presentation of the question rather than waiting until the audio reading has been completed. Previous responses can be changed by the patient at any time. Patients are also permitted to skip a question if desired, although they must confirm this choice.

Figure 1 here

The FACT-G and the SF-36 had both been previously adapted for computer administration, and only slight modifications were made for this project, e.g., simplified instructions, one item per screen. Conversion of the SGUQ to the computer required the addition of visual aids to illustrate the concept of probability (e.g., two out of ten people dying is represented by blocking out two of ten figures appearing on the screen; see Figure 1C). Programming logic allows for the unique design of the questionnaires where, depending on the response (take the pill, not take the pill, indifferent), the program proceeds to the next question or terminates the SGUQ.

Patient Recruitment

This ongoing project is being conducted at three cancer care centers in the Chicago area with adult patients who provide signed, informed consent in accordance with local institutional review boards and the U.S. Department of Health and Human Services guidelines. We also conducted limited pilot testing with six clients at a local literacy tutoring organization. These participants provided verbal informed consent as approved by the organization's review board. Study identification numbers are used to protect confidentiality, and interviewers record information about gender, age, ethnicity, education and cancer diagnosis. Eligibility criteria are broad to ensure maximum generalizability: any type or stage of cancer, any treatment status, English language preference, and sufficient ability to see, hear and interact with a computer touchscreen and headset. A purposeful sampling strategy is used to balance the number of low and high literacy patients. Specifically, study enrollment is offered to all patients with limited formal education (high school equivalency or less), and to every fourth patient with higher education. After enrollment, patients complete a brief reading comprehension test that is later scored to classify their literacy level (47). Those reading at or below the sixth-grade level are classified as low literate. This cut-off was chosen to correspond to the reading level of the QOL questionnaires.

QOL Assessment

Study interviewers spend approximately five minutes instructing participants in the use of the headphones and sitting with them during a brief practice session consisting of two sample questions. The interviewers then allow the participants to complete the QOL assessment on their

own, but remain nearby in case further assistance is needed. After the practice session, the participant completes the FACT-G (27 items) and the SF-36 (36 items), in random order, followed by the SGUQ. The six literacy tutoring clients completed only the SF-36. A set of four evaluation questions is presented after each questionnaire: 1) "Did the survey ask important questions?" (yes, somewhat, no); 2) "How easy was it to understand?" (very easy, easy, hard, very hard); 3) "How easy was it to do?" (very easy, easy, hard, very hard); 4) "Was the survey too personal?" (yes, somewhat, no). At the end of the assessment, participants answer additional evaluation questions on the computer and by the interviewer. The interviewer later records the amount of help s/he provided with the use of the touchscreen and with the survey questions using a four-point scale (none, some, a lot, continuous help).

Data Analysis

Sociodemographic and interview data are entered into a relational database. Data from the touchscreen program are imported into the database, and a SAS (48) dataset is then created. Descriptive summaries of the variables were generated for this report, and standard statistical tests for continuous and categorical data were used to compare the responses of low and high literacy patients.

RESULTS

We enrolled 34 participants for the pilot testing phase of the project (28 cancer patients and six clients from a literacy tutoring program). Literacy level was not measured, but we did enroll participants across a wide range of educational levels; for example, 38% did not complete high school and 15% had a college degree. Participants also differed in terms of previous

computer experience: 26% had never used a computer before and 35% used one almost every day. The 20 women and 14 men ranged in age from 21 to 78 years, and nearly half were ethnic minorities. The cancer patients had a variety of diagnoses. After minor touchscreen programming modifications, recruitment for the main study started in August 2000. Among 319 patients approached, 126 (40%) were enrolled and 108 (34%) either did not meet eligibility criteria or were excluded due to high levels of formal education. The remaining 85 patients refused to participate, citing time constraints as the most common reason ($n=41$). The first 126 patients were predominantly female (70%) and ethnic minorities (71%), with a mean age of 51 years (Table 1). Nearly 40% had never used a computer before. Although most patients had attended high school, 51% have been classified as low literate, i.e., reading at or below the sixth-grade level. Half of the Latino patients, 62% of the African-American patients and half of all other patients have been classified as low literate.

Table 1 here

Study interviewers reported that 39 patients (31%) did not require any help using the touchscreen, including seven who had never used a computer before. The remaining patients needed "some" (59%) or "a lot" (10%) of assistance, primarily at the beginning of the assessment. Most commonly, some respondents touched the ear icon, which repeats the sound for a particular response choice, instead of touching the response button itself (see Figure 1). The interviewers simply explained these features again and most patients were able to complete the assessment on their own. A small number of patients ($n=12$) required additional assistance and the interviewers reported that many of these patients appeared to simply need reassurance

while using this new technology. Computer problems such as “freezing up” were rare and were easily solved by restarting the system. In most of these cases, the software program saved existing data and brought the patient back to the place where s/he previously left off.

All but six patients reported that the touchscreen was easy or very easy to use (Table 2). Nearly everyone also reported that the health status questionnaires (FACT-G and SF-36) and the SGUQ were easy/very easy to do (Table 2). When asked about preferences, the majority of the low (69%) and high literacy (59%) patients preferred using the touchscreen rather than having an interviewer ask the questions ($p=0.172$). Average completion time was 33 and 28 minutes for low and high literacy patients, respectively ($p=0.041$), and over 80% in each group said that the assessment was not too long (results not shown). Most also said they usually would have enough time to do the assessment while waiting to see the doctor (Table 2). Only 17 patients said they would not be willing to do future assessments. This question was administered by the computer, so we do not have an explanation for this response. Individual item response was nearly 100%; in other words, patients rarely left an item blank. Several patients commented on the usefulness of the multimedia approach:

- "Hearing it and reading it helps."
- "I liked the fact that it was visual and auditory."
- "Comfortable - good combination."
- "[The sound] helps you concentrate better."
- "The sound is very helpful because I don't read too good and listening to the recording really helps."
- "Listening to the questions makes it easier for me."
- "Gives you more privacy."

Table 2 here

One of the primary study aims is to test the equivalence of QOL assessment across low and high levels of literacy. After completion of the study ($n=400$), psychometric measurement equivalence will be evaluated to determine whether health status items perform similarly across literacy levels. Statistical equivalence will be evaluated to determine if literacy level independently contributes to differences in health status and preference-based QOL scores. These analyses will be reported at a later date.

DISCUSSION

The ability to read and write English is a common inclusion criterion for most research studies in the U.S. that assess QOL and other patient-reported outcomes. Low literate and non-English-speaking patients often are excluded from these studies because they are unable to complete the required set of questionnaires. Our knowledge about QOL in these individuals is subsequently limited. To improve methods for obtaining self-report data from cancer patients with low literacy, we successfully developed and tested a multimedia program for QOL assessment. An ethnically diverse group of participants with a range of literacy skills, education levels and computer experience reported that the touchscreen computer and questionnaires were easy to use and understand, and commented on the usefulness of the multimedia approach. Most said they would be willing to complete a QOL assessment each time they visit the doctor.

As reforms in healthcare are implemented, more patients who previously received care only in the public sector will receive care in the private sector, which means that more providers

will become involved in treating low literacy patients (49). In addition, research on the relationship between literacy and health has been limited, thereby making it difficult to determine the direct and indirect causal pathways linking literacy and health outcomes (4). The Talking Touchscreen (TT) will allow low literacy patients to be included more readily in clinical trials, clinical practice research, QOL studies and health promotion/disease prevention initiatives.

Physicians, nurses and patients express interest in incorporating QOL assessment into clinical practice, yet barriers remain, including the time, effort and cost required to accomplish valid assessment, and interpretation of the data (50-53). The TT is a practical, user-friendly data acquisition method that provides greater opportunities to assess patient-reported outcomes. Future research plans include the addition of an automatically-generated summary report that will provide information for use in the same clinical encounter and the ability to track outcomes over time.

The TT also may provide appropriate communication tools for healthcare providers and organizations as they incorporate cultural competency principles into health services delivery practices for minorities and underserved groups (54). Available research suggests that Latinos and persons with low socioeconomic status are less likely to access appropriate and preventive healthcare, and may be less likely to comply with treatment and healthy behavior changes (55). The TT is currently being adapted for Spanish-speaking patients, and could be adapted for use in health promotion and risk identification/screening programs. Culturally appropriate communication interventions can raise awareness of health problems and recommended actions, and provide information needed for informed decision-making (56). Interactive health communications such as the TT have the potential to simultaneously improve health outcomes, decrease healthcare costs and enhance patient satisfaction (57).

Our initial data suggest that patients would be willing to participate in QOL assessments and that it is feasible to implement the TT in clinical settings. In terms of costs, the software (license fee approximately \$2,000 per year) can be installed on a standard touchscreen computer with a sound card (approximately \$2,100). Text and sound files for other questionnaires can be added by local data management/programming staff (effort approximately 0.10 FTE (full-time equivalent)). Further study is required, and is planned, to determine whether the use of the TT in clinical settings will be cost-effective. This will include measuring the costs of its use in different settings and its direct benefits, including improved satisfaction with medical care and possibly improved QOL.

CONCLUSIONS

Results from this ongoing, federally funded outcomes research study suggest that it is feasible to implement computerized QOL assessment with low literate cancer patients. This will provide greater opportunities to evaluate measurement properties of self-report instruments in this important and large vulnerable population, and to further investigate the association between literacy and health outcomes. Thus, the TT has the potential to improve the method of outcomes assessment and the usefulness of self-report data.

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Table 1. Characteristics of Study Participants (n=126)

	<i>n</i> (percent)
Current Diagnosis	
Breast cancer	50 (39.7)
Lung cancer	15 (11.9)
Ovarian or cervical cancer	12 (9.5)
Lymphoma or Myeloma	11 (8.7)
Colorectal cancer	14 (11.1)
Other cancer	21 (16.7)
Not applicable/missing	3 (2.4)
Gender	
Female	88 (69.8)
Male	38 (30.2)
Age in years	
Mean [SD]	50.9 [13.7]
Range	21 - 80
Ethnicity	
Asian or Pacific Islander	1 (0.8)
Black/African-American	70 (55.5)
Hispanic/Latino	16 (12.7)
White, Non-Hispanic	37 (29.4)
Other	2 (1.6)
Education	
0 – 6th Grade	7 (5.6)
7th – 8th Grade	8 (6.3)
Some High School	35 (27.8)
High School Grad/GED	44 (34.9)
Some College, Jr. College Degree	19 (15.1)
College Degree	13 (10.3)
Literacy Level	
Low (< 7 th -grade reading comprehension)	64 (50.8)
High	50 (39.7)
Pending classification	12 (9.5)
Previous Computer Experience	
None	49 (38.9)
A few times/year	18 (14.3)
Every month/week	31 (24.6)
Almost every day	25 (19.8)
Unknown	3 (2.4)

Table 2. Evaluation of the Talking Touchscreen (n=126)

How hard was it for you to use the touchscreen?	<i>n</i> (percent)
Very easy	51 (40.8)
Easy	68 (54.4)
Hard	5 (4.0)
Very Hard	1 (0.8)
How easy was it to do the FACT-G?	
Very easy	81 (64.8)
Easy	39 (31.2)
Hard	5 (4.0)
Very hard	---
How easy was it to do the SF-36?	
Very easy	78 (62.9)
Easy	43 (34.7)
Hard	2 (1.6)
Very hard	1 (0.8)
How easy was it to do the Standard Gamble Utility Questionnaire?	
Very easy	59 (48.8)
Easy	52 (43.0)
Hard	8 (6.6)
Very hard	2 (1.6)
Preference	
Prefer touchscreen	78 (64.4)
Prefer interviewer	14 (11.6)
No preference	29 (24.0)
Would you have enough time to do the surveys while waiting to see the doctor?	
Yes	54 (44.6)
Sometimes	57 (47.1)
No	10 (8.3)
Would you be willing to do the surveys each time you visit the doctor?	
Yes	46 (38.0)
Sometimes	58 (47.9)
No	17 (14.1)

Missing responses were excluded from this table.

Figure 1. Screen Images from the Talking Touchscreen: A) Instructions; B) One item from the FACT-G; C) One question from the Standard Gamble Utility Questionnaire.



**This program will read each question and answer out loud.
Touch an ear to hear that question or answer again.
Touch a gray button to select your answer or to skip to the next screen.**



Next Question -->

I am content with the quality of my life right now.



Not at all

A little bit

Somewhat

Quite a bit

Very much



<- Previous Question



Next Question ->



Would you take the imaginary pill that could give you perfect health for the rest of your life, if you knew that 2 out of 10 people who take the pill will die immediately? OR Would you prefer not to take the imaginary pill, and therefore stay in your current state of health for the rest of your life?

I would take the pill.

I would not take the pill.

I think that the 2 choices are equal.



Next Question -->