

**Health Literacy and Related Psychosocial Factors and Measurement Issues: A Qualitative Study and a Secondary Analysis of the Health and Retirement Study**

**By**

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## **Dedication**

This dissertation is dedicated to my family and friends who supported me through this process in various ways, especially Marlanna. To my son Novan, for being by my side, making sacrifices with me along the way. To Nicole, for brightening my days (and helping keep things in perspective) with 4 little white teeth and a huge smile.

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## TABLE OF CONTENTS

DEDICATION	ii
ACKNOWLEDGEMENTS	iii
LIST OF FIGURES	v
LIST OF TABLES	vi
LIST OF APPENDICES	vii
LIST OF ABBREVIATIONS	viii
ABSTRACT	ix
CHAPTER	
1. Introduction	1
2. Health Literacy, Psychosocial Factors, and Health Behaviors: A Secondary Analysis of the Health and Retirement Study	9
3. The Health Literacy-Related Healthcare Experience: A Qualitative Study.	59
4. Patient Understanding and Perceptions of Health Literacy and Numeracy Testing: Findings from Cognitive Interviews	91
5. Summary of the Three Papers	138
APPENDICES	142

## LIST OF FIGURES

### FIGURE

1.1	Causal Pathways Between Health Literacy and Health Outcomes	53
1.2	Study Sample Flow	53
2.1	Challenges, Emotions, and Coping	90

## LIST OF TABLES

### TABLE

1.1	Health and Retirement Study Psychosocial and Behavioral Variables	54
1.2	Socio-demographic Characteristics	55
1.3	Psychosocial and Behavioral Factors Stratified by Objective Health Literacy	56
1.4	Psychosocial and Behavioral Factors Stratified by Self-Reported Health Literacy	57
1.5	Multivariate Adjusted Association of Adequate Objective Health Literacy with Behavioral and Psychosocial Factors	58
1.6	Multivariate Adjusted Association of Adequate Self-Reported Health Literacy with Behavioral and Psychosocial Factors	58
3.1	Cognitive Interviewing Procedures	134
3.2	Health Literacy Assessments	135
3.3	Health Literacy of Participants	136
3.4	Most Salient Test Issues Categorized per the Willis, Schechter, & Whitaker (1999) Classification System	137

## LIST OF APPENDICES

### APPENDIX

A. Health and Retirement Study Variables	142
B. Short Test of Functional Health Literacy	146
C. Rapid Estimate of Adult Literacy in Medicine	149
D. Lipkus Expanded Numeracy Scale health-related items	150

## LIST OF ABBREVIATIONS

HRS - Health and Retirement Study

REALM - Rapid Estimate of Adult Literacy in Medicine

REALM-SF - Rapid Estimate of Adult Literacy in Medicine – Short Form

SILS – Single Item Literacy Screener

STOFHLA - Short Test of Functional Health Literacy

TOFHLA - Test of Functional Health Literacy



## ABSTRACT

**Purpose:** Despite the well-known positive relationship between inadequate health literacy and adverse health outcomes, little is known about the impact of health literacy and health literacy testing on patient psychosocial factors. Meanwhile, experts have advised against routine health literacy screening due to potential for shame-related harm, and providers remain largely unaware of their patients' health literacy and health literacy-related challenges. The purpose of this dissertation was to (1) examine relationships between health literacy and psychosocial factors in a Health and Retirement Study sample of adults, (2) learn about the health literacy-related healthcare experience from the perspectives of African American adults with hypertension, and (3) learn about the health literacy testing experience through cognitive interviewing with African American adults with hypertension.

**Methods:** In a secondary analysis of Health and Retirement Study data, logistic regression was conducted to examine relationships between health literacy and psychosocial and health behavioral variables in a subsample who partook in health literacy testing (n=373). In an original study, qualitative data was collected from a sample of African American adults with hypertension (n=15). Narrative interviews were conducted to explore the health literacy-related healthcare experience, and cognitive interviews were conducted to learn about the cognitive and experiential dimensions of health literacy testing.

**Results:** Quantitative results provided evidence that health literacy is related to breast screening practices, tobacco and exercise behaviors, and perceptions of control over health and social standing in the HRS sample. Qualitative analysis of narrative interviews indicated that health literacy-related experiences in the healthcare setting involve practical challenges (primarily related to medication), negative emotions (feeling of anxiety and stigmatization), and both adaptive and maladaptive coping techniques. Findings from cognitive interviews revealed that participants at times felt discomfort, embarrassment, and stress with each of the instruments used in this study; additionally, findings suggest there may be a potential bias in some of the content of the tests.

## CHAPTER 1

### **Introduction**

I first became interested in health literacy in my time as a nurse practitioner in an urban clinic caring for uninsured adults with hypertension. Here I assisted patients in managing complicated medication regimens that demanded skill and determination. The determination in patients was evident, so when blood pressure was poorly controlled, when patients were documented to be “non-compliant” or “non-adherent,” or lengthy office visits were spent reviewing regimens with patients, I began to suspect that patients were experiencing challenges with health literacy. Considering this, it became obvious to me why traditional written methods I had been employing had been ineffective to help them with their hypertension self-management. At the same time, there wasn’t a simple solution and I was aware that this topic needed to be approached with sensitivity.

I returned to graduate school to pursue my PhD in nursing with the intent to investigate this phenomenon. In this research, I mean to increase understanding of the psychosocial and behavioral outcomes of having limited health literacy in the healthcare setting, and of undergoing health literacy screening in the healthcare setting in a population at risk for limited health literacy. By increasing knowledge about the psychosocial and behavioral responses to health literacy-related challenges, I believe this research may ultimately increase our understanding of the mechanisms underlying the relationship between limited health literacy and adverse health outcomes. By studying African Americans with hypertension, a population at greater risk

compared to Caucasians for limited health literacy, hypertension, and disproportionately adverse outcomes related to hypertension, this research addresses an important health disparity in this country.

### **Statement of the Problem**

Health literacy, the capacity of individuals to obtain and understand health information needed to make health decisions, is recognized by the Institute of Medicine and the federal government as fundamental to quality health care (Nielsen-Bohlman, Panzer, & Kindig, 2004; U.S. Department of Health and Human Services, Healthy People 2020, 2011; U.S. Department of Health and Human Services, National Action Plan to Improve Health Literacy, 2010; Adams et al., 2003). However, findings from the National Assessment of Adult Literacy (a nationally representative assessment of literacy among adults in the U.S.) suggest that the health literacy of a third of adults in the U.S. is limited (Kutner, Greenberg, Jin, & Paulsen, 2006), while reports from health literacy research estimate limited health literacy in 33%-51% of adults in outpatient settings (Gazmararian et al., 1999; Schillinger et al., 2002; Walker, Pepa, & Gerard, 2010; Williams et al., 1998; Wolf et al., 2007), and up to 60% in hospitalized adults (Morris et al., 2011). Fewer years of schooling is associated with limited health literacy; African American individuals and Spanish-speaking Hispanic individuals are also more likely to have limited health literacy (Kutner et al., 2006, Paasche-Orlow et al., 2005; Nielsen-Bohlman, Panzer, & Kindig, 2004; Gazmararian et al., 1999).

Limited health literacy has consistently been shown to be a strong predictor of poorer health outcomes (Berkman, Sheridan, Donahue, Halpern, and Crotty, 2011). Individuals with limited health literacy are prone to greater use of emergency services (Baker et al., 2004; Murray et al., 2009; Cho et al., 2008), higher rates of hospitalization (Baker et al., 1998, Baker,

Gazmararian, Williams, et al., 2002), and higher rates of mortality (Baker et al., 2007; Sudore et al., 2006). Limited health literacy is also associated with less use of preventive services (Cho, Lee, Arozullah, and Crittenden, 2008; White, Chen, and Atchison, 2008), and poorer adherence to medication regimens (Kripalani, Gatti, and Jacobsen, 2010; Murray et al., 2004).

While research consistently demonstrates the relationship between health literacy and health outcomes, the mechanisms underlying this relationship are not yet fully understood. Commonly cited theoretical models attempt to explain this relationship (Baker, 2006; Nutbeam, 2000; Paasche-Orlow and Wolf, 2007; Von Wagner et al., 2009). Each of these theoretical models suggests that health literacy influences health outcomes at least partially through its effect on patients' self-efficacy, health-related knowledge, perceptions, and health behaviors. However, these models have not yet been tested in full, and further work is needed to examine the relationships in these frameworks (Osborn, Paasche-Orlow, Bailey, & Wolf, 2011).

### **Purpose**

Broadly speaking, the purpose of this dissertation is to examine the relationship between health literacy and psychosocial factors and health behaviors. More specifically, the purpose is to: (a) assess relationships between health literacy items available in the Health and Retirement Study (HRS) databases (including a literacy screening item and Test of Functional Health Literacy items), psychosocial variables available in the HRS databases (including perceived colon cancer risks, perceived social standing, and perceived healthcare discrimination), and behavioral outcome variables available in the HRS databases (including immunization uptake, cholesterol testing, cancer screenings, physical exercise behavior, and tobacco use); (b) learn more about the health literacy-related experience from the perspective of adults with hypertension at risk for limited health literacy; and (c) examine the cognitive and experiential

dimensions of clinical screening of health literacy. The results of this research have the potential to: (1) empirically validate (or refute) proposed links in existing frameworks of the relationship between health literacy and health outcomes, (2) be used in the development of interventions for individuals with limited health literacy, and (3) offer evidence for the potential utility and/or harm associated with clinical screening of health literacy. This dissertation was therefore an initial step in a research trajectory focused on the psychological and behavioral factors associated with limited health literacy in at-risk populations with chronic disease.

I used data from two studies to meet these aims. The first is a secondary analysis of data generated from the HRS, a biennial longitudinal interview survey of U.S. adults over the age of 50 sponsored by the National Institute on Aging and conducted by the Institute for Social Research (ISR) at the University of Michigan (Juster and Suzman, 1995; U.S. Department of Health and Human Services, The Health and Retirement Study, 2007). The second is from a qualitative study in which I conducted in-person narrative and cognitive interviews with a sample of African American adults with hypertension in Detroit, Michigan. Results are presented in three manuscripts. In chapter 2 I present the first manuscript, titled, Health Literacy, Psychosocial Factors, and Health Behaviors: A Secondary Analysis of the Health and Retirement Study. In chapter 3 I present the second manuscript, titled, The Health Literacy-Related Healthcare Experience: A Qualitative Study. In chapter 4 I present the third manuscript, titled, Patient Understanding and Perceptions of Health Literacy and Numeracy Testing: Findings from Cognitive Interviews. In chapter 5 I summarize and integrate the findings from the three studies and discuss potential implications.

## References

- Adams, K., & Corrigan, J.M. (2003). *Priority areas for national action: Transforming health care quality*. Institute of Medicine. Washington, DC: The National Academies Press.
- Baker, D.W., Parker, R.M., Williams, M.V., & Clark, W.S. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine*, *13*, 791–798.
- Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R.M., Green, D., et al. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, *92*, 1278-83.
- Baker, D.W., Gazmararian, J.A., & Williams M.V. (2004). Health literacy and use of outpatient physician services by Medicare managed care enrollees. *Journal of General Internal Medicine*, *19*, 215.-20
- Baker, D.W. (2006). The meaning and measure of health literacy. *Journal of General Internal Medicine*, *21*, 878-883.
- Baker, D.W., Wolf, M.S., Feinglass, J. Thompson, J.A., Gazmararian, J.A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, *167*(14), 1503-1509.
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, *155*(2), 97-107.
- Cho, Y.I., Lee, S.Y., Arozullah, A.M., & Crittenden, K.S. (2008). Effects of health literacy on health status and health service utilization amongst the elderly. *Social Science and Medicine*, *66*, 1809-16.
- Gazmararian, J.A., Baker, D.W., Williams, M.V., et al. (1999). Health literacy among Medicare

- enrollees in a managed care organization. *Journal of the American Medical Association*, 281, 545–51.
- Juster, F.T., & Suzman, R.M. (1995). An overview of the health and retirement study. *Journal of Human Resources*, 30, S7–S56.
- Kripilani, S., Gatti, M.E., & Jacobsen, T.A. (2010). Association of age, health literacy, and medication management strategies with cardiovascular medication adherence. *Patient Education and Counseling*, 81, 177-181.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (Report no. NCES2006-483). U.S. Department of Education. Washington, DC: US Department of Education, National Center for Education Statistics. Retrieved March 29, 2013 from National Center of Education Statistics website: <http://nces.ed.gov/naal>.
- Morris, N.S., Grant, S., Repp A., Maclean, C., & Littenberg, B. (2011). Prevalence of limited health literacy and compensatory strategies used by hospitalized patients. *Nursing Research*, 60, 361–366.
- Murray, M.D., Wu, J., Tu, W., Clark, D.O., Weiner, M., Morrow, D.G., & Brater, D.C. (2004). Health literacy predicts medication adherence. American Society for Clinical Pharmacology and Therapeutics. *Clinical Pharmacology & Therapeutics*, 76.
- Murray, M.D., Tu, W., & Wu, J. et al. (2009). Factors associated with exacerbation of heart failure include treatment adherence and health literacy skills. *Clinical Pharmacology & Therapeutics*, 85, 651.-8
- Nielsen-Bohlman, L., Panzer, A.M., & Kindig, D.A. (2004). Institute of Medicine Committee

- on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67(12), 2072-2078.
- Osborn, C.Y., Paasche-Orlow, M.K., Bailey, S.C., & Wolf, M.S. (2011). The mechanisms linking health literacy to behavior and health status. *American Journal of Health Behavior*, 35(1), 118-128.
- Paasche-Orlow, M., Parker, R.M., Gazmaranian, J.A., Nielsen-Bohlman, L., & Rudd, R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20(2), 175-84.
- Paasche-Orlow, M., & Wolf, M. (2007). The causal pathways linking health literacy to health outcomes. *The American Journal of Health Behavior*, 31(1), 19-26.
- Schillinger, D., Grumbach, K., & Piette, J., et al. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*, 288, 475–482.
- Sudore RL, Yaffe K, & Satterfield S, et al. (2006). Limited literacy and mortality in the elderly: The health, aging, and body composition study. *Journal of General Internal Medicine*, 21, 806–812.
- Sudore RL, Mehta KM, & Simonsick EM, et al. (2006). Limited literacy in older people and disparities in health and healthcare access. *Journal of the American Geriatric Society*, 54, 770-6
- U.S. Department of Health and Human Services. (2007). National Institute on Aging. Growing Older in America: The Health and Retirement Study. Washington, DC: National Institutes of Health.



- U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2020. (2011). Washington, DC. Retrieved March 29, 2013 from: <http://healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=18>.
- U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. (2010). National Action Plan to Improve Health Literacy. Washington, DC.
- Von Wagner, C., Steptoe, A., Wolf, M.S., & Wardle, J. (2009). Health literacy and health actions: A review and a framework from health psychology. *Health Education and Behavior, 36*(5), 860-77
- Walker, J., Pepa, C., & Gerard, P.S. (2010). Assessing the health literacy levels of patients using selected hospital services. *Clinical Nurse Specialist, 24*, 31–37.
- White, S., Chen, J., & Atchison, R. (2008). Relationship of preventive health practices and health literacy: A national study. *American Journal of Health Behavior, 32*(3), 227-242.
- Williams, M.V., Baker, D.W., Parker, R.M., & Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of patients with hypertension and diabetes. *Archives of Internal Medicine, 158*, 166–172.
- Wolf, M.S., Gazmararian, J.A., & Baker, D.W. (2007). Health literacy and health risk behaviors among older adults. *American Journal of Preventive Medicine, 32*, 19-24

## CHAPTER 2

### **Health Literacy, Psychosocial Factors, and Health Behaviors: A Secondary Analysis of the Health and Retirement Study.**

Health literacy, the capacity of individuals to obtain and understand health information needed to make health decisions, is recognized by the Institute of Medicine and the federal government as fundamental to quality health care (Nielsen-Bohlman, Panzer, & Kindig, 2004; U.S. Department of Health and Human Services, Healthy People 2020, 2011; U.S. Department of Health and Human Services, National Action Plan to Improve Health Literacy, 2010). However, findings from the National Assessment of Adult Literacy (a nationally representative assessment of literacy among adults in the U.S.) suggest that the health literacy of a third of adults in the U.S. is limited (Kutner, Greenberg, Jin, & Paulsen, 2006), while reports from health literacy research estimate limited health literacy in 33% -51% of adults in outpatient settings (Gazmararian et al., 1999; Schillinger et al., 2002; Walker, Pepa, & Gerard, 2010; Williams et al., 1998; Wolf et al., 2007), and up to 60% in hospitalized adults (Morris et al., 2011). Fewer years of schooling and greater age are associated with limited health literacy; African American individuals and Spanish-speaking Hispanic individuals are also more likely to have limited health literacy (Kutner et al., 2006, Paasche-Orlow et al., 2005; Nielsen-Bohlman, Panzer, & Kindig, 2004; Gazmararian et al., 1999).

Limited health literacy has consistently been shown to be a strong predictor of poorer health outcomes (Berkman, Sheridan, Donahue, Halpern, and Crotty, 2011). Individuals with

limited health literacy are prone to greater use of emergency services (Baker et al., 2004; Murray et al., 2009; Cho, Lee, Arozullah, and Crittenden, 2008), higher rates of hospitalization (Baker et al., 1998, Baker, Gazmararian, Williams, et al., 2002), and higher rates of mortality (Baker et al., 2007; Sudore et al., 2006). Limited health literacy is also associated with less use of preventive services (Cho et al., 2008; White, Chen, and Atchison, 2008), and poorer adherence to medication regimens (Kripalani, Gatti, and Jacobsen, 2010; Murray et al., 2004).

While research consistently demonstrates the relationship between health literacy and health outcomes, the mechanisms underlying this relationship are not yet fully understood. Commonly cited theoretical models attempt to explain this relationship (Baker, 2006; Nutbeam, 2008; Paasche-Orlow and Wolf, 2007; Von Wagner et al., 2009). Each of these theoretical models suggests that health literacy influences health outcomes at least partially through its effect on patients' self-efficacy, health-related knowledge, perceptions, and health behaviors. However, these models have not yet been tested in full, and further work is needed to empirically validate the proposed relationships in these frameworks (Osborn, Paasche-Orlow, Bailey, & Wolf, 2011).

### **Specific Aims and Hypotheses**

To test the hypotheses of this study, I conducted a secondary analysis of data from individuals who participated in the Health and Retirement Study (HRS), a longitudinal interview survey of U.S. adults over the age of 50 conducted by the Institute for Social Research (ISR) at the University of Michigan. The aim of this study was to test relationships between health literacy, psychosocial factors, and health behaviors in adult HRS participants.

Specific hypotheses included:

1. Limited health literacy is significantly associated with poorer health behaviors.

To test this hypothesis, I assessed relationships between health literacy items available in the HRS databases (including the literacy screening item and the Test of Functional Health Literacy items), and behavioral outcome variables available in the HRS databases (including immunization uptake, cholesterol testing, cancer screenings, physical exercise behavior, and tobacco use).

2. Limited health literacy is significantly associated with maladaptive psychosocial factors.

To test this hypothesis, I assessed relationships between health literacy and psychosocial variables available in the HRS databases (including perceived colon cancer risks, perceived social standing, and perceived healthcare discrimination).

Understanding of all the factors related to health literacy and further development of relevant health literacy theory is crucial for the development of effective health literacy interventions. To my knowledge this will be the first study to test relationships between health literacy and health behaviors, and health literacy and psychosocial factors in a nationally representative sample of U.S. adults. As such, I anticipated that this study would reveal important information to help guide the development of interventions to improve the health of individuals with limited health literacy.

### **Conceptual Framework**

According to Paasche-Orlow and Wolf (2007), health literacy, which is impacted by individual socioeconomic, demographic, cognitive, and physical characteristics, influences health outcomes by affecting an individual's ability to use the healthcare system, interact with healthcare providers, and to participate in self-care behaviors. Their conceptual model, depicted in Figure 1, guided this study. While issues related to healthcare utilization and provider-patient

interactions were acknowledged as influential to health outcomes, this study focused on the intrinsic patient factors involved in self-care behaviors and their influence on health outcomes.

### **Review of the Literature**

**Health literacy.** Health literacy is conceptually defined as the extent to which individuals are able to attain and understand health information required to make suitable health decisions (Nielson-Bohlman et al., 2004). Technical reading skills, reading comprehension, numeracy, and problem-solving skills are the defining attributes of health literacy that most commonly appear in the literature (Speros, 2005). Health literacy also includes the ability to reveal personal information to health care providers, understand complex disease-specific vocabulary, perform self-care regimens, and navigate health care systems (Evangelista et al., 2010). The National Assessment of Adult Literacy groups health literacy into four categories: below basic, basic, intermediate, and proficient (Kutner et al., 2006). They refer to basic and below basic (difficulty with, or the inability to perform common tasks with carefully chosen written materials believed to be representative of real health-related materials) as limited and inadequate. For this study, the term “limited health literacy” is used to represent limited and inadequate health literacy, or less than intermediate or proficient health literacy.

Relationships between limited health literacy and adverse health outcomes have been well documented (Berkman et al., 2011). Baker and colleagues (1998), in a study of 958 Medicare patients, found the risk of hospitalization among those with limited health literacy twice as likely as those with adequate health literacy (31.5% versus 14.9%,  $p < 0.001$ ). Wolf, Gazmaranian, and Baker (2005) surveyed 2,923 new Medicare enrollees and found those with limited health literacy to have poorer self-reported physical health (67.7 vs 78.0,  $p < 0.001$ ) and self-reported mental health (76.2 vs 84.0,  $p < 0.001$ ) than those with adequate health literacy.

Large prospective studies of the elderly have also shown limited health literacy to be independently associated with nearly two times the risk of death. In one 6-year prospective cohort study of 3,260 Medicare enrollees in four U.S. cities, after adjusting for demographics, socioeconomic status, and baseline health, the hazard ratio for all-cause mortality was 1.52 (95% C.I., 1.26-1.83) for limited health literacy compared to those with adequate health literacy (Baker et al., 2007). In another, a 5-year prospective cohort study of 2,512 diverse older adults in two U.S. cities, those with limited health literacy had a higher risk of death (19.7% vs 10.6%,  $p < 0.001$ ) compared with those with adequate literacy; after adjusting for demographics, socioeconomic status, co-morbid conditions, self-rated health status, and health care access measures, limited health literacy remained independently associated with all-cause mortality (HR 1.75; 95% CI, 1.27 to 2.41) (Sudore et al., 2006).

**Health literacy and psychosocial factors.** Several conceptual models have been created to describe the relationship between health literacy and health outcomes (Baker, 2006; Nutbeam, 2000; Paasche-Orlow and Wolf, 2007; von Wagner et al., 2009). In each, patient psychosocial factors are suggested to be one way in which health literacy impacts health outcomes. My own systematic review of studies synthesized results of results of nineteen studies, including over 20,000 adults with a range of chronic diseases to examine the relationship between health literacy and psychosocial factors in adults with chronic disease (presented for preliminary examination). The review showed that the evidence for the relationships between health literacy and psychosocial factors is limited and varies between (and within) the psychosocial domains. Health beliefs and perceptions (risk perceptions and perceptions of healthcare) had the most consistent associations with health literacy in adults with chronic disease. Self-efficacy was also

related to health literacy in adults with chronic disease, although the relationship was inconsistent and variable among samples with different demographic and disease characteristics.

The most commonly reported psychosocial correlate or outcome of health literacy in adults with chronic disease was health beliefs. Two studies examined the relationship between health literacy and disease-specific beliefs. In one, adult individuals with asthma with inadequate health literacy were more likely than those with adequate health literacy to have inaccurate beliefs about the curability of asthma (54 vs 25%,  $p=.004$ ), timeline of asthma (23 vs 9%,  $p=.07$ ), and identity of asthma (60% vs. 34%,  $p=.01$ ) (Federman, Wisnivesky, Wolf, Leventhal, & Halm, 2010). These relationships remained significant in multivariable analyses. In the other, adults with asthma demonstrated health literacy to be associated with inaccurate asthma timeline beliefs and curability beliefs (Adjusted OR: 1.84, 95% C.I. 1.2-2.82; OR: 2.22, 95% C.I. 1.29-3.82, respectively) (Federman et al., 2013).

Two other studies examined the relationship between health literacy and beliefs about medication. In one that examined older adults with chronic disease, an association was found between inadequate health literacy and unfavorable views of generic medication ( $p < 0.0001$ ), which remained significant in multivariable analysis ( $\beta=-2.06$ ,  $p=0.001$ ) (Iosufescu et al., 2008). In another that examined adults with hypertension, a significant relationship between inadequate health literacy and inaccurate hypertension medication beliefs in was not identified ( $\text{Chi}^2=.41$ ,  $p=0.52$ ) (Gatti, Jacobson, Gazmararian, Schmotzer, & Kripalani, 2009).

Other commonly reported psychosocial factors related to health literacy in adults with chronic disease were related to perceptions, such as perceptions of risk. Two studies examined the relationship between health literacy and perceptions of personal health risk(s). Boulware, Carson, Troll, Powe, & Cooper (2009) examined a predominantly African-American sample of

adults with hypertension and found that those with inadequate health literacy perceived a lower risk of developing chronic kidney disease ( $p < 0.01$ ). Darlow, Goodman, Stafford, Lachance, & Kaphingst (2012) studied predominantly African American and Hispanic obese women and found that perceptions of their weight as a personal health problem was associated with greater perceived risk for diabetes in those with adequate health literacy, (OR, 4.91; 95% CI, 1.68-14.35,  $p = 0.004$ ), while those with inadequate health literacy did not make this association (OR, 1.71; 95% CI, 0.68-4.32,  $p = 0.25$ ).

Other studies examined the relationship between health literacy and perceptions of (and preferences for) individuals' healthcare experiences. In one, a large epidemiological study including a diverse sample of >12,000 adults with type 2 diabetes mellitus, inadequate health literacy was significantly associated with reports of healthcare provider discrimination in multiple models, including a fully adjusted model with many variables (OR=1.10, 95% CI: 1.04-1.16) (Rees et al., 2011). In another, a study of adults with cardiovascular disease, inadequate health literacy was significantly associated with feeling uncomfortable having discussions with nurses or doctors about their condition(s) ( $p = .014$ ) and less support discussing health problems with family, friends, and health professionals ( $p = .020$ ) (Ussher et al., 2010). In a study of adults with diabetes, the relationship between health literacy and preferences for type of diabetes support was examined. Patients with inadequate health literacy preferred phone support over internet or group visits compared to patients with adequate health literacy (adjusted OR 1.74, 95% CI 1.19-2.54), and were more likely to perceive a benefit to improved communication (52% vs 31%,  $p < 0.001$ ), however in an unadjusted model only (Sarkar et al., 2008). In a study of adults with cardiovascular disease, the relationship between health literacy and preferences for participation in decision-making was examined. Patients with inadequate health literacy were



more likely than those with adequate health literacy to prefer a passive decision-making style in adjusted analyses ( $P=0.01$ ) (Naik, Street, Castillo, & Abraham, 2010).

Self-efficacy, the confidence in one's capability to perform a behavior (Bandura, 1997), was also a reported correlate of health literacy among adults with chronic disease, however evidence was inconsistent. Macabasco-O'Connell and colleagues (2011) found that patients with heart failure with adequate health literacy had higher self-efficacy than those with inadequate health literacy (5.0 vs. 4.1, 95% CI 1.55-.43, adjusted difference using bootstrapping). Osborn, Cavanaugh, Wallston, and Rothman (2010) found health literacy to be associated with greater self-efficacy in adults with diabetes, however in isolation only ( $r=0.14$ ,  $p<0.01$ ), and in path analyses with numeracy, that effect was reduced to non-significant. McCleary-Jones (2011) examined health literacy, self-efficacy, and self-care in an African American sample with diabetes and found health literacy was not significantly associated with self-efficacy, but predicted general diet self-care  $\beta$  (SE) 0.480(.104)( $p<0.001$ ) and foot self-care  $\beta$  (SE) 0.487(.156)( $p=0.003$ ).

**Health literacy and health behaviors.** There is evidence in the health literacy literature for associations between health literacy and health behaviors including immunization uptake and cancer screenings. Two large nationally representative studies (Bennett, Chen, Soroui, and White, 2009; White et al., 2008) demonstrated an association between limited health literacy and decreased probability of having received an influenza vaccination in the previous 12 months in older adults. Additionally, in a study of diverse community-dwelling older adults in two major cities, multivariate analyses demonstrated that individuals with limited health literacy were twice as likely to be lacking an influenza vaccination in the previous 12 months (odds ratio (OR)=1.70, 95% CI=1.20–2.41) (Sudore et al., 2006). Limited health literacy has also been associated with

decreased use of mammography services in women over the age of 40 (Guerra, Krumholz, and Shea, 2005) and over the age of 65 (White, Chen, and Atchison, 2008). It has also been associated with decreased use (and knowledge of) colorectal cancer screening (Peterson et al., 2007; Miller, Brownlee, McCoy, and Pignone, 2007), and decreased use of Papanicolaou screening in both women under the age of 40 (White et al., 2008) and over the age of 40 (Garbers and Chiasson, 2004).

Several studies have demonstrated associations between health literacy and various health behaviors, including risk and self-care behaviors. Von Wagner, Knight, Steptoe, and Wardle (2007) randomly sampled 759 adults in the United Kingdom for interview to examine associations between health literacy and health behaviors; multivariable logistic regression analysis demonstrated that for each greater point of health literacy the likelihood of eating at least five portions of fruit and vegetables a day increased (OR 1.02; 95% C.I. 1.003 to 1.03), as did the odds of being a non-smoker (OR 1.02; 95% C.I. 1.0003 to 1.03). Wolf, Gazmaranian, and Baker (2007) conducted similar analyses among nearly 3000 Medicare enrollees in several U.S. cities and found associations between health literacy and tobacco and alcohol use; however these associations were insignificant after controlling for relevant covariates. Huizenga and colleagues (2008) examined 160 primary care adults of middle age for relationships between health literacy, numeracy, and obesity. Although health literacy was not associated with BMI, participants with limited numeracy skills had a mean BMI of 31.8 (9.0) compared to those with adequate numeracy skills who had a mean BMI of 27.9 (6.0),  $P = 0.008$ . Numeracy was negatively and significantly correlated with BMI ( $\rho = -0.26$ ,  $P = 0.001$ ), and this persisted after adjusting for relevant covariates ( $\beta = -0.14$ ;  $P = 0.010$ ).

## **Methods**

### **Study Design and Data Sources**

To explore these hypotheses, I conducted a cross-sectional analysis of data generated from the HRS. The HRS is a biennial longitudinal interview survey of U.S. adults over the age of 50 sponsored by the National Institute on Aging and conducted by the Institute for Social Research (ISR) at the University of Michigan (Juster and Suzman, 1995; U.S. Department of Health and Human Services, The Health and Retirement Study, 2007). Advantages of using data sets produced by the HRS include: (1) samples have been selected using a multi-stage area probability sampling design consistently since 1992, (2) the baseline surveys include a broad range of health measures that have demonstrated concurrent, discriminant, and construct validity (Wallace and Herzog, 1995), and (3) the HRS is the only nationally representative, publically available dataset that reports the health literacy of participants from valid and reliable health literacy measures (Dr. Helen Levy, University of Michigan Institute of Social Research, personal contact, June 4, 2013).

The HRS began collecting data on issues of aging, health, and retirement in 1992. Since then, interviews have been repeated on the original sample (along with new added cohorts) every two years. These biennial surveys are considered the core surveys, collecting the most data on issues of physical health and functioning, cognitive functioning, health insurance, disability, health care expenditures, income, work, and assets. To complement the core surveys, supplemental questionnaires and off-year studies have been administered to both random and purposefully selected respondents.

Internet based surveys are one type of supplemental questionnaire created to complement data collected in the biennial core interviews. They are conducted in the alternate years, focused

on specific topics, and target a subsample of the full HRS sample. Topics covered in the internet survey include: economics and retirement; health and health behaviors; and psychosocial items including perceptions and knowledge. In the 2009 study, an assessment of health literacy was added. However, only a random subsample was selected to undergo comprehensive health literacy testing with both reading comprehension and numeracy items

The Psychosocial and Lifestyle Questionnaire is another supplemental questionnaire designed to elicit participants' views of their life, health, and well-being. This questionnaire has been given to a random 50% of the core participants since 2006. Participants who receive this questionnaire are those who are interviewed face to face; the questionnaire is left behind with them to complete and mail-in.

### **Sample**

For this study, I primarily used data from HRS 2009 internet survey. Eligibility for the internet survey was determined by whether participants reported regular use of the internet in the HRS 2008 core survey. I linked data from the 2009 internet survey to the HRS 2008 core survey to obtain a more comprehensive list of covariates on the same respondents. I used household and person numbers in order to distinguish persons who participated in both waves. I further selected individuals who were administered the Psychosocial and Lifestyle Questionnaire (from which the psychosocial items of interest for this study were obtained) and were offered all of the questions about health literacy in the internet survey.

### **Variables and Instruments**

Prior to any data management activities, I reviewed the HRS 2008 core and HRS 2009 supplemental questionnaires to identify items that would potentially represent the constructs of interest for the study. The selected psychosocial and behavioral variables and measures are

listed below (and detailed Appendix A). Health literacy is measured using items from the Test of Functional Health Literacy (TOFHLA) (Parker, Baker, Williams, and Nurss, 1995) and a literacy screener (Chew, Bradley, and Boyko, 2004).

The TOFHLA is a measure of an individual's ability to read and understand two passages, and to understand and use quantitative information (Parker et al., 1995). The HRS employed seven TOFHLA reading comprehension items and seven TOFHLA numeric items (all of which are detailed in Appendix A). I created an interval scale, assigning respondents one point for each correct answer out of 14. I also created an ordinal scale like that of Parker and colleagues (1995), which assigned inadequate health literacy to those with <60% correct, marginal health literacy to those with 60-75% correct, and adequate health literacy to those with greater than 75% correct. Health literacy determined by these TOFHLA items is termed from here on as objective health literacy.

The Chew health literacy screener is a single item screening question that asks "How confident are you filling out medical forms by yourself?" (Chew, Bradley, and Boyko, 2004). This screening question has been shown to be a valid and reliable predictor of functional health literacy (Chew et al., 2004; Chew et al., 2008). Possible responses are on a Likert style scale and range from 0-4, zero being "extremely" and 4 being "not at all." I made this a dichotomized variable based on the recommended cut-off of 2 or less to identify adequate health literacy (Chew et al., 2008; Sarkar, Schillinger, López, and Sudore, 2011). Health literacy determined by this screener is termed from here on as self-reported health literacy.

### **Analytical Methods**

While I wanted to determine the contribution of objective health literacy to outcome variables across the entire range of scores by analyzing objective health literacy as a continuous

variable, the data was not normally distributed. Scores for objective health literacy ranged from 0-14 but were negatively skewed. This was obvious through the descriptive data and histogram, but confirmed with with a skew value of -2.48 (standard error, SE, 0.09), kurtosis of 11.44 (SE 0.18), and significant Kolmogorov-Smirnov statistic. Due to this skew, I conducted the analyses below with a dichotomous objective health literacy variable, which I created by merging the inadequate and marginal categories, as has been done by experts in the field (Gazmararian, Baker, Parker, and Blazer 2000; Scott, Gazmararian, Williams, and Baker 2002; Lee, Gazmararian, & Arozullah, 2006). I ran parallel analyses using the continuous variable and findings were grossly unchanged from those reported below.

To examine the associations between health literacy and psychosocial factors and between health literacy and health behaviors, I conducted bivariate analyses. I used Chi-squared tests for categorical outcomes and Mann-Whitney U tests for the two continuous psychosocial outcome variables. The Mann-Whitney U test is the recommended non-parametric alternative to the Student's t-test when assumptions of normality are violated (Sheskin, 2011). I selected this test upon determining that scores were also skewed for perceived control of health and perceived social standing.

I then conducted several multiple regression models to achieve the aims of the current study. The first aim was to examine the relationship between health literacy and psychosocial factors. For this analysis, I used logistic regression, regressing each categorical psychosocial variable against objective health literacy adjusting for age, sex, race, and education. I did parallel analyses, regressing each categorical psychosocial variable against self-reported health literacy adjusting for age, sex, race, and education. I used linear regression for the interval level psychosocial outcome variables (perceived control of health and perceived social standing);

again I examined objective health literacy as a predictor, and then repeated the analyses examining self-reported health literacy as a predictor.

The second aim was to examine the relationship between health literacy and health behaviors. I used logistic regression to estimate the independent relationship between objective health literacy and the dichotomous outcomes of flu immunization uptake, cholesterol testing, mammography, breast self-exam, prostate examination, current smoking status, and participation in moderate and vigorous physical activity while controlling for age, sex, race, and education. I repeated these analyses using logistic regression to estimate the independent relationship between self-reported health literacy and the dichotomous outcomes of flu immunization uptake, cholesterol testing, mammography, BSE, prostate examination, current smoking status, and participation in moderate and vigorous physical activity while controlling for age, sex, race, and education.

## **Results**

The aim of this study was to test relationships between health literacy, psychosocial factors, and health behaviors in adults with data collected from a national dataset (The Health and Retirement Study). Specifically, this study explored relationships between health literacy and psychosocial factors, and relationships between health literacy and health behaviors. The following sections detail the characteristics of the sample analyzed for this study, associations among variables in this study, and findings from multivariable regression analyses conducted to achieve the overall aims of the study.

### **Characteristics of the Health and Retirement Study Sample**

The data used for this study were collected from participants in the 2008 core HRS who also participated in the 2009 supplemental internet survey. Of 5,742 HRS respondents invited to

participate in the internet survey, 4,433 participated (yielding a response rate of 77.2%). Of the 4,433 initial participants that started the internet survey, many completed as few as 3 sections only, leaving a total of 4,351 from which completed interviews were obtained. Of these, 1902 completed the Psychosocial and Lifestyle Questionnaire. Of those, 707 underwent comprehensive health literacy testing with both reading comprehension and numeracy items. See Figure 3.

### **Characteristics of the Final Sample**

Participants in the final sample were predominantly white (92%), and approximately half were female (57%). Participants had a mean age of 66, and most were married (81%). The sample was well educated with almost 95% of participants having at least a high school education. College and post-college educated participants made up 45% and 24% of the sample respectively. Objective health literacy scores ranged from 0-14, with a mean score of 12.45 (and standard deviation of 1.72). The characteristics of the participants in the original and final sample are displayed in Table 1.2.

### **Associations among the Study Variables**

**Associations of health literacy with psychosocial factors.** The rates of perceptions of control over health, social standing, healthcare discrimination, and risk of colon cancer, stratified by objective and subjective health literacy level are shown in Tables 1.3 and 1.4, respectively. As noted above, I used Chi-square tests to determine associations of health literacy with categorical variables (perceived healthcare discrimination and perceived cancer risks), and I applied the Yates correction for continuity as recommended for each condition in which there were two categories per variable (Sheskin, 2011). I used the Mann-Whitney U test to determine



associations of health literacy with continuous variables (perceived control over health and perceived social standing).

Associations between objective health literacy and the selected psychosocial factors were insignificant. In detail, the Chi-square test for independence indicated no significant association between objective health literacy and perceived healthcare discrimination ( $\chi^2= 0.00$ ,  $p=1.00$ ), perceived risk of colon cancer death ( $\chi^2= 2.93$ ,  $p=0.09$ ), and perceived risk of colon cancer diagnosis ( $\chi^2= 3.14$ ,  $p=0.08$ ), and perceived benefit of colon cancer screening ( $\chi^2= 3.80$ ,  $p=0.051$ ). The Mann-Whitney U test revealed no significant difference in the levels of perceived social standing of those with objective inadequate health literacy (Md=7) and those with objective adequate health literacy (Md=7),  $z= -0.217$ ,  $p=0.83$ ; nor were there significant differences between those with objective inadequate health literacy (Md=8) and those with objective adequate health literacy (Md=8) for perceived control over health ( $z= -0.09$ ,  $p=0.93$ ).

Upon examination of relationships between self-reported health literacy and psychosocial factors, the Chi-square test for independence indicated no significant association between self-reported health literacy and perceived risk of colon cancer death ( $\chi^2= 2.45$ ,  $p=0.12$ ), perceived risk of colon cancer diagnosis ( $\chi^2= 0.85$ ,  $p=0.36$ ). However, individuals with self-reported adequate health literacy were more likely to correctly respond that colon cancer screening indeed reduces the risk of dying from colon cancer, 89.1% versus 81.9%, ( $\chi^2 = 4.94$ ,  $p=0.026$ ). Also, Mann-Whitney U testing demonstrated significant differences in perceived control over health between those who self-reported adequate health literacy (Md=8) and those who self-reported inadequate health literacy (Md=7),  $z= -4.91$ ,  $p<0.0005$ , as well as significant differences in perceived social standing between those who self-reported adequate health literacy (Md=7) and those who self-reported inadequate health literacy (Md=6),  $z= -4.15$ ,  $p<0.0005$ .

**Associations of health literacy with behavioral variables.** A significant association was demonstrated between objective health literacy and breast self-examination (BSE). Reports of monthly performance of BSE was higher in the women of the study with inadequate objective health literacy compared to those with adequate objective adequate health literacy (72% versus 49.4%) ( $\chi^2 = 8.056$ ,  $p=0.005$ ).

Significant associations were demonstrated between self-reported health literacy and mammography, moderate exercise, and tobacco use. Annual mammography was significantly higher in the women with adequate self-reported health literacy compared to those with inadequate self-reported health literacy (85% versus 69%) ( $\chi^2 = 8.67$ ,  $p=0.003$ ). Participation in moderate exercise two or more times per week was significantly higher in individuals with adequate self-reported health literacy compared to those with inadequate self-reported health literacy (66% versus 54%) ( $\chi^2 = 6.76$ ,  $p=0.009$ ). Current tobacco use was significantly lower in individuals with adequate self-reported health literacy compared to those with inadequate self-reported health literacy (8% versus 14%) ( $\chi^2 = 5.08$ ,  $p=0.024$ ). The rates of flu immunization uptake, cholesterol testing, mammography, BSE, prostate examination, current smoking status, and participation in physical activity, stratified by objective and self-reported health literacy levels, are shown in Tables 1.3 and 1.4, respectively.

### **Multivariable Findings**

I next conducted multivariable modeling to evaluate the influence of health literacy on psychosocial processes and behaviors, with analyses selected based on the types and distributions of the outcome variables: Logistic regression for the dichotomous outcome variables (including perceived cancer risks, perceived healthcare discrimination, current use of tobacco, participation in moderate and vigorous physical activity  $\geq 2$  times weekly, annual flu

immunization, monthly breast self-examination (BSE), annual cholesterol testing, and annual mammography and prostate examination) and linear regression for the continuous outcome variables (including perceived control of health and perceived social standing). Each multivariable analysis controlled for the socio-demographic characteristics of gender, education, race, and age because these variables have been previously identified as confounding variables in the relationship between health literacy and health outcomes (Paasche-Orlow et al., 2005; Morrow et al., 2006, Baker et al., 2000; Paasche-Orlow et al., 2006; Ussher et al., 2010).

**Logistic regression.** I performed logistic regression to assess the impact of objective health literacy on several psychosocial and behavioral outcomes. Models contained the five independent variables of age, sex (when appropriate), race, education, and objective health literacy. While the explained variance in the outcomes was limited, several of the full models containing all predictors were statistically significant; in two of these, objective health literacy was isolated as a unique and statistically significant predictor. In one, objective health literacy was a statistically significant predictor of participation in BSE (Odds ratio [OR] = 0.369,  $p=0.004$ ). In another, objective health literacy was a statistically significant predictor of current tobacco use (OR = 0.456,  $p=0.025$ ). These findings suggest that respondents who had inadequate health literacy were more than twice as likely to report monthly performance of BSE and current use of tobacco as those with adequate health literacy, controlling for age, sex, race, and education.

I also performed logistic regression to assess the impact of self-reported health literacy on all binary study outcomes with models also controlling for age, sex, race, and education. Self-reported health literacy was a statistically significant predictor of mammography (OR= 2.215,  $p=0.010$ ), and moderate exercise (OR= 1.512,  $p=0.033$ ). These findings suggests that

respondents with adequate self-reported health literacy were more likely to report having had a mammogram in the last two years, and participating in moderate exercise two or more times per week than those with inadequate self-reported health literacy, controlling for age, sex, race, and education. Additionally, like objective health literacy, self-reported health literacy appeared to predict current tobacco use (OR= 0.550, p=0.054), however this did not reach statistical significance.

**Linear regression.** I used standard multivariate linear regression to assess the ability of objective health literacy to predict perceived control over health and perceived social standing after controlling for the influence of age, sex, race, and education. In preliminary analyses I examined normality, linearity, multicollinearity, and homoscedasticity. I looked at normal probability plots of the regression standardized residual for normality as well as a scatterplot of the standardized residuals for homoscedasticity and outliers. I also reviewed the correlations tables closely for any strong correlations between the independent variables. In the adjusted models that examined the ability of objective health literacy to predict perceived control over health and perceived social standing, the models were statistically significant but weak, explaining only very small amounts of the variance in these psychosocial factors. Objective health literacy did not make a strong or statistically significant unique contribution to explaining perceived control over health or perceived social standing in either model.

I then used linear regression to assess the ability of self-reported health literacy to predict perceived control over health and perceived social standing after controlling for the influence of age, sex, race, and education. Each model was significant, and while the R Square values were modest, self-reported health literacy made a statistically significant unique contribution to

explaining each of these (perceived control of health  $\beta$  0.151,  $p < 0.0005$ ; perceived social standing  $\beta$  0.112,  $p = 0.002$ ).

### **Relationships in a Hypertensive Subsample**

The aim of this study was to examine relationships between health literacy and psychosocial and behavioral variables in adult respondents to the HRS. Because behavioral interventions are in design to reduce the negative impact of limited health literacy on chronic health outcomes by targeting chronic disease management (Sheridan et al., 2011), examining the impact of health literacy on the health behaviors of adults with one or more chronic diseases is important. To learn about these relationships in adults with a common chronic disease requiring self-management, I further narrowed the sample to those with hypertension. From the sample of participants selected for the present study ( $N=707$ ), I isolated participants that responded that they had been diagnosed with high blood pressure by a physician ( $N=373$ ). In Table 1.2 I report the demographic characteristics of this hypertensive subsample, as well as significant differences identified from a sensitivity analysis between the participants in the hypertensive sample and the participants in the primary sample that were excluded from the hypertensive sample (i.e., the normotensive participants). There was a statistically significant difference in age between these groups, as well as employment. Participants in the hypertensive sample were, on average, of older age and less employed. I repeated the same analyses on this subsample, including multivariate analyses controlling for the influence of age, sex, race, and education.

Several findings in the hypertensive subsample were similar to those determined in the multivariate analyses of the primary sample. Linear regression analyses in the hypertensive subsample similarly demonstrated the ability of self-reported health literacy to predict perceived control over health ( $\beta$  0.151,  $p < 0.0005$ ) and perceived social standing ( $\beta$  0.112,  $p = 0.002$ ).

Findings from logistic regression also demonstrated similar relationships between objective health literacy and BSE (OR= 0.397, p=0.058), objective health literacy and current tobacco use (OR= 0.399, p=0.077), and self-reported health literacy and mammography (OR= 1.95, p=0.080); however, in this hypertensive subsample these relationships approached but did not reach statistical significance.

A different multivariate finding in the hypertensive subsample was a positive relationship between self-reported health literacy and perceived healthcare discrimination (OR= 0.433, p=0.009). This finding suggests that hypertensive participants with inadequate self-reported health literacy were almost 50% more likely to report healthcare discrimination than those with adequate self-reported health literacy. Another dissimilar finding in the hypertensive subsample compared to the primary sample involved the relationship between self-reported health literacy and moderate exercise; the relationship became negative and lost statistical significance (OR= 0.81, p=0.27).

## **Discussion**

### **Findings**

To the best of my knowledge, this secondary analysis is the first study to investigate the relationships between health literacy and psychosocial processes and preventive health behaviors in a nationally representative sample of adults. The principal findings of this study include that after adjusting for socio-demographic variables, inadequate objective health literacy (health literacy measured with items from the TOFHLA) was significant in determining the likelihood of reporting current tobacco use and reporting participation in monthly BSE, while inadequate self-reported health literacy (determined by the Chew literacy screener “How confident are you filling out medical forms by yourself?”) was significant in determining the likelihood of

reporting current tobacco use, lack of mammography uptake in the last 2 years, and participation in moderate exercise < 2 times per week. Inadequate self-reported health literacy was also independently associated with lower perceived social standing and lower perceived control over health.

### **Comparison to Findings of Previous Research**

**Health literacy and breast cancer screening practices.** Findings from this study confirm those of previous studies by demonstrating that women with inadequate self-reported health literacy were significantly less likely to have had a mammogram in the last 2 years (Pagan et al., 2012; Garbers et al., 2009; White et al., 2008; Guerra, Krumholz, and Shea, 2005). However the discovery of a negative relationship between objective health literacy and monthly BSE practices in the women in this sample, to my knowledge, has not been identified in previous literature. Alternatively, one study found a positive association between health literacy and having *ever* conducted a breast self-exam in a diverse sample of nearly 300 women from a federally qualified health center (Armin et al., 2014).

The finding that women with inadequate health literacy were significantly *more* likely to report conducting monthly BSE, is counterintuitive as individuals with (what is conceptually defined as) a reduced capacity for understanding, processing, and acting on health information were more likely to report participation in a traditional health screening. It is possible that some variety among respondents was not controlled for by adjusting for the socio-demographics in this study. It is also plausible that women with inadequate health literacy replace mammography with BSE. Other considerations include the possibility that women with lower health literacy have different cancer risk factors, or have been educated differently on the benefits and limitations of BSE, which at this time is actually not recommended as a breast cancer screening

method by the U.S. Preventative Task Force or World Health Organization (U.S. Preventative Task Force, 2002; World Health Organization, 2014). These differences may be a function of access, patient-provider communication, or psychosocial factors (such as self-efficacy, knowledge, or motivation), which are all proposed mechanisms linking health literacy to health behaviors and outcomes (Paasche-Orlow and Wolf, 2007). Because mammography is known to be effective in reducing breast cancer mortality, and BSE is not (Nelson et al., 2009), future research is needed to explore the knowledge, beliefs, and breast cancer screening practices of women of all health literacy levels.

**Health literacy and tobacco use.** Findings from this study indicated that participants with inadequate objective or self-reported health literacy were more likely to report that they currently smoked. Prior research on the impact of health literacy on smoking status is limited. Some studies suggest differences in smoking behaviors of their participants by health literacy level in bivariate analyses only (Wolf et al., 2005), and findings from studies examining the direct relationship between health literacy and smoking are inconsistent. Von Wagner and colleagues explored relationships between health literacy and health behaviors in a United Kingdom sample of 759 adults selected through random location sampling. In a multivariate logistic regression model, lower health literacy increased the odds of reporting being a current smoker. Alternatively, Baker and colleagues (2007), who examined the relationship between health literacy and mortality in a Medicare sample of over 3000 older adults in 4 different U.S. cities, found significant univariate relationships between health literacy and past and current smoking behaviors, but these relationships lost significance in adjusted analyses. Additionally, Arnold and colleagues (2001) were unable to find a relationship between health literacy and



current smoking in a diverse convenience sample of 600 pregnant women from two different sites.

While prior research on the relationship between health literacy and smoking status is limited, more recently the impact of health literacy on smoking beliefs and cessation outcomes have been explored. Steward and colleagues (2013) explored relationships between health literacy and smoking cessation predictors in a diverse sample of over 400 smokers with low socioeconomic status; in adjusted analyses significant relationships were demonstrated between lower health literacy and less smoking knowledge and lower risk perceptions. Then, Steward and colleagues (2014) explored health literacy and cessation outcomes for another diverse group of 200 smokers enrolled in a cessation program. A significant relationship between lower health literacy and smoking relapse prior to the end of treatment was identified in analyses adjusted for demographic characteristics, socioeconomic status, and nicotine dependence. Additionally, in the study by Arnold and colleagues (2001), despite finding no association between health literacy and current smoking, significant relationships were identified between lower health literacy and less knowledge of (and concern for) the effects of smoking for pregnant women and children in multivariate analyses.

**Health literacy and exercise behavior.** Findings from this study also demonstrate a positive relationship between adequate self-reported health literacy and an increase in the likelihood of reporting exercising at a moderate level two or more times per week. Previous health literacy research involving physical activity is limited and largely focused on physical activity self-efficacy. In one study, Osborn and colleagues (2011) tested pathways between health literacy, knowledge, self-efficacy, health status, and physical activity using path analysis with data collected from 330 adults with hypertension. The path from health literacy to physical

activity was insignificant. In another, Dominick and colleagues (2013) sampled 89 sedentary adult Latina participants of a randomized control trial of a print-based physical activity intervention and examined relationships between health literacy and physical activity self-efficacy, 6-month change in physical activity self-efficacy, and 6 month change in physical activity. Controlling for covariates (and intervention assignment when appropriate), significant associations were noted between health literacy and baseline physical activity self-efficacy and between health literacy and change in physical activity self-efficacy, however no significant association was found between health literacy and changes in physical activity.

**Health literacy and perceived social standing.** Perceived social standing was measured in the present study with an item that asked respondents to select a rung on a ladder that represents where they believe they stand in society, with the top representing those who are doing the best. Findings from the present study suggest that the higher one's health literacy is, the higher they perceive themselves to stand socially. These results are consistent with those of Van De Heide and colleagues (2013), who examined the health literacy of the general population of the Netherlands and its associations with demographic and socio-economic characteristics. Using the Dutch data from the European Health Literacy Survey (HLS-EU) (N=925), they demonstrated significant positive relationships between three of four domains of health literacy measured in the HLS-EU, (understanding, appraising and applying health information) and perceived social status (measured with a similar 10 point scale). Additionally, there are qualitative studies that provide theoretical support for a relationship between health literacy and perceived social standing by describing the negative self-perceptions had by individuals with inadequate health literacy. In the study by Baker and colleagues (1996), many of the patients with inadequate health literacy described feeling bad about themselves, worthless, or lazy for not

having obtained health literacy. In another small qualitative study of 8 adults recruited from a community literacy program, participants with inadequate health literacy revealed worries that they may be seen by others as a bad people or incompetent members of society (Brez and Taylor, 1997).

**Health literacy and perceived control over health.** While findings from the present study demonstrate a positive relationship between health literacy and perceived control over health, current literature does not address this relationship. In my systematic review of the literature for psychosocial correlates of health literacy (for which 591 abstracts were reviewed and 53 full manuscripts were read), perceived control did not emerge as a variable examined in relation to health literacy. However, recent interest has been generated around condition-specific perceived control and health literacy. In a large sample of rural heart failure patients, and in a small unpublished study of adults with type 2 diabetes, positive relationships between health literacy and perceived control over specific respective health conditions have been demonstrated in multivariable analyses (Moser et al., 2014; Ferguson, 2013). It is certainly plausible that individuals with adequate health literacy would believe themselves to be more in control over their health than those with inadequate health literacy. Future research is needed to establish this relationship.

**Health literacy and perceived healthcare discrimination.** One additional interesting finding in this study was the significant relationship between self-reported health literacy and perceived healthcare discrimination in the hypertensive subsample. These findings suggest that hypertensive participants with inadequate self-reported health literacy were nearly twice as likely to report receiving poorer service or treatment than other people from doctors or hospitals three or more times per year. Because this relationship did not exist in the broader sample, it is

possible that adults with hypertension have perceptions and experiences that are unique and distinct from that of someone without hypertension. For instance, the interactions a hypertensive individual has with the healthcare system may have a lifestyle or medication focus; alternatively the expectations or needs a hypertensive individual has of the healthcare system may involve multiple visits, adjustments of regimens, and emergency care. There is also the possibility that this finding is partially a function of age or employment status, both of which were significantly different between samples. Further research is needed to re-examine the association between self-reported health literacy and perceived healthcare discrimination in the general population, confirm and further describe it in a hypertensive population, and explore it in other chronic diseases.

### **Strengths and Limitations**

This study has important strengths. It uses data from the HRS, the only dataset of its kind that reports the health literacy of participants using items from validated instruments. It is also, to my knowledge, the first to examine relationships between health literacy and psychosocial variables in a national study, increasing the generalizability of the study findings. The large sample size also allowed for the control of factors known to be related to health literacy and health outcomes, as well as successful conduction of logistic regression without common problems related to sample size such as extremely high parameter estimates and complete separation of groups (Tabachnick and Fidell, 2007). In addition, items of interest for this study examined in the final sample had very little or no missing data.

This study also has limitations that must be considered. The first limitations involve potentially limited generalizability and external validity. Despite sampling methods intended to obtain a nationally representative sample, there was some amount of reading involved in all

modes used by the HRS to recruit and collect data, which may have led to self-selection bias (those with the lowest literacy refusing to participate in the HRS at all). Then, the HRS subsample used for this study was invited from the core sample based on their 2008 report of regular internet access and use, which may have led to another recruitment bias. Either of these biases may have contributed to the overrepresentation of more educated adults in this sample, thereby underestimating the rates of inadequate health literacy (which were in fact much lower in this sample than they are in the general population). Additionally, minorities are underrepresented in this sample, and as a result, it is important that the relationships demonstrated in this study be examined in other racial and ethnic populations.

The second set of limitations is related to the measurement of health literacy. Health literacy as a concept is comprised of not only reading comprehension and numeracy, but an interaction between knowledge and societal and cultural influences that are difficult to measure (Nielson-Bohlman et al., 2004). In fact, experts agree that *all* existing measures of health literacy are inadequate or incomplete (Pleasant and McKinney, 2011) and that none comprehensively assess the capacity of an individual (Baker, 2006). An additional limitation may be the actual subset of items used in this study. The Short Test of Functional Health Literacy in Adults reduced the original test from 67 to 36 items and proved to have validity in diverse populations and ability to predict major health outcomes and important health behaviors (Baker et al., 1999; Baker et al., 2007; Murray et al., 2004). However, in this study only 16 items were used, and these alone have not been validated as a measure of health literacy. The literacy screener, which proved to have some predictive validity in this study, has limitations inherent in self-report such as social desirability and recall bias. Additionally, the screener has demonstrated only fair validity in a veteran population, and poor validity in a Medicaid

population (Chew et al., 2008; Daniel et al., 2010). Validity of this screening question (or any of the available single-item literacy screeners) has yet to be established in the general population or in adults with chronic diseases like hypertension.

### **Recommendations for Future Research**

Future research is needed to re-examine relationships explored in this study in socioeconomically diverse samples. Participants in this study were well educated. As a result, findings need to be interpreted with caution. Additionally, future studies should take into consideration the many potentially important latent variables that were not considered or could not be incorporated in this secondary analysis. For example, along with the relationships between health literacy and many health behaviors and major health outcomes (Berkman et al., 2011), relationships between health literacy and cognitive processes have been well documented (Morrow et al., 2006; Federman et al., 2009). It is possible that adverse health behaviors and outcomes lead to a cognitive decline and impair health literacy, rather than health literacy influencing health behaviors and outcomes. Future research should ideally include important variables like working memory and processing speed (Morrow et al., 2006), and be conducted longitudinally to examine how health literacy may impact change in psychosocial processes, health behaviors, and health outcomes over time.

### **Implications for Clinical Practice**

The findings of this study have implications for clinical practice. While it has for a long time been acknowledged that health educators and healthcare providers need to be conscious of the health literacy skills of their target population or patients and adjust their education and interventional efforts accordingly (Gazmaranian et al., 2003), findings from this study specifically suggest that clinicians need to ensure that patients of all health literacy levels receive

and understand current and personally relevant breast screening recommendations. Additionally, clinicians need to be aware that current tobacco users may have health literacy challenges that complicate their already tough cessation efforts. Finally, clinicians must recognize that a patient's health literacy may impact not only their lifestyle and preventive health behaviors, but their personal psychological healthcare experience. To minimize these negative effects, healthcare providers should strive to create clinical environments that are "shame-free" to reduce the potential for stigmatization or alienation of patients with health literacy challenges.

### **Conclusion**

The purpose of this study was to examine relationships between health literacy and behavioral and psychosocial outcomes in adult participants of the HRS. Results provided evidence for significant relationships between health literacy and the behavioral outcomes of breast screening, exercise, and current tobacco use; additionally, significant relationships between health literacy and the psychosocial outcomes of perceived social standing and perceived control over health were identified. Future research is needed to further understand the impact of health literacy on these important health behaviors and to better describe the psychosocial experience of individuals with inadequate health literacy. Practice implications include increasing provider awareness of the impact of health literacy on important health practices, as well as enhancing sensitivity around the topic of health literacy to minimize psychosocial challenges and maximize the healthcare and health of individuals with inadequate health literacy.

## References

- Armin, J., Torres, C.H., Vivian, J., Vergara, C., & Shaw, S. (2014). Breast self-examination beliefs and practices, ethnicity, and health literacy: Implications for health education to reduce disparities. *Health Education, 73*(3), 274-284
- Arnold, C.L., Davis, T.C., Berkel, H.J., Jackson, R.H., Nandy, I., & London, S. (2001). Smoking status, reading level, and knowledge of tobacco effects among low-income pregnant women. *Preventive Medicine, 32*(4), 313-320.
- Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine, 5*, 329-344.
- Baker, D.W., Parker, R.M., Williams, M.V., & Clark, W.S. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine, 13*, 791-798.
- Baker, D.W., Williams, M.V., Parker, R.M., Gazmararian, J.A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling, 38*(1), 33-42.
- Baker, D.W., Gazmararian, J.A., Sudano, J., & Patterson, M. (2000). The association between age and health literacy among elderly persons. *The Journals of Gerontology, 55*(6), S368-74.
- Baker, D.W., Gazmararian, J.A., Williams, M.V., Scott, T., Parker, R.M., Green, D, et al. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health, 92*, 1278-83.
- Baker, D.W., Gazmararian, J.A., & Williams M.V. (2004). Health literacy and use of outpatient



- physician services by Medicare managed care enrollees. *Journal of General Internal Medicine*, 19, 215-20
- Baker, D.W. (2006). The meaning and measure of health literacy. *Journal of General Internal Medicine*, 21, 878-883.
- Baker, D.W., Wolf, M.S., Feinglass, J. Thompson, J.A., Gazmararian, J.A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503-1509.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman and Company
- Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality & Social Psychology*, 51(6), 1173-1182.
- Bennett, I.M., Chen, J., Soroui, J.S., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Annals of Family Medicine*, 7, 204-11.
- Bennett, J.A. (2000). Mediator and moderator variables in nursing research: Conceptual and statistical differences. *Research in Nursing and Health*, 23(5), 415-420.
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 97-107.
- Boulware, L. E., Carson, K. A., Troll, M. U., Powe, N. R., & Cooper, L. A. (2009). Perceived susceptibility to chronic kidney disease among high-risk patients seen in primary care practices. *Journal of General Internal Medicine*, 24(10), 1123-1129.

- Brez, S.M. & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040-1047.
- Chew, L.D., Bradley, K.A. & Boyko, E.J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine*, 36(8), 588-94.
- Chew, L.D., Griffin, J.M., Partin, M.R., Noorbaloochi, S., Grill, J.P, Snyder, A., et al. (2008). Validation of screening questions for limited health literacy in a large veterans outpatient population. *Journal of General Internal Medicine*, 23(5), 561–566.
- Cho, Y.I., Lee, S.Y., Arozullah, A.M., & Crittenden, K.S. (2008). Effects of health literacy on health status and health service utilization amongst the elderly. *Social Science and Medicine*, 66, 1809-16.
- Cornett, S. (2009). Assessing and addressing health literacy. *The Online Journal of Issues in Nursing*, 14(3), 2.
- Daniel, D., Greene, J., & Peters, E. (2010). Screening question to identify patients with limited health literacy not enough. *Family Medicine*, 42(1), 7-8.
- Darlow, S., Goodman, M. S., Stafford, J. D., Lachance, C. R., & Kaphingst, K. A. (2012). Weight perceptions and perceived risk for diabetes and heart disease among overweight and obese women. *Preventing Chronic Disease*, 9, E81.
- Dominick, G.M., Dunsiger, S.I., Pekmezi, D.W., & Marcus, B.H. (2013). Health literacy predicts change in physical activity self-efficacy among sedentary Latinas. *Journal of Immigrant and Minority Health*, 15(3) 533-539.
- Evangelista, L., Rasmusson, K., Laramée, A., Barr, J., Ammon, S., Dunbar, S., Ziesche, S.,

- Patterson, J.H., & Yancy, C. (2010). Health literacy and the patient with heart failure – Implications for patient care and research: A consensus statement of the Heart Failure Society of America. *Journal of Cardiac Failure, 16*(1), 9-16.
- Farrell, T.W., Chandran, R., & Gramling, R. (2008). Understanding the role of shame in clinical assessment of health literacy. *Family Medicine, 40*(4), 235-236.
- Federman, A.D. et al. (2009). Health literacy and cognitive performance among older adults. *Journal of the American Geriatric Society, 57*(8), 1475–1480.
- Federman, A. D., Wisnivesky, J. P., Wolf, M. S., Leventhal, H., & Halm, E. A. (2010). Inadequate health literacy is associated with suboptimal health beliefs in older asthmatics. *Journal of Asthma, 47*(6), 620-626.
- Federman, A. D., Wolf, M., Sofianou, A., Wilson, E.A., Martynenko, M., Halm, E.A. et al. (2013). The association of health literacy with illness and medication beliefs among older adults with asthma. *Patient Education and Counseling, 92*(2), 273-8
- Ferguson, B., Lowman, S.G., & DeWalt, D.A. (2011). Assessing literacy in clinical and community settings: The patient perspective. *Journal of Health Communication, 16*(2), 124-134.
- Ferguson, M.O. (2013). Low health literacy is associated with perceived control in a group of poorly controlled diabetic patients. Oral presentation at: 5th Annual Health Literacy Research Conference, Washington, D.C.
- Fiscella, K., & Holt, K. (2008). Racial disparities in hypertension control: Tallying the death toll. *Annals of Family Medicine, 6*(6), 497–502.
- Garbers, S., & Chiasson, M.A. (2004). Inadequate functional health literacy in Spanish as a

- barrier to cervical cancer screening among immigrant Latinas in New York City. *Preventing Chronic Disease, 1*, A07.
- Garbers, S., Schmitt, K., Rappa, A.M., & Chiasson, M.A. (2010). Functional health literacy in Spanish-speaking Latinas seeking breast cancer screening through the National Breast and Cervical Cancer Screening Program. *International Journal of Women's Health, 1*, 21–9.
- Gatti, M. E., Jacobson, K. L., Gazmararian, J. A., Schmotzer, B., & Kripalani, S. (2009). Relationships between beliefs about medications and adherence. *American Journal of Health-System Pharmacists, 66*(7), 657-664.
- Gazmararian, J.A., Baker, D.W., Williams, M.V., et al. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA. 281*, 545–51.
- Gazmararian, J.A., Baker, D.W., Parker, R., & Blazer, D.G. (2000). A multivariate analysis of factors associated with depression: evaluating the role of health literacy as a potential contributor. *Archives of Internal Medicine, 160*(21), 3307-14.
- Gazmararian, J.A., Williams, M.V., Peel, J., & Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling, 51*(3), 267-75.
- Graham, J., Bennett, I.M., Holmes, W.C., & Gross, R. (2007). Medication beliefs as mediators of the health literacy-antiretroviral adherence relationship in HIV-infected individuals. *AIDS and Behavior, 11*, 385-92
- Guerra, C.E., Krumholz, M., & Shea, J.A. (2005). Literacy and knowledge, attitudes and behavior about mammography in Latinas. *Journal of Health Care for the Poor Underserved, 16*, 152-66.
- Huizinga, M.M., Beech, B.M., Cavanaugh, K.L., Elasy, T.A., & Rothman, R.L. (2008). Low

- numeracy skills are associated with higher BMI. *Obesity*, 16(8),1966-8.
- Iosifescu, A., Halm, E.A., McGinn, T., Siu, A.L., & Federman, A.D. (2008). Beliefs about generic drugs among elderly adults in hospital-based primary care practices. *Patient Education and Counseling*, 73(2), 377-83.
- James, P.A., Oparil, S., Carter, B.L., Cushman, W.C., Dennison-Himmelfarb, C. et al. (2014). Evidence-based guideline for the management of high blood pressure in adults: Report from the panel members appointed to the Eighth Joint National Committee (JNC 8). *JAMA*, 311(5), 507-520.
- Juster, F.T., & Suzman, R.M. (1995). An overview of the health and retirement study. *Journal of Human Resources*, 30, S7–S56.
- Kalichman, S.C., Pope, H., White, D., Cherry, C., Amaral, C., Swetzes, C., Flanagan, J., & Kalichman, M. (2008). Association between health literacy and HIV treatment adherence: Further evidence from objectively measured medication adherence. *Journal of the International Association of Physicians in AIDS Care*, 7(6), 317-323.
- Keusch, G.T., Wilentz, J., & Kleinman, A. (2006). Stigma and global health: Developing a research agenda. *The Lancet*, 367(9509), 525-527.
- Kim, S.H., Yu, X. (2010). The mediating effect of self-efficacy on the relationship between health literacy and health status in Korean older adults: A short report. *Aging and Mental Health*, 14(7), 870-3.
- Kripalani, S., Henderson, L.E., Chiu, E.Y., Robertson, R., Kolm, P., & Jacobson, T.A. (2006). Predictors of medication self-management skill in a low-literacy population. *Journal of General Internal Medicine*, 21(8), 852–856.
- Kripilani, S., Gatti, M.E., & Jacobsen, T.A. (2010). Association of age, health literacy, and

- medication management strategies with cardiovascular medication adherence. *Patient Education and Counseling*, 81, 177-181.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy* (Report no. NCES 2006-483). U.S. Department of Education. Washington, DC: US Department of Education, National Center for Education Statistics. Retrieved March 29, 2013 from National Center of Education Statistics website: <http://nces.ed.gov/naal>.
- Lee, S.D., Gazmararian, J.A., & Arozullah, A.M. (2006). Health literacy and social support among elderly medicare enrollees in a managed care plan. *Journal of Applied Gerontology*, 25, 324-337
- Macabasco-O'Connell, A., DeWalt, D. A., Broucksou, K. A., Hawk, V., Baker, D. W., Schillinger, D., et al. (2011). Relationship between literacy, knowledge, self-care behaviors, and heart failure-related quality of life among patients with heart failure. *Journal of General Internal Medicine*, 26(9), 979-986.
- McCleary-Jones, V. (2011). Health literacy and its association with diabetes knowledge, self efficacy and disease self-management among African Americans with diabetes mellitus. *The ABNF Journal*, 22(2), 25-32.
- Mancuso, C.A., & Rincon, M. (2006). Impact of health literacy on longitudinal asthma outcomes. *Journal of General Internal Medicine*, 21, 813-7
- Mancuso, J.M. (2010). Impact of health literacy and patient trust on glycemic control in an urban USA population. *Nursing and Health Sciences*, 12, 94-104
- Miller, D.P., Brownlee, C.D., McCoy, T.P., & Pignone, M.P. (2007). The effect of health

- literacy on knowledge and receipt of colorectal cancer screening: A survey study. *BMC Family Practice*, 8, 16.
- Morris, N.S., Grant, S., Repp A., Maclean, C., & Littenberg, B. (2011). Prevalence of limited health literacy and compensatory strategies used by hospitalized patients. *Nursing Research*, 60, 361–366.
- Morrow, D., Clark, D., Wanzu, T., Wu, J., Weiner, M., Steinley, D. & Murray, M.D. (2006). Correlates of health literacy in patients with chronic heart failure. *The Gerontologist*, 46(5), 669-676.
- Moser, D.K., Pelter, M.M., Nesbitt, T., Robinson, S., Biddle, M.J., Cooper, L. et al. (2014). Which patients with heart failure have the poorest health literacy? *Circulation*, 124, A9157
- Murray, M.D., Wu, J., Tu, W., Clark, D.O., Weiner, M., Morrow, D.G., & Brater, D.C. (2004). Health literacy predicts medication adherence. American Society for Clinical Pharmacology and Therapeutics. *Clinical Pharmacology & Therapeutics*, 76.
- Murray, M.D., Tu, W., & Wu, J. et al. (2009). Factors associated with exacerbation of heart failure include treatment adherence and health literacy skills. *Clinical Pharmacology & Therapeutics*, 85, 651.-8
- Naik, A. D., Street, R., J., Castillo, D., & Abraham, N. S. (2011). Health literacy and decision making styles for complex antithrombotic therapy among older multimorbid adults. *Patient Education & Counseling*, 85(3), 499-504.
- Nelson, H.D., Tyne, K., Naik, A., et al. (2009). Screening for Breast Cancer: Systematic

- Evidence Review Update for the US Preventive Services Task Force. Rockville, MD: Agency for Healthcare Research and Quality. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK36392/>
- Nielsen-Bohlman, L., Panzer, A.M., & Kindig, D.A. (2004). Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Washington, DC: National Academies Press.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67(12), 2072-2078.
- Osborn, C. Y., Bains, S. S., & Egede, L. E. (2010). Health literacy, diabetes self-care, and glycemic control in adults with type 2 diabetes. *Diabetes Technology & Therapeutics*, 12(11), 913-919.
- Osborn, C. Y., Cavanaugh, K., Wallston, K. A., & Rothman, R. L. (2010). Self-efficacy links health literacy and numeracy to glycemic control. *Journal of Health Communication*, 15 (Suppl 2), 146-158.
- Osborn, C.Y., Paasche-Orlow, M.K., Bailey, S.C., & Wolf, M.S. (2011). The mechanisms linking health literacy to behavior and health status. *American Journal of Health Behavior*, 35(1), 118-128.
- Paasche-Orlow, M., Parker, R.M., Gazmaranian, J.A., Nielsen-Bohlman, L., & Rudd, R. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20(2), 175-84.
- Paasche-Orlow, M.K., Cheng, D.M., Palepu, A., Meli, S., Faber, V., & Samet, J.H. (2006). Health literacy, antiretroviral adherence, and HIV-RNA suppression: A longitudinal perspective. *Journal of General Internal Medicine*, 21(8), 835-40e.



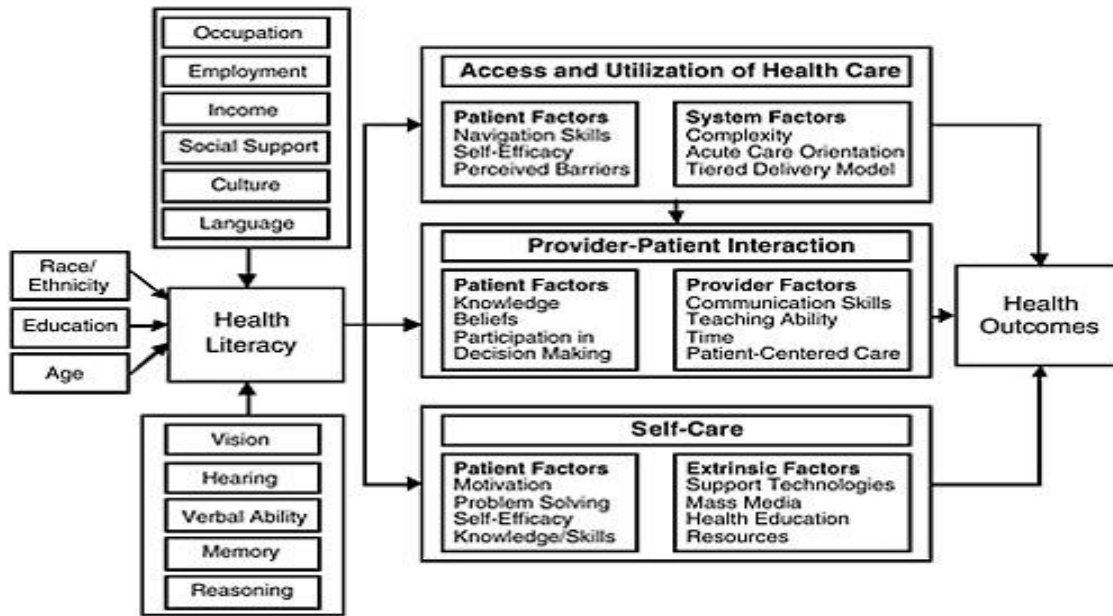
- Paasche-Orlow, M., & Wolf, M. (2007). The causal pathways linking health literacy to health outcomes. *The American Journal of Health Behavior*, 31(1), 19-26.
- Paasche-Orlow, M., & Wolf, M. (2008). Evidence does not support clinical screening of literacy. *Journal of General Internal Medicine*, 23(1), 100-2.
- Pagán, J., Brown, C., Asch, D., Armstrong, K., Bastida, E., & Guerra, C. (2012). Health literacy and breast cancer screening among Mexican American women in south Texas. *Journal of Cancer Education*, 27(1), 132-7.
- Parikh, N.S., Parker, R.M., Nurss, J.R., Baker, D.W., & Williams, M.V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling*, 27,33-39.
- Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10, 537-41.
- Persell, S., Osborn, C.Y., Richard, R., Skripkauskas, S., & Wolf, M.S. (2007). Limited health literacy is a barrier to medication reconciliation in ambulatory care. *Journal of General Internal Medicine*, 22(11), 1523-1526.
- Peterson, N.B., Dwyer, K.A., Mulvaney, S.A., Dietrich, M.S., & Rothman, R.L. (2007). The influence of health literacy on colorectal cancer screening knowledge, beliefs and behavior. *Journal of the National Medical Association*, 99, 1105.-12
- Pleasant, A., & McKinney, J. (2011). Coming to consensus on health literacy measurement: An online discussion and consensus-gauging process. *Nursing Outlook*, 59(2):95-106.
- Rees, C. A., Karter, A. J., Young, B. A., Spigner, C., Grembowski, D., Schillinger, D., et al.

- (2011). Correlates of patient-reported racial/ethnic health care discrimination in the Diabetes Study of Northern California (DISTANCE). *Journal of Health Care for the Poor and Underserved*, 22(1), 211-225.
- Sarkar, U., Piette, J. D., Gonzales, R., Lessler, D., Chew, L. D., Reilly, B., et al. (2008). Preferences for self-management support: Findings from a survey of diabetes patients in safety-net health systems. *Patient Education and Counseling*, 70(1), 102-110.
- Sarkar, U., Schillinger, D., López, A., & Sudore, R. (2011). Validation of self-reported health literacy questions among diverse English and Spanish-speaking populations. *Journal of General Internal Medicine*, 26(3), 265-71.
- Schillinger, D., Grumbach, K., & Piette, J., et al. (2002). Association of health literacy with diabetes outcomes. *JAMA*, 288, 475–482.
- Scott, T.L., Gazmararian, J.A., Williams, M.V., & Baker, D.W. (2002). Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*, 40(5), 395-404.
- Sheridan, S.L., Halpern, D.J., Viera, A.J., Berkman, N.D., Donahue, K.E., and Crotty, K. (2011). Interventions for individuals with low health literacy: A systematic review. *Journal of Health Communication*, 16(3), 30-54.
- Sheskin, D.J. (2011). *Handbook of parametric and nonparametric statistical procedures*. Danvers, MA: Chapman & Hall.
- Speros, C. (2005). Health literacy: A concept analysis. *Journal of Advanced Nursing*, 50, 633-640.
- Stewart, D.W., Adams, C.E., Cano, M.A., Correa-Fernandez, V., Li, Y., Waters, A.J., Wetter,

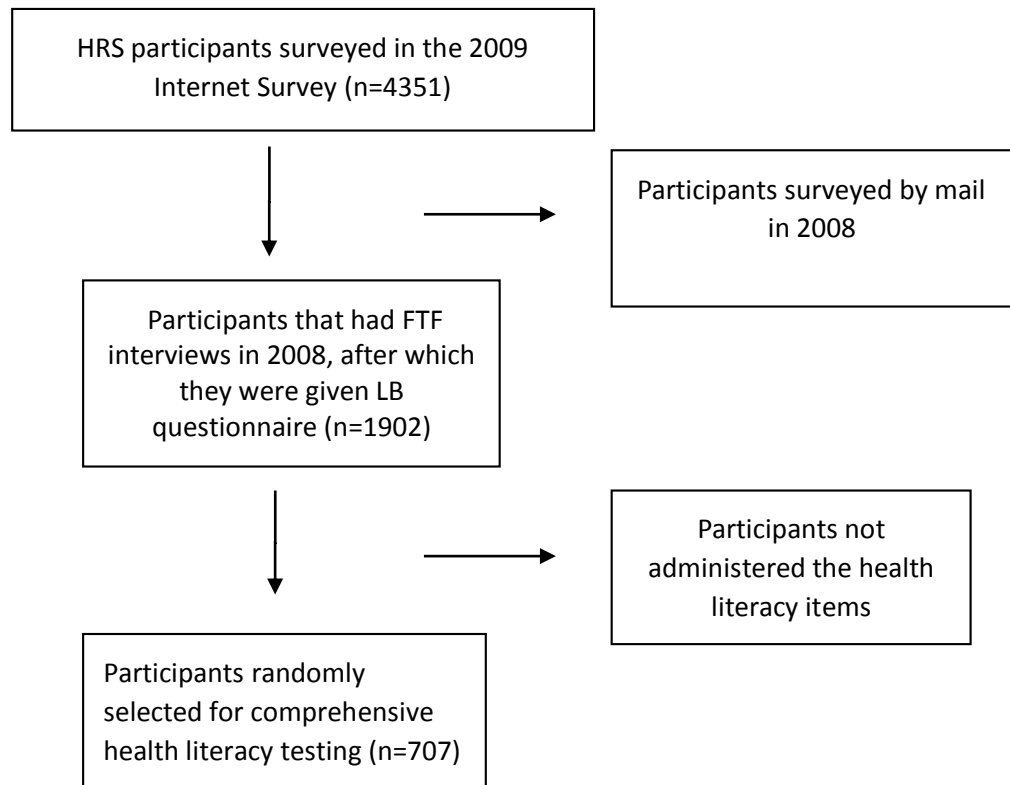
- D.W., & Vidrine, J.I. (2013). Associations between health literacy and established predictors of smoking cessation. *American Journal of Public Health, 103*, e43-e49.
- Stewart, D.W., Cano, M.A, Correa-Fernández, V., Spears, C.A., Li, Y., Waters, A.J., Wetter, D.W., & Vidrine, J.I. (2014). Lower health literacy predicts smoking relapse among racially/ethnically diverse smokers with low socioeconomic status. *BMC Public Health, 14*, 716.
- Sudore, R.L., Yaffe, K., Satterfield, S., Harris, T.B., Mehta, K.M., Simonsick, E.M. et al. (2006). Limited literacy and mortality in the elderly: The Health, Aging, and Body Composition Study. *Journal of General Internal Medicine, 21*, 806–812.
- Sudore, R.L., Mehta, K.M., Simonsick, E.M., Harris, T.B., Newman, A.B., Satterfield, S., et al. (2006). Limited literacy in older people and disparities in health and healthcare access. *Journal of the American Geriatric Society, 54*, 770.-6
- Tabachnick, B.G., & Fidell, L.S. (2007). *Using Multivariate Statistics*. Boston, MA: Pearson Education.
- U.S. Department of Health and Human Services. (2007). National Institute on Aging. *Growing Older in America: The Health and Retirement Study*. Washington, DC: National Institutes of Health.
- U.S. Department of Health and Human Services. (2011). Office of Disease Prevention and Health Promotion. *Healthy People 2020*. Washington, DC: National Institutes of Health. Retrieved March 29, 2013 from: <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=18>.
- U.S. Department of Health and Human Services. (2010). Office of Disease Prevention and

- Health Promotion. *National Action Plan to Improve Health Literacy*. Washington, DC. National Institutes of Health.
- U.S. Preventive Services Task Force. (2002). Screening for breast cancer: recommendations and rationale. *Annals of Internal Medicine*, *137*(5), 344–346.
- Ussher, M., Ibrahim, S., Reid, F., Shaw, A., & Rowlands, G. (2010). Psychosocial correlates of health literacy among older patients with coronary heart disease. *Journal of Health Communication*, *15*(7), 788-804.
- Van De Heide, I., Rademakers, J., Schipper, M., Droomers, M., Sørensen, K., & Uiters, E. (2013). Health literacy of Dutch adults: A cross sectional survey. *BMC Public Health*, *13*, 179.
- Van Geest, J.B., Welch, V.L., & Weiner, S.J. (2010). Patients' perceptions of screening for health literacy: Reactions to the Newest Vital Sign. *Journal of Health Communication*, *15*(4), 402-412.
- Von Wagner, C., Knight, K., Steptoe, A., & Wardle, J. (2007). Functional health literacy and health promoting behaviour in a national sample of British adults. *Journal of Epidemiology and Community Health*, *61*, 1086-90.
- Von Wagner, C., Steptoe, A., Wolf, M.S., & Wardle, J. (2009). Health literacy and health actions: a review and a framework from health psychology. *Health Education and Behavior*, *36*(5), 860-77
- Waite, K.R., Paasche-Orlow, M., Rintamaki, L.S., Davis, T.C., & Wolf, M.S. (2008). Literacy, stigma, and HIV medication adherence. *Journal of General Internal Medicine*, *23*, 1367.-72
- Walker, J., Pepa, C., & Gerard, P.S. (2010). Assessing the health literacy levels of patients using

- selected hospital services. *Clinical Nurse Specialist*, 24, 31–37.
- Wallace, R.B., & Herzog, A.R. (1995). Overview of the health measures in the Health and Retirement Study. *Journal of Human Resources, Supplement*, 30(4), S84-S107.
- White, S., Chen, J., & Atchison, R. (2008). Relationship of preventive health practices and health literacy: A national study. *American Journal of Health Behavior*, 32, 3, 227-242.
- World Health Organization (WHO). (2014). Screening for breast cancer. Available at: <http://www.who.int/cancer/detection/breastcancer/en/index.html>.
- Wolf, M.S., Gazmararian, J.A., Baker, D.W. (2005). Health literacy and functional health status among older adults. *Archives of Internal Medicine*, 165(17), 1946-52
- Wolf, M.S., Williams, M.V., Parker, R.M., Parikh, N.S., Nowlan, A.W., & Baker, D.W. (2007) Patients' shame and attitudes toward discussing the results of literacy screening. *Journal of Health Communication*, 12, 721–732.
- Wolf, M.S., Gazmararian, J.A., & Baker, D.W. (2007). Health literacy and health risk behaviors among older adults. *American Journal of Preventive Medicine*, 32, 19-24.
- Wolf, MS, Davis, TC, Osborn, CY, Skripkauskas, S, Bennett, CL, & Makoul, G. (2007). Literacy, self-efficacy, and HIV medication adherence. *Patient Education and Counseling*, 65, 253.-60.
- Williams, M.V., Baker, D.W., Parker, R.M., & Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of patients with hypertension and diabetes. *Archives of Internal Medicine*, 158, 166–172.



**Figure 1.1.** Causal pathways between limited health literacy and health outcomes. Paasche-Orlow and Wolf (2007).



**Figure 1.2.** Study sample flow. **HRS**, Health and Retirement Study; **HTN**, hypertension; **FTF**, face-to-face; **LB**, “Leave-Behind” questionnaire that included the Psychosocial and Lifestyle Questionnaire.

**Table 1.1. Health and Retirement Study Psychosocial and Behavioral Variables.**

	Variable	Measure
Psychosocial Variables	Perceived healthcare discrimination <sup>a</sup>	Everyday Discrimination Scale (Williams, Jackson, and Anderson, 1997; Williams, Neighbors, and Jackson, 2003).
	Perceived control of health <sup>b</sup>	Control Over Health item from the National Survey of Midlife Development in the U.S. (Ryff, Love, & Radler, 1995)
	Perceived social standing <sup>b</sup>	MacArthur Scale of Subjective Social Status (1999).
	Perceived risks of colon cancer <sup>b</sup>	Colon cancer items from the National Survey of Medical Decisions (Couper, Zikmund-Fisher, Singer et al., 2006)
Health Behaviors	Flu immunization <sup>a</sup>	In last two years, yes/no.
	Cholesterol blood test <sup>a</sup>	In last two years, yes/no.
	Prostate exam or mammography <sup>a</sup>	In last two years, yes/no.
	Breast self-examination monthly <sup>a</sup>	Yes/no.
	Current tobacco use <sup>b</sup>	Yes/no.
	Frequency of moderate exercise <sup>a</sup>	<2 times per week , or ≥2 times per week
	Frequency of vigorous exercise <sup>a</sup>	<2 times per week , or ≥2 times per week

<sup>a</sup> From the 2008 core survey

<sup>b</sup> From the 2009 internet survey

**Table 1.2. Socio-demographic and HTN-Related Characteristics**

	Entire Sample (N=1902)	Final sample that had health literacy testing (N=707)	Hypertensive subsample of the final sample (N=373)
Variable	Mean +/- SD or %	Mean +/- SD or %	Mean +/- SD or %
Age (years)	66.25 +/- 8.92	65.80 +/- 9.05	68.08 +/- 8.87*
Gender (Female)	58.0	57.1	53.6
Race/Ethnicity			
White	91.0	92.1	90.1
Black	6.8	5.2	6.7
Other <sup>a</sup>	2.2	2.7	3.2
Hispanic	4.4	4.4	4.0
Education			
0-8 years	0.7	1.0	0.3
9-11 years	4.3	4.6	4.9
12 years	27.7	25.3	25.2
College	45.6	45.2	46.1
Post-college	21.6	23.9	23.6
Marital Status			
Married or Live-in Partner	77.0	80.8	78.6
Unmarried <sup>b</sup>	23.0	19.2	21.4
Employment			
Employed	35.0	36.4	29.0*
Unemployed <sup>c</sup>	11.6	12.4	13.1
Retired	48.7	46.8	54.4
Homemaker	4.7	4.4	3.5

Note: Final sample N=707. Valid percentages reported due to missing data. HTN = hypertension; SD = standard deviation.

<sup>a</sup>Other race includes American Indian, Alaskan Native, Asian, and Pacific Islander. <sup>b</sup>Unmarried includes separated, divorced, never married, widowed, and one refusal to respond.

<sup>c</sup>Unemployed includes unemployed and looking for work, laid off, disabled, sick or other leave, and one refusal to respond.

\*Sensitivity analyses (between the hypertensive subsample and those in the final sample that were excluded from the hypertensive subsample) were reported; \*p<0.05, 2 tailed.



**Table 1.3. Psychosocial and behavioral factors stratified by *objective* health literacy level.**

	<u>Health Literacy</u>			<b>P*</b>
	<b>Total</b>	<b>Inadequate/Marginal (%)</b>	<b>Adequate (%)</b>	
<b>Perceived control over health (Median). N=704.</b>	8	8	8	0.93 (MWU)
<b>Perceived social standing (Median). N=686.</b>	7	7	7	0.83 (MWU)
<b>Perceived healthcare discrimination (denies or less than 3 times per year). N=355.</b>	82.2	82.6	82.1	1.00
<b>Perceptions of colon cancer</b>				
• <b>Perceived risk of diagnosis (correct) N=697.</b>	13.4	7.8	14.3	0.08
• <b>Perceived risk of death (correct) N=701.</b>	13.2	7.8	14.5	0.09
• <b>Perceived benefit of screen (correct) N=704.</b>	87.6	81.7	88.8	0.051
<b>Flu immunization. N=704.</b>	67.0	69.6	66.6	0.60
<b>Cholesterol testing. N=702.</b>	90.7	88.7	91.1	0.52
<b>Mammography. N=401.</b>	82.0	76.0	82.9	0.32
<b>Breast-self exam. N=402.</b>	52.2	72.0	49.4	0.005
<b>Prostate examination. N=302.</b>	78.8	80.0	78.5	0.93
<b>Current tobacco abuse. N=704.</b>	9.1	13.9	8.1	0.074
<b>Exercise (≥2 times/week)</b>				
• <b>Moderate. N=704.</b>	63.9	61.7	64.3	0.67
• <b>Vigorous. N=703.</b>	68.0	63.5	68.9	0.31

\*Chi-square unless otherwise noted. MWU; Mann-Whitney U Test (2 tailed significance value for Z-test). Valid percents are reported due to small amounts of missing data. N=707 unless otherwise noted; N for sex appropriate annual screenings are with little or no missing data, however represents male or female respondents as expected.

**Table 1.4. Psychosocial and behavioral factors stratified by *self-reported* health literacy level.**

	<b>Health Literacy</b>			<b>P*</b>
	<b>Total</b>	<b>Inadequate (%)</b>	<b>Adequate (%)</b>	
<b>Perceived control over health (Median).</b>	8	7	8	<0.005 (MWU)
<b>Perceived social standing (Median). N=689.</b>	7	6	7	<0.005 (MWU)
<b>Perceived healthcare discrimination (denies or less than 3 times per year). N=670.</b>	82.1	77.9	83.1	0.20
<b>Perceptions of colon cancer.</b>				
• <b>Perceived risk of diagnosis (correct). N=704.</b>	13.4	10.7	14.1	0.36
• <b>Perceived risk of death (correct). N=700.</b>	13.1	8.9	14.3	0.12
• <b>Perceived benefit of screen (correct).</b>	87.6	81.9	89.1	0.026
<b>Flu immunization</b>	66.9	67.1	66.8	1.00
<b>Cholesterol testing. N=705.</b>	90.5	88.6	91.0	0.46
<b>Mammography. N=404.</b>	82.2	69.4	84.9	0.003
<b>Breast self-exam. N=405.</b>	52.1	61.1	50.2	0.12
<b>Prostate examination. N=302.</b>	78.8	75.3	80.0	0.48
<b>Current tobacco abuse</b>	9.1	14.1	7.7	0.024
<b>Exercise (≥2 times/week)</b>				
• <b>Moderate</b>	63.8	54.4	66.3	0.009
• <b>Vigorous. N=706.</b>	68.0	63.1	69.3	0.18

\*Chi-square unless otherwise noted. MWU; Mann-Whitney U Test (2 tailed significance value for Z-test). Valid percent is reported due to small amounts of missing data. N=707 unless otherwise noted; N for sex appropriate annual screenings are with little or missing data, however represents male or female respondents as expected.

**Table 1.5. Multivariate adjusted association of adequate objective health literacy with behavioral and psychosocial factors.**

<b>Logistic regression</b>	<b>Adjusted* OR**</b>	<b>CI</b>	<b>P</b>
Flu immunization	0.93	(0.58-1.51)	0.78
Cholesterol testing	1.72	(0.86-3.44)	0.12
Mammography	1.54	(0.74-3.21)	0.25
Breast self-exam	0.37	(0.19-0.73)	0.004
Prostate examination	1.02	(0.50-2.10)	0.95
Current tobacco abuse	0.46	(0.23-0.91)	0.025
Exercise			
• Moderate	0.94	(0.61-1.46)	0.79
• Vigorous	0.93	(0.59-1.46)	0.75
Perceptions of colon cancer.			
• Perceived risk of diagnosis	1.89	(0.90-3.96)	0.09
• Perceived risk of death	1.75	(0.83-3.68)	0.14
• Perceived benefit of screen	1.72	(0.98-3.02)	0.06
Perceived healthcare discrimination	1.04	(0.59-1.84)	0.90
<b>Linear regression</b>	<b><math>\beta</math> (SE)</b>	<b><math>\beta</math>s</b>	<b>P</b>
Perceived control over health	$\beta$ -0.14 ± 0.21	$\beta$ s -0.02	0.52
Perceived social standing	$\beta$ -0.12 ± 0.17	$\beta$ s -0.03	0.47

\*Adjusted for age, gender, race, and education. \*\*Logistic regression unless otherwise noted with a  $\beta$ .  $\beta$ ; unstandardized slope coefficient.  $\beta$ s; standardized slope coefficient. SE; Standard Error.

**Table 1.6. Multivariate adjusted association of adequate self-reported health literacy with behavioral and psychosocial factors.**

<b>Logistic regression</b>	<b>Adjusted* OR**</b>	<b>CI</b>	<b>P</b>
Flu immunization	0.94	(0.62-1.43)	0.78
Cholesterol testing	1.41	(0.77-2.59)	0.26
Mammography	2.22	(1.21-4.66)	0.010
Breast self-exam	0.66	(0.39-1.13)	0.13
Prostate examination	1.27	(0.68-2.40)	0.46
Current tobacco abuse	0.55	(0.30-1.01)	0.054
Exercise			
• Moderate	1.51	(1.03-2.21)	0.033
• Vigorous	1.21	(0.81-1.80)	0.35
Perceptions of colon cancer.			
• Perceived risk of diagnosis (correct)	1.39	(0.78-2.50)	0.27
• Perceived risk of death (correct)	1.68	(0.89-3.16)	0.11
• Perceived benefit of screen (correct)	1.63	(0.97-2.72)	0.064
Perceived healthcare discrimination	0.69	(0.43-1.12)	0.13
<b>Linear regression</b>	<b><math>\beta</math> (SE)</b>	<b><math>\beta</math>s</b>	<b>P</b>
Perceived control over health	$\beta$ 0.759 ± 0.188	$\beta$ s 0.148	<0.0005
Perceived social standing	$\beta$ 0.460 ± 0.147	$\beta$ s 0.112	0.002

\*Adjusted for age, gender, race, and education. \*\*Logistic regression unless otherwise noted with a  $\beta$ .  $\beta$ ; unstandardized slope coefficient.  $\beta$ s; standardized slope coefficient. SE; Standard Error.

## CHAPTER 3

### **The Health Literacy-Related Healthcare Experience: A Qualitative Study.**

The Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielson-Bohlman, Panzer, and Kindig, 2004, p. 36). Health numeracy is defined as "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck, Ahlers-Schmidt, Paschal, and Dsimuke). These skills are considered important assets for personal health and livelihood (Nielson-Bohlman et al., 2004; Nutbeam, 2008). Individuals with proficient health literacy and numeracy can act on written or spoken verbal and numerical health and healthcare-related materials in ways that are well-suited for them and compatible with their values. However, health literacy and numeracy are limited in the general population (Kutner, Greenberg, Jin, & Paulsen, 2006; Fagerlin, Ubel, Smith, and Zikmund-Fisher, 2007). While acknowledging the importance of the quantitative aspects of health information, for purposes of this research, the term "health literacy" will henceforth refer to both health literacy and health numeracy.

Because health literacy is such a valuable asset, individuals who lack it may struggle in many ways. It is possible that in addition to concrete appreciable barriers that patients face with regard to accessing, processing, and understanding relevant health information, having

limited health literacy in the healthcare environment may induce emotional responses, such as shame, or processes of stigmatization.

Goffman defines stigma as a process in which a discrediting attribute is assigned to an individual that causes them to feel reduced from “a whole and usual person to a tainted, discounted one” (Goffman 1963, pp. 3). Previous studies have suggested that stigmatization may occur in the healthcare environment around limited health literacy. In fact, studies have found that nearly half of individuals with limited health literacy report efforts to conceal it from others (Parikh et al., 1996; Wolf et al., 2007). The social and emotional consequences for stigmatized individuals can be very damaging (Goffman, 1963). In those with mental illness and infectious disease, stigmatization adversely affects their health seeking behaviors (Corrigan, 2004; Herek, Capitanio, & Widaman et al., 2003; Jaramillo, 1998).

The study of health literacy is relatively new (Berkman et al., 2011; Golbeck et al., 2005). While the disproportionately poor health outcomes have been well-documented in individuals with limited health literacy (Berkman et al., 2011), the overall qualitative health literacy-related experience in the healthcare setting has not been well described. Therefore the purpose of this qualitative study is to learn more about the health literacy-related experience from the perspective of adults with hypertension at risk for limited health literacy and numeracy.

### **Review of the Literature**

To explore what was known stigma, shame, and social marginalization in the context of limited health literacy, I conducted a systematic review of the available literature in PubMed, CINAHL, and PsycInfo databases using the keywords ‘health literacy,’ ‘literacy,’ ‘numeracy,’ ‘reading,’ ‘reading ability,’ with ‘social stigma,’ ‘stigma,’ ‘shame,’ or ‘marginalization.’ I identified ten qualitative and mixed methods studies that reported original research exploring this

phenomenon. The most commonly reported experiences included negative patient-provider interactions, internal feelings of shame and self-blame, and fear of exposure.

Many participants in the studies reported negative patient-provider interactions. In one, 321 older adults with coronary artery disease were administered surveys to determine psychosocial correlates of health literacy (Ussher, Ibrahim, Reid, Shaw, & Rowlands, 2010). Lower health literacy was associated with reports of increased discomfort about asking providers for explanations of health information ( $p = .014$ ), and less support with discussing health problems ( $p = .020$ ). In a qualitative study of 60 adults with limited health literacy in an urban setting, participants were interviewed in focus groups. They recalled staff being frustrated, angry, and unkind toward them when they struggled through paperwork (Baker et al., 1996). In a study of eight participants recruited from a literacy program, findings from semi-structured interviews indicated that patients were more willing to seek and accept help with literacy-related challenges from providers who had “time to spend with you...who wouldn’t just come in and leave again” (Brez & Taylor, 1997, p. 1043). In a study of eleven participants recruited from an urban clinic, participants were asked health literacy screening questions and asked for feedback about the items. Being questioned by a clinician with terms like ‘help’ and ‘how often’ (with regard to needing assistance with written health materials) was cited as potentially embarrassing (Farrell, Chandran, & Gramling, 2008).

Feelings of shame and self-blame were expressed by many patients interviewed in the studies. While there were no descriptions of overt experiences of shaming, patients reported that they felt ashamed and that they deserved blame for their limited health literacy. In the study by Baker and colleagues (1996), participants described feeling bad about themselves, worthless, or lazy for not having obtained health literacy. In the study by Brez and Taylor (1997), participants

revealed worry that they may be seen as bad people or incompetent members of society. In two other studies, participants with limited health literacy admitted outright to feelings of shame. In one, 202 adults underwent health literacy testing and a semi-structured interview about their perceived difficulty with reading health materials. Of those who demonstrated limited health literacy who admitted to literacy challenges, 40% admitted shame (Parikh et al., 1996). In another, 283 adults underwent health literacy testing and structured interviews investigating how well documentation of test results in their medical records would be accepted. Nearly half (47.6%) of participants with the lowest level of health literacy admitted to literacy-related shame, and those with limited health literacy were more likely than those with adequate health literacy to report feelings of shame with disclosure of their results to their doctor ( $P < 0.05$ ) (Wolf et al., 2007).

A few studies explored patients' perceptions of health literacy testing. In one, most of the participants denied their own discomfort with health literacy testing, but when asked in the third person, a large minority admitted that testing may cause patients discomfort generally (Ferguson et al., 2011). In a few others, patients' views of routine clinical health literacy screening were explored. While most of the participants in these studies supported the idea generally, they expressed concern about the setting, and some desired only private areas (Farrell et al., 2008; Brez & Taylor, 2008; Ferguson, Lowman, & DeWalt, 2011). In one, many participants failed to answer questions about routine health literacy screening (VanGeest, Welch, and Weiner, 2010).

While the health literacy-related stigma experience has been explored, the studies had a narrow focus and mainly employed structured interviewing. There remains a lack of understanding about the broader experience of accessing healthcare in the context of limited

health literacy. This study seeks to increase the understanding of the patient experience by offering an analysis of stories narrated in patients' own words. Additionally, this study explores how patients cope with managing hypertension while also having limited health literacy.

This study focuses on African American adults with hypertension. This focus is important because African Americans have a higher prevalence of limited health literacy compared to Caucasians (Nielson-Bohlman et al., 2004), and a higher rate of hypertension with poorer hypertension outcomes compared to Caucasians (James, et al., 2014). Examining the health literacy-related healthcare experience in African Americans with hypertension has not only the potential to increase understanding about the underlying mechanisms in the relationship between health literacy and health, but addresses a health disparity in hypertension that is estimated to be the main contributor of disproportionate mortality among African Americans (Fiscella and Holt, 2008).

### **Research Questions**

Research questions posed by this study include: (1) What are the health literacy-related challenges encountered by African American individuals with hypertension in the healthcare setting? (2) What are the emotional and behavioral responses to health literacy-related challenges experienced by African American individuals with hypertension in the healthcare setting?

### **Methods**

#### **Design**

The constructivist paradigm informs this inquiry of the health literacy-related healthcare experience. In constructivism (or social constructivism), individuals are believed to have understandings of their world and assign subjective meanings to their experiences (Creswell, 2013). These understandings and meanings are greatly influenced by social and historical



circumstances (Creswell, 2013). To learn about these constructions, Lincoln and Guba (1985) advocate an approach that allows for a “flow of naturalistic inquiry” (p. 188). While this approach involves careful selection of a specific research method, it also involves the researcher acting as a human instrument, conduction of research in the natural setting, purposive sampling methods, and inductive data analyses.

This qualitative study was exploratory in nature. I conducted in-person interviews using a narrative approach followed by probe questions. For analysis, I employed procedures derived from grounded theory, including constant comparison, which is the process of comparing each incident in the data with other incidents for similarities and differences, allowing for the differentiation of themes from each other and for the delineation of properties and dimensions specific to the themes identified (Strauss and Corbin, 1998). While grounded theory is often utilized to generate theories, the methodology can be practiced in research that is more descriptive in nature (Strauss and Corbin, 1998).

### *Setting*

I recruited participants and collected data in a private primary care physician’s office in Detroit, Michigan serving a population of approximately 70% African American and 30% Caucasian patients of both sexes and all ages. The racial variation of patients seen at this site, and the variable education level of Detroit residents (National Center for Education Statistics, 2010) provided a diverse sample.

### **Sampling**

Because the purpose of a qualitative study is to obtain rich and deep information, purposive samples are suited and cases are to be carefully selected to shed light on the topic of study (Ulin, Robinson, and Tolley, 2005). Additionally, purposive samples are believed to

increase the researcher's ability to uncover multiple realities (Lincoln and Guba, 1985). For inclusion, individuals had to: (1) self-identify by date of birth as 35 years of age or older, (2) self-identify as African American or Black, (3) be patients at the health clinic where data was collected (must have been present for an appointment, or have a history of having had an appointment at the site), (4) report having had a diagnosis of hypertension by a physician, (5) be willing and able to provide informed consent, and (6) have a corrected visual acuity of 20/50 or better.

### **Sample Size**

I sought an initial sample size of 15. Creswell (2013) noted that in his review of qualitative studies, most narrative studies had approximate sample sizes of 1-2 and most grounded theory studies had approximate sample sizes of 20-30. Creswell (2013), however, agreed with Charmaz (2006) that upon data saturation (ceasing to discover new insights or properties from successive interviews), data collection should be discontinued. I determined that I had achieved saturation upon analyzing the first 15 interviews, so without returning to the field I maintained the original sample of 15 participants.

### **Procedure**

At the start of the office day on the pre-determined mornings, the office staff briefly told patients about my study upon check-in. I then sequentially approached individuals in the waiting room and inquired about their willingness to participate in a study addressing difficulty in the understandability of health materials. I gave potential participants an overview of the study, i.e., the interview would take approximately 30 minutes, the interview would follow their appointment with the physician, the interview would take place in a private exam room within the clinic, and participation was confidential and voluntary without any follow up necessary. I

then notified the physician of individuals who expressed interest, and asked him to formally end his visits with them by stating outright that the study was unrelated to their health care visit, general care, or relationship with him or the office. Following appointments, interested potential participants were then referred to meet me in a designated administrative room in the clinic that held two desks and three chairs.

Prior to collecting any data, I read the potential participants the informed consent statement, while they were given a copy from which they could follow along. I explained the study procedure in great detail and answered any questions at that time. After obtaining informed consent, I assessed visual acuity with the Snellen eye chart. To proceed, potential participants were to have a corrected visual acuity of 20/50 or better.

### **Interview Process**

I began each interview by asking participants with the Single Item Literacy Screener (SILS) question “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” (from “1,” never, to “5,” always) (Morris, MacLean, Chew, and Littenberg, 2006). Then, I administered the following standard (although untimed) health literacy assessments: the Rapid Estimate of Adult Literacy in Medicine Short Form (REALM-SF) (Arozullah et al., 2007), the Short Test of Functional Health Literacy (STOFHLA) (Baker, Williams, Parker, Gazmararian, and Nurss, 1999), and the health-related subscale of the Lipkus Expanded Numeracy Scale (Lipkus, Samsa, and Rimer, 2001) (Appendix B-D). At the start of these tests, I asked participants to consider not only questions and answers, but how they felt during each test. I encouraged them to state aloud any thoughts they had during or after each or all of the tests. I asked retrospective probe questions to learn about their testing experience. The results of this cognitive testing are reported in another paper

of this dissertation, “Patient Understanding and Perceptions of Health Literacy and Numeracy Testing: Findings from Cognitive Interviews.”

Following this testing, I conducted interviews with each participant using the narrative approach; I asked participants to take their time and reflect, then to share a story of a significant experience in a healthcare setting in which they had difficulty understanding health-related information. I administered probing questions to elicit story details to learn about their health literacy-related challenges in the healthcare setting (Aim 1) and their subsequent emotional and behavioral responses to these challenges (Aim 2). If it had not yet emerged from the interview, at the end I’d ask participants: “Did you feel any shame or embarrassment related to this incident?” and “Do you believe that anyone may feel ashamed or embarrassed in a situation like this?” I’d also ask these questions about patients in general and whether any person could potentially have these perceptions or experiences around understanding health-related materials in the healthcare setting.

To learn about hypertension-related issues, I asked participants about the actual healthcare setting and context. I also asked participants to describe their actions in the situation and how they problem solved. Because self-management of hypertension (especially medication adherence) is a crucial factor in overall health disparities for African Americans (Sabate et al., 2003), and suspected to be one mediator between health literacy and health outcomes (Pignone and DeWalt, 2006), I explored the impact of health literacy-related challenges on hypertension self-management behaviors.

## **Analysis**

I recorded interviews digitally and had them transcribed. After screening them for any identifiable data, I imported them into Atlas (Atlas.ti 7) software for analysis. I then

systematically coded and constantly compared transcripts following the three phase procedure of Strauss and Corbin (1998) – open, axial, and selective coding. I identified categories during open or substantive coding. These were validated by a second researcher. I then conducted axial coding, which involved identifying conditions (or situations), actions (individual’s responses to conditions), and consequences (outcomes of actions or inactions taken by individuals in certain conditions) as recommended by Strauss and Corbin (1998). In the final stages of analysis, I coded selectively and linked concepts together, examining linkages and contemplating possible relationships between concepts. I used diagrams of networks to facilitate analysis.

## **Results**

### **Participant Demographics and Health Literacy**

The sample consisted of 9 females and 6 males between the ages of 42 and 70. Health literacy levels varied per the measure used. While 11 participants demonstrated adequate health literacy by the STOFHLA (Baker et al., 1999), only seven reported adequate health literacy with the SILS (Morris et al., 2006) and only 6 participants demonstrated a 9<sup>th</sup> grade or higher reading level by the REALM-SF (Arozullah et al., 2007). Performance on the Lipkus Expanded Numeracy Scale health-related items was poor overall for participants in this study. One participant had a perfect score of 8, but the next highest score was 4, and the mean score was 2.0 (standard deviation 2.24, median 1, mode 0). Table 3.1 details the health literacy of participants.

### **Themes**

The participants’ narratives varied from a brief story with basic facts to detailed accounts. While most participants shared a single episode that stood out to them as particularly troubling, some offered multiple stories of challenging situations that were more typical. The major themes

identified include health literacy-related challenges, negative emotions, adaptive coping, and maladaptive coping.

**Theme one: Challenges.**

Participants were eager to share examples of practical challenges they'd encountered in the healthcare setting related to health literacy. Situations ranged from low in risk (to their physical health) to life-threatening. Challenges that were seemingly lower in risk included those related to comprehension of general health literature. A very common issue described by participants was difficulty understanding basic health-related patient information materials. Most patients used the term "pamphlets," and this term seemed to encompass multiple types of materials given to patients or available in waiting rooms. One participant's comment, which embodies many others who recounted similar sentiments, said with passion "*[I] get pamphlets from the hospitals and I don't understand half of [them]!*"

Participants also described a lack of understanding of diagnoses. This left them unable to make health-related decisions and unable to address their health conditions with their family. Some had difficulty articulating their health history and health conditions to the various providers they would see in community clinics, urgent cares, and emergency department settings. As to be expected, the greater (or more prolonged) the misunderstanding (or lack of understanding), the more upset it seemed to make the participant. One participant described the following situation:

*"When I first got real sick...I went to the doctor... they sent me home with discharge papers [about] what was wrong... and I couldn't, the medical words were so big I couldn't understand how to put an answer; much less what it meant. So I had two*

*months before I went back to the doctor's before I realized what was really wrong with me."*

Others related challenges understanding their prescribed medications. One participant described having a regimen with multiple medications that he was unsure of.

*"You be wondering, like, 'Okay, what is this word?' ... You'll be like, 'Okay, is this what I suppose to be taking.' Like, you know, prescriptions, yeah, when you got so many different medications and they just 'x,' you know... You be like 'Okay, what is this I'm taking? I'll look at the prescription and I be like 'Okay what is this medicine?' because I don't know the medical term."*

Others described difficulty with medication reconciliation, which is the formal process of identifying a comprehensive and accurate list of the patient's current medications that they are taking, and comparing it to those in the patient's record or medication orders. This mechanism is important in the management of hypertension, for which many patients take multiple medications. One participant, describing an office visit during which he was asked to report his current medications, stated *"I couldn't remember the name of it. With the medicine they give you a label, I mean a little pamphlet of what the medicine is and what it does and side effects or whatever to it, but I didn't have that with me."*

Many participants experienced health literacy-related challenges that were high risk, and even life-threatening. Three participants were seen in the emergency room and/or hospitalized due to their inability to read and understand written health instructions. Two of them misunderstood dosage directions.

*“[The nurse] told me how to not take all my medicine at once, because that’s what I was in [the hospital] for... my heart rate had dropped down... [I was to] take the medicine every eight hours and... stretch them out.”*

*“I misunderstand about the medication they give me. Sometimes it might say maybe once or twice [per] day. Okay. How people take overdose because they misunderstand it. It might say once a day, they take it twice a day. So you’re doing harm to yourself.”*

Another participant, who also had challenges reconciling her medication list, had an interaction between medications.

*“One time when I was with another doctor he gave me a medication and it went and affected with my other medication, and I didn’t know, so I had to go to the emergency room”*

Participants in these situations appeared very cognizant of how their health was compromised. They were appropriately serious when sharing these stories, and story details included descriptions of negative emotions. Some participants even became emotional during the interview.

## **Theme two: Negative emotions**

Participants were very open and unveiled a myriad of negative emotions that resulted from health literacy-related challenges. Some volunteered this facet of their experience on their own; others responded to my inquiry, which included asking each participant “How did that situation make you feel?” These emotions fell into two subgroups, stigma and anxiety.

**Stigma.** While many participants denied experiencing internalized stigma, embarrassment and shame around health literacy, several participants speculated that *others* facing health literacy-related challenges would likely experience these feelings resulting from



health literacy-related challenges. Some stated that in general, individuals with limited health literacy would be left feeling “unsure,” “inadequate,” or “bad” about themselves. Participants also believed that individuals with limited health literacy would fear disclosure of their health literacy status. The following are examples of this:

*“I am the type to ask questions. So if I don’t understand something, I don’t have a problem asking. I’m not embarrassed to ask.... But there are some people who are embarrassed”*

*“Most of this stuff I’ve seen before... I couldn’t – you know, I could read it but... they’re not going to tell you.”*

*“They ain’t going to tell you, ‘I can’t read.’”*

*“They don’t want you to know that they can’t read, they can’t write.”*

*“I don’t think they’re going to tell you straight up, but you’ll find out.”*

A few participants admitted to their own desire to conceal their health literacy challenges, and a couple admitted to embarrassment resulting from their limited health literacy. One participant actually cried during her interview and expressed *“I hate going to people for help. I hate it.”* Another described feeling embarrassed at a pharmacy:

*“I went to the [pharmacy] once and they didn’t give me a prescription that I was supposed to have... I had to call back [to the doctor’s office]... so that was kind of embarrassing at the pharmacist... it’s my medicine and I need it, so that was a bad situation.”*

Self-blame, which is a feature of internalized stigma, was expressed by only one participant, who stated, *“Sometimes I feel it’s just me”*... *“I tried to get the understanding and education back when, but it never happened. I don’t know what happened.”* Others defended

themselves explaining that opportunities were limited for members of their age cohort, their generation, or their family. One participant explained that being a Southern African American left her with limited reading ability:

*“I came from down South, [a city in] Alabama... you didn’t have money and stuff, and it was just easy to go to school, sit back there in the back or whatever and just sit, and they don’t care as long as you pick cotton and pick potatoes”*

A couple of participants blamed their limited literacy on not having graduated from high school. This was expressed by two participants as a matter-of-fact, without sadness or regret. Two others seemed to use high school graduation as a proxy for reading ability when talking about other people in general; they’d compare those who did not graduate from high school with those who did, without referring specifically to literacy level.

**Anxiety.** Almost every participant developed anxiety (or, speculated that *others* would experience anxiety) resulting from health literacy-related challenges. Terms participants used to describe how they (or others) would feel include: “nervous,” “scary,” “scared,” “confusing,” “questionable,” and “upset.” One participant said she had to work to “stay calm” when she experienced health literacy-related challenges. Another described the following emotional process that would result from not understanding her medication instructions:

*“I go over something and keep going over it and I still can’t catch on, it [upsets my] nerves”*

Most of the participants’ anxiety pertained to medication. Seven participants focused the majority of their interview emphasizing the importance of understanding their medication and medication regimen. Three participants were adamant that they “*need to know*” about their medication, two explained that they needed to know “*what [the medicine] is for,*” and two

participants stated it was “*critical*” to take their medication and make it to their blood pressure medication follow-up visits. Most participants explained that their blood pressure medications were priority, but a couple had co-morbidities including a psychiatric disorder and epilepsy for which they relied on medication. As mentioned previously, participants seemed very aware of the serious risks of misunderstanding prescribed regimens.

### **Theme three: Adaptive Coping**

Participants detailed many constructive ways in which they would handle health literacy-related challenges. These included the following coping mechanisms: (1) using surrogate readers, (2) relying spoken communication, (3) securing and maintaining copies of written health-related materials, and (4) self-advocating in the clinical context.

**Surrogate readers.** Many participants described using other individuals with higher literacy as a resource when they ran into challenges with reading or comprehending health-related material. Some brought family members with them regularly to appointments in which they anticipated having to complete paperwork, or read prescriptions, instructions or other materials. Some participants had one person in their life that they relied upon. For example, one participant stated “*Most of the time my daughter comes with me [to appointments]*” and another stated “*I normally bring my niece... when I [come] to the clinic.*” Other participants had multiple people that would help them. For example, one participant had different family members or friends accompany them to office visits or the hospital, stating: “*I always have someone with my when I go to the doctor’s or the hospital because I want them to explain it to me [what] the doctor [has] written down.*”

Some participants cited healthcare providers and staff as suitable surrogate readers. Some identified nurses or nurse practitioners as good choices for surrogate readers, and few

participants stated that they trusted anyone who worked in the doctors' office to read or translate written material for them. One participant recounted:

*"The lady at the front...she called [for me]...I even put the pharmacy on my telephone and said 'Here you go, tell them what I need'"*

One participant, who denied having difficulty himself, recommended that if a patient seemed reluctant to provide informed consent, providers should read the consent form to them. He suggested that a patient's refusal to sign a consent form is a sign of limited health literacy. In fact he stated "the majority of the time, that's what it is." He advised:

*"If they come to a point and they say no [refuse to consent], [say] 'You want me to read it to you? I mean it'll only take us a few minutes.' ...Offer to read it to them."*

For some participants, it appeared that use of a surrogate reader was something that was learned. It also appeared that use of a surrogate was a coping mechanism for those with basic literacy problems. One participant, who had one specific surrogate reader herself, explained the following: *"My father, he was illiterate... and my stepmother always helped him."*

**Spoken communication.** Participants who admitted to difficulty with written health-related materials relied on spoken communication to obtain health information. Some described applying concentrated effort during visits to listen and memorize information that they would recall later. For example, a participant stated *"You don't really understand that writing, so all you can do is just try to remember what they did tell you."* Another statement from a participant exemplifies this, and suggests she has done this life-long to cope with general literacy problems.

*"Some things I can deal with on my own, like my name. I always write my name and the address where I live. Where I go I always learn the phone number, because I always try to learn... I try to learn that number because sometimes [pause], [these are] things I*

*don't talk about" ... "I try to listen to things when people tell me something about my medication or about other things, to understand. I've been learning how to do things like that."*

Another participant mentioned the consent process of our research study, stating *"I may not have been able to read it but I understood it because you was telling me it."* He recommended *"Talk to [patients]... that'd help a lot of people."*

**Keeping copies.** Other participants described strategies of requesting and maintaining copies of written health-related material. Some brought copies to their surrogate reader. One participant stated *"If I get something that I don't understand I always tell them to give me a copy of medical papers or of papers that I need for her [the surrogate reader] to know or just say I need to keep so I don't bother them" ... "I'd try to hold onto the paper and take it to her [the surrogate], let her look at it before I even go do anything."*

Some obtained copies and were determined to gain an understanding of the information through their own investigation. Participants seemed active in problem-solving. Although many participants would not state exactly how they'd resolve the disparities, they expressed that it was important that they'd gain this understanding one way or another. One participant's statement embodies this: *"You still gotta go through it. If not then – I mean, you gotta find out something,"* and another stated she'd *"think about the situation and try to find a solution for it."* One participant took copies of written health information to the internet to seek out information with easier readability. One stated that he just needed the extra time. He told a story of a time in which he was asked to read and sign a *"big stack"* of paperwork. He said he told them *"I'll see you tomorrow. I'm gonna read every last page of this [paperwork]. You know, so I'll see you tomorrow!"*

Others kept copies on their person. They'd present these copies to pharmacists or providers when they believed they wouldn't be able to articulate their condition, regimen, or aspects of the work-up they had undergone or were undergoing.

**Self-advocacy.** Some participants were assertive in communicating their needs to providers, hospital and office staff members, and pharmacists. They were aware of their best interests and their rights. One participant made sure that her primary care provider oversaw all her regimen and medications she was prescribed by other physicians and specialists. *"I see different people, and so I try to make sure that all those people fax over [to her primary care provider] my information so that [a medical error] doesn't happen, because I don't want to die over a medication."* One participant stated that she'd confront the pharmacist at each prescription pick-up and ensure he reviewed her medications for interactions. *"The first thing I'll ask, 'Did you check all my medications out?'"* Another stated that she'd always ask the pharmacist to repeat instructions to her. *"Before I leave the pharmacy I look at the paper and ask the pharmacist [the meaning of terms and how to take the medication] and yeah, I ask three times!"*

When some participants did not understand a piece of written health-related material, they'd advocate for themselves by telephoning in to their doctors' offices. There were more reports of phoning in than there were reports of participants asking for clarification *in* the clinic. One participant stated *"If I didn't understand I would call them and ask them, 'What is this word?' Explain this to me."* Another, speaking of patients generally with regards to medication instructions, stated *"They're gonna take the medicine, but they gonna find out what's going on. [They'll call] the physician. Because who else can you call because ain't nobody else gonna really know."* One participant explained that after a hospitalization, she'd call the hospital

nurses station and would ask for clarification from any of the nurses on the floor which she stayed. Another stated that she expected her primary care provider to oversee her care generally and endorse any medication that she took; when she had to use clinic or emergency services, she'd call and have him review her medication list with her by phone.

#### **Theme four: Maladaptive Coping**

Some participants detailed maladaptive coping techniques that they'd employ when faced with a health literacy-related challenge. These techniques were flawed and unsuitable for successful long-term self-management of hypertension. These techniques impacted how they took their antihypertensive medication, usually resulting in medication non-adherence. Additionally, these techniques impacted patient-provider communication, through a process of non-communication, or stonewalling.

**Medication adherence.** Some participants reacted to the practical and emotional challenges that resulted from limited health literacy by delaying, refusing to initiate, or discontinuing prescribed medical regimens. One striking example of a participant leaving a hospitalization against medical advice follows:

*"They brought me a big stack they wanted me to read and sign away... [he] said 'I'm out of here... I'm in here for hip surgery and I can't take this. I can't take it. And it didn't do me no good. I'm in worse pain now than I was, and I told them I would never come back.'"*

Other participants described how health-literacy related challenges impacted their actual medication-taking behavior. One said that confusion about a medication label led her to stop taking it completely, and she has yet to restart it or discuss it with her provider. Another said that she often lacks understanding when initially prescribed a medication, in which case she just

won't take the medication at all. Another wanted to take her medication, but delayed starting it. She stated *"Sometimes [the pharmacist] be real busy, but then you should read yourself. I got a little – I wasn't uncomfortable with it, just a little nervous, because I'm saying, like, I think I'm going to wait a little longer before I take this."*

**Stonewalling.** Many participants described situations in which they received written materials in a clinic setting, desired an oral explanation to accompany the written material, but believed that their provider did not have the time to grant this request, or their provider was offended by this request. In this circumstance, participants would 'stonewall,' or shut down and stop talking and asking questions. One participant perceived her provider to be short on time.

*"[Providers] want to run through it, and they leave you really questionable, because they don't have the time to explain each question, and that's confusing. And then, right at that point, I won't ask no more, because I don't have a full understanding...If I don't know it, I'm gonna tell the person if they ain't got enough time, then I'm gonna leave it alone, instead of committing myself to something that I really don't understand."* Alternatively, patients may stop asking questions, but continue a regimen. *"They just go along with it, whatever it is."*

A couple of participants withheld questions because they believed their provider found them to be argumentative when they asked questions. One participant said that he did not want to "argue" with the pharmacy about his medicine. Another participant said he was cautioned by a nurse that he was "talking back to [the doctors], and [doctors] don't like that."

## **Discussion**

The results were organized around the four major themes discovered in the interviews: challenges, negative emotions, adaptive coping and maladaptive coping. Figure 2.1 provides an



overview of these themes as well as their proposed linkages. What follows is a discussion of how these themes relate to the literature, and how they hypothetically relate to each other.

Participants in this study faced health literacy-related challenges in the healthcare setting that were common and inconvenient in nature, but sometimes very serious and threatening to their health and livelihood. Participants described mishaps that ranged from missing routine appointments to medication errors resulting in hospitalizations. While researchers have made speculations, there are no reports to my knowledge that detail patient-reported tangible and practical barriers faced in the context of chronic disease and limited health literacy. Considering that providers are largely unaware of the health literacy and health literacy-related challenges that many of their patients face in seeking health and healthcare (Bass et al., 2002; Paasche-Orlow et al., 2005; Kelly and Haidet, 2007), findings from this study are important for increasing the awareness of and decreasing the burdens associated with these health literacy-related challenges.

The internalized stigma and shame that study participants described that resulted from health literacy-related challenges were striking. Findings of patients feeling “unsure,” “inadequate,” or “bad” about themselves were consistent with studies that have explored health literacy and health literacy-related stigmatization in the healthcare environment. In the study by Baker and colleagues (1996), many described feeling bad about themselves, worthless, or lazy for not having obtained health literacy. In the study by Brez and Taylor (1997), participants revealed worries that they may be seen by others as bad people or incompetent members of society. Reports of concerns about disclosure of health literacy levels are also supported in the literature. Parikh and colleagues (1996), in their study of 202 adults in clinics and emergency departments, found that many with limited health literacy denied having any literacy trouble. Of

those who were found to have limited health literacy that admitted to literacy limitations, 67% never shared this with their spouses, 53% never shared this their children, and 19% never shared this with anyone. Wolf and colleagues (2007), in their study of 283 adults in clinics and emergency departments, also discovered that while most patients with limited literacy expressed that they would not mind their physician knowing about their literacy, they would not want this information available to all of the healthcare staff or to the public, and 31% maintained they'd be moderately or strongly opposed to having their levels documented in their record at all.

As a researcher, I was interested in patterns of stigma and made stigma the primary focus of this investigation. However, the study design allowed for participants to share a full range of potential emotional responses, which created a more complicated nuanced picture of the health literacy-related experience for these participants. Beyond internalized stigma and shame, anxiety was uncovered as a significant reaction for participants facing health literacy challenges in the healthcare environment. Participants experienced a high level of fear and worry, usually around not being able to read and understand medication information. Considering the hazardous nature of many of the incidents participants described, it would be appropriate to feel “scared” and “nervous” about potential medication errors or other high-risk mistakes. There is a need to further characterize health-related and health literacy-related anxiety and consider its role in adaptive or maladaptive health behaviors in patients with hypertension and other chronic diseases.

Another important finding from this study is that health literacy-related challenges and emotions at times result in medication non-adherence. A positive relationship between health literacy and medication adherence has been previously demonstrated in the literature. Murray and colleagues (2004) examined the relationship between health literacy and medication

adherence by electronic monitoring of pill bottles (calculating the percent of drug taken over 6-12 months) in a sample of 242 adults with coronary artery disease of the average age of 60, of which 63% were African American. Higher health literacy was a univariate predictor of adherence ( $p=0.005$ ), and remained significant in a multiple variable model that controlled for demographic factors ( $p=0.007$ ). Kripilani et al. (2010) examined the relationship between health literacy and medication adherence in a sample of 434 adults with coronary artery disease, of average age 64, of which 91% were African American. Health literacy predicted medication refilling even when controlling for patient characteristics (OR 1.9, CI: 1.1-3.4). The qualitative findings in the present study complement these previous studies in helping to explain the mechanisms underlying the positive relationship between health literacy and medication adherence in African Americans with cardiovascular disease.

This is not a traditional grounded theory study from which I'd be able to generate theory. However, while analyzing the data I developed hypotheses about relationships between the themes (Figure 1). It is plausible that these relationships could be informed by the Theory of Sense of Coherence (SOC) (Antonovsky, 1979). SOC refers to how well which individuals cope with major and chronic stressors. SOC theory assumes that life challenges and stressors are universal, but individual responses and coping mechanisms differ greatly, and in fact diverge at times (some individuals adapt successfully and others have great difficulty in doing so). One's SOC is based on their overall disposition and feeling of confidence that (1) one's internal and external stimuli and environments are predictable and understandable; (2) resources are available to meet the demands imposed by these stimuli and environments; and (3) these challenges are worthy of one's investment (Antonovsky, 1987). These concepts from SOC theory have relevance in understanding how hypertensive African Americans with health literacy-related

challenges cope to access the healthcare system and use health information to self-manage their hypertension. It seems that hypertensive African American adults with a strong SOC perceive health literacy-related challenges as understandable, manageable, and meaningful, and therefore develop adaptive coping processes. Alternatively, hypertensive African American adults with a weaker SOC, or a SOC that is compromised by negative emotions such as anxiety or stigma, may feel defeated and overwhelmed by health literacy-related challenges, leading to maladaptive coping. Future research is needed to confirm these proposed links between these themes in African Americans with hypertension and health literacy-related challenges.

### **Conclusion**

Findings from this study contribute in raising awareness of the practical obstacles and emotional reactions experienced by African American individuals with hypertension when they are unable to understand health information. Increasing insights into this health literacy-related experience can assist healthcare professionals to recognize opportunities to help prevent some of the challenges faced by these individuals. Also, the finding that internalized stigma and anxiety accompany these challenges suggest that healthcare professionals need to increase sensitivity and create a shame-free environment where patients can obtain adequate health information to aid in not only preventing misunderstandings, but reducing stigma and anxiety. Insights into the coping techniques used to overcome these challenges may assist in the development of interventions to enhance hypertension self-management and improve outcomes in this population.

## References

- Antonovsky, A. (1979). *Health, stress, and coping: New perspectives on mental and physical well-being*. San Francisco, CA: Jossey-Bass.
- Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well*. San Francisco, CA: Jossey-Bass.
- Appleton, J. & King, L. (1997). Constructivism: A naturalistic methodology for nursing Inquiry. *Advances in Nursing Science*, 20 (2), 13-22.
- Arozullah, A.M., Yarnold, P.R., Bennett, C.L., et al. (2007). Development and validation of a short-form, rapid estimate of adult literacy in medicine. *Medical Care*, 45, 1026–33.
- Baker, D.W., Williams, M.V., Parker, R.M., Gazmararian, J.A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38(1), 33-42.
- Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, 5, 329-344.
- Bass, P.F., Wilson, J.F., Griffith, C.H., et al. (2002). Residents' ability to identify patients with poor literacy skills. *Academic Medicine*, 77, 1039–41
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., & Crotty, K. (2011). Limited health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 129-130.
- Barnsteiner, J.H. (2008). Medication Reconciliation. In R. G. Hughes Editor, *Patient Safety and*

- Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality. Obtained on September 16, 2014 from: <http://www.ncbi.nlm.nih.gov/books/NBK2648/>
- Brez, S.M. & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040-1047.
- Corrigan, P.P. (2004). How stigma interferes with mental health care. *The American Psychologist*, 59(7), 614-25.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Sage Publications.
- Creswell, J.W. (2013). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks, CA: Sage Publications.
- Ekman I., Fagerberg B., & Lundman B. (2002). Health-related quality of life and sense of coherence among elderly patients with severe chronic heart failure in comparison with healthy controls. *Heart Lung*, 31(2), 94–101.
- Eriksson, M., & Lindstrom, B. (2006). Antonovsky's Sense of Coherence scale and the relation with health: A systematic review. *Journal of Epidemiology and Community Health*, 12(5):376–381.
- Fagerlin, A., Ubel, P. A., Smith, D. M., & Zikmund-Fisher, B. J. (2007). Making numbers matter: Present and future research in risk communication. *American Journal of Health Behavior*, 31(Suppl. 1), S47-56.
- Farrell, T.W., Chandran, R., & Gramling, R. (2008). Understanding the role of shame in clinical assessment of health literacy. *Family Medicine*, 40(4), 235-236.
- Ferguson, B., Lowman, S.G., & DeWalt, D.A. (2011). Assessing literacy in clinical and

- community settings. *Journal of Health Communication*, 16(2), 124-134.
- Fiscella, K., & Holt, K. (2008). Racial disparity in hypertension control: Tallying the death toll. *Annals of Family Medicine*, 6(6), 497–502.
- Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Newark, New Jersey: Englewood Cliffs Prentice Hall.
- Golbeck, A.L., Ahlers-Schmidt, R., Paschal, A.M., & Dsimuke, S.E. (2005). A definition and operational framework for health numeracy. *American Journal of Preventive Medicine*, 29, 375–6
- Herek, G.M., Capitanio, J.P. & Widaman, K.F. (2003). Stigma, social risk, and health policy: Public attitudes toward HIV surveillance policies and the social construction of illness. *Health Psychology*, 22(5), 533–540.
- James, P.A., Oparil, S., Carter, B.L. et al. (2014). Evidence-based guideline for the management of high blood pressure in adults: Report from the panel members appointed to the Eighth Joint National Committee (JNC 8). *Journal of the American Medical Association*, 311(5), 507-520.
- Jaramillo, E. (1998). Pulmonary tuberculosis and health-seeking behaviour: How to get a delayed diagnosis in Cali, Columbia. *Tropical Medicine & International Health*, 3, 138–144.
- Kelly, P.A. & Haidet, P. (2007). Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling*, 66(1), 119-22.
- Kripilani, S., Gatti, M.E., & Jacobsen, T.A. (2010). Association of age, health literacy, and medication management strategies with cardiovascular medication adherence. *Patient Education and Counseling*, 81, 177-181.

- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy*. Washington, DC: National Center for Education Statistics. (NCES Report 2006483).
- Lincoln YS, Guba EG. *Naturalistic Inquiry*. London: Sage; 1985.
- Lipkus, I.M., Sampson, G., & Rimer, B.K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, 21, 37-44.
- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12, 8-13.
- Morris, N.S., MacLean, C.D., Chew, L.D., & Littenberg, B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice*, 7, 21.
- Murray, M.D., Wu, J., Tu, W., et al. (2004). Health literacy predicts medication adherence. *Clinical Pharmacology & Therapeutics*, 76.
- National Center for Education Statistics. (2010). The Nation's Report Card Reading 2009 Trial Urban District Snapshot Report: Detroit Public Schools. Obtained on February 14, 2013 from:  
[www.eric.ed.gov/ERICWebPortal/search/simpleSearch.jsp?newSearch=true&eric\\_sortField=&searchtype=advanced&pageSize=10&ERICExtSearch\\_SearchCount=1&ERICExtSearch\\_SearchValue\\_0=detroit+public+education&eric\\_displayStartCount=11&ERICExtSearch\\_Operator\\_1=and&\\_pageLabel=ERICSearchResult&ERICExtSearch\\_SearchType\\_1=kw&ERICExtSearch\\_SearchValue\\_1=&ERICExtSearch\\_SearchType\\_0=kw](http://www.eric.ed.gov/ERICWebPortal/search/simpleSearch.jsp?newSearch=true&eric_sortField=&searchtype=advanced&pageSize=10&ERICExtSearch_SearchCount=1&ERICExtSearch_SearchValue_0=detroit+public+education&eric_displayStartCount=11&ERICExtSearch_Operator_1=and&_pageLabel=ERICSearchResult&ERICExtSearch_SearchType_1=kw&ERICExtSearch_SearchValue_1=&ERICExtSearch_SearchType_0=kw)
- Nielson-Bohlman, L., Panzer, A.M., & Kindig, D.A. (2004). *Health literacy: A prescription to*



- end confusion*. Institute of Medicine. Washington, DC: National Academies Press.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67(12), 2072-2078.
- Paasche-Orlow, M.K., Parker, R.M., Gazmararian, J.A., et al. (2005). The prevalence of limited health literacy. *Journal of General Internal Medicine*, 20, 175-184.
- Paasche-Orlow, M., & Wolf, M. (2007). The causal pathways linking health literacy to health outcomes. *The American Journal of Health Behavior*, 31(1), 19-26.
- Parikh, N.S., Parker, R.M., Nurss, J.R., Baker, D.W., & Williams, M.V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling*, 27, 33-39.
- Pignone, M.P., & DeWalt, D.A. (2006). Literacy and health outcomes: Is adherence the missing link? *Journal of General Internal Medicine*, 21(8), 896-899.
- Sabate, E., & World Health Organization. (2003). *Adherence to Long-Term Therapies: Evidence for Action*. Geneva, Switzerland: World Health Organization.
- Strauss, A., & Corbin, J. (1998). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage Publications.
- Ulin, P.R., Robinson, E.T., & Tolley, E.E. (2005). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey Bass.
- Ussher, M., Ibrahim, S., Reid, F., Shaw, A., & Rowlands, G. (2010). Psychosocial correlates of health literacy among older patients with coronary heart disease. *Journal of Health Communication*, 15(7), 788-804.
- Van Brakal, W.H. (2006). Measuring health-related stigma: A review of the literature. *Psychology, Health, and Medicine*, 11(3), 307-334.
- Van Geest, J.B., Welch, V.L., & Weiner, S.J. (2010). Patients' perceptions of screening for

health literacy: Reactions to the Newest Vital Sign. *Journal of Health Communication*, 15(4), 402-412.

Wolf, M.S., Williams, M.V., Parker, R.M., Parikh, N.S., Nowlan, A.W., & Baker, D.W. (2007). Patients' shame and attitudes toward discussing the results of literacy screening. *Journal of Health Communication*, 12, 721-732.

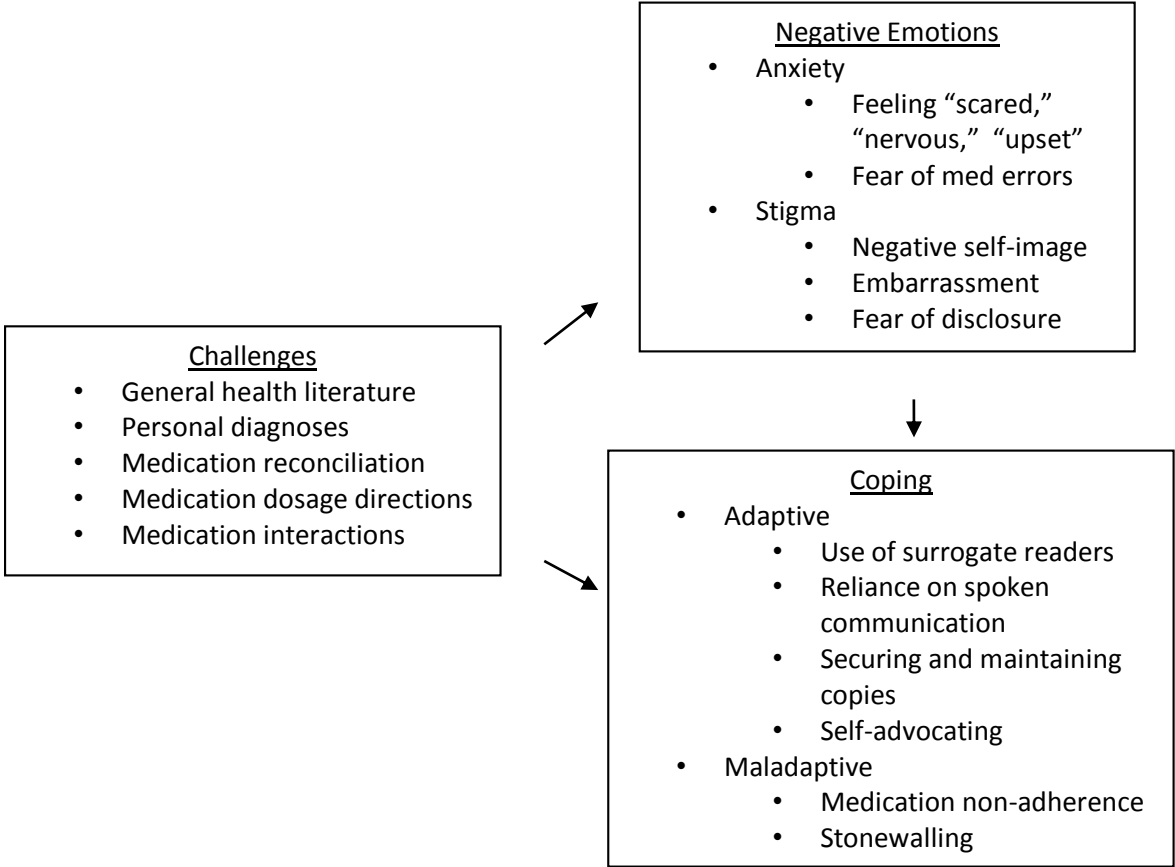


Figure 2.1. Challenges, emotions, and coping.

## CHAPTER 4

### **Patient Understanding and Perceptions of Health Literacy and Numeracy Testing:**

#### **Findings from Cognitive Interviews**

Health literacy and health numeracy, skills that enable individuals to make appropriate and effective health decisions, are valued assets for personal health and livelihood (Nielson-Bohlman, Panzer, and Kindig, 2004; Golbeck, Ahlers-Schmidt, Paschal, and Dsimuke, 2009; Nutbeam, 2008). However, many people lack these skills in the general population (Kutner, Greenberg, Jin, & Paulsen, 2006; Fagerlin, Ubel, Smith, and Zikmund-Fisher, 2007). Those who lack adequate health literacy and health numeracy suffer poorer health outcomes compared to those with adequate health literacy and health numeracy (Berkman et al., 2011; Estrada et al., 2004; Rothman et al., 2005).

Despite the importance of health literacy and numeracy for health-related decision-making, and the prevalence of limited health literacy and numeracy, many healthcare providers remain unaware of the health literacy levels of their patients (Bass, Wilson, Griffith, & Barnett, 2002; Kelly & Haidet, 2007). Meanwhile, there is some evidence of benefits from multifaceted interventions for individuals with limited health literacy (Clement, Ibrahim, Crichton, Wolf, & Rowlands, 2009). Therefore, the idea of clinical screening of health literacy and numeracy should be considered. However, individuals who have limited health literacy and numeracy may be subject to stigmatization in the healthcare setting. Not being able to understand medical information in the healthcare setting may be a source of shame for patients. Concern for

potential shame-related harm related to health literacy and numeracy measurement has led some experts to discourage routine health literacy screening in the health care setting (Paasche-Orlow & Wolf, 2008).

The study of health literacy and health numeracy is relatively new (Berkman et al., 2011; Golbeck et al., 2005). Efforts to conceptually define and measure these constructs date back only to the 1990s. While studies have examined general patient perspectives on health literacy testing in the healthcare setting (Wolf et al., 2007; Farrell et al., 2008; Brez & Taylor, 2008; Ferguson, Lowman, & DeWalt, 2011; VanGeest, Welch, and Weiner, 2010) the qualitative experience of individuals undergoing health literacy and health numeracy testing in the healthcare setting has not been examined with cognitive interviewing. Therefore the purpose of this qualitative study was to examine cognitive and experiential dimensions of clinical screening of health literacy and health numeracy. To achieve this aim, cognitive interviewing was conducted.

### **Specific Aims**

Specific aims of this study were: (1) to obtain information about how patients respond to items in common assessments of health literacy and health numeracy and (2) to learn about the subjective experience of patients participating in common assessments of health literacy and health numeracy.

### **Cognitive Interviewing**

Cognitive interviewing is a method of testing survey questions in which researchers administer surveys in individual interviews, probe to explore how respondents understand the questions, and seek to learn how respondents formulate their answers (Groves, Fowler, and Couper, 2009). Cognitive interviewing is based on “protocol analysis,” a technique invented by

Ericsson and Simon (1983). In protocol analysis, information about cognitive processes is sought by probing subjects' internal states with verbalization procedures. Building on the work of Ericsson and Simon (1983), survey methodologists and cognitive psychologists initiated the Cognitive Aspects of Survey Methodology movement, a paradigm shift after which the *effect* of survey errors became less of a focus and the cognitive *causes* became more emphasized; following this movement, cognitive interviewing procedures came to be used for testing survey questions with the goal of improving data quality (Groves et al., 2009; Tourangeau, 2003). These procedures include think-alouds, confidence ratings, paraphrasing, definitions, and probes (Groves et al., 2009; Jobe and Mingay, 1989). Definitions are detailed in Table 3.1.

### **Review of the Literature**

I selected the following health literacy measures for use in this study: (1) the shortened version of the Rapid Estimate of Adult Literacy in Medicine (REALM), the Rapid Estimate of Adult Literacy in Medicine Short Form (REALM-SF) (Davis et al., 1991; Davis et al., 1993; Arozullah et al., 2007), (2) the shortened version of the Test of Functional Health Literacy in Adults (TOFHLA), the Short Test of Functional Health Literacy in Adults (STOFHLA) (Parker, Baker, Williams, & Nurss, 1995; Baker, Williams, Parker, Gazmararian, & Nurss, 1999), and the Single Item Literacy Screener (SILS) (Morris, MacLean, Chew, and Littenberg, 2006). I chose the shortened versions of the REALM and the TOFHLA as they are the most commonly used measures of health literacy in research (Clancy, 2009; Berkman et al., 2011). I selected the health-related subscale of the also commonly used Lipkus Expanded Numeracy Scale to test health numeracy in this study (Lipkus, Samsa, and Rimer, 2001). These measures are detailed in the sections that follow, and listed in Table 2.

#### **Rapid Estimate of Adult Literacy in Medicine**

The Rapid Estimate of Adult Literacy in Medicine Shortened Form (REALM-SF) (Arozullah et al., 2007), derived from the Rapid Estimate of Adult Literacy in Medicine (Davis et al., 1991; Davis et al., 1993), is a test of word recognition and pronunciation. Patients are presented with a list of medical words that are listed in ascending order of difficulty and number of syllables. They are asked to read as many as they can, starting with the first word. When they encounter a word they cannot read, they are asked to try their best, or say “blank” and go on to the next word. If they stop, they’re asked to scan the rest of the list and see if any can be pronounced.

The REALM was originally developed with 125 words chosen from commonly used lay medical terms found in patient education materials, forms, and posters (Davis et al., 1991). This test was modeled after Slosson Oral Reading Test – Revised (SORT-R) a widely accepted reading recognition test (Slosson, 1990). Scoring for this original version is 0-125, with one point for each correctly pronounced word. Dictionary pronunciation is the standard for scoring. Score is then categorized into grade ranges: 0-78 represent 3rd grade or lower, 79-103 represent grade levels 4-6, 104-114 represent a 7th-8th grade level, and 115 and above correspond to a 9th grade level or higher. Those with 3rd grade level or less are not expected to be able to read most low-literacy materials, those with grade levels 4-6 are believed to need low literacy materials and help with prescription labels, those with 7-8th grade levels will still likely struggle with most patient education materials, and those with a 9th grade level or higher should be able to read most patient education materials (Davis et al., 1991).

The REALM was administered by Davis and colleagues (1991) with the SORT-R and the reading recognition portion of Peabody Individual Achievement Test – Revised (PIAT-R, Markwardt, 1989), to 207 public and private practice patients with a mean age 47 years (range

17-87), of which 54% were African American and 46% were Caucasian, 76% were female, and 42% did not complete high school. Test-retest reliability of the REALM was excellent at 0.98 ( $p < 0.0001$ ). Concurrent validity was supported as REALM results correlated highly with the other recognition tests (with Pearson coefficients 0.95 and 0.94 respectively,  $p < 0.0001$ ).

The REALM was then reduced to 66 medical terms (Davis et al., 1993). These terms were retained based on psychometric evaluation including item difficulty and discrimination (words at the lowest levels were retained), and the frequency of words in patient materials. Scoring for this version is 0-66 with the following categories: 0-18 represent 3rd grade or lower, 19-44 represent grade levels 4-6, 45-60 represent a 7th-8th grade level, and 60-66 correspond to a 9th grade level or higher (Davis et al., 1993). This shortened version of the REALM was administered by Davis and colleagues (1993) with the reading recognition portion of PIAT-R, the SORT-R, and the Wide Range Achievement Test – Revised (Jastak & Wilkinson, 1987) to 203 clinic patients with a mean age of 43 years (range 16-86), of which 76% were African American and 24% were Caucasian, 82% were female, and 53% did not complete high school. Test-retest reliability of the REALM was excellent at 0.99 ( $p < 0.001$ ), and results correlated significantly with each of the other tests (with Pearson coefficients 0.97, 0.96, & 0.88 respectively).

Psychometric evaluation of the 66-item REALM has since been conducted in diverse populations. In one, scores were examined among subgroups within a sample of 1610 middle-aged patients, of which 66% were male and 65% African American and 35% Caucasian (Shea et al., 2004). Mean scores significantly increased with education and significantly decreased with age, while gender differences for mean scores were not significant. Mean score for African Americans (55.6) was significantly lower than for Caucasians (61.0). Cronbach's alpha for the



total group, for the total 66 items was 0.96. Ultimately, the scale demonstrated the ability to reliably distinguish between limited and adequate health literacy, however item analysis suggested a content bias for African American patients. In another study, the 66-item REALM was administered to over 1000 middle-aged patients with cancer, of which 56% were female and 36% African American and 63% Caucasian (Dumenci et al., 2013). Scores were examined using item, factor, and logical analysis. While the researchers were critical of the REALM (as a word recognition test) as a predictor of the construct of health literacy as defined by the Institute of Medicine, the scale reliably measured the ability to read and pronounce written health terms. Furthermore, the 66-item REALM has demonstrated predictive validity in important studies of health literacy and major health outcomes (Sudore et al., 2006; Kripilani et al., 2010).

The REALM was again reduced in 2007 with the goal of shortening the time for clinical administration. This version, renamed The Rapid Estimate of Adult Literacy in Medicine-Short Version (REALM-SF), cut the items from 66 to seven (Arozullah et al., 2007). After administering the 66-item REALM to 1336 patients, individual items were evaluated as potential predictors of the REALM score by stepwise multiple regression analysis (and further evaluated with factor analysis). Items with stable model coefficients and 1 underlying factor were retained. The REALM-SF and the original REALM were highly correlated in that original development sample ( $r = 0.95$ ,  $P < 0.001$ ), and testing was repeated in a validation sample of 164 subjects, demonstrating high correlation as well ( $r = 0.94$ ,  $P < 0.001$ ). In field testing using 50 subjects, the REALM-SF was additionally correlated with the WRAT ( $r = 0.83$ ,  $P < 0.001$ ). Researchers have since employed the REALM-SF in several research studies. While some were unable to correlate the REALM-SF with outcome variables, due in part to homogenous (high) scores (Cardozo et al., 2012; Case, Fried, and O'Leary, 2013), some have been able to

demonstrated predictive validity in studies investigating factors related to health behaviors, beliefs, and knowledge (Mooss, Brock-Getz, Ladner, and Fiaño, 2013; Politi et al., 2013).

### **Test of Functional Health Literacy in Adults**

The Short Test of Functional Health Literacy in Adults (STOFHLA) (Baker, Williams, Parker, Gazmaranian, and Nurss, 1999), derived from the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, and Nurss, 1995), is a reading comprehension test in which participants complete multiple choice passages with every 5th to 7th word removed. Sentences are to be completed with one of four multiple choice words (of which one is right and the others are grammatically incorrect or out of context). This method for testing employs the Cloze procedure (Taylor, 1953).

The TOFHLA was developed initially by a literacy expert's review of 30 actual commonly reviewed patient education materials from hospitals (Parker et al., 1995). Passages believed to be widely used and of varying difficulties were selected from instructions for the preparation for an upper gastroscopy radiographic procedure, the patient rights and responsibility portion of a Medicaid application, and a standard consent, with readability grades of 4, 10, and 19 respectively per the Gunn Fog index (Laubach & Koschnick, 1977). Initial psychometric evaluation was conducted with 200 Southern adults of average age 40, of which 91% were African American, 51% were female, and 41% were without a high school education (Parker et al., 1995). Each participant underwent testing with the TOFHLA, as well as the REALM and WRAT-R. Correlations with the REALM and WRAT-R were 0.84 and 0.74 respectively by Spearman's rank ( $p < 0.001$ ). Internal consistency and test-retest reliability excellent with Cronbach's  $\alpha$  0.98 and Spearman-Brown equal-length coefficient 0.92.

The Short Test of Functional Health Literacy in Adults was developed to shorten the time for administration (Baker et al., 1999). The 3 prose passages were reduced to 2 based on data from a large study that utilized it as a measure (Baker et al., 1999; Williams et al., 1995). Those retained were chosen based on grade level, keeping the lowest two, the gastroscopy preparation instructions and the Medicaid application. Range for the STOFHLA score is 0-36; one point is given for each of the 36 reading items. Cutoffs were determined using age and education-stratified distributions based on the original study by Parker and colleagues (1995). This resulted in the following categorization: inadequate (scores 0-16), marginal (17-22), and adequate health literacy (23-36). Psychometric evaluation of this shortened version was conducted with 211 adults of average age 44, of which 53% were female, 94% were African American, and 42% did not complete high school (Baker et al., 1999). Each participant underwent testing with the STOFHLA and the REALM. Correlation between STOFHLA and REALM was 0.81 and Cronbach's  $\alpha$  for the 36 reading comprehension items was 0.97.

Further testing of the STOFHLA was conducted to evaluate for differences between subgroups. Aguirre and colleagues (2005) examined validity and reliability in a diverse sample of over 2000 patient that included an English-speaking (predominantly African American) group, a Hispanic group who chose to take it in English, and a Hispanic group who chose to take it in Spanish. For each group, Cronbach's  $\alpha$  were above 0.95 and the item-total correlations were positive, consistent, and high. There were significant differences in scores between groups (with inadequate levels noted for 19% of the English-speaking group, 8% of the Hispanic group who chose to take it in English, and 33% of the Hispanic group who chose to take it in Spanish,  $p < 0.0001$ ), but differences in performance between groups were in numerous items without consistent patterns. Within each group, women, younger, and more educated subjects scored

significantly higher (age and sex remained significant after stratifying for education). Predictive validity has also been demonstrated for the STOFHLA in important studies examining health literacy and health behaviors, such as cardiovascular medication adherence (Murray et al., 2004) and health literacy and major health outcomes, such as mortality (Baker et al., 2007).

### **Lipkus Expanded Numeracy Scale**

The Lipkus Expanded Numeracy Scale is a test designed to determine how adept people are with basic math concepts (Lipkus, Samsa, and Rimer, 2001). The scale primarily assesses an individual's number sense (including their ability to compute probability, compare different forms of numbers, and understand the relative risk magnitude of different forms of numbers in disease risk education). This scale was created based on general numeracy questions previously used in risk communication research. Specifically, authors used items employed by Schwartz and colleagues (1997), who administered a 3-item numeracy test (made up of probabilities, proportions, and percentages) to female veteran patients to assess their basic quantitative ability. Only 16% of the 287 respondents in that study correctly answered all of the questions.

Lipkus and colleagues (2001) expanded the 3-item general numeracy test adding 8 items that were framed in a health context. They developed questions requiring similar computations, but focused attention on commonly used materials in risk communication for educational materials, decision aids, and consent processes. This health-related subscale is made up of 8 items with both multiple choice and open-ended response options. It specifically assesses how well one can (1) perform simple math tasks with risk levels using proportions and percentages, (2) convert percentages to proportions (and vice versa), and (3) convert probabilities to proportions. These 8 health-related questions, combined with three general numeracy questions, make up the Lipkus Expanded Numeracy Scale (Lipkus et al., 2001).

The Lipkus Expanded Numeracy Scale was administered to 463 healthy adults over the age of 40 who were, in general, white and well-educated (Lipkus et al., 2001). Many performed poorly on basic problems. Approximately 20-30% of participants were unable to identify the greater of two risk magnitudes (questions 1 and 2 of the health-related subscale), and could not make conversions between percentages and proportions (questions 5 and 6). Approximately half of the participants were unable to convert a probability to a proportion (question 7). Factor analysis was conducted to classify all of the numeracy items. A single-factor solution was found to be appropriate, suggesting this expanded scale was a reliable measure of numeracy in this particular population.

While the seminal work of Schwartz and colleagues (1997) and Lipkus and colleagues (2001) has been very influential in the risk communication and decision sciences, recent studies have identified psychometric concerns associated with test of Lipkus and colleagues (2001) (Cokely, Ghazal, and Garcia-Retamero, 2014). For example, findings from studies utilizing university student samples (Cokely and Kelley, 2009) and large nationally representative samples (Galesic and Garcia-Retamero, 2010) revealed negative skew in scores, with most participants getting the majority of questions correct. This raises concerns for the ability of this instrument to correctly estimate variation in individuals with high numeracy. Another concern is that there is little known about the relationship between the Lipkus Expanded Numeracy scale and individual cognitive abilities; it has yet to be demonstrated whether this test has the ability to provide any more predictive power than cognitive ability instruments that have been well-established as predictors of behavioral and health outcomes (Liberalli et al., 2011; Cokely et al., 2014). Then, even if the Lipkus Expanded Numeracy Scale scores and other abilities are compared, the ceiling effects may complicate this evaluation with limited variability among

those with the highest numeracy, suggesting it to be a weaker predictor than other study variables (Del Missier et al., 2012; Cokely et al., 2014).

Despite these limitations, the Lipkus Expanded Numeracy Scale and the test on which it was based of Schwartz and colleagues (1997) has been used in over 100 studies examining primarily medical decision making and risk behaviors, but also economic and consumer decision-making and behaviors (Cokely et al., 2012; Lipkus & Peters, 2009). In this study, I used the health-related subscale of the Lipkus Expanded Numeracy Scale for assessing health numeracy, therefore, the psychometric properties detailed previously have limited applicability to what was administered in this study (with the exception of the factor analysis of the subscale that was conducted by the creators). However the subscale was appropriate for this study for the following reasons: (1) it fit in better with the battery of testing (which included other assessments created from health materials), (2) it is possibly easier than the general numeracy test (as demonstrated by slightly better performance in the original sample), (3) assessment of health-related numeracy better supported the study's purpose, (4) upon recruitment participants were told they were to be working with health education materials, and (5) factor analysis of the health-related subscale along with the general numeracy items demonstrated that both type of question corresponded to the same construct of global numeracy (Lipkus et al., 2001). This subscale will be henceforth referred to as the Lipkus Expanded Numeracy Scale health-related items.

## **Methods**

### **Design and Setting**

I conducted cognitive interviews with African American adults with hypertension. I recruited participants and collected data in Detroit, Michigan at a private primary care physician

office serving a population of approximately 70% African American and 30% Caucasian patients of both sexes and all ages.

### **Sampling**

For inclusion, individuals had to: (1) self-identify by date of birth as 35 years of age or older, (2) self-identify as African American or Black, (3) be patients at the health clinic where data was collected (must have been present for an appointment, or have a history of having had an appointment at the site), (4) report having had a diagnosis of hypertension by a physician, (5) be willing and able to provide informed consent, and (6) have a visual acuity of 20/50 or better.

### **Procedure**

At the start of the office day on the pre-determined mornings, the office staff briefly told patients about the study and my presence in the waiting room upon check-in. I then sequentially approached individuals in the waiting room and inquired about their willingness to participate in a study addressing difficulty in the understandability of health materials. I gave potential participants an overview of the study, i.e., the interview would take approximately 30 minutes, the interview would follow their appointment with the physician, the interview would take place in a private exam room within the clinic, and participation was confidential and voluntary without any follow up necessary. I notified the physician of those who expressed interest, and asked the physician to formally end visits with these patients and to state outright that the study was unrelated to their health care visit, general care, or relationship with him or the office. Following appointments, interested potential participants were then referred to meet me in my designated private administrative room in the clinic that held two desks and three chairs.

Prior to any data collection, I read the informed consent statement to potential participants. I explained the study procedure in great detail and answered any questions at this

time. After obtaining informed consent, I tested visual acuity with the Snellen eye chart. To proceed, potential participants were to have a corrected visual acuity of 20/50 or better.

I began the interview by asking participants the SILS question “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” (from “1,” never, to “5,” always) (Morris et al, 2006). I then administered the following assessments as ordered: the REALM-SF (Arozullah et al., 2007), the Lipkus Expanded Numeracy Scale health-related items (Lipkus et al., 2001), and the STOFHLA (Baker et al., 1999). At the start of the numeracy test, I advised participants that this test could be considered difficult by individuals of all education levels (Lipkus et al., 2001). While I did this with the intention of providing assurance, reducing anxiety, and facilitating rapport, I am also aware that this instruction may have influenced participants responses, as discussed further in the limitations section below. At the start of the STOFHLA, to gain richer feedback on the content of this (relatively longer) test and achieved a more relaxed and sensitive testing environment conducive for cognitive interviewing, I instructed participants to take their time. While I did record their time for completion, I did not share this with them, nor did I stop them at 7 minutes as recommended by Baker and colleagues (1999).

## **Cognitive Interview**

### **Think Aloud Technique**

Prior to the administration of each measure, I asked participants to “think aloud” (speak their thoughts aloud as they complete each measure). I instructed participants to focus not only on what they thought of the questions and how they were coming to their answers, but also how they felt when thinking aloud. While some of the tests have time limits, such as the STOFHLA



(which authors instruct to stop after 7 minutes), in the interest of gaining rich qualitative data, I did not time the assessments and I told participants to take their time.

## **Probes**

During testing, I asked participants to elaborate their thoughts, using probing questions. Retrospective probing was done upon completion of each measure (specific questioning to increase understanding of how the subject came to their answers) (Collins, 2003). To obtain objective information about how participants came to their answers (Aim 1), I asked probe questions related to basic cognitive processes of survey taking, including understanding and judgment of items (Tourangeau, 1984). I asked participants to paraphrase and offer definitions when appropriate, and I explored participants' perceptions of the test purpose, their impressions of specific items. I asked retrospective probe questions about the subjective experience of undertaking the health literacy assessments (Aim 2). These probes included: (1) "How did you feel about being asked this question?" (2) "How did you feel while taking this test?" (3) "How easy or difficult did you find this test to take?" (4) "Do you think that patients' health literacy should be tested routinely in doctors' offices?" (5) "If not, why not?" (6) "Did you feel uncomfortable while taking this test?" (7) "Do you think it would be common for someone to feel uncomfortable while taking this test?" (8) "Did you experience any shame or embarrassment while taking this test?" (9) "Do you think it would be common for someone to experience shame or embarrassment while taking this test?" I asked these questions as ordered, deferring the specific questions about emotion and stigma (6-9) while I awaited participants' organic words and statements. If descriptions of these types of feelings did not emerge from a participant, I'd then ask specifically whether the tests caused discomfort or shame.

## **Data Analysis**

The analysis of cognitive interviews is usually conducted informally rather than formally (Willis et al., 2005). However, for purposes of method evaluation (beyond simple question modification) and to help clarify outcomes of heavily probed interviews, Willis and colleagues (1999) developed a coding system in which cognitive processing problems are categorized into the following types: 1) comprehension in the encoding process (for example, participants not understanding a term in a question), (2) recall and retrieval (for example, participants not being able to remember “over the last 6 months”); (3) bias and sensitivity, which reflects the judgment process of the respondent (for example, participants perceiving a question to imply something negative or to be of a sensitive nature); and (4) the response process (participants being unable to fit their responses into the categories given). This coding system provided a framework for analyzing the interview data.

## **Results**

I conducted cognitive interviews with 15 participants using the battery of tests detailed in Table 3.2. Participants ranged in age from 42 to 70 (mean age 56.47, standard deviation 10.03). Nine participants were female and 6 were male. In the sections that follow I discuss the following findings from cognitive interviewing procedures consistent with Groves and colleagues (2009) for each health literacy assessment: participants’ confidence in completing each assessment, participants’ cognitive perceptions of the test purpose and test items, findings from think-aloud procedures, and details of participants’ subjective experience of each assessment elicited through probe questioning. I also explain participant views on the practice of routine clinical health literacy screening, practical administration issues, and participants’ performance on each assessment (detailed in Table 3.3). Finally, I identified examples of 3 of

the four major problem categories as delineated by Willis and colleagues (1999), and detail the most common in Tables 3.4.

## **REALM-SF**

**Confidence ratings.** Each participant who completed the REALM-SF stated that it was easy or simple. Even participants who struggled with word pronunciation and had imperfect scores denied having difficulty with the word list. However, in participants who were unable to complete (or refused to take) the test, discomfort was noted (and a low level of confidence was obvious), so I did not elicit a confidence rating from these participants.

**Paraphrasing and definitions.** Many participants correctly identified the REALM-SF as a reading and recognition test, from which they were simply being asked to correctly pronounce words. However, most believed that the purpose of the REALM-SF was to test their understanding of medical information. Without my asking, six participants tried to define terms to me, or explained that they merely recognized the terms but could not define the terms. One participant stated that she thought the 7 items were a list of medical diagnoses.

Four participants offered feedback on individual items on the word list. Two participants identified “jaundice” as difficult to pronounce. Another stated that “rectal” stood out to her, and asked why we included that on the list and what was meant by that. Another participant stated that she found the term “behavior” upsetting, as it triggered memories. She stated “some people behave bad... have attitudes ... lash out.”

**Think-alouds.** Because of the nature of this assessment, it was not possible to employ some of the cognitive interview techniques, such as the concurrent think-aloud. Insights from retrospective think-alouds were also limited as participants offered little or no feedback

immediately following this first brief exam. Participant feedback about the REALM-SF was obtained primarily through questioning.

**Responses to probe questions.** General evaluations of the REALM-SF ranged from patients reports of indifference to patient refusals to read the items. Approximately half of the participants (n=8) were neutral or accepting of the test. These participants did not reveal they liked the REALM-SF, but stated it was (or *they* were) “okay,” “alright,” “fine,” or that the test didn’t “bother them” or that they didn’t have a “problem with it.”

Five participants revealed that the REALM-SF made them uncomfortable (or, would make *others* uncomfortable). When I asked one participant how the test made him feel, he told me he felt embarrassed. He was specifically embarrassed about the procedure. He stated “Well, to read it out to you is kind of embarrassing.” Another participant divulged that the test made him feel shy. He stated “Might make me feel shy a little bit, but that’s only because, you know, when you pronounce them words you want to pronounce them right. If you don’t pronounce them right people [may] laugh at you, and, you know...” Some discussed how in general, or under certain circumstances, the test would make people uncomfortable. One participant stated that while he was comfortable with me, he is sometimes uncomfortable reading aloud in front of others. He went on to speculate that others, especially those with limited literacy, would feel uncomfortable reading aloud in front of someone else. Another participant stated that he would be uncomfortable if he was asked to read the items to someone that was unaware of his literacy level. He explained that since he’d already disclosed his reading limitations to me, he felt comfortable reading the word list aloud to me.

Two participants refused to participate in this assessment. They took one look at the list of items and declined to read them to me. I graciously moved forward with the rest of the battery

of tests. What followed the REALM-SF was the first written exam, which they both readily participated in.

**Testing and test results.** I administered the REALM-SF as the first health literacy assessment to each participant. While many participants sought my help and would re-try reading items, I assigned a point for each item pronounced correctly on the first try without my help. Participants' scores ranged from zero to 7. While the mean score was 5.13 (standard deviation 2.19), only 6 participants demonstrated a 9th grade or higher reading level.

**Summary.** In summary, most participants perceived the REALM-SF to be a list of medical diagnoses. Those who agreed to participate in the REALM-SF found it to be easy, however nearly half admitted that reading aloud made them (or could generally make *others*) feel uncomfortable, and a couple of participants refused it altogether. Specific items disliked by participants included “jaundice,” “rectal,” and “behavior.” Performance on the REALM-SF in this sample was poor. Only 6 participants achieved >9th grade level.

#### **Lipkus Expanded Numeracy Scale Health-Related Items.**

**Confidence ratings.** With a couple of exceptions, participants admitted that the numeracy test was challenging. Five participants described the test to be “confusing,” a couple described it as “hard” (or “very hard”), and a couple others described it as “difficult.” Other descriptors used by participants include “tricky,” “complicated,” and “a struggle.” Some participants were elusive about their confidence in this test. Two participants denied that the test was difficult for them, but admitted they guessed on most of their answers; one stated she was “neutral” and did not want to rate her confidence in taking this test. Alternatively, one participant, the only to achieve a high score, stated it was easy for her.

Several participants who disclosed their struggles with the numeracy test explained to me that they personally had challenges with numeracy. Some example quotes include: “I don’t understand the number thing,” “I’m not good with the numbers,” and “When I see numbers I flip!” Two participants explained that their limited literacy made this test a challenge; one admitted he struggled with reading some of the longer words in the questions, and another expressed concern that she couldn’t correctly spell her answers.

**Paraphrasing and definitions.** While some participants accurately perceived the Lipkus Expanded Numeracy Scale health-related items as an assessment of an individual’s numeracy, many expressed that they were unclear about the purpose of the test. Many believed that the purpose was to inform them of (or test them on their knowledge of) health risks related to infectious disease. Based on the questions participants asked, it was apparent that many were focused on the disease-related content in the questions, rather than the calculations they were being asked to perform. For example, participants asked “How do I know which is the biggest risk of getting a disease? I haven’t did any research” and “Is those just random questions or is it facts?” and “Are viral diseases different than any other kind of diseases?”

When I asked specifically what participants believed the purpose of the test was, most affirmed that they believed it was to increase knowledge about diseases. A few participants specifically thought the goal was to increase awareness about the transmission of infectious diseases. While one participant discussed overall hygiene and hand-washing in the transmission of general infectious diseases, two participants discussed the asymptomatic nature and transmission of sexually transmitted infections (STIs). One stated “It’s possible that anybody could contract a disease from somebody and have it and not knowing. You know, they don’t tell you they got it until you have sex with them.” Another explained “It made me think of my own

activities. You got to be careful and think about you own personal self and your history and what you should do or not do with someone else ... After you do have any [STI], I mean, it's another situation. It's emotion[al]." One participant, believing that the numeracy test was a teaching tool about diseases, believed it to be irrelevant to him, stating "As far as the percentage of the diseases and everything, I think that's not something we need to know unless it was a problem [specific to a particular individual]... they don't need to know, not really, unless it's pertaining to them. Someone with a disease."

Several participants offered feedback on specific content on the Lipkus Expanded Numeracy Scale health-related items. The most common feedback pertained to items 3 and 4. Question 3 asks "If Person A's risk of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk?" Question 4 asks "If Person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?" Five participants expressed that this one was difficult to understand, saying these questions "threw [them] off" and were "contradictory," and "tricky." Three of these simply believed both question 3 and 4 were asking the same question, which seemed to frustrate them, one saying "Asking the same thing but just like rewording it or something. So it's like, okay, what was the logic of that?" The other two explained that they disliked the choice of words. One said that while she understands percentages when she is shopping, "the wording" on items 3 and 4 "it's kind of throwing you, I guess, with the A and B, or whatever"... "But if it was a name or something that you can kind of relate to a little bit more [it would be more understandable]." The other identified the term "double that" as puzzling. She stated that she thought that term meant "just as bad." When I clarified and told her "twice the risk" or "two times the risk," she then understood and was able to answer this question correctly.

Other specific numeracy items identified by participants include question 7, which was perceived by three participants as very difficult, much more so than the other questions. Questions 1 and 2 were pinpointed by one participant who stated that he did not understand what was meant by the term “represents” in these questions.

**Think-alouds.** Most participants offered verbal feedback while they took the numeracy test. Of those who did, each did some reading aloud of the test questions. A few participants gave clues to their question-answering process. Some participants understood the questions to be open-ended and formulated ambiguous responses to questions, often times saying (and recording) “low” or “high,” or comparing possible responses as “higher” or “lower.” For example, one participant verbalized “Like one in 1,000, well I guess that would be higher than one in ten. That would be higher than one in ten.” Participants also made statements to themselves like “It’s mostly about 50” and that the occurrences were “possible” or “not possible,” or that there was “a chance” or “no chance”

Other verbalizations made during the numeracy test included self-talk. While some encouraged themselves, saying things like “Oh, I see!” and “That’s it!” others expressed frustration, saying things like “What is B? Who is A? ... What?” or “I don’t know that one. [That one] is a big question” or “What in the world?!”

**Responses to probe questions.** General feedback from participants about the numeracy test was negative. Most participants admitted, upon my inquiry, that they were [or others would be] uncomfortable taking the numeracy test, and a few admitted to feeling embarrassed. These feelings ranged from mild to strong feelings of discomfort and embarrassment. Many participants simply responded “yes” or “kind of” when I asked about discomfort toward the end of the interview, elaborating very little. Others expressed that they were uncomfortable with and



embarrassed by the level of difficulty of the test, and some were very upset with the content of the test.

Those who were made uncomfortable by the level of difficulty of the test revealed that the testing experience made them feel bad about themselves. One participant stated: “I felt that I should know how to do that, like, right now, right away. It should just come to me, without having to stop and really think. And still I’m confused with my answers. Still, I don’t like the answers that I gave. I went into myself, because I felt like I should know that. I used to be kind of smart, you know. But now it’s kind of like...I used to be smart.” Another stated “[I was] uncomfortable because I wasn’t understanding it was the thing ...I’m embarrassed because I haven’t really no knowledge of what it was about.” A couple of participants described their feelings when they struggled to come up with answers. One stated “I think [with] the percentages especially. If I sat there long enough and messed with it and didn’t get a satisfactory answer with myself, it would just make me frustrated.” Another stated “Well, you get kind of uncomfortable when you can’t get an answer out.”

A few participants were made uncomfortable by the content of the test. One woman personalized the disease-related content. One woman became very upset and stated “This [numeracy test], it makes me want to cry, because I don’t know what my health is. It’s very poor.” Another participant told me that the numeracy test made her uncomfortable because of the “actual information” on the test. One other participant admitted she had some feelings about the content on the test, but would not speak more about it. She stated “Yeah, I had some feeling about it. I have some feeling about it but I wanted to be positive about it though”... and didn’t want to “throw out the wrong vibes.”

**Testing and test results.** The Lipkus Expanded Numeracy Scale health-related items were administered as the first of 2 written assessments. Performance was poor overall for participants in this study. One participant scored a perfect 8 out of 8 possible, but the next highest score was 4, and the mean score was 2.0 (standard deviation 2.24, median 1, mode 0).

**Summary.** In summary, most participants perceived the Lipkus Expanded Numeracy Scale health-related items to be patient information on infectious diseases, especially STIs. Nearly every participant found it to be very difficult, especially items 3, 4, and 7. Most participants admitted they felt uncomfortable (and some admitted to feeling embarrassed) due to the test content and the test difficulty. Performance in this sample was very poor. Only 1 participant correctly answered more than 60% of the questions.

## **STOFHLA**

**Confidence ratings.** A few participants stated that the STOFHLA was easy, and a few described it to be very hard. Several participants however explained that the test was difficult initially, but became easy further into the test. One example is the following participant's statement: "At first I didn't understand it... until I started reading it... at first it was difficult, until you get to reading it and see what it's about." Five participants agreed that as the test went along, they came to understand that the multiple choice items were plugged into logical sentences from which they could use the context to aid in their decision-making. One participant explained "One sentence was... going towards the next one... I really had to read it to understand it, and before I put [the answer] inside the blanks I had to read the next line to understand it." Another stated "When I first started I still had to go down a couple of sentences because I noticed that they was combining, so I had to read the whole couple of lines. Then I knew what it was."

**Paraphrasing and definitions.** Most participants appeared to understand that the STOFHLA was a test of their ability to read and understand typical medical information that one may encounter in the healthcare setting. However, like with the REALM and the Lipkus Expanded Numeracy Scale health-related items, four participants believed that the STOFHLA was a teaching tool for patients. One of these participants commented that the content of the test was probably very “helpful information” for patients. Another stated she believed the purpose of the STOFHLA was to “make [patients] understand about different things that might be going on with you or with a person.” An additional misunderstanding had by participants included the perception that the content was personally relevant to them. One of which believed that her own eligibility for Medicaid was being evaluated. I (promptly) clarified this for a couple of participants.

Several participants offered feedback on specific content in the STOFHLA. One participant stated she “couldn’t figure out” the following sentence from Passage A (the X-ray instructions): “You must have an empty stomach when you come in for \_\_\_\_\_ [it].” Another participant perceived the following sentence, also from Passage A as out of context: “Do not \_\_\_\_\_ [even] drink water.” The time estimate for the X-ray made another patient confused. One participant believed the 1-3 hours was too long of a time estimate for an X-ray, making him unsure of how to complete the following statement in Passage A: “The X-ray will \_\_\_\_\_ [take] from 1 to 3 \_\_\_\_\_ [hours] to do.” One participant stated that the following sentence in Passage B (the Medicaid term agreement) “threw her off”: “If you want TANF for any family \_\_\_\_\_ [member], you will have to sign a different application form.” She did not know what TANF (Temporary Assistance for Needy Families) meant. One participant remarked that he felt

that for many of the blanks in the cloze passages there was more than one appropriate choice available.

**Think-alouds.** Despite my encouragement, only 8 participants offered verbal feedback during the STOFHLA. There was no insight to be made into the cognitive question answering process, except a few participants practiced the cloze passages with different word choices inserted into the blanks. Each participant who did think aloud primarily read aloud to themselves. A couple did some positive self-talk, coaching themselves, saying things like “read the whole thing and think” and “It’s okay, these are commonsense questions.” Four participants expressed alarm or frustration at the content of the test, saying things like “Where did they come up with this one?” “What the ...? That one threw me off!” and “What we talking about?”

**Responses to probe questions.** General evaluations of the STOFHLA ranged from participant reports of enjoying the test, to participant descriptions of feeling very stressed by the test. Approximately half of the participants said it was “okay,” “alright,” “fine,” “not bad,” “not too bad,” or that it “wasn’t bad.” A few participants found the experience pleasant, calling the STOFHLA “fun,” and “funny.” One even said “I liked it. I like taking tests like that anyways.” Alternatively, a few participants negative general feedback included initial statements that the test was “confusing,” and “stressful”

Five participants revealed that the STOFHLA made them uncomfortable or embarrassed (or, could make others uncomfortable or embarrassed). Two participants admitted that they felt embarrassment, but only upon my inquiry and they did not elaborate. Three others explained that in general, or under certain circumstances, the STOFHLA could make people uncomfortable or embarrassed. One participant stated that while she was comfortable taking the STOFHLA, patients who did not graduate from high school would be embarrassed and may feel bad taking

the STOFHLA. Another participant, who also denied his own discomfort with the STOFHLA, advised that the test could cause discomfort in patients with limited literacy, to the point they'd refuse to participate. He stated "[Some people], they're going to feel bad because maybe they can't read or they can't comprehend the first question so they [say] 'No, no that's alright. I don't want to do this.'" Another participant endorsed this same speculation about the STOFHLA, stating "I'm in the medical field so I was pretty much okay with it. But if I wasn't I probably really couldn't associate it... [other] people trying to understand certain things, and they can't, [they may feel] stupid, you know."

**Testing and test results.** I administered the STOFHLA as the final health literacy assessment. Participants' scores ranged from 10 to 36, with a mean score of 28.07 (standard deviation 10.96). Eleven participants demonstrated adequate health literacy with total scores of greater than 23 (Table 3).

**Summary.** In summary, many participants perceived the STOFHLA to be patient information. Most participants found it to be a little difficult at first, but it seems they "got the hang" of completing the Cloze passages as they went along. Participants were troubled with items involving X-ray preparation (which seemed confusing), X-ray time estimations (which seemed inaccurate) and TANF (which was to some, unfamiliar). Participant reactions on the STOFHLA were split; approximately half of participants were uncomfortable and stressed, while half were fine and some even enjoyed taking the STOFHLA. Performance on the STOFHLA in this sample was much higher than it was for the other tests. Eleven participants demonstrated adequate health literacy.

### **Participant Views on Routine Clinical Screening**

Views on routine clinical administration of these tests were split among the participants. Half of the participants were supportive of this idea. Of those supporters, a couple demonstrated awareness that the utility of testing was for clinicians to have knowledge of the health literacy of their patients, with which they could tailor their education efforts. One participant said “It would be great. You can have a feel of people. You really can. If they will allow, you [can] help [them] out.” Another participant also thought routine testing was a good idea and that it would help the provider “know what direction to go in” with a patient. On the other hand, as I discussed previously, many participants believed that the tests were informative and immediately benefited the patient.

Many participants who supported the idea of routine testing suggested stipulations for testing. Most commonly, participants suggested that it be made clear that participation in routing testing is optional, and it be made easy for patients to decline without embarrassment. One participant stated “Tell them they don’t have to take it if they don’t want to. Somebody who couldn’t read the paper [would feel] ashamed about it.” Another participant stated that time should be spent with the patient prior to testing to build a rapport. He stated that then, “If [a patient] felt like it was too difficult for them they would mention that before they even started the test” and that clinicians would then discover that “some people are going to have a problem with it but I mean you’re going to find out [prior to testing].” Another stated that patients need a chance to “see how they feel about it” prior to the start of testing because “some of them might be ashamed and embarrassed.”

Participants who supported the idea of routine testing also did so with conditions related to privacy and confidentiality of testing and scorekeeping. One participant stated that if test scores were to be documented, they would have to stay in the chart and “go no farther than that.”

Another participant stated that only the doctor should have access to the results of the tests, not the nurses or other staff members. Another participant stated that tests should be administered by nurse practitioners only. Another participant considered the testing of every single patient to be okay, but disagreed with obtaining personal identifiers and assigning scores or levels to individual patients.

Six participants were undecided or opposed to routine testing of patients with the REALM, STOFHLA, and Lipkus Expanded Numeracy Scale health-related items. One stated he didn't know because elderly patients and those with little education would feel discomfort. Another participant was unsure because she believed there were many that would dislike testing, saying "some people don't like new things." Another thought it was a good idea but expressed concern that it would burden those without adequate literacy, saying "Not putting nobody down, but a lot of people, they can't read and they don't know how to prepare [themselves] for something like this." One participant was against routine testing, arguing that all three tests would be too hard for someone without a high school education, and could possibly make these individuals feel bad. Another participant similarly opposed routine testing, explaining that those with less education would be more burdened by testing than those more highly educated. One participant, who refused the REALM, expressed her specific opposition to routine administration of the REALM. Another was against routine administration of the numeracy test, because of the disease-related content.

### **Categorization of Types of Problems Observed**

Of the cognitive processing problem types proposed by Willis and colleagues (1999), discussed previously, the most commonly observed issues identified with the REALM-SF, the Lipkus Expanded Numeracy Scale health-related items, and the STOFHLA were related to

sensitivity in the judgment process and comprehensibility in the encoding process. In the former, participants' impressions of testing procedures and test content at times made them guarded or influenced their judgment of the purpose of the test or question. In the latter, participants had difficulty understanding items, due to different features unique to each assessment. Issues related to comprehension, sensitivity, and the response process were identified in this study. Examples of the most common and salient are detailed in Table 3.4.

### **Discussion**

Health literacy measurement is crucial for determining the ability of individuals to use health information, for guiding quality improvement efforts, and for holding healthcare providers and organizations responsible for making health information comprehensible (Clancy, 2009). Health literacy measurement is also important in building knowledge of the relationship between inadequate health literacy and poorer health outcomes (Paasche-Orlow and Wolf, 2007). However, findings from this study reveal that well-accepted and utilized instruments for assessing health literacy presented challenges for this group of middle-aged African Americans with hypertension. Specifically, consistent with Willis (2005), issues related to item comprehension and sensitivity were discovered in these interviews. This may introduce measurement concerns related to the reliability and validity of these tools (which are important when evaluating patient health literacy needs or the effectiveness of interventions), as well as the possibility of burdening, stigmatizing, offending, or confusing patients who undertake health literacy testing.

Notable findings from this study include the reports of discomfort related to the REALM-SF from over half of participants in this sample. This is inconsistent with feedback from participants who initially tested these items. Arozullah and colleagues (2007), who developed



and validated this tool, conducted field testing with the REALM-SF on all male sample of 50 veteran internal medicine clinic patients of which 74% were African American of the average age of 61. In this study, the tool was validated against other health literacy measures, but additionally, participants were asked about their subjective impressions of the REALM-SF. Ninety-six percent denied feeling offended by the REALM-SF and 90% stated they'd be willing to share results with their doctor. While it is possible that the participants in that study were genuinely more comfortable with the REALM-SF than participants in the present study, perhaps certain demographic features, such as their veteran status, made them less candid or less likely to report discontentment with the testing process. Additionally, those participants underwent a structured interview, whereas in the present study, feedback was sought through cognitive interviewing, which may have been more revealing.

Other feedback elicited in this study pertaining to the REALM-SF is supported by previous literature. For example, the identification of “jaundice” as a troublesome word is not unique to this study. Shea, Beers, McDonald and colleagues (2004), who sought to evaluate the validity and reliability of the 66-item REALM among patient subgroups in a diverse sample of 1,610 primary care patients, found scores for this item statistically significantly different between groups. Sixty-seven percent of African Americans correctly pronounced “jaundice,” compared to 87% of Caucasians (Shea et al., 2004).

The refusal to participate in the REALM has also been seen in other studies. Green and colleagues (2011), who sought to evaluate for demographic and clinical characteristics associated with limited health literacy in a diverse sample of 288 adults with end-stage renal disease, had 10% of participants refuse to participate in the REALM. In their study, REALM refusers were more likely to be without a high school education compared to participants who agreed to take

the REALM (OR=3.5, CI 1.3-8.9). While I did not collect quantitative data on education levels of the participants in the present study, those who refused to participate in the REALM volunteered in their narratives that they did not complete their schooling.

Other important findings involve the negative experience of numeracy testing reported by participants in this study. Although participants in previous numeracy research studies have been reported to be generally unreceptive to objective numeracy tests (Fagerlin, Zikmund-Fisher, and Ubel et al., 2007), this is the no other qualitative study, to my knowledge, to query African Americans about their subjective impressions of the Lipkus Expanded Numeracy Scale or its the health-related subscale. The participants in this study found the disease-related content alarming, and a few became concerned about their own personal risks of contracting a sexually transmitted infection in particular. However, because participants received only health-related numeracy questions, these results are limited in their generalizability. It is unknown whether participants would have been as focused on the disease-related content had I administered the Lipkus Expanded Numeracy Scale in its entirety (including the 3 general numeracy items). In any case, participants in this study were especially reactive to the *infectious* disease content of the disease-related questions. It is possible that regional public health scares or racial disparities in “re-emerging” infectious diseases like HIV and tuberculosis (Morris et al., 2006; Strully, 2011) may have provoked this response in this population. It is plausible that health-related questions using non-transmittable or less historically stigmatizing health topics would have been more acceptable to the participants (for example, questions about heart disease), and that health-related questions preceded by 3 general numeracy items may have been taken less personally by participants.

It is important to note that in my attempt to dispel embarrassment, reduce feelings of alienation, and give participants permission to struggle, I advised each participant at the start of

numeracy testing that the Lipkus Expanded Numeracy Scale health-related items have been found to be challenging by individuals of all education levels. Therefore, findings of feelings of humiliation by participants related to test difficulty should be interpreted with caution. It is unknown whether this intervention primed them to have a negative emotional response (without which they would have been less humiliated), or spared them embarrassment (meaning they could have felt even more humiliation). While research validity may have been undermined with this deviation from the strict scientific process, the results may be generalizable to the clinical setting. It is not uncommon for clinicians to administer assessments to patients with unrehearsed or improvised test introductions and instructions believed to be appropriate to the patient. In fact, unlike the REALM and STOFHLA, the Lipkus Expanded Numeracy Scale is without directions for administration.

Other remarkable findings during numeracy testing were revealed during think-alouds. Participants verbalizations suggested a high rate of “fifty-fifty chance” thinking. “Fifty-fifty chance” thinking is a reasoning that the odds of an occurrence are “fifty-fifty,” as though they it will happen, or it won’t. Previous decision-making and risk perception research has demonstrated that adults with limited numeracy have a higher rate of answering “fifty-fifty chance,” “50,” 50%, or 50 out of 100 when asked numeracy questions, especially when the question is understood to be the respondents’ personal risk, rather than a percent of the population (Bruine de Bruin et al., 2000; Fischhoff and Bruine de Bruin, 1999). These findings suggest that efforts need to be made in patient education to dispel this common perception and inform patients of their actual personal health risks, especially in the setting of known or suspected limited numeracy.

Despite methodological concerns, participant feedback about items from the Lipkus Expanded Numeracy Scale suggest that this tool may not be appropriate for this population. Recognizing the aversive nature of existing objective numeracy tests, including the Lipkus Expanded Numeracy Scale in particular, and the potential for lower completion rates (and higher attrition rates in longitudinal studies), Fagerlin and colleagues designed the Subjective Numeracy Scale (SNS). The SNS is an 8-item general numeracy scale that consists of 4 items that ask participants to rate their quantitative abilities in different settings, and 4 items that inquire about their preferences for the presentation of quantitative information. The SNS correlated well with the Lipkus Expanded Numeracy Scale in 3 studies utilizing convenience samples including over 700 adults that were predominantly Caucasian but of diverse educational backgrounds. In one of the studies, participants received either the SNS or the Lipkus Expanded Numeracy Scale, and rated their annoyance, stress, and frustration with each. Statistically significantly higher negative ratings came from those who completed the Lipkus Expanded Numeracy Scale. The SNS should be considered for, and tested in, an African American population. Since participants in the present study easily volunteered their beliefs about their quantitative abilities and preferences for numerical information, I speculate that the population would be receptive to it. However, if objective measures continue to be used, the disease-related content on this tool should be re-evaluated by numeracy experts and tested in an African American population.

Participants in this study had the best performance and reported the fewest comprehension challenges with the STOFHLA. However, participants focused largely on the content in the STOFHLA passages. In the first passage, the accuracy of the medical instructions was of concern to the participants, rather than the context, vocabulary, or grammar that was relevant for choosing the correct answer. This finding is consistent with that found by Shaw and

colleagues (2012), who sought to assess health literacy and self-care in a diverse sample of 296 adults with chronic disease; they used qualitative methods to explore patient perspectives of health literacy in a subset of participants (n=47) using focus groups. African Americans described considering what their own doctor would recommend to determine the “correct” response to STOFHLA items (Shaw et al., 2012). In the second STOFHLA passage, which was composed of a part of a Medicaid application patient rights and responsibilities form, participants experienced confusion and concern. Some were unfamiliar with the term TANF (Temporary Assistance for Needy Families), which caused confusion. Others recognized this term and wondered if they were applying for Medicaid, or became concerned about their Medicaid eligibility and status. This finding suggests that this specific content be re-evaluated and potentially substituted with a more generic patient rights agreement or drawn from a different set of health-related materials.

Participant views on routine clinical screening discovered in this study suggest that there is embarrassment around health literacy and health literacy testing. Although most participants supported the idea of routinely conducting these tests, a significant minority strongly opposed it. Those who did support routine testing were adamant that testing should be without any coercion, conducted in privacy, and scores stored confidentially. These findings offer evidence to support claims that the potential harm resulting from routine clinical screening may outweigh benefits.

### **Conclusion**

In conclusion, challenges in health literacy research continue to include the refinement and validation of measures. By analyzing verbalizations of middle-aged African American adults with hypertension (during and after health literacy assessment) and systematically classifying the types of issues experienced with each measure (Groves et al., 2009; Willis, 2005),

this study sheds light on the question-answering process and comprehension demands imposed by each measure, and a potential bias in some of the content of the tests. Also, insight is offered into the experiential dimensions of health literacy test-taking, which at times included discomfort, embarrassment, and stress for participants in this study.

## References

- Aguirre, A.C., Ebrahim, N., & Shea, J.A. (2005). Performance of the English and Spanish STOFHLA among publicly insured Medicaid and Medicare patients. *Patient Education and Counseling*, 56, 332-339.
- Arozullah AM, Yarnold PR, Bennett CL, et al. Development and validation of a short-form, rapid estimate of adult literacy in medicine. *Med Care*. 2007;45:1026–33.
- Baker, D.W., Williams, M.V., Parker, R.M., Gazmararian, J.A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38(1), 33-42.
- Baker, D.W., Wolf, M.S., Feinglass, J. Thompson, J.A., Gazmararian, J.A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503-1509.
- Bass PF, 3rd, Wilson JF, Griffith CH, et al. Residents' ability to identify patients with poor literacy skills. *Acad Med*. 2002;77:1039–41
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., & Crotty, K. (2011). Limited health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 129-130.
- Black W. C., Nease R. F., Tosteson A. N. (1995). Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J. Natl. Cancer Inst.* 87, 720–731
- Brez, S.M. & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040-1047.
- Bruine de Bruin W, Fischhoff B, Halpern-Flesher B, et al. (2000). Expressing epistemic

- uncertainty: “It’s a fifty-fifty chance”. *Organizational Behavior and Human Decision Processes*, 8, 115–31.
- Bruine de Bruin W, Fischhoff B, Millstein S, Halpern-Felscher B. Verbal and numerical expressions of probability: “It’s a fifty-fifty chance.”. *Organization Behavior and Human Decision Processes* 2000;81:115–131.
- Cardozo, E. R., Neff, L. M., Brocks, M. E., Ekpo, G. E., Dune, T. J., Barnes, R. B., & Marsh, E. E. (2012). Infertility patients' knowledge of the effects of obesity on reproductive health outcomes. *American journal of obstetrics and gynecology*, 207(6), 509-e1.
- Case, S. M., Fried, T. R., & O’Leary, J. (2013). How to ask: Older adults’ preferred tools in health outcome prioritization. *Patient education and counseling*, 91(1), 29-36.
- Clancy, C. (2009). An Overview of Measures of Health Literacy. Institute of Medicine (US) Roundtable on Health Literacy. *Measures of Health Literacy: Workshop Summary*. Washington (DC): National Academies Press (US). Available from: <http://www.ncbi.nlm.nih.gov/books/NBK45375/>
- Clement S, Ibrahim S, Crichton N, Wolf M, Rowlands G. (2009). Complex interventions to improve the health of people with limited literacy: A systematic review. *Patient Education and Counseling*, 75, 340-51.
- Cokely, E.T., & Kelley, C.M. (2009). Cognitive abilities and superior decision making under risk: A protocol analysis and process model evaluation. *Judgment and Decision Making*, 4, 20–33.
- Cokely, E. T., Galesic, M. E., Schulz, E., Ghazal, S., & Garcia-Retamero, R. (2012). Measuring risk literacy: The Berlin Numeracy Test. *Judgment and Decision Making*, 7(1), 25–47.
- Collins, D. (2003). Pretesting survey instruments: An overview of cognitive methods. *Quality*



- of Life Research*, 12(3), 229-238.
- Cokely, E.T., Ghazal, S., & Garcia-Retamero, R. (2014). Measuring numeracy. In B. L. Anderson & J. Schulkin (Eds.), *Numerical Reasoning in Judgments and Decision Making about Health* (pp. 11-38). Cambridge, UK: Cambridge University Press.
- Davis, T.C., Crouch, M.A., Long, S.W., Jackson, R.H., Bates, P., George, R.B. (1991). Rapid assessment of literacy levels of adult primary care patients. *Family Medicine*, 23(5), 433-436.
- Davis, T.C., Long, S.W., Jackson, R.H., Mayeaux, E.J., George, R.B., Murphy, P.W., et al. (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, 25(6), 391-5.
- DeMuro, C. J., Lewis, S. A., DiBenedetti, D. B., Price, M. A., & Fehnel, S. E. (2012). Successful implementation of cognitive interviews in special populations. *Expert Review of Pharmacoeconomics & Outcomes Research*, 12, 181–187.
- Dumenci, L., Matsuyama, R. K., Kuhn, L., Perera, R. A., & Siminoff, L. A. (2013). On the Validity of the Shortened Rapid Estimate of Adult Literacy in Medicine Scale as a Measure of Health Literacy. *Communication methods and measures*, 7(2), 134-143.
- Estrada, C.A., Martin-Hryniewicz, M., Peek, B.T., Collins, C., & Byrd, J.C. (2004). Literacy and numeracy skills and anticoagulation control. *American Journal of the Medical Sciences*, 328, 88–93.
- Fagerlin, A., Ubel, P. A., Smith, D. M., & Zikmund-Fisher, B. J. (2007). Making numbers matter: Present and future research in risk communication. *American Journal of Health Behavior*, 31(Suppl. 1), S47-S56.
- Farrell, T.W., Chandran, R., & Gramling, R. (2008). Understanding the role of shame in clinical

- assessment of health literacy. *Family Medicine*, 40(4), 235-236.
- Ferguson, B., Lowman, S.G., & DeWalt, D.A. (2011). Assessing literacy in clinical and community settings: The patient perspective. *Journal of Health Communication*, 16(2), 124-134.
- Fischhoff, B., De Bruin, W.B. (1999). Fifty-fifty=50%? *Journal of Behavioral Decision Making*, 12, 149-63
- Galesic, M., & Garcia-Retamero, R. (2010). Statistical numeracy for health: A cross-cultural comparison with probabilistic national samples. *Archives of Internal Medicine*, 170, 462-468.
- Gazmararian, J.A., Baker, D.W., Williams, M.V., et al. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA*, 281(6), 545-551.
- Golbeck, A.L., Ahlers-Schmidt, R., Paschal, A.M., & Dsimuke, S.E. (2005). A definition and operational framework for health numeracy. *American Journal of Preventive Medicine*, 29, 375-6.
- Groves, R.M., Fowler, F.J., Couper, M.P., Lepkowski, J.M., Singer, E., & Tourangeau, R. (2009). *Survey Methodology*. (2<sup>nd</sup> ed.). Hoboken, New Jersey: Wiley.
- Izumi, S., Vandermause, R., & Benavides-Vaello, S. (2013). Adapting Cognitive Interviewing for Nursing Research. *Research in Nursing and Health*, 36(6), 623-633.
- Kelly, P.A. & Haidet, P. (2007). Physician overestimation of patient literacy: a potential source of health care disparities. *Patient Education and Counseling*, 66(1), 119-22.
- Kirk J. K., Grzywacz J. G., Arcury T. A., Ip E. H., Nguyen H. T., Bell R. A., & Quandt S. A. (2012). Performance of health literacy tests among older adults with diabetes. *Journal of General Internal Medicine*. 27, 534-540.

- Kripilani, S., Gatti, M.E., & Jacobsen, T.A. (2010). Association of age, health literacy, and medication management strategies with cardiovascular medication adherence. *Patient Education and Counseling*, 81, 177-181.
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy.
- Laubach, R.S., & Koschnick, K. (1977). *Using Readability: Formulas for Easy Adult Materials*. Syracuse, NY: New Readers Press.
- Liberali, J. M., Reyna, V. F., Furlan, S., Stein, L. M. & Pardo, S. T. (2011). Individual differences in numeracy and cognitive reflection, with implications for biases and fallacies in probability judgment. *Journal of Behavioral Decision Making* 25(4), 361-381.
- Lipkus, I.M., Samsa, G., & Rimer, B.K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, 21, 37-44.
- Mooss, A., Brock-Getz, P., Ladner, R., & Fiaño, T. (2013). The relationship between health literacy, knowledge of health status, and beliefs about HIV/AIDS transmission among Ryan White clients in Miami. *Health Education Journal*, 72(3), 292-299.
- Morris, N.S., MacLean, C.D., Chew, L.D., & Littenberg, B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. *BMC Family Practice*, 7, 21.
- Morris, M., Handcock, M., Miller, W., Ford, C., Schmitz, J., & Hobbs, M. (2006). Prevalence of HIV infection among young adults in the United States: Results from the Add Health Study. *American Journal of Public Health*, 96(6):1090-1097.
- Murray, M.D., Wu, J., Tu, W., Clark, D.O., Weiner, M., & Morrow, D.G. (2004). Health

- literacy predicts medication adherence. *Clinical Pharmacology & Therapeutics*, 76.
- Nielson-Bohlman, L., Panzer, A.M., & Kindig, D.A. (2004). *Health literacy: A prescription to end confusion*. Institute of Medicine. Washington, DC: National Academies Press.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67(12), 2072-2078.
- Paasche-Orlow, M.K., & Wolf, M.S. (2008). Evidence does not support clinical screening of literacy. *Journal of General Internal Medicine*, 23, 100–2.
- Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10, 537-41.
- Politi, M. C., Kaphingst, K. A., Kreuter, M., Shacham, E., Lovell, M. C., & McBride, T. (2014). Knowledge of health insurance terminology and details among the uninsured. *Medical Care Research and Review*, 71(1), 85-98.
- Rothman, R.L., Davis, D., Gregory, R., Wallston, K.A., Sparks, J., & Dewalt, D.A. (2005). Diabetes numeracy skills and relationship to glycemic control. *Diabetes, supplement, American Diabetes Association*.
- Shaw, S.J., Armin, J., Torres, C.H., Orzech K. M., & James, V. (2012). Chronic disease self management and health literacy in four ethnic groups. *Journal of Health Communication*, 17(Suppl. 3), 67–81.
- Shea, J.A., Beers, B.B., McDonald, V.J., Quistberg, D.A., Ravenell, K.L., & Asch, D.A. (2004). Assessing health literacy in African American and Caucasian adults: Disparities in Rapid Estimate of Adult Literacy in Medicine (REALM) scores. *Family Medicine*, 36, 575–581.
- Slosson, R.L. (1990). *Slosson Oral Reading Test-Revised*. East Aurora, N.Y.: Slosson

Educational Publications.

- Strully, K.W. (2011). Health care segregation and race disparities in infectious disease: The case of nursing homes and seasonal influenza vaccinations. *Journal of Health and Social Behavior, 52*(4), 510–526.
- Sudore, R.L., Yaffe, K., Satterfield, S., Harris, T.B., Mehta, K.M., Simonsick, E.M., Newman, A.B., Rosano, C., Rooks, R., Rubin, S.M., Ayonayon, H.N., & Schillinger, D. (2006). Limited literacy and mortality in the elderly: the Health, Aging, and Body Composition Study. *Journal of General Internal Medicine, 21*, 806–812.
- Taylor, W.S. (1953). The Cloze procedure: A new test for measuring readability. *Journalism Quarterly, 30*, 415-33.
- Tourangeau, R. (2003). Cognitive aspects of survey measurement and mismeasurement. *International Journal of Public Opinion Research, 15*(1), 1-5.
- Tourangeau, R. (1984). Cognitive science and survey methods: A cognitive perspective. In T. Jabine, M. Straf, J. Tanur, & R. Tourangeau (Eds.), *Cognitive aspects of survey design: Building a bridge between disciplines* (pp. 73–100). Washington, DC: National Academy Press.
- Waters, E.A., Hay, J.L., Orom, H., Kiviniemi, M.T., & Drake, B.F. (2013). "Don't know" responses to risk perception measures: Implications for underserved populations. *Medical Decision Making, 33*, 271-281.
- Williams, M.V., Parker, R.M., Williams, M.V., Parikh, N.S., Pitkin, K., & Coates, W.C. (1995). Inadequate functional health literacy among patients at two public hospitals. *Journal of the American Medical Association, 274*, 1677-82.
- Willis, G.B. (2005). *Cognitive interviewing: A tool for improving questionnaire design*.

Thousand Oaks, CA: Sage Publications.

- Willis, G.B., Schechter, S., & Whitaker, K. (1999). A comparison of cognitive interviewing, expert review, and behavior coding: What do they tell us? Paper presented at the Section on Survey Research Methods, American Statistical Association. Washington, DC. 1999.
- Van Geest, J.B., Welch, V.L., & Weiner, S.J. (2010). Patients' perceptions of screening for health literacy: Reactions to the Newest Vital Sign. *Journal of Health Communication, 15*(4), 402-412.
- Wolf, M.S., Williams, M.V., Parker, R.M., Parikh, N.S., Nowlan, A.W., & Baker, D.W. (2007). Patients' shame and attitudes toward discussing the results of literacy screening. *Journal of Health Communication, 12*, 721-732.
- Woloshin, S., & Schwartz, L.M. (1999). How can we help people make sense of medical data? *Effective Clinical Practice, 2*, 176-83.
- Zikmund-Fisher, B.J., Smith, D.M., Ubel, P.A., & Fagerlin, A. (2007). Validation of the Subjective Numeracy Scale: Effects of low numeracy on comprehension of risk communications and utility elicitation. *Medical Decision Making, 27*, 663-671.

<b>Cognitive Interviewing Procedures (Groves et al., 2009)</b>	
<b>Concurrent think-alouds</b>	Participants verbalize their thoughts while answering survey or interview questions
<b>Retrospective think-alouds</b>	Participants detail how they came to their answers after they provide each answer or at the end of the survey or interview
<b>Confidence ratings</b>	Participants rate their confidence in their answers
<b>Paraphrasing</b>	Participants repeat questions in their own words
<b>Definitions</b>	Participants define terms in the questions
<b>Probes</b>	Participants respond to various follow-up questions designed to explore their perspective of the survey response strategies

**Table 3.1. Cognitive Interviewing Procedures**

Instrument	Design	Reliability & Validity	
SILS	Asks, “How often do you need to have someone help you when you read instructions, pamphlets, or otherwise written material from your doctor or pharmacy?”	Testing conducted in an elderly, educated Caucasian population. Construct validity (reading comprehension) supported with a score >2 predicting STOFHLA performance with the AUROC 0.73 (95% CI: 0.69-0.78). Sensitivity and specificity for score >2 was 54% and 83% (Morris et al., 2006).	Scored 1-5 with 1 being ‘Never’ and 5 being ‘always.’ Score>2 considered positive for limited health literacy.
REALM-SF	A reading recognition test for which a list of words were selected from commonly used lay medical terms found in patient materials.	Formal testing conducted in 2 samples where the REALM-SF and the original REALM were highly correlated in each (r = 0.95, P < 0.001; r = 0.94, P < 0.001). Field testing demonstrated the REALM-SF to be correlated with the WRAT (r = 0.83, P < 0.001) (Arozullah et al., 2007).	Points are assigned for each of correctly pronounced item. Dictionary pronunciation is the standard for scoring. Total score categorized into grade ranges.
STOFHLA	Reading passages developed by literacy experts’ review of actual common hospital readings. Every 5th to 7th word is removed, with 4 multiple choice words to choose from.	Testing conducted in middle-aged African American clinic population. Internal consistency with Cronbach’s $\alpha$ =0.97 and criterion/concurrent validity with REALM: r=0.81 (Baker, 1999).	One point for each correct multiple choice word in 2 passages with 36 missing items; scoring categorized into inadequate, marginal, and adequate health literacy.
Lipkus Expanded Numeracy Scale	Three general and eight health-related open-ended response and multiple choice questions that assess one’s understanding of proportions, percentages, and probabilities.	Testing conducted in 3 samples of middle-aged, educated Caucasians. Cronbach’s $\alpha$ for the health-related subscale were 0.70-0.75, while 0.57-0.63 for the three general numeracy items (Lipkus et al., 2001).	One point assigned for each correctly answered question. Eight health-related items are summed for a total score.

**Table 3.2. Health literacy assessments.**



Participant	Single-Item Literacy Screener <sup>a</sup>	REALM <sup>b</sup> (Number correct out of 7)	S-TOFHLA <sup>c</sup> (Number correct out of 36 and time for completion)	Numeracy <sup>d</sup> (Correct out of 8)
1	3 (Inadequate)	0 ( $\leq 3^{\text{rd}}$ grade)	10 (Inadequate), 7 min	1
2	1 (Adequate)	7 ( $\geq 9^{\text{th}}$ grade)	35 (Adequate), 4 min	8
3	3 (Inadequate)	5 (7 <sup>th</sup> -8 <sup>th</sup> grade)	32 (Adequate), 10 min	0
4	2 (Adequate)	5 (7 <sup>th</sup> -8 <sup>th</sup> grade)	34 (Adequate), 5 min	4
5	4 (Inadequate)	1 (4 <sup>th</sup> -6 <sup>th</sup> grade)	0 (Inadequate), NA	0
6	2 (Adequate)	5 (7 <sup>th</sup> -8 <sup>th</sup> grade)	19 (Marginal), 10 min	3
7	4 (Inadequate)	7 ( $\geq 9^{\text{th}}$ grade)	32 (Adequate), 15 min	3
8	1 (Adequate)	6 (7 <sup>th</sup> -8 <sup>th</sup> grade)	36 (Adequate), 5 min	0
9	5 (Inadequate)	4 (7 <sup>th</sup> -8 <sup>th</sup> grade)	19 (Marginal), 5 min	0
10	3 (Inadequate)	7 ( $\geq 9^{\text{th}}$ grade)	33 (Adequate), 7 min	1
11	4 (Inadequate)	4 (7 <sup>th</sup> -8 <sup>th</sup> grade)	34 (Adequate), 11 min	4
12	1 (Adequate)	7 ( $\geq 9^{\text{th}}$ grade)	33 (Adequate), 10 min	2
13	2 (Adequate)	7 ( $\geq 9^{\text{th}}$ grade)	36 (Adequate), 10 min	3
14	3 (Inadequate)	7 ( $\geq 9^{\text{th}}$ grade)	36 (Adequate), 12 min	1
15	2 (Adequate)	5 (7 <sup>th</sup> -8 <sup>th</sup> grade)	32 (Adequate), 15 min	0
Mean(SD)	2.67(1.23)	5.13(2.19)	28.07(10.96)	2(2.24)

**Table 3.3. Health literacy of participants.**

**Table 3.4. Most Salient Test Issues Categorized per the Willis, Schechter, and Whitaker (1999) Classification System**

Measure	Survey item or feature	Type of issue identified	Patient Quotes
REALM	Jaundice	Comprehension in the encoding process	<p>“One word because I don’t know the meaning of if, and I don’t even think I pronounced it right. J-A-U-N-D-I...”</p> <p>“Say jaundice, you might say I know that word, but somebody [may not know it]... I’m trying to think of a way to try to pronounce jaundice.”</p>
	Word list	Sensitivity	<p>“Well, to read it out to you is kind of embarrassing.”</p> <p>“[The REALM]... might make me feel shy a little bit, but that’s only because, you know, when you pronounce them words you want to pronounce them right.”</p>
Lipkus Expanded Numeracy Scale health-related items	Which <i>represents</i> the biggest risk? If Person B’s risk is <i>double that</i> of Person A’s, what is B’s risk?	Comprehension in the encoding process	<p>“Which of the following numbers—I’m struggling with that word—represent the biggest risk of getting a disease?”</p> <p>“Okay, if person one has one percent risk in 10 years and person B has <i>double that</i>, it’s just as bad. I mean, that’s what I think. It’s just as bad.” *</p>
	Disease-related content	Sensitivity	<p>“It’s possible that anybody could contract a disease from somebody and have it and not knowing. You know, they don’t tell you they got it until you have sex with them.”</p> <p>“You got to be careful and think about you own personal self and your history &amp; what you should do or not do with someone else.”</p>
STOFHLA	Cloze passages	Response process	<p>“Suppose neither one of them [words make sense in the sentence]?”</p> <p>“It could be all of the above.”</p>
	Medicaid content	Comprehension in the encoding process  Sensitivity	<p>“I didn’t know what—[I’m] not familiar [with TANF].”</p> <p>“[TANF]—that one threw me. I didn’t understand that.”</p> <p>“After I figured it was talking about an application, I figured it was talking [about] my family member and the application.”</p> <p>“I got a feeling that... I’m [applying for] Medicaid”</p>

\*Upon probing it was discovered that the participant was able to correctly answer the question when the term *double that* was replaced with *twice* the risk or *two times* the risk

## CHAPTER 5

### **Summary of the Three Papers**

Associations of limited health literacy with adverse health outcomes (Berkman et al., 2011) and poorer health behaviors (White, Chen, and Atchison, 2008; Bennett, Chen, Soroui, and White, 2009) have been well-documented. This dissertation project sought to investigate the psychosocial outcomes of health literacy and health literacy testing. This was accomplished by (a) assessing relationships between health literacy and psychosocial and behavioral variables in the Health and Retirement Study; (b) exploring the qualitative health literacy-related healthcare experience from the perspective of African American adults with hypertension; and (c) conducting cognitive interviews of African American adults with hypertension undergoing health literacy testing.

The first manuscript, “Health Literacy, Psychosocial Factors, and Health Behaviors: A Secondary Analysis of the Health and Retirement Study,” has as its main finding that objective health literacy, health literacy measured with items from the Test Of Functional Health Literacy in Adults (Parker, Baker, Williams, and Nurss, 1995), did not prove to be a strong or statistically significant predictor of psychosocial processes or behaviors in models controlling for sex, age, race, and education. However, self-reported health literacy, determined by the Chew health literacy screener “How confident are you filling out medical forms by yourself?” (Chew, Bradley, and Boyko, 2004), was significantly (and inversely) related to perceived social

standing, perceived control over health, and perceived healthcare discrimination in linear and logistic regression models controlling for sex, age, race, and education.

In the second study, “The Health Literacy-Related Healthcare Experience: A Qualitative Study,” African American adults with hypertension described many practical health literacy related obstacles in the healthcare setting, usually involving medication errors. These challenges were often accompanied by emotional responses, including internalized stigma and anxiety. Participants revealed a broad range of techniques they used to cope with these challenges and emotions that were both adaptive and maladaptive.

In the third manuscript, “Patient Understanding and Perceptions of Health Literacy and Numeracy Testing: Findings from Cognitive Interviews,” participant perspectives on the Rapid Estimate of Adult Literacy in Medicine Short Form (REALM-SF) (Arozullah et al., 2007), the Lipkus Expanded Numeracy Scale health-related items (Lipkus et al., 2001), and the Short Test of Functional Health Literacy in Adults (STOFHLA) (Baker et al., 1999) are detailed. Participants found the read-aloud procedure of the REALM-SF (Arozullah et al., 2007), and the infectious disease content (and level of difficulty) of the numeracy items distressing, and they felt uncomfortable. Participants found the STOFHLA to be the most acceptable, although the Cloze procedure, Medicaid content, and specifics of the X-ray instructions were at times confusing and distracting. Views on routine health literacy screening suggest that participants’ perceive the overall testing experience to be potentially stigmatizing. Findings from these cognitive interviews add to existing evidence that the potential harm associated with routine clinical screening of patients’ health literacy skills may outweigh the benefits at this time (Paasche-Orlow and Wolf, 2008), and that there is a potential bias in some of the content of existing tests of health literacy (Shea et al., 2004).

## **Conclusions**

In conclusion, findings from this dissertation support the notion that there are important health literacy-related psychosocial factors that belong in existing proposed conceptual models of the relationship between health literacy and health outcomes (Berkman et al., 2010; Paasche-Orlow and Wolf, 2007; Baker, 2006). Further exploration of these psychosocial factors, examination of the relationships between health literacy, psychosocial factors, health behaviors and outcomes, and further determination of the risks and benefits of health literacy screening is warranted to mitigate health literacy-related health disparities.

## References

- Baker, D.W. (2006). The meaning and measure of health literacy. *Journal of General Internal Medicine, 21*, 878-883.
- Bennett, I.M., Chen, J., Soroui, J.S., & White, S. (2009). The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. *Annals of Family Medicine, 7*, 204-11.
- Berkman, N.D., Davis, T.C., & McCormack, L. (2010). Health literacy: What is it? *Journal of Health Communication, 15*, 9-19.
- Chew, L.D., Bradley, K.A. & Boyko, E.J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine, 36*(8), 588-94.
- Paasche-Orlow, M., & Wolf, M. (2007). The causal pathways linking health literacy to health outcomes. *The American Journal of Health Behavior, 31*(1), 19-26.
- Paasche-Orlow, M., & Wolf, M. (2008). Evidence does not support clinical screening of literacy. *Journal of General Internal Medicine, 23*(1), 100-2.
- Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine, 10*, 537-41.
- Shea, J.A., Beers, B.B., McDonald, V.J., Quistberg, D.A., Ravenell, K.L., & Asch, D.A. (2004). Assessing health literacy in African American and Caucasian adults: Disparities in Rapid Estimate of Adult Literacy in Medicine (REALM) scores. *Family Medicine, 36*(8), 575-81.
- White, S., Chen, J., & Atchison, R. (2008). Relationship of preventive health practices and health literacy: A national study. *American Journal of Health Behavior, 32*, 3, 227-242.

## Appendix A. Health and Retirement Study Variables.

Domains	Variables (and sources where applicable)	Type (SPSS code [type])	Answer
Socio-demographics	Age [PR_DOB_YEAR] OR [CA_RS_AGE]	Scale [Continuous]	
	Gender	Nominal	Male (1)/Female (2)
	Race	Nominal	Caucasian (1)/African American (2)/Other (3)
	Education [PR_YRS_OF_EDUCATION]	Ordinal	<i>Originally 0-17, kept continuous for analyses, categorized for reporting of demographics to: 0-8 years (1)/ 9-11 years(2)/ 12 years(3)/ College (4)/ Post-college (5)</i>
	Marital Status [A008_09] or [A008_MARITAL STATUS]	Nominal	<i>Originally 1-7: married, living with partner as if married, separated, divorced, widowed, never married.</i>  <i>Categories changed to: Married or living with partner (1)/ separated, divorced, widowed, never married (2)</i>
Employment [A009M1_09] CURRENT JOB STATUS	Nominal	<i>Originally 1. Working now, 2. Unemployed &amp; seeking work, 3. Temporarily laid off, on sick or other leave, 4. Disabled, 5. Retired, 6. Homemaker, 7. Other, 8. Don't know.</i> <i>Categories changed to: Employed (1)/ Unemployed (2)/ Retired (3)/ Homemaker (4)</i>	

Health Literacy	<u>Literacy Screener</u> [F001_09]/[F001_MEDFORMS] How confident are you filling out medical forms by yourself? (Chew, Bradley, and Boyko, 2004).	Ordinal	Extremely (0)/Quite a bit (1)/Somewhat (2)/A little bit (3)/Not at all (4)/Don't know (8)
	<u>TOFHLA numeracy items</u> [F003_09]/[ F003_PRESCRIPTION BOTTLE LABEL] – TOFHLA If you take your first tablet at 7:00 a.m., when should you take your next? [F004_09]/[ F004_PRESCRIPTION BOTTLEAMPM] – TOFHLA  [F005_09]/[ F005_BLOODSUGARNORMAL] – TOFHLA Your blood sugar today is 160.  [F006_09]/[ F006_APPOINTMENTPROMPTMONTH] – TOFHLA When is your next appointment?  [F007_09]/[ F007_APPOINTMENTPROMPTDAY] – TOFHLA When is your next appointment?  [F008_09]/[ F008_PRESCRIPTIONLABEL]- TOFHLA If you eat lunch at 12:00 noon, and you want to take this medication before lunch, what time should you take it? [F009_09]/[ F009_PRESCRIPTIONLABELAMPM]- TOFHLA	Nominal	1:00-12:00 (1-12)  A.M.,P.M., Don't know (1, 2, 8)  Yes, No, Don't know (1, 5, 8)  January - December (1-12)  Day 1-31 (1-31)  1:00-12:00 (1-12)  A.M.,P.M., Don't know (1, 2, 8)
	<u>STOFHLA reading passages using a modified Cloze procedure.</u> <i>Passages:</i> <i>The doctor has sent you to have a ____ x-ray.</i> <i>You must have a ____ stomach when you come in for ____.</i> <i>The x-ray will ____ from 1 to 3 ____ to do.</i> <i>The day before the x-ray: for supper have only a ____ snack of fruit, ____ and jelly, with coffee or tea.</i> [F010_09]/[ F010_STOMACH]-TOFHLA [F011_09]/[ F011_EMPTY]- TOFHLA [F012_09]/[ F012_IT]- TOFHLA [F013_09]/[ F013_TAKE]- TOFHLA [F014_09]/[ F014_HOURS]- TOFHLA [F015_09]/[ F015_LITTLE]- TOFHLA [F016_09]/[ F016_TOAST]-TOFHLA	Nominal	1.Stomach, 2.Diabetes, 3.Stitches, 4. Germs 1.Asthma, 2.Empty,3.Incest 4.Anemia 1.Is, 2. Am, 3. If, 4. It 1.Take, 2.View, 3.Talk, 4. Look 1.Beds, 2.Brains,3.Hours,4.Diets 1.Little,2.Broth,3.Attack,4.Nausea 1.Toes,2.Throat,3.Toast,4.Thigh



### Outcome Variables

Perceived social standing	<p>Position on Social Ladder [C059_09]/[H_C059_] <i>MacArthur Scale of Subjective Social Status (1999)</i>. Retrieved June 27, 2013 from: <a href="http://www.macses.ucsf.edu/research/psychosocial/usladder.php">http://www.macses.ucsf.edu/research/psychosocial/usladder.php</a></p> <p>Please click on the rung on the ladder where you would place yourself in society, with those at the top of the ladder being the best off and those at the bottom being the worst off.</p>	Scale [Continuous]	Currently 1-10, actual value. Ladder rungs featured with zero at the bottom, 10 at the top. Will categorize.
Perceived control	<p>[C030_09]: Domain Specific Control over Health. RATE CONTROL OVER HEALTH from the <i>National Survey of Midlife Development in the United States (MIDUS)</i> (Ryff, Love, and Radler, 1995) Think about a 0 to 10 scale where “0” means “no control at all” and “10” means “very much control.” How would you rate the amount of control you have these days over your health?</p>	11 point scale [Continuous]	1-10, actual value. Zero is no control, 10 is very much control.
Perceived healthcare discrimination	<p>Everyday Discrimination Scale (<i>Williams, Jackson, and Anderson, 1997; Williams, Neighbors, and Jackson, 2003</i>).</p> <p>In day-to-day life, how often have any of the following things happened to you? Item [Q30f] You receive poorer service or treatment than other people from doctors or hospitals.</p> <p>From the 6-item scale (Cronbach’s <math>\alpha</math> from 2008 HRS 0.82)</p>		<ol style="list-style-type: none"> <li>1. Almost every day</li> <li>2. At least once a week</li> <li>3. A few times a month</li> <li>4. A few times a year</li> <li>5. Less than once a year</li> <li>6. Never</li> </ol>
Risk perceptions	<p><u>Colon cancer</u> from the <i>National Survey of Medical Decisions (Couper, Zikmund-Fisher, Singer et al., 2006)</i></p> <p>[F018_09]/ [F018_KNOWDEATHS]/COLON CANCER DEATHS Out of every 100 people, about how many do you think will die of colon cancer?</p> <p>[F019_09]/[F019_KNOWDIAGNOSED]/COLON CANCER DIAGNOSED Out of every 100 people, about how many will be diagnosed with colon cancer at some time in their lives?</p> <p>[F020_09]/ [F020_KNOWREDUCERISK]/COLON CANCER SCREENING</p>		<p>0-100 Actual value</p> <p>0-100 Actual value</p>

	Do you think regular colon cancer screening for people over age 50 does or does not reduce the risk of dying from colon cancer?		1.Does, 5.Does not, 8.Don't know
Health Behaviors	<p>[B010_09]/[B010_SMOKENOW]/SMOKE CIGARETTES NOW</p> <p>[LC109]/[PREVENTATIVE FLU SHOT SINCE PREV WAVE] In the last two years, have you had a flu shot? (A flu shot may now be given in the nose)</p> <p>[LC110]/ [CHOLESTEROL TEST SINCE PREV WAVE] In the last two years, have you had a blood test for cholesterol?</p> <p>[LC111]/[ CHECK FOR BREAST LUMPS SINCE PREV WAVE] In the last two years, have you had any of the following medical tests or procedures?(If R is female) Do you check your breasts for lumps monthly?</p> <p>[LC112]/ [MAMMOGRAM/XRAY OF BREAST SINCE PREV WAVE] Did you have a mammogram or x-ray of breast to search for cancer in the last two yrs?</p> <p>[LC114]/[PROSTATE EXAM SINCE PREV WAVE] In the last two years, have you had any of the following medical tests or procedures?(If R is male) An examination of your prostate to screen for cancer?</p> <p>[LC223]/[HOW OFTEN VIGOROUS ACTIVITY]</p> <p>[LC224]/[HOW OFTEN MODERATE ACTIVITY]</p>		<p>1.Yes, 5.No, 9. Question Skipped</p> <p>For Items 109-114:</p> <ol style="list-style-type: none"> <li>1. Yes</li> <li>1. No</li> <li>8. Don't know</li> <li>9. Refused</li> </ol> <p>For items 223-225:</p> <ol style="list-style-type: none"> <li>1. &gt; Once per week</li> <li>2. Once per week</li> <li>3. 1-3 times per month</li> <li>4. Hardly ever or never</li> <li>7. Every day</li> <li>8. Don't know</li> <li>9. Refused</li> </ol>

**Appendix B. STOFHLA (Baker et al., 1999)**

PASSAGE A

Your doctor has sent you to have a \_\_\_\_\_ X-ray.

- a. stomach
- b. diabetes
- c. stitches
- d. germs

You must have an \_\_\_\_\_ stomach when you come for \_\_\_\_\_.

- |           |        |
|-----------|--------|
| a. asthma | a. is. |
| b. empty  | b. am. |
| c. incest | c. if. |
| d. anemia | d. it. |

The X-ray will \_\_\_\_\_ from 1 to 3 \_\_\_\_\_ to do.

- |         |           |
|---------|-----------|
| a. take | a. beds   |
| b. view | b. brains |
| c. talk | c. hours  |
| d. look | d. diets  |

THE DAY BEFORE THE X-RAY.

For supper have only a \_\_\_\_\_ snack of fruit, \_\_\_\_\_ and jelly, with coffee or tea.

- |           |           |
|-----------|-----------|
| a. little | a. toes   |
| b. broth  | b. throat |
| c. attack | c. toast  |
| d. nausea | d. thigh  |

After \_\_\_\_\_, you must not \_\_\_\_\_ or drink

- |              |          |
|--------------|----------|
| a. minute,   | a. easy  |
| b. midnight, | b. ate   |
| c. during,   | c. drank |
| d. before,   | d. eat   |

anything at \_\_\_\_\_ until after you have \_\_\_\_\_ the X-ray.

- |         |        |
|---------|--------|
| a. ill  | a. are |
| b. all  | b. has |
| c. each | c. had |
| d. any  | d. was |

THE DAY OF THE X-RAY.

Do not eat \_\_\_\_\_.

- a. appointment.
- b. walk-in.

- c. breakfast.
- d. clinic.

Do not \_\_\_\_\_, even \_\_\_\_\_.

- |           |            |
|-----------|------------|
| a. drive, | a. heart.  |
| b. drink, | b. breath. |
| c. dress, | c. water.  |
| d. dose,  | d. cancer. |

If you have any \_\_\_\_\_, call the X-ray \_\_\_\_\_ at 616-4500.

- |               |               |
|---------------|---------------|
| a. answers,   | a. Department |
| b. exercises, | b. Sprain     |
| c. tracts,    | c. Pharmacy   |
| d. questions, | d. Toothache  |

**PASSAGE B**

I agree to give correct information to \_\_\_\_\_ if I can receive Medicaid.

- a. hair
- b. salt
- c. see
- d. ache

I \_\_\_\_\_ to provide the county information to \_\_\_\_\_ any

- |          |              |
|----------|--------------|
| a. agree | a. hide      |
| b. probe | b. risk      |
| c. send  | c. discharge |
| d. gain  | d. prove     |

statements given in this \_\_\_\_\_ and hereby give permission to

- a. emphysema
- b. application
- c. gallbladder
- d. relationship

the \_\_\_\_\_ to get such proof. I \_\_\_\_\_ that for

- |                 |                |
|-----------------|----------------|
| a. inflammation | a. investigate |
| b. religion     | b. entertain   |
| c. iron         | c. understand  |
| d. county       | d. establish   |

Medicaid I must report any \_\_\_\_\_ in my circumstances

- a. changes
- b. hormones
- c. antacids
- d. charges

within \_\_\_\_\_ (10) days of becoming \_\_\_\_\_ of the change.

- |          |          |
|----------|----------|
| a. three | a. award |
| b. one   | b. aware |

- c. five
- d. ten

- c. away
- d. await

I understand \_\_\_\_\_ if I DO NOT like the \_\_\_\_\_ made on my case,

- |         |               |
|---------|---------------|
| a. thus | a. marital    |
| b. this | b. occupation |
| c. that | c. adult      |
| d. than | d. decision   |

I have the \_\_\_\_\_ to a fair hearing. I can \_\_\_\_\_ a hearing

- |           |            |
|-----------|------------|
| a. bright | a. request |
| b. left   | b. refuse  |
| c. wrong  | c. fail    |
| d. right  | d. mend    |

by writing or \_\_\_\_\_ the county where I applied.

- a. counting
- b. reading
- c. calling
- d. smelling

If you \_\_\_\_\_ TANF for any family \_\_\_\_\_, you will have to

- |          |              |
|----------|--------------|
| a. wash  | a. member,   |
| b. want  | b. history,  |
| c. cover | c. weight,   |
| d. tape  | d. seatbelt, |

\_\_\_\_\_ a different application form. \_\_\_\_\_, we will use

- |           |             |
|-----------|-------------|
| a. relax  | a. Since,   |
| b. break  | b. Whether, |
| c. inhale | c. However, |
| d. sign   | d. Because, |

the \_\_\_\_\_ on this form to determine your \_\_\_\_\_.

- |           |                   |
|-----------|-------------------|
| a. lung   | a. hypoglycemia.  |
| b. date   | b. eligibility.   |
| c. meal   | c. osteoporosis.  |
| d. pelvic | d. schizophrenia. |

**Appendix C. REALM-SF (Arozullah et al., 2007)**

REALM-SF Form

Patient name \_\_\_\_\_ Date of birth \_\_\_\_\_ Reading level \_\_\_\_\_

Date \_\_\_\_\_ Examiner \_\_\_\_\_ Grade completed \_\_\_\_\_

<b>Word</b>	
Menopause	<input type="checkbox"/>
Antibiotics	<input type="checkbox"/>
Exercise	<input type="checkbox"/>
Jaundice	<input type="checkbox"/>
Rectal	<input type="checkbox"/>
Anemia	<input type="checkbox"/>
Behavior	<input type="checkbox"/>

**Appendix D. Lipkus Expanded Numeracy Scale health-related items (Lipkus, Samsa, & Rimer, 2001).**

1. Which of the following numbers represents the biggest risk of getting a disease?	___ 1 in 100, ___1 in 1000, __ 1 in 10
2. Which of the following numbers represents the biggest risk of getting a disease?	___ 1%, ___ 10%, ___ 5%
3. If Person A's risk of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk?	_____
4. If Person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?	_____
5. If the chance of getting a disease is 10%, how many people would be expected to get the disease:	Out of 10? _____ Out of 100? _____
6. If the chance of getting a disease is 20 out of 100, this would be the same as having a ___% chance of getting the disease.	_____ %
7. The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected?	_____