Developing a Preference Assessment Tool for Use among Minority and Low Literacy Primary Care Patients

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Abstract

Incorporating patients’ preferences into healthcare decisions has been identified as one mechanism for reducing health disparities. Some research suggests that providers need to tailor medical recommendations to the preferences of their patients. Yet there are few tools to facilitate clarification of preferences for health services. This paper reports the process of testing an innovative preference elicitation technique—conjoint analysis—among minorities and low literacy patients using the example of colorectal cancer (CRC) screening. CRC screening exemplifies preference-sensitive healthcare as there exist several screening options. However, screening rates among minorities are low. Better methods for preference assessment could improve patient-provider communication and increase patient adherence. This study used qualitative methods and piloting to refine and finalize a conjoint analysis preference assessment instrument. We conclude that conjoint analysis is a viable preference assessment methodology for use in vulnerable populations with appropriate tailoring of materials. Future work will evaluate integrating this method into clinical decision tools.

Key Words: conjoint analysis, patient preference, minorities, low literacy

Introduction

Incorporating patients’ preferences into healthcare decision-making has been identified as a key mechanism for achieving high quality, patient centered care and for reducing health disparities (IOM, 1999). The importance
of preferences was highlighted in the Institute of Medicine report Crossing the Quality Chasm: “The system of care should be designed to meet the most common types of needs but have the capability to respond to individual choices and preferences” (IOM, 2001). There is research to suggest that observed health disparities in health outcomes may be due in part to subgroup differences in preferences for health services (Byrne, O’Malley & Suarez, 2004; Suarez et al, 2005). This line of thinking is challenged by research contending that poor patient-provider communication is one reason health disparities persist (Ashton et al, 2003). It would follow from this contention that providers need to do a better job of assessing their patient’s preferences for healthcare and in tailoring recommendations accordingly. In fact, Healthy People 2010 recommends that one method to improve the provision of culturally competent care is for providers to be educated regarding variation in preferences for health services among patients of different racial/ethnic backgrounds (US Department of Health and Human Services, 2000).

Yet there are no guidelines for how patients’ preferences for healthcare services should be assessed in clinical settings. Existing preference assessment methods are complex and likely to be particularly difficult for vulnerable populations, such as racial/ethnic minorities and individuals with low literacy (Bowling & Ebrahim, 2001; Woloshin et al, 2001; Giesler et al, 1997 & Shumway et al, 2003). Better tools for preference assessment in these populations are needed to improve patient-centered care and reduce health disparities.

Preference-sensitive care situations, defined by Wennberg and colleagues as “care situations in which there exist two or more medically justifiable options,” (Wennberg, 2002) are specifically the type of medical scenario where patient preference assessment is critical. These types of care situations often necessitate informed and/or shared decision making (I/SDM) between patient and provider. Sepucha and colleagues define a “high quality medical decision” as one that is consistent with the patient’s underlying values and preferences (Sepucha, Fowler & Mulley, 2004), therefore making preference assessment a requirement in provision of high quality care.

Colorectal cancer (CRC) screening represents an excellent example of preference-sensitive care since there are several medically-equivalent test options. According to the American Cancer Society, and other professional groups, CRC screening should be done by all individuals starting at age 50 by one of the following modalities: 1) annual fecal occult blood test (FOBT) or fecal immunochemical test (FIT); 2) flexible sigmoidoscopy (SIG) every 5 years; 3) annual FOBT/FIT and SIG every 5 years; 4) colonoscopy (COL) every 10 years; or 5) double contrast barium en-
ema (DCBE) every 5 years (American Cancer Society, 2001). In fact, the United States Preventive Services Task Force recommends “The choice of [CRC] screening strategy should be based on patients’ preferences, medical contraindications, and availability of services” (USPSTF, 2002).

Despite the existence of options, CRC screening rates remain significantly lower than rates for other cancers (breast, prostate, cervical) (Seef, Shapiro & Nadel, 2002), and are even lower for minority populations (Nelson et al, 2002; Vlahov et al, 2005; Thompson et al, 2005). Moreover, interventions have been only minimally effective for increasing screening rates, and very few interventions have been directed toward vulnerable populations (Vernon, 1997; Levin et al, 2002; Subramanian et al, 2004).

Barriers to CRC screening include concerns about discomfort, the invasive and potentially embarrassing aspects of endoscopy, fear of pain, and inconvenience (Greisinger et al, 2006; Klabunde, Schnick & Davis et al, 2006; Denberg et al, 2005; Worthley et al, 2006; Fisher et al, 2006; Zimmerman et al, 2006). There is a paucity of literature regarding barriers to screening among racial/ethnic minority and/or low literacy populations; however, there is some research to suggest that poor acculturation and language skills are barriers to CRC screening, along with a general lack of knowledge about test options (Shah, Zhu & Potter, 2006; Goodman, Ogdie & Kanamori, 2006; Shokar, Vernon & Weller, 2005). Low literacy has been identified as a potentially overlooked barrier to CRC screening (Dolan et al, 2004). A recent study by Shokar and colleagues found that CRC knowledge was very low among a racially/ethnically diverse primary care patient population, and that the test terminology was a large barrier to screening (Shokar, Vernon & Weller, 2005). Another study found African Americans who reported having good patient-provider communication were more likely to have completed CRC screening than those who reported poor communication (Dolan et al, 2004). Healthy People 2010, and others, have recommended that helping providers understand the preferences of their patients will improve physician-patient communication and the provision of culturally competent care (US Department of Health and Human Services, 2000; IOM, 2001).

While there have been some studies showing variation in patients’ preferences for CRC screening options (Katz et al, 2004; Ling et al, 2001; Pignone, Bucholtz & Harris, 1999; Wolf et al, 2006; Janz et al, 2006), none have evaluated preferences specifically among racial/ethnic minorities and/or low literacy populations. More importantly, no studies have developed and tested a method for reliably collecting preference data from these vulnerable groups. The USPSTF and others endorse the notion that recommending the test that the patient prefers is one method for...
increasing patient adherence to screening (USPSTF, 2002). Yet without valid tools for conducting preference assessment, matching tests to patients is virtually impossible. Moreover, helping patients to clarify which characteristics of a screening test were important to them would have implications for improving physician-patient communication and I/SDM (Sheridan, Harris & Woolf, 2004; O’Conner et al, 2003).

Preference Assessment Overview

Current preference elicitation methods, such as willingness to pay (WTP), standard gamble (SG), and time trade off (TTO) tend to focus on the population’s preference for various health states (e.g., quality of life) rather than preferences for specific services or characteristics of services (Petrou & Henderson, 2003). In addition, these methods are complex and generally require a level of cognition that may easily go beyond that of minority and/or low literacy populations (Bowling & Ebrahim, 2001; Woloshin et al, 2001; Giesler et al, 1997 & Shumway et al, 2003), as suggested by the Shokar study (Goodman, Ogdie & Kanamori, 2006). The study presented here was designed to determine if an innovative preference elicitation technique in healthcare—conjoint analysis—could be reliably used in minority and low literacy patient populations. In recent years, conjoint analysis has been applied to evaluate preferences for many types of healthcare decisions, such as miscarriage management, use of in vitro fertilization, management of knee injuries, and HIV testing, among others (Phillips, Maddala & Johnson, 2002; Ryan & Farrar, 2000; Ryan et al, 2001; Ryan, 1999).

Conjoint analysis is a preference assessment methodology from marketing research (Cattin & Wittink, 1982; Green & Rao, 1971). It has been used for several decades to determine the preferences of consumers for various types of products. Because conjoint analysis is used to elicit preferences for items (e.g., products), it has been relatively easily adapted to assessing patients’ preferences for healthcare treatments. Conjoint analysis is a unique preference assessment methodology because it assesses preferences through evaluating respondents’ views toward hypothetical product scenarios (Ryan & Farrar, 2000; Ryan et al, 2001). These scenarios are created using product characteristics based on actual product attributes and levels of attributes. For example, a conjoint analysis study of preferences for cars might focus on color, size and number of doors as potential attributes, or actual product characteristics. Through an exercise of rating several scenarios, preferences for a specific type of product (e.g., red, sedan, 4-door) can be obtained (Ryan & Farrar, 2000).

Thus, conjoint analysis represents a potentially innovative method
for helping vulnerable populations, and their providers, clarify preferences for important health service attributes or characteristics. Conjoint analysis is especially useful when the choices involve tradeoffs between attributes (Ryan et al, 2001), such as is the case with CRC screening (e.g., there may be a need to accept a lower accuracy test to avoid an invasive test). There are five stages to a conjoint analysis preference assessment study: 1) determine the product attributes; 2) determine the levels associated with the attributes chosen; 3) develop scenarios using combinations of attributes and levels; 4) assess preferences using rating, ranking or discrete choice approaches; 5) analyze responses (Ryan, McIntosh & Shakley, 1998). While conjoint analysis has been used successfully to evaluate patients' preferences for a range of healthcare decisions (Phillips, Maddala & Johnson, 2002; Ryan & Farrar, 2000; Bryan et al, 1998; Ryan, McIntosh & Shakley, 1998), no studies have used the methodology in racial/ethnic minority and/or low literacy populations.

Study Objectives

The objectives of this study were to develop the tools to assess preferences for CRC screening test options among minority and low literacy primary care patients using conjoint analysis. The long term goal of this research is to determine the validity of this innovative preference assessment methodology for use in clinical settings to assist minority and low literacy patients in making preference-sensitive healthcare decisions. This paper reports the steps used in development and pilot-testing of this tool, and provides recommendations for evaluating preferences in these populations using conjoint analysis.

Methods

This paper reports on the first three stages of conjoint analysis listed above, specifically as they relate to the research objective of developing the tools to assess preferences in racial/ethnic minority and/or low literacy patients using the conjoint analysis methodology.

Conjoint Analysis Stages 1 and 2: Determining Attributes and Levels

There are two ways to determine the attributes and levels for the product under consideration (Ryan, McIntosh & Shakley, 1998; Ryan & Hughes, 1997); through literature review and talking with potential consumers, in this case patients. Both methods were employed in this study. We conducted a thorough literature review in early 2004 regarding barriers to CRC screening. At the time, barriers reported in the literature included invasiveness, embarrassment, perceived discomfort, test accuracy, need to take time off for the test, and cost. These issues continue
to be reported in the literature as barriers to CRC screening (Greisinger et al, 2006; Klabunde, Schneck & Davis et al, 2006; Denberg et al, 2005; Worthley et al, 2006; Fisher et al, 2006). At the time, few studies had been done among racial/ethnic minorities or low literacy individuals. In addition, none of the studies provided information regarding “levels” of these potential attributes. A more recent literature review revealed that there is still a paucity of research focusing on barriers to CRC screening in vulnerable populations. Those that have been done suggest that culture, language, and lack of knowledge about CRC test options are additional barriers to screening among racial/ethnic minorities (Zimmerman et al, 2006; Shah, Zhu & Potter, 2006; Goodman, Ogdie & Kanamori, 2006), and that low literacy itself is a potential barrier (Shokar, Vernon & Weller, 2005).

We therefore conducted qualitative interviews with 74 racial/ethnic minority and/or low literacy primary care patients of an urban community health center. The goal of these interviews was fourfold: 1) to determine if individuals of different racial/ethnic minority groups perceived similar or different screening attributes to be important; 2) how individuals in these groups wanted to get information about attribute levels (e.g., what level of detail would be meaningful to them); 3) to determine whether participants could complete a set of rating and ranking exercises using a set of attributes we developed from the literature; and 4) to validate the conjoint analysis preference assessment with the independent attribute rating and ranking exercises.

**Study Site**

This study was conducted in community health centers affiliated with Harris County Hospital District (HCHD). The district includes 11 health centers which together have close to 500,000 physician visits per year. HCHD has a racially/ethnically diverse patient base, and provides care to the majority of Hispanic and African American patients in the Houston area. Studies conducted within HCHD have demonstrated the generally low socioeconomic status and low literacy levels of its patients (Guest, 2002; Jibaja-Weiss et al, 2006; Pavlik, Hyman & Vallbona, 1996; Djojonegoro, 2000).

**Participant Recruitment**

Patients were recruited from waiting areas of one community health center. Participants were eligible if they met the following criteria: age between 50 and 79 and no prior history of CRC or colon polyps. We recruited participants who were white, African American and Hispanic to reach a goal of 25 participants from each racial/ethnic group. We tried
to recruit a balance of male and female participants from each racial/ethnic group, but obtained more female participants due to their increased representation in the waiting area. Hispanic participants could choose to complete the interview in English or Spanish.

We did not administer a literacy test due to time constraints of the interview. Therefore, we base our description of some members of our population as low literacy based on low levels of educational attainment, shown to be associated with literacy (Schillinger et al, 2006). Moreover, prior work in this population has demonstrated that literacy levels remain low despite having more than a high school education (Jibaja-Weiss et al, 2006). Thus for purposes of this study we have defined our population as “racially/ethnically diverse and/or low literacy.” A description of the final sample is provided in the Results section.

**Interview Administration**

A semi-structured list of questions was used to guide the interviews, starting with whether patients had ever heard of colorectal cancer and, if so, what they had heard about it. The questions proceeded to ask individuals what they knew, if anything, about tests that might be used to prevent CRC and what type of information they would want to know before making a CRC screening/testing decision. Once a set of potential attributes was obtained, respondents were asked how they would prefer to learn about that attribute. For example, for the accuracy attribute, levels could be provided descriptively (e.g., very accurate vs. not very accurate), proportionally (e.g., this test will find cancer in 75/100 individuals who have cancer vs. 50/100 individuals who have cancer), or as a percentage (this test will find cancer 75% of the time if there is something to find vs. 50% of the time).

**Feasibility of Rating and Raking and Validation of Conjoint Analysis**

Finally, we asked individuals to both rate and rank the list of attributes we developed from the literature (accuracy, discomfort, embarrassment, invasiveness, need to take time off work, cost). Participants were first asked to rate each of the attributes on a scale from 1 (“not very important”) to 10 (“extremely important”) in their decision-making, assuming they were making a decision to get a CRC or another preventive test. Participants were then asked to rank the attributes from most to least important in making this same decision. Feedback on the exercise was obtained, and answers were compared to determine the internal validity of the responses. We then compared the ratings given to the conjoint analysis scenarios to the independent attribute ratings and rankings to assess validity (Ryan, McIntosh & Shakley, 1998).
Conjoint Analysis Stage 3: Generating Scenarios

From the interviews, we developed an initial list of attributes and levels related to CRC screening. We created scenarios and pilot-tested them among 15 racial/ethnic minority and/or low literacy (5 white, 5 African American, 5 Hispanic) patients from the same community health center. We refined the scenarios and conducted a second pilot test, among 15 racial/ethnic minorities from the community health center. We further refined the scenarios and updated them with graphics for our final assessment tool.

Results

Phase I Participants

Given the qualitative nature of phase I, limited demographic characteristics of participants were collected. Of the 74 subjects interviewed, 33.8% (n=25) were white, 36.5% (n=27) were African American and 30% (n=22) were Hispanic. The average age was 59.2 (range: 50-79). Approximately two-thirds (66.2%) were female and 63.5% (n=47) had a high school education or lower level of educational attainment.

Conjoint Analysis Stages 1 and 2

The leading attributes reported by respondents in each of the three racial/ethnic groups included test procedure (e.g., invasiveness), test accuracy, discomfort, need for follow up testing, test preparation, and cost. Although there was slight variation in the importance placed on the various attributes across the groups, each group responded with a similar set of top 6 attributes. Examples of quotes from male and female participants from each racial/ethnic group that were used in determination of these attributes are provided in Table 1. For each of the attributes, the type of description respondents indicated would be useful for the levels was also similar. For example, individuals from each racial/ethnic group told us that they would rather have accuracy information as some type of “likelihood or percentage” whereas they preferred to hear a much more general discussion of discomfort (e.g., “some vs. none”).

Conjoint Analysis Stage 3

The first set of attribute/level combinations developed from the in-depth interviews is provided in Table 2. We used this full table to generate our initial set of scenarios for pilot testing. One example of a hypothetical scenario from round 1 is given in Figure 1. Participants were shown eight scenarios similar to that shown in Figure 1 representing eight hypothetical CRC screening tests. These scenarios were available in English or Spanish. Participants were asked
TABLE 1. Quotes about colorectal cancer screening from Phase I study participants and associated attributes.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Female Participant</th>
<th>Male Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>White Participant</td>
<td>“I think most people do not do that test [colonoscopy] out of, uh, you know, embarrassment … but it’s good that you don’t have to do it that often.”</td>
<td>“I would do the [colonoscopy], just in case there may be something further down there that’s not detected [with other tests].”</td>
</tr>
<tr>
<td>TEST FREQUENCY</td>
<td></td>
<td>TEST ACCURACY</td>
</tr>
<tr>
<td>African American Participant</td>
<td>“… or they feel they’re in discomfort, you know? A lot of…they just feel discomfort, I guess, you know, the way I do, I see it.”</td>
<td>“…but getting preparation to do the test is a big barrier to gettin’ it done…”</td>
</tr>
<tr>
<td>DISCOMFORT</td>
<td></td>
<td>TEST PREPARATION</td>
</tr>
<tr>
<td>Hispanic Participant</td>
<td>“Well, if I didn’t do [colonoscopy] I would be more nervous they would find something that has advanced to a point to where you can’t really do nothing about it.”</td>
<td>“I’d do the yearly one…’cause I’m not for an [invasive] test like that [colonoscopy].”</td>
</tr>
<tr>
<td>TEST ACCURACY</td>
<td></td>
<td>TEST PROCEDURE (INVASIVENESS)</td>
</tr>
</tbody>
</table>

TABLE 2. First set of attributes and levels generated from qualitative interviews with 74 racial/ethnic minority and/or low literacy primary care patients in an urban community health center.

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of test</td>
<td>1. Invasive (tube inserted)</td>
</tr>
<tr>
<td></td>
<td>2. Not invasive (no tube inserted)</td>
</tr>
<tr>
<td>Type of preparation</td>
<td>1. Restricted diet</td>
</tr>
<tr>
<td></td>
<td>2. Restricted diet + empty colon</td>
</tr>
<tr>
<td>Accuracy for finding cancer</td>
<td>1. 50%</td>
</tr>
<tr>
<td></td>
<td>2. 75%</td>
</tr>
<tr>
<td></td>
<td>3. 95%</td>
</tr>
<tr>
<td>Discomfort</td>
<td>None, Some</td>
</tr>
<tr>
<td>Test frequency</td>
<td>1. Yearly</td>
</tr>
<tr>
<td></td>
<td>2. Every 5 years</td>
</tr>
<tr>
<td></td>
<td>3. Every 10 years</td>
</tr>
<tr>
<td>Insurance coverage</td>
<td>1. Yes-test covered</td>
</tr>
<tr>
<td></td>
<td>2. Test is covered with a co-pay</td>
</tr>
<tr>
<td></td>
<td>3. No-test is not covered</td>
</tr>
</tbody>
</table>
FIGURE 1. Example of one hypothetical colorectal cancer screening scenario generated from the first set of attributes and levels.\(^1\)

<table>
<thead>
<tr>
<th>Possible Test #1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of test</td>
</tr>
<tr>
<td>Type of preparation</td>
</tr>
<tr>
<td>Accuracy for finding cancer</td>
</tr>
<tr>
<td>Discomfort</td>
</tr>
<tr>
<td>Test frequency</td>
</tr>
<tr>
<td>Insurance coverage</td>
</tr>
</tbody>
</table>

How likely are you to choose this test for colorectal cancer screening?

<table>
<thead>
<tr>
<th>How likely are you to choose this test for colorectal cancer screening?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>Very unlikely</td>
</tr>
</tbody>
</table>

\(^1\) Participants were shown 8 scenarios similar to that in Figure 1 and provided in booklet format, and asked to rate them individually on the corresponding scale.

to rate each test separately on the corresponding scale. The pilot test of this version of the tool revealed that: 1) the table format listing attributes and levels across from one another was difficult for participants to comprehend; 2) the “type of procedure” attribute was incomplete in that it did not specifically describe whether a non-invasive test involved “handling stool,” as would be required in an FOBT; and 3) cost was driving preferences, that is if there was any co-pay listed at all, the patients were rating the hypothetical test as a “0” (not at all likely to do) while rating a hypothetical test with no co-pay listed as a “10” (very likely to do). Based on this feedback, we refined the attribute levels and omitted cost as an attribute. We omitted cost in order to determine what specific features of the tests respondents were willing to trade off without having to consider financial concerns. While some would argue that cost should be included, others would contend that true preference-assessment should be done without cost. We did continue to evaluate cost through a follow up question to our revised scenario format. After individuals rated the revised scenario, we then asked how their rating would change if the test cost $25. While we expected ratings to go down in each case, we would be able to evaluate the relative downward shifts in ratings relative to cost.

The revised set of attributes and levels we created based on this feedback is presented in Table 3. In response to the overall issue of difficulty in comprehension of the table format, we updated our final hypothetical scenarios to include graphics and slightly revised our rating question with a focus on how much the respondent liked the description provided. We also provided an “information sheet” to participants ahead of time which gave a brief definition of the terms that would be used in the upcoming exercise (e.g., we use
the term “accuracy” to describe the ability of a test to find colorectal polyps or other colon problems, if there is something to find). An example of one of the final hypothetical scenarios is given in Figure 2. As with the test example provided in Figure 1, participants view eight hypothetical test scenarios like that in Figure 2, and rate them on the corresponding scale.

**TABLE 3. Revised colorectal cancer screening attributes and levels based first pilot test among 15 racial/ethnic minority and/or low literacy patients in an urban community health center**

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedure during test</td>
<td>1. Collect stool sample</td>
</tr>
<tr>
<td></td>
<td>2. Short tube without sedation</td>
</tr>
<tr>
<td></td>
<td>3. Long tube with sedation</td>
</tr>
<tr>
<td></td>
<td>4. X-ray or CT scan</td>
</tr>
<tr>
<td>Advance prep needed</td>
<td>1. Special diet required</td>
</tr>
<tr>
<td></td>
<td>2. Special diet and laxatives or enemas to empty the colon</td>
</tr>
<tr>
<td>Accuracy for finding cancer</td>
<td>1. 50-75%</td>
</tr>
<tr>
<td></td>
<td>2. 95%</td>
</tr>
<tr>
<td>Discomfort</td>
<td>1. None</td>
</tr>
<tr>
<td></td>
<td>2. Some</td>
</tr>
<tr>
<td>Test frequency</td>
<td>1. Yearly</td>
</tr>
<tr>
<td></td>
<td>2. Every 5-10 years</td>
</tr>
</tbody>
</table>

**Validation of Conjoint Analysis**

In a subgroup of participants in the second pilot test, we evaluated whether the ratings given to the hypothetical test scenarios were consistent with the rankings given to the individual attributes. Among each of the six participants who completed both sections, we found high correlation between the responses. We are conducting further work with larger samples to obtain measures of the internal consistency and validity of the conjoint analysis methodology.

**Discussion**

Improving the quality of care for vulnerable populations is a national priority. The problem of health disparities is increasing in the U.S. and is compounded by a continually growing minority and low literacy populations. As of 2005, racial/ethnic minorities represented about one-third of the U.S. adult population, and 45% of children under age five were from a racial/ethnic minority (US Census Bureau, 2005). It is estimated that nearly half of U.S. adults read below an 8th grade level, and even more have difficulty understanding and processing health-related information (IOM, 2004). Some research suggests that observed disparities in health outcomes may be a result of subgroup differences in preferences
FIGURE 2. Example of a final hypothetical colorectal cancer screening scenario generated from the second set of attributes and levels.\(^1\)

<table>
<thead>
<tr>
<th>Possible Test #1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collect stool sample</td>
</tr>
<tr>
<td>No discomfort</td>
</tr>
<tr>
<td>Take laxatives</td>
</tr>
<tr>
<td>Every 5-10 years</td>
</tr>
<tr>
<td>50-75% accurate</td>
</tr>
</tbody>
</table>

How much do you like this test?

\(^1\) Participants were shown 8 scenarios similar to that in Figure 2 and provided in booklet format, and asked to rate them individually on the corresponding “ruler-scale.” The final set of ratings provides the data to determine preferences for a specific CRC screening test.

for health services (Byrne, O’Malley & Suarez-Almazor, 2004; Suarez-Almazor, 2005). However others contend that there may be a failure of providers to tailor communication to the needs of diverse individuals (Ashton et al, 2003). This line of thinking assumes preference assessment would be necessary for tailoring to occur.

However, there are few preference elicitation methods that can be used in vulnerable patient populations. This paper reports the process of developing and testing a preference assessment tool for use among racial/ethnic minority and low literacy patients. We conclude that conjoint analysis is a viable preference assessment methodology for use in these vulnerable populations with appropriate tailoring of materials.
There is a need for clinical decision tools to assist providers and patients themselves in clarification of preferences for healthcare decisions which are preference-sensitive. The significance of patients’ preferences to decision making has been highlighted by the definition of a “high quality decision” as one that is consistent with a patient’s underlying values and preferences (Sepucha, Fowler & Mulley, 2004). The International Panel of Decision Aids Standards (IPDAS) recommends that a preference assessment exercise be included in any decision tool intended to improve I/SDM in health. Finally, Healthy People 2010 states that it is necessary for providers to understand the preferences of their patients in order to provide culturally competent care (US Department of Health and Human Services, 2000).

In the example of CRC screening, national organizations and others endorse the idea of matching a patient’s preferences to a specific test in order to increase adherence (USPSTF, 2002). However, this idea has not been tested due in large part to the fact that valid tools for assessing CRC screening preferences do not exist. The notion of providing “preference tailored care” has implications for improving the quality of care for all patients faced with making preference-sensitive healthcare decisions, but may be particularly important for vulnerable patients such as racial/ethnic minorities and/or low literacy patients.

Based on our study, we provide the following recommendations to researchers and healthcare providers interested in preference assessment among racial/ethnic minority and/or low literacy populations. First, until a broader knowledge base regarding perceptions of healthcare among minority and low literacy populations exists, the best method for determining the attributes that are most salient to the specific populations is through group or individuals interviews. These interviews are also critical in determining how the levels of each attribute should be described to be meaningful to the population. Second, simplification of text and inclusion of graphics is key to the comprehension of the exercise and also important for engaging the participant in the exercise. Third, the option to conduct interviews and provide tools in different languages is important.

Finally, continued work in the validation of conjoint analysis is needed through independent attribute rating or ranking exercises to ensure that the method continues to perform reliably across different patient populations and in different types of preference-sensitive care situations.
Limitations

There are some limitations that affect the interpretation of our development process. Because of our interest in developing the tool for use in low literacy and minority populations, we had small numbers of participants in each phase of the pilot test within each racial/ethnic group. The majority of the participants could be categorized as being of low literacy, based on educational attainment and also on prior work in this population. We may not have accurately described all the attributes that are important to racially/ethnically and/or low literacy patients; however this is one of the largest studies with qualitative data from minority and/or low literacy patients related to CRC screening barriers. Since this was a development process study, we believe that the same process can be applied in other racial/ethnic minority and/or low literacy groups with few changes. Finally, we did not compare conjoint analysis to other preference assessment methods so we can only comment about the ability of this specific method to produce accurate preference data in these populations.

Conclusion

We found that conjoint analysis represents an innovative, valid and comprehensible preference assessment technique that can be used among racial/ethnic minority and low literacy patients. Assessing preferences through soliciting feedback about hypothetical product (i.e., health care service) options was easy for participants to relate to and understand. From the ratings given to these hypothetical products, a final individualized preference structure could be obtained. This methodology and resulting preference profile could be integrated into clinical decision tools designed to assist patients with making informed medical decisions. Providing the preference profile to the patient’s provider prior to or during the medical visit would allow the provider to tailor his or her communication to the preferences of the individual patient. This type of interaction would have positive implications for patient-provider communication and for provision of culturally competent care, both of which have been identified as mechanisms for increasing patient satisfaction and compliance with services (IOM, 2001; US DHHS, 2000; Dolan et al, 2004). Researchers are in the early stages of determining how to best include a preference elicitation exercise in decision tools, as recommended by IPDAS. The conjoint analysis method tested through the process outlined in this paper represents a potentially innovative method for achieving preference assessment in vulnerable populations. Future work by the research team will evaluate integrating this method into
clinical decision tools to improve informed decision making and patient-provider communication.

References

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