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Developing a Computer Touch-Screen Interactive Colorectal Screening Decision Aid for a Low-Literacy African American Population: Lessons Learned

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Abstract

African Americans have higher colorectal cancer (CRC) mortality than White Americans and yet have lower rates of CRC screening. Increased screening aids in early detection and higher survival rates. Coupled with low literacy rates, the burden of CRC morbidity and mortality is exacerbated in this population, making it important to develop culturally and literacy appropriate aids to help low-literacy African Americans make informed decisions about CRC screening. This article outlines the development of a low-literacy computer touch-screen colonoscopy decision aid using an innovative marketing method called perceptual mapping and message vector modeling. This method was used to mathematically model key messages for the decision aid, which were then used to modify an existing CRC screening tutorial with different messages. The final tutorial was delivered through computer touch-screen technology to increase access and ease of use for participants. Testing showed users were not only more comfortable with the touch-screen technology but were also significantly more willing to have a colonoscopy compared with a “usual care group.” Results confirm the importance of including participants in planning and that the use of these innovative mapping and message design methods can lead to significant CRC screening attitude change.

Keywords

colorectal cancer (CRC); screening; colonoscopy; computer touch-screen; perceptual mapping

INTRODUCTION

Colorectal cancer (CRC) is the third leading cause of cancer death in the United States; however, survival rates are high if detected early through screening techniques such as colonoscopy (Cokkinides, Bandi, Siegel, Ward, & Thun, 2008; Winawer et al., 2003). African Americans, however, exhibit significantly lower rates of screening behavior and

have significantly higher CRC mortality (Centers for Disease Control and Prevention, 2007). Specific barriers to screening have been elucidated in a number of studies (James, Campbell, & Hudson, 2002; Katz et al., 2004; Palmer, Midgett, & Buadoo, 2008), indicating the need to develop specific messages to address these barriers. Tailored messaging has a long history as a health communication technique and has been used in encouraging CRC screening in minority populations with some success (Basch et al., 2006; Holt et al., 2011; P. D. Morgan, Fogel, Tyler, & Jones, 2010; Powe, Ntekop, & Barron, 2004). Despite these successes, communicating CRC risk is especially challenging for patients with low literacy, many of whom are older minorities (Greiner, Born, Nollen, & Ahluwalia, 2005). Our goal was to create a tailored decision aid for this population to encourage understanding of the benefits of colonoscopy and to communicate CRC risk by using perceptual mapping and vector analysis methods, applying them through computer touch-screen (CTS) technology. These methods yield three-dimensional computer models that represent how a survey group conceptualizes decision elements—in this case, the perceived risks and benefits of colonoscopy—and mathematically models messages designed to “move” a person to a desired action (intent to have colonoscopy). Though used in marketing (M. G. Morgan, Fischhoff, Bostrom, & Atman, 2002), these methods have seen only limited application as a way to customize health information to a particular group. Perceptual mapping is grounded in two theoretical frameworks: (a) *illness self-regulation theory* (Cameron & Leventhal, 2003; Leventhal, Leventhal, & Cameron, 2001) and (b) *information-communication theory* (Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004; Woelfel & Fink, 1980), both based on the individual’s conceptual map or model of health threatening situations. *Illness self-regulation theory* contends that when individuals are confronted with a health crisis (disease or health threat), they form a mental representation of the condition, what caused it, what its effects might be, how long it might last, and how to control it. These conceptualizations are what Leventhal et al. call the individual’s “common-sense model” of the illness. Individuals then appraise various coping strategies. Based on these concepts, perceptual mapping provides a valid representation of how people conceptualize the elements that constitute the most salient factors associated with their likelihood of performing the desired action, or with the cognitive and tangible barriers to the behavior, which allows us to more effectively develop tailored decision aids to address them and “move” the individual toward the desired decision.

The feasibility of using CTS technology to foster behavior change in low-adherence populations has been demonstrated as an effective health communication strategy. CTS can be connected to any computer to allow users to touch the screen as the program directs instead of using a mouse. A special driver translates the touch into something the operating system can understand, much as a computer mouse driver translates a mouse’s movements into a click or drag. This can be especially useful for addressing sensitive topics such as CRC screening because an intervention can be administered privately. Generally preferred over pamphlets and leaflets by users (Graham et al., 2010), research using this technology has found it to be useful in motivating behavior change and influencing treatment decisions, as well as increasing knowledge, self-efficacy, and adherence, particularly in primary care settings (Berry et al., 2010; Graham et al., 2010; Lawrence et al., 2010; Lin, Neafsey, & Anderson, 2010). Although little research with CTS has been done specifically with low

literacy populations, CTS is an ideal tool in that it does not require knowledge of computers and mimics common everyday tasks such as using a bank ATM machine. There is also the ability to provide voice-over via built-in speakers, which further alleviates literacy barriers.

Our goal in using these innovative methods to create the colonoscopy CTS tutorial was to strengthen the connection between the decision aid framing/content and the subjects' mental maps of the risks and benefits of colonoscopy. This article outlines the process by which this computer touch-screen decision aid was developed, results of its use, and the lessons learned.

METHODS

Several methods were used to develop the CTS tutorial, including focus groups, survey data, segmentation analysis, perceptual mapping, and vector modeling (see Figure 1).

Survey Data Collection

To develop the messages we first surveyed 102 low literacy African Americans between the ages of 50 and 74 years at a General Internal Medicine Clinic in a large urban teaching hospital over an 8-week period. Research assistants used scheduling records from the clinic to determine eligibility and obtain a convenience sample of patient participants to complete the survey. Literacy level was established using the eight-item standardized Rapid Estimate of Adult Literacy in Medicine–Revised (REALM-R; Davis et al., 1993) and participants who scored a 6 or below were eligible for the survey. The survey was written at a sixth-grade reading level, but each question on the survey was read aloud by the research assistant. Each survey took approximately 20 minutes to administer and participants received a gift card as an incentive.

Questions for the survey were developed from our prior work involving: (a) focus groups conducted with low-literacy African American patients (Bass et al., 2011), (b) in-depth interviews with third-year residents in the Internal Medicine Department (Ward et al., 2010), and (c) an extensive review of the available research literature on CRC screening (Ward et al., 2008). The questions on the survey fell into three categories: (a) personal attitudes and preferences regarding preventive screening and health maintenance (11 questions), (b) perceived barriers to having a colonoscopy (16 questions), and (c) perceptions of colonoscopy (8 questions; see Table 1). Patient participants were asked to rate how much they agreed or disagreed with each of the statements in the three question blocks of the survey. All questions and procedures were approved by the university's institutional review board.

Segmentation Analysis to Develop a Patient Typology

Before perceptual mapping and vector modeling were conducted, we used a *k*-means cluster analysis procedure (SPSS statistical package version 19.0) to assess whether patient attitudes related to screening differed significantly enough to identify subgroups within the patient sample. The variables specified for clustering included 11 questions involving personal behaviors, attitudes, and preferences linked to health maintenance and preventative screening in general and colonoscopy specifically. This analysis found that there were three

distinct cluster groupings, each of which was named to reflect their distinct characteristics: *Ready Screeners* (50%), *Fearful Avoiders* (30.4%), and *Cautious Screeners* (19.6%). Figure 2 presents the survey mean values across these three clusters.

As illustrated in Figure 2, the *Ready Screeners* are characterized by a willingness to go to the doctor, an openness to having preventive testing to find medical problems early, and an overall sense that screening is “worth the effort.” The *Ready Screeners* strongly agree that screening is a way to stay healthy and that if they had cancer they would want to know. They would comply if their doctor recommended screening and they do not need to be pushed by family or friends to be screened. This group strongly believes that if they get cancer, it is “God’s will.” Overall, the *Ready Screeners* trust the medical establishment, are very positive about the benefits of screening, and display few barriers to having a colonoscopy. The majority (65%) had, in fact, had a colonoscopy. The main message strategy to motivate this group is to emphasize that doctors recommend colonoscopy and that it is worth the effort.

Approximately one third of the sample (30.4%) was categorized as *Fearful Avoiders*. This group differed from the first in that they have a strong dislike of doctors and medical procedures. They not only profess a dislike of medicine but they also trust their bodies to tell them if there is a problem, making preventive screenings unnecessary. This self-trust appears to mask an overall fear of having medical tests and also a fear of receiving a cancer diagnosis—reflected in their agreement with the statement that “I would rather not know if I have cancer.” Although they agreed that screening tests are “worth the effort” and should be done to stay healthy, especially if a doctor recommends them, few have acted accordingly—with only 24.3% of this cluster having had a colonoscopy. Similar to the *Ready Screeners*, the *Fearful Avoiders* also believe that getting cancer is “God’s will.” This may indicate a deep spiritual belief often seen in older African Americans (Hamilton, Crandell, Carter, & Lynn, 2010). Message strategies to motivate this group include emphasizing the importance of having a colonoscopy and its accuracy, that it is better to know you have cancer because screening can detect it early enough to be cured and that family members would want you to be screened to be healthy.

The final cluster, *Cautious Screeners*, represented 19.6% of the sample. This patient type is similar to the *Ready Screeners* in many ways. They see screening tests as valuable and “worth the effort.” They also strongly believe that screenings help a person “stay healthy.” The main difference between this cluster and the *Ready Screeners* is that they are more likely to say they do not like going to the doctor—though less so than the *Fearful Avoiders*. The *Cautious Screeners* also do not feel overly influenced by a doctor’s recommendation or by pressure from family or friends to be screened. This group was “cautious” in that they want to make their own decisions regarding health and, while they did not mind going to and talking with a physician, a physician’s recommendation for screening is not their primary motivator to action. In addition, this is the only group that disagreed with the statement “Getting cancer is God’s will,” reflecting their independence of thought regarding illness and their health. More than half of the *Cautious Screeners* (57.6%) had already had a colonoscopy. The main message strategy recommendation for this group is to emphasize the importance of making a decision that could positively affect their health.

Perceptual Mapping

Based on the cluster analysis results we developed perceptual maps and performed message vector analyses for each of the three cluster groups (Figure 3). These techniques use multidimensional scaling methods to yield a graphic three-dimensional, multicolored display of how respondents perceive the relationships among a set of elements (Cox & Cox, 2000). This allows us to study how framing effects, perceptions of risks/ benefits, and attitudes toward risk contribute to cognitive and affective dimensions of decision making. The resulting maps reflect how the decision elements are conceptualized relative to each other and relative to “Self,” a group average. This paper-and-pencil assessment method is easy to use and does not require those with low literacy to make complicated or abstract decisions.

Perceptual mapping techniques have a solid history as mathematical modeling tools (Borg & Groenen, 1997; Gardenfors, 2000). In some disciplines (e.g., geography), the term *cognitive mapping* is used to describe the maps people carry in their heads of geographic areas (Herschfeld & Gelman, 1994; Kitchin & Freundschuh, 2000). *Perceptual mapping* is the term used in psychology, marketing, sociology, and political science when using multidimensional scaling to model fundamental social-psychological processes. The more user-friendly versions of software for these mapping techniques have evolved since the 1970s and have been used in a variety of commercial and educational contexts (Barnett & Boster, 1997; Leventhal et al., 2004; Woelfel, 1995) but have not been used extensively in health and risk communication except by study authors (Bass, Gordon, Ruzek, & Hausman, 2008; Ruggieri et al., in press). Our approach is based on the perceptual mapping methods and influence strategies initially set forth by Joseph Woelfel and Edward L. Fink (1980) in the combined theory and methodology they term *Galileo*. Our computer software program converts the scaled judgments into distances and assembles the map elements into a structural whole. Input associations among the risks/benefits are derived from the interitem correlations of all elements, where the absolute values of the correlations are converted to a 0 to 10 scale base. The software then performs a metric multidimensional scaling analysis and produces graphic arrays of the distances among the elements. The graphic plots can be displayed in two or three dimensions for visual interpretation (see Figure 3). The percentage of variance accounted for by each model is provided as an index of the explanatory power of the map. The resulting maps thus display the risk/benefit elements relative to each other, and to “Self.” Essentially, the maps provide a snapshot of the respondents’ conceptualization of the situation, and reveal the relative importance of different decision elements.

Vector Modeling

Once perceptual maps are developed, vector analytic procedures are applied to determine a message strategy. To optimally position the target concept in the perceptual space, target vectors (dotted lines in Figure 3) are used to start the mathematical vector resolution process. By specifying the target vector and the number of concepts to be used in the final message, the software creates all possible vector resolutions, using the specified number of concepts, then rank orders the solutions for best fit to the target vector. Figure 3 depicts how different clusters thought about colonoscopy and what barriers or facilitators may exist in the decision making process. The vectors identify optimum message associations for moving respondents (the aggregated “Self”) within the model. These message strategies involve the

dynamics of “pulling” concepts closer together by emphasizing their association, or “pushing” concepts farther apart by emphasizing their differences. The final form of the message (content, wording, imagery, and format) is then constructed to include and illustrate the concepts identified as optimal for addressing the respondent’s concerns, knowledge, and perceptions of the risks/benefits. (For further details about our use of the perceptual mapping approach, see <http://chpsw.temple.edu/publi-chealth/research-centers-and-labs/risk-communication-laboratory-rci>)

Development of Tutorial

Vector modeling produced key message strategies to address all three clusters, but because we could not create three separate decision aids we focused on a message strategy that would be applicable for all clusters. Specifically, we focused on the following messages, addressing the most significant barriers and facilitators of the three clusters to mathematically “move” the groups to being more willing to have a colonoscopy. They were as follows:

- a. Importance of going to the doctor and getting a recommendation.
- b. Importance of having a colonoscopy and its accuracy.
- c. That having a colonoscopy is “worth the effort.”
- d. That it is better to know if you have cancer and not to fear it.
- e. That family is important and would want you to be tested.

Using these messages as the focus of the tutorial, we partnered with the Patient Education Institute, whose mission is to develop, implement, and evaluate interactive patient education tutorials. Their *X-Plain* tutorial series consists of the largest library of theory-based interactive multimedia tutorial programs available for patient education (<http://www.patient-education.com/>), and are implemented in a variety of settings including hospitals, physician offices, and corporate wellness centers. We used their existing web-based colonoscopy tutorial and in consultation with the Patient Education Institute, revised the tutorial to address the key messages found through our perceptual mapping and vector modeling analyses. Our resulting tutorial had significantly different graphics, used culturally appropriate photos, and the text was significantly altered not only to address low literacy needs but also to focus on identified concepts. Specifically, we used photographs instead of graphics depicting African American patients, wrote text at a sixth-grade reading level, and added “testament” videos showing actual clinic patients from our study who had had a colonoscopy. These added features reinforced key messages, allowing users to see and hear people like them discuss the importance of having a colonoscopy. The text was also significantly altered by deleting much of the physiological–medical information about colon cancer and colonoscopy and focusing more on the psychosocial issues found to be important to our participants when making a decision about colonoscopy (see Figure 4).

TUTORIAL RESULTS

Although this article does not report extensively on results from testing our tutorial in a randomized controlled trial, a brief discussion of findings is provided for context. The

finished CTS tutorial was tested with users of the same university General Internal Medicine Clinic. All participants recruited ($n = 60$) were African Americans older than 50 years, had low literacy based on the REALM-R, and had never had a colonoscopy. They were randomly assigned to either the Usual Care group ($n = 27$) or the CTS tutorial group ($n = 33$). The Usual Care group received a two-page handout about colonoscopy that is normally provided to patients. The CTS group was provided the CTS tutorial and after a brief explanation, allowed to advance through the tutorial at their own pace. Both interventions occurred in a private space in the clinic.

Results of this phase of the study show that the CTS tutorial group was significantly more willing to have a colonoscopy and understood the barriers to colonoscopy more than the Usual Care group. They also liked their tutorial decision aid significantly more than the Usual Care Group. Analyses of variance indicated that in comparison with the usual care print document, the touch-screen tutorial was judged to be superior on its length ($p = .009$), the amount of information it provided ($p = .001$), the usefulness of the information ($p = .005$), its balance ($p = .001$), and its ease of use ($p = .000$). Users of the tutorial (compared with the Usual Care group) also judged its information value higher relative to deciding to have a colonoscopy ($p = .006$). Overall attitude toward having a colonoscopy ($p = .001$) and likelihood of having a colonoscopy ($p = .002$) were also significantly higher for the CTS tutorial group. The results of this direct comparison of our tutorial with the usual care materials confirms that developing a tailored tutorial decision aid using the perceptual mapping, vector message design, and CTS methods employed in this study can be extremely effective in encouraging behavior for low-literacy minority patients.

DISCUSSION/LESSONS LEARNED

It is clear from this study that using a research-based approach to the development of low-literacy materials can be highly effective—as long as members of the target population are involved in all areas of development. In this case, that included initial focus groups, pilot testing of resulting questionnaires, and larger sample surveys. At each stage in the process, feedback from the primary target group provided valuable guidance for refining the approach, instrumentation, and final data collection. Pilot testing of the tutorial proved particularly important for addressing the needs and abilities of these low literacy participants. The use of touch-screen technology for delivery of the tutorial worked very well in that participants did not need computer skills or literacy skills—they needed only to touch the screen to advance to the next slide, and text information was read aloud by the slide voice-over.

The segmentation approach used in this study was also extremely helpful for identifying critical differences in how African American participants in our study conceptualized the risks and benefits of colonoscopy, identifying three clearly defined groups. It was clear that the *Ready Screeners* needed little encouragement—they trust the medical system, would rather know if they have cancer, do not mind doing screening tests, and overall, feel screening is worth the effort. The *Cautious Screeners* are somewhat more neutral about going to the doctor, but still feel they would rather know if they have cancer, and feel that screening is worth the effort. The *Fearful Avoiders* turn out to be the group most in need of

information and encouragement—as such, they are the most important group to target for future screening campaigns. At 30.4% of our study, they reflect a significant priority population. It should be noted that our initial plan did not account for possible segment differences in the sample. The clear delineation of perceptions among the three clusters proved challenging in that we could only develop one tutorial that needed to address all the significant messages for the three cluster types. We had to weigh the benefits of emphasizing messages for one cluster while not necessarily emphasizing benefits for another cluster. We felt, however, that if we emphasized concepts for the *Fearful Avoiders* group, we would provide beneficial messages to address their specific concerns about colonoscopy and address the relatively minor concerns of the *Ready Screeners* and *Cautious Screeners* clusters.

In addition to the cluster analysis, the perceptual mapping procedure used in this study provided highly valuable models of how each type of patient conceptualizes the risks and benefits of CRC screening. The resulting three-dimensional maps not only show how risks and benefits are associated with each other in the patient's mind, but also effectively position the “self” within the interacting mix of decision elements. The vector message design procedure was then very effective at identifying optimum message elements to build into the screening tutorial. This was clear from the fact that, compared with the Usual Care group, those viewing the CTS tutorial liked it more, came away with a clearer understanding of the risks and benefits, found the tutorial more useful for decision making, and declared greater intent to be screened. These results show that our methods can be highly effective in creating messages specific to a target group's perceptions and could be used to address a variety of health-related decision making. Using the methods was also quite easy with low-literacy populations, providing evidence of its utility in the field.

Finally, although we used the tutorial in a clinical setting, the application of using a CTS intervention is also applicable to other community-based settings. African Americans have often been targeted for health education interventions in faith-based organizations such as churches, including CRC screening (Holt et al., 2011; P. D. Morgan, 2010). Because CTS applications are self-directed and we found most users were more comfortable with the technology than using a mouse, it could easily be adapted in these community settings. This could be accomplished without the use of health educators or clinicians, making the feasibility of this type of intervention possible.

Limitations

It should be noted that the cluster/segmentation analysis and the subsequent perceptual mapping and vector modeling methods were based with a convenience sample of low-literacy African American patients at an urban General Internal Medicine Clinic and may not be generalizable to other groups of low-literacy African Americans. Although the tailored CTS tutorial was very effective with this group, targeted messages may be different for other low-literacy African Americans or other groups, requiring development of different CRC decision aids. Despite this limitation, evidence for the effect of this highly focused method is compelling and could be tested in a variety of populations.

Conclusion

The overall procedures used in this project proved highly successful in producing a colonoscopy CTS tutorial for low-literacy African Americans. The resulting tutorial was not only judged by study participants to be more interesting and understandable compared to the “usual care” materials used in the hospital clinic, but the tutorial was also judged to be more helpful in the decision-making process. As a result, significantly more patients receiving the tutorial (compared with the Usual Care clinic materials), declared their intention to obtain a screening colonoscopy. This significant result indicates not only the benefit of the study methods but also the need to include participants in all areas of decision aid development. Without the unique insights and input of the group being targeted, the development of a health decision aid cannot be specific to their needs and consequently cannot truly motivate them to make healthier decisions.

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FIGURE 1.
diagram of study Phases and computer touch-screens (cts) tutorial development

FIGURE 2.
Patient types based on cluster analysis

FIGURE 3.
Perceptual Maps by cluster group

FIGURE 4.
screen captures of developed colorectal cancer (crc) tutorial

TABLE 1

survey Items by Question block

<i>Block One: Overall Screening and Health Attitudes/ Behavior</i>	
1	Don't go to doctor unless needed
2	Trust body to tell if testing is needed
3	Don't get tested unless feel something is wrong
4	Rather not know about cancer
5	Fear of cancer keep from testing
6	Cancer is God's will
7	Screening tests not good at finding problems
8	Get colonoscopy only if family/friends recommended
9	Get colonoscopy if trusted doctor recommended
10	Feel uncomfortable and embarrassed
11	Colonoscopy is worth effort
12	Screening tests done as way of not getting sick
<i>Block Two: Perceived Barriers to Colonoscopy</i>	
1	Cost is prohibitive
2	No transportation
3	No time off
4	No child care
5	No adult care
6	Too much bother
7	Too unfamiliar
8	Embarrassing
9	Not the best method
10	Scared to know
11	Worry about sedation
12	Worry about pain
13	Worry about complications
14	Women more willing
15	Don't want rectum probed
16	Seems sexual
<i>Block Three: Perceived Facilitators of Colonoscopy</i>	
1	Most accurate
2	Finds problems early
3	Can remove growths
4	Not done often
5	Provides peace of mind
6	Recommended by doctors
7	If insurance covers, I'll do it

8 Being sedated is good

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