

Development and Assessment of Algorithms for Delivering Tailored or Targeted Patient
Decision Support in Two Disease Models

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Abstract

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Patient decision support refers to the provision of appropriate information to a patient about his or her health conditions to aid in the goal of informed medical decision-making. Medical decisions in which there are multiple valid options in which the risks and benefits differ, deemed “preference-sensitive” decisions, necessitate shared decision-making and patient decision support. Tailoring and targeting can be used to adapt the content or the amount of information delivered to the patient. Tailored or targeted health information for patient decision support has long been shown to be more effective than generic information at modifying health behaviors. To increase adoption in clinical care, one goal in developing targeting frameworks is to choose theory constructs and personal characteristics measured by a few data items that are simple to collect. Thus, in developing parsimonious algorithms, it is important to understand the relationships

between socio-demographic characteristics and theories of health behavior. Finally, to ensure acceptance of algorithms in patient decision support, it is critical to understand patient perceptions of such algorithms, particularly what additional factors are important in decision-making.

This dissertation addresses these needs in two parts: Part 1) development of algorithms to guide content and intensity of patient decision support in the context of colorectal cancer screening, and Part 2) assessment of patient perceptions of the use of algorithms to guide patient decision support in the context of heart disease prevention. In the Part 1 of this dissertation, I conducted two studies that consider health beliefs, demographics, and patient behavior in the context of colorectal cancer screening behavior. The first study sought to understand the relationship between socio-demographic characteristics and constructs of the health belief model in the context of colorectal cancer screening behavior in a racially, ethnically, and linguistically diverse population. The second study sought to develop a practical regression model to predict the probability of completing colorectal cancer screening and, from this model, a framework for targeting patient decision support materials based on level of probability of completing CRC screening. In Part 2 of this dissertation, I conducted one study to assess the use of an algorithm in patient decision support for heart disease prevention therapy. This study was a qualitative analysis of interviews conducted after a discrete choice experiment (DCE) for heart disease prevention. I sought to understand new factors that were influencing heart disease prevention therapy choices and perception of DCE-based “values concordant” choice results.

In the first part of the dissertation, I observed several key differences across racial/ethnic and language groups in terms of health beliefs about CRC and CRC screening. These differences were largely dependent upon primary spoken language, which may

approximate level of acculturation. Non-English speaking Hispanics typically reported lower perceived susceptibility to CRC than non-Hispanic Whites, and higher perception of several barriers to CRC screening (prior testing experience, preparation for the test, need for sedation). Non-English speaking Asians also reported lower perceived susceptibility than non-Hispanic Whites, but lower perception of several barriers to CRC screening (need for additional testing, fear of results of the test, concern about complications from the test, need for sedation, anxiety about the procedure). These results may suggest topic areas that could be highlighted in CRC screening promotion interventions that are targeted at specific racial/ethnic and language groups. In the second study, I developed a simple model for predicting CRC screening completion. From that model I developed an intervention framework that may be useful for targeting the amount of information to patients based on how likely they are to complete screening. In the final study, I found several new factors that were influencing heart disease prevention decisions: medication avoidance/naturalness, competing demands, and familiarity. Participants were receptive to the DCE-based “values concordant” choice, even if they did not ultimately agree with it.

The results of this dissertation may be informative to patient decision support researchers considering methods for targeting or tailoring decision support intervention for CRC screening or heart disease prevention. Future research should confirm the differences in health beliefs about CRC that we observed across racial/ethnic and language groups. Additionally, the targeting framework that we developed for CRC screening promotion interventions should be evaluated. Finally, future work in DCE for heart disease prevention therapy decision-making should incorporate the new attributes.

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Dedication

For Jason, Mom, Dad, and Eric

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Chapter 1. Introduction

Background

Patient Reported Outcomes and Personalized Adaptation Strategies for Patient Decision

Support

Patient decision support refers to the provision of appropriate information to a patient about his or her health conditions to aid in the goal of informed medical decision-making.¹ Shared decision-making is the process by which a medical care provider interacts with a patient to arrive at an informed and values concordant decision with regards to a medical procedure.² Medical decisions in which there are multiple valid options in which the risks and benefits differ, deemed “preference-sensitive” decisions, necessitate shared decision-making and patient decision support.²⁻⁴ Examples of such preference-sensitive decisions include deciding between different colorectal cancer (CRC) screening tests and heart disease prevention therapy options.

Patient decision aids (PtDAs) are evidence-based educational tools that can be used as adjuncts to counseling for improving patient decision-making. PtDAs are different from other education tools in that they must provide balanced information about the risks and benefits of the various treatment or screening options in preference sensitive decision scenarios.⁵ Repeated literature reviews from the Cochrane Collaboration have shown that PtDAs are effective at improving knowledge about a health decision, decision quality, reducing decisional conflict, and increasing active patient participation in medical decision-making.⁶ PtDAs should present information relevant to an individual patient, but the best methods of doing so are not clear.

Patient reported outcomes (PROs) are broadly defined as health related information collected directly from patient report.⁷ As part of the Patient Protection and Affordable Care

Act (PPACA), the United States Congress established the Patient Centered Outcomes Research Institute (PCORI). This group is charged with the mission of conducting research on how to “provide information about the best available evidence to help patients and their health care providers make more informed decisions.” PCORI’s top three items on their research agenda surround the provision of appropriate information to patients based on personal characteristics, beliefs, and values.⁸ In addition, the Health Information Technology for Economic and Clinical Health Act of 2009, a component of the American Reinvestment and Recovery Act, established the idea of “meaningful use” of electronic health (EHR) record data. One major goal of the meaningful use clause is to “use EHR technology to identify patient-specific education resources and provide those to patients as appropriate.”⁹ Toward this type of meaningful use, EHR data should be coupled with PRO data for algorithm-based targeting or tailoring of patient decision support.

The idea of adapting standard health educational information for individual patients is not new, but the technological ability to couple EHR data with PRO measures to deliver both clinically and personally relevant information is less established. Tailoring and targeting health information for patient decision support refers to the continuum of specification of components of educational materials given specific characteristics about a group or individual.¹⁰ Tailoring refers to information specification at an individual level, whereas targeting refers to information specification at a group level.¹¹ Any personal information can, in theory, be used to tailor or target information. Demographic information, such as sex and age, or socio-economic characteristics, such as income or education level, can be used to tailor or target information. Behavioral tailoring or targeting typically uses constructs of theories of health behavior, such as perceived severity of disease.

Information specification for patient decision support in medical decision making have long been shown to be more effective at modifying health behavior (including cancer screening uptake) than generic health information because they increase personal relevance of information for the individual.¹²⁻¹⁶ Theory-based tailoring appears to be more effective than non-theory-based tailoring.^{10,13} There also appears to be an additional increase in effect on behavior modification when demographic and previous behavior characteristics are added to theory-based tailoring frameworks for tailoring patient decision support materials.¹³ In research on minority populations, studies have shown that the additional of cultural constructs may also increase intervention effect on behavior change.^{17,18} There is also emerging evidence that targeting patient decision support to the patient's level of activation, defined as the willingness or ability to participate in healthcare decision-making, may be effective at producing behavior change.¹⁹⁻²¹

While increasing the complexity of a tailoring scheme has been shown to increase the effect of the patient education information on behavioral change, well-matched targeted information for a very specific group have been shown to be equally as effective as individually tailored information, and is simpler and, presumably, less costly, to implement.¹⁵ Competing goals in health promotion research are to discover the most effective intervention and to discover an intervention that can be translated into clinical practice.²² A necessary precondition of a tailoring or targeting framework is that the information used to inform the framework be thoughtfully and meaningfully answerable by the target audience in the target environment.¹⁵ If the goal is to implement tailored or targeted patient decision support in a busy clinical setting, for example, one must consider patient time constraints in the construction of a tailoring scheme. Consequently, despite a computer's capability of

processing almost infinitely complex algorithms, it is of interest to develop algorithms for targeting or tailoring that balance parsimony with accuracy.

The goal in developing a tailoring or targeting framework, therefore, should be to choose a combination of theory constructs and demographic characteristics in which the required data points are few and simple to collect. Given previous research showing the increasing effectiveness of tailoring or targeting schemes that include theories of health behavior, it is important to explore whether simpler measures can approximate theory measures. If simple demographic characteristics, for example, can provide similar predictive impact as a more difficult to collect theory construct, then the demographic characteristic should be favored. Research to understand the relationship of socio-demographic characteristics as they relate to theories of health behavior is necessary.

Preference Sensitive Medical Decision 1: Colorectal Cancer Screening Test

Colorectal cancer screening test choice is the first of two preference sensitive medical decisions that this dissertation is considering. Colorectal cancer (CRC) is the third leading cause of cancer death in the United States.²³ Modern CRC screening tests are effective at finding cancer or pre-cancerous growths.²⁴⁻²⁶ The United States Preventive Services Task Force recommends regular screening for adults ages 50-75.²⁷ The three most common CRC screening tests are fecal occult blood test (FOBT), flexible sigmoidoscopy, and colonoscopy. These three tests have different risks, benefits, requirements, and costs, as well as differences in test performance.

Risks associated with screening vary across the three most common tests. Bowel perforation and gastrointestinal bleeding are among the serious potential side effects of endoscopic screening. FOBT, itself, is associated with minimal to no risk. However, since

colonoscopy is used to follow up positive FOBT, there is a small chance of any of the potential complications from colonoscopy.²⁸ Colonic perforation can occur during sigmoidoscopy, but it is rare, occurring less than 3 per 100,000 procedures.²⁸ Perforation is more common during colonoscopy, about 100-200 per 100,000 procedures, but is still rare.²⁹

Benefits associated with screening also vary across the three most common tests. FOBT has been shown to reduce incidence of CRC by about 20% and mortality from CRC by 15-33%.^{24-26,30} In two recent reports, flexible sigmoidoscopy showed mortality reduction of between 26% and 31%, and 21-23% reduction in incidence.^{31,32} Colonoscopy's direct affect on incidence and mortality is less well established, but through polypectomy, colonoscopy is associated with a 53% reduction in mortality and between a 76 and 90% reduction in incidence.^{33,34}

The requirements and natures of the three screening tests also vary. FOBT is the simplest; it is completed at home, involves essentially no preparation or recovery time, but it requires yearly completion.²⁹ There are some recommended dietary restrictions, depending on brand of FOBT. Flexible sigmoidoscopy, on the other hand, requires about a half day for preparation, about one hour for recovery, and is completed in a medical facility every five years.^{29,35} Colonoscopy requires a full day for preparation and another for recovery, is also completed in a medical facility, but is only necessary every 10 years.^{29,35}

Additionally, simply because CRC screening is a clinical procedure, there are many barriers that hinder completion of CRC screening, such as lack of patient knowledge, poor or non-language concordant physician communication, and costs or insurance coverage.^{36,37} Consequently, despite the efficacy of CRC screening tests, adherence to recommended

screening remains low.²⁴⁻²⁶ Only 65% of adults in the United States are up to date with recommended screening practices.³⁸ This figure is much lower in racial and ethnic minority groups in the United States; among Asian and Hispanic Americans specifically, only 45% and 47%, respectively, are up to date with CRC screening.^{39,40}

Patient decision support has been shown to increase adherence to CRC screening, but implementation is difficult and expensive, and without significant effort by clinical or project staff, patient use of educational materials tends to be low.⁴¹⁻⁴⁵ Previous research testing the effect of patient decision support on CRC screening rates showed that some patients completed CRC screening in response to an inexpensive reminder letter while others wanted more information from a patient decision aid before considering CRC screening.^{41,42} These findings suggest that some patients may be motivated to complete CRC screening by a simple, inexpensive cue-to-action, such as a reminder letter from their physician, while others need more formal decision support. It is our belief that tailoring patient decision support to the information needs of the individual patient, both in terms of content and amount of information, would increase use and effect of patient decision support on CRC screening adherence, while reducing the costs of implementation.

Previous research has suggested that making a decision about CRC screening is a multi-stage process, conceptualized by theories such as the Transtheoretical Model.^{43,46-48} We believe that the information needs of an individual patient may depend on what stage of decision making he or she is in.⁴⁹ Providing “one size fits all” interventions may be missing patients whose information needs differs from what is offered. Targeting patient decision support to these stages may better address the individual’s information needs and make information more salient and personally relevant.⁵⁰

Current research typically assesses likelihood of CRC screening completion using a one item intention-to-be-screened model, based on the Theory of Planned Behavior (TPB).^{51,52} This is a coarse measure and, while it has been shown to be an accurate predictor of CRC screening behavior in many patients, it may not be particularly sensitive to *gradations* of readiness to be screened for CRC.⁵³ Additionally, it has been shown to be problematic at capturing the participants' intent, particularly among the racial/ethnic minorities.⁵⁴ Other models of health behavior may be better able to capture the gradations in readiness to make a decision about CRC screening.

The Health Belief Model (HBM) describes how individual's perceptions of illness and health can help predict use of preventive health services. Several prior studies have applied most of the constructs of the HBM to predicting CRC screening behavior, and there is strong support for association as expected with screening behavior (e.g., a patient with high perceived susceptibility is more likely to complete screening). There is less established evidence for the relationship of perceived severity with screening behaviors than for the other constructs of the HBM.⁵⁵⁻⁶¹ Several studies in Asian and Latino populations that have shown certain constructs of the HBM, most prominently perceived barriers, to be strongly associated with completing CRC screening.⁶²⁻⁶⁴

Another health behavior theory, the Transtheoretical Model (TTM) or Stages of Change, proposes that behavioral change involves distinct stages, and that interventions aimed at behavioral change should be stage specific.⁶⁵ TTM proposes that individuals weigh benefits versus barriers to taking action and, that when the benefits outweigh the barriers, action becomes more likely. Consistent with the TTM, previous research has shown promise for improving adherence to CRC screening with interventions that tailor patient decision

support information by “stage of readiness.”^{43,47,48,66} Most previous research looking at the effect of stage targeted patient decision support on CRC screening rates have offered stage-targeted information after a “one-size-fits-all” decision support intervention. This approach does not address the varied information needs of patients who may be in different stages of readiness to complete CRC screening and does not reduce intervention costs.

Preference Sensitive Medical Decision 2: Heart Disease Prevention Therapy

The second preference sensitive medical decision that this dissertation is considering is coronary heart disease prevention therapy. Coronary heart disease is one of the top causes of death in the United States.⁶⁷ There are many well-proven interventions to reduce the risk of a heart-related event, but many patients who are at risk fail to adopt or adhere to preventive therapies.^{68,69} One possible reason for patient failure to adhere to prescribed therapies may be due to differences in what the patient and the provider consider to be important attributes of a treatment.⁷⁰ Previous research has shown that therapy choices for heart disease prevention vary widely from patient to patient.⁷¹ Taking into account patient values and preferences when making a decision about preventive therapy may result in a choice that is more appropriate for the individual patient and may increase adherence to the therapy.⁶⁹

One potential component of patient decision support tools that helps patient to clarify their values is choice-based conjoint analysis, or discrete choice experiment (DCE). DCE may be more cognitively and analytically difficult than some other types of values clarification exercises, but it also has several distinct advantages. First, it may help patients consider the characteristics of a particular medical therapy separately from preconceived

notions about the therapy. And second, the results of a DCE can be used in an algorithm to produce a simulated choice that reflects the individual's values.

Originally developed by market researchers several decades ago, conjoint analysis subsumes the premises of consumer theory in which an individual's utility for a particular product is considered to be summation of his utilities for the attributes of that product.⁷² Utilities, in this context, are numeric representations of the value an individual places upon a particular characteristic of a product.⁷³ Conjoint analysis has become an increasingly common tool in health care.⁷⁴ Choice-based conjoint (CBC), also called discrete choice experiment (DCE), is a type of conjoint analysis that derives attribute utilities using a series of choice tasks.⁷⁵ Respondents are presented with side-by-side hypothetical "products" described by different combinations of attributes, or characteristics, of that product. Respondents are asked to choose between these hypothetical products, or indicate no preference for either. Conjoint analysis can be used to predict the share of the market a particular product should gain based on the consumer utilities derived during conjoint tasks.⁷⁶ In a process sometimes referred to as Market Simulation, through the use of a Hierarchical Bayesian analytic technique, the results of a conjoint analysis exercise can be used to suggest optimal product choice at the individual level. Use of market simulation in health care decision-making has not been well studied.

Because the DCE and simulation require patient effort and analytic support, a necessary precondition is that it provides different information than simpler methods. The market simulation used in this study produced markedly different results for preferred therapy choice compared to directly querying the patient.⁷⁷ Given these results, it is important to explore whether DCE with a market simulation algorithm is acceptable to

patients as a form of medical decision-making support for heart disease prevention and how patients feel about the simulated choices generated by the market simulation algorithm.

Objectives

This dissertation will address gaps in research on targeted patient decision support in two parts: Part 1) development of algorithms to guide content and intensity of patient decision support in the context of colorectal cancer screening, and Part 2) assessment of patient perceptions of the use of algorithms to guide patient decision support in the context of heart disease prevention.

In Part 1 of this dissertation, I propose two studies that consider health beliefs, demographics, and patient behavior in the context of colorectal cancer screening behavior. Part 1 will utilize data collected for the Colorectal Cancer (CRC) Screening Adherence Trial, which was a three arm cluster randomized trial examining the effect of primary care provider recommendation of fecal occult blood test (FOBT) only, colonoscopy only, or a choice of either test on screening behavior. The study included people at average risk for CRC, aged 50-79, who were patients in the Community Health Network in San Francisco, CA.⁷⁸ The first proposed study seeks to understand the relationship between socio-demographic characteristics and constructs of the health belief model in the context of colorectal cancer screening behavior in a racially, ethnically, and linguistically diverse population. Because there are important racially/ethnically-based disparities in screening uptake, it is important to explore how patient decision support can be effectively targeted to improve screening in these groups.^{79,80} This study is important because it will help us to link simple socio-demographic characteristics with complex health beliefs in the context of colorectal cancer screening. The second proposed study seeks to develop a practical regression model to

predict the probability of completing colorectal cancer screening and, from this model, a framework for targeting patient decision support materials based on level of probability of completing CRC screening.

In Part 2 of this dissertation, I propose one study that will assess the use of an algorithm in patient decision support for heart disease prevention therapy. Part 2 will utilize data that was collected for the Heart Disease Prevention Discrete Choice Experiment (DCE) study, which was a mixed methods study looking at the differences between directly selected and statistically predicted (using a market simulation algorithm based on a discrete choice experiment) choice of heart disease prevention therapy. For this part of the dissertation, I will consider the qualitative data from the Heart Disease Prevention DCE study. Participants were interviewed about the discrete choice experiment and the market simulation algorithm results, as compared to their directly selected heart disease prevention therapy. The specific aims for both parts of this dissertation are below.

Part 1: Algorithm Development in Colorectal Cancer Screening Decision Making

Aim 1. To describe the relationship between socio-demographic characteristics and health beliefs regarding CRC screening among adults aged 50-79 years who are at average risk for CRC and not up-to-date with recommended CRC screening.

In a secondary analysis of the CRC Screening Adherence Trial data, we will explore and describe socio-demographic characteristics as they relate to the constructs of the health belief model.

Aim 2.1 (Primary). To develop a statistical model to predict probability of completing CRC screening among adults aged 50-79 years who are at average risk for CRC and not up-to-date with recommended CRC screening

Aim 2.2 (Secondary). Using the predicted probabilities of completing CRC screening, develop a simple targeting framework for patient decision support materials based on level of probability of completing CRC screening

In a secondary analysis of the CRC Screening Adherence Trial data, we will construct a model to predict probability of completing recommended CRC screening based on constructs of the health belief model, socio-demographic characteristics, health status, and previous health behaviors. We will, secondarily, use the predicted probability of completion of CRC screening from the model to develop a simple tailoring framework for patient decision support materials based on level of probability of completion of screening.

Part 2: Assessment of Algorithm Use in Heart Disease Prevention Decision Making

Aim 3. To explore attributes of decision making as they relate to an algorithm used in patient decision support.

Using qualitative data collected during the Heart to Heart Market Simulation study, we will explore how people are making decisions about heart disease prevention and whether those attributes differ from those used in a market simulation algorithm for heart disease prevention decision-making in a hypothetical patient decision-making scenario.

Conceptual Model

Figure 1.1 presents a conceptual model that illustrates the relationship between individual characteristics and the decision to use health services. This conceptual model guided the design and analysis of the dissertation aims. The framework includes elements of the Andersen-Newman model of healthcare utilization and depicts the direct link between individual socio-demographic characteristics, the pre-disposing, enabling, and need factors, with the decision to use health services.⁸¹ The model expands on the health beliefs component of the Andersen-Newman Model, adding in information needs and topic-specific decision-making factors, showing one possible pathway through which individual level characteristics relate indirectly to health care utilization. The benefit of this expansion is the potential for intervention using factors that are more malleable than those typically considered to describe pre-disposing, enabling, and need factors (e.g., income as a enabling factor).

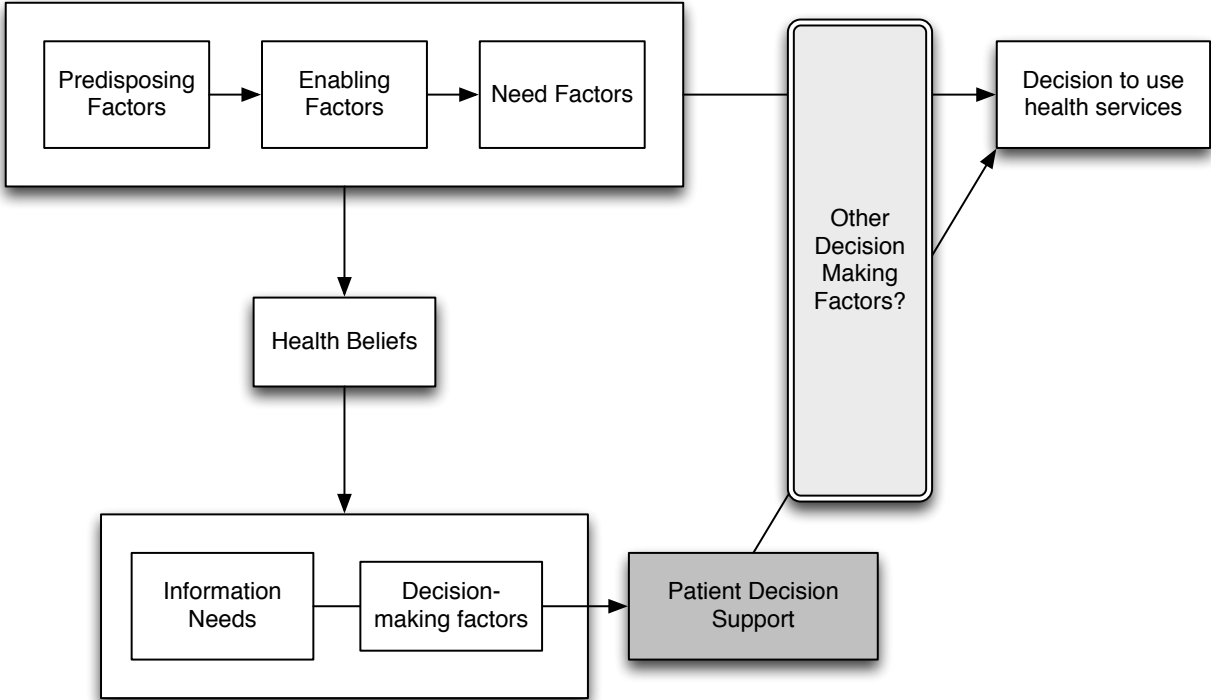
Central to this dissertation is the acknowledgment of the influence of individual socio-demographic characteristics and, by proxy, culture, on health beliefs and healthcare decision-making.⁸² Health behavior theory has typically relegated social context (i.e., socio-demographics and culture) to a peripheral role in terms of influence on health beliefs. In recent years, however, research is increasingly acknowledging that social context plays a more central role.⁸³ Social context is illustrated in the model in the top box, and it is connected unidirectionally with the health beliefs box.

The remainder of the conceptual model illustrates one potential pathway through which individual characteristics relate indirectly with health behavior. Following the influence of individual factors, health beliefs, in turn, influence information needs and decision-

making factors. The model also acknowledges that it is incomplete, and that other factors are likely influencing the decision to use health services.

The following three dissertation chapters focus on the pathways depicted in the conceptual model and attempt to identify some of the other decision making factors that the model does not incorporate. Chapter 2 investigates how individual level socio-demographic characteristics relate to health beliefs about colorectal cancer (CRC) and CRC screening. Chapter 3 presents the development of a model using socio-demographic characteristics and some health beliefs to predict healthcare decision-making for the purpose of designing and delivering interventions to promote CRC screening. Finally, Chapter 4 explores what other factors may be influencing decision-making for heart disease prevention therapy choices.

Figure 1.1. Conceptual Model



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Chapter 2. Race/ethnicity and primary language: Health beliefs about colorectal cancer screening in a diverse, low-income population

Abstract

Objectives: This study, informed by the Health Belief Model (HBM), involved a large multi-ethnic population enrolled in a colorectal cancer (CRC) screening program. We aimed to determine if perceptions of susceptibility to and severity of CRC and benefits and barriers to screening differ by race/ethnicity and primary language.

Methods: Participants completed a baseline survey (2007-2008) including items that measured the HBM. HBM constructs were scored on a scale of 1-5 and dichotomized for analysis. Logistic regression was used to test multivariable associations between race/ethnicity-language with health beliefs.

Results: 933 (93.5%) participants were included in this analysis. Participants were mostly Asian (29.7%) or Hispanic (34.3%). 40% and 23% of Asian and Hispanic participants, respectively, spoke English. 53.7% were female, and the mean age was 58.4. Non-English speaking Hispanics ($p<0.001$) and English-speaking Asians ($p=0.002$) reported lower perceived susceptibility than non-Hispanic Whites. Non-English speaking Hispanics reported more perceived barriers and non-English speaking Asians had fewer perceived barriers than non-Hispanic Whites. English-speaking Hispanics and Asians were not different from non-Hispanic Whites in terms of health beliefs.

Conclusion: We found that racial/ethnic and language groups perceived susceptibility and barriers differently. Further analysis is needed to determine the independent effect of these health beliefs on screening behavior.

Introduction

Colorectal cancer (CRC) is the third leading cause of cancer death in the United States among men and women of all races and ethnicities.¹ CRC screening is effective, but many adults are not up to date with recommended screening.²⁻⁵ Further, racial/ethnic minority populations report lower screening rates than non-Hispanic White populations, particularly in the less acculturated.⁶⁻¹⁰ Studies that have considered the affect of acculturation on CRC screening behavior have often found that the more acculturated tend to complete screening more than the less acculturated.¹¹⁻¹³

Although extensive research has been done to understand factors contributing to screening disparities by race/ethnicity and acculturation little has been written about individual health beliefs across racial/ethnic and acculturation level groups.¹⁴⁻¹⁸ The Health Belief Model (HBM) is a behavioral theory that was developed to explain how an individual's beliefs and perceptions of an illness influence preventive health behaviors, including CRC screening. The HBM posits that the way an individual perceives several concepts with respect to a disease can predict why people participate in preventive health care. These concepts include susceptibility to and seriousness of a disease, and the benefits and barriers to a behavior preventing a disease.¹⁹ There is evidence that supports a relationship between these concepts and CRC screening completion in racial/ethnic minority populations. Studies in Hispanic and Asian populations in the US have shown that those who perceived fewer barriers were more likely to complete screening.^{14,15,17} Additionally, some research has shown that those with higher perceived susceptibility and greater worry about getting CRC (a sub-concept of susceptibility) are more likely to complete screening.^{17,18,20}

Constructs of the HBM, particularly perceived barriers, have been used successfully in informing the design of interventions to promote cancer screening, and some of these

interventions have been in racially and ethnically diverse populations. Tu and colleagues²¹ conducted a large randomized trial testing the effectiveness of an intervention to promote CRC screening in a Chinese population where a health educator addressed specific barriers to screening completion. Nearly 70% of those who received the intervention completed screening, compared with less than 30% of the control arm. Allen and Barzagan, similarly, found that an intervention aimed at urban Hispanics and African-Americans that addressed perception of barriers, such as cost of testing or fear of test results, achieved an increase in participation in breast cancer screening.²² The findings from these previous studies suggest that understanding key differences in health beliefs across racial/ethnic groups may be useful for targeting health information for CRC screening promotion. Using this knowledge in the intervention design stage may result in more effective interventions.²³⁻²⁵

Guided by the HBM, we examined the relationship between race/ethnicity and language preferences on individual health beliefs across 4 racial/ethnic groups (non-Hispanic Whites, non-Hispanic Blacks, Asians, and Hispanics) and reported primary language (English, Non-English) as a proxy for level of acculturation.²⁶

Methods

We analyzed data collected as part of the Colon Cancer Screening Adherence Study²⁷, a randomized trial of competing strategies for CRC screening promotion conducted in a low income, predominantly non-white safety-net population in San Francisco. Participants completed a survey upon entry to the study that included items measuring constructs of the HBM and self-reported race/ethnicity and primary spoken language. The purpose of this analysis is to establish whether health beliefs about CRC and CRC screening differ across racial/ethnic and language groups.

Study Design

The CRC Adherence Study was a three-arm randomized trial in which patients were randomized to an offer of fecal occult blood test (FOBT) only, colonoscopy only, or a choice of either by their primary care physician. The purpose of the study was to estimate the effect of choice on CRC screening decision-making and behavior; thus, barriers inherent to the public hospital system were reduced or eliminated to the extent possible. For example, screening instructions were provided in the patients' preferred language, all costs of screening tests were covered, colonoscopies were scheduled directly within two weeks of enrollment in the study, transportation to and from the endoscopy center was provided if necessary, and FOBT cards were returned to research staff upon completion. The research staff were all bilingual, and they all spoke English (English and Spanish; English and Mandarin Chinese; English and Cantonese Chinese). A detailed description of the participants' recruitment has been reported in the literature.²⁷ This analysis used only data collected at study enrollment.

Study Participants

Three clinics in the San Francisco Community Health Network participated in the study. Eligible participants were patients at one of these clinics, aged 50-79 years, at average risk for CRC, and not up-to-date with recommended screening. Participants were enrolled in the study between 2007-2008, and 933 (93.5%) of 997 study participants had complete baseline data and were included in this analysis.

Dependent variables.

We measured perceived susceptibility, perceived severity, perceived benefits, and perceived barriers using a 23-item survey (Table 2.1) that resulted in 17 construct or sub-

construct measures. The development of these items is described in detail elsewhere.^{28,29} Each survey item used a 5-point Likert response scale and each summary score was calculated by averaging the items used to measure the specific construct. Each construct score ranged from 1 to 5, and higher score indicated greater perception. The average score was dichotomized using 3 as a cutoff. For instance, a score less than 3 indicated lower perception while 3 or greater indicated higher perception of that construct. See Table 2.1.

Perceived susceptibility consisted of two components, cognitive perceived susceptibility and affective perceived susceptibility.³⁰ Cognitive perceived susceptibility measured the perception of personal susceptibility of getting colorectal cancer and included three survey items. Affective perceived susceptibility measured worry about diagnosis and treatment for colorectal cancer and included two survey items.

Perceived severity was collected using three survey items that measured the extent of the individuals' perception of the seriousness of getting a CRC, such as likelihood of dying from CRC if you get it. The items were summed to generate an average score.

Perceived benefit was collected using two survey items that measured perception of beneficial aspects of screening, such as decreasing chance of death from CRC.

Perceived barriers were measured with thirteen items, and each item was scored separately. For each item, respondents rated how important the barrier would be to them in making a decision about CRC screening. A sample barrier was participants' fear of test results.

Independent Variables

The primary predictors for this analysis were race/ethnicity and primary spoken language, measured by participant self-report. A combination of race and ethnicity was used to create four categories: non-Hispanic White, non-Hispanic Black, Hispanic, and Asian. Those who responded as “Other” for race/ethnicity were too few to be examined separately (n=35) and were, therefore, excluded. We further categorized racial/ethnic groups by primary spoken language as English or non-English.^{9,31} This resulted in six categories: non-Hispanic White -English; non-Hispanic Black-English; Hispanic-English; Hispanic-non-English; Asian-English; and Asian-non-English.

Analyses adjusted for covariates that included seven major areas: health access^{10,11}, demographics^{12,32}, health status^{12,32}, physician recommendation of screening^{17,33}, physician characteristics,^{34,35} socioeconomic status¹², and social support³². The variables are presented in detail in Table 2.2 and in our conceptual model in Figure 2.1.

Analytic Methods

To examine whether health beliefs differed across racial/ethnic and language groups, we first performed descriptive analyses, looking at the proportion of each group reporting high versus low perception of each HBM construct. Next, using each of the dichotomized HBM construct or construct components as outcomes, we performed seventeen separate logistic regressions with robust standard errors to test potential associations with race/ethnicity and primary language, controlling for the demographic characteristics and other covariates described above. We used Wald tests, at an alpha level of 0.025, for establishing associations between race/ethnicity and primary language groups and each HBM construct.

Results

Participants included in the analysis were mostly Asian (30.7%) or Hispanic (35.6%). All non-Hispanic White and Non-Hispanic Black participants spoke English. Fewer than half of Asian and Hispanic participants spoke English (40% and 23%, respectively). Slightly more than half (53.7%) were female and the mean age was 58.5 years. Non-Hispanic Whites were less likely to be female and somewhat more likely to be more educated than any other racial/ethnic and language groups. English-speaking Asian participants were somewhat older than other racial/ethnic groups. We observed the opposite trend among Hispanics, with those who did not speak English being somewhat older than others (Table 2.3).

Cognitive Susceptibility

Hispanic respondents, regardless of primary language, and English-speaking Asian respondents reported lower cognitive perceived susceptibility than other racial/ethnic groups (Table 2.4). In multivariable analysis, English-speaking Hispanic respondents remained significantly more likely to report lower cognitive perceived susceptibility (OR 0.40; $p=0.003$) than English-speaking non-Hispanic Whites. Non-English speaking Hispanic respondents were even more likely to report lower cognitive perceived susceptibility (OR 0.16; $p<0.0001$). Additionally, English-speaking Asian respondents were also more likely to report lower cognitive perceived susceptibility (OR 0.40; $p=0.002$) (Table 2.5).

Affective Susceptibility, Severity, and Benefits

There were no significant differences across racial/ethnic and language groups in perception of affective susceptibility, severity, or benefits. Few respondents reported an elevated sense of worry (affective susceptibility). There were also no differences in sense of worry between racial/ethnic and language groups ($p=0.29$). Nearly all respondents,

regardless of racial/ethnic subgroup and primary language, reported high perceived severity of CRC ($p=0.17$). Nearly all respondents reported lower rather than higher perceived benefits of screening and this did not differ across racial/ethnic and language groups ($p=0.71$) (Table 2.4 and Table 2.5).

Perceived Barriers

Perception of barriers to screening varied considerably across racial/ethnic and language groups (Table 2.4). Among non-English speaking Hispanics, discomfort during the test was significantly less important than it was to English-speaking non-Hispanic Whites (OR 0.37 $p=0.001$). Prior testing experience (OR 18.3; $p<0.0001$), and the preparation for the test (OR 3.06; $p<0.0001$) were all significantly more important to non-English speaking Hispanics than to English-speaking non-Hispanic Whites. Perception of the need for sedation during the test was marginally different for non-English speaking Hispanics (1.11; $p=0.045$). With the exception of discomfort during the test, perceived barriers to screening did not differ between English speaking Hispanics and Whites. (Table 2.5)

Among non-English speaking Asians, the perception of potential need for additional testing (OR 0.14; $p<0.0001$), fear of the results of the test (OR 0.20; $p=0.001$), concern about possible complications from the procedure (OR .23 $p<0.0001$), and the need for sedation (OR 0.30; $p=0.002$) was significantly lower than among non-Hispanic English-speaking Whites. Report of anxiety about the procedure as a potential barrier was marginally different for non-English speaking Asians (OR .44; $p=0.04$). English speaking Asians and non-Hispanic Whites were similar in their perception of barriers. Perception of the cost of testing, however, was marginally different for English-speaking Asians than for English

speaking non-Hispanic Whites (OR 1.97; $p=0.03$) but not for non-English speaking Asians ($p=0.52$) (Table 2.5).

Discussion

This study examined how individual perceptions of health beliefs differ across racial/ethnic and language groups guided by theoretical frameworks of HBM. In general, our findings show that participants who spoke English report comparable health beliefs across all constructs (perceived susceptibility, perceived severity, perceived benefits, and perceived barriers) regardless of race/ethnicity. However, we observed differences on reports of health beliefs between participants who did and did not speak English and between racial/ethnic groups in participants who did not speak English. Specifically, non-English speaking Asians and Hispanics reported a lower perception of susceptibility to CRC than did English-speaking non-Hispanic Whites. Additionally, non-English speaking Hispanics reported higher perception of several barriers to CRC screening completion than English-speaking non-Hispanic Whites. Non-English speaking Asians, however, typically reported lower perception of barriers to CRC screening completion.

Our results concerning the dependence of health beliefs were dependent on primary spoken language are consistent with some previous research that has shown, in similar populations to those in our study, distinct health beliefs about cancer and cancer screening, and possible differences in these populations compared to non-Hispanic White populations.³⁶⁻³⁸ Our study expands these findings by directly comparing health beliefs across racial/ethnic and language groups. Lower perception of personal susceptibility to CRC among non-English speaking Hispanics and Asians, as compared to non-Hispanic Whites, could be a contributor to disparities in screening. While both Asians and Hispanics do have a lower risk of CRC than non-Hispanic Whites in the US, it is still a top cause of

cancer death in both racial/ethnic groups. Previous work has established a relationship between perceived susceptibility and CRC screening completion.^{14,17} In a study that included Hispanics, Shokar and colleagues found that people with lower perception of susceptibility to CRC were less likely to complete screening. However, they did not see differences in perception of susceptibility between Hispanics and non-Hispanic Whites.¹⁷ One possible reason for the difference in findings is that we separated perceived susceptibility into cognitive and affective perceived susceptibility, whereas Shokar did not. Affective perceived susceptibility was not different across racial/ethnic and language groups in our study. To our knowledge, no other study has reported on differences in perceived susceptibility comparing Asians and non-Hispanic Whites.

There was considerable variation in the racial/ethnic groups who did not speak English with regards to perception of barriers to screening; several barriers were clearly of greater importance to non-English speaking Hispanics than to non-Hispanic Whites (prior testing experience, preparation for the test, need for sedation). These differences may be important in understanding screening disparities between non-Hispanic Whites and non-English speaking Hispanics. Several past meta-analyses of studies using the HBM have all shown support for perceived barriers being influential in predicting screening behavior.^{25,39,40} The specific differences in perception of barriers that we observed suggest certain areas where Hispanics may differ from non-Hispanic Whites, which could explain some of the disparities in CRC screening for Hispanics. These barriers could be targeted in interventions to promote CRC screening in these populations.

Interestingly, non-English speaking Asians reported *lower* perception of several barriers than non-Hispanic Whites (need for additional testing, fear of results of the test,

concern about complications from the test, need for sedation, anxiety about the procedure). This observation does not explain why there appears to be similar disparities in CRC screening for Asians as there are for Hispanics, as compared to non-Hispanic Whites.^{8,41} Past research considering how perception of barriers affects CRC screening in Asian populations has been mixed. Nguyen and colleagues found in a Vietnamese population that greater perception of some barriers lead to lower screening uptake, but greater perception of other barriers was associated with greater screening uptake.¹⁴

The results of our study should be interpreted with the following limitations in mind. First, these data were obtained from a trial in which many barriers to CRC screening were mitigated. It is possible that this understanding affected participants' reporting of potential barriers to screening. However, this would most likely cause all respondents to report fewer barriers. Second, the participants in our study were low-income and receiving care at a safety net. Therefore, results may not be generalizable to higher-income populations or to individuals with private health insurance. Finally, our assessment of barriers, while specific to CRC screening, was not specific to a particular CRC screening test (e.g., barriers to completing FOBT). There may be some variation in how participants interpreted barriers as we assessed them.

The results of this study give insight into differences in health beliefs about CRC and CRC screening between minority populations and non-Hispanic White populations in the US. These findings may suggest areas that could be targeted in interventions to promote CRC screening in these populations. An intervention directed toward non-English speaking Hispanic populations, for example, might focus more heavily on information about test preparation and sedation than would one directed toward an Asian population. Future

studies will examine the independent effect of the differences in health beliefs that we observed on screening behavior in this population.

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Figure 2.1. Conceptual model depicting the relationship between socio-demographic and health factors with individual health beliefs

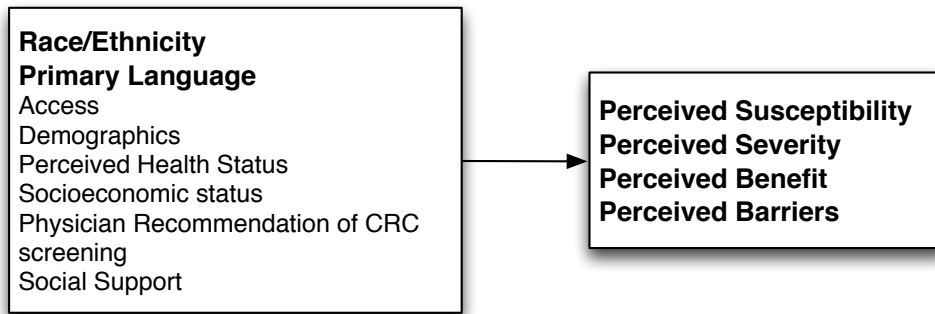


Table 2.1. Dependent variables - Health Belief Model assessment measures

Health Belief Model Variables		
Construct	Definition	Items/Assessment
Perceived susceptibility	Cognitive – perception of personal risk of colon cancer	<ul style="list-style-type: none"> - Compared to other people your age, what do you think your chance is of getting colorectal cancer? - How likely do you think it is that you could develop colorectal cancer sometime in the future? - I do not need to worry about developing colorectal cancer because I get regular doctor check-ups.
	Affective – worry about personal risk of colon cancer	<ul style="list-style-type: none"> - I don't want to be screened for colorectal cancer because I am afraid of the results. - I do not want to know that I have colorectal cancer because I'm afraid of the treatment.
Perceived severity	Perception of severity of colon cancer	<ul style="list-style-type: none"> - How serious would it be if you developed colorectal cancer? - Most people who develop colorectal cancer die from the disease. - If I were to develop colorectal cancer, it would totally change my life.
Perceived benefits	Perceived benefits of colon cancer screening	<ul style="list-style-type: none"> - Finding colorectal cancer early will decrease my chances of dying from colorectal cancer. - Finding colorectal cancer early will make the treatment easier.
		<p><u>Even if you have never been screened</u>, on a scale of 1 to 5 where 1 is “not at all important” and 5 is “extremely important”, please check the box that best describes how important the following factors <u>would be</u> for you if you were making this decision.</p> <p>Prior experience with testing. . .</p> <p>Cost . . .</p> <p>Discomfort . . .</p> <p>Embarrassment . . .</p> <p>Accuracy of results. . .</p> <p>Not enough time. . .</p> <p>Avoiding need for additional tests. . .</p> <p>Fear of the results. . .</p> <p>Transportation problems. . .</p> <p>Anxiety about the procedure. . .</p> <p>Concern about complications. . .</p> <p>Preparation . . .</p> <p>Need for sedation. . .</p>
Perceived barriers	Perceived barriers to screening	

Table 2.2. Independent Variables

Domain	Variables
Health Care Access	Insurance Status
	Transportation to colonoscopy needed
Acculturation	Primary spoken language
Demographics	Sex
	Age
	Race/Ethnicity
Health Status	Self reported health status
MD Recommendation	Any CRC test recommended
	Any CRC test discussed
Physician Characteristics	Sex of physician
	Language spoken by physician
SES	Educational level
	Income
	Employment Status
Social Support	Married or Partnered

Table 2.3. Characteristics of study sample, by race/ethnicity and primary spoken language

	All N=933	White n=143	Black n=171	Asian		Hispanic	
				English n=114	Non-English n=173*	English n=76	Non-English n=256*
Age (m)	58.5	55.9	56.2	60.5	59	57.4	60.6
Gender (%F)	53.7	24.1	41.5	64.9	69.4	38.2	71.5
Education (%)							
<High School	33.4	5.6	16.4	17.5	45.1	22.4	66.4
HS Grad	28.8	24.2	41.5	31.6	39.9	30.3	14.5
Some College	18.9	31.5	30.4	11.4	4.1	29.0	12.9
College +	18.9	38.8	11.7	39.5	11.0	18.4	6.3
Unemployed	65.9						
Annual Income							
<\$10,000	57.1	49.4	57.9	51.8	37.0	46.1	81.3
\$10,000- \$19,999	31.9	38.2	29.8	40.4	41.0	38.2	17.2
\$20,000- \$29,999	8.0	7.9	7.6	7.9	16.8	11.8	1.2
>=\$30,000	3.0	4.5	4.7	0.0	5.2	4.0	0.4

*Non-English Speaking

Table 2.4. Proportion reporting higher vs. lower perception of each HBM construct, by race/ethnicity and primary spoken language

	All N=933	White n=143	Black n=171	Asian		Latino	
				English n=114	Non-English n=173	English n=76	Non-English n=256
Cognitive Susceptibility	0.47	0.66	0.53	0.47	0.67	0.43	0.20
Affective Susceptibility	0.10	0.11	0.11	0.18	0.10	0.15	0.05
Severity	0.97	0.95	0.97	0.94	0.98	0.99	0.97
Benefits	0.03	0.08	0.05	0.02	0.02	0.01	0.02
Barriers							
Prior testing experience	0.58	0.53	0.61	0.47	0.18	0.53	0.93
Cost	0.65	0.61	0.56	0.72	0.69	0.68	0.65
Discomfort	0.45	0.48	0.50	0.46	0.51	0.57	0.32
Embarrassment	0.23	0.21	0.23	0.15	0.13	0.34	0.31
Test Accuracy	0.97	0.94	0.98	0.95	0.97	0.97	0.98
Time	0.22	0.22	0.23	0.25	0.33	0.20	0.13
Need for additional Testing	0.20	0.25	0.23	0.24	0.08	0.26	0.19
Fear of test results	0.22	0.23	0.22	0.25	0.12	0.25	0.27
Transportation	0.14	0.13	0.19	0.14	0.08	0.09	0.18
Anxiety	0.29	0.27	0.32	0.27	0.20	0.25	0.36
Complications	0.38	0.31	0.43	0.34	0.22	0.36	0.51
Prep	0.47	0.36	0.44	0.44	0.32	0.45	0.67
Sedation	0.58	0.55	0.57	0.57	0.36	0.61	0.74

Table 2.5. Multivariate results by race/ethnicity and primary spoken language

	White	Black		Asian				Latino			
		OR	p	English	p	Non-English	p	English	p	Non-English	p
Cognitive Susceptibility	ref	.63	0.078	0.40	(0.002)	1.10	(0.81)	0.40	(0.003)	0.16	(<0.0001)
Affective Susceptibility	ref	0.88	(0.74)	1.37	(0.46)	0.91	(0.89)	1.33	(0.51)	0.50	(0.23)
Severity	ref	1.43	(0.56)	0.43	(0.18)	1.50	(0.75)	3.25	(0.28)	0.88	(0.89)
Benefits	ref	0.51	(0.22)	0.35	(0.17)	0.62	(0.74)	0.24	(0.17)	0.62	(0.59)
Barriers											
Prior testing experience	ref	1.46	(0.13)	0.69	(0.21)	0.60	(0.28)	0.99	(0.96)	18.30	(<0.0001)
Cost	ref	0.89	(0.62)	1.97	(0.03)	1.28	(0.52)	1.39	(0.30)	1.01	(0.98)
Discomfort	ref	1.14	(0.58)	0.91	(0.72)	0.63	(0.22)	1.41	(0.24)	0.37	(0.001)
Embarrassment	ref	1.06	(0.84)	0.63	(0.21)	0.47	(0.09)	1.87	(0.07)	1.13	(0.71)
Test Accuracy	ref	1.83	(0.38)	0.84	(0.79)	1.78	(0.50)	1.75	(0.48)	2.30	(0.38)
Time	ref	1.12	(0.71)	1.15	(0.67)	0.91	(0.84)	0.81	(0.56)	0.48	(0.07)
Need for additional Testing	ref	0.71	(0.24)	0.89	(0.73)	0.14	(<0.0001)	0.88	(0.71)	0.51	(0.09)
Fear of test results	ref	0.82	(0.50)	1.04	(0.91)	0.20	(0.001)	1.08	(0.83)	0.81	(0.56)
Transportation	ref	1.21	(0.58)	1.01	(0.98)	0.42	(0.13)	0.61	(0.30)	1.12	(0.80)
Anxiety	ref	1.04	(0.89)	0.74	(0.33)	0.44	(0.04)	0.81	(0.52)	1.15	(0.67)
Complications	ref	1.42	(0.18)	0.86	(0.61)	0.23	(<0.0001)	1.05	(0.89)	1.21	(0.53)
Prep	ref	1.31	(0.28)	1.33	(0.32)	0.66	(0.28)	1.49	(1.91)	3.06	(<0.0001)
Sedation	ref	1.00	(1.00)	1.09	(0.76)	0.30	(0.002)	1.32	(0.36)	1.81	(0.045)

Chapter 3. Development of a practical framework for targeting patient decision support on colorectal cancer screening

Abstract

Objective: To develop a practical and useful model for predicting probability of colorectal cancer (CRC) screening completion among a racially and ethnically diverse safety net population and a subsequent framework for targeting patient decision support to level of activation.

Methods: Using prospectively collected data from participants in a randomized trial to promote CRC screening, we built a practical model to predict probability of CRC screening completion. We evaluated the model using a cross-validation method by randomly splitting the data in to training and validation samples. We then trichotomized the predicted probabilities into low, medium, and high probability groups for designing and delivering targeted patient decision support interventions. We cross-validated the groups by defining cut-points in the training sample, applying them to the validation sample, and comparing across the samples for homogeneity.

Results: A model using simple demographic and psychosocial measures predicted screening behavior adequately, with an AUROC of 0.63 in the validation sample. The cut-points in the probabilities formed groups that were homogeneous across the training and validation samples.

Conclusions: The model and subsequent framework may be useful for designing and delivering targeted interventions to promote CRC screening. Future research is required to validate the framework groups.

Introduction

Colorectal cancer (CRC) is the third leading cause of cancer death in the United States. CRC screening is effective at finding cancer or pre-cancerous growths.¹⁻⁴ The United States Preventive Services Task Force recommends regular screening for adults ages 50-75.⁵ However, completion of recommended screening remains suboptimal.²⁻⁴ Despite significant increases in screening completion over the last decade, only 65% of adults are up to date with recommended screening practices.⁶ This figure is much lower in racial and ethnic minority groups in the United States; among Asian and Hispanic Americans specifically, only 45% and 47%, respectively, are up to date with CRC screening.^{7,8}

Patient decision support has been shown to increase completion of CRC screening, but implementation can be difficult and expensive.⁹⁻¹³ Additionally, in the absence of significant effort by research or clinic staff, uptake of patient decision support materials tends to be low, which can minimize the effect on screening rates.^{10,13,14} One possible reason for low uptake may be that patient decision support materials are not targeted at patients' information needs.¹⁵ Patient decision support strategies for CRC screening promotion may be more effective when targeted at the information needs of specific groups. But identifying the information needs of a patient or a group of patients can be challenging.

One potential approach for identifying information needs is to measure patient activation.^{16,17} Patient activation is defined as a patient's willingness and ability to participate in and make health care decisions.¹⁸ There is some evidence that patient decision support interventions targeted at patient activation level improve participation in preventive care more effectively than non-targeted interventions.^{18,19} Hibbard and colleagues developed the Patient Activation Measure (PAM) to formally assess patient activation level.¹⁶ While the PAM has been validated and shown to be a useful tool for

targeting interventions, it consists of 13-22 items, depending on the version, and is therefore time-intensive to administer and complete. Using a time-intensive instrument such as the PAM to identify patients for targeted decision support may not be feasible in a busy clinic setting.²⁰ It may, alternatively, be possible to identify information needs by identifying how likely a patient is to complete CRC screening using existing clinical data and a few simple patient-reported items.

The goals of this project were twofold. First, we sought to develop a simple, practical model to predict the individual probability of completing screening using as few items as possible, while still maintaining reasonable predictive accuracy. And second, using the results of this model, we sought to develop a three-level framework for use in designing and delivering patient decision support interventions targeted at the information needs of patients at low, medium, and high probability of completing CRC screening in a multi-ethnic, low-income population. We present the development of the model and the subsequent intervention design framework in this paper.

Methods

Study Design

The data used in this analysis come from the CRC Adherence Study, which was a randomized trial. Participants were randomized to one of three study arms in which their primary care provider offered fecal occult blood test (FOBT) only, colonoscopy only, or a choice of either test. The purpose of the study was to estimate the effect of choice on CRC screening decision-making and behavior; thus, barriers inherent to the public hospital system were reduced or eliminated to the extent possible. A detailed description of the participants' recruitment has been reported in the literature.²⁴ Participant enrollment began

in 2007, and data collection was completed in 2012. Participants were followed-up for CRC screening completion for 12 months after study enrollment. This paper used data collected at baseline and follow-up.

Study participants

Three clinics in the San Francisco Community Health Network (CHN) participated in the study. The CHN is the primary “safety net” within which the majority of people with low-income or inadequate or no insurance receive medical care; within the CHN, FOBT and colonoscopy are available to all city residents regardless of their insurance status. Eligible participants were patients at one of these clinics, aged 50-79 years, at average risk for CRC, and not up-to-date with recommended screening. Participants were enrolled in the study between 2007-2008. 806 (81%) of 997 study participants had complete data and were included in this analysis. Excluded participants were more likely to be male (54% vs. 45%) and less likely to be adherent (52% vs. 68%). Among the included participants, adherence to any CRC screening test did not differ across the study arms.

Part 1: Developing the model

Dependent Variable

Our outcome of interest was completion of any colon cancer screening test. Completion of screening was assessed prospectively up to 12 months after enrollment in the study. FOBT was considered to be complete when the FOBT kit was returned to the study office (it was then submitted to the appropriate physician office for processing). Colonoscopy was considered to be complete if there was documentation in the medical record of completion. If neither test was completed within 12 months according to these

definitions, research staff called study participants to verify non-completion. Patient self-report of out-of-system screening was recorded as completion. We modeled our dependent variable using logistic regression.

Candidate Variables

Prior to beginning construction of the prediction model, we selected a pool of candidate variables. These variables were either well represented in the literature as being associated with screening behavior or were among psychosocial characteristics that measured the Health Belief Model or patient trust in primary care provider or trust in the medical profession in general.²²⁻²⁴ Prior to constructing the prediction models, we characterized the candidate variables according to the difficulty of collecting them. We categorized the candidate variables as: 1) Existing data – information likely to be in a patient medical record, 2) Simple measures – information not typically in a medical record, but conceptually simple to collect (e.g., primary language), or 3) Psychosocial measures – items measuring constructs of the Health Belief Model (HBM) and patient trust, which are more conceptually difficult. HBM constructs were measured using items previously developed by Janz and colleagues.^{22,24} Patient trust was assessed using two subscales of the Wake Forest Trust Scale: trust in primary care provider, which measures the level of trust a patient has for his or her personal doctor; and trust in doctors in general, which measures the level of trust a patient has in medical care providers as a group.²³

Independent variables were all collected at baseline with the exception of patient trust, which was added to the baseline survey in 2008. Participants who enrolled prior to this time completed the trust items at a follow-up visit. A prior analysis revealed no

meaningful differences in trust based on time of assessment.²⁵ All candidate variables are described in detail in Appendix 3.1.

Variable Selection and Model Construction

Variable selection was based on our previous research and a recent review of the literature.²¹ Because of the purpose of the framework to result from the model (delivering education), the risks associated with misclassification (i.e., classifying someone as likely to complete screening when they are actually unlikely) are minimal. Therefore, our goal was to build a simple and practical model that could be feasibly used in a busy clinic setting to inform a targeting framework. We selected variables iteratively so as to achieve a balance between parsimony, in terms of number and complexity of variables, and accuracy, in terms of ability to predict CRC screening behavior. We chose variables for our model based *first* on difficulty of collection (existing data, simple measures, psychosocial measures, described above) and *second* on evidence in the literature for association with CRC screening behavior. Instead of relying on individual variable significance, which can result in over fitting and poor prognostic performance in new data, we built and assessed whole models to find our final model. Ultimately, we built and assessed fifteen models using different combinations of the candidate variables.

Model Assessment

To test the performance of each of the fifteen potential models, we used a cross-validation method, randomly subsampling training and validation datasets. We built each model in the “training” sample and assessed discrimination (predictive performance) and calibration (model fit) statistics in the “validation” sample. To assess predictive performance, we calculated the area under the receiver operator curve (AUROC), or c-

statistic, and to assess calibration, we used the Hosmer-Lemeshow (H-L) statistic for goodness of fit.²⁶

In this report, we present three of the fifteen potential models for comparison, of which we selected one as our final model. To fulfill our goal of a simple and practical model, we considered the balance of model performance with number and complexity of the measures necessary to power the model. We selected as our final model the one that best balanced simplicity and practicality with performance.

Part 2: The intervention design framework

Generating the framework groups

Following the selection of the final model, we developed a three-level intervention design framework based on high, medium, or low probability of completing screening.^{9,27,28} We defined the three groups according to the individual probability of completing screening. First, we predicted individual probability of completing CRC screening from the model in both the training and validation datasets, defined in the model construction stage, using the final model. We then will cut the predicted probabilities of completing colorectal cancer screening, assigning people to the three levels of readiness to complete screening.

Evaluating the framework groups

To evaluate the framework, we defined cut points for in the predicted probabilities of completing CRC screening in the training sample and then apply the same cut points to the validation sample. We compared the distribution of screening completion and socio-demographic and psychosocial variables across the three groups in the two datasets, and to similar groups described in the literature.^{9,27} We revised the cut points iteratively to increase

homogeneity of the comparative groups and similarity to the characteristics described in the literature (Figure 3.1).

Results

Study Population

Eight hundred and six participants were included in this analysis. The mean age of included participants was 58, most were female (55%), self-reported as either Asian (33%) or Latino (32%), and spoke English (55%). Participants were enrolled between March 2007 and October 2008. About 68% completed screening within 12 months of study enrollment. For this analysis, we include participants who had no missing data and had completed the patient trust survey, added later in the study. The randomly selected cross-validation samples were 402 in the training sample and 404 in the validation sample (Table 3.1). There were not differences across the subsamples. Because we had a large number of outcomes, we felt that this sample size was large enough to allow for construction of a valid model.²⁹

Part 1: Developing the model

We constructed and tested three different models with different numbers of covariates and levels of performance. All model performance statistics are in Table 3.2 and Figure 3.2 and model covariates, coefficients, and standard errors are in Appendix 3.2.

Model 1: Existing Data Model

We constructed this model using covariates categorized as “existing data.” We included insurance status, patient gender, age, race/ethnicity, PCP gender, and patient-PCP

gender concordance. This model had an AUROC of 0.59 and was well calibrated (Hosmer-Lemeshow $p=0.27$). The sensitivity and specificity were 94.6% and 10.2%.

Model 2: Existing Data and Simple Measures Model

For our next model, we added some simple measures to the previous existing data model. In addition to the variables included in the previous model, we added self-reported health status, family history of CRC, language, PCP-patient language concordance, and past PCP recommendation of CRC screening. This model would require that four simple measures be collected: health status, family history of CRC, primary language, and PCP recommendation of screening. This model had an AUROC of 0.63, and was well calibrated (H-L $p=0.13$). The sensitivity and specificity were 91.0% and 17.3%.

Model 3: All Covariates Model

In this model, we included all candidate variables, adding to the previous models some additional simple measures, the two patient trust scores, and scores for constructs of the Health Belief Model. This model would require the collection of the 40 items, including seven items to collect the simple measures, ten to measure trust, and twenty-three to measure the Health Belief Model constructs. This model had an AUROC of 0.61, but was not well calibrated (H-L $p<0.0001$). The sensitivity and specificity were 88.9% and 21.9%.

Other Models

We considered several other models that we do not report in detail here. We tested models including variables summarizing the Health Belief Model and patient trust in doctors in general. These models had either poor performance, poor calibration, or required too many complex measures to be useful in a practical scenario.

Model Selection: Model 2

The model that best balanced simplicity with accuracy was Model 2. While Model 1 does not require any data collection, we felt that the predictive ability of the model was too low to be useful. Model 3 did not improve on Model 2's predictive ability and required the collection of a larger number of more complex psychosocial measures (Table 3.2 and Figure 3.2).

Part 2: The intervention design framework

The individual predicted probabilities in the training and validation samples had similar distributions. The means were similar (0.66 training; 0.68 validation) and both were left skewed. We trichotomized the training sample into three equal groups of 134 individuals of low, medium, and high screening probability. Cut points in the predicted probabilities of screening completion were 0.62 (low), 0.74 (medium), and 1.0 (high). We applied these cut points to the validation sample. When we compared the distribution of screening completion rates and socio-demographic characteristics in the low, medium, and high screening probability groups in training and validation samples, we found few differences. In the validation sample, the low screening probability group had slightly more males (32% vs. 24%, $p=0.05$) (Table 3.3, Figure 3.3, Appendix 3.3).

Discussion

For this project, we developed and compared three predictive models and used the results to construct a useful framework for designing multi-level interventions to promote colorectal cancer screening. We presented three models with different levels of complexity,

with the goal of selecting the model that best balanced simplicity with accuracy. The model we selected contained mostly information that is likely to be in a patient medical record, supplemented by a few simple measures. The model's AUROC was 0.63, indicated adequate ability to discriminate between those who would become screened and those who would not.

Our previous research indicated that complex psychosocial characteristics, particularly trust in primary care provider, are predictive of CRC screening behavior.²⁵ Interestingly, however, we found that these complex psychosocial characteristics did not improve the predictive capability of the model enough to justify the difficulty of collection. The resulting practical model includes simpler psychosocial characteristics, such as perceived health status and physician gender concordance, and simple demographic characteristics. It requires the collection of only four simple measures, fulfilling our goal of simplicity. Additionally, it has an adequate predictive ability, fulfilling our goal of reasonable predictive accuracy.

The Adherence Study data provides a unique platform to identify individual level characteristics that predict CRC screening in the absence of system-level barriers, which were largely removed as part of the study.²¹ Patients who became screened during the study period likely represent: 1) Patients who would complete CRC screening, regardless of the presence or absence of system-level barriers, and 2) Patients who want to complete CRC screening, but might not in the presence of system-level barriers. Previous research that has assessed why some people do not complete CRC screening has found system level barriers to be important.^{30,31} This may suggest that many more patients are interested in completing screening than actually do. The framework that we developed can be used to categorize

individuals into low, medium, and high probability of going on to complete screening in the future for the purpose of targeting interventions to the information needs of these groups. Because we were assessed screening behavior in the near absence of system level barriers likely increases the usefulness of our model and subsequent framework. Of note, however, the cut point that we proposed for the low group was higher than other studies have observed⁹, and was numerically close to the cut point for the medium group. But because of the near absence of system level barriers, this may be an appropriate representation of patients who would be of low and medium likelihood to complete CRC screening in the presence of the existing health system.

The framework is designed to be both a model for targeted intervention design and a mechanism for the delivery of such interventions. There has been extensive research considering effective and efficient methods of CRC screening promotion. Many studies have found that highly intensive interventions, usually including counseling of patients, has the greatest impact on increasing preventive health behaviors.^{12,32} Other studies, however, have shown that, while some populations require intensive interventions, others respond well to more modest interventions.^{10,11} Patients who are unlikely, in their current mindset, to complete screening may not be receptive to intensive interventions. Patients who are highly likely to complete screening probably don't need an intensive intervention to convince them to complete CRC screening. Patients in the middle, however, may benefit the most from an intensive intervention. Our framework could be used to combine more and less intensive interventions into one multi-staged intervention to provide the appropriate intervention intensity based on how likely it is that they will complete screening.

This analysis has some limitations. First, this is a secondary analysis and the data were not collected for the purpose of building a prediction model. Second, the study for which the data were collected was a multi-arm study and subjects in each of the arms may be different. However, we randomly selected our samples for training and validating the models, which should equally distribute any differences. Finally, the racial/ethnic composition of our study sample is more diverse than the national population, and the model and subsequent framework may not be useful in other populations. However, this is also a major strength of the study. Our sample is comprised of understudied racial/ethnic groups that have significant CRC screening disparities. The model and subsequent framework may be useful for designing and delivering targeted interventions to promote CRC screening in these populations. Future evaluation is required to validate the framework groups.

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Figure 3.1. Model and framework construction

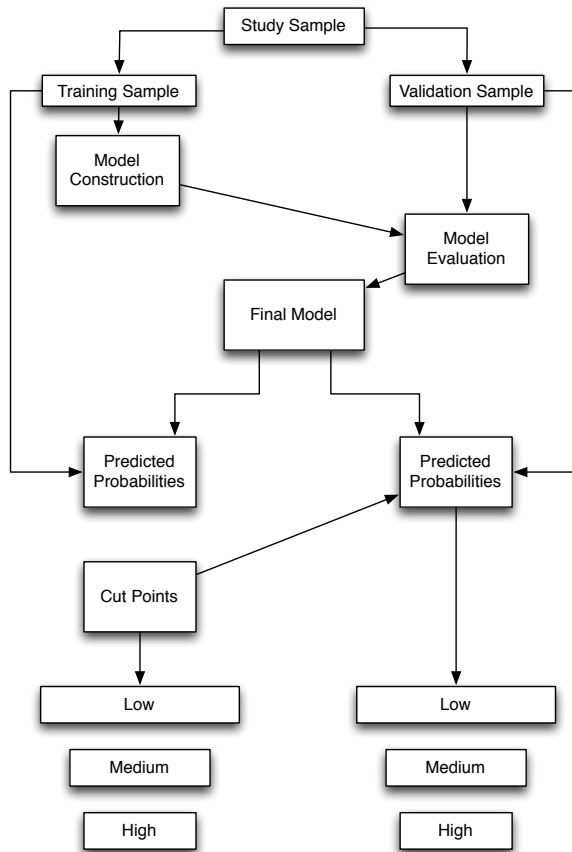


Table 3.1. Demographic characteristics of the sample

	Training n=402	Validation n=404	Total N=806
Race/Ethnicity			
Asian*	27.4%	33.4%	30.4%
Latino	36.3%	32.2%	34.2%
African-American	17.4%	15.6%	16.5%
Caucasian or other**	18.9%	18.8%	18.9%
Language			
English	53.5%	54.7%	54.1%
Spanish	30.1%	24.0%	27.1%
Chinese or Other	21.3%	16.4%	18.9%
Screening			
Completed	68.6%	66.6%	67.6%
Gender			
Female	53.7%	56.7%	55.2%
Age			
Mean (sd)	58.5(7.0)	58.0(6.7)	58.2(6.8)

*Predominantly Chinese

**Predominantly Caucasian

No significant differences across subsamples

Table 3.2. Model performance statistics

		Model 1	Model 2	Model 3
Hosmer-Lemeshow		9.96 (p=.27)	12.5 (.13)	38.5 (p<0.001)
AUROC		0.59	0.63	0.61
Number of Covariates		6	11	33
Measures to collect		0	4	40
Existing Data	Insurance	✓	✓	✓
	Gender	✓	✓	✓
	Age	✓	✓	✓
	Race/Ethnicity	✓	✓	✓
	PCP Gender	✓	✓	✓
	Gender Concordant	✓	✓	✓
	Perceived Health		✓	✓
Simple Measures	Screening Recommended		✓	✓
	Screening Discussed			✓
	Language		✓	✓
	Language Concordant		✓	✓
	Education			✓
	Income			✓
	Family History CRC		✓	✓
Trust	PCP Trust Score			✓
	Doctors Trust Score			✓
	Perceived Susceptibility			✓
HBM Constructs	Perceived Severity			✓
	Perceived Benefits			✓
	Perceived Barriers			✓

Figure 3.2. ROC Curve, Model 2

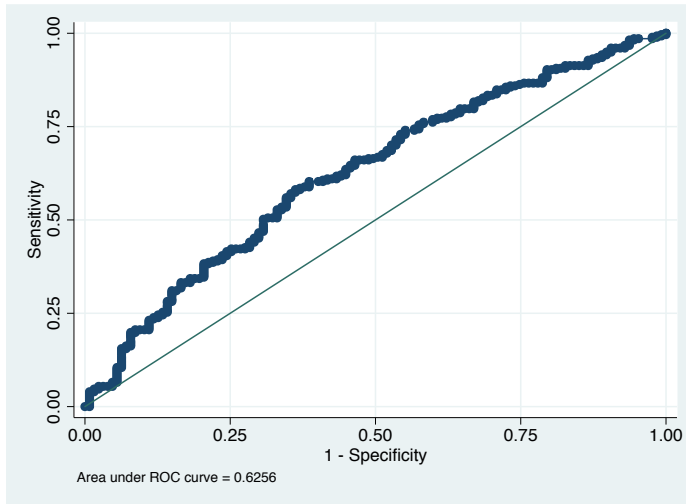
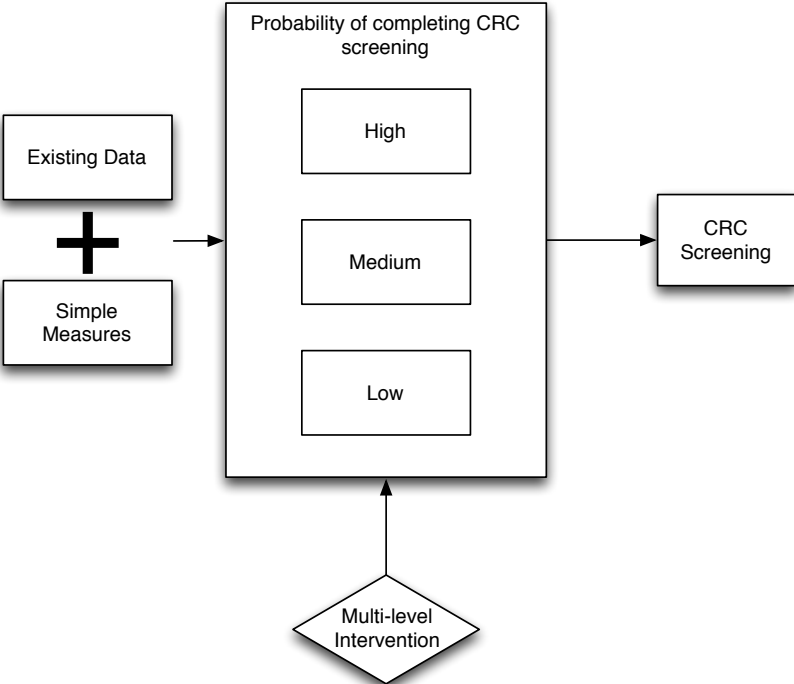


Table 3.3 Intervention design framework groups

	Low Cut point: 62.1%		Medium Cut point: 73.3%		High Cut point: 100.0%	
	Training	Validation	Training	Validation	Training	Validation
Race/Ethnicity						
Asian*	5.97%	5.41%	20.9%	25.4%	55.2%	59.8%
Latino	32.8%	38.7%	51.5%	42.5%	24.6%	18.9%
African-American	38.8%	33.3%	9.0%	9.7%	4.5%	8.2%
Non-Hispanic White or other**	22.4%	22.5%	18.7%	22.4%	15.7%	13.2%
Language						
English	79.1%	77.5%	47.8%	57.5%	33.6%	36.5%
Spanish	20.9%	21.6%	47.8%	36.6%	21.6%	15.1%
Chinese or Other	0.0%	0.9%	4.5%	6.0%	44.8%	48.4%
Screening						
Completed	53.0%	56.8%	67.2%	68.7%	79.9%	76.7%
Gender						
Female	67.9%	75.7%	63.4%	55.2%	38.8%	37.1%
Age						
Mean (sd)	55.4	56.1	59.4	58.2	60.6	59.1

Figure 3.3. Intervention Targeting Framework



Appendix 3.1. Detailed description of all candidate variables

Candidate Variables		
Construct	Definition	Items/Assessment
<i>Health Belief Model Constructs</i>		
Perceived susceptibility	Cognitive – perception of personal risk of colon cancer	<ul style="list-style-type: none"> - Compared to other people your age, what do you think your chance is of getting colorectal cancer? - How likely do you think it is that you could develop colorectal cancer sometime in the future? - I do not need to worry about developing colorectal cancer because I get regular doctor check-ups. <p><i>5-point Likert Scale response categories; scored as average of responses</i></p>
	Affective – worry about personal risk of colon cancer	<ul style="list-style-type: none"> - I don't want to be screened for colorectal cancer because I am afraid of the results. - I do not want to know that I have colorectal cancer because I'm afraid of the treatment. <p><i>5-point Likert Scale response categories; scored as average of responses</i></p>
Perceived severity	Perception of severity of colon cancer	<ul style="list-style-type: none"> - How serious would it be if you developed colorectal cancer? - Most people who develop colorectal cancer die from the disease. - If I were to develop colorectal cancer, it would totally change my life. <p><i>5-point Likert Scale response categories; scored as average of responses</i></p>
Perceived benefits	Perceived benefits of colon cancer screening	<ul style="list-style-type: none"> - Finding colorectal cancer early will decrease my chances of dying from colorectal cancer. - Finding colorectal cancer early will make the treatment easier. <p><i>5-point Likert Scale response categories; scored as average of responses</i></p>
Perceived barriers	Perceived barriers to screening	<p>Even if you have never been screened, on a scale of 1 to 5 where 1 is “not at all important” and 5 is “extremely important”, please check the box that best describes how important the following factors would be for you if you were making this decision.</p> <ul style="list-style-type: none"> Prior experience with testing. . . Cost . . . Discomfort . . . Embarrassment . . . Accuracy of results. . . Not enough time. . . Avoiding need for additional tests. . . Fear of the results. . . Transportation problems. . . Anxiety about the procedure. . .

		<p>Concern about complications. . . Preparation . . . Need for sedation. . .</p> <p><i>5-point Likert Scale response categories; scored individually</i></p>
<i>Patient Trust Measures</i>		
Trust in PCP	Individual trust in personal primary care provider	<p>1. Sometimes my PCP (doctor or nurse practitioner) cares more about what is convenient for him/her than about my medical needs. 2. My PCP is extremely thorough and careful. 3. I completely trust my PCP's decisions about which medical treatments are best for me. 4. My PCP is totally honest in telling me about all of the different treatment options available for my condition. 5. All in all, I have complete trust in my PCP.</p> <p><i>1 Strongly disagree; 2 Disagree; 3 Neither agree nor disagree; 4 Agree; 5 Strongly Agree</i> <i>Scored as sum of responses, range 5 - 25</i></p>
Trust in Doctors in General	Individual trust in doctors, not necessarily PCP	<p>1. Sometimes doctors care more about what is convenient for them than about their patients' medical needs. 2. Doctors are extremely thorough and careful. 3. I completely trust doctors' decisions about which medical treatments are best. 4. A doctor would never mislead me about anything. 5. All in all, I trust doctors completely.</p> <p><i>1 Strongly disagree; 2 Disagree; 3 Neither agree nor disagree; 4 Agree; 5 Strongly Agree</i> <i>Scored as sum of responses, range 5 - 25</i></p>
<i>Other Candidate Variables</i>		
Race/Ethnicity	Race or ethnicity of individual	<p>What race do you consider yourself to be? Please check ALL that apply. (Asian; Black or AA; PI; White) Do you consider yourself to be Hispanic or Latino? (Yes; No)</p>
Language	Preferred language of individual	Verbally assessed
Gender	Individual gender at birth	What is your sex/gender? (Female; Male)
Education	Individual level of education	What is the highest level of education you have completed? Please check ONE. (<HS; HS Grad; College Grad)

	attained	
Employment	Reported employment status	What is your employment status? (Employed; Unemployed)
Income	Reported family income	What is the total yearly income of your entire household, before tax deductions, from all sources? (<10K; 10K-19999; 20K-29999; ≥30K)
Insurance	Reported insurance type	What type of medical insurance do you have? Please check ALL that apply. (None; Public; Private)
Primary Care Provider Gender	Gender of primary care provider seen by individual patient	Assessed in medical record
CRC screening discussed	Colonoscopy or FOBT previously discussed with PCP	Has your doctor <u>ever discussed</u> this test with you? (Yes; No; Don't Know)
CRC screening recommended	Colonoscopy or FOBT previously recommended by PCP	Has your doctor <u>ever recommended</u> that you have this test? (Yes; No; Don't Know)
Perceived health status	Individual perception of health status	Compared to other adults your age, would you say your health is: (much worse; worse; same; better; much better)
Family History of CRC	Report of a blood relative with CRC	Have any of the following members of your family (by blood) been diagnosed with colorectal cancer? (Yes; No; Don't Know)

Appendix 3.2. Model Coefficients

	Model 1		Model 2		Model 3	
	Coefficient	Standard Error	Coefficient	Standard Error	Coefficient	Standard Error
Insurance Status						
None (0)	--	--	--	--	--	--
Any (1)	0.0409682	0.3121905	0.0765661	0.3366964	0.0621381	0.4143501
Primary Spoken Language						
English (0)			--	--	--	--
Spanish (1)			0.9719696	0.5150078	0.6003042	0.6860914
Chinese or other (2)			0.8826458	0.5780949	0.6347983	0.6775297
Gender/Sex						
Female (0)	--	--	--	--	--	--
Male (1)	0.747855	0.2609544	0.8485752	0.2839315	1.067524	0.3349975
Age (Continuous)	0.0238405	0.0172321	0.012645	0.0177529	0.0169378	0.0225193
Race/Ethnicity						
Non-Hispanic White/Other (0)	--	--	--	--	--	--
Asian (1)	0.8119294	0.3677104	0.5852453	0.4601439	0.7468405	0.5458202
African-American (2)	-0.393356	0.3565529	-0.3223837	0.3711795	-0.5109292	0.4325165
Latino (3)	0.2802848	0.3265726	-0.3930709	0.4671918	-0.3422065	0.6156524
Physician Gender						
Female (0)	--	--	--	--	--	--
Male (1)	0.2816304	0.2399807	0.3133389	0.2503992	0.2478286	0.2844297
Perceived Health Status						
Worse/Much worse (0)			--	--	--	--
Same (1)			0.2005988	0.3457502	0.185961	0.4020704
Better (2)			0.4909477	0.348346	0.3777736	0.4036566
Much Better (3)			0.4757345	0.4347744	0.6272518	0.5611852
Screening Recommended?						
No (0)			--	--	--	--
Yes (1)			0.5048545	0.2785861	1.170658	0.8863162
Screening Discussed?						
No (0)					--	--
Yes (1)					-0.580507	0.8769623
Physician-patient gender concordance						
No (0)	--	--	--	--	--	--
Yes (1)	0.1894177	0.244691	0.2686707	0.2539633	0.4367889	0.2897928

Physician-patient language concordance						
No (0)			--	--	--	--
Yes (1)			0.1631391	0.3870757	-0.3042591	0.4334693
Educational status						
<High School (0)					--	--
HS Graduate (1)					-0.1216359	0.4041224
Some college (2)					-0.2545282	0.4382632
College+ (3)					0.1350501	0.4670225
Family yearly income						
<\$10,000 (0)					--	--
\$10,000-\$19,999 (1)					-0.0353425	0.3090899
≥\$20,000 (2)					0.0666923	0.4733898
Family History of CRC						
No (0)			--	--	--	--
Yes (1)			-0.6427754	1.486423	0.1621453	1.53305
Don't know (2)			1.098968	1.769982	1.448767	1.868419
Health Beliefs (Continuous) (1-5)						
Cognitive susceptibility					0.2282337	0.1788543
Affective susceptibility					-0.0925557	0.1921766
Severity					-0.2065795	0.3101588
Benefits					-0.7001192	0.2508247
Barrier: Prior testing experience					0.4106932	0.142895
Barrier: Cost of test					-0.1095785	0.0989432
Barrier: Discomfort					-0.2012127	0.1313848
Barrier: Embarrassment					-0.0689353	0.148655
Barrier: Accuracy of test					-0.0653305	0.1942889
Barrier: Not Enough Time					0.0781566	0.1426893
Barrier: Need for additional testing					-0.0742917	0.1528977
Barrier: Fear of test results					0.1398834	0.1678572
Barrier: Transportation					0.015502	0.1596604
Barrier: Anxiety about procedure					0.1963785	0.1781386
Barrier: Concern about complications					-0.2900304	0.1636022
Barrier: Preparation					-0.0230274	0.1348515
Barrier: Sedation					0.043442	0.121744
Patient Trust (Continuous) (5-25)						
Trust in primary care provider					0.1300292	0.058372
Trust in medical care providers					0.0039891	0.0480785
Constant	-1.468444	1.058652	-1.293764	1.834474	-3.190125	3.158356

Appendix 3.3. Intervention design framework groups, all covariates

	Training Sample			Validation Sample		
	Low % or mean	Medium % or mean	High % or mean	Low % or mean	Medium % or mean	High % or mean
Insurance Status						
None (0)	16%	13%	13%	23%	13%	14%
Any (1)	84%	87%	87%	78%	87%	86%
Primary Spoken Language						
English (0)	79%	48%	34%	78%	58%	37%
Spanish (1)	21%	48%	22%	22%	37%	15%
Chinese or other (2)	0%	5%	45%	1%	6%	48%
Gender/Sex						
Female (0)	68%	63%	39%	76%	55%	37%
Male (1)	32%	37%	61%	24%	45%	63%
Race/Ethnicity						
Non-Hispanic White/Other (0)	22%	19%	16%	23%	22%	13%
Asian (1)	6%	21%	55%	5%	25%	60%
African-American (2)	39%	9%	5%	33%	10%	8%
Latino (3)	33%	52%	25%	39%	43%	19%
Physician Gender						
Female (0)	78%	61%	58%	79%	70%	53%
Male (1)	22%	39%	42%	21%	30%	47%
Perceived Health Status						
Worse/Much worse (0)	30%	6%	10%	23%	12%	12%
Same (1)	39%	32%	41%	39%	25%	30%
Better (2)	24%	44%	37%	29%	49%	45%
Much Better (3)	8%	18%	13%	9%	15%	13%
Screening Recommended?						
No (0)	34%	14%	8%	35%	18%	9%
Yes (1)	66%	86%	92%	65%	82%	91%
Screening Discussed?						
No (0)	31%	14%	10%	34%	17%	11%
Yes (1)	69%	86%	90%	66%	83%	89%
Physician-patient gender concordance						
No (0)	46%	44%	49%	38%	31%	36%
Yes (1)	54%	56%	51%	62%	69%	64%
Physician-patient language concordance						
No (0)	13%	31%	47%	14%	27%	56%

Yes (1)	87%	69%	53%	87%	73%	44%
Educational status						
<High School (0)	31%	43%	38%	27%	31%	35%
HS Graduate (1)	28%	17%	27%	34%	28%	35%
Some college (2)	23%	21%	14%	27%	20%	9%
College+ (3)	17%	19%	21%	12%	20%	21%
Family yearly income						
<\$10,000 (0)	57%	65%	52%	66%	59%	45%
\$10,000-\$19,999 (1)	33%	30%	35%	22%	33%	37%
≥\$20,000 (2)	10%	5%	13%	13%	8%	18%
Family History of CRC						
No (0)	1%	0%	2%	0%	0%	0%
Yes (1)	99%	100%	89%	100%	100%	93%
Don't know (2)	0%	0%	9%	0%	0%	7%
Age (Continuous)	55.39	59.4	60.55	56.05	58.23	59.08
Health Beliefs (Continuous) (1-5)						
Cognitive susceptibility	2.83	2.63	2.87	2.75	2.57	2.78
Affective susceptibility	1.93	2.02	1.81	1.96	1.98	1.92
Severity	4	4.11	3.97	3.92	4.01	3.92
Benefits	1.65	1.65	1.69	1.65	1.62	1.64
Barrier: Prior testing experience	2.87	3.06	2.67	3.06	2.99	2.4
Barrier: Cost of test	2.99	2.96	3.25	2.96	3.14	3.31
Barrier: Discomfort	2.49	2.24	2.38	2.25	2.37	2.57
Barrier: Embarrassment	1.7	1.85	1.65	1.78	1.89	1.51
Barrier: Accuracy of test	4.2	4.22	4.33	4.1	4.18	4.33
Barrier: Not Enough Time	1.64	1.62	1.81	1.69	1.82	1.84
Barrier: Need for additional testing	1.47	1.66	1.56	1.69	1.73	1.45
Barrier: Fear of test results	1.57	1.84	1.49	1.76	1.78	1.52
Barrier: Transportation	1.29	1.5	1.38	1.61	1.65	1.38
Barrier: Anxiety about procedure	1.99	2.07	1.73	1.94	1.94	1.87
Barrier: Concern about complications	2.16	2.32	1.94	2.11	2.29	1.97
Barrier: Preparation	2.39	2.57	2.34	2.43	2.55	2.2
Barrier: Sedation	2.9	2.88	2.55	2.95	2.84	2.55
Patient Trust (Continuous) (5-25)						
Trust in primary care provider	21.23	20.11	20.82	21.12	20.83	21.28
Trust in medical care providers	18.33	18.09	18.56	18.25	18.79	18.6

Chapter 4. Individual responses to a discrete choice experiment for heart disease prevention therapy: What new attributes are influencing choices?

Abstract

Background: Discrete choice experiment (DCE) is a type of explicit values clarification, which is capable of deriving the relative value (utility) an individual places on attributes of therapy choices and predicting the most values concordant choice. Unfortunately, little is known about whether patients bring additional attributes to play in making decisions during DCE and how they respond when given the results of the DCE.

Objective: To learn whether our DCE captured all relevant attributes for decision-making about coronary heart disease (CHD) prevention and about perceptions of receiving DCE-based optimal choice and attribute importance ranking.

Methods: From among 113 participants, we analyzed a random sample of 20 semi-structured interviews conducted after a DCE on CHD prevention therapy and a selection of a preferred CHD prevention approach. From responses to the DCE, we calculated attribute utilities and simulated an “optimal” therapy choice. In the interviews, participants described the attributes they considered in selecting a CHD prevention therapy and reacted to feedback of the results of the DCE. Two independent reviewers reviewed transcribed interviews to understand themes in analysis.

Results: Participants largely made decisions using attributes included in the DCE; however, many actively included other attributes such as naturalness, competing demands, and familiarity with the therapy. Participants were intrigued with the DCE results and found them useful, but did not always agree with them or change their preferred approach.

Conclusions: Patients use a range of attributes when making decisions about CHD prevention. Further, providing DCE to patients may be useful in patient decision support for CHD prevention therapy.

Introduction

Coronary heart disease (CHD) is one of the top causes of death in the United States ¹. There are numerous evidence-based preventive therapies shown to reduce the risk of a heart-related event, but many patients who are at risk fail to adopt or adhere to them ^{2,3}. One possible reason for non-adherence to prescribed therapies may be because a patient does not agree with the physician prescribed therapy, due to differences in what the patient and the provider consider to be important characteristics, or attributes, of a therapy choice ⁴. In fact, previous research has shown that patients' choices for heart disease prevention vary widely from patient to patient ⁵. Taking into account patient values and preferences during the decision-making process about preventive therapy may increase patient adherence to the therapy ³.

There are two major categories of methods for eliciting patients' values. There are *implicit* methods, in which patients receive information about different aspects of a decision (e.g., cost, time, effectiveness) and are able to consider their potential value on their own (or with a simple prompt to "consider which attributes are most important to you"). There are also *explicit* methods (e.g., rating and ranking and discrete choice experiment), in which patients are asked to compare the relative importance of several potentially relevant characteristics of a decision.

Discrete Choice Experiment (DCE) is one explicit values elicitation method used in health care decision-making. DCE is based on the assumption that the value a person has for a whole product is a sum of the value he or she has for the attributes of that product. Individuals are presented with side-by-side hypothetical "products," consisting of a number of attributes with different levels, and are asked

to choose between them. DCE can ascertain individuals' priorities by estimating the relative importance of different attributes and levels. The combination of attribute levels that produces the highest utility (as derived from responses to the hypothetical product comparisons) is considered to be the "optimal" choice ⁶. Figure 4.1 is an example of a side-by-side comparison of hypothetical heart disease prevention therapies used in a DCE.

A major strength of DCE is that it is able to predict a therapy choice that is theoretically most congruent with the patients' values. However, a weakness of DCE is that it is based on a set of previously established attributes, and it ignores other attributes that may be important to patients. Thus, if a patient places high value in other attributes not included in the DCE, the predicted optimal therapy may not reflect what the patient wants, leading him or her to feel disconnected and dissatisfied with the DCE-predicted therapy choice ³.

Although there is a growing literature on assessing patients' preferences about attributes of different health services using DCE ⁷, little is known about individuals' perceptions about the process of participating in DCE, whether individuals consciously bring new attributes to play in making decisions during DCE, and how individuals respond to the results of the DCE. To address this gap, we investigated individuals' perceptions about DCE immediately after completing a DCE. Specifically, we identified new attributes that individuals bring to a DCE, and the role of these attributes in decision-making around heart disease prevention therapy. Additionally, we explored individuals' responses when provided with the results of a DCE, both the predicted optimal therapy choice and the ranking of the attributes

according to importance. We also considered whether their responses differed based on the concordance or discordance of their therapy choice and the choice generated by the DCE.

Methods

Sample

Data used in this study came from the Heart Disease Prevention DCE study.⁸ This study was a mixed methods study that employed DCE to examine patients' values and preferences for heart disease prevention. It included 113 men and women who were between the ages of 30 and 75, had not had a heart attack or stroke, and did not have congestive heart failure. Participants were recruited from a registry of people interested in participating in decision support studies. Individuals were recruited into the registry through a mix of mass informational emails and television and print advertisement, and contacted to opt in to studies for which they were eligible.

DCE Process

Participants were initially presented with a hypothetical patient profile that described a person who is at moderate risk for heart disease (uncontrolled hypertension and high cholesterol), with \$60,000 family income, and who is not currently doing anything to prevent heart disease (Figure 4.2) and asked to respond as if they had that heart disease risk profile. They were then provided with minimal information about the attributes of heart disease prevention therapy that were developed for the DCE: 1) ability to reduce risk of heart attack, 2) other health benefits, 3) how easy or difficult it is to do the therapy, 4) chance of having a bad

reaction, and 5) out of pocket costs (Figure 4.2 and Table 4.1). Participants selected a preferred CHD prevention therapy from among these choices: aspirin daily, blood pressure lowering medication daily, cholesterol lowering medication daily, or physical activity 4 times per week. They also indicated their most and least important attributes of CHD prevention therapy. They then completed a 17-item DCE, and, again, selected a preferred heart disease prevention therapy. This second selection was included to allow the participants to make a choice on their own after completing the values elicitation exercise.

Next, a member of the research team analyzed the DCE results and performed a simulation to calculate the participant's utility scores for each attribute and its levels and predict the subject's "optimal" therapy choice, based on the attribute levels associated with the real treatment options (Table 4.2).^{6,9}

Participants were considered to be *therapy concordant* if the DCE generated "optimal" therapy matched the one they selected on their own (post DCE) and *therapy discordant* if it did not match. Using the DCE-generated utility scores, with higher scores indicating greater importance of the attribute, all five attributes were ranked.

A detailed description of the DCE process and participant recruitment have been reported elsewhere in the literature ⁸.

Participant Interviews

After participants completed the DCE, we conducted in-depth, face-to-face interviews with each participant using a semi-structured interview guide. The general guiding questions for the study were how participants arrived at their directly

selected therapy choices (both before and after the DCE), how they ranked their most and least important attributes included in the DCE, and participants' perceptions of the DCE-based ranking of all five attributes and of the "optimal" therapy choice. The interviewer (JMG) asked each participant to describe how he or she ranked the attributes included in the DCE and which attributes (those in the DCE and others) were considered as important in selecting their preferred heart disease prevention therapy. She then presented each participant with the results of the DCE-based simulation, first the attribute ranking and, second, the simulated "optimal" therapy choice. Each participant was asked to reflect on differences or similarities between their own choices and the results of the simulation. All data collection was completed in 2007. Study activities are depicted in Figure 4.3. For the analyses presented here, we used only data from the sample of the semi-structured interviews, selected randomly until we reached thematic saturation (N=20).

Data Analysis

Interviews were digitally recorded, transcribed verbatim, and checked for accuracy. The transcripts were uploaded into ATLAS.ti version 7.0 for analysis ¹⁰. The interview analysis was conducted in three stages ¹¹. First, we developed a tentative coding structure based on the interview questions. Second, two members of the research team (AB, LKK) independently reviewed each transcript to identify main ideas and meanings not captured in the initial coding structure. We generated tentative labels to capture the essence of each idea, specifically new attributes and reactions to the DCE simulated choice, as we compared and contrasted our notes. We resolved all disagreements through discussions. Third, we clustered similar ideas

together into themes and codes representative of each theme. We evaluated atypical cases that did not fit patterns identified for the majority.

Results

The included participants were mostly female (65%), White (45%), college educated (60%), and had an average age of 50 years (± 11). Seventy percent of the participants were therapy discordant (Table 3). The characteristics of the participants in this sample were similar to the participants in the full study.

Interview Themes

We identified themes regarding new attributes used for decision-making for CHD heart disease prevention therapy that were not included in the original DCE exercise. These themes included attributes of the CHD prevention therapies (medication avoidance/naturalness) and environmental or situational attributes that are not actually characteristics of the individual therapies options (competing demands; familiarity). Because we also solicited responses to the DCE process, specifically about reactions to the DCE-generated choice, we were able to identify themes regarding perceptions about overall DCE process.

New Attributes

Medication Avoidance/Naturalness

Many participants reported their dislike for initial pharmacological therapies, and showed tendency to choose “something more natural” that did not involve medication use. Most of these participants chose exercise as their therapy of choice but their DCE-generated results involved some type of medication use such as aspirin

or blood pressure medication. One participant who chose exercise defended her selection upon learning that the DCE-generated therapy choice was aspirin, saying:

If I had to be on a medication, I would probably do something more homeopathic, because I am not really into synthetic drugs. FEMALE, 50 years old (Own choice: Exercise; DCE: Aspirin)

Rather than excluding medication use as a therapy for CHD, the participants tended to show their order of therapy preferences. One participant who chose exercise as her therapy of choice (while the DCE produced blood pressure medication use) summed up this sentiment:

I wouldn't say that I would never take the medicine. I would try the exercise first and say that I will come back in two months and then if I still have high blood pressure and my cholesterol is still high, then we will talk about medicine. Female, 44 years old (Own choice: Exercise; DCE: BP Medication)

When participants tended to consider the ability of the therapy to reduce risk of heart disease as a very important attribute during the DCE, the optimal choice generated by the DCE was often blood pressure medication. Several of these same participants also reported preference for natural therapies, such as exercise, as their own treatment of choice, instead of medication use. This discordance in therapy of choice may indicate that participants are bringing other important attributes into the therapy decision-making or that they do not recognize that BP medication is likely to be most effective in meeting their goal of risk reduction.

Competing Demands: Health and Family Obligations

Many participants reported the importance of considering competing demands on choosing a therapy of choice. The competing demands included a variety of factors such as current health status and family obligations.

Some participants, whose chosen therapy was discordant with the DCE results, reported that, although they had chosen exercise, adherence to exercise would depend on the physical abilities of the individual.

If you have bad joints or something like that you're kind of limited a little bit.

Male, 30 years old (Own Choice: Exercise; DCE: BP Medication)

Similarly, another participant reported that limitations imposed by his current physical health might be motivation to choose alternative therapies.

Well I think that if they can't get physical, they might need to start taking that aspirin.

Male, 42 years old (Own Choice: Exercise; DCE: Aspirin)

The competing demand of family and the participants' obligation to the family were another very important attribute that emerged from the interviews. In the hypothetical scenario, participants were told to consider being part of a family of four with an annual household income of \$60,000. Although out-of-pocket cost was an important attribute, participants tended to consider this attribute within the context of their obligation to their families rather than on its own. Both participants who were therapy concordant and discordant brought up family and family obligations. One female participant, whose therapy was concordant with the DCE results, reported that decision-making involves consideration of many factors, including family.

It's a difficult decision to try to figure out how to balance financial pressure and your family and the health benefits.

Female, 38 years old (Own choice: Exercise; DCE: Exercise)

Similarly, a male participant reported the importance of one's obligation to provide for the family in health decision-making. In this case, he opted for the less expensive alternative in terms of out of pocket costs because those funds were needed to support his family:

So the difference between \$25 and a hundred bucks is in this day and time at \$60,000, even with four kids, I mean a family of four. You don't, if you're not here you're not gonna be able to make the money to take care of the family.

Male, 46 years old (Own choice: Exercise; DCE: BP Medication)

Familiarity with Therapies

Some participants reported their familiarity with a therapy option to be important in decision-making. Participants described general familiarity and also having a personal experience with the therapy. One participant referred to television ads, saying, "You see the [TV] advertisements for them [referring to St. John's aspirin]" suggesting how media exposure enables familiarity to new therapy options. Another participant brought up how exposure to information through multiple media sources reinforces familiarity with a therapy.

I think that [exercise is] important. One, I've heard it on television and on the internet and everywhere, but it's my opinion on heart disease that I believe that some people have a predisposition for it, but I really believe that exercise makes a difference.

Male 42, (Own Choice: Exercise; DCE: Aspirin)

Personal experience with a therapy of choice was also important. One participant whose therapy choice was concordant with DCE stated that she chose blood pressure medication because she is on this therapy in his real life.

Reaction to DCE results

Some participants felt that the DCE-generated attribute order was slightly incorrect but typically did not have strong feelings about it. Others, however, took the time to reconsider their attributes upon hearing the DCE attribute ranking results. Most participants' responses ranged from neutral to being intrigued by the predicted "optimal" choice, regardless of whether they ultimately agreed with it.

Reaction to DCE Attribute Ranking

A lot of participants were relatively ambivalent about the DCE-generated ranking of treatment attributes. Overall, the attribute that a participant indicated as most important appeared as one of the top two or three attributes in the DCE-generated ranking. When the participant's most important attribute and the attribute that showed the highest utility agreed, many respondents were pleased, saying:

It just seemed like common sense to me....I'm glad.

Male 64 years old (Own top ranked attribute: Ability to reduce risk; DCE: Ability to reduce risk)

Some participants whose highest- or lowest- ranked attribute differed from the DCE-generated rankings considered the difference and realized that the simulated results may have actually been more accurate than their selection. One participant selected chance of adverse reaction as most important. But after hearing that her simulated most important attribute was risk reduction, she came to realize that risk reduction was, in fact, more important to her.

To me, whatever was going to reduce the risk of a heart attack...[That] was my primary concern... I was thinking about the adverse effects, but I was more concerned with reduc[ing] the risk of heart attack the most. If that included taking some drugs and I was going to have a bad reaction then so be it.

Female, 50 years old(Own top ranked attribute: Chance of adverse reaction; DCE: Ability to reduce risk)

There were some participants, however, who were displeased by differences in attribute ranking, even when the utility scores indicated that the results were similar. For example, one participant selected risk reduction as most important and out-of-pocket costs as least important. The DCE simulation revealed that risk reduction was highly dominant in their decision making, meaning that the majority of their decision was based on that attribute. Out of pocket costs, however, came in second. The utility score for that attribute was very low, indicating that it was, indeed, relatively unimportant to this participant. Nonetheless, the participant seemed dissatisfied with the DCE generated attribute ranking.

I think [out of pocket costs] should have come in last, I really wish it had. I don't know why it didn't. I wish it had come in last.

Male, 42 years old

Many participants were relatively ambivalent about the order of the middle attributes (not most or least important) generated by DCE. For example, one participant described the attribute ranking as “pretty close.” Only one participant showed interest in re-ordering the attributes.

“Optimal” Choice

Many of the participants reacted positively to the DCE generated “optimal” therapy choice, regardless of whether it matched their selected preferred therapy choice or not. Some began to reconsider their own choice and others expressed a

desire for more information about the DCE generated choice. Few were completely opposed to the DCE generated choice. One therapy-discordant female participant was interested in learning more about the DCE generated optimal choice, stating:

I would want to know percent of risk reduction and other health benefits and side effects and cost and all that.

Female 52 years old (Own Choice: Aspirin; DCE: Physical Activity)

A few therapy-discordant participants reported that the DCE-generated “optimal” choice might be better than the one they selected as their preferred treatment. One female participant explained her approval of the DCE generated choice.

I just know that there are so many other things that come with physical activity. It raises your...circulation, ..., your cholesterol will go down, your weight will probably go down...you're increasing your oxygen intake, it just has so many good side effects that I would do that...and it's free. It doesn't even cost what an aspirin cost. I would do that.

Female: 51 years old (Own Choice: Aspirin; DCE: Physical Activity)

Therapy-concordant participants generally felt positive about the DCE “optimal” choice. One concordant participant, however, appeared to be surprised that a computer program was able to predict the same choice that she selected, stating she was not sure how she felt about it, that “maybe I’m an easy read.”

There were a few participants, however, who were adamantly against their DCE generated “optimal” choices. One participant had selected physical activity as her preferred therapy, but the generated “optimal” choice was blood pressure medication.

I don't think that I would take blood-pressure medication unless I absolutely, positively have to. I prefer to exercise.

Female, 49 years old (Own choice: Physical Activity; DCE BP Medication)

Discussion

In this paper, we present the findings of interviews among individuals who participated in the Heart Disease Prevention DCE. We found that, in addition to using the attributes included in the DCE for decision-making, many individuals actively brought new attributes, beyond the attributes that were included in the DCE, to the decision-making process to select their preferred therapy choice. Individuals whose selected preferred therapy choice and generated “optimal” choice were discordant in general talked more often about other attributes than did concordant individuals. The major new attributes that emerged in these interviews were: 1) medication avoidance/naturalness; 2) competing health and family demands; and 3) awareness of therapies. Our results also showed that participants largely responded positively to DCE-generated attribute ranking and “optimal” therapy choice, even if they did not agree with them.

Many of our participants described their desire to avoid medications in favor of more natural or homeopathic therapies, at least as an early prevention effort. This idea is consistent with findings from other CHD prevention decision-making studies¹². Other studies have found that some individuals tend to seek natural approaches or health products rather than prescription medications¹³. Similarly, many participants in our study stated a preference for trying more “natural” health products for a health condition prior to using medication.

Other important attributes that we found were not actually characteristics of the therapy options themselves, but rather environmental or situational attributes that may affect choice. Health care decisions are not made in a vacuum. Competing demands, such as other health concerns or obligation to family, are not attributes of a preventive therapy, but they are important contextual factors in selecting the most appropriate therapy¹⁴. For example, two people who similarly value the attributes of heart disease prevention therapies may live their lives with very different demands on their life and time. As our participant cites, one person may have deteriorated joints that do not allow for sufficient physical activity, whereas another does not. Therefore, two people may feel similarly about the importance of certain attributes of preventive therapies, but may do best with two different therapy choices.

Additionally, a subject's familiarity or experience with therapy options is not an attribute of the therapy choices themselves, but rather is a characteristic of the circumstances or environment in which the choice is being made. Subjects cited this attribute to explain why they preferred a certain therapy, such as preferring aspirin because of the recent media campaigns for low-dose aspirin. This study did not provide in-depth information about therapy choices. Education about therapy options may reduce subjects' focus on the familiar option above others. However, other research that incorporated patient education showed that patients still tended to prefer CHD prevention therapy options with which they are familiar^{12,15}.

Future CHD DCE studies should evaluate the new attributes that we found in this study and explore methods of acknowledging or including them. Medication avoidance/naturalness, as a characteristic of therapy choices, might be included in

the DCE as an additional attribute. The DCE can then assess the relative importance of “naturalness” as it balances with side effects, risk reduction capability, and the other original attributes. Treatment familiarity might be addressed by providing more comprehensive information about all of the therapy choices. Competing health and family demands, on the other hand, are somewhat immutable factors. It may be possible to expand the existing attribute, “How easy or difficult to do,” to include some aspects of competing demands.

To our knowledge, this is the first study that provides insights into the individuals’ perceptions of DCE in patient decision support. Our finding that participants generally reacted positively to the results of the DCE-based simulated “optimal” therapy choice provides some promise for the usefulness of this method in patient decision support. Our results cannot suggest whether the DCE generated “optimal” choice or the participant selected preferred therapy choice is a better choice in terms of outcomes or adherence, or what a patient may ultimately choose. Larger quantitative studies that employ DCE to provide patients with a simulated “optimal” therapy choice and follow patients forward to determine what patients choose, their outcomes, and their long-term adherence are needed. Our results do, however, potentially suggest that the DCE results may be of some interest to patients. Providing the DCE results may present an opportunity, particularly in the therapy-discordant, to examine the reasons for the discordance, such as differences in knowledge about the therapies, inclusion of other attributes in the decision-making process, or improper heuristics in decision-making (e.g., elevating the risk-reducing potential of exercise).

Our study had several limitations. First, this study used a hypothetical patient scenario. Given the hypothetical scenario, responses may be different than real patient choices. Second, we did not provide participants with more than minimal information about the therapy options. Providing systematic education on therapy choices, such as a patient decision aid, could affect directly selected therapy choices.

Our results do, however, suggest that patients may bring new attributes (currently unstudied) that may be important patients making a decision about CHD prevention therapy. Additionally, patients may be amenable to receiving DCE-based simulated "optimal" choice for CHD prevention therapy, even if they do not agree with the choice. Future studies should compare a decision aid alone vs. a decision aid with values elicitation using a DCE and simulation of optimal treatment in patients actually making the decision about CHD prevention. These patients should be followed longitudinally to determine whether concordant patients who receive the concordant choice are more likely to have high adherence than discordant patients.

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Figure 4.1. Sample DCE side-by-side comparison

If you were this person, which of these two options would you choose to prevent a heart attack?

A

Option 1	or	Option 2
Adoption of Treatment – Difficult		Adoption of Treatment – Easy
Chance of Side Effects – Moderate chance		Chance of Side Effects – Very small chance
Ability to Reduce Heart Attack – 30%		Ability to Reduce Heart Attack – 10%
Other Health Benefits – None		Other Health Benefits – Many
Out-of-Pocket Cost – More than \$100		Out-of-Pocket Cost – Less than \$25

Prefer Option 1 Prefer Options Equally Prefer Option 2

1 **2** **3**

Figure 4.2. Hypothetical patient profile and attribute descriptions provided to participants

REMEMBER TO ANSWER QUESTIONS BASED ON THE FOLLOWING INFORMATION.

You are 50 years old and have the following heart disease risk factors:

- High blood pressure
 - 150/90
- Abnormal (high) cholesterol
 - Total cholesterol 220
 - HDL cholesterol 40
 - LDL cholesterol 140
- You do not have diabetes
- You are relatively inactive but are not overweight
- You do not smoke
- You do not have a family history of heart disease
- You have health insurance with a co-payment for medications
- Your yearly family income for a family of 4 is \$60,000

Right now you are not taking any medication or doing anything to prevent a heart attack or heart disease.

You have a 13% chance of having a heart attack in the next 10 years.

When considering a treatment choice for heart disease prevention you may want to consider the following things:

- The ability of the treatment to reduce risk of heart attack.
 - By ability to reduce risk of heart attacks we mean the ability of a treatment to prevent heart attacks from occurring.
- Other health benefits of the treatment
 - Sometimes treatments for one condition can provide benefits beyond the condition for which they are used. For example, exercising daily can improve a number of health conditions.
- How easy or hard is it to adopt this treatment.
 - By this we mean how easy or hard would it be for you to make this treatment part of your life, sometimes everyday, and keep up with it.
- Side effects of the treatment.
 - By side effects of treatment we mean important adverse or bad reactions to the treatment.
- Out of pocket costs.
 - By out of pocket costs we mean the amount of money you would have to pay after Medicare or health insurance has been applied.

Table 4.1. Attributes and levels used in DCE task side-by-side comparisons

Attribute	Levels
Ability to Reduce Heart Attacks*	13% to 11%
<i>Absolute Risk Reduction</i>	13% to 9%
	13% to 6%
<i>Relative Risk Reduction</i>	10%
	30%
	50%
Other Health Benefits	None
	Medium
	Many
How Easy or Difficult to Do	Easy
	Neither Easy Nor Difficult
	Difficult
Chance of Having a Bad Reaction	Very Small
	Small
	Moderate
Out-Of-Pocket Costs	<\$25
	\$25-\$100
	>\$100

*Participants were randomized to receive absolute or relative risk reduction presentation. The results of this sub-analysis are previously reported.(8)

Figure 4.3. Study activities

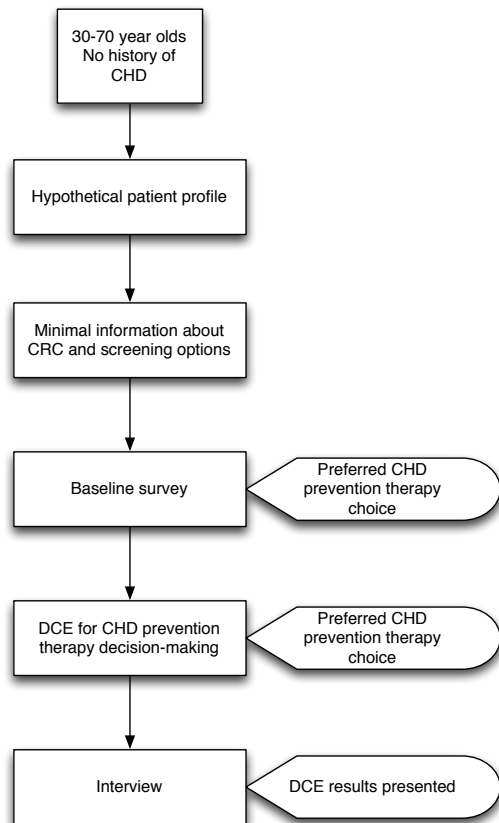


Table 4.2. Attribute levels assigned to therapy options to identify optimal therapy choice

	Attributes				
	Ability To Reduce Heart Attacks	Other Health Benefits	How Easy or Difficult to Do	Chance of a Bad Reaction	Out-of-Pocket Costs
Aspirin Daily	13% to 9% (15)	None(15)*	Easy (16,17)	Moderate(15)	Less than \$25 (18)
Blood Pressure Medication Daily	13% to 9%(19–21)	Medium (22,23)	Easy (16,17)	Small (24)	Between \$25-\$100 [†]
Cholesterol Lowering Medication Daily	13% to 9% (18)	None(25)	Easy (16,17)	Small (26)	Between \$25-\$100 (18)
Exercise 4 Times per Week	13% to 11% (27)	Many [§]	Difficult (16)	Very Small [§]	Less than \$25 [‡]

*Review conducted prior to Ridker et al 2005 (28) which found stroke benefit for women

[†] Assumption based on generic blood pressure medication at \$5/month

[‡] Assumed low cost (i.e. not an organized gym or club membership)

[§] Assumption based on other attribute assignments to other treatment options

Table 4.3. Sample and study population demographic characteristics

	Sample	Study Population
	n=20	N=113
Age (mean(sd))	50 (11)	51 (11)
Sex (%F)	65%	71%
Race (% White)	45%	60%
Education (% College+)	60%	54%
Discordant (%)	70%	77%

Chapter 5. Conclusions

Introduction

In this dissertation, I present several different methods for targeting patient decision support interventions. This dissertation explores several different possible methods for helping patients make appropriate preventive care decisions.

Chapters 2 and 3 present methods for improving the relevance of information provided to patients for colorectal cancer screening promotion. Chapter 2 examined the relationship between socio-demographic characteristics and health beliefs in the context of colorectal cancer screening in a racially and ethnically diverse safety-net population. Chapter 3 presents the initial construction of a framework for designing and delivering targeted patient decision support interventions powered by a statistical model to predict probability of completing CRC screening. Chapter 4 presents a qualitative analysis considering important attributes of decision-making for heart disease prevention therapy and the acceptability of the use of discrete choice experiment modeled attribute importance and therapy choices.

This final chapter is organized in the following fashion: the following two sections synthesize results of chapters 2, 3, and 4 and describe this dissertation's contributions to the field of patient decision support. The final section presents suggestions for future research and concluding remarks.

Promoting Colorectal Cancer Screening in Racial/Ethnic Minority Populations

Racial/ethnic minority populations report lower screening rates than non-Hispanic White populations, particularly when considering level of acculturation.¹⁻³

Promoting colorectal cancer screening is difficult and expensive, and while some are

very effective, many interventions produce only a modest increase in screening completion.⁴⁻⁶ It is important that we develop new ways to promote CRC screening among the populations, particularly groups for whom there are screening disparities. Providing patients with the most relevant or appropriate information about colorectal cancer and colorectal cancer screening has been shown to increase the effect of an intervention.^{6,7} In the first part of this dissertation, I considered two different potential methods for targeting patient decision support about colorectal cancer screening to promote screening in racial/ethnic minority populations.

The analysis presented in Chapter 2 showed that some health beliefs about CRC and CRC screening might be unique to different racial/ethnic and language groups. Understanding such differences in health beliefs may advance our understanding of how to address disparities in CRC screening uptake. These differences, primarily observed in perception of barriers to screening, could be selectively leveraged in designing interventions to promote CRC screening for specific racial/ethnic and language groups. My analyses suggests that Hispanics who do not speak English, for example, are much more likely to think that the preparation for CRC screening was an important barrier. An intervention designed with this in mind should provide information or support to specifically address how to get through the preparation successfully.

Chapter 3 outlines the construction and validation of a prediction model that determines how likely a person is to get screened, followed by the creation of the intervention design framework. The ultimate goal was to create a practical framework upon which an intervention targeted a readiness to complete screening could be placed; I sought to find a model that was simple, in terms of number of

covariates and complexity of covariates, but also reasonably accurate, in terms of predictive capability. Thus, I developed and tested several models and compared their calibration and discrimination. The model I eventually selected is based on several covariates that likely already exist in a patient's medical record and four additional relatively simple psychosocial and demographic characteristics. Because there are few data points that need to be collected in order to use the framework, it may be feasible for use in a busy clinic setting. For example, an intervention designed to target the information needs of patients at different levels of readiness to complete CRC screening could be delivered to the appropriate patients using the framework.

These results provide practical methods for designing targeted CRC screening promotion interventions in racial/ethnic minority populations. By targeting the amount or type of information provided to patients in promotion of CRC screening, it may be possible to both increase the intervention effect and increase the cost-effectiveness.

Making a decision about heart disease prevention therapy

Many patients who are at risk for heart disease fail to adhere to prescribed preventive therapies.^{8,9} Helping patients and physicians work together to identify the most values concordant choice for heart disease prevention may help increase adherence.⁹ DCE is one type of values clarification method. A major strength of DCE is that it is able to predict a therapy choice that is theoretically most congruent with the patients' values. However, a weakness of DCE is that it is based on a set of previously established attributes, and it ignores other attributes that may be

important to patients. Thus, if a patient places high value in other attributes not included in the DCE, the predicted optimal therapy may not reflect what the patient wants, leading him or her to feel disconnected and dissatisfied with the DCE-predicted therapy choice ⁹.

Chapter 4 presents a qualitative analysis of interviews conducted after a DCE in which participants discussed what factors they considered in making a decision about heart disease prevention. We found that, in addition to using the attributes included in the DCE for decision-making, many individuals actively brought new attributes, beyond those included in the DCE, to the decision-making process to select their preferred therapy choice. Individuals whose selected preferred therapy and generated “optimal” therapy were discordant typically talked more often about other attributes than did concordant individuals. The major new attributes that emerged in these interviews were: 1) medication avoidance/naturalness; 2) competing health and family demands; and 3) awareness of therapies. Our results also showed that participants largely responded positively to DCE-generated attribute ranking and “optimal” therapy choice, even if they did not agree with them. Our results cannot suggest whether the DCE generated "optimal" choice or the participant selected preferred therapy choice is a better choice in terms of outcomes or adherence, or what a patient may ultimately choose. Our results do, however, potentially suggest that the DCE results may be of some interest to patients. Providing the DCE results may present an opportunity, particularly in the therapy-discordant, to examine the reasons for the discordance, such as differences in knowledge about the therapies, inclusion of other attributes in the decision-making

process, or improper heuristics in decision-making (e.g., elevating the risk-reducing potential of exercise).

Conclusions

Many factors influence how patients make decisions about their health care. Understanding these factors and how they play into the decisions about preventive care may help in designing targeted preventive care promotion strategies. The findings in this body of research suggest three innovative methods for improving patient decision support in two disease models. First, health beliefs about CRC and CRC screening may differ across racial/ethnic and acculturation groups. Interventions for specific racial/ethnic or acculturation groups should focus on health beliefs that are salient to the target audience. This could suggest that simple socio-demographic measures, rather than complex psychosocial measures, could be useful for determining what information to promote CRC screening might be most useful for a particular patient. Following that, I found that an algorithm that uses simple measures may be useful for identifying how likely a patient is to complete CRC screening. By stratifying patients by how likely they are to complete CRC screening, CRC promotion strategies can be targeted to the information needs of these distinct groups. Finally, patients may use attributes that were not included in our DCE to make decisions about heart disease prevention. However, the participants in our study were receptive to the DCE-based “values concordant” choice. Presentation of the DCE-based choice, particularly when it differs from the directly selected choice, may provide an opportunity for discussion about how the patient is making their

decision. This discussion may identify gaps in knowledge or improper decision-making heuristics.

Future Research

The first part of this dissertation represents preliminary work in developing targeting methods for patient decision support to promote CRC screening in racial/ethnic minority populations. Further research is needed to confirm and validate our findings. First, the differences in health beliefs across racial/ethnic and acculturation groups that I presented in Chapter 2 should be confirmed. Future work to explore how the differences in health beliefs across racial/ethnic and acculturation groups that we identified relate to CRC screening behavior is also necessary. Second, the prediction model and framework I presented in Chapter 3 should be validated. Future research should compare the results of our new simple model with the existing, but lengthy, Patient Activation Measure.¹⁰ The second part of this dissertation provides evidence to the usefulness of DCE with modeled “values concordant” choice. Future work should use real patients, provide the DCE in the context of a formal decision aid, feed back the results of the DCE to the patient and, follow them forward in time for actual treatment choices.

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Vitae

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