

Hispanic Patients' Role Preferences in Primary Care Treatment Decision Making

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ABSTRACT

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Background: Shared decision making is considered to be a crucial component of high quality and safe patient-centered primary care treatment. Hispanics are the fastest growing minority group in the United States and they experience substantial health disparities. The aim of this study was to examine the factors that correlate with Hispanics' decision role preferences for participation in treatment decision making with their primary care clinician.

Methods: Hispanic patients (n=772) were recruited from five zip codes in the Washington Heights/Inwood community of New York City and survey data were collected via interview by bilingual community health workers in four New York-Presbyterian Ambulatory Care Network clinics. Data were analyzed using multinomial logistic regression to investigate the association between sociodemographic and health factors and role preference in primary care treatment decision making (passive, shared, active); passive role as the reference range.

Results: Most survey respondents preferred to participate in medical treatment decisions in a shared or active role (90%) and also had inadequate health literacy (95%). The odds of wanting to participate in decision making in a shared role with a primary care provider significantly increased with younger age (OR=0.98, 95% CI [0.96- 0.99], p =0.01), less than 21 years living in the United States (OR=0.48, 95% CI [0.27- 0.88], p =0.02), more adequate health literacy (Newest Vital Sign) (OR=.46, 95% CI [0.25- 0.83], p =0.01), better ability to understand

health instructions, pamphlets or written health materials (OR=0.55, 95% CI [0.31- 0.99], p =0.05), and higher social role performance (OR=0.97, 95% CI [0.94- 0.99], p =0.04).

Statistically significant odds for preference for an active role were higher education (OR=3.11, 95% CI [1.20- 8.04], p =.02), less than 21 years living in the United States (OR=0.37, 95% CI [0.19- 0.73], p =0.004), and younger age (OR=0.98, 95% CI [0.95- 0.99], p =0.02). However, the overall models demonstrated poor fit with study data explaining 10% -14% of the variation of the dependent variable.

Conclusion: Understanding the factors that influence Hispanic patients' role preference in primary care treatment decisions is crucial to providing higher quality patient-centered care and to possibly reducing Hispanics' health disparities. Our analysis suggested a number of patient specific factors that should be used to inform future informatics, clinical and public health primary care interventions for Hispanic patients. In addition, our analysis also underscores the need for more theoretical and analytical research to further characterize the factors that contribute to Hispanic patients' role preference in primary care treatment decision making.

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DEDICATION

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CHAPTER 1 INTRODUCTION

Patient-Centered Care

In 1988 the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) introduced the phrase “patient-centered care,” focusing clinicians on the patient instead of on the disease (Gerteis, 1999). The concept of patient-centered care as an integral component of the delivery of quality care was further circulated by the widely read Institute of Medicine (IOM) report, *Crossing the Quality Chasm*. In the report, patient-centered care is defined as "care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions"(IOM, 2001). The IOM definition of patient-centered care highlights the importance of clinicians and patients working together to in the context of clinical decisions.

The past decade has seen a shift in health care policy and clinical practice from a provider-centered to a more patient-centered care (Barry & Edgman-Levitan, 2012). This movement toward patient centered care has culminated on the national level with the creation of the Patient-Centered Outcomes Research Institute (Selby, Beal, & Frank, 2012). Shared decision making and role preferences are central to patient-centered care.

Patient-Centered Medical Home

A current model of primary care delivery that has evolved from the patient-centered care movements is the patient-centered medical home (PCMH). The PCMH is the main model currently proposed for the redesign of our healthcare system. The PCMH model is an approach to delivering comprehensive primary care for patients of all ages (AAFP, 2007). The National

Committee for Quality Assurance (NCQA) is the certifying body for PCMH status and defines a medical home as:

A model of care that strengthens the clinician-patient relationship by replacing episodic care with coordinated care and a long-term healing relationship. Each patient has a relationship with a primary care clinician who leads a team at a single location that takes collective responsibility for patient care, providing for the patient's health care needs and arranging for appropriate care with other qualified clinicians. The medical home is intended to result in more personalized, coordinated, effective and efficient care (NCQA, 2008).

The PCMH model was introduced by the American Academy of Pediatrics in 1967 as a way to coordinate the care of special needs children (Sia, Tonniges, Osterhus, & Taba, 2004). In 2007, the Joint Principles of the PCMH model were developed and agreed upon by the American College of Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics, and the American Osteopathic Association, representing over 300,000 physicians (AAFP, 2007). Since then, the PCMH model has been endorsed by the American Medical Association and eighteen specialty physician organizations, ten national nursing organizations, many other healthcare organizations, and over 1000 medical home stake holders and supporters (PCPCC, 2013) . The widely agreed upon Joint Principles (described below) define the intent of patient-centered care:

Personal provider: Each patient has an ongoing relationship with a personal health care provider, who is trained to provide first contact, continuous, and comprehensive care.

Provider directed medical practice: The personal provider at the practice level leads a team of individuals that collectively take responsibility for ongoing patient care.

Whole-person orientation: The personal provider is responsible for providing all of the patient's healthcare needs or for arranging care with other qualified professionals.

Care is coordinated and integrated: Coordination occurs across all elements of the complex healthcare system and the patient's community.

Quality and safety: Care delivery is patient, system, and provider focused.

Enhanced access: Care is available through open scheduling, expanded hours, and other innovative options for communication between patients, their personal provider, and practice staff.

Payment: This principle recognizes the added value provided to patients who have a patient-centered medical home so as to promote sustainability of the model. Delivering an advanced level of primary care takes a team of professionals routinely working together to provide patient-centered services. Expanded services beyond the actual patient encounter need to demonstrate value, such as improved health outcomes, before increasing reimbursement (AAFP, 2007).

Shared Decision Making

The goal of the "patient-centered" portion of the medical home is to have activated, engaged patients who want better service and transparency in health care and seek to form partnerships with their providers (Nutting et al., 2011). Shared decision making (SDM) is considered to be a vehicle by which patient-centered care is delivered in the PCMH structured

primary care settings (Barry & Edgman-Levitan, 2012). Shared decision making is described by Charles, Gafni and Whelan (1997) as “at least two participants, the clinician and patient, are involved; that both parties share information; that both parties take steps to build a consensus about the preferred treatment; and that an agreement is reached on the treatment to implement” (p. 685) (Charles, Gafni, & Whelan, 1997). Ideally, the agreed upon treatment plan is consistent with medical science and tailored to each patient’s needs, values and preferences.

SDM has become the preferred paradigm of patient/clinician communication for the primary care setting (McGregor, 2006; Zikmund-Fisher et al., 2010). For example, two major sections, 3021 and 3506, of the Affordable Care Act and ensuing regulations encourage delivery systems to engage in SDM (“ARRA,” 2009; Bozic & Chiu, 2011; CMS, 2011). Specifically, the Congressional final ruling for Medicare accountable care organizations requires delivery systems that participate in the Medicare Shared Savings Program to engage in SDM (CMS, 2011).

Research has shown that SDM assists patients to understand their treatment (C. M. Ruland, Brynhi, Andersen, & Bryhni, 2008), facilitates patient engagement in care (Stacey, 2011), increases compliance with treatment (Chewning & Sleath, 1996), promotes patient safety (C. M. Ruland, 2004) and improves patient satisfaction in outcome (J. D. Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). The use of SDM patient-decision aids (including pamphlets, videos, or web-based tools describing the available options and helping patients understand these options and the possible benefits and harms) has been shown to contribute to increased patient knowledge, more accurate risk perception, a greater number of decisions consistent with patients’ values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided (Stacey, 2011). Increased knowledge of the factors which affect patient role involvement in clinical decision making can assist in developing

informatics interventions to improve SDM and communications between patients and providers (C M. Ruland et al., 2008). The goal of these informatics projects would be to deliver more effective patient and clinician decision support and patient decision aid technologies. This would result more in more empowered patients who assume a more active role in their own health, ultimately achieving increased patient engagement, a crucial component of patient-centered care.

Hispanics and SDM

Hispanics are the largest and fastest growing population group in the United States, accounting for 16.3% (50.5 million/310 million) of the US population in 2010 (Ennis, 2011). Disparities in the health status of Hispanics have been well documented (Nelson, 2002; Thomas, 2011). Hispanics have been shown to have significantly higher rates of diabetes (Cowie et al., 2006), hypertension, asthma (Moorman et al., 2011) and obesity than their white counterparts (Roger et al., 2012). In addition, while cancer is the largest cause of death in Hispanics (Ennis, 2011; Siegel, Naishadham, & Jemal, 2012), evidence suggests that screening rates for many types of cancer (Wells & Roetzheim, 2007) are lower than in comparable white populations (Cokkinides, Bandi, Siegel, & Jemal, 2012). Because of their well-documented health disparities (Adler & Rehkopf, 2008), , Hispanics patients warrant further research in interventions to improve their health outcomes.

A growing body of literature underscores that the individual desire by patients to participate in SDM varies based on a number of individual and group factors including culture, age, health status, and gender (Charles, Gafni, Whelan, & O'Brien, 2006; Chewning et al., 2012; S. R. Patel & Bakken, 2010). A number of studies have highlighted the need for additional research exploring the interaction of cultural and other variables with role preferences when participating in medical decisions (Charles et al., 2006; Chewning et al., 2012; McCaffery,

Smith, & Wolf, 2010; S. R. Patel & Bakken, 2010). For example, evidence has suggested that a person's cultural background will significantly influence their desired role in treatment decision making with a provider (S. R. Patel & Bakken, 2010). At the same time, membership to a specific cultural group is not a valid single predictor for role preference (Charles et al., 2006). The implication of these finding is that a "one size fits all" approach to understanding SDM preferences is not accurate. Instead, individual patient factors within the context of a person's cultural groups and community environment will better predict desire to participate in SDM (Charles et al., 2006).

Primary Care

A decade ago, primary care medicine, as compared to specialty and inpatient medical care, was described by four pillars: first-contact care; continuity of care over time; concern for the entire patient instead of a specific organ system; and coordination of a patient's care throughout the entire healthcare system (Bodenheimer & Pham, 2010). Over time, the definition of primary care has evolved to satisfy the demands of patients, insurers and policy makers. These pressures include computerization of treatment information to facilitate quality measurement; systems that focus on chronic and preventative care; and population health level management of patients. The present patient-centered concept of primary care is embodied by the PCMH model and is the working definition of primary care services used in this dissertation.

Problem Statement

Research suggests that the patient's relationship with their primary care provider may improve an individual's overall health (Mark W Friedberg, Hussey, & Schneider, 2010; Lee & Scal, 2008). Currently, primary care services in the ambulatory care setting are mainly provided via interactions between patients and providers (e.g. Physicians, Nurse Practitioners, Physicians

Assistants and Registered Nurses). The goal of patient-centered care is to improve quality and safety of healthcare by placing an engaged patient and the provider at the center of a person's primary care (IOM, 2001). Shared decision making is the process that enables patient-centered care to happen (Nutting et al., 2011). However, current research is very limited regarding preference for involvement in SDM among Hispanic patients in the primary care setting. The patient's role preference may also be influenced by the clinical setting. Previous findings specific to Hispanic role preference in shared decision making come from mental health (Cortes, Mulvaney-Day, Fortuna, Reinfeld, & Alegría, 2009; S. R. Patel & Bakken, 2010) and oncology settings (Hawley et al., 2008). The findings suggest that, as a group, Hispanic patients may prefer a more passive role in treatment decision making compared to non-Hispanics. More research is needed to understand Hispanic patient desire in the primary care setting, and the individual factors that influence their role preference for SDM.

Little is known about patients' role preference and factors that influence SDM in the primary care setting. Furthermore, even less is known about Hispanic patients' role preferences to participate in SDM in primary care. Currently, there is a gap in knowledge of how the socio-demographic health status (comorbidities, self-reported overall health status, mental health status) and social role performance factors are related to an individual's decision control preference in the primary care setting.

Purpose of the Study

The goal of this study is to investigate decision making role preference of Hispanic patients and the relationships between patient factors and Hispanic patients' role preferences in the primary care setting.

Research question. Which socio-demographic variables (age, gender, education, health literacy, insurance, acculturation) and health status (comorbidity, self-reported overall health status, mental health status, social role performance) factors influence the likelihood of Hispanic patients' preferences for shared or active decision roles for primary care decision making?

Significance

There are significant gaps within current SDM research especially within Hispanic SDM in the primary care setting. To date, there has been only one study that has investigated the topic of SDM and Hispanic patients in the primary care setting (Gourlay, Lewis, Preisser, Mitchell, & Sloane, 2010). This study did not examine role preference, but rather investigated the perceptions of informed and shared decision making in an ethnically diverse sample within a primary care setting. During our literature search, we were unable to find any research specific to Hispanic patient role preference for SDM in the primary care setting. This gap is important to investigate and may ultimately contribute to improved Hispanic patient health and a possible decrease in health disparities.

Over the past few decades, research has shown that persistent health disparities exist in a variety of patient groups including low income, Hispanic, African American, Native American, lesbian, gay, bisexual, and transgender patients (Adler & Rehkopf, 2008; IOM, 2011; C. J. L. Murray et al., 2006; Saha et al., 2008). The SDM goals include enhancing patient knowledge of expected direction and magnitude of treatment effects, elevating patient involvement, and reducing decisional conflict between clinician recommendations and patient preferences and actions (Stacey, 2011). These goals may help reduce some of the factors that contribute to health disparities in the aforementioned patient groups. There is evidence that this is the case in certain settings. For example, asthma significantly effects the Hispanic population (Moorman et al.,

2011). Notably, in a randomized control trial of patients with poorly controlled asthma, patients who participated in asthma treatment SDM: 1) showed significantly better adherence to asthma treatment; 2) had significantly better clinical outcomes after 1 year (asthma-related quality of life, health care use, rescue medication use, asthma control, and lung function); and 3) after 2 years, SDM resulted in significantly lower rescue medication use (Wilson et al., 2010). Shared decision making interventions may help improve patient/clinician communication, lack of trust between patient and clinician and patient engagement in treatment plans (Stacey, 2011; Stein et al., 2013; Wilson et al., 2010).

Existing research related to role preference in SDM for Hispanic patients in the Primary care setting has been limited by a number of factors: limited sample size, lack of research in the ambulatory setting, lack of research in Hispanic populations, and weakness of instrumentation (Janz et al., 2004; S. R. Patel & Bakken, 2010; Peek, Tang, Cargill, & Chin, 2011).

By investigating the factors associated with preference to participate in SDM, this study will provide prerequisite fundamental knowledge to enhance provider/clinician communication, clinical decision support, SDM aids, and patient centered care.

This dissertation study is part of the Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) project (1R01HS019853), The Washington Heights and Inwood neighborhoods of Northern Manhattan have been designated as medically underserved areas by the Centers for Medicare and Medicaid Services, due to their level of poverty, number of elderly, infant mortality rates, and ratio of primary care providers per individual (Pati, 2002). Washington Heights and Inwood are predominantly Hispanic neighborhoods (71%) (NYCDHMH, 2006). The WICER project goal is to gain an

understanding of the Washington Heights Inwood community's health needs in order to eventually improve the health of the community.

Conceptual Framework

This study is informed by a number of theoretical frameworks, including the Charles' (1999) Model of treatment decision making and Degner's (1997) model for the Control Preferences Scale (CPS). These theoretical frameworks were combined to provide the basis of this dissertation study. The Charles' model for treatment decision making establishes the theoretical construct for a number of modes of decision making between patients and their provider (C. Charles, A. Gafni, & T. Whelan, 1999). The Charles model explicitly identifies different analytic steps in the treatment decision-making process and is applicable to the primary care setting (C. Charles et al., 1999). Table 1.1 outlines the components of the Charles model. In this model the analytic steps are information transfer, deliberation and decision about implementing treatment. Those steps are compared with the different types of decision making: paternalistic, shared and informed. The Charles model places the emphasis on active participation from both the patient and the professional in the decision-making process and ultimate decision. In the shared approach, both the patient and the professional bring preferences and facts into the decisional process. They then deliberate together in order to reach a joint or shared decision. The shared approach is in contrast to both the paternalistic style, where the professional makes the decision based on what he/she finds to be in the patient's best interest and to informed choice, where the patient makes the decision alone, based on information received from the professional (C. Charles et al., 1999).

Table 1.1

Charles Model of Treatment Decision Making

| | Paternalistic | Shared Decision Making | Informed |
|---------------------------------------|---|---|---|
| Information transfer | One way: from provider to patient, minimum necessary for informed consent | Two way: provider provides all medical information needed for decision-making, patient provides information about her preferences | One way: from provider to patient, all medical information needed for decision-making |
| Deliberation | Provider alone, or with other providers | Provider and Patient (plus potential others) | Patient (plus potential others) |
| Decision about implementing treatment | Provider | Provider and Patient | Patient |

The Charles Model of treatment decision making does not explicate measurement of concepts and variables; thus, a second framework that informed the current study was the conceptual underpinnings of the Control Preferences Scale (CPS). The CPS construct is defined as the degree of control a person wants to exercise when decisions are being made about medical treatment (Degner, 1997). This conceptual model was developed to measure preference for control as opposed to preference for information in patients with cancer (Degner, 1997). In this model the psychological dimension of control over treatment decision-making is viewed on a continuum. Relinquishing decision control is on one end (passive), holding all control (active) is on the other, with shared decision control between patient and provider in the middle. In the CPS conceptual model (Figure 1.1), the “ideal point” represents the specific amount of control

that a person wants to exercise for an individual treatment decision. Furthermore, the ideal point varies between different treatment decisions and may fluctuate over time (Degner, 1997; Degner, Kristjanson, Bowman, & et al., 1997; Singh et al., 2010).

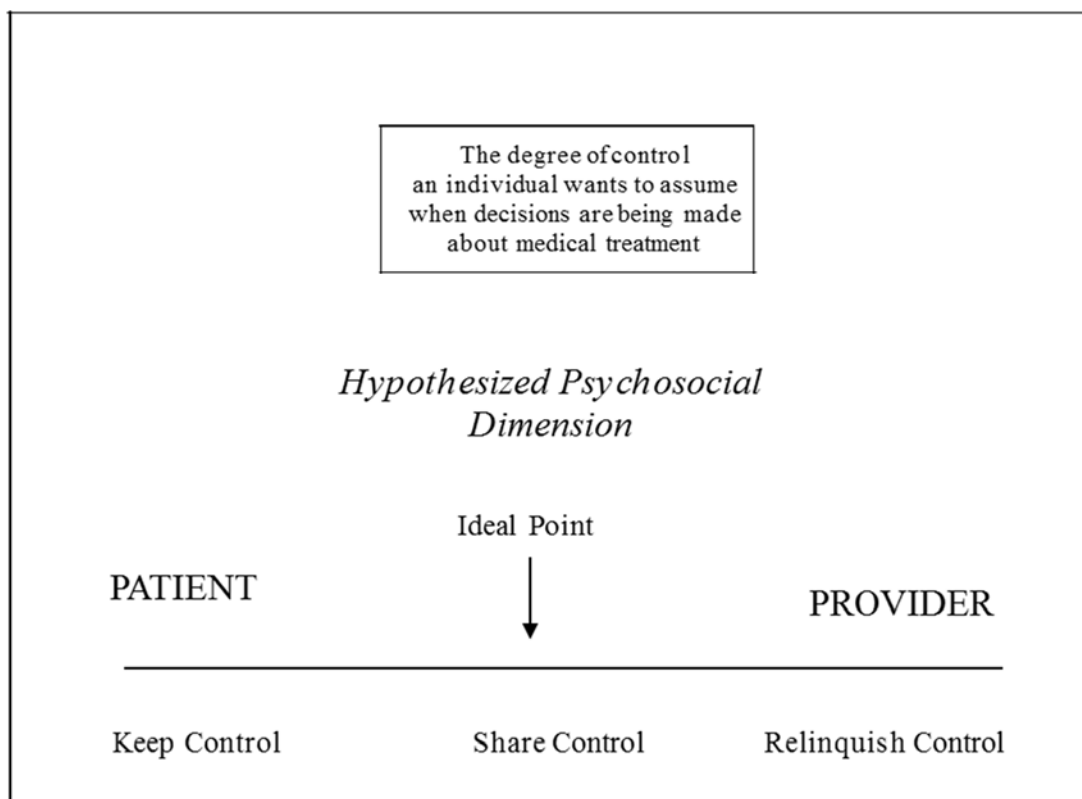


Figure 1.1. The Control Preferences Scale Construct (Degner, 1997)

To explicate the variables of interest in the analysis, a theoretical substruction was performed based on the Charles Model, conceptual underpinnings of the CPS, and the concepts and related variables that were identified in the literature (Figure 1.2).

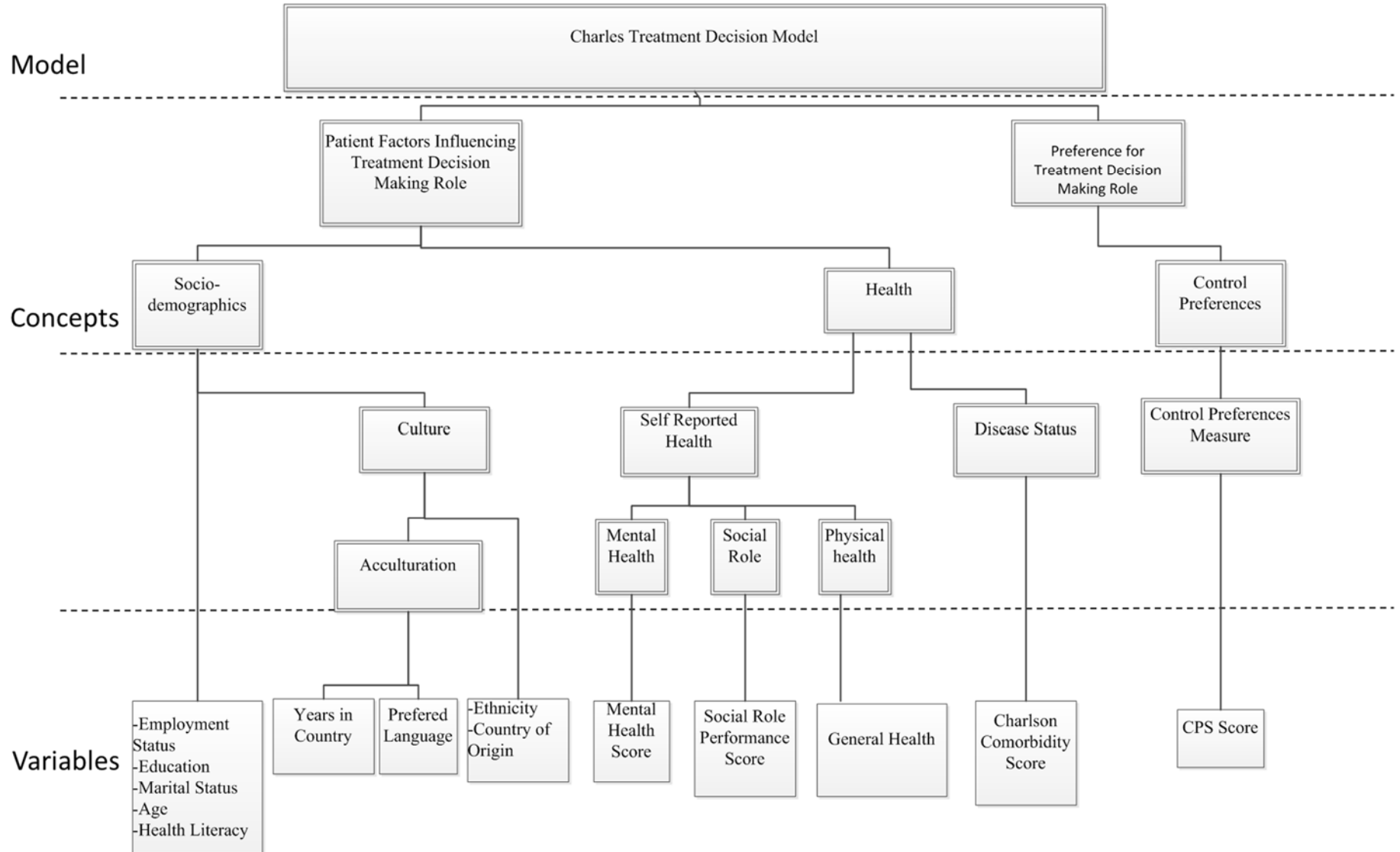


Figure 1.2. Theoretical Substruction of Study Concepts and Measures

Table 1.2 lists the variables collected and analyzed to answer the research questions.

Table 1.2

Concepts and Variables Measured

| Concept | Variable |
|---|---|
| Demographic information | Age, gender, marital status, educational level, insurance status |
| Health literacy | Newest Vital Signs Health literacy Chew - item 1 (confident filling out medical forms) Health literacy Chew - item 2 (difficulty learning about medical condition because of reading issues) Health literacy Chew - item 3 (need help with instructions, pamphlets, or other written material) |
| Role preference in healthcare decision making | Control preference score |
| Comorbidity | Charlson index score |
| Self-reported overall health status | Health status |
| Mental health status | Depression score |
| Social role performance | Social role performance scale score |
| Acculturation | Language preference for survey administration, number of years lived in the United States |

Shared decision making in the primary care setting is the ideal model for Hispanics to receive quality and safe ambulatory healthcare services (Mark W. Friedberg, Van Busum, Wexler, Bowen, & Schneider, 2013). One of the stated goals of Healthy People 2020 is to “empower

individuals toward making informed health decisions” (Health, Services, Prevention, & Promotion, 2013). The appropriate use of SDM is crucial to reaching that goal (Hawley et al., 2008; IOM, 2001). Amongst other factors, cultural characteristics may influence role preference in SDM for Hispanic patients. However, these factors are not adequately understood. To better understand Hispanic patients' treatment decision-making role preferences, this dissertation will explore the correlates of patient’s desire to participate in shared decision making with their primary care provider.

CHAPTER 2 REVIEW OF LITERATURE

Shared decision-making has been embraced as a challenge to the paternalistic one-directional model (Brock & Wartman, 1990). The SDM model involves a two-way exchange of information as well as discussion of treatment preferences. The Charles treatment decision making model in medical encounters (Charles et al., 1997; C. Charles et al., 1999) defines a number of essential components of SDM: two participants, the provider and patient, are involved in the treatment decision making; the provider and patient take steps to participate in the process of treatment decision making by expressing treatment preferences; information is exchanged between the provider and patient; and both parties agree on the treatment to implement.

To inform our study, we reviewed the existing literature related to associates of role preference in medical shared decision making. The methods used and results of the literature review are described below.

Methods

Inclusion and Exclusion Criteria

We searched for studies and reviews to describe correlates of preference to participate in SDM. Qualitative and quantitative studies were included if they had a measure of patient desire or intent to participate in SDM. Studies in English, performed in the United States, and published in peer reviewed journals between January 2002 and February 2013 were included in this review. Dissertations, government reports, editorials, and brief reports were excluded.

Search Strategies

PubMed, Scopus, Medline, Web of Science were searched with the core concepts *shared decisions and patient participation in decision-making*. Actual search terms are displayed in

Appendix A. The phrases used and required search iterations varied by search engine. The results from all digital databases were compiled in Endnote version 6X. Endnote was used to identify duplicate citations and to facilitate screening of titles and abstracts. As documented in Figure 2.1, the initial search resulted in the identification of 2097 records for review. Since correlates/predictors of SDM preference were not index terms in any of the research databases, all titles and abstracts were screened for potential relevance. Titles and abstracts were screened according to inclusion criteria (original research or systematic review, adult patients, adult contexts, decision-making), yielding 108 articles for analysis. While reviewing the articles identified in the initial searches, an ancestral approach was used to identify additional references that were not identified in the research database searches (Polit & Beck, 2010). After excluding irrelevant records and full-text articles that failed to meet the study's inclusion criteria, the 27 articles comprised the sample for analysis.

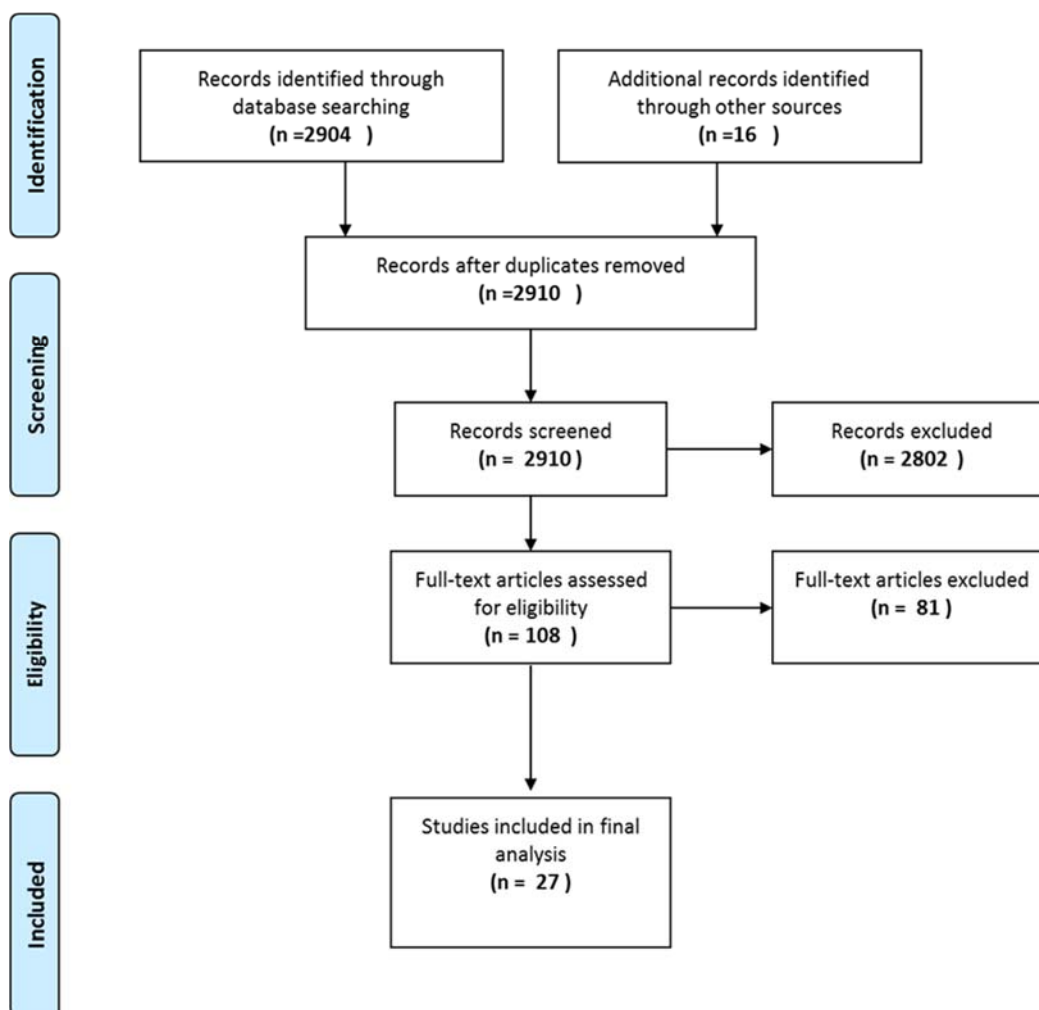


Figure 2.1 Article search and selection process

Data Extraction and Management

Study information extracted from each article included authors, title, year of publication, sample size, study populations, study design, correlates measured, study objective, results strengths, weaknesses, and measures of SDM preference. Extracted data were stored in a custom Microsoft Access database. We organized studies based on the instrumentation used to measure role preference for SDM and study population (e.g., cancer patients, general public, mental health, OB/GYN).

Table 2.1

Data Extraction

| Field | Variables |
|--------------------------|---|
| Authors | Authors last name, first name |
| Title | Article Title |
| Year | Year of publication |
| Sample Size | Number of individuals in study |
| Participants Description | Description of participants in study and study setting (e.g., women in abortion clinic) |
| Location | Setting |
| Study Design Type | One group pre-post One group post only Pooled analysis RCT Repeated measures Survey Systematic review Two group pretest Two group post-test only Within group Qualitative |
| Study Objective | Author's stated reason for performing study |
| Results | Summarized results |

| | |
|-------------------------|---|
| methods | Summarized methods |
| Conclusions | Summary of authors' conclusion |
| Latinos | Yes/No |
| Primary Care | Yes/No |
| Cancer | Yes/No |
| Mental Health | Yes/No |
| Other special | |
| Population | Yes/No |
| Limited Correlates | Yes/No |
| Only Self-Reported | |
| Health Status | Yes/No |
| Small Sample | Yes/No |
| Objective Clinical Data | Yes/No |
| Clinical Data Source | Clinician Chart Patient |
| Strengths | List of methodological strengths |
| Weaknesses | List of methodological weaknesses |
| Variables | Variables measured |
| SDM Measures | Measures used to assess role preference for SDM |

Results

Twenty-seven articles met all eligibility criteria for this review (Figure 2.1). The majority of studies employed survey methodology (n=18), followed by systematic reviews (n=4), qualitative studies (n=3), and intervention studies (n=2).

Sample

We categorized the role preference findings for five different health population groups: (1) oncology; (2) mental health; (3) general not specific to a clinical site or disease state; (4) primary care; and (5) other (see Table 2.3). More than three quarters of the articles addressed the first two population groups: oncology (n=11) and mental health studies (n=8) made up the majority of the literature.

The sample sizes of the studies in this review ranged from 1 to 9,949 study participants. Over 79 percent of the studies had a research sample of over 90 participants.

Factors Associated with Role Preference in Medical Decision Making

Qualitative findings. The three qualitative studies in the results differed in methods. Grounded theory, semi-structured interviews, and focus groups were used (Table 2.2). The qualitative research identified to a number of underlying themes in role preference for Hispanic patients. A number of cultural factors emerged from the identified qualitative research. The difference in a common language between provider and patient emerged in all of the qualitative research as a barrier to participating in SDM (Browner & Preloran, 2004; Cortes et al., 2009; Katz et al., 2011). When compared to non-Hispanics, Hispanics preferred to have the clinician make medical decisions (Cortes et al., 2009; Katz et al., 2011). Hispanics relied more on their support network (i.e., family, friends, and religion) to aid when contemplating treatment options (Katz et al., 2011). For Hispanics, greater trust in the provider was also related to referrals or

“word of mouth” recommendations from friends and family. To gauge trustworthiness, Non-Hispanics reported relying on other sources like clinician rating and educational status, such as board certification (Katz et al., 2011).

Individual, as well as cultural, themes arose from the qualitative research, as well. For example, respondents indicated that the amount of previous interaction with the healthcare system was associated with SDM role preference. In other words, their medical history and comorbidity also caused patients to desire a more shared role preference in medical decision making (Browner & Preloran, 2004; Cortes et al., 2009).

Quantitative findings. While in the studies in this review, more patients favored participating in decisions rather than delegating them to a provider, the findings for associations, correlates or predictor variables for desire to participate in SDM are inconclusive and vary based on individual demographics and other factors.

Socio-demographic factors. All 24 quantitative studies investigated the association between age and decision making preference; five found an association, three described that younger patients preferred a more active role in medical decision making than older patients (G. S. Chung, R. E. Lawrence, F. A. Curlin, V. Arora, & D. O. Meltzer, 2012; Dillard, Couper, & Zikmund-Fisher, 2010; Flynn, Smith, & Vanness, 2006) and another two found the opposite result (Oneal et al., 2008; Williams et al., 2008). A number of studies found that women prefer a shared role in treat decision making as compared to men (G. S. Chung et al., 2012; Gourlay et al., 2010; Maly, Umezawa, Leake, & Silliman, 2004). Although one study found an association between being male and preferring an active role (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008). However, the sample for this Veteran’s Administration study was predominantly male (94%). Four out of 27 studies described an association between education level and preference,

all finding that people with higher education preferred more active involvement (G. S. Chung et al., 2012; Gourlay et al., 2010; E. Murray, Pollack, White, & Lo, 2007; Williams et al., 2008).

Race and ethnicity were associated with decision-making preference in four studies, with non-Hispanic patients more likely to prefer to be involved than African Americans and Hispanics in three studies (W. Levinson, Kao, Kuby, & Thisted, 2005; E. Murray et al., 2007; S. R. Patel & Bakken, 2010). There was one exception in which investigators reported African Americans having more desire to participate in SDM than their white counterparts (Peek et al., 2011). Both of the studies that measured health literacy found that increased literacy correlated to increased desire to participate in SDM (Hawley et al., 2008; Naik, Street, Castillo, & Abraham, 2011). Moreover, marital status was not shown to be correlated with preferred role in treatment decision making (Grace S Chung, Ryan E Lawrence, Farr A Curlin, Vineet Arora, & David O Meltzer, 2012; Dillard et al., 2010; Flynn et al., 2006; Gourlay et al., 2010; Hart, Smith, Tademy, McClish, & McCreary, 2009; Hawley et al., 2008; Janz et al., 2004; S. R. Patel & Wisner, 2011; Peek et al., 2011; Rodriguez et al., 2008).

Health factors. A number of other variables including anxiety, social role performance, social support, and depression were associated with role preference. Although the design of these studies presented were descriptive, a few indicated that the majority of patients with a mental health diagnosis preferred a shared role in clinical decision making (Jared R. Adams, Robert E. Drake, & George L. Wolford, 2007; Oneal et al., 2008; S. R. Patel & Bakken, 2010).

Control preferences. In the identified quantitative literature, patient decision role preferences were measured with a variety of instruments. These measures include the Autonomy Preference Index (API), the Control Preferences Card Sort (CPS), modified CPS (no cards used), the Health Opinion Survey (HOS), and the Problem Solving Decision Making Scale (PSDMS).

These measures vary in their role preference domains, scale response categories, summary scores, and reporting methods. The most frequently used measures were the CPS (n=8), API or API-modified (n=4) and PSDM (n=3 (see Table 2.1). Other measures were used in a total of five analyses.

Among the included studies, the CPS measure was not uniformly administered. The original CPS utilizes five cards that are used to elicit the respondent's role preference for given scenarios (Degner, 1997). Four of the eight studies that employed the CPS used a modified version without the cards (Hart, Smith, Tademy, McClish, & McCreary, 2009; Hawley et al., 2008; Janz et al., 2004; Rodriguez et al., 2008). These studies replaced the cards with a Likert-type question.

Clinical Setting. In the identified literature, patients' desire to participate in SDM was higher when dealing with specialized medical treatment decisions as opposed to primary care decisions. Over 77% of the oncology and mental health analyses found the majority (>50%) of their respondents wanted to participate in decision making in a shared or active role. In contrast, only 50% of the groups surveyed in primary care populations, found that the majority of their respondents wanted to participate in decision making rather than delegate decisions to the physician (Table 2.3).

Discussion

Although the body of literature in this review suggests that age, race/ethnicity, education level, gender, and health literacy are correlated with the desire to participate in SDM, the fact that only exploratory research with small samples exist for Hispanic primary care patients, suggests that more rigorous research is needed. The reviewed studies demonstrated that to date

there have been no studies with large sample sizes that specifically investigated the correlates of Hispanic desire to participate in SDM in the primary care setting.

Only a small section of the literature specifically studied Hispanic role preference (Hawley et al., 2008; Maly, Umezawa, Ratliff, & Leake, 2006; S. R. Patel & Bakken, 2010). Furthermore, of the research reported with Hispanic respondents, only six studies described collecting data in Spanish (Gourlay et al., 2010; Hawley et al., 2008; Maly et al., 2004; Maly et al., 2006; E. Murray et al., 2007; S. R. Patel & Bakken, 2010). In addition, the evidence is lacking for the primary care population group. Table 2.3 illustrates that only three of the studies investigated SDM preference in the primary care setting and none were specific to Hispanic patients.

In this review, health status and comorbidity was not specifically measured in the primary care setting. The result is an inability to interpret how role preference varies with changes in health status in the ambulatory care setting. Previous research has strongly suggested that health status and its corollary, disease history, are closely related to role preference in medical decision making (Arora, Ayanian, & Guadagnoli, 2005; Say, Murtagh, & Thomson, 2006). In this review, specific disease population groups display preferences for participation in SDM that suggest that health status is an important correlate to characterize. For example, this review found that women being seen at an abortion clinic preferred to take a much more active role when deciding about reproductive health issues (Dehlendorf, Diedrich, Drey, Postone, & Steinauer, 2010; S. R. Patel & Wisner, 2011). In addition, both the oncology and mental health population displayed much higher desire to participate in medical decision making than patients that were primarily dealing with non-mental chronic illnesses.

Research has also shown that diagnosis and health status may affect patients' SDM preference (Arora et al., 2005). Most of the studies in this literature review did not demonstrate reliable assessments of a respondent's overall health. Three studies did calculate the Charlson Comorbidity Indexes in addition to obtaining self-reported health status (G. S. Chung et al., 2012; Maly et al., 2004; Maly et al., 2006). Comorbidity was not examined in the majority of the studies which leaves out an important contextual variable pertaining to a patient's desire to participate in SDM.

Finally, sample size of a study is considered when attempting to measure precision and to assure that difference is detected if it exists (Fleiss, Levin, & Paik, 2003). The majority of the studies in this review contained very large sample sizes, presumably providing adequate power. For the most part, studies that contained a nationally representative proportion of Hispanics had very large samples (G. S. Chung et al., 2012; Hawley et al., 2008; W. Levinson et al., 2005; Maly et al., 2006). The one exception is Patel and Bakken (2010). Although the study contained a significant proportion of Hispanics, the small sample (n=60) did not provide the power to significantly correlate individual factors with decisional role preference.

Limitations

For this review, only one individual searched, compiled, and reviewed the articles, so inter-rater reliability has not been evaluated. To reach a higher level of reliability, at least one more reviewer needs to be included in this study. In addition, because only one person collated the review, oversights could have occurred that might have been detected by additional reviewers.

Conclusion

The findings from the literature review suggest that individual and population-level factors are related to the variance in the role preference for patient treatment decision making. Cultural factors may influence role preference. Research suggests that for medical decision making, Hispanics are more likely to have their clinicians be the decider (Katz et al., 2011; W. Levinson et al., 2005; S. R. Patel & Bakken, 2010). Furthermore, Hispanics are more influenced by their family, friends, and community than non-Hispanic whites when making treatment decision and rating clinicians (Browner & Preloran, 2004; Chewning et al., 2012; Katz et al., 2011; W. Levinson et al., 2005). Role preference maybe influenced by setting (Chewning et al., 2012). Limited research suggests that individual level factors (socio-demographic and health) may influence desire to participate in SDM for Hispanic primary care patients. Nonetheless, large studies that specifically investigate Hispanic population in a primary care setting are needed.

Table 2.2.

Characteristics of Selected Studies

| Author | Study Objective | Sample & Size | Data Analysis | Study Design | Variables | Measures |
|---|---|---|---------------|-----------------|---|---|
| Adams et al., 2007(Jared R. | Explore perceived roles and preferences for shared decision making among persons with severe mental illnesses. | Adult clients with severe mental illness in a community mental health center, (n=30) | Correlational | Survey | age (older than 50 years), sex, education , self-reported substance abuse, and self-reported diagnosis of schizophrenia | The Autonomy Preference Index Decision-Making scale (API-D),Control Preferences Scale(CPS) |
| Browner et al.,(Browner & Preloran, 2004) | To illuminate how prior expectations of patients and clinicians can influence medical encounters and affect patients' choices whether to accept or reject medical testing or treatment. | Genetic testing clinic (n=1) | Qualitative | Grounded Theory | | |

| | | | | | | |
|---|---|--|--------------|-----------------------------------|---|--|
| Chewning et al., 2012(Chewning et al., 2012) | Empirical literature on patient decision role preferences regarding treatment and screening was reviewed to summarize patients' role preferences across measures, time and patient population. | Systematic review | Descriptive | Systematic review | | The Autonomy Preference Index Decision-Making scale (API-D),Control Preferences Scale(CPS), PDSMS, HOC |
| Chung et al., 2012(G. S. Chung et al., 2012) | To examine the associations between a preference for physician- directed decision-making and patient health status and socio- demographic characteristics. | Hospital patients (n=9949) | Multivariate | Survey | Demographic information included age, sex, race/ethnicity, marital status and level of education | non-validated custom |
| Cortes et al.,(Cortes et al., 2009) | Investigate the steps participants undertook in the process of becoming "activated" to formulate effective questions and develop decision-making skills in relation to their care. | Respondents at two outpatient mental health clinics (n=141) | Qualitative | Semi- structured interviews | | |

| | | | | | | |
|--|--|---------------------------------------|---------------|--------|--|---|
| Dehlendorf et al., 2010 (Dehlendorf et al., 2010) | This study compared decision-making references for contraception to preferences for general health among reproductive-aged women | Women at abortion clinics (n=257) | Comparative | Survey | Socio-demographic insurance | Problem-Solving Decision-Making Scale(PSDMS) |
| Dillard et al., 2010 (Dillard et al., 2010) | To examine relationships between perceived risk of cancer and behaviors during decision making for 3 screening tests. | Nation-wide telephone survey (n=1729) | Descriptive | Survey | Socio-demographics disease history | |
| Flynn et al., 2006 (Flynn et al., 2006) | Distinguishing patients' desired roles is an essential step towards promoting care that respects and responds to individual patients' preferences. | Home survey (n=5199) | Descriptive | Survey | Socio-demographic, health, and physician-patient, relationship factors | Health Opinion Survey, API's decision-making preference scale |
| Gourlay et al., 2010 (Gourlay et al., 2010) | Our objective was to describe primary care patients' perceptions of informed and shared decision making about cancer screening tests in a diverse sample | Primary care clinics (n=724) | Correlational | Survey | Socio-demographic, health | Decisional Conflict Scale(DSC) |

| | | | | | | |
|---|---|---|--------------|-------------------|--|---------------------------------|
| Hart et al., 2009 (Hart et al., 2009) | To examine general health decision-making roles among African American men ages 40 to 70 recruited in barbershops in the Richmond, Virginia, metropolitan area. | African American men in Barber shops (n=40) | Multivariate | Survey | Socio-demographics, self-reported health | Control Preference scale(CPS) |
| Hawley et al., 2008 (Hawley et al., 2008) | To evaluate Latina breast cancer patient perspectives regarding informed decision making related to surgical treatment decision making for breast cancer. | Women from SEER registry (n=2030) | Multivariate | Survey | Tumor size, socio-demographic | Control Preferences Scale (CPS) |
| Hubbard et al., 2008 (Hubbard, Kidd, & Donaghy, 2008) | A systematic review of the literature about patients' preferences for involvement in cancer treatment decision making was conducted. Establishing preferences is important if the aim is to make health care more sensitive to the needs and expectations of each individual patient. | Systematic review | Descriptive | Systematic review | | |

| | | | | | | |
|--|--|---|--------------|--------------|--|---|
| Janz et al., 2004 (Janz et al., 2004) | This study explored patient preferences for involvement in the breast cancer treatment decision and concordance between patients' and physicians' views on decisional role. The impact of demographic and psychosocial characteristics on patients' decisional role was also examined. | Breast cancer center patients (n=162) | Multivariate | Survey | Socio-demographic, role preference, clinical | Control Preferences Scale(CPS) |
| Katz et al.,(Katz et al., 2011) | This study examined whether Hispanics in the U.S. differ from non-Hispanic Whites with respect to key decision making preferences | Back and Knee pain patients at a urban hospital | Qualitative | Focus groups | Grounded theory | |
| Kumar et al., 2010 (Kumar et al., 2010) | To examine patient and provider characteristics and patient-provider communication behaviors associated with the decision-making role preferences of patients with HIV. | HIV clinic (n=434) | Multivariate | Survey | viral load, socio-demographic, depression | CESD-10screening instrument Interpersonal Processes of Care Survey23 |

| | | | | | | |
|---|--|--|--------------|--------|---|---|
| Levinson et al., (W. Levinson et al., 2005) |) To assess public preferences for participation in decision making in a representative sample of the U.S. population. 2) To understand how demographic variables and health status influence people's preferences for participation in decision making. | Nationally representative sample of U.S. households (n=2765) | Multivariate | Survey | Socio-demographics | General Social Survey (GSS) |
| Maly et al., 2004 (Maly et al., 2004) | To identify the impact of patient age and patient-physician communication on older breast cancer patients' participation in treatment decision-making | Breast cancer patients in outpatient oncology offices (n=222) | Multivariate | Survey | Age ,patient-physician interaction ethnicity, education, financial adequacy, stage of breast cancer, comorbidity, and social support | Perceived Efficacy in Patient–Physician Interactions (PEPPI),Participatory Decision-Making (PDM) |
| Maly et al., 2006 (Maly et al., 2006) | The purpose of the current study was to examine racial/ethnic group differences in the treatment decision-making process of older breast carcinoma patients and the | Breast cancer patients in outpatient offices (n=257) | Multivariate | Survey | Age ,patient-physician interaction ethnicity, education, financial adequacy, stage of breast cancer, comorbidity, and social support | Patient–Physician Interactions Questionnaire (PEPPI),Participatory Decision-Making (PDM) |

| | | | | | | |
|--|--|--------------------------------|--------------|--------|--|---|
| | differential impact on treatment received. | | | | | |
| Murray et al., 2007 (E. Murray et al., 2007) | To determine the congruence between patients' preferred style of clinical decision-making and the style they usually experienced and whether this congruence was associated with socio-economic status and/or the perceived quality of care provided by the respondent's regular doctor. | Telephone interview (n=3177) | Descriptive | Survey | Socio-demographic factors | Piloted custom scales |
| Naik et al., 2011 (Naik et al., 2011) | To evaluate the effect of functional health literacy (FHL) on preferences for decision-making; and among those initially preferring a passive decision-making role, to explore how preferences change if | VA cardiology patients (n=118) | Multivariate | Survey | Socio-demographic, cardiovascular disease severity | Problem-Solving Decision-Making Scale(PSDMS)-Modified |

their physician actively encourages
their involvement.

| | | | | | | |
|---|---|--|---------------|--------|--|--|
| Oneal et al., 2008 (Oneal et al., 2008) | This pilot study compared preferences for involvement in decision-making between older and younger adults with serious mental illness. | Adults from mental health clinic (n=33) | Correlational | Survey | Mental health, socio demographic, ethnicity, diagnosis, physical and mental health(sf-12) | Control Preferences Scale(CPS) , Autonomy Preference Index (API),Decision Self-Efficacy Scale |
| Patel & Bakken , 2010 (S. R. Patel & Bakken, 2010) | This study explored preferences for treatment decision making using the Control Preferences Scale and Problem Solving Decision Making Scale among a sample of ethnically diverse adults seeking treatment for anxiety and depression. | Convenience sample of adults in a depression clinic (n=60) | Correlational | Survey | Preferred role | Problem Solving Decision Making Scale(PSDMS), Control Preference Scale(CPS) |
| Patel & Wisner, 2011 (S. R. Patel & Wisner, 2011) | To explore women's perspectives about the treatment decision-making process for depression during pregnancy and after birth. | Web survey for postpartum women (n=100) | Correlational | Survey | Socio-demographic, role preference, pregnancy status, post-partum status, treatment preference | Decisional Conflict Scale(DCS), Problem Solving Decision Making |

Scale(PSDMS),Control
Preference Scale(CPS)

| | | | | | | |
|--|--|---|--------------|--------------------------------|---|--|
| Peek et al., 2011 (Peek et al., 2011) | To explore potential contributors to communication and SDM disparities in African Americans. | Community Health Centers (n=974) | Multivariate | Two group post-test only | Socio-demographic, Health status | Patient-Practitioner Orientation Scale (PPOS) |
| Rodriguez et al., 2008 (Rodriguez et al., 2008) | To assess patients' preferred role and perceived level of involvement in medical decision making and tested the effects of patients' age and role preference on perceived involvement in medical decision making | Older VA patients in primary care and cardiologist clinic (n=90) | Multivariate | Survey | Heart Disease severity Socio-demographic Health status B-type natriuretic peptide (BNP) | Control Preferences Scale(PCS),Perceived Involvement in Care Scale (PICS) Short Form-36 health |
| Singh et al., 2010 (Singh et al., 2010) | To collect normative data, assess differences between demographic groups, and indirectly compare US and Canadian medical systems relative to patient expectations of | (n=3276) | Multivariate | Pooled Analysis | country, sex, and age, tumor stage | Control Preferences Scale(PCS) |

involvement in cancer treatment
decision making.

| | | | | | | |
|--|---|----------------------------------|--------------|----------------------|--|--|
| Williams et al., 2008 (Williams et al., 2008) | We assessed the extent to which a sample of African American men wished to engage in SDM regarding PCS and the demographic and psychological characteristics el associated with SDM preferences. | Members of the Masons (n=286) | Multivariate | Two group pretest | age, education, marital status, employment status, access to and utilization of medical care, health insurance, personal history of cancer, and family history of prostate cancer, prostate cancer screening history | Problem-Solving Decision Making Scale(PSDMS) - modified |
|--|---|----------------------------------|--------------|----------------------|--|--|

Table 2.3.

Extracted Elements of Studies

| | Predictors evaluated | | | | | Sample population characteristics | | | | | |
|-----------------------------|----------------------|--------|--|-------------------------------|---------------------|-----------------------------------|-----------------------|----------|------------------|-----------------|----------------------------|
| | Age | Gender | Self - Reported Health Status | Objective Health Status | Race / Ethnicity | Other Correlates | General Population | Oncology | Mental Health | Primary Care | Other |
| Adams et al., 2007 | ☒ | ☒ | | ☒ | ☒ | ☒ | | | ☒ | | |
| Browner & Preloran, 2004 | | | | | | | | | | | Genetic Coun- seling |
| Chewning et al., 2012 | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | |
| Chung et al., 2012 | ☒ | ☒ | | ☒ | ☒ | ☒ | | | | | Inpatient |
| Cortes et al., 2009 | | | | | | | | | ☒ | | |

| | | | | | | | | | |
|----------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|--------------------|
| Dehlendorf et al., 2010 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | | Abortion Clinic |
| Dillard et al., 2010 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | |
| Flynn et al., 2006 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | |
| Gourlay et al., 2010 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | |
| Hart et al., 2009 | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | | | | AA Men |
| Hawley et al., 2008 | <input checked="" type="checkbox"/> | | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | |
| Hubbard et al., 2008 | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | |
| Janz et al., 2004 | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> | | <input checked="" type="checkbox"/> | |

Katz et al. 2011

Chronic
Knee and
Back Pain

Kumar et al., 2010

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☒

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HIV

Levinson et al.,

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Maly et al., 2004

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Maly et al., 2006

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Murray et al., 2007

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☒

Naik et al., 2011

☒ ☒

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Cardiology

| | | | | | | | | | | | |
|---------------------------|---|---|--|-----|---|---|---|---|---|---|------------|
| Oneal et al., 2008 | ☒ | ☒ | | ☒ | ☒ | ☒ | | | ☒ | | |
| Patel & Bakken , 2010 | ☒ | ☒ | | ☒ | ☒ | ☒ | | | ☒ | | |
| Patel & Wisner, 2011 | ☒ | ☒ | | ☒ | ☒ | ☒ | | | ☒ | | |
| Peek et al., 2011 | ☒ | ☒ | | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | ☒ | Diabetics |
| Rodriguez et al., 2008 | ☒ | ☒ | | ☒ ☒ | ☒ | ☒ | | | | | Cardiology |
| Singh et al., 2010 | ☒ | ☒ | | ☒ | | ☒ | | | ☒ | | |
| Williams et al., 2008 | ☒ | | | ☒ | | ☒ | | | ☒ | | |

CHAPTER 3 METHODOLOGY

This chapter presents the study methods including: the aim, ethical considerations, research design, recruitment procedures, settings, sample population, data collection procedures, study measures, and data analysis.

Methods

Aim. The aim of this study was to examine the factors that are associated with Hispanic patients' decision role preferences for participation in healthcare decision making with their primary care clinician. The associated research question is:

Which socio-demographic (age, gender, education, health literacy, insurance, acculturation) and health status (comorbidity, self-reported overall health status, mental health status, social role performance) factors influence the likelihood of Hispanic patients' preferences for shared or active decision roles for primary care decision making?

Ethical Considerations

The protocol for the Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) Ambulatory Care Network (ACN) Survey was approved by the Columbia University Medical Center (CUMC) Institutional Review Board (IRB). Informed consent was obtained from all study participants in their language of choice (English or Spanish).

Research Design

This study utilized a cross-sectional design to analyze baseline survey data collected in the ambulatory care setting as part of the WICER project (1R01HS019853). The underlying assumption of this dissertation study are the same as any correlational study. That is: the study variables exist in the population; a conceptual framework or previous research supports the possibility of relationships between the variables; the samples are representative of the population; the variables can be measured accurately; there is no manipulation of the variables (Wood, 1998).

Potential correlation between independent variables (e.g. age, gender, race/ethnicity, education, marital status, employment status, health literacy, preferred language, country of origin) and the dependent variable (i.e. Control Preferences Score) are supported by previous research outlined in Chapter Two.

Research Setting

The research setting was the Ambulatory Care Network (ACN), community based clinics, of New York-Presbyterian Hospital. Four ACN clinics in Washington Heights Inwood participated. The ACN clinics only serve Medicaid/Medicare/ State Children's Health Insurance Program (SCHIP) or uninsured patients. In addition, all of the clinics provide primary care based on the PCMH model and have been NCQA certified since 2010 (Carrillo et al., 2011). All physicians in the clinics also hold faculty positions in the College of Physicians and Surgeons at Columbia University.

Sample

The convenience sample consisted of 772 respondents who completed the WICER ACN survey during an ACN visit in one of the four participating clinics between January 1, 2012 and March 31, 2013. Adult respondents who were 18 years or older, Hispanic, English or Spanish speaking were eligible for study participation. Respondents were only included in the sample if they agreed to linkage with survey data and electronic data and had data available to create a Charlson Comorbidity Index score. Respondents who were unable or unwilling to give consent were excluded from participation.

Data Collection

Trained WICER staff approached patients while they waited to be seen in the waiting room of the ACN clinics and ascertained their interest in participating in the survey. Before conducting the survey interview, bilingual study personnel obtained informed consent from the participant in their language of choice (English or Spanish).

Interviews were conducted in either English or Spanish. Study personnel also measured and recorded the blood pressure (BP), as well as height and weight of respondents for calculation of body mass index. The survey process took approximately one hour to complete. All of the surveys were initiated at the clinics. If surveys were not completed at that time, surveyors performed follow up calls to complete unanswered sections. At the end of the survey interview, respondents received their choice of three incentives worth \$25: two movie tickets, a \$25 value metro card or a \$25 food voucher to a local grocery store.

Ninety nine percent of the survey data were entered directly into a web-based application on a tablet computer during the interview. In instances of technical issues (e.g., poor network connectivity), data were entered on paper during the interview and subsequently entered by the interviewer into the computer. When the surveys were completed, data from the iPad were stored in an application data store. After all of the surveys were administered the responses were electronically transferred to the WICER research data warehouse (Figure 3.1) (Wilcox, Gallagher, Boden-Albala, & Bakken, 2012).



Figure 3.1 Data management schematic.

Measures

The concepts that were investigated in this study were potential correlates of desired role in shared decision making with primary care clinician. The independent variables were related to socio-demographic, social role performance, acculturation, and health status concepts. The primary dependent variable in this study was the Control Preferences Scale (CPS) score which measures desired role in treatment decision making (Degner, 1997). Operationalization of these variables is described in Table 3.1.

Table 3.1

Conceptualization and Measurement of Study Variables

| Construct | Variable | Definition | Data type | Measure |
|---|--|---|---------------------------------|--|
| Role preference in healthcare decision making | Control Preference score | The degree of control an individual wants to assume when decisions are being made about medical treatment | Categorical | 5 item CPS score |
| Demographic information | Age, Gender, Marital status, Educational level, Insurance status | | Categorical Continuous (age) | |
| Health literacy | Health literacy | The degree to which individuals have the capacity to obtain, process, and | Categorical | Newest Vital Sign One item assessing need for help to |

| Construct | Variable | Definition | Data type | Measure |
|-------------------------------------|-------------------------------------|---|------------------|--|
| | | understand basic health information and services needed to make appropriate health decisions. | | complete medical forms |
| Comorbidity | Charlson Comorbidity Index score | A score generated by taking into account both the number and the severity of the illness. | Continuous | Charlson Comorbidity Index |
| Self-reported overall health status | Health status | Individual's health as described by respondent. | Categorical | One item from SF-8 Health Survey (SF-8) |
| Mental health status | Mental Health Score | Measure levels of emotional distress. | Continuous | PROMIS Short Form v1.0 - Emotional Distress - Depression 4a |
| Social role performance | Social role performance Scale score | Assesses the perceived ability to perform one's usual social roles and activities. | Continuous | PROMIS Short Form v1.0 - Ability to Participate in Social Roles & Activities |
| Acculturation | Language survey | The process of | Categorical | Language |

| Construct | Variable | Definition | Data type | Measure |
|-----------|----------------------------|---|-------------|--|
| | performed in? | cultural and psychological change that results following meeting between cultures | | preference |
| | Years in the United States | | Categorical | Born in the United States, immigrated <21 years ago, immigrated > 20 years ago |

Control Preference Scale in Shared Decision Making

The CPS was used to measure a patient's preferred role in decision making. More specifically, the CPS assesses the degree of control an individual wants to assume when decisions are being made about his/her own medical treatment. The CPS has been validated in studies that measure preferred role in both chronic and acute illness (Chewning et al., 2012; Hart et al., 2009; Hawley et al., 2008; Janz et al., 2004; Rodriguez et al., 2008). In this study, to assess each patient's preferred role, we included a modified CPS (J. R. Adams, R. E. Drake, & G. L. Wolford, 2007; Rodriguez et al., 2008). The measure consists of a single-item Likert scale, on which patients indicate the degree of control they prefer to have in medical decision making by selecting the statement which they agree with the most. Consistent with the use in (Rodriguez et al., 2008) we are using the CPS as a categorical variable. In the analyses, responses were consolidated to reflect a desire for a passive decision-making role (options 4 and 5), shared role (option 3), or active role (options 1 and 2).

Socio-demographic factors

Socio-demographic variables are summarized in Table 3.1. Gender was measured as Male, Female, Transgender (Male to Female), Transgender (Female to Male). Age was reported in years. Marital status was measured as married, currently living with a partner but not married, single/never married, divorced or separated, and widowed. Marital status responses were recoded into two categories, partnered and non-partnered. Respondents who were currently married or currently living with a partner were recoded as partnered, and rest of answers were coded as non-partnered.

Education was measured by nine categories, however, it was recoded to three levels: less than high school graduate, high school graduate and at least some college (Singh et al., 2010). Insurance type was originally assessed by five categories: Medicare, Medicaid, Veteran's Affairs (VA), private insurance and no insurance, but then recoded to insured versus not-insured.

Acculturation

The concept of acculturation was assessed by separate variables (Charles et al., 2006), Country of origin was measured by asking, "Where were you born?" There were eight choices for birthplaces: United States, Dominican Republic, Cuba, Mexico, Ecuador, Puerto Rico, Russia, and other countries. County of origin was recoded to United States, Dominican Republic, and other. Preferred language for survey completion, English or Spanish was recorded. The third acculturation variable was assessed by asking "How many years have you lived in the community where you currently live?" The responses to those two questions were then recoded into the following categories: born in the United States; lived in the United States less than 21 years; lived in the United States more than 20 years.

Place of birth was assessed to understand the demographics of the sample. However, place of birth was not used beyond descriptive analysis. Instead, the variable years in the United States,

was used in the bivariate and multivariate analysis. This variable described both the immigration status and years spent in the United States after immigration.

Self-Reported Health Status

Self-reported general health status was measured as a Likert scale single question, “Would you say that in general your health is,” with five responses: excellent, very good, good, fair, and poor. The questions were scored from five to one, with excellent registering five points and poor equaling one point. Low scores indicate assessment of general health as poor and likely to get worse (Maruish & Turner-Bowker, 2009). This question is taken from a single-item scale of general health domain in the Short Form-8 Health Survey (SF-8) which is a short form of Short Form-36 Health Survey (SF-36) (Turner-Bowker, Bayliss, Ware, & Kosinski, 2003; Yen, Chen, & Eastwood, 2009). The SF-8 was developed to be a parsimonious measure of physical and mental health status that is not specific to age, disease or treatment group. The self-reported health variable was then recoded to two variables: good or better if the response was excellent, very good or good. If the response was fair or poor then the variable was recoded to not good.

Health Literacy

The Newest Vital Sign (NVS) health literacy measure has been validated for both the English (NVS-E) and the Spanish versions (NVS-S). The language version used in the survey was based on individual preference. In previous research, both the NVS-E and the NVS-S demonstrated good reliability. The internal consistency was assessed as Cronbach’s $\alpha = 0.76$ for the NVS-E and Cronbach’s $\alpha = 0.69$ for the NVS-S (Weiss et al., 2005). Additionally, the criterion-related validity with Test of Functional Health Literacy in Adults (TOFHLA) was English version ($r = 0.59, P < .001$) and Spanish version ($r = 0.49, P < .001$) (Weiss et al., 2005).

The Newest Vital Sign is scenario based and consists of six questions testing reading, interpretation, and numeracy skills. These NVS questions are based on a nutritional label from an ice cream container (Weiss et al., 2005). The Spanish and English instruments have identical

content. Participants were given the label and then asked six questions about how they would interpret and act on the information contained on the label. A point was scored for each correct answer, and the total NVS score ranges from 0 to 6 and was categorized into three levels: high likelihood of marginal or inadequate literacy (0-1), possibility of marginal or inadequate literacy (2-3), and adequate literacy (4-6) (Weiss et al., 2005).

Health literacy was also evaluated by three separate 1-item measures (Chew, Bradley, & Boyko, 2004): 1) How confident are you filling out medical forms by yourself (not at all, a little bit, somewhat, quite a bit, extremely) 2) How often do you have problems learning about your medical condition because of difficulty understanding written information (sometimes, often always, occasionally, and never)? and 3) How often do you need to have someone help you when you read instructions, pamphlets, or other written material (sometimes, often always, occasionally, and never)? The Chew et al. items (2004) are valid measures of health literacy. The area under the receiver operating characteristic (ROC) curve of the questions was 0.76 for the three questions in a study of Veterans Affairs (VA) clinic patients (n=332. For the purposes of this study, the responses for each question were categorized into two categories, inadequate and adequate.

Comorbidities

The Charlson Comorbidity Index was used as an objective measure of severity of comorbid illness. Originally developed in an inpatient setting, the Charlson's Comorbidity Index has been well validated in a number of populations and settings, including community primary care locations (Sharabiani, Aylin, & Bottle, 2012). This index is calculated by using International Classification of Diseases, 9th revision (ICD-9) codes to predict the risk of death from 17 comorbid diseases over a one year period(see Table 3.1) (Charlson, Pompei, Ales, & MacKenzie, 1987; Huntley, Johnson, Purdy, Valderas, & Salisbury, 2012).

The original version of the Charlson's Comorbidity Index was created and validated by reviewing paper charts. In this study, severity of illness was assessed by the Deyo version of the

Charlson Comorbidity Index(Deyo, Cherkin, & Ciol, 1992). Furthermore, the ICD-9 diagnoses used to compute our respondent's Charlson's Comorbidity Index was extracted from patient's clinical data in the CUMC campus of New York-Presbyterian (NYP) clinical data warehouse for respondents who consented to have their clinical data linked and available for analysis during the initial survey process. The extracted data consisted of all inpatient and outpatient ICD-9 coded diagnoses entered in the respondents' electronic health record within 12 months of the survey date. Working diagnoses were excluded from the final extracted ICD-9 data.

Table 3.2 shows the score for each category of ICD-9 coded diagnosis. The index score is the total of a person's individual category score. For example, if a person had an ICD-9 diagnosis of HIV and Diabetes, their Charlson Comorbidity Index score would be eight (six points for the HIV diagnosis and two points for the Diabetes history.)

Table 3. 2

Disease diagnoses utilized to score the Charlson Comorbidity Index

| Diseases | Score |
|-----------------------------|-------|
| Acute myocardial infarction | 1 |
| Congestive heart failure | 1 |
| Peripheral vascular disease | 1 |
| Cerebral vascular accident | 1 |
| Dementia | 1 |
| Pulmonary disease | 1 |
| Connective tissue disorder | 1 |
| Peptic ulcer | 1 |
| Liver disease | 1 |
| Diabetes | 2 |

| | |
|------------------------|---|
| Diabetes complications | 2 |
| Paraplegia | 2 |
| Renal disease | 2 |
| Cancer | 2 |
| Metastatic cancer | 3 |
| Severe liver disease | 3 |
| HIV | 6 |

PROMIS Measures

In this study, three variables were measured (i.e. Depression, Anxiety and Social Role Performance) utilizing PROMIS instruments (Cella et al., 2010; Cella et al., 2007). All of the PROMIS measures share a number of characteristics. First, they are based on item response theory (IRT) (Bjorner, Kosinski, & Ware, 2005; Bjorner, Kosinski, & Ware Jr, 2003). Item response theory item development differs from the more traditional measurement development. Unlike traditional psychometrics, IRT questions are not developed based on their ability, with a group of other questions in a scale, to measure a construct. Instead, each item is probabilistically analyzed to assess the relationship between a person's response to that survey question and his or her standing on the construct (e.g., emotional distress) being measured by the scale (Bjorner et al., 2003). The IRT models are optimized to predict the probability of choosing each response category as a function of an underlying, unobserved trait and item parameters (Cella et al., 2010).

Second, PROMIS scales have very good external validity, since they have been validated and normed on a sample that represents the marginal distributions of race/ethnicity (White vs. a combined group of African American, Hispanic, and other respondents) and education (high school or less vs. more than high school) from the 2000 census (Cella et al., 2007). In addition, all of the

PROMIS measures used in this survey have been validated in a Spanish speaking sample (Cella et al., 2010).

Scoring. Computation of the PROMIS short forms required a two-step process (Liu et al., 2010). First, the raw score for each scale was assessed. Each question has five response options ranging in value from one to five. To find the total raw score, the values of the response to each question must be summed. For example, for the eight-item form, the lowest possible raw score is 8; the highest possible raw score is 40. Second, the raw score was re-scaled into a standardized T-score with a mean of 50 and a standard deviation (SD) of 10 (Liu et al., 2010). Therefore, a person who had a T-score of 40 was one SD below the U.S. general population mean. These conversions are only valid when all questions on the short form have been answered. For example, in an eight-item form, if a raw score of 24 converts to a T-score of 61.6 with a standard error (SE) of 1.8. The resulting 95% confidence interval around the actual observed score ranges from 58.1 to 65.1 ($T\text{-score} + (1.96 * SE) = 61.6 + 3.5 = 58.1 \text{ to } 65.1$).

The interpretation of the score varies among the different PROMIS measures. A higher PROMIS T-score represents more of the concept being measured. For depression and anxiety, a T-score of 60 is one SD worse than average. For example when two people that were administered the PROMIS anxiety scale, the person that received a T-score of 60 is assessed as more anxious than an individual with a T-score of 55 (Cella et al., 2010; Liu et al., 2010). In contrast, for the PROMIS social role performance scale, a higher score indicates higher performance.

Social Role Performance. The PROMIS Social role short form was used to measure social role performance (Hahn et al., 2010). These items were developed to measure social function, and covers four domains: family, friends, work and leisure. Reliability coefficients were high (0.98), and item-total correlations were acceptable (0.65–0.85 for Ability; 0.47–0.82 for Satisfaction) (Hahn et al., 2010).

The social role short form consists of eight questions related to the four domains. An example question is “I am satisfied with my ability to work (include work at home)”. The responses are score cumulatively and are on a Likert scale, with the options: not at all, a little bit, somewhat, don’t know, quite a bit, very much. A higher score represents higher satisfaction.

Convergent validity analysis demonstrated that for satisfaction with participation in the social roles bank, correlations with the SF-36 scales ($r=0.57-0.59$) were less than the FACIT-Functional Well-Being Scale ($r=0.76$). For satisfaction with discretionary social activities, correlations with the SF-36 ranged from 0.44 (Role Physical) to 0.53 (Social Functioning). The correlation with the FACIT-Functional Well-Being Scale was 0.76.(Cella et al., 2010).

Mental health status. This PROMIS mental health measure is an eight-item short form that provides a dimensional assessment of emotional distress, applicable across a wide variety of health conditions (Pilkonis et al., 2011). Four items related to depression and four to anxiety. An example of a depression question is, “In the past 7 days I felt fearful”; with the responses on a Likert scale: never, rarely, sometimes, often, and always.

These PROMIS items are not currently intended to be screening or diagnostic tools (Cella et al., 2010; Pilkonis et al., 2011). During development of the depression item banks most of the behavioral and somatic items were removed, rendering the questions more effective at measuring self-reported outcomes and the internal psychological experiences (Pilkonis et al., 2011). This characteristic of the items allows for the questions to be more useful for assessing mood in chronic medical conditions where physical symptoms often confound the measurements (Kendel et al., 2010; Pilkonis et al., 2011).

Content validity for the anxiety and depression measures were assessed by subject matter experts, the mean adjusted item–total correlation for the depression short form was .83 and .79 for the anxiety short form (Pilkonis et al., 2011). Confirmatory factor analysis (CFA) of the anxiety and depression items has shown that scales both adequately measure the constructs of interest

(Pilkonis et al., 2011). For depression, CFA utilizing robust weighted least squares (WLSMV) estimator, has demonstrated comparative fit index [CFI] = .929, Tucker–Lewis index [TLI] = .995, and root mean square error of approximation [RMSEA] = .086), Similarly, for anxiety CFI = .901, TLI = .992, and RMSEA = .082 (Pilkonis et al., 2011). In other word, the PROMIS measures have demonstrated that they accurately detect depression and anxiety in a study population.

Furthermore, the internal consistency of the measures has been high. The alpha coefficients for depression short form was .95 and .93 for the anxiety short form (Pilkonis et al., 2011).

Data Management

Survey responses were entered on an iPad using an application built using Lime Survey, a web-based data management tool, on a secure server. In rare instances, data was collected on paper (due to technical difficulties) but was subsequently entered into the iPad later. The survey data were then stored in the WICER research database by automated processes (see Figure 3.1). Data were extracted from the WICER research database and loaded into Statistical Package for the Social Science (SPSS) Version 20.0 for data analysis installed on a password protected personal computer that has natively encrypted hard drive.

Data Retrieval

The majority of those data analyzed in this study are stored and retrieved from the WICER research database. Only those historical diagnosis data required to calculate a respondent's Charlson Comorbidity Index were gathered from a different source. To retrieve those necessary Charlson Comorbidity Index related data from the ACN's electronic health record (EHR) two important tasks were performed. First, survey respondents were linked to their medical record number (MRN) in the EHR in a stepwise process:

1. Programming scripts were run to match patients by name and survey date to names and encounter dates in the EHR.

2. If there was no match a search engine that utilizes a Soundex (Zobel & Dart, 1996), phonetic searching, algorithm was employed to find non-matching patients in step one.
3. If no match was established in step two, the Charlson Comorbidity Index was not calculated for the respondent.

Second, a report request was submitted to the DISCOVERY committee, which is the New York Presbyterian Health System data governance body, for review and approval of use of clinical data for research purposes (see Figure 3.2). Once the report request was approved, the MRNS were used as an identifier to pull out the correct historical clinical diagnoses from the EHR for the survey participants.

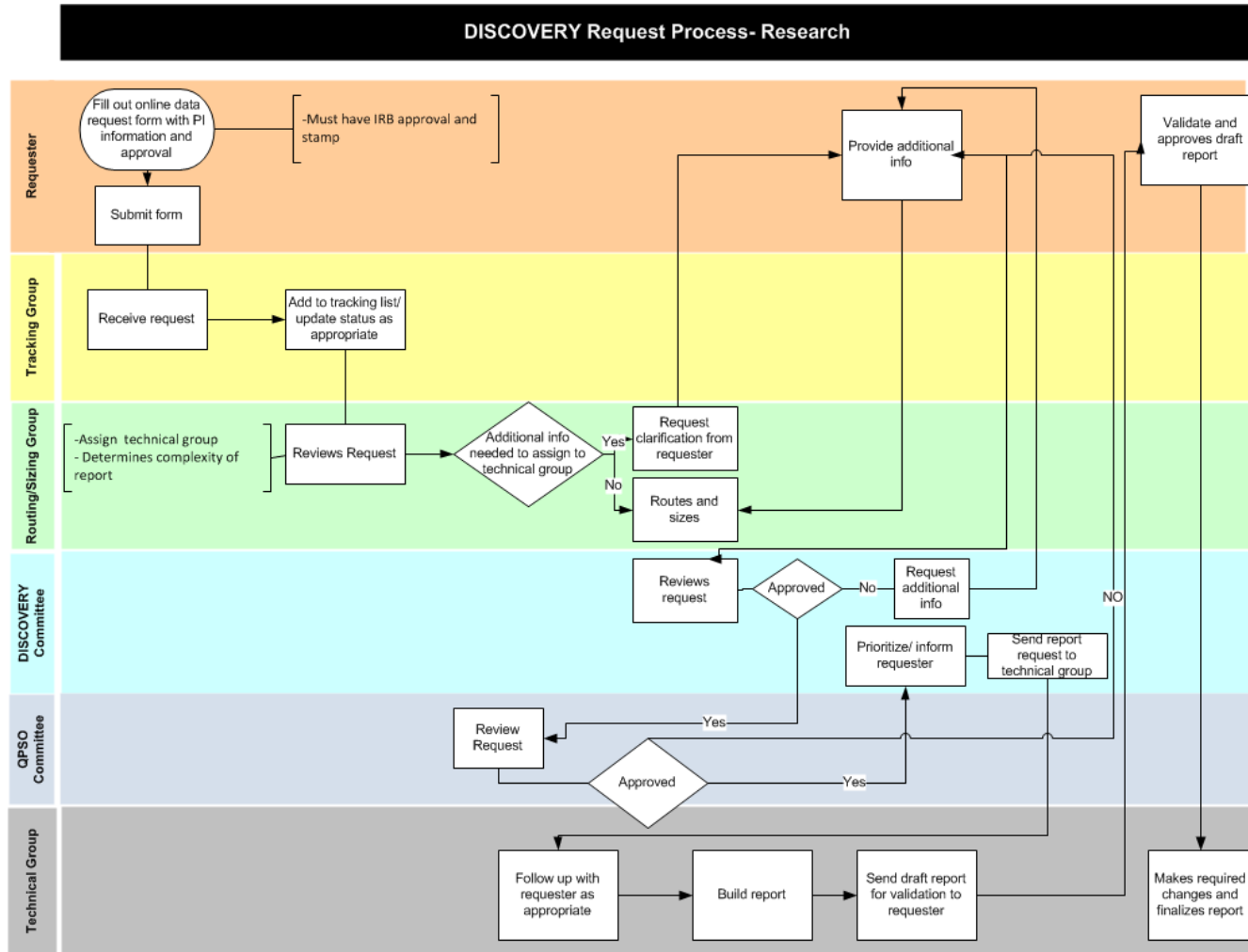


Figure 3.2 DISCOVERY committee approval process

Data Quality

Prior to beginning of data analysis, the extracted data set was cleaned and double-checked for accuracy by a trained WICER data analyst. When the CPS question was not answered the entire survey responses were removed from the analysis (n=89). Twenty-two duplicate surveys that represented either redundant data entry or two surveys completed for a single respondent were also removed. After data were cleaned, the sample decreased from n=883 to n= 772.

Missing data were only imputed for items within the PROMIS Social Role questions. Mean item substitution was employed when less than 20% of items were missing. For example, the social role scale had 8 items, if one item was missing, then the missing item was replaced with mean of the other 7 items per the PROMIS scoring guidelines (PROMIS, 2013).

Statistical Analysis

The analytic plan is designed to answer the research question—Which socio-demographic (age, gender, education, health literacy, insurance, acculturation) and health status (comorbidity, self-reported overall health status, mental health status, social role performance) factors influence the likelihood of Hispanics' preferences for shared or active decision control roles for healthcare decision making in primary care—was analyzed using SPSS Version 20.0 software. Variables used in the analysis are described in Table 3.1 and composite scores and recoding for variables are presented in Table 3.3.

Table 3.3

Composite Scores and Recoded Variables

| Variables | Computation of Composite Scores/Recoded Variables |
|---------------------------|--|
| Control Preferences Scale | <p>Active = I prefer to make the decision about which treatment I will receive, I prefer to make the final decision about my treatment after seriously considering my clinician's opinion</p> <p>Shared = I prefer that my clinician and I share responsibility for deciding which treatment is best for me</p> <p>Passive = I prefer that my clinician makes final decision about which treatment will be used but seriously considers my opinion, I prefer to leave all decision regarding treatment to my clinician</p> |
| Marital status | <p>Partnered = married, currently living with a partner but not married</p> <p>Not Partnered = single/never married, divorced or separated, widowed</p> |
| Health status | <p>Not Good = fair, poor, very poor</p> <p>Good or Better = excellent, very good, good</p> |
| Insurance | <p>Insured = Medicare, Medicaid, Veteran's Affairs (VA), private Insurance</p> <p>Uninsured = no insurance, not Insured</p> |

| Variables | Computation of Composite Scores/Recoded Variables |
|--|--|
| Educational level | <p data-bbox="518 260 1305 365">Less than High school = never went to school, eighth grade or less, some high school, not a high school graduate</p> <p data-bbox="518 407 1289 512">High school = some high school, not a high school graduate, high school graduate or GED</p> <p data-bbox="518 554 1330 730">Some college or more = some college or technical, trade or vocational school, associate degree, bachelor's degree, master's degree, doctoral degree</p> |
| Years in the United States | <p data-bbox="518 768 1284 947">Born in the United States = lived in United States since birth in United states less than 21 years = Lived in the United States twenty or less years</p> <p data-bbox="518 989 1312 1094">In United states greater than 20 = Lived in the United States 21 of more years ago</p> |
| Confident filling out medical forms | <p data-bbox="518 1136 1208 1178">Inadequate literacy = somewhat, quite a bit, extremely</p> <p data-bbox="518 1209 1029 1241">Adequate literacy = not at all ,a little bit</p> |
| Difficulty learning about medical condition because of reading issues. and Need help with instructions, pamphlets, or other written material | <p data-bbox="518 1293 1102 1335">Inadequate literacy = sometimes, often, always</p> <p data-bbox="518 1367 1021 1398">Adequate literacy = occasionally, never</p> |

Initially, descriptive analysis was used to examine the frequency and distribution of study variables calculating mean and standard deviation, median and range, frequency and percentage as appropriate. These data were assessed for normality through histograms.

Following the descriptive analysis, association between each independent variable and the dependent variable was assessed by performing crosstab analysis. Based on their distribution, continuous variables(i.e. age, PROMIS depression score, PROMIS social role score, PROMIS anxiety score, Charlson Comorbidity Index) were converted to categorical variables for the crosstab analysis (Munro, Visintainer, & Page, 2001). After the crosstab examination, polychotomous logistic regression (also called multinomial logistic regression in SPSS) analyses were conducted to examine the relationship between the independent variables and the dependent variable. The passive role was chosen as the reference group. The level of significance for testing of each model was set to an alpha of 0.05.

Three different multivariate analyses were performed where the independent variables were entered into the model differently: Forward Stepwise, Backward Stepwise, and all in at once (Garson, 2013). Furthermore, instead of allowing the software to select, we chose the order that the variables were entered into the model. The order of variables entered reflected the conceptual underpinnings of this study, where socio-demographic factors were entered first, followed by health factors. (Munro et al., 2001). This method evaluates all variables in relation to the dependent variable and other independent variables through the use of partial correlation coefficients. The variable with the highest correlation to the dependent variables is entered into the model first, subsequent variables with high partial correlations are then entered and removed, based on strength of association with the dependent variable (Gray & Kinnear, 2012).

CHAPTER 4 RESULTS

In this chapter the characteristics of the study population are presented. The results of bivariate and multivariate analysis were used to answer the study research question: Which socio-demographic (age, gender, education, health literacy, insurance, acculturation) and health status (comorbidity, self-reported overall health status, mental health status, social role performance) factors influence the likelihood of Hispanic patients' preferences for shared or active decision making control roles for primary care decision making?

Descriptive Sample Characteristics

Demographic measures. The self-reported demographics of the sample are described in Table 4.1. The average respondent age was 49.3 years old (SD =16.7, Range: 18-91). The sample population was predominantly female (84.7%) and foreign-born (86.0%). In addition, Dominicans were the largest foreign born population group (72.3%). The majority of the respondents was not partnered (63.3%), and had a high school or higher education (51%). Most of the participants had some form of health insurance (94.4%), mostly government funded (i.e., Medicaid and/or Medicare).

Self-reported health. Approximately half of the respondents reported that their overall health was not good (52.4%) as compared to good or better.

Health literacy measures. Both health literacy measures, NVS and Chew's health literacy screening questions (2004), were categorized into two levels: inadequate and adequate literacy. The majority of NVS responses were characterized as inadequate literacy (95.1%). For the Chew (2004) items, most respondents indicated having inadequate literacy related to filling out medical forms by themselves (68.6%), difficulty learning about medical condition because of reading issues (52.9%) and needing help with instructions, pamphlets, or other written material (53.4%).

Health measures. The health measures for the sample are described in Table 4.2. The mean PROMIS anxiety score (t-score) was 49.6 (SD=11.1). Respondents reported a mean PROMIS depression t-score of 48.2 (SD=9.98) and an average PROMIS social role performance t-score of 53.4 (SD=9.43). As Figure 4.1 illustrates, the Charlson Index score in our sample reflects few comorbidities (Mean = 0.89; SD = 1.78).

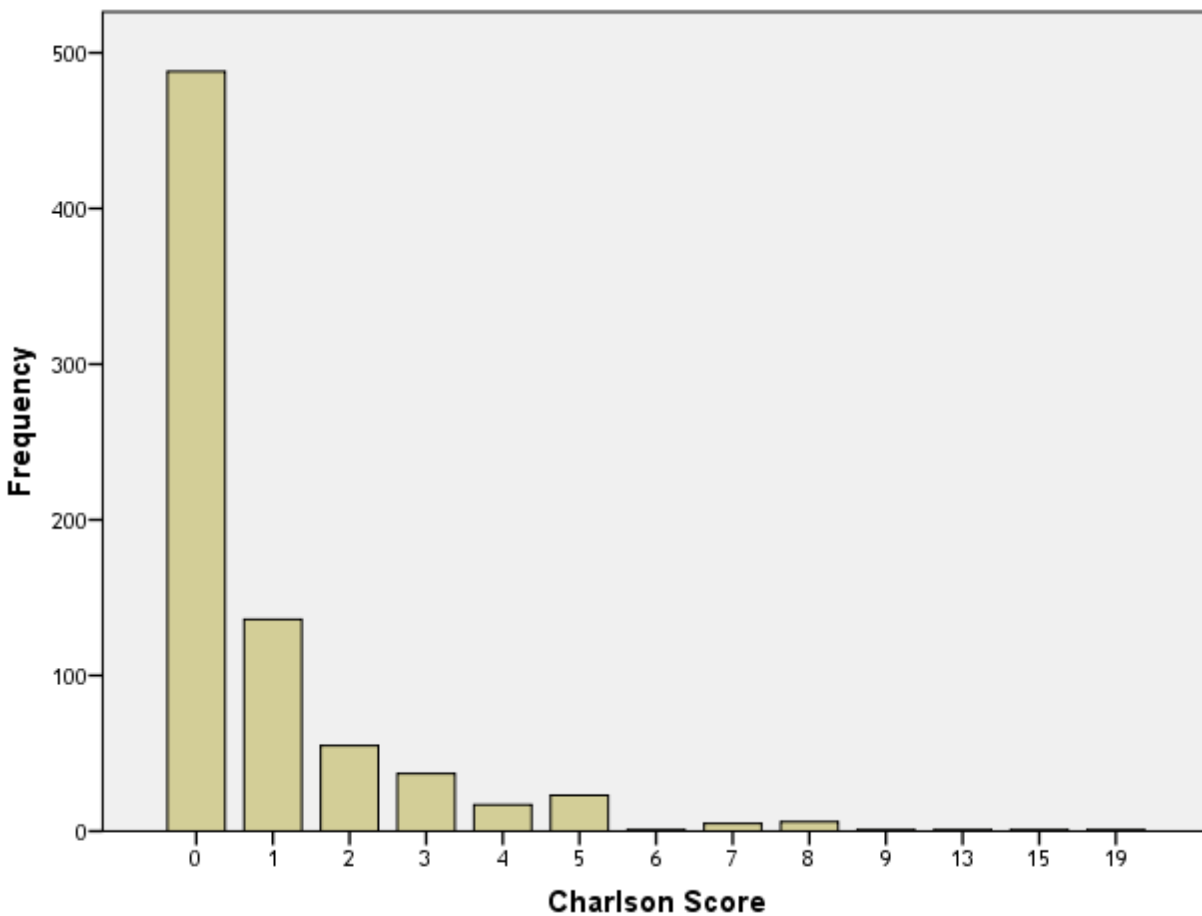


Figure 4.1 Distribution of Charlson Comorbidity Index Scores.

Treatment decision making role preference. Patients in this sample overwhelmingly stated that they wanted to be engaged participants of their primary care decision making. In fact, the majority (90%) of respondents preferred an active or shared role in medical treatment decision making as compared to 10.5% passive role preference.

Table 4.1

Characteristics of the Study Sample (n= 770)

| Variables | n (%) |
|-----------------------------------|------------|
| Gender | |
| Men | 117 (15.2) |
| Women | 654 (84.7) |
| Not answered | 1 (.10) |
| Marital status | |
| Partnered | 283 (36.7) |
| Not partnered | 489 (63.3) |
| Education | |
| Less than high school graduate | 381 (49.4) |
| High school graduate | 170 (22.0) |
| At least some college | 218 (28.2) |
| Not answered | 3 (.40) |
| Years in the United States | |
| Born in the United States | 116 (15.0) |
| In United States < 21 years | 323 (41.8) |
| In United States > 20 Years | 330 (42.7) |
| Not answered | 3 (.40) |
| Birth place | |
| United States | 116 (15.0) |
| Dominican Republic | 558 (72.3) |
| Other countries | 96 (12.4) |
| Not answered | 2 (.3) |

| Variables | n (%) |
|---|------------|
| Preferred survey language | |
| Spanish | 639 (82.8) |
| English | 133 (17.2) |
| General health status | |
| Not good | 402 (52.1) |
| Good or better | 365 (47.3) |
| Not answered | 5 (.60) |
| Health literacy (Newest Vital Sign) | |
| Adequate literacy | 38 (4.90) |
| Inadequate literacy | 732 (94.8) |
| Not answered | 2 (.30) |
| Health literacy Chew - item 1 (confident filling out medical forms) | |
| Adequate literacy | 252 (32.6) |
| Inadequate literacy | 513(66.5) |
| Not answered | 7 (.90) |
| Health literacy Chew - item 2 (difficulty learning about medical condition because of reading issues) | |
| Adequate literacy | 350 (45.3) |
| Inadequate literacy | 415 (53.8) |
| Not answered | 7 (.90) |
| Health literacy Chew - item 3 (need help with instructions, pamphlets, or other | |

| Variables | n (%) |
|---------------------|---------------|
| written material) | |
| Adequate literacy | 344 (44.6) |
| Inadequate literacy | 421 (54.5) |
| Not answered | 7 (.90) |
| Variables | M(SD) |
| Age (years) | 49.34 (16.70) |

Table 4.2

Health Characteristics of the Study Sample (n= 772)

| Variables | M(SD) |
|--|--------------|
| PROMIS anxiety scale (t-score) | 49.6 (11.10) |
| PROMIS depression scale (t-score) | 48.2 (9.98) |
| PROMIS social role performance scale (t-score) | 53.4 (9.43) |
| Charlson Index | 0.89(1.78) |

Bivariate Analysis Results

Alpha for significance for bivariate analysis was set at $p < 0.20$ for selection of variables for inclusion in multivariate analysis. For respondents' Control Preferences Score, there were statistically significant differences in gender, age, education, survey language preference, years in the United States, PROMIS depression scale, PROMIS social role performance scale, race, health literacy (Chew-item 1, 2, and 3) and self-reported general health status (Table 4.3).

Table 4.3

Bivariate Analysis of Sample (n=772)

| Variables | Active % | Passive % | Shared % | p |
|------------------------------|------------|-----------|------------|-------|
| Gender | | | | .083 |
| Male | 27 (23.1) | 19 (16.2) | 71 (60.7) | |
| Female | 152 (23.2) | 81 (10.5) | 511 (66.3) | |
| Marital status | | | | .274 |
| Partnered | 57 (20.1) | 32 (11.2) | 194 (68.6) | |
| Not partnered | 123 (25.2) | 49 (10.0) | 317 (64.8) | |
| Education | | | | <.000 |
| <High school graduate | 70 (18.4) | 56 (14.7) | 255 (66.9) | |
| High school graduate | 45 (26.5) | 14 (8.20) | 111 (65.3) | |
| At least some college | 64 (29.4) | 11 (5.0) | 143 (65.6) | |
| Chronic stress –Health Scale | | | | .310 |
| Serious illness | 44 (21.5) | 27 (12.7) | 146 (65.8) | |
| No serious illness | 136 (24.0) | 54 (9.80) | 365 (66.2) | |
| General health status | | | | .094 |
| Not good | 90 (24.4) | 51 (12.7) | 261 (64.9) | |
| Good or better | 90 (24.7) | 29 (7.90) | 246 (67.4) | |

| Variables | Active % | Passive % | Shared % | p |
|---|------------|------------|------------|------|
| Years in the United States | | | | .003 |
| Born in the United States | 34 (29.3) | 4 (3.4) | 78 (67.2) | |
| In the United States < 21 years | 133 (23.8) | 69 (12.4) | 356 (63.8) | |
| In the United States >20 Years | 13 (13.5) | 8 (8.3) | 75 (78.1) | |
| Preferred survey language | | | | .043 |
| Spanish | 145 (22.7) | 75 (11.7) | 419 (65.6) | |
| English | 35 (26.3) | 6 (4.5) | 92 (69.2) | |
| Health insurance status | | | | |
| Insured | 235 (23.4) | 107 (10.7) | 661 (65.9) | |
| Not Insured | 14 (20.9) | 7 (10.4) | 46 (68.7) | |
| Health literacy (Newest Vital Sign) | | | | .537 |
| Adequate literacy | 7 (18.4) | 2 (5.3) | 29 (76.3) | |
| Inadequate literacy | 173 (23.6) | 79 (10.8) | 480 (65.6) | |
| Health literacy Chew – item 1 (confident filling out medical forms) | | | | .014 |
| Adequate literacy | 59 (23.4) | 39 (15.5) | 154 (61.1) | |
| Inadequate literacy | 121 (23.6) | 41 (8.0) | 351 (68.4) | |

| Variables | Active % | Passive % | Shared % | p |
|---|-------------|------------|------------|------|
| Health literacy Chew - item 2 (difficulty learning about medical condition because of reading issues) | | | | .004 |
| Adequate literacy | 87 (24.9) | 21 (6.0) | 242 (69.1) | |
| Inadequate literacy | 92 (22.2) | 58 (14.0) | 265 (63.9) | |
| Health literacy Chew - item 3 (need help with instructions, pamphlets, or other written material) | | | | .134 |
| Adequate literacy | 88 (25.6) | 36 (10.5) | 220 (64.0) | |
| Inadequate literacy | 91 (21.6) | 43 (10.2) | 287 (68.2) | |
| Variables | M(SD) | M(SD) | M(SD) | |
| Age (years) | 48.2 (16.8) | 56.8(16.8) | 49.3(16.4) | .022 |
| PROMIS anxiety scale (t-score) | 50.7(11.2) | 50.7(11.9) | 49.0(11.2) | .346 |
| PROMIS depression scale (t-score) | 49.9(10.6) | 49.2(11.1) | 47.4(9.5) | .012 |

| Variables | Active % | Passive % | Shared % | p |
|--|-----------|------------|-----------|------|
| PROMIS social role performance scale (t-score) | 54.3(9.0) | 54.5(11.1) | 52.9(9.3) | .063 |
| Charlson Index | 0.7(1.4) | 0.9(1.9) | 1.1(1.9) | .025 |

Multivariate Analysis Results

Three multivariate analyses, with differing entry methods were performed (i.e. entered together, forward stepwise and backward stepwise). Although the entry methods differed, the variables entered remained the same. (i.e. gender, marital status, years in the United States, education, chronic stress –health scale, general health status, preferred survey language, health insurance status, health literacy (NVS), Health literacy Chew-item 1, health literacy Chew-item 2 ,health literacy Chew-item 3 ,PROMIS anxiety scale (t-score), PROMIS depression scale (t-score),PROMIS social role performance scale (t-score), and Charlson Comorbidity Index).

All entered together. The model where all of the variables were entered at the same time demonstrated a low goodness of fit (Goodness of Fit $\chi^2=1295.18$, $p>0.05$). Furthermore, the Cox and Snell (0.12) and Nagelkerke's (0.14) pseudo R measures, also indicated a low goodness of fit (Gray & Kinnear, 2012). The Cox and Snell and Nagelkerke's rough approximations of R^2 (Gray & Kinnear, 2012) indicated that the model with all of the variables entered in accounted for 12% to 14% variation in the CPS measure.

Table 4.4 shows that in this model that some college education (OR=3.11, 95% CI [1.20- 8.04], $p=.02$), living in the United States a longer period of time (OR=0.37, 95% CI [0.19- 0.73], $p=0.004$) and younger age (OR=0.98, 95% CI [0.95- 0.99], $p=0.02$) were also significantly associated with active as compared to passive role preference in treatment decision making. Furthermore, in this analysis with shared role preference as the dependent variable, significant associations were: younger age (OR=0.98, 95% CI [0.96- 0.99], $p=0.01$), more adequate health literacy(NVS) (OR=.46, 95% CI [0.25- 0.83], $p=0.01$), better ability to understand health instruction, pamphlets or written health material (OR=0.55, 95% CI [0.31- 0.99], $p=0.05$), at least some college education (OR=3.11, 95% CI [1.20- 8.04], $p=0.02$), living in the United States a longer period of time (OR=0.48, 95% CI [0.27- 0.88], $p=0.02$), and lower social role performance (OR=0.97, 95% CI [0.94- 0.99], $p=0.04$).

Table 4.4

Multivariate Analysis for Variables All Entered at Once

| Variables | CPS Active OR (CI) ^a | p | CPS Shared OR (CI) ^a | p |
|---------------------------------------|------------------------------------|--------|------------------------------------|-------|
| Gender | | | | |
| Female(reference) | 1 | | 1 | |
| Male | 0.64 (.296,1.38) | 0.251 | 0.05(0.25,0.99) | 0.46 |
| Marital status | | | | |
| Partnered(reference) | 1 | | 1 | |
| Not partnered | 1.23(0.64,2.369) | 0.530 | 0.89(0.49,1.57) | 0.66 |
| Years in the United States | | | | |
| In United States >20 Years(reference) | 1 | | 1 | |
| Born in the United States | 0.91(0.19,4.47) | 0.910 | 0.91(0.20,4.11) | 0.90 |
| In United States < 21 years | 0.37(0.19,.725) | 0.004* | 0.48(0.27,0.88) | 0.02* |
| Education | | | | |
| <High school graduate(reference) | 1 | | 1 | |
| High school graduate | 1.63(0.70,3.79) | 0.26 | 1.15(0.54,2.48) | 0.72 |
| At least some college | 3.11(1.20,8.04) | 0.02* | 1.90(0.77,4.48) | 0.17 |
| Chronic stress –Health Scale | | | | |
| Serious illness (reference) | 1 | | 1 | |
| No serious illness | 1.23(0.61,2.48) | 0.18 | 0.90(0.49,1.68) | 0.90 |
| General health status | | | | |

| Variables | CPS Active OR (CI) ^a | p | CPS Shared OR (CI) ^a | p |
|--|------------------------------------|------|------------------------------------|-------|
| Not Good (reference) | 1 | | 1 | |
| Good or better | 1.01(0.510,2.00) | | 1.45(0.62,2.12) | 0.67 |
| Preferred survey language | | | | |
| Spanish | | | | |
| English | | | | |
| Health insurance status | | | | |
| Insured (reference) | 1 | | 1 | |
| Not Insured | 4.30(0.51,36.02) | 0.18 | 4.11(0.53,32.0) | 0.18 |
| Health literacy (Newest Vital Sign) | | | | |
| Adequate literacy(reference) | 1 | | 1 | |
| Inadequate literacy | 0.88(0.09,8.86) | 0.91 | 0.46(0.25,0.83) | 0.01* |
| Health literacy Chew – item 1 (confident filling out medical forms) | | | | |
| Adequate literacy (reference) | 1 | | 1 | |
| Inadequate literacy | 0.53(0.27,1.02) | 0.06 | 1.67(0.84,3.31) | 0.14 |
| Health literacy Chew - item 2 (difficulty learning about medical condition because of reading issues) | | | | |
| Adequate literacy(reference) | 1 | | 1 | |
| Inadequate literacy | 1.32(0.62,2.83) | 1 | 1.67(0.84,3.31) | 0.05 |

| Variables | CPS Active OR (CI) ^a | p | CPS Shared OR (CI) ^a | p |
|---|------------------------------------|-------|------------------------------------|-------|
| Health literacy Chew - item 3 (need help with instructions, pamphlets, or other written material) | | | | |
| Adequate literacy(reference) | 1 | | 1 | |
| Inadequate literacy | 0.81(0.42,1.56) | 0.53 | 0.55(0.31,0.99) | 0.05* |
| Age (years) | 0.97(0.95,0.99) | 0.03* | 0.98(0.96,0.99) | 0.03* |
| PROMIS anxiety scale (t-score) | 0.98(0.93,1.04) | 0.28 | 0.97(0.93,1.01) | 0.19 |
| PROMIS depression scale (t-score) | 1.03(0.98,1.09) | 0.22 | 0.99(0.95,1.05) | 0.89 |
| PROMIS social role performance scale (t-score) | 1.00(0.96,1.03) | 0.82 | 0.97(0.94,0.99) | 0.04* |
| Charlson Index | 1.11(0.78,1.58) | 0.57 | 1.15(0.84,1.27) | 0.38 |

a. The reference category is passive

* p < 0.05

Backward and forward stepwise entry. The variables gender, marital status, years in the United States, education, chronic stress –health scale, general health status, preferred survey language, health insurance status, health literacy (NVS), health literacy Chew-item 1, health literacy Chew-item 2, health literacy Chew-item 3, PROMIS anxiety scale (t-score), PROMIS depression scale (t-score), PROMIS social role performance scale (t-score), Charlson Index were entered into a multinomial regression model. These variables were first entered forward stepwise then backward stepwise. The results of these two analyses were identical; goodness of fit was poor (Goodness of Fit $\chi^2=1291.57$, $p>0.05$). In addition, the Cox and Snell (0.083) and Nagelkerke's (0.10) pseudo R measures for these analyses accounted for less of the variation in the dependent variable. Comparatively, 8.5-10% of variation of the dependent variable was explained in the backward/forward entry analysis versus 12% - 14% of variation of the dependent variable in the analysis that entered all of the independent variables at once.

In backward/forward entry analysis, some college education (OR=3.58, 95% CI [1.47- 8.68], $p=0.005$), living in the United States longer (OR=0.39, 95% CI [0.20- 0.75], $p=0.0054$) and younger age (OR=0.97, 95% CI [0.95- 0.99], $p=0.03$) were significantly associated with active role preference in treatment decision making. Also in this analysis, with shared role preference as the dependent variable, significant associations were: younger age (OR=0.97, 95% CI [0.95- 0.99], $p=0.03$), some college education (OR=2.40, 95% CI [1.20- 5.50], $p=0.04$), higher levels of depression (OR=0.97, 95% CI [0.95- 0.99], $p=.04$), and lower social role performance (OR=0.97, 95% CI [0.94- 0.99], $p=0.03$).

Table 4.5

Multivariate Analysis for Variables Entered Forward and Backward Stepwise

| Variables | CPS Active | p | CPS Shared | p |
|--|----------------------|--------|----------------------|-------|
| | OR (CI) ^a | | OR (CI) ^a | |
| Years in the United States | | | | |
| In United States \geq 20 Years(reference) | 1 | | 1 | |
| Born in the United States | 1.12(0.30,4.51) | 0.87 | 1.17(0.31,4.38) | 0.82 |
| In United States < 21 years | 0.39(0.20,0.75) | 0.005* | 0.51(0.30,0.91) | 0.02* |
| Education | | | | |
| <High school graduate(reference) | 1 | | 1 | |
| High school graduate | 1.96(0.89,4.33) | 0.97 | 1.51(0.74,3.11) | 0.26 |
| At least some college | 3.58(1.47,8.68) | 0.005* | 2.40(1.05,5.50) | 0.04* |
| Age (years) | 0.97(0.95,0.99) | 0.03* | 0.98(0.96,0.99) | 0.01* |
| PROMIS depression scale (t-score) | 1.01(0.98,1.04) | 0.22 | 0.97(0.95,0.99) | 0.04* |
| PROMIS social role performance scale (t-score) | 0.84(0.96,1.03) | 0.82 | 0.97(0.94,0.99) | 0.03* |

a. The reference category is passive

* $p < 0.05$

CHAPTER 5 DISCUSSION

The aim of this study was to investigate possible predictors of adult Hispanic patients' desire to participate in shared decision making with their primary care clinicians based on the Charles Treatment Decision Model (Charles et al., 1999). More specifically, our study investigated the desired role preference of Hispanic patients (Table 1.1) in a primary care setting. In the following section, we will review the various methodological approaches utilized in our analysis, and compare our results with an external body of research, in order to understand the significance of the research results regarding the impact of our chosen predictors and their individual or synergistic impact on the control preference role.

Comparison among Regression Model Approaches

In our analysis we chose to use three different methods to enter the variables into multinomial regression analysis. The entry methods were: all in at once, forward stepwise and backward stepwise. This approach was adopted for a few reasons. First, in the literature there was a general concern that forward stepwise approach may mask the contribution of variables (Munro et al., 2001). It is assumed that as a statistical program enters and removes variables from a model, variables may not stay in the model long enough to display their influence on other variables (Cohen, 1991). Second, a related concern is that two variables might have a synergistic effect. Individually the variables may not correlate with the dependent variable, but when placed together they do contribute a significant influence. Consequently, leaving the variables out of the final model solely on bivariate analysis may alter the findings (Munro et al., 2001).

Our analysis indicated that using three different entry methods resulted in some variation across the analyses. All variables measured in this study were entered into all of the models regardless of their statistical level of association in the bivariate analysis. We also did not let the SPSS statistical program choose the order of variable entry into the different models, instead we

dictated the entry order. Therefore, socio-demographic variables were entered and then health related factors for all three multinomial regression analyses.

In all three of our analyses, older Hispanic patients were less likely to prefer an active (OR=0.98, 95% CI [0.95- 0.99], $p=0.02$) and shared role (OR=0.98, 95% CI [0.96- 0.99], $p=0.01$). Contrarily, Hispanic patients who immigrated to the United States less than 21 years ago were less likely to prefer an active (OR=0.37, 95% CI [0.19- 0.73], $p=0.004$) and shared (OR=0.48, 95% CI [0.27- 0.88], $p=0.02$) role in comparison to a passive role with their primary care clinician. These findings suggest that both age and the level of acculturation (measured by number of years lived in the United States) are relevant factors when predicting role preference for Hispanic patients. Also, worse social role performance was significantly associated with more preference for shared treatment decision making in all of the regression analyses, (OR=0.97, 95% CI [0.94- 0.99], $p=0.04$). Finally, some or more college education was also significantly associated with active role preference in all of our multinomial regressions (OR=3.11, 95% CI [1.20- 8.04], $p=0.02$). These findings underscore the positive relationship between formal education and Hispanic patient involvement in treatment decisions in the primary care setting.

In the regression analyses that utilized forward or backward stepwise entry, worse depression scores were found to be statistically associated with increased patient desire to participate in SDM (OR=0.97, 95% CI [0.95- 0.99], $p=0.04$). In addition, entering all of the conceptually relevant variables at once and not removing any variables from the model appears to improve the amount of variation of the CPS score explained by the model.

In our analysis we had poor model fit, the variation explained by the independent variables was highest (11% to 14%), when all of the variables were entered into the model and stayed in the model (Table 4.4). There are a number of possible explanations for the poor model fit. It is possible that by recruiting patients in the waiting room we had a biased sample. These patients are already engaged in their care due to fact that they chose to visit their primary care provider. A comparative

assessment utilizing statistical sampling from the same community would reveal if a priori patient activation is the reason for our poor model fit. A second possible explanation for the poor model fit is that we did not utilize a “power predictor” in our models. In other words, the explanatory variables that we utilize in our analyses were too individually or communally weak as predictors. Our analysis did not include measures of patient perceptions of their provider. It is possible that that a measure of a patient satisfaction with their provider may be a very strong explanatory variable. Third, Charles and her colleagues (2006) noted that while a patient’s culture has significant effects on SDM, there is a lack of theoretical understanding of the influence of culture in SDM. They have stated that, “with few exceptions, culture has been a relatively neglected topic in the literature focusing on the development of conceptual models of treatment decision-making”(Charles et al., 2006). For example, some researchers have pointed out that the acculturation variable used in our research is simplistic and probably miss the complexity of individual level cultural adaptations that are related to the construct (Abraído-Lanza, Armbrister, Flórez, & Aguirre, 2006).

Discussion of Findings

Socio-demographic factors. Previous research has identified a number of socio-demographic and health-related factors that are associated with a patient’s preferred role in medical decision making (Table 2.3). A number of studies have demonstrated that younger, female (Grace S Chung et al., 2012; Gourlay et al., 2010; Maly et al., 2004; Say et al., 2006), more health literate and better educated patients prefer shared role preference in medical decision making (Davis, Schoenbaum, & Audet, 2005; Say et al., 2006). Our results were consistent with these studies. As in Chewing et al., (2012) we also did not find an association between marital status and respondents’ CPS (Chewning et al., 2012). In our study, respondents’ education was significantly correlated with role preference. Some college or higher increased the odds that patients would prefer active and shared role as compared to passive role in decision making. Previous studies have identified the

same correlation in other populations and settings (Chung et al., 2012; Gourlay et al., 2010; E. Murray et al., 2007).

Previous quantitative and qualitative research have noted the associations between acculturation factors like birth country and years in the country (Browner & Preloran, 2004; Cortes et al., 2009; Cowie et al., 2006; Hawley et al., 2008; Wells & Roetzheim, 2007). In our analysis, we measured the two concepts in one single variable. Our findings, like others, indicated that less time in the United States increases the odds of participating in SDM.

Health Literacy. A breast cancer-related study amongst Hispanic women found a significant correlation between health literacy and role preference (Hawley et al., 2008). We found an association with control preference and health literacy. Adequate health literacy as measured by the NVS, increased a respondents desire to participate in SMD in a shared way by 50%. In addition, we found that a Hispanic patient's ability to understand medical instructions, pamphlets, or other written material found was associated with 45% increased odds of participating in shared decision making. These findings were in keeping with the previous literature (Hawley et al., 2008; Katz et al., 2011; Kumar et al., 2010; W. Levinson et al., 2005; Naik et al., 2011; S. R. Patel & Bakken, 2010; Peek et al., 2011).

However, some of the findings were inconsistent with those reported in the literature. Previous studies showed that females were more likely to prefer a shared decision making role (Chung et al., 2012; Gourlay et al., 2010; Maly et al., 2004; Say et al., 2006). We found was no statistical association between gender and control preference (Table 4.2). This is probably due to the predominance of females in the sample.

Health Factors. Research has shown that health status and disease history are closely related to role preference in medical decision making (Arora et al., 2005; Say et al., 2006). Our investigation of patient health related variables was aimed at understanding the health status factors that may contribute to role preference in the primary care setting (Figure 1.1). Therefore, our study

included self-reported measures (SF 8, PROMIS Anxiety Scale, PROMIS Social Role Performance Scale, and PROMIS Depression Scale) as well as an objective measure of health (Charlson Comorbidity Index). We found that decreased social role performance was positively correlated with a Hispanic patient's desire to have a share role in treatment decision making with their primary care provider. To our knowledge, this is a novel finding in that there was no identified existing literature that measured this correlation.

Few studies have included objective measures of health. We did not find that a Charlson Comorbidity Index had a strong correlation with CPS. The Charlson Comorbidity Index scores for our sample lacked variability. Eighty one percent had a Charlson Comorbidity Index of zero or one. The Charlson Comorbidity Index may be a more appropriate for inpatient settings while calculating one-year survivability (Deyo et al., 1992).

Although SDM and mental health status has been previously studied, only two other study had a mental illness measure and was designed to determine a correlation between role preference and depression diagnosis (Kumar et al., 2010; S. R. Patel & Bakken, 2010). In the Kumar and colleagues study depression correlated with passive role preference, and the authors hypothesized that the feelings of hopelessness that accompany depression would cause more depressed patients to delegate decisions to providers (Kumar et al., 2010). In contrast, in a study of patients being treated for anxiety and depression, Patel and Bakken (2010) that 98% wanted to participate in SDM.

Our study indicated that respondents with higher levels of measured depression were more likely to want to participate in a shared manner in their treatment decisions. A number of studies that only included patients with mental illness have found high levels of desire to participate in treatment decisions in a shared role amongst patients with mental health diagnoses (Oneal et al., 2008; Patel & Bakken, 2010). An explanation that has been put forward is that having a mental health diagnosis increases the odds that a person has had more contact with the health care system

and is therefore more comfortable communicating with clinicians (Oneal et al., 2008). This higher level of patient engagement argument is plausible and is supported by qualitative work that suggests a similar notion for desire to participate in SDM in the same setting (Browner & Preloran, 2004). Contrary to these findings other research has found no relationship with depression and decisional role preference (Petersen, 2003). In light of the small body of evidence related to depression and role performance's relationship with role preference in medical treatment decision making, it is difficult to draw conclusions. Clearly, more research is needed on this topic both general and in Hispanic populations.

Significance of Study

This is the first study with a large sample size to investigate the correlates of role preference in treatment decision making for Hispanic patients in a primary care setting. Our findings confirm other studies that have demonstrated in terms of the influence of age, education, health literacy, depression and contributed novel findings in regards to social role performance and Hispanic Patient's SDM preference in the inpatient and specialty care setting. The identification of factors associated with Hispanic patients' participation in SDM will aid in enhancing care in the PCMH model. One NCQA stated goal is that all patients participate in shared role when making medical treatment decisions in a PCMH primary care setting (NCQA, 2008). Our findings provide prerequisite fundamental knowledge to support improvement in a number of areas including: provider/clinician communication, patient centered care and clinical decision support. For example, given that younger patients are more likely to prefer to want to participate in SDM, a public health intervention could be tailored to engage them versus older Hispanic patients. Our findings describing the relationships between primary care Hispanic patient's factors and there decisional role preference has implications for engaging the present and ongoing generations of Hispanics by means of informatics, clinical, and public health interventions.

Informatics Implications

Informatics plays an important role in improving patient safety and the quality of care a patient receives through informatics tools to support SDM (Ruland, 2004). The relationship between variables investigated in our study and their relationship to desired role in SDM for Hispanic primary care patients can be utilized by informatics tools in a number of ways: 1) to customize the user experience. For example, content language can be initiated in Spanish based on patient characteristics. 2) To target sub-populations of patients. For example, since while taking all other variables into consideration, age and education level are strongly correlated SDM, one might design a tool that solicits involvement in treatment decisions in a different way than you might from older, less educated patients. 3) To screen and validate patient SDM role preference. At the same time it is recognized that patients have varying desires to participate in SDM based on socio-demographic and health related characteristics factors (Say et al., 2006). While some of these factors (i.e., age, gender, health insurance status, and general health status) have been described and understood in the non-Hispanic populations (Garfield, Smith, Francis, & Chalmers, 2007; Sapana R. Patel et al., 2008), these factors have not been fully studied in our study population.

Currently, there is increasing informatics research and implementation related to developing tools and methods to determine patient preferences for SDM and to develop tools to support SDM, called decision aids (Patel et al., 2008; Ruland & Bakken, 2002). Researchers have developed SDM decision aids and decision support for patients that are both electronic and paper based. (Patel, Bakken, & Ruland, 2008; Ruland, White, Stevens, Fanciullo, & Khilani, 2003; Stein et al., 2013). This very active area of research has yielded a range of information about options and outcomes and a guide to help patients consider their own treatment decision preferences. Decision aids are often designed to be used as a complement to the medical consultation and have been shown to be effective in prompting greater involvement by patients. Currently, decision aids have been developed and made available for several dozen conditions (Elwyn et al., 2010; Lenz et al.,

2012; Sepucha, 2012; Sheehan & Sherman, 2012; J. Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012; Thistlethwaite, Evans, Tie, & Heal, 2006; Wills et al., 2006).

The findings of our study will serve as a foundation for future tailored decision support tools and appropriate decision aids for Hispanics. This automatic customization will be based on individual patient factors and will be appropriate to where a person is in the deliberation and treatment decision phases. For example, the correlates in our multivariate models may, in the future, contribute to algorithms that generate personalized primary care treatment plans. These treatment plans would contain appropriate decision aids for patients and decision support content for providers.

Clinical Implications

Generally speaking, patient-centered care aims to place the patient and the provider in a dialogue where information related to treatment decisions and overall health can be exchanged. For this exchange to occur a patient's health literacy level becomes one of the crucial factors for effective communication (Naik et al., 2011). While most patients (over 80% in our study) desire an active or shared role in treatment decision making, their health literacy is very low. We found over 93% of respondents had low numeracy as measured by NVS. Nationally the average is approximately 60% low numeracy health literacy (Naik et al., 2011). The intersection of the desire to participate in SDM and the low health literacy of Hispanic patients will cause primary care clinics to have to tailor their communication to fit health information needs. Clinician training, standardized protocols and literacy appropriate protocols will aid in more effective communication between provider and patient (Bodenheimer & Pham, 2010; Wendy Levinson, Lesser, & Epstein, 2010).

More specifically, the clinics in our survey were all PCMH certified primary care settings. Even though our study cannot determine if PCMH has had an effect on desire to participate in SDM, since CPS was not measured prior to PCMH implementation. The high level of desire to

participate in SDM in our sample suggests that the PCMH model may be effective in increasing patient engagement among Hispanic patients. No longer can a patient rely on the physician, nurse practitioner, registered nurse, or physician's assistant for help in navigating through the treatment decisions process. In the PCMH setting, this increased patient engagement need cannot be satisfied by the primary care provider who has limited time to evaluate and treat a patient (Rittenhouse, Shortell, & Fisher, 2009). New models of team based health management, that include community health workers, caregivers and others must be employed more effectively to support Hispanic patients in treatment decision making (Nutting et al., 2011).

Finally, our research found that worse depression levels and worse social role performance score were positively associated with desire to participate in SDM. Currently, in an effort to improve mental and behavior screening in the primary care setting, NCQA guidelines call for annual depression screening (NCQA, 2008). Our findings suggest that there is a statistically significant association between desire to participate in SDM and mental health. This underscores the clinical importance of determining a patient's mental health status in the primary care setting.

Public Health Implications

Our findings help to better understand the factors that influence a person's desired role in SDM. Studies have indicated that increased SDM can increase patient compliance (Stacey, 2011) and improvement of patient satisfaction with their provider and treatment (Tariman et al., 2010).

In keeping with these goals the US Preventive Services Task Force has emphasized the importance of SDM in their campaigns (Moyer, 2012; USPSTF, 2009). This study demonstrates that the factors (age, education level, years lived in the United States, health literacy, level of depression, and level of social role performance) may affect patient preference for involvement. Health professionals should be more sensitive to individual patient preferences and provide better patient-centered care to help achieve the national health goals for Hispanics.

Limitations

There are several limitations in this study. Because our study relied on self-report, social desirability bias can be reflected in the responses (Polit & Beck, 2010). For example, survey participants may respond based on what they think the researcher wants to hear. Self-report bias may be magnified by having a single instrument measure a specific concept (Waltz, Strickland, & Lenz, 1991). To address some of these concerns, our study included several measurement tools for variables such as health literacy and health status.

Second, the use of a convenience sample may limit the generalizability of this study (Polit & Beck, 2010). Because nonprobability sampling was used, the results of the study cannot be generalized to all primary care Hispanics patients. The resulting sample was more female than the Washington Heights and Inwood community (NYCDHMH, 2006) thus is not representative of the population. Because the term Hispanic refers to a broad group of national and cultural origins, the external validity of the findings need to be assessed in other Hispanic populations. Most of our sample was born in the Dominican Republic (n=558; 72.3%). Our mainly Dominican Hispanic sample may not reflect the characteristics of other Hispanic communities where other Caribbean, Central or South American Hispanic cultures are more predominant. Another threat to external validity is threatened by the study setting. All of the respondents were recruited from clinics that are supported by a large academic medical center in an urban area. Due to the single setting, findings may not be applicable to Hispanics in rural or suburban settings or to Hispanics who are seen at primary care settings that are not supported by a large academic medical center.

Future Research

While our findings will add to a better understanding of Hispanic patients' treatment decision-making role preferences, our model ultimately explained a small amount of variation in respondents' control preference score. To be able to better characterize decisional role preference, there are still a number of areas of investigation related to role preference that should be explored.

Because our study was cross-sectional we were only able to capture a snapshot in time of the factors that contribute to CPS. Additional longitudinal descriptive studies of how a patient's preferred role changes over time within different conditions and as health status changes are needed to better understand how patients perceive the decision process and which decisions patients want to share (Chewning et al., 2012). Decisions involved in calibrating ongoing treatment for chronic conditions are equally important as initial diagnostic test or treatment decisions; however, they are not sufficiently studied (Garfield, Smith, Francis, & Chalmers, 2007). It might be the case that additional decision preference tools and new approaches are needed to study these aspects of the full trajectory of care.

While Hispanic patients in our study reported a similar rate of desire to participate in shared decision making as other groups, other studies have shown that they are more likely to have a mismatch between actual and preferred involvement (Hawley et al., 2008). Research has shown that this match is important for achieving decision and treatment satisfaction (Lantz et al., 2005; Vogel, Helmes, & Hasenburg, 2008).

Only a small number of studies have investigated the degree of congruence between patients' role preferences and the actual role that they perceived themselves to have played in treatment decision making (J. D. Tariman et al., 2010). This body of research suggests that even though some patients do attain their role preference, there are many others who do not (Chewning et al., 2012). It is not clear why some attain their role preference and others do not, however, and this topic has not been considered in great detail in the Hispanic population in the primary care setting. More research is needed to better understand the factors related to discordance between Hispanic patients' preferred and actual roles.

CONCLUSION

Shared decision making is at the center of the current patient-centered care movement. Supporting Hispanics' ability to participate in SDM has the potential to improve their health status

and quality of care (Mark W. Friedberg et al., 2013). While more research is needed to further understand the factors that characterize role preference for medical decision making amongst Hispanics with their primary care clinician, this study has confirmed the influence of age, depression, years lived in the United States and education on control preference for Hispanics. In addition, our research indicated novel findings that better social role performance increases desire for shared role preference. Our findings will add to knowledge that will be incorporated into informatics interventions for personalized decision aids and public policy to support interventions that may improve SDM for patients.

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APPENDIX A.

Search Strings and Results

| Database Name | Search Phrase | # Hits |
|------------------|---|-----------|
| Scopus | (TITLE-ABS-KEY("shared decision making")) AND ((patient)) AND (preferences) AND (LIMIT-TO(PUBYEAR, 2013) OR LIMIT-TO(PUBYEAR, 2012) OR LIMIT- | 396 |

| Database Name | Search Phrase | # Hits |
|------------------|---|--------|
| | TO(PUBYEAR, 2011) OR LIMIT-TO(PUBYEAR, 2010) ORLIMIT-TO(PUBYEAR, 2009) OR LIMIT-TO(PUBYEAR, 2008) OR LIMIT-TO(PUBYEAR, 2007) OR LIMIT-TO(PUBYEAR, 2006) OR LIMIT-TO(PUBYEAR, 2005) OR LIMIT-TO(PUBYEAR, 2004) OR LIMIT-TO(PUBYEAR, 2003) OR LIMIT-TO(PUBYEAR, 2002)) AND (LIMIT-TO(LANGUAGE, "English")) AND (LIMIT-TO(AFFILCOUNTRY, "United States")) | |
| PubMed | (("decision making"[MeSH Terms] OR ("decision"[All Fields] AND "making"[All Fields]) OR "decision making"[All Fields] OR ("shared"[All Fields] AND "decision"[All Fields] AND "making"[All Fields]) OR "shared decision making"[All Fields]) AND ("physician-patient relations"[MeSH Terms] OR ("physician-patient"[All Fields] AND "relations"[All Fields]) OR "physician-patient relations"[All Fields] OR ("patient"[All Fields] AND "physician"[All Fields]) OR "patient physician"[All Fields])) AND ("loattrfull text"[sb] AND "2002/1/01"[PDat] : "2013/3/30"[PDat] AND "humans"[MeSH Terms] AND English[lang])) | 2546 |
| Web of Knowledge | Topic=(decision making) | 1709 |

| Database Name | Search Phrase | # Hits |
|---------------|---|--------|
| | <p>Refined by: Topic=(shared) AND Publication</p> <p>Years=(2013 2011 OR 2012 OR 2010 OR 2009 OR 2008 OR 2007 OR 2006 OR 2005 OR 2003 OR 2002)</p> <p>Timespan=All Years.</p> <p>Search language=Auto Lemmatization=On</p> | |
| | <ol style="list-style-type: none"> 1. exp Decision Making/ 2. (physicians and patients).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier] 3. exp Professional-Patient Relations/ or exp Nurse-Patient Relations/ or exp Physician-Patient Relations/ 4. 2 or 3 5. 1 and 4 6. exp *Decision Making/ 7. 4 and 6 8. limit 7 to (english language and yr="2002 -Current" and "all adult (19 plus years)") 9. shared.ti. 10. 6 and 9 11. limit 7 to (english language and yr="2002 -Current") | 2715 |

APPENDIX B.

WICER Survey Questions Used

SECTION A: DEMOGRAPHIC AND SCREEN

A.1. Household ID: _____

A.2. Individual ID: _____

A.3. First Name: _____ Last Name: _____

A.4. What is your gender?

1. Male
2. Female
3. TRANSGENDER (MALE TO FEMALE)
4. TRANSGENDER (FEMALE TO MALE)

A.4a. Do you think of yourself as (IF NEEDED SAY: "Straight or Heterosexual people have sex with, or are primarily attracted to people of the opposite sex, Gay (and Lesbian) people have sex with or are primarily attracted to people of the same sex, and Bisexuals have sex with or are attracted to people of both sexes."):

1. Straight or heterosexual
2. Gay
3. Lesbian
4. Bisexual
5. Other
- 7. Don't Know
- 8. Refused

A.5. What is your date of birth? ____/____/____

Month/ Day/ Year

A.6. COMPUTER CALCULATED AGE _____

SECTION B: HEALTH AND HEALTHCARE BEHAVIOR

First, we'd like to start by asking you some questions about hypertension, also called high blood pressure or just pressure.

B.1. What type of health insurance do you currently have? If you have more than one kind of health insurance, tell me all of the plans that you have **DO NOT READ ANSWERS, RECORD ALL THAT ARE MENTIONED.* If participant gives you the name of the insurance company, probe to determine if Medicare, Medicaid or private. Refer to insurance list if you are unsure of classification.

| | | |
|-----------------------------------|--|--|
| | | |
| 1. MEDICARE | | |
| 2. MEDICAID | | |
| 3. VA (US DEPARTMENT OF VETERAN'S | | |
| 4. PRIVATE | | |

| | | |
|--------------------------|--|--|
| 5. NONE | | |
| 6. OTHER, SPECIFY: _____ | | |

-7. DON'T KNOW

-8. REFUSED

SECTION D: HEALTH

The following questions are about how you feel and how well you are able to do your usual activities.

D.1.a. Would you say that in general your health is _____?

PLEASE READ

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
6. -7 DON'T KNOW
- 8. REFUSED

SECTION E: MENTAL HEALTH

The following questions are about how you feel mentally.

Note to Interviewer: Only ask section B and C if the participant answers yes to an item in section

a. If they say no to a, then b and c can be skipped and you can move on to the next item. Ask every item in order.

| | a. In your lifetime did you ever have a period of at least two weeks | | b. When this occurred, were you bothered by this problem: [Read List] | | | | c. Did this occur during the past | |
|---|--|----|---|--------------------|--------------|--------|-----------------------------------|----|
| | Yes | No | Several Days | More than half the | Nearly every | DK/REF | Yes | No |
| E1. Little interest or pleasure in doing things | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| E2. Feeling down, depressed, or hopeless | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| E3. Trouble falling or staying asleep, or sleeping too much | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| E4. Feeling Tired or having little energy | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| E5. Poor appetite or overeating | 1 | 2 | 1 | 2 | 3 | 8/9 | | |

| | | | | | | | | |
|---|---|---|---|---|---|-----|--|--|
| <p>E6. Feeling bad about yourself – or</p> | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| <p>that you are a failure or have let yourself or your family down</p> | | | | | | | | |
| <p>E7. Trouble concentrating on things, such as reading the</p> | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| <p>E8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual</p> | 1 | 2 | 1 | 2 | 3 | 8/9 | | |
| <p>E9. Thoughts that you would be better off dead, or of hurting yourself</p> | 1 | 2 | 1 | 2 | 3 | 8/9 | | |

[IF 'YES' TO ANY QUESTIONS E1-E9 GO TO E10; OTHERWISE GO TO E11.]

E10. How difficult have these problems ever made it for you to do your work, take care of things at home, or get along with other people? Would you say: [READ CHOICES]

- 1 Not difficult at all
- 2 Somewhat difficult
- 3 Very difficult, or
- 4 Extremely difficult
- 7 [VOL] Don't know
- 8 [VOL] Refused

E11. These questions relate to how you felt in the last 7 days. * SHOW HAND CARD*****

| | Never | Rarely | Sometimes | Often | Always | Don't | Refused |
|---|-------|--------|-----------|-------|--------|----------|---------|
| | | | | | | K | |
| E11a. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11b. In the past 7 days I found it hard to focus on anything | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11c. In the past 7 days my worries | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11d. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11e. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11f. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |

| | | | | | | | |
|---------------------|---|---|---|---|---|----|----|
| E11g. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |
| E11h. In the past 7 | 1 | 2 | 3 | 4 | 5 | -7 | -8 |

SECTION H: SOCIOECONOMIC RESOURCES

H.5. What is the highest level of education you completed?

1. Never went to school
2. Eighth grade or less
3. Some high school, not a high school graduate
4. High school graduate or GED
5. Some college or technical, trade or vocational school
6. Associates degree
7. Bachelor's degree
8. Master's degree
9. Doctoral degree
- 7. DON'T KNOW
- 8. REFUSED

H.10. What is your current occupation?

Specify: _____

-8. REFUSED

RACE. ETHNICITY. ACCULTURATION

Now we'd like to ask questions about your background.

H.16. Where were you born?

1. United States (*SKIP TO H.22.)

2. Dominican Republic
3. Cuba
4. Mexico
5. Ecuador
6. Puerto Rico
7. Russia
8. Other country, Specify: _____

-7. DON'T KNOW

-8. REFUSED

H.17. At what age did you move to the United States?

| _|_| Enter age in years

-7. DON'T KNOW

-8. REFUSED

H.22. Are you of Hispanic, Latino or Spanish origin?

1. Yes

2. No

-7. DON'T KNOW

-8. REFUSED

H.23. Which of the following best describes your race? Select one or more responses.

1. White

2. Black or African American

3. Asian or Pacific Islander

4. American Indian or Alaska Native

5. Other race, Specify: _____

-7. DON'T KNOW

-8. REFUSED

H.25. How many years have you lived in the community where you currently live?

| _|_|_| Enter number of years

-7. DON'T KNOW

-8. REFUSED

SECTION I: SOCIAL RELATIONS



Now I will ask you questions about your social relationships.

I.1. Which best describes your marital status? (*CHOOSE ONLY ONE)

1. Married

2. Currently living with a partner but not married

3. Single, never married

4. Divorced or separated

5. Widow

-8. REFUSED

I.2. How many are under 18 years old?

| _|_|_| Enter number of people

-7. DON'T KNOW

-8. REFUSED

I.16. In the past 7 days...

| | Not at | A little | Some | Quite | Very | Don't | Refused |
|---|---------------|-----------------|-------------|--------------|-------------|--------------|----------------|
| I.17.a. [SRPSAT07] I am satisfied with how much work I can do (include work at home) | | | | | | 7 | 8 |
| I.17.b. [SRPSAT24] I am satisfied with my ability to work (include work at home) | | | | | | 7 | 8 |
| I.17.c. [SRPSAT47] I am satisfied with my ability to do regular personal and household responsibilities | | | | | | 7 | 8 |
| I.17.d. [SRPSAT49] I am satisfied with my ability to perform my daily routines | | | | | | 7 | 8 |
| I.17.e [SRPSAT50] I am satisfied with my ability to meet the needs of those who depend on me | | | | | | 7 | 8 |

| | | | | | | | |
|--|--|--|--|--|--|---|---|
| I.17.f. [SRPSAT39] I am satisfied with my ability to do household chores/tasks | | | | | | 7 | 8 |
| I.17.g. [SRPSAT06] I am satisfied with my ability to do things for my family | | | | | | 7 | 8 |
| 1.17.h. [SRPSAT38] I am satisfied with the amount of time I spend performing my daily routines | | | | | | 7 | 8 |

SECTION M: HEALTH LITERACY

We are asking participants to help us learn how well patients can understand the medical information that doctors give them. Would you be willing to help us by looking at some health information and then answering a few questions about that information? Your answers will help us learn how to provide medical information in ways that patients will understand.

****Read to Subject: "This information is on the back of a container of a pint of ice cream."***

NOTE: IF a participant asks if they have answered correctly or incorrectly, say something like: "I can't show you the answers until you are finished, but for now you are doing fine. Now let's go on to the next question."

| ANSWER CORRECT? | | NO |
|--|--|-----------|
| M1. If you eat the entire container, how many calories will you eat? | | 0 |
| M2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? <i>ANSWER: Any of the following is correct: 1 cup (or any amount up to 1 cup)</i> <i>Half the container</i> <i>NOTE: If patient answers "two servings", ask "how much ice cream would that be if you were to measure it into a bowl?"</i> | | 0 |
| M3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? <i>ANSWER: 33 is the only correct answer</i> | | 0 |
| M4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? <i>ANSWER: 10% is the only answer</i> | | 0 |
| <i>READ TO SUBJECT: Pretend you are allergic to the following</i> | | |
| M5. Is it safe for you to eat this ice cream? <i>ANSWER: No</i> | | 0 |
| <i>ASK ONLY IF PATIENT RESPONDS NO TO QUESTION 5. M6.</i> Why not? <i>ANSWER: because it has peanut oil</i> | | 0 |

Newest Vital Sign Score: ___/6

M7. How confident are you filling out medical forms by yourself?

1. Always

2. Often
3. Sometimes
4. Occasionally
5. Never
- 6.-7. DON'T KNOW
- 7.-8. REFUSED

M8. How often do you have problems learning about your medical condition because of difficulty understanding written information?

1. Always
2. Often
3. Sometimes
4. Occasionally
5. Never
6. -7. DON'T KNOW
7. -8. REFUSED

M9. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

1. Always
2. Often
3. Sometimes
4. Occasionally
5. Never
6. -7. DON'T KNOW
7. -8. REFUSED