## HEALTH STATUS AND HEALTH LITERACY IN OLDER ADULTS

A Dissertation

by

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## DOCTOR OF PUBLIC HEALTH

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#### ABSTRACT

This study aimed to examine the relationship between health literacy and the health status of older adults. The first section of the study consisted of a comprehensive literature review of prior research regarding cognitive, health, and behavioral factors associated with functional health literacy in older adults. Factors in older adults that influence health literacy include: demographics, including age, race, socioeconomic status, and education; cognitive abilities; health and disease knowledge; health beliefs including mistrust of traditional and nontraditional medicine; reading levels; communication skills; social support; healthcare access; preventive care behaviors; and hospitalizations.

The second section of the study involved a comprehensive review of instruments testing health literacy. Most instruments testing health literacy revolve around medical term recognition and are based on clinical experiences and not on the practical application of using health knowledge to maintain and improve one's health. Instruments examined include the REALM, REALM-R, TOFHLA, S-TOFHLA, MART, NVS, DAHL, SAHLSA, OHLI, and screening questions. The most widely used instrument at this time is the S-TOFHLA and most of the newer instruments use it as the standard when testing their validity.

The third section of this study used primary data to examine health literacy, patient activation and health status in older adults. The study participants were older adults (n=533) recruited from senior centers, aging programs, and churches in southeast

Texas between 2010 and 2012. Participants completed a survey regarding demographics and health status, functional health literacy and the shortened Patient Activation Measure. Using multivariate linear regression, health literacy was related to mental health ( $\beta$ = -.191, *p*<.000) and number of days of limited physical activities ( $\beta$ = -.123, *p*=.019); patient activation was related to overall general self-reported health status ( $\beta$ = -.234, *p*<.000) and number of days of limited physical activity ( $\beta$ = -.159, *p*<.001); and the interaction was related to poor physical health  $\beta$ = -.994, *p*<.000). The only statistically significant relationship with the interaction of the two was with the number of days of limited physical activity.

Health literacy is related to the health status of older adults but better instruments are needed to more accurately assess levels of functional health literacy, especially in older adults. Patient activation is also related to the health status of older adults but the only statically significant relationship between the interaction of patient activation and health literacy was with the number of days of limited physical activity.

# DEDICATION

This dissertation is dedicated to my family who supported and encouraged me throughout this scholastic endeavor and especially to my husband, Ron Fulton, who was patient throughout the entire experience.

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#### NOMENCLATURE

- CDC Centers for Disease Control and Prevention
- DAHL Demographic Assessment for Health Literacy
- FACS Functional Assessment of Communication Skills for Adults
- FHL Functional Health Literacy
- IALSS International Adult Literacy and Life Skills Survey
- MART Medical Achievement Reading Test
- MHMC Mercy Hospital and Medical Center
- MMSE Mini Mental State Examination
- MOS Medical Outcome Study
- NAAL National Assessment of Adult Literacy
- NALS National Adult Literacy Survey
- NVS Newest Vital Sign
- OHLI Oral Health Literacy Instrument
- PAM Patient Activation Measure
- REALM Rapid Estimate of Adult Literacy in Medicine
- REALM-R Rapid Estimate of Adult Literacy-Revised
- SAHLSA The Shortened Assessment of Health Literacy for Spanish-speaking Adults
- S-TOFHLA Shortened Test of Functional Health Literacy in Adults
- TOFHLA The Test of Functional Health Literacy in Adults

- WHO World Health Organization
- WMS Wechsler Memory Scale II

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#### **INTRODUCTION**

In 1974, Simonds coined the term "health literacy" (Simonds, 1974). He suggested teaching Americans about health issues would improve their health status. Despite this, the topic sat relatively dormant in the literature for about fifteen years before researchers realized its significance in relation to health status.

In the last twenty-five years, scientists have begun to define health literacy. There are several different definitions of functional health literacy (FHL) depending on the organization focus of the defining body. For example, Healthy People 2010 (cite) defined health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services for appropriate health decisions." The World Health Organization (1998) took a more global approach and defines health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health". By defining health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient", the American Medical Association Council of Scientific Affairs demonstrates their interest in the clinical/biomedical model (Ad hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999).

Recognizing that health literacy involves not only cognitive skills but also the physical ability to complete the desired behavior or action, Nutbeam (2000) posited there

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are three levels of health literacy. Level one is "functional health literacy" that involves communication and understanding information such as reading comprehension and oral skills. Level two is "interactive health literacy" and involves the development of personal skills, including self-help and social support groups. The third level Nutbeam described is "critical health literacy." He described this level as personal and community empowerment to improve social and economic determinants of health and the opportunities to build capacity. This level also includes achieving public policy changes to foster greater FHL. Nutbeam (2008) later argued that there are two different types of health literacy: clinical competencies and personal assets. Clinical competencies focuses on the knowledge base of the individual and personal assets focuses on the ability of the individual to act upon that knowledge. Most of the research and measurement to date has been on the clinical aspects and implications of health literacy.

While there is some research on health literacy and health outcomes, little is known about health literacy and older adults. Given the current understanding and familiarity with measuring health literacy and its relationship to health status and outcomes, this dissertation examines the following three research questions in three separate studies:

- 1. What is the relationship between health literacy and health outcomes in older adults?
- 2. What is the state of the science of measuring health literacy?

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3. In older adults, do functional health literacy and patient activation relate to health status when controlling for demographics?

This dissertation is divided into three related investigations. Study one explored the relationship between health literacy and older adults and extended previous reviews with a focus on adults over 60 years of age. This paper answered the following questions: What is the coverage of health literacy in the aging population in the extant literature? How has the topic differed in the last two decades? What are the determinants of health literacy? What are the gaps in the research? What are the implications for research to fill in the gaps and for public health practice?

The second study explored the evolution of scientifically testing for health literacy. Even though Simonds (1974) coined the term "health literacy" forty years ago, researchers have only recently begun attempting to measure it. Wanting to improve clinical encounters and patient comprehension of medical issues, clinicians created the first instruments to measure reading abilities and word recognition of standard medical jargon. They believed that a person's reading level and familiarity of medical jargon indicated his or her level of health literacy. These measures limited responses to clinical terms and did not measure any sort of health literacy in everyday circumstances. Later attempts to shorten the instruments so the assessment could be given in a shorter period of time continued to be based on the earlier clinical measures. This study reviewed the major instruments in the United States of America including the following: the REALM, Shortened REALM, REALM-R TOFHLA, TOFHLA-S, S-TOFHLA, SAHLSA, MART, NVS, DAHL, OHLI, COPD-Q, and health literacy screening questions. It explored their development, efficacy, limitations, and shortcomings. Further, this study made future research and instrument development suggestions.

The third section is an empirical study that investigated health literacy and its relationship with patient activation and the health status of older adults. Few current studies exist that examined the FHL of older adults and its relationship with health literacy. Most of the data in these studies were gathered in 1997 for Prudential HealthCare Plans. Examination of these data clearly established a relationship between functional health literacy and health status in older adults.

This also study included the Shortened Patient Activation Measure developed by Hibbard et al. (2004). The Shortened Patient Activation Measure consists of thirteen items that measure a person's belief that an active role in his or her health is important, confidence and knowledge to take action to improve and maintain health, taking action, and the ability to continue living a healthy lifestyle and self-manage his or her health. Research on the relationship of patient activation and the health status of older adults clearly demonstrates the more activated a patient, the better health-related outcomes (Skolasky et al., 2010).

Using multivariate regression and adjusting for demographics, it examined the interaction between health literacy and patient activation and its relationship with health status in older adults. 533 older adults in south-central Texas completed a health status survey along with a one question health literacy assessment and the shortened Patient Activation Measure. Health status was measured using the four questions The Centers for Disease Control and Prevention (CDC) include in the National Health Interview

Survey (CDC, 2011) known as CDC HRQOL 14 "Healthy Days Measure." Data analysis included a question totaling the number of chronic diseases and suggestions and implications for future research concerning health literacy and older adults are included in this section.

# HEALTH LITERACY AND HEALTH STATUS IN OLDER ADULTS Overview

Since 1974, when Simonds coined the term health literacy, researchers have studied various aspects of health literacy (Simonds, 1974). Only in the last two decades have scientists commenced to systematically study health literacy and its effects on health outcomes, but little has been written about health literacy and older adults. This chapter extends previous reviews with a focus on adults over 60 years of age. it will examine the following questions: What is the coverage of health literacy in the aging population in the extant literature? How has the topic differed in the last two decades? What are the determinants of health literacy? What are the gaps in the research? What are the implications for research to fill in the gaps and for public health practice?

#### Methods

This review began with a search of the scientific literature using the Texas A&M University Library. The initial search used the terms "health literacy" and "health outcomes" and employed Academic Search (EBSCO), CAB Abstracts (Ovid), Medline (Ovid), MLA International Bibliography (EBSCO), Omnifile FT Mega (Wilson), Science Direct, and Web of Science. The same search engines were utilized for the second search using the terms "health literacy and "outcomes." Period goes INSIDE the quotation marks. Change this throughout. A third search utilized the same search engines for the terms "health literacy" and health status" and the fourth search used the terms "health literacy and older adults." The same terms were then used to search Google Scholar and ProQuest Dissertations and Theses databases. Once articles were identified that related to the topic, keywords were examined to determine whether or not there was a need to search for other terms and concluded that the terms. These terms were then deemed sufficient for this study. Next, the pearling method was used to discern whether or not there were any relevant articles previous searches excluded Smith and Shurtz, 2012). This method entails examining relevant articles for references pertinent to the investigation. There were no time limitations on any of the searches in order to get the historical perspective. The articles were chosen based on the following criteria:

- They must have measured health literacy with the Rapid Estimate of Adult Literacy in Medicine (REALM), the Shortened REALM, REALM-Revised, the Texas of Functional Health Literacy in Adults (TOFHLA), the TOFHLA-Shortened, Medical Achievement Reading Test (MART), the Newest Vital Sign, or the Single Item Literacy Screener;
- They must have measured at least one health status;
- They must be an original study;
- They must be an empirical study and not reference based with some sort of quantitative measure;
- They must be in the English language; and
- They must be conducted in an English speaking Country.

#### **Early Literature**

Much of the early literature about health literacy centers on the need to comprehensively define it. While there are many definitions of health literacy, most center on the organizational focus of the entity defining it and most are based on the biomedical model and clinical encounter. The American Cancer Society emphasizes a clinical aspect with its definition of health literacy as "the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services in a way that enhance health" (Greenberg, 2001). Further, the American Medical Association Council of Scientific Affairs demonstrates their interest in the clinical/biomedical model in defining health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient (Ad hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999)." One of the broadest definitions of health literacy is from the World Health Organization (WHO). WHO defines health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (World Health Organization, 1998).

Taking a more comprehensive approach, Nutbeam (2000) recognized that health literacy involves not only cognitive skills but also the physical ability to complete the desired behavior or action. He posits there are three levels of health literacy:

- Level one is "functional health literacy". This involves communication and understanding information such as reading comprehension and oral skills.
- Level two is "interactive health literacy" and encompasses the development of personal skills, including self-help and social support groups.

• Level three is "critical health literacy." This level is personal and community empowerment to improve social and economic determinants of health and the opportunities to build capacity. This level also includes achieving public policy changes to foster greater FHL.

Nutbeam (2008) later described that there are two different types of health literacy: clinical competencies and personal assets. Clinical competencies include healthcare access, understanding healthcare instructions, and communicating with healthcare workers. Personal assets include skill sets to apply health information to daily living and health maintenance regimens and the ability to investigate health information including using the Internet to gather that information. Most of the research and measurement to date has been on the clinical aspects and implications of health literacy.

In addition to the attempt to define health literacy, a further objective of early health literacy research was to determine the prevalence of adequate and inadequate health literacy. In the first United States comprehensive survey of general literacy, the National Adult Literacy Survey (NALS) was administered to a nationally representative sample in 1992. Upon examination of the data from NALS, researchers concluded that reading skills steadily declined with age (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). While health literacy was not included in this first survey, the low reading levels of the nation brought to light the difficulty people, especially older adults, have when reading health information. Concurrently, researchers started to develop special instruments to assess health literacy. Three of the most popular are the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991), the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, 1995), and the shortened version of the TOFHLA, the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, and Nurss, 1999.

The REALM is a three to five minute exam in which people are asked to read aloud 125 medical words taken from patient education materials (brochures and handouts) and intake forms. Health literacy along with general literacy was ranked on how well the participant correctly pronounced the words on the instrument. The more words correctly pronounced, the higher the level of health literacy.

The TOFHLA is a twenty-two minute timed multiple choice exam of fifty items that tests reading comprehension and numerical ability (Parker, 1995). In the numeracy portion, participants are given cue cards or prescription bottles to read and are then orally asked questions about the information they read. This section directly tests the patient's ability and understanding of numerical skills and following directions. Section two uses a modified Cloze procedure reading comprehension evaluation. The Cloze procedure is a respected reading comprehension tool in which every fifth to seventh word is omitted and the patient must choose the correct word to fill in the blank (Abraham & Chapelle, 1992). The reader chooses from four possible answers, only one of which is correct. Items for this section were taken from actual patient instructions for an upper gastroenterology series and the standard Medicaid form advising patients of their rights and responsibilities. This instrument is scored and there are three possible outcomes: inadequate health literacy ("unable to read and interpret texts"); marginal

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health literacy ("difficulty reading and interpreting health texts") and adequate health literacy)"can read and interpret most health texts").

The S-TOFHLA is a twelve minute timed survey and is available in both Spanish and English (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). This instrument is an abbreviated version of the TOFHLA it uses medical terms that a person might encounter in a health care setting and it is divided into two parts: numeracy and reading comprehension. The S-TOFHLA measures a person's ability to read and understand health information using fewer questions than the TOFHLA. This instrument centers on preparation for a gastrointestinal radiographic procedure and people completing the examination score in the same three categories as in the TOFHLA.

Most of the instruments used today were developed using one of those three instruments as a foundation. This includes written instruments and screening questions used in clinical situations.

Using the instruments available at the time and to determine the health literacy for older adults, Gazmararrian, Baker, Williams, Parker, Scott, Green, Fehrenback, Ren and Koplan (1999) studied a cross-section of 3,260 new Medicare enrollees ages 65 and older in Prudential HealthCare Plans in Cleveland, Houston, South Florida, and Tampa (hereafter called the Prudential study). Researchers conducted one-on-one comprehensive one hour interviews with each participant and included testing with the Short Test of Functional Health Literacy in Adults (S-TOFHLA) along with measuring other variables.

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Overall, 23.5% of the English-speaking and 34.2% of the Spanish speaking participants had inadequate health literacy. 10.4% of the English speakers and 19.7% of the Spanish speakers had marginal health literacy. Health literacy levels also differed by study location, other demographic characteristics and other variables that will be discussed later.

After early studies showed the prevalence of inadequate health literacy, researchers began to look at inadequate health literacy, healthcare access and disparities. The team investigating the Prudential study published multiple papers using the same data to further explore health literacy and health status. Further examination using a bivariate analysis of the Prudential study showed that inadequate health literacy is independently associated with not receiving preventive care such as mammograms, flu vaccinations, pneumococcal vaccinations, and Papanicolaou smears (Scott, Gazmararian, Williams, & Baker, (2002).

Later, other researchers analyzed data from the 2003 National Assessment of Adult Literacy (NAAL) to develop a predictive model of health literacy (Martin et al., 2009). Sponsored by the National Center for Education Statistics, the NAAL is a study that administers a reading test in order to determine literacy levels in the United States. The first survey, The National Adult Literacy Survey (NALS), was a general literacy survey that occurred in 1992 and brought to light the problem of illiteracy in the United States. The NALS was updated to the NAAL and was administered in 2003 to over 19,000 people aged 16 and over (National Center for Education Statistics) The NAAL contained a section to measure health literacy and Martin et al. reported a significant relationship between age and health literacy. They concluded that certain demographic variables are adequate predictors of those with low health literacy and will be discussed later. Further, Baker et al. (2007), using the Prudential data, concluded that poor health literacy was a predictor of higher mortality. Using data from the 1997 survey and 2003 mortality data, they determined that inadequate health literacy as measured by the STOFHLA was an independent predictor of all-cause mortality and of cardiovascular death.

#### **Determinants of Health Literacy**

#### Intrapersonal Determinants

#### Age

In a study of 2774 new enrollees over 65 years of age in Prudential SeniorCare (hereafter called the Prudential SeniorCare Study for this paper) in Cleveland, Houston, Tampa, and South Florida, Baker, Gazmararian, Sudano, and Patterson (2000) found health literacy was lower in the oldest age groups even when adjusting for performance on the Mini Mental State Examination (MMSE), newspaper reading frequency, and health status. They examined cognitive, health, and behavioral factors associated with FHL among older adults, attempting to determine whether or not there were any negative associations between age and functional health literacy that existed after adjusting for cognitive dysfunction, chronic medical condition, physical functioning, mental health, corrected visual acuity and self-reported reading of a newspaper. The differences in FHL across age groups were measured by administering the short version of the Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) developed by Parker (1995). The S-TOFHLA is one of the most utilized measures of health literacy and is easily administered in seven minutes.

The mean age of the participants was 73.1 ( $\pm$  6.3). 84.1% were Caucasian, and 31.7% did not complete high school. S-TOFHLA scores showed a large difference among age groups with the 65-69 group scoring 81.9, the 70-74 group scoring 75.6, the 75-79 group scoring 69.9, the 80-84 group scoring 60.8 and the 85 and older group scoring 48.6 (p<.001). FHL was also related to reading a newspaper. The mean S-TOFHLA was 52.1 for those who never read a newspaper, 70.4 for those who read a newspaper less than four days a week and 77.1 for those who read a newspaper at least five times a week (p<.001). There were also differences with performance on the MMSE (Spearman correlation coefficient 0.58). The mean S-TOFHLA scores ( $\pm$  *SD*) by the MMSE quartiles (lowest to highest) were 47.2 (24.7), 72.2 (22.8), 79.3 (20.2) and 89.8 (13.1). The MMSE is an eleven question examination that requires only five to ten minutes to administer and is widely used to cognitive screening measure (Fulstein, M., Folstein, S., & McHugh, 1975) (Pedraza et al., 2012). The presence of different chronic medical conditions was not significantly related to FHL.

This study was not without limitations. Evidence exists that older adults' ability to quickly perform cognitive tasks declines with age (Salthouse, 1996), and since the MMSE and the S-TOFHLA are both timed exams, the oldest participants of the study may have had more difficulty completing the cognitive tasks of both exams. Further, the study was limited by the participant makeup. Only 37% of all new enrollees in the

health plan participated in the study and those in the group who did not had a higher socioeconomic status based on their ZIP codes. In addition, this study was taken from a convenience sample of new Medicare enrollees and was not representative of the older adult population since many of the enrollees with higher incomes refused to participate in this study. Lastly, this was a cross-sectional study that did not follow participants as they aged into another age group. This limitation prohibits making any inferences about a causal relationship between getting older and declining health literacy. Another study demonstrating the relationship of health literacy with age was done by analyzing the data from the 2003 National Assessment of Adult Literacy (NAAL) (Martin, et al., 2009). Based on a 0 to 500 point scale, the NAAL had a mean score of 245 (SD=55) and classified health literacy into one of four levels: below basic (0-184), basic: (185-225), intermediate (226-309), and proficient (310-500). The sample mean of health literacy scores in people 50-64 years of age was 246.4, and that dropped to 220.6 for 65-74 year olds and 208.4 for Americans 75 and older (p < 0.001) showing that as people aged, their health literacy tended to decline.

Data from the Prudential SeniorCare Study further suggested a connection between race and limited health literacy. Analyzing that data, Howard, Sentell, & Gazmararian (2006) investigated the role of race and health literacy in older adults. Adequate health literacy was found in 71% of white but only 36% of black participants. Further, only 10 % of whites had marginal and 19 % had inadequate health literacy. This contrasted with 12% of blacks with marginal health literacy and 52% with inadequate health literacy (p < .001). Further investigation of those data by Gazmararian et al., (1999) showed that Caucasians in the sample had higher health literacy than Blacks, English-speaking Hispanics, and Spanish-speaking Hispanics. Of the Caucasians in the study, 18.9% scored in the inadequate health literacy category, 10.1% scored in the marginal category and 71% scored in the adequate category. English-speaking Hispanics scored 29.5% in the inadequate category, 14.8% scored marginal, and 35.9% scored as having adequate health literacy. Of Spanish only Hispanics, 34.3% scored as inadequate, 20%, and 45.7% were rated as adequate. Among African-Americans, 52.1% scored as inadequate, 12% as marginal, and 35.9% in the adequate category (p<.001), indicating there may be a cultural bias in the instruments used here.

The relationship between education levels and health literacy is well documented. Using data from 2003 NAAL, Martin et al. (2009) determined that the educational attainment was strongly associated with health literacy. There was a large difference in literacy scores between those with the highest education and those with the lowest education. Those with lower than a high school education scored 49.3; those with a high school or GED scored 66.9; those with some college scored 73.4 and those with a Bachelor's degree scored 82.2 on the NAAL.

In a later study, the Health ABC Study, Sudore et al., (2006) assessed the health literacy of 2,500 Medicare eligible black and white 70-79 years old people living in Memphis, Tennessee and Pittsburgh, Pennsylvania. The mean age was 76. The criteria to qualify for the study included: (1) English speaking; (2) ability to walk one quarter of a mile; (3) ability to climb a set of stairs; (4) be able to perform basic activities of daily living; and (5) must be living in the community. Participants were chosen randomly based on their ZIP code and researchers assessed their health literacy using the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM was the first assessment available for health literacy and is based on medical word recognition and pronunciation of 66 common medicals terms (Davis, Crouch, & Long, 1991). This study took into account age, race, annual income, health status, education, and comorbidities of cardiac disease, stroke, cancer, hypertension, diabetes mellitus, obesity and depression. Stratified analysis showed that 34% of African-American men with more a high school education had limited health literacy and 80% African-American men without a high school education had limited health literacy (Table 1). Only 10% of white men with a high school education or more had limited health literacy but for those without a high school education, 46.7% had limited health literacy. For African-American women with a high school education or more, 21.3% had limited health literacy in contrast 66% African-American women who did not have a high school education and had inadequate health literacy. Of the white women in the study, 3.4% with at least a high school education had limited health literacy and 32.9% of those without a high school education had limited health literacy (p < .001). Table 1 clearly demonstrates the relationship with education and adequate health literacy.

|                        | With High School | Without High School |
|------------------------|------------------|---------------------|
|                        | education        | Education           |
| African American Men   | 34%              | 80.7%               |
| White men              | 10%              | 47%                 |
| African American Women | 21%              | 66%                 |
| White Women            | 3%               | 33%                 |

 Table 1. Prevalence of Limited Health Literacy by Race

#### Activities of Daily Living

Using data from the Prudential SeniorCare Study, Wolf, Gazmararian and Baker (2005) studied health literacy and its relationship with activities of daily living. Adjusting for prevalence of chronic diseases smoking status, annual income, education, alcohol use, and site, participants with inadequate health literacy had worse physical functioning than individuals with adequate health literacy. Those with marginal health literacy had higher rates of self-reported instrumental activities of daily living, fewer limitations in daily activities because of physical health, and reported more accomplishments because of physical health than those with inadequate health literacy.

### **Cognitive** Abilities

Federman, Sano, Wolf, Siu, and Halm (2009) determined that lower cognitive function in older adults was strongly associated with low health literacy. Using a crosssectional cohort of 414 independently living older adults ages sixty and older recruited from senior centers and senior apartment buildings in New York City, Federman et al. measured health literacy in participants with the S-TOFHLA, as well as immediate and delayed recall with the Wechsler Memory Scale II (WMS), verbal fluency with Animal Naming, and global cognitive function with the MMSE. Using multivariate logistic regression, Federman, et al. determined that all measures of abnormal cognitive function were significantly associated with inadequate health literacy even after adjusting for education and other demographics. Participants with abnormal cognitions had three to five times greater adjusted odds ratio of inadequate health literacy.

#### Knowledge

In 2003, Gazmararian, Williams, Peel, and Baker with the Prudential SeniorCare Study selected 636 new Medicare enrollees with at least one of the following chronic diseases: asthma, diabetes, congestive heart failure; and hypertension, and asked participants about knowledge of each of the participant's specific diseases ()). They concluded that on the S-TOFHLA (total scale 1 to 100), for every ten point increase, the percent correct for asthma increased by 2.8 points, 1.7 point for congestive heart failure, 2.5 points for diabetes, and 1.3 points for hypertension. As FHL increased, so did the scores on the knowledge portion concerning his or her specific chronic disease, demonstrating that health literacy plays a vital part in the knowledge of asthma, diabetes, congestive heart failure and hypertension.

In a study of 489 Medicare outpatients patients in Chicago, Cho, Lee, Arozullah, and Crittenden (2008) determined that those with inadequate health literacy had significantly poorer knowledge of their disease(s) and treatments than those with adequate health literacy. They concluded that even though health literacy was positively correlated with disease knowledge (r = 0.65), health behavior (r = 0.42), preventative care (r = 0.21), and medication compliance (r = 0.20), health literacy had a direct effect on health status ( $\beta = 0.48$ ), hospitalizations ( $\beta = -0.24$ ) and emergency room visits ( $\beta = -0.35$ ) and was not influenced by those four factors.

#### Beliefs

Many low-income seniors, especially African-Americans and seniors with inadequate health literacy do not trust generic medications. Iosifescu, Halm, McGinn, Siu, and Federman (2008) studied 311 adults over 65 years of age at two primary care practices at an inner-city tertiary care hospital that serves predominantly low-income patients in East Harlem, New York City. The researchers tested health literacy with the STOFHLA and interviewed participants about their beliefs concerning generic medication usage and insurance status. Using multivariate linear regression, they concluded that only black race and inadequate health literacy were significantly associated with negative beliefs about generic medication. Those with inadequate health literacy tended to believe that generic medications were not as effective or were unsafe compared to name brand drugs. They also believed that generic drugs had more side effects than name brand drugs.

#### Reading

The International Adult Literacy and Life Skills Survey (IALSS), administered in 1994, 1996, 1998, and 2003 is a comparative survey to assess the world's reading and numeracy levels. The IALSS involves 21 countries, including the United States. Wister, Malloy-Weir, Rootman, and Desjardins (2010) used the Canadian data and took a subsample of older adults who were 66 years and older. There were five levels of literacy with increasing difficulty but because they were interested factors associated with inadequate health literacy, they dichotomized the results into adequate and inadequate health literacy. They found that those people who read manuals, reference books, and journals for learning or used the Internet for learning had a higher likelihood of adequate health literacy as defined by their scores on the IALSS. However, they were unsure what the relationship was leading to the question: Did people with adequate health literacy read more because they understood it or did they understand what they read because they had adequate health literacy?

#### Interpersonal Determinants

#### *Communication*

Social communication is extremely important when working with one's healthcare provider. If the patient cannot understand instructions and cannot express that he or she does not understand what the healthcare provider is trying to convey, then treatment adherence may be difficult.

Hester (2009) recruited 65 older adults (63 – 93 years) from senior centers and churches in Maryland and Pennsylvania. All participants resided independently in senior citizen complexes or private houses. Functional health literacy was assessed using the STOFHLA and social communication skills were assessed using the Social Communication subtest of the Functional Assessment of Communication Skills for Adults (FACS). The FACS is an assessment of social communication skills such as conversation skills, agreeing, disagreeing, understanding facial cues and vocal tones, understanding figurative language, and following directions (Frattali, Thompson, Holland, Wohl, and Ferketic, 1995). The subtest consists of twenty-one items and provides quantitative data on social skills. Of all the areas studied, facial expression and expressing disagreement had the strongest relationship with functional health literacy. As facial expression and expressing disagreement scores dropped, so did their functional health literacy scores.

#### Social Support

Lee, Arozullah, Cho, Crittenden, and Vicencio (2009) studied 489 Medicare enrollees at the Mercy Family Health Center in Chicago. Criteria for eligibility were over 65 years old, a Medicare recipient, at least one outpatient visit between 1999 and 2003, correctly answering three questions on the MMSE, able to speak English, have good vision and hearing, and not reside in a nursing home. Health literacy was assessed with the STOFHLA and social support was measured with the 21 item Medical Outcome Study (MOS). The MOS is an instrument to measure social support that assesses the level of perceived support a person has (Sherbourne and Stewart, 1991). The researchers assessed health status using the question: "How would you rate your health?" on a 5point Likert scale from poor, fair, good, very good, and excellent. Mental health and physical health were measured by the widely used12-Item Short-Form Health Survey (SF-12). The SF-12 is a short alternative to the MOS (Ware, Kosinski, & Keller, 1996). The researchers found that in participants with low health literacy, social support was only associated with mental health. In the high health literacy group, social support was associated with all of the health status measures. They concluded that in order to produce a salutary health effect, one might enhance social support in older adults. Weaknesses of the study included self-reported health measures and the fact that the sample was a cross section of older adults in Chicago including only Blacks and Whites, which was not generalizable to the population as a whole.

#### Organizational (Organizations, Social Institutions)

#### Healthcare Access

Sudore et al. (2006), collected data on 2512 black and white independently living older adults aged 70-79 at baseline of a three year study. They recruited participants at senior centers and senior residential apartments in Pittsburgh and Memphis. Participants had to speak English, be able to walk one mile, perform basic activities of living, climb a flight of stairs, have no clinical dementia, and be enrolled in Medicare. They used the REALM to assess functional health literacy. Demographic information including age, sex, income levels, education, and race was collected at the baseline and health status measures were assessed during year three. This study determined that there is an association between limited health literacy and socioeconomic status, comorbidities, and poor access to healthcare. Those older adults with limited health literacy were less likely to have a physician, health literacy may be an independent risk factor for health disparities and older people.

Cho et al. (2008) studied 489 Medicare patients at the Mercy Hospital and Medical Center (MHMC) in Chicago, Illinois. Criteria to qualify to participate in the study included: over age 65; Medicare recipients, a patient at the MHMC; mentally competent; possess good vision and hearing; currently living at home in Illinois; and the ability to complete the interview in English. This team used the S-TOFLHA (The Shortened version of the Test of Functional Health Literacy in Adults developed by Parker. The S-TOFHLA has proven to be one of the best measures of health literacy and is easily administered in seven minutes. Participants were categorized into three levels: (1) inability to read health texts, (2) unable to interpret health texts, and (3) adequate health literacy (able to read and interpret most health related texts). The inability to read health texts was interpreted as inadequate health literacy and the inability to interpret health texts was interpreted as marginal health literacy. Variables in the study included the following: *health literacy* (as determined by the S-TOFHLA), *disease knowledge*, *health behavior*, *preventive care utilization*, *medication compliance and understanding of the medication regimen*, *health status*, *health care utilization*, and *socio-demographic variables* including *race/ethnicity*, *gender* and *educational attainment*. Study findings concluded that health literacy was significantly directly related to all of the variables in the study with no mediators.

#### **Preventive Care**

The Prudential SeniorCare Study demonstrated that limited health literacy is independently associated with lower utilization of healthcare preventive services. After adjusting for amount of education, race, years of schooling completed, income, and health status, Scott, Gazmararian, Williams, & Baker (2002) determined that individuals with low health literacy were more likely to report not participating in preventive services even though they were available to them and they were aware of their availability. They were less likely to receive influenza and pneumococcal vaccinations, mammograms, and Papanicolaou smears.

#### *Hospitalizations*

Additional examination of the data in the Prudential SeniorCare Study by Baker, Gazmararian, Williams, Scott, Parker, Green, Ren, and Peel (2002) determined that poor health literacy was an independent risk factor for hospitalization admissions. Participants with lower health literacy were more likely to be hospitalized (52% higher risk) than those with adequate health literacy. Further, those with limited health literacy were also more likely to be hospitalized two or more times. Using data obtained in the Prudential SeniorCare Study, Howard, Gazmararian, and Parker (2005) compared emergency room costs of the study participants with their level of health literacy and concluded that older adults with limited health literacy. Emergency room costs were significantly higher as well as greater inpatient services costs. A comparison of health status and health literacy is shown in Table 2.

| Authors             | Title   | Key elements   | Comments                       |
|---------------------|---|--|--------------------------------|
| Scott, et al., 2002 | FHL and preventive health care use  | FHL independently associated with                    | These services                 |
| Scott, et al., 2002 | among Medicare enrollees in a   | preventive care such as mammograms,                  | were available to              |
|                     | managed care organization   | vaccinations, and Papanicolaou Smears                | participants                   |
| Baker et al., 2000  | The Association between age and   | Different chronic conditions had no                  | Mostly low-                    |
| Dakei et al., 2000  |   | statistically significant relationship               | income                         |
|                     | FHL among elderly persons   | with FHL. Showed demographic                         | participants                   |
|                     |   |  | participants                   |
| Martin et al., 2009 | Developing predictive models of FHL   | relationships<br>NAAL. Direct relationship with age  | Decreases with                 |
| Martin et al., 2009 | Developing predictive models of FHL   | NAAL. Direct relationship with age                   |                                |
| Wolf,               | Health literacy and functional health                                       | Inadequate FHL related to more                       | age<br>Examined daily          |
| Gazmararian.        |   |  |                                |
| Baker 2005          | status among older adults   | physical limitations                                 | living activities              |
| Federman et al.,    | Health literacy and cognitive   | Low FHL associated with abnormal                     | Examined delayed               |
| 2009                | performance in older adults   | cognitive functioning                                | recall                         |
| Gazmararian et al., | Health literacy and knowledge of  | Low FHL had lower knowledge of                       | Disease specific               |
| 2003                | chronic disease   |  |                                |
| 2003                | chionic disease   | disease specific conditions including                | knowledge plays                |
|                     |   | diabetes, asthma, congestive heart                   | key role in                    |
|                     |   | failure, and hypertension                            | managing chronic               |
| Cho et al., 2008    | Effects of health literacy on health  | Low FHL had lower knowledge of                       | conditions<br>Examined chronic |
| Cho et al., 2008    | Effects of health literacy on health status and health services utilization | their disease and treatments                         |                                |
|                     |   | their disease and treatments                         | diseases patients              |
| Tf                  | among the elderly   | Minterest and a second in the stimul                 |                                |
| Isoefescu et al.,   | Beliefs about generic drugs among   | Mistrust generic medications                         |                                |
| 2008                | elderly adults in hospital-based  |  |                                |
| 11                  | primary care practices  | Less FILL and sisted with more                       | Communication                  |
| Hester, 2009        | An investigation of the relationship  | Low FHL associated with poor<br>communication skills | Communication                  |
|                     | between health literacy and social  | communication skills                                 | skills are                     |
|                     | communication skills in older adults  |  | important for                  |
|                     |   |  | patients working               |
|                     |   |  | with healthcare                |
|                     |   |  | team to                        |
|                     |   |  | understand                     |
|                     |   |  | instructions and               |
|                     |   |  | express feelings               |
| I ( 1 2000          |   |  | and beliefs                    |
| Lee et al., 2009    | Health literacy, social support, and  | Low FHL associated with low social                   | Study used only                |
|                     | health status among older adults  | support, higher FHL associated with                  | blacks and whites              |
|                     |   | greater social support and social                    | so cultural                    |
|                     |   | support was associated with all of the               | differences not                |
| 0 1 4 1 2005        | <b>T</b> • •, <b>11</b> •, • • • • •  | health status measures                               | examined                       |
| Sudore et al., 2006 | Limited literacy in older people and  | There was association between limited                | Less likely to have            |
|                     | disparities in health and healthcare  | FHL and socioeconomic status,                        | a doctor, health               |
|                     | access.   | comorbidities, and poor access to                    | insurance or                   |
|                     |   | healthcare   | receive                        |
| Character 1, 2000   |   |  | vaccinations                   |
| Cho et al., 2008    | Effects of health literacy on health  | FHL related to disease knowledge,                    |                                |
|                     | status and health services utilization                                      | health behaviors, preventive care,                   |                                |
|                     | among the elderly   | medication compliance, health status,                |                                |
| Commencia da 1      | Equation of the state 1's and 1's and 1's                                   | and healthcare utilization                           |                                |
| Gazmararian et al., | Functional health literacy and the risk                                     | Low FHL more likely to be                            |                                |
| 2002                | of hospital admission among   | hospitalized and more likely to be                   |                                |
|                     | Medicare managed care enrollees   | hospitalized more often.                             |                                |
| Howard et al.,      | The impact of low health literacy on  | Low FHL had higher emergency room                    |                                |
| 2005                | the medical costs of Medicare   | and inpatient services costs                         |                                |
|                     | managed care enrollees  |  |                                |

Table 2. Health literacy and health status

## Discussion

This review indicates that there are large gaps in the literature related to health literacy, health status, and its determinants. Most of the information at this time about health literacy and older adults comes from the large Prudential SeniorCare Study conducted in Cleveland, Ohio; Houston, Texas; South Florida; and Tampa, Florida since 1997. While it was a large investigation with over 3,000 participants, the data have aged. Additionally, the study did not include the upper eastern and western coasts of the USA. Further, upper income SeniorCare enrollees tended to opt out of the study thus skewing the results to lower income participants. The study was conducted in urban settings and ignored the differing demographics between older adults living in rural and urban settings. Another area neglected by the literature is relationship between cultural factors and health literacy, and the population of the United States is very diverse. A wellknown example is that of an immigrant Hmong family and their young daughter with a seizure disorder are reported in the book, The Spirit Catches You and You Fall Down by Ann Fadiman (1997). The family believed that spirits were responsible for their daughter's seizures and so defied western medicine by not giving modern medical treatments. This resulted in a less than optimal seizure control and health outcome. Their lack of knowledge and skills concerning biomedical health issues and how to take care of their families lead to less than optimum health outcomes.

With immigration and the influx of other cultures into the United States, cultural differences are starting to come to light. Cultural differences in health literacy that need objective evaluation include patient-centered care, patient advocacy, medical care

delivery (such as those from a state-paying healthcare system), the effect of the mass media on certain populations, the use of community resources and health education opportunities in other cultures.

A limitation of many studies of health literacy was that all used instruments that incorporated word recognition and had time restraints. Older adults sometimes take longer to process information (Federman et al., 2009) and therefore the health literacy test may not have been an accurate assessment.

Research needs to address communication and health literacy. These studies should examine provider factors such as communication skills, teaching ability, and time spent with providers concerning day-to-day health maintaining activities. With the rise in popularity of the Internet and easily accessible health related information on the Internet, there is little research concerning association between Internet usage, health information, and health literacy.

Another fertile area for research would be system factors such as acute care orientation and health literacy. Questions may include, "How does healthcare delivery relate to health literacy?" and "Where does health literacy fit in with the Chronic Care Model (Glassgow, et al., 2001) (Wagner, 1998) (Wagner et al. 2001) especially with older adults?" As baby boomers age, the percentage of the population who are older adult grows and brings even more emphasis on aging and health issues than ever before. Questions one might ask include: "Is there a relationship between the graying of a population and health literacy levels?" "If baby boomers tend to be better educated than their parents, will health literacy issues change?" Further, there is very little research on health literacy and health outcomes of older adults. This issue has largely been unaddressed by current literature. Mortality among the older population and its relationship with health literacy has largely been ignored by researchers. The Prudential SeniorCare Study did report on mortality data but no other studies to date include mortality, older adults, and health literacy. Other research should include the relationship between legislative activities and health literacy such as how do Medicare policies and practice relate to functional health literacy.

As the population ages, the study of health literacy and older adults becomes more important to researchers, healthcare providers, health services providers, older adults, and legislative bodies. People are living longer, and suffer more chronic diseases than in younger populations. Clearly, health literacy is a large force in maintaining an optimum level of health.

## THE EVOLUTION OF MEASURING HEALTH LITERACY

#### **Overview**

The term "health literacy" was first used in 1974 by Simonds (Simonds, 1974). Simonds believed that teaching Americans about health issues would improve their health status and he posited that health education should be a policy issue and must be addressed via three domains: (1) the healthcare system; (2) the educational system; and (3) the mass communication system. He applied the term "health literacy" to teaching about health issues in grades kindergarten through grade twelve.

Forty years later, there are numerous definitions of health literacy depending on the organizational focus of the defining entity. The majority of these definitions are based on the clinical encounter and the biomedical model. In Healthy People 2010, health literacy is defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services for appropriate health decisions." The American Cancer Society also emphasizes clinical aspects with its definition of health literacy as "the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways that enhance health" (Greenberg, 2001). The American Medical Association Council of Scientific Affairs demonstrates their interest in the clinical/biomedical model in defining health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient (Ad hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999)."

One of the broadest definitions of health literacy is from the World Health Organization (WHO). WHO defines health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (World Health Organization, 1998). Recognizing that health literacy involves not only cognitive skills but also the physical ability to complete the desired behavior or action, Nutbeam (2000) posits there are three levels of health literacy. Level one is "functional health literacy" that involves communication and understanding information such as reading comprehension and oral skills. Level two is "interactive health literacy" and involves the development of personal skills, including self-help and social support groups. The third level Nutbeam describes is "critical health literacy." He describes this level as personal and community empowerment to improve social and economic determinants of health and the opportunities to build capacity. This level also includes achieving public policy changes to foster greater FHL. Nutbeam (2008) later argues that there are two different types of health literacy: clinical competencies and personal assets. Most of the research and measurement to date has been on the clinical aspects and implications of health literacy.

Since Simonds' initial work, several studies have established health literacy as a major influence on health status and disparities (Mika et al., 2005). In an editorial published in *The Journal of General Internal Medicine*, the United States Surgeon

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General, Dr. Richard H. Carmona, discussed the importance of addressing of health literacy in improving the state of the nation's health (Carmona, 2006). He says, "The poor state of health literacy is in crisis. It is an underlying cause of disparities. It is also a source of extensive disempowerment and perpetuates preventable disease."

Realizing the importance of health literacy and health status, researchers began to look at ways to measure health literacy. This paper discusses the evolution and uses of those instruments employed to determine functional health literacy levels.

#### Methods

Using the Texas A&M University Library website, three separate searches were conducted in the "General" category using the Academic Search Complete (EBSCO), MLA International Bibliography, Omnifile FT Mega (Wilson), CAB Abstracts Ovid), Medline, (Ovid), Web of Science, and the Science Direct databases. The first search used the terms "health literacy" and "assessment". This search resulted in 811 hits. The second search used the terms "health literacy" and "measurement" and resulted in 721 hits. "Health literacy" and "instruments" were the terms used in the third search. This search resulted in 216 hits. The same terms were then used to search ProQuest Dissertations and Theses database and Google Scholar and resulted in one hit and 315 hits respectively. Article selection criteria included the following: the research must have been conducted using the scientific method and conducted in the United States of America; must include some type of instrument and a set measurement; and must undergo a statistical evaluation. Eighteen articles fit the selection criteria and will be discussed here.

#### Written Instruments

#### Rapid Estimate of Adult Literacy in Medicine (REALM)

Since basic literacy may be an underlying factor in health literacy, the first instrument developed was based on word recognition and pronunciation. In 1991, researchers developed the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991). This instrument was developed for patients in primary care as a tool for physicians to use to assess their patients' reading abilities. Before development of the REALM, standardized reading tests were long and burdensome to administer, making it difficult to quickly assess reading levels. The REALM was designed to be a medical word recognition test where study participants were given a sheet of paper with 125 medical words on it which were developed standard patient education materials and patient intake forms at six public and private primary care clinics. The test was developed to identify patients reading on a low level and to assess on which grade level the subject read. Participants were asked to read the words aloud and the assistants made note of which words were pronounced correctly. The REALM takes about three to five minutes to administer and score. Research assistants administered three other wellrespected and standardized reading tests to which they compared the REALM: the Slosson Oral Reading Test (SORT), Peabody Achievement Test-Revised (PIAT-R) recognition and the PIAT-R comprehension exam. The SORT is a well-recognized test used to identify individuals from preschool through adulthood with reading difficulties and to assign reading levels (Tramill and Tramill, 1981). This test contains 200 words in ascending order of difficulty and takes three to five minutes to administer. Individuals

are then assigned a grade level based on the difficulty level of the words correctly read. The PIAT-R is a standardized reading comprehension assessment that contains 66 items in which an individual must read a sentence and then identifies one of four pictures that most accurately describes the sentence (Hanson-Divers, (1997). Items in the test are in ascending order of difficulty and the assessment is terminated when the individual erroneously identifies the corresponding picture. The PIAT-R takes from 22-25 minutes to administer. The REALM had very high correlations with the PIAT-R.

Two hundred and seven study participants were chosen from a convenience sample in six primary care clinics in Louisiana and Arkansas. Patients ranged in age from 17 to 87 with a mean age of 47. African Americans accounted for 54% with Caucasians accounted for 46%. High school drop outs accounted for 42% and 76% of the sample were females.

In order to score test results, the researches divided responses into four ranges described in Table 3.

| Raw Score     | Grade Range  |  |  |
|---------------|--|--|--|
| • 0-78        | Below third grade. Will not be able to read most literacy materials. |  |  |
| • 79-103      | Fourth to sixth grade. Will need low literacy materials; may not be  |  |  |
|               | able to read prescription labels                                     |  |  |
| • 104-114     | Seventh to eighth grade. Will struggle with most patient education   |  |  |
|               | materials; will not be offended by low literacy materials            |  |  |
| • 115 – above | High school. Will be able to read most patient education materials   |  |  |

Table 3. Four ranges of health literacy as tested by the REALM

Reliability was excellent Cronbach's  $\alpha$ , was.98. Criterion validity was very high when checked with the SORT: r= .95 and the PIAT-R: r=.98. Content validity and face validity were based on the words chosen.

One of the REALM's strengths was that there was finally an instrument to measure reading ability based on word recognition skills that was easily and quickly administered. There were, however, several weaknesses in the validation study. The study did not include younger patients from non-university clinics. The study also did not take patient characteristics such as poor eyesight, hearing impairment, and other characteristics that may affect reading levels into account. Another weakness is it is difficult to translate into Spanish. Further, patients may be embarrassed about their inabilities to read and may not be able to concentrate as they should. Lastly, this was a word recognition test and did not measure any type of comprehension or skill ability. A later study upheld Davis et al. findings but also showed that African Americans scored lower on the REALM even if their academic achievement was the same as whites (Shea, 2004). This may indicate a cultural bias in the instrument.

## Shortened REALM

Two years later, the REALM was shortened and studied (Murphy et al., 1993; Davis, 1993). The objective of the shortened version was to have an instrument that can provide reading grade estimates for patients who read below a ninth grade level in one to two minutes. This instrument was also designed based on word pronunciation/recognition and included 66 words on three lists (22 words on a list) of increasing difficulty. The first list contains small one and two syllable words, the second list contains two and three syllable words, and the third is comprised of much longer and more difficult words. In order to compare reading levels, the researchers compared the REALM with the SORT and the PIAT-R. Words on the instrument were taken from standard patient education materials and patient intake forms.

This instrument was administered to 203 patients in four university primary care clinics comprised of indigent and low-income patients. They ranged in age from 16 - 86 with a mean age of 43. Females made up 82% of and study and 76% were African American. Only 47% of participants completed high school.

Like the REALM, the Shortened REALM divided scores into four grade ranges shown in Table 4:

| Score   | Grade Range             |
|---------|-------------------------|
| 0-18    | Third grade and below   |
| 19 – 44 | Fourth to sixth grade   |
| 45 - 60 | Seventh to eighth grade |
| 61 – 66 | Ninth grade and above   |

Table 4. The Four Ranges of FHL for the Shortened REALM

Test-retest reliability was excellent with Cronbach's  $\alpha$ =.99. Criterion validity was excellent and established by comparison with the SORT: r = .96, PIAT-R: r = .97, and the WRAT-R: r = .88. The Wide Range Achievement Test (WRAT) is a widely used test to determine grade level reading proficiency (Tramill and Tramill, 1981). This test consists of 42 words in ascending order of difficulty and is based on correct pronunciation of the words. The WRAT takes about five minutes to administer and individuals are assigned grade levels according to accurate responses.

There were several strengths in using this instrument. It had excellent test-retest reliability and criterion validity. Further, it only takes a short period of time to administer and administrators need very little training. Murphy notes that one of the weaknesses of this shortened version is that it omits every fifth word of the longer version; making it difficult to test for specific information included in the longer version (Murphy et al., 1993).

#### REALM-R

It was not until ten years later that the REALM would undergo a revision and would become the Rapid Estimate of Adult Literacy-Revised (REALM-R) (Bass, Wilson, & Griffith, 2003). Trying to make the Shortened REALM even shorter and easier and faster to administer, Bass, et al. revised the instrument to consist of only eight words instead of the 66 on the Shortened Realm. The words chosen *were osteoporosis, allergic, jaundice, anemia, fatigue, directed, colitis, and constipation.* These words were taken from standard patient education materials and patient intake forms. To make it a less intimidating test and to help the participant become more at ease, smaller words like flu and pill were included at the beginning but were not scored.

Subjects were recruited from a convenience sample of patients at the General Internal Medicine Clinic at the University of Kentucky. There were 157 patients in the study who ranged in age from 18 to 93 years old. Thirty-two percent did not complete high school.

Administration and scoring of the REALM-R takes less than two minutes. If patients score less than or equal to six, poor health literacy is indicated. The reliability of the instrument was excellent with a Cronbach's  $\alpha = .91$ . Criterion validity was checked against the WRAT-R and was questionable with r = .64. The WRAT-R was not

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used with the original REALM but the S-REALM had a validity of r = .88 when compared to the WRAT-R.

Strengths included the time it takes to administer and score the instrument. One to two minutes is a more feasible time to administer this type of testing in a busy medical practice. There were, however, several weaknesses. Those limitations include the population studied. It was a fairly well-educated sample with few minority and few elderly patients. Also, the selection of words may not be applicable to other clinical settings or geographical areas (Arozullah et al., 2006). Thirdly, this instrument only measures grade levels below the ninth grade and only identifies those who are "at-risk" of low health literacy

In general, there are several weaknesses that are pervasive through all of the REALM instruments. These instruments only measure readability and not the individual's comprehension of a word or the ability to use the information. All three versions are only available in English (Nurss et al., 1995). Attempts to translate these instruments into Spanish were difficult due to difficulties with the phonetic structure of the Spanish language (Nurss et al., 1995). With the brevity of the instrument, the validity decreased from r = .88 to r = .64. Since participants were pronouncing fewer words, they may have been reluctant to pronounce certain words aloud such as *sexuality, testicle,* or *menstrual*.

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#### Test of Functional Health Literacy in Adults

Two years after Davis and Murphy developed the Shortened REALM, Parker began to develop a "valid, reliable instrument to measure the functional health literacy of patients" (Parker, 1995). She wanted to measure the ability to process numeracy as well as health reading and comprehension skills. Using actual hospital materials, the instrument she created, the Test of Functional Health Literacy in Adults (TOFHLA), was a multiple choice exam consisting of fifty items testing reading comprehension and seventeen numerical ability items. The TOFHLA takes up to 22 minutes to administer and is divided into two timed parts: the numeracy section and the reading comprehension component. The numeracy section directly tests quantitative literacy by assessing the individual's ability to use and understanding of numerical skills and following directions concerning medical regimens with numerical instructions. In this section, patients are given cue cards or prescription bottles to read and are then orally asked questions about the information. The reading comprehension component assesses the individual's ability to understand use written information. This section uses a modified cloze procedure (Abraham & Chapelle, 1992). The Cloze procedure is a well-respected reading comprehension tool in which every fifth to seventh word is omitted and the patient must choose the correct word to fill in the blank. The reader chooses from four possible answers, only one of which is correct. This instrument tests reading comprehension levels of fourth grade, 10<sup>th</sup> grade, and 19<sup>th</sup> grade. Items chosen for this test were taken from actual patient instructions for an upper gastrointestinal (GI) series and the standard Medicaid form advising patients of their rights and responsibilities.

This instrument was tested at the Grady Memorial Hospital in Atlanta, Georgia and at Harbor – UCLA Medical Center medical clinic and emergency care center in Torrance, California. Using a convenience sample, participants were recruited from patients who presented for acute care at this facility. Participants who were selected met the following criteria: no smell of alcohol on their breath, at least 18 years old, had easy to understand speech, not in police custody, no sign of psychiatric illness, and a requisite level of visual acuity (at least 20/50 vision using the Rosenbaum hand-held vision chart). There were 200 English speaking patients admitted to the study.

The instrument was scored into three sections: (1) 0 - 59 inadequate health literacy ("unable to read and interpret texts"); (2) 60 - 74 marginal health literacy ("difficulty reading and interpreting health texts"); and (3) 75 - 100 adequate health literacy ("can read and interpret most health texts"). The TOFHLA showed strong testretest reliability Cronbach's  $\alpha$ =.98. Content validity was affirmed using the REALM: r= .83 and the WRAT-R: r = .74 for comparison.

There were several strengths associated with the TOFHLA. Firstly, the TOFHLA was the first instrument to measure reading and comprehension skills. Having a strong reliability and validity in English, it measures a wide range of reading levels. The TOFHLA is available in Spanish and there are large print editions for those with poor eyesight. Since its introduction, the TOFHLA has become the reference standard and is widely used by researchers and practitioners to measure the health literacy of patients.

As strong a measure as the TOFHLA appears to be, there are some weaknesses inherent in the instrument. The TOFHLA takes a full 22 minutes to administer and is a timed test. This length and the actual timing of the test often contribute to patient frustration. The limited sample when the TOFHLA was tested is another weakness. Because of the demographics of the group, 91% of the participants were African American, 7% were Caucasians, and only 1% were Hispanic, the results cannot be generalized to the population as a whole. Further, since the TOFHLA tests overall health literacy, there is no way for practitioners and researchers to test for specific areas of health literacy. For instance, if a person has asthma, then that person may educate himself or herself about asthma and their health literacy for asthma may be very high, but it may be very low for gastrointestinal illnesses.

## Test of Functional Health Literacy in Adults in Spanish (TOFHLA-S)

At the same time Parker developed the TOFHLA, they developed a Spanish version of the instrument. The objective for the TOFHLA-S was the same as for its English version; to develop a valid instrument that tests not only word recognition associated with health literacy, but also comprehension and numeracy (Parker, 1995). The study design of the TOFHLA-S was exactly the same as its English counterpart. The Spanish version was created from the TOFHLA by translating it into Spanish and then back into English. Any discrepancies were addressed and corrected by bilingual staff members and a Spanish literacy expert. The scoring remained the same as the English TOFHLA. The test-retest reliability for the TOFHLA-S was Cronbach's alpha:  $\alpha = .98$ . No validity tests were performed on the TOFHLA-S because there is not a REALM or a WRAT-R in Spanish.

Much like the English TOFHLA, the TOFHLA-S has strengths and weaknesses. In 2005, Aguirre et al. (2005) confirmed the performance of the TOFHLA-S among Spanish speakers for assessing reading levels. Other strengths of the TOFHLA-S are that it measures comprehension, numeracy and a wide range of reading levels and provides some type of instrument to measure health literacy in Spanish speakers. Weaknesses of the TOFHLA-S were much the same as for the TOFHLA with a few additional limitations. Those include limited sample size from one specific area of the United States. The majority of Hispanics in the study were immigrants from Puerto Rico and not other Central American countries. There are no validation studies of the Spanish version of the TOFHLA so content validity could not be established. Aguirre et al. (2005) found that Hispanics who took it in English did better than Hispanics who took it in Spanish, thereby further questioning the validity of the instrument for Spanish speakers. Comparing the Spanish version to the English version proved difficult since each version is not comparable to its counterpart. An additional weakness was the relatively long time (22 minutes) it takes to administer the exam.

## Shortened Test of Functional Health Literacy in Adults (Brief) (S-TOFHLA)

In 1999, Baker, Williams, Parker, Gazmararian, and Nurss created a shortened version of the TOFHLA, the S-TOFHLA, that took only 12 minutes to administer. Their objective was to pare down the TOFHLA and to create a shorter but reliable and valid instrument to more quickly identify those with poor functional health literacy. The project design was the same as the TOFHLA but was shorter. Instead of two timed tests for a total of 22 minutes, the S-TOFHLA consisted of two timed tests for a total of 12 minutes. Four numeracy items were selected from the original 17 based on their perceived importance in the health care system and how often patients answered the questions on the TOFHLA correctly. Thirty-six reading comprehension items were chosen from the original close items on the TOFHLA. Participants were recruited and chosen for the study using the same procedure and criteria as for the original TOFHLA.

Scoring the S-TOFHLA utilized the same categories as the original TOFHLA but since there were fewer items on the test, there were lower scores. The scoring for the S-TOFHLA was as follows:

- 0-53: Inadequate health literacy
- 54 66: Marginal health literacy
- 67-100: Adequate health literacy

The test-retest reliability for the reading section was very strong with Cronbach's  $\alpha$ =.97 and the reliability for the reading was lower, but still in an acceptable range: Cronbach's  $\alpha$  = .68. The correlation between the REALM and the S-TOFHLA was 0.80 overall, .61 on the numeracy section and .81 on the reading portion.

As with the original TOFHLA, the S-TOFHLA had several strengths and weaknesses. Strong reliability and good validity were strengths of the S-TOFHLA as was the shortened amount of time the test required. Perhaps the greatest weakness of the S-TOFHLA was the sample pool. Participants were chosen using the same criteria and techniques as participants for the original study for the TOFHLA. The majority of the sample was African American of low socio-economic background with little education.

#### Medical Achievement Reading Test (MART)

Two years after the development of the original TOFHLA, Hanson-Divers (1997) developed the Medical Achievement Reading Test (MART). Her objective was to create a quick and easily administered literacy test that can accurately assess individual reading levels in a health care setting. She designed a word recognition test using words from patient education materials, a medical dictionary, and common prescription labels. The MART was created using the Wide Range Achievement Test (WRAT), a standardized reading test that is used to determine grade-level reading ability by the pronunciation of words. The MART was comprised of 42 medically oriented words. Further difficulty is created by using very small letters (with a font about the size found on prescription labels) on a sheet of paper that has a very glossy cover. The purpose of the difficulty is to make the person taking the test feel more comfortable if he or she is unable to read and pronounce the words.

Hanson-Divers recruited 405 participants from one high school, one state-funded university one adult basic education program, and one mall in North Carolina. The mean age of the group was 36.5 years old and 56.6% were female. Thirty-eight percent of the sample was African American, 56% were Caucasian, and 6% were other. All of the adult education students were black.

Scoring was based on the number of correctly pronounced words. That number directly corresponded to an exact grade level. The MART presented a strong test-retest reliability with a Cronbach's  $\alpha = .98$ . The MART was not tested for validity. The

researchers assumed that since it was designed from the WRAT and used the same format, the proven content validity of the WRAT would apply to the MART.

The MART's strengths included a strong reliability and was quick and easy to administer as it took 3-5 minutes. Other strengths include putting participants into specific grade levels and its appearance. Participants are told that the glossy cover and the small print may make it hard to see to supposedly put them to ease if they have difficulty reading.

Weaknesses of the MART are numerous including the fact that the instrument only measures word recognition and not comprehension skills. Furthermore, the MART cannot be generalized to the rest of the population because the sample population was 56% Caucasian and chosen from North Carolina and not a nationwide random sample. In addition, the MART assumed content and criterion validity instead of testing it with the REALM and/or TOFHLA. In addition, test administrators had to attend three hours of training and there were differences in interviewers possibly creating interviewer bias. Also, there may have been a nonresponse bias in that people approached to participate in the study may have declined because of low literacy status.

## Newest Vital Sign (NVS)

One of the latest instruments to measure health literacy is the Newest Vital Sign (NVS) developed in 2005 (Weiss et al., 2005). Their objective was to develop a quicker and more accurate tool for screening for health literacy in Spanish and in English. They believed that the TOFHLA and the REALM took too long to administer in a clinical setting. The NVS was developed by a panel of health literacy experts using health

literacy scenarios and concepts used in health literacy research. The patient taking this test was shown the nutrition label from and ice cream container and asked six questions about the label. They were allowed to hold the label during the entire session. Questions about the nutrition label included numeracy as well as some reasoning skills. For example, the label included peanut oil as an ingredient and participants were asked, "Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream?" The average time for English speakers was 2.9 minutes and for Spanish speakers it was 3.4 minutes.

Weiss et al. (2005) recruited participants in waiting rooms of three primary care practices in Tucson, Arizona. One of the three practices was a publicly funded clinic primarily serving individuals who speak Spanish. In order to enroll in this study, participants had to be over 18 years old, speak English or Spanish, and have good visual acuity. There were 250 in each language group. The English speaking participants ranged in age from 18-35 years old with the mean age of 41.3 years old. The Spanish speaking participants ranged in age from 18-77 years old with the mean age of 40.8 years old. Non-Hispanic Whites made up 43% and Hispanics comprised another 43% of the English speaking participants. The only African Americans in the study participated in the English version and comprised 5% of the participants. In the Spanish speaking portion, 100% of the participants were Hispanic. In the English version, participants had a wide range of education ranging from 2 - 24 years of schooling with the mean of 12.7 years of schooling. The Spanish speaking participants had less schooling ranging from 0 - 23 years with the mean of 10.7 years

Individuals who participated in this study were put in one of three categories:

- 0-1: High likelihood of limited health literacy. Weiss went on to instruct physicians to be careful working with these patients in this category because they may not understand physician recommendations.
- 2-3: Possibility of health literacy
- 4-7: Almost always indicates adequate health literacy.

The reliability of the English version was acceptable with a Cronbach's  $\alpha = .76$ and the validity tested against the English TOFHLA was acceptable with r = .69. The reliability of the Spanish version was questionable with a Cronbach's  $\alpha = .69$ . The correlation of the Spanish version with the TOFHLA-S was poor with a Pearson r = .59.

The NVS did have several strengths when compared to other instruments. It was the first literacy screening instrument that can be administered in about three minutes as compared to the S-TOFHLA that takes three to five minutes. The NVS had a strong numeracy evaluation. Since the label is readily seen on food products, study participants may feel at more ease in taking the test and may attend to instructions to, "always read the label." Besides label familiarity, the NVS employed reasoning skills in interpreting label information. In a 2006 study, Baker demonstrated that the NVS was a more accurate picture of health literacy than other instruments (Baker, 2006).

The NVS does have weaknesses that may influence results in other practices. Firstly, the Spanish NVS was not as good as English because the psychometric properties were not as strong (unacceptable validity when compared to the TOFLHA). In a later study, Osborn (2007) examined the NVS, REALM and the S-TOFHLA. She determined that the NVS was not as accurate as the TOFHLA in predicting health outcomes but was more strongly correlated to the TOFHLA than the REALM.

# The Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA)

A year after the NVS, Lee et al. (2006) developed and validated a health literacy test for the Spanish speaking population that was easy to use and could be used anywhere. Their instrument, the Short Assessment of Health Literacy for Spanish Speaking Adults (SAHLSA), was based on the REALM and is a word-recognition test that includes a comprehension section of multiple choice questions. The instrument consists of words on laminated flash cards and requires the participant to read aloud the list of 50 medical terms (similar to REALM) and to associate that term to another term that closely matches it. Participants then chose the smaller word that was a closer match to the large word. Words used were medical terms taken from "a medical dictionary based on commonality of usage in everyday life conversations." This instrument was developed using a Delphi process with five experts who were both fluent in English and Spanish and worked with Spanish speakers in academic, medical, and public health settings.

Subjects were recruited in North Carolina and selection criteria included fluency in English or Spanish, ages 18 – 80 years old, no signs of cognitive impairment, visual acuity, and not intoxicated by drugs or alcohol. There were 202 English and 201 Spanish speaking participants. The main reason English speakers were included was to verify the design of the association of words in the SAHLSA using the correlation between the REALM score and the SAHLSA score. Females comprised about 56% of study participants. The mean age of Spanish speakers was 34.2 years as compared with 43.7 years for English speakers. Spanish speakers also tended to have less schooling with 10.1 years versus 13.0 years of schooling by the English speakers.

Because there was no appropriate Spanish instrument to use to determine grade levels, scoring of the SAHLSA was based on distributions of educational attainment and TOFHLA-S scores. There was a high degree of correlation r = .76 with the English SAHLSA suggesting the design of the association questions was adequate. In the Spanish SAHLSA, the Cronbach's  $\alpha = .92$  showing strong reliability of the test-retest method. The SAHLSA showed a questionable correlation with the yielding a Pearson's r = .65.

Results show the instrument has good reliability and evaluates the participants' comprehension of the subjects. It takes a relatively short period of time to administer (three to six minutes) and administrators need minimal training. Guessing by the participant is not a concern if clear instructions are given before the test is given. There are some limitations however. Since there are many different Latino subpopulations, this instrument may not yield the same results as it did for this group in North Carolina. Also, the sample size for the Spanish portion was relatively small and was comprised of 56% females. Further, participants recruited at a university based hospital may be more receptive to a health literacy test than other community based settings. In addition, in

order to design appropriate patient education materials, the SAHLSA needs to be able to assign participants into grade equivalent levels.

#### The Demographic Assessment for Health Literacy (DAHL)

The Prudential Medicare Study was conducted in 1997 in four locations in the United States: Cleveland, Ohio; Houston, Texas; South Florida; and Tampa, Florida. Using data from this survey and data from the National Health Interview Survey (NHIS) conducted in 1995 and in 2005, researchers looked into the question of whether or not one could use certain demographics on national surveys to predict health literacy (Hanchate, 2008). Hanchate administered the TOFHLA to survey participants and compared them to survey scores. There were 2,834 from the Prudential Medicare Study and 6,819 from the NHIS study. He specifically looked at eight factors: sex, age, race/ethnicity, marital status, years of schooling completed, annual income, TOFHLA scores, and self-reported health/chronic conditions. Hanchate suggested using this method of comparison and called it the Demographic Assessment for Health Literacy (DAHL).

There was a statistically significant correlation with four of the demographic factors with inadequate health literacy and with health outcomes. Using linear regression, he found a correlation of the following: years of schooling, age, sex, age, and race/ethnicity. He concluded that the DAHL was correct 79% of the time and the sensitivity for detecting inadequacy was 59% and the specificity was 84%. If he used a DAHL of 69, the sensitivity increased to 72% but the specificity lowered to 77%. He posited that an acceptable sensitivity and specificity was 70 – 80%.

This study had several strengths and weaknesses. Firstly, the data were easy to obtain and find. The researcher did not have to spend the time conducting a demographic study and could directly administer the TOFHLA to study participants. Secondly, the study had several strong statistical measures supporting the hypothesis that a correlation between demographics and the TOFHLA exists. However, there were weaknesses to the study that complicates using this method as a way of defining inadequate health literacy. Since this study used the Prudential Medicare Study, the study was conducted with an elderly sample and not with a true representation of the population at large. Not all indicators were included in the NHIS that were in the Prudential Medicare Study. Another challenge to this method is that health outcomes are not stable; they can change over time. There was no way to determine their health status change. Further, researchers could not look at other contributing factors such as was the participant born in or out of the United States and what was their first language.

A comparison of the major health literacy written instruments can be found in Table 5.

| Name of       | Citation               | N    | Reliability    | Validity          |
|---------------|------------------------|------|----------------|-------------------|
| Instrument    |                        |      |                | -                 |
| REALM         | Davis et al., 1991     | 207  | $\alpha = .98$ | <i>r</i> = .95    |
| Shortened     | Murphy et al., 1993    | 203  | $\alpha = .99$ | <i>r</i> = .96*   |
| REALM         |                        |      |                |                   |
| REALM-R       | Bass, III et al., 2003 | 157  | $\alpha = .91$ | <i>r</i> = .64*   |
| TOFHLA        | Parker, 1995           | 200  | $\alpha = .98$ | <i>r</i> = .83*   |
| TOFHLA-S      | Aguirre et al., 2005   | 1066 | $\alpha = .98$ |                   |
| S-TOFHLA      | Baker et al., 1999     | 211  | $\alpha = .97$ | <i>r</i> = .80*   |
| MART          | Hanson-Divers, 1997    | 405  | $\alpha = .98$ |                   |
| NVS (English) | Weiss et al., 2005     | 250  | $\alpha = .76$ | <i>r</i> = .69**  |
| NVS (Spanish) | Weiss et al., 2005     | 250  | $\alpha = .69$ | <i>r</i> = .59*** |
| SAHLSA        | Lee et al., 2006       | 202  |                | <i>r</i> = .76    |
| (English)     |                        |      |                |                   |
| SAHLSA        | Lee et al., 2006       | 201  | $\alpha = .92$ | <i>r</i> =65      |
| (Spanish)     |                        |      |                |                   |

**Table 5. Major Health Literacy Instruments** 

\*When compared to the REALM

\*\*When compared to the TOFHLA

\*\*\*When compared to the TOFHLA-S

## **Other Health Literacy Assessments**

One group of pharmacists, both academic and practicing, wanted to evaluate

pharmacy related educational materials routinely given to patients with their

prescriptions (Miller, De Witt, McCleeary, & O'Keefe, 2009). They had three objectives

to their study:

- To evaluate the understanding of pharmacy-relevant educational pamphlets using the Cloze procedure;
- To compare the results of the Cloze experiment with the gold standard of health literacy evaluations, the S-TOFHLA;
- 3. To use what they learned from the Cloze procedure to rewrite pharmacyrelated educational material.

The study was a descriptive, cross-sectional in-person 45 minute interview to assess levels of understanding of pharmaceutical educational pamphlets using the Cloze procedure.

Sabbahi, Lawrence, Limeback, and Rootman (2009) developed an instrument to determine oral health literacy in adults. Developed on the TOFHA model, the Oral Health Literacy Instrument (OHLI) contained both reading comprehension and numeracy assessments. Researchers recruited 100 participants from patients attending the dentistry clinics in Toronto, Canada. The instrument included oral health knowledge (38 items) and numeracy (17 items).

Other researchers worked to develop and validate an instrument that would measure patients' knowledge of chronic obstructive pulmonary disease (COPD). Maples, Franks, Ray, Stevens, & Wallace (2010) developed the Chronic Obstructive Pulmonary Disease knowledge Questionnaire (COPD-Q) to assess patients who needed extra education and counseling concerning caring for their COPD. Researchers developed a questionnaire based on current COPD care guidelines, a review of the literature, and clinical experience. Twenty-three expert content jurors evaluated the truefalse instrument and made suggestions for change. The instrument was then pilot tested on ten COPD patients who rated the questionnaire for understanding and interpretation. The group concluded that the COPD-Q would be a useful tool for healthcare providers to use when working with COPD patients.

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## **Screening Questions**

Realizing the limitations of formal questionnaires for instruments such as the length of time to administer and the embarrassment participants may feel when they cannot answer the questions correctly, practitioners and researchers have developed screening questions. They hypothesized that if they could get the assessment down to a few questions, then patients could be quickly and easily assessed at any point during a clinical encounter. Most question developers compared their questions to the REALM or the TOFHLA to establish validity.

The first screening questions were studied by Williams et al. (1995). The researchers wanted to develop a screening tool to quickly identify those people with inadequate health literacy. They conducted the study in two public hospitals; in Atlanta, Georgia and Torrance California, both large urban areas.

Participants were selected the same way they were selected in the previously discussed Parker study (1995) testing the TOFHLA. They had to be at least 18 years old, able to understand their speech, no psychiatric illness, not in police custody, native language must be English, not drunk or under the influence of alcohol or drugs, and wanted to participate. Participants were recruited after they were triaged and waiting to see a health care provider.

Questions were developed by the research team around issues that arose when they tested the TOFHLA earlier and asked participants about their self-identified reading ability. Before participants answered the questions, they completed a TOFHLA to test their health literacy as compared to their self-report. Question administrators had to complete 15 hours of training before they could administer the questionnaire. The questions and their sensitivity and specificity included:

- (1) "Can you read a newspaper?" Sensitivity = 16.7%, Specificity = 99.4%(Only 5.3% admitted they could not read a newspaper)
- (2) "Can you read forms and written materials obtained from the hospital?"Sensitivity = 19.8, Specificity = 99.3%
- (3) "Do you usually ask somebody to help you read materials you receive from the hospital?" Sensitivity = 51.4%, Specificity = 88.6%.

The major strength of these questions was the high specificity. Even so, the sensitivity was very low indicating that people with lower literacy underreport their reading ability. Williams et al. (1995) concluded that these questions correlate poorly with health literacy and recommended against using these questions to screen for functional health literacy.

Nine years later another group of researchers developed a set of screening questions to use for testing health literacy (Chew, Bradley, & Boyko, 2004). Their objective was to develop questions that when used in a clinical setting would accurately determine a patient's health literacy. Chew's team developed 16 screening questions to use at the preoperative clinic at the Veterans Administration Puget Sound Health Care System in Seattle, Washington.

Participants were selected from patients who presented to this clinic and were eligible for the study if they spoke English, were not too ill to participate, had visual acuity, did not have severe cognitive impairment and did not have an overt psychiatric illness. Participants were administered the S-TOFHLA to determine the health literacy before they answered the questions.

Questions were developed based on five domains identified in a qualitative study on health literacy (Baker et al., 1996). Those domains are "navigating the health care system, completing medical forms, following medication instructions, interacting with providers, and reading appointment slips." Researchers also included the sixth theme of including a surrogate reader. There were 16 questions that were scaled from one to four and there were no time restraints. Of the 16, only three proved to be predictive. Those questions are: (1) "How often do you have problems learning about your medical condition because of difficulty understanding written information?" (2) "How confident are you filling out medical forms by yourself?" and (3) "How often do you have someone help you read hospital materials?"

Chew, Bradley, and Boyko (2004) concluded that those three questions were appropriate to use when determining a patient's health literacy level. Each one of the questions has the potential to identify 80% of adult patients with limited health literacy. A further strength was that patients questioned in this manner were much less likely to suffer embarrassment from not being able to read medical terms. In a later study, Chew et al. (2008) used these same questions and determined that any of these questions were useful for determining adequate or marginal health literacy in a large Veterans Administration. Even with the promising results of the study, there were some limitations. The sample was mainly white male veterans in an ambulatory surgical setting so results cannot be applied to a larger more diverse population. The sample size was also too small to determine whether or not one of the three questions performed significantly better than self-reported education. In addition, patients were not told of the purpose of the study so those with poor literacy skills may have avoided participation. Lastly, the exploratory nature of the analyses and the multiple comparisons allow for a higher possibility of finding a Type I error.

Wallace, Rogers, Roskos, Holiday, and Weiss (2006) further studied the questions earlier studied by Chew et al. (2008) with the objective to evaluate their accuracy in identifying patients with limited or marginal health. Their comparison of health literacy was the REALM. Using a convenience sample, participants were recruited from a university-based primary care clinic using the same guidelines that were used in previous studies. Participants had to be at least 21 year old, able to speak English, have visual acuity, able to hear, and not have significant dementia or overt psychiatric illness. There were 305 participants ranging in age from 18 to 89 years old. The mean age of the participants was 49.5 and 67.5% were female. Caucasians accounted for 85.2%, 11.8% were African American, and 2.9% were Hispanic. Eighty-eight (28.8%) had less than a high school education.

Using the three questions Chew et al. (2008) determined to be good indicators of health literacy, Wallace et al. (2006) concluded that only one question was suitable for detecting marginal and inadequate health literacy in this population. The question that the researchers determined to be the better measure was, "How confident are you filling out medical forms yourself? Extremely, Quite a Bit, Somewhat, A little bit, and Not at all". For detecting limited health literacy, the somewhat response had a sensitivity of 83% and a specificity of 65%. For detecting limited marginal health literacy, the response had a sensitivity of 77% and a specificity of 74%. Study results were later reinforced using patients in a university vascular surgery clinic (Wallace et al., 2007).

This was considered by some to be a significant study because it identified one question that would assess limited health literacy and limited marginal health literacy. This was an improvement over the original study by Chew, Bradley, and Boyko (2004). in that it used 305 participants of English speaking men and women. As in the earlier study, there are limitations. Of the 305 participants 67.5% of them were females. Another limitation is that there was no random selection of patient raising selection bias. The third limitation is that the study was conducted at a single primary care clinic.

The same year the Wallace et al. (2006) study was published, Morris, MacLean, Chew and Littenber (2006) published their evaluation of the Single Item Literacy Screener (SILS), a brief instrument to identify limited reading ability. The objective was to determine the accuracy of the SILS to identify limited reading ability using the S-TOFHLA. Morris et al. randomly selected 999 adults 18 and older with diabetes residing in Vermont and bordering states from primary care clinics in the Vermont Diabetes Information System. Participants ranged in age from 22 – 93 with a mean age of 64.7. Females accounted for 54% of participants, 24% had less than a high school education, and 97% were Caucasians.

The 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?"

Scaled responses included 1-Never, 2-Rarely, 3-Sometimes, 4-Often, 5-Always. Scores greater than two were considered positive answers.

This question had a sensitivity of 54% and 83% when detecting limited health literacy. While both of those are acceptable, the sensitivity is not optimal. The question did not perform well (sensitivity of 34%) with marginal health literacy. This was similar to Chew et al. (2008).

Morris et al. (2006) concluded that this form of measurement performed moderately well ruling out limited reading ability in adults. However, there were limitations with the study. First, it did not perform well with those of marginal reading ability. Secondly, participants were the recipients of health care in a single area of the USA and were mostly female and white. Thirdly, most were well off enough financially to have health insurance and lastly, some of them had the SILS read out loud to them while the majority read the question themselves.

While all of the previously discussed health literacy instruments measure the health literacy of adults, a few studies were conducted measuring the health literacy of caretakers of pediatric patients. Parental health literacy can be very important to the health outcomes of some pediatric patients. Bennett, Robbins, and Haecker (2003) wanted to identify screening items that could be used in clinical practices that would screen for parental literacy. He used the REALM to examine the validity of the screening questions.

Participants were 98 adults who were primary caretakers of children under the age of six. They were recruited in the waiting areas of physicians and pediatricians in

three public health care centers in Philadelphia. The mean age of the caretaker was 29.5 (SD=10.4) years, 89% were African American, and the mean years of school completed was 11.1 (SD=1.8). Mothers made up 82% of the sample. The mean age of their children was 32.9 months (SD=22.4). Interviews took three to five minutes and all questions were administered orally and recorded by a single interviewer.

The research team started out with 17 questions in three domains (literacy activity at home, the literacy skill of the respondent, and parental literacy skill), but found only three to be good indicators. Those questions and their sensitivity and specificity are:

• "How many years of school have you completed?"

 $\circ$  Sensitivity = 1.0 CI(.89 - 1.00), Specificity = .14 (0.5 - .2 5)

• "Is your child's other parent living with you now?"

 $\circ$  Sensitivity = .84 CI(.67 - 1.00) Specificity = .54 CI(.40 - .60)

• "Do you ever read books for fun?"

• Sensitivity = .40 CI(.24 - .59) Specificity = .92 CI(.82 - .97)

One of the strengths of this study was the sensitivity and specificity of the second question, "Is your child's other parent living with you?" This question deserves further study as a predictor of parental health literacy because answering "no" was statistically significantly associated with low literacy with an odds ratio of 2.63 (95% CI=5.30-7.75). One significant limitation of the study is that it was very demographically limited; the sample was mostly poor African American women from an urban setting. Because of

the limited study population, you cannot make any conclusions as to how this could apply to other parents of small children.

## Discussion

Measuring functional health literacy proved to be difficult and existing instruments do not measure the broad spectrum of functional health literacy. There are some limitations in using the instruments and methods developed for testing functional health literacy. Most assess reading skills and medical terminology word recognition thus measuring familiarity with the language of the instrument. If functional health literacy is the ability to understand and use health information to promote and maintain good health then there are still no effective instruments to measure this concept. The first instruments developed to measure health literacy only measured reading ability and work recognition skills for clinical encounters. The ability to read and/or a higher level of education does not guarantee functional health literacy. Both the REALM and the TOFHLA were developed around word recognition and the TOFHLA measures word recognition around a specific type of medical/clinical encounter. A person can have adequate health literacy and not be acquainted with specific medical terms used in a clinical setting. In the same way, one can have the ability to read difficult clinical material but have no understanding of the information.

Generalizability is difficult because current instruments do not address age, education, or cultural differences. Older adults bring different experiences into the testing arena than younger adults. They may have more familiarity with some procedures because of medical history or as Rosen (1980) reported, they may have delayed recall thereby scoring lower on current examinations. On the other hand, younger adults may have more education or exposure to medical terminology due to Internet exposure. Also, cultural differences may play a hand in resulting scores. Current instruments were developed mainly for people who experienced life in the United States. Immigrants with different health and medical belief systems such as those from Laos (Fadiman, 1997) may find the instruments more challenging or be less able to apply them to their daily routine.

Further, since functional health literacy is situational there are no means to measure how health literacy changes with the situation. For example, a person may be very knowledgeable about arthritis, but know very little about diabetes. He or she may not understand basic instructions about diabetes prevention or care but need very little instruction about caring for his or her arthritis.

There were some limitations of this study. First, all instruments were developed and tested on the general population and not on older adults. Older adults may need a different type of instrument do to cognitive processing differences (Federman et al., 2009). Another limitation was the lack of recently developed instruments testing health literacy and those that exist test medical word recognition and not activities of daily living. Since most researchers agree that health literacy involves not only cognitive skills but also the physical ability to complete the desired behavior or action, in order to assess functional health literacy, one would need to assess physical abilities associated with functional health literacy: Nutbeam (2008) suggests that there are two distinct types of functional health literacy: clinical competency and personal asset. All of the instruments discussed here neglect to measure one's capacities. The closest measures of capability are the questions asking if the person needed help in following some type of instruction or reading materials and the NVS food label instrument. Even so, these neglect to assess everyday health behaviors out of the clinical setting such as the ability to correctly wash fruit before eating it, proper tooth brushing, or thoroughly washing hands. One major drawback of the question assessments is that in order to assess validity, they were compared to the REALM or TOFHLA, two instruments that measure reading skills and word recognition. When reviewing the literature, there were no measures for functional health literacy regarding daily living behaviors.

## Summary

Even though Simonds (1974) coined the term "health literacy" forty years ago, researchers have only recently begun attempting to measure it. Wanting to improve clinical encounters and patient comprehension of medical issues, clinicians created the first instruments to measure reading abilities and word recognition of standard medical jargon. They believed that a person's reading level and familiarity of medical jargon indicated his or her level of health literacy. These measures limited responses to clinical terms and did not measure any sort of health literacy in everyday circumstances. Later attempts to shorten the instruments so the assessment could be given in a shorter period of time continued to be based on the earlier clinical measures.

Perhaps it is time to begin investigating Nutbeam's (2008) premise that two distinctly different types of health literacy exists: clinical health literacy and health literacy for personal asset in daily living situations. While the clinical aspect is important, most people make decisions based on their personal experience as well as knowledge and do not spend the majority of their time in their physician's office. Personal and self-care/management have become even more important as health care costs continue to escalate while the number of uninsured increases. By measuring one's level of health literacy, interventions and health literature will be more successful when developed around those levels as they will more likely reach that person in a meaningful way. Developing measures for health literacy for personal asset as well as clinical measures should make programs and communications more successful thus improving health outcomes.

# THE RELATIONSHIP BETWEEN HEALTH LITERACY, PATIENT ACTIVATION, AND HEALTH STATUS OF OLDER ADULTS

#### Overview

The recognition of functional health literacy (FHL) began in 1974 when Simonds coined the term, health literacy (Simonds, 1974). Since then, researchers examined aspects of FHL and its relationship with health status. There are several different definitions of FHL depending on the organization focus of the defining body. For example, Healthy People 2010 defines health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services for appropriate health decisions." The American Cancer Society emphasizes a more clinical aspect and defines FHL as "the capacity to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways that enhance health" (Greenberg, 2001). By defining health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient", the American Medical Association Council of Scientific Affairs demonstrates their interest in the clinical/biomedical model (Ad hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Perhaps one of the most inclusive definitions of health literacy was developed by Nutbeam (2008) who described two different dimensions of health literacy: clinical competencies and personal assets. Clinical competencies focuses on the knowledge base of the individual and personal assets focuses on the ability of the

individual to act upon that knowledge. To date, most of the research and measurement of FHL has been on the clinical aspects and consequences of low FHL.

Few studies exist that examined the FHL of older adults and its relationship with health status. In a large study of Medicare enrollees in the Prudential SeniorCare Healthplan in Cleveland, Houston, South Florida, and Tampa, Gazmararian, Baker, Williams, Parker, Scott, Green, Fehrenback, Ren and Koplan (1999) studied a crosssection of 3,260 new Medicare enrollees ages 65 and older. They determined that 23.5% of the English speaking and 34.2% of the Spanish speaking participants had inadequate health literacy and 10.4% of the English speakers and 19.7% of the Spanish speakers (p<.001) had only marginal health literacy.

A further examination of the Prudential SeniorCare Study data indicated that inadequate health literacy is independently associated with not receiving preventive care such as mammograms, flu vaccinations, and Papanicolaou smears (Scott, Gazmararian, Williams, & Baker, (2002)). Using mortality data from 2013, the Prudential SeniorCare Study also showed that poor health literacy was a predictor of higher all-cause mortality and of cardiovascular death (Baker, Wolf, Feinglass, Thompson, Gazmararian, and Huang (2007).

Drawing upon earlier research into the Chronic Illness Care Model (Bodenheimer, et al. 2002) that suggests patients and their families who are integrated into their health care team as members with the skills, knowledge, and motivation to participate in a team approach have better health outcomes than those who do not take an active role in their chronic disease management, Hibbard, et al. (2004) developed the Patient Activation Measure (PAM). PAM was based on six domains of patient activation: self-management of symptoms and health problems, engagement in activities that maintain functioning and reduce health declines, involvement in their treatment and diagnostic choices, collaboration with healthcare providers, ability to select healthcare providers and facilities based on quality of care, and the ability to navigate the health care system. Hibbard et al. (2005) shortened the original assessment instrument of twenty-two items to thirteen items. The first two items focus on the person's belief that an active role is important. Six items center on confidence and knowledge to take action, items nine through eleven address taking action and two items examine the person's ability to stay the course and take action. The thirteen items on the Patient Activation Measure include:

- Taking an active role in my own health care is the most important factor in determining my health and ability to function.
- When all is said and done, I am the person who is responsible for managing my health condition(s).
- I know what each of my prescribed medications does.
- I am confident that I can follow through on medical treatments I can do at home.
- I am confident I can tell my health care provider concerns I have even when he or she does not ask.
- I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.

- I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition(s).
- I understand the nature and causes of my health conditions(s).
- I know the different medical treatments options available for my health condition(s).
- I know how to prevent further problems with my health condition(s).
- I have been able to maintain the lifestyle changes for my health that I have made.
- I am confident that I can figure out solutions when new situations or problems arise with my health condition(s).
- I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

Each item has the possibility of the following six responses: *Strongly Agree, Agree, Disagree, Strongly Disagree, Don't Know,* and *Not Applicable.* 

Hibbard et al. (2005) posited that patients in the lowest stages of activation may not understand their part in maintaining optimum health and may believe that their health care provider will provide all the care necessary to improving and maintaining their health. Hibbard et al. believed that in these stages, patients need to improve their understanding and knowledge about their conditions(s). Hibbard et al. further posited that as patients progress to higher levels of activation, so does their understanding, knowledge, and skills for self and collaborative care to gain and maintain optimum health. In the higher levels of activation, health care providers should seek to build selfefficacy so patients can maintain healthy behaviors/lifestyles while under stress.

Research on the relationship of patient activation and health status clearly demonstrates the more activated a patient, the better health-related outcomes. In a large study, Greene and Hibbard (2010) studied the electronic records of 25,047 patients in Minnesota and found that patient activation was related to a broad range of outcomes including lower smoking rates, lower likelihood to be obese, less likely to use the emergency department, participating in more cancer screenings, having blood pressure within the normal range, and fewer hospitalizations and doctor visits. To date, little research exists studying older adults and patient activation. Williams and Heller (2007) conducted a secondary analysis of the data from the Medicare Current Beneficiary Survey of 9,520 Medicare beneficiaries. They analyzed the relationships between patient activation, health status and health behaviors. They found that the more activated the participant, the more likely he or she was to have Medicare supplemental insurance and report better health. Participants with higher patient activation were also more skilled and motivated, more likely to participate in preventive behaviors and screenings and had fewer doctor visits. In a study of patient activation and older adults, Skolasky et al. (2010) established that older adults with higher patient activation had higher functional status, higher health care quality, and were more likely to maintain a healthier lifestyle than those with lower patient activation.

#### **Purpose of Study**

The purpose of this study was to examine the relationship between health literacy, patient activation and health status in adults over sixty years of age. The following hypothesis was tested: there is an interaction between heath literacy and patient activation and health status in older adults. This examines whether or not the relationship of health literacy and health status is enhanced with increased levels of patient activation.

#### Methods

## Study Sample

Data from this study were collected by the Brazos Valley Area Agency on Aging headquartered in Bryan, Texas and the Houston-Galveston Area Agency on Aging headquartered in Houston, Texas. The Area Agencies on Aging collect data from participants in its programs and other older adults living in their service areas for program planning and funding purposes. Because of the use of secondary administrative data, this study was reviewed by the Texas A&M Internal Review Board and was deemed exempt

The survey administrator recruited 601 participants from senior centers, churches and Area Agencies on Aging program participants in southeast Texas. Requirements for participation included the ability to understand English, to be over sixty years of age, able to answer health related questions in a meaningful manner, and the ability to finish the questionnaire in one sitting. Participants were given as much time as needed to finish the questionnaire. No identifying information such as name or address was collected and questions and answers were not shared among participants. Sixty-eight incomplete surveys were not included in the data analysis resulting in 533 final participants.

## Measures and Procedures

Senior Center staff recruited older adults who participated in center activities to complete the surveys and church leaders and active church members recruited older adults in their congregations to complete the surveys. The survey administrator then met with groups of participants and instructed them on how to record their best answers. If participants had difficulties understanding the questions, then the administrator explained what the item meant. Each participant completed his or her own survey. Upon completion of the survey, refreshments were provided.

The entire survey consisted of thirty-seven items assessing demographic information and health status, the thirteen question shortened PAM (Hibbard et al., 2005), and one screening question to measure functional health literacy (Wallace et al., 2006). Health literacy was measured by asking, "How confident are you filling out medical forms yourself?" Participants were given the choices of" *Extremely*", "*Quite a Bit*", "*Some What*", "*A Little Bit*", and "*Not at All*". Participants circled the response appropriate for them. The surveys were administered and collected by the same person in order to maintain internal validity.

Health status was measured using the four questions The Centers for Disease Control and Prevention (CDC) include in the National Health Interview Survey (CDC, 2011). Known as CDC HRQOL 14 "Healthy Days Measure", the first question was, "Would you say that in general your health is: Excellent, Very Good, Good, Fair, Poor?" and participants circled the appropriate response. The second question was, "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" and there was a blank for them to write in the number of days appropriate for them. Question three was, "Now thinking about your mental health, which includes stress, depression and problems with emotions, for how many days during the past 30 days, was your mental health not good?" followed by a blank for them to write in the number of days. The fourth question concerning health status stated, "During the past <u>30 days</u>, for about how many days did poor physical or mental health keep you from doing your usual activities, such as selfcare, work or recreation?" This was followed by a line for the participant to write in their answer. A further question included in the survey asking them to check any chronic conditions they had. This question said, "Please indicate which chronic conditions you have: (please check all that apply)". Choices were diabetes, heart disease, hypertension (high blood pressure), lung disease (asthma, emphysema, bronchitis), Arthritis/rheumatic disease, cancer, and other chronic disease. For this analysis, the number of diseases were then totaled.

## Analysis

All data were entered into an Excel spreadsheet by the survey administrator and then reentered by an independent contractor. The data were then compared for accuracy and verified by summing method. The summing method involves summing the data in each column and then compare that column to the one the other data entry personnel entered. Any discrepancies were then checked by comparing the participation number and the survey completed by that participant and then corrected accordingly. The data were imported into SPSS and all analysis was completed using SPSS 16.0. The functional health literacy-patient activation interaction variable was calculated by multiplying the health literacy and the patient activation variables together. The aggregate variable combining the four health status questions plus the total number of diseases was created in SPSS by analyzing the descriptives of the four variables and saving the standardized value as one variable. This dealt with the skewness of the health status data. Standardizing all four variables around the same mean created a more normal distribution thus yielding a more accurate linear regression (Tabachnick and Fidell, 1996).

## Results

Participants ranged in age from sixty to ninety-nine years old with the mean and median age of seventy-six. The majority of participants (57%) identified as "White" and 32.6% identified as "Black". Hispanics accounted for 7.0% of study participants. The majority of participants were high school graduates (34%) and 28.9% had some college or vocational school education. Forty-six percent of participants reported an income of less than \$15,000 as opposed to only 4.4% reporting an income from \$50,000-\$75,000. Females accounted for 78.8% of survey participants. Participant demographics are presented in Table 6.

| Demographic Characteristics       | n   | %    |
|-----------------------------------|-----|------|
| Sex                               |     |      |
| Female                            | 420 | 78.8 |
| Male                              | 113 | 21.2 |
| Household Companion               |     |      |
| Lives alone                       | 280 | 52.5 |
| Lives with others                 | 253 | 47.5 |
| Race                              |     |      |
| Native American                   | 22  | 4.1  |
| Asian                             | 7   | 1.3  |
| Black                             | 174 | 32.6 |
| Hawaiian                          | 3   | .6   |
| Hispanic                          | 42  | 7.9  |
| White                             | 304 | 57   |
| Other race                        | 10  | 1.9  |
| Educational Attainment            |     |      |
| Less than high school             | 71  | 13.2 |
| Some high school                  | 47  | 8.8  |
| High school graduate              | 181 | 34   |
| Some college or vocational school | 154 | 28.9 |
| College graduate                  | 73  | 13.7 |
| Graduate school                   | 7   | 1.3  |
| Income                            |     |      |
| Less than \$15,000                | 251 | 47.1 |
| \$15,000 - \$24,999               | 142 | 27.1 |
| \$25,000 - \$49,000               | 117 | 22.3 |
| \$50,000 - \$75,000               | 23  | 4.4  |

 Table 6. Demographic Characteristics of Study Respondents (N=533)

Using the question, "How confident are you filling out medical forms yourself?", only 14.8% (n=79) tested in the inadequate health literacy range. There were 136 participants (25.5%) who scored in the marginal health literacy range and 59.7% (n=318) scored in the adequate health literacy range. Only 19.5% of males (n=21) scored in the inadequate health literacy range as compared to 13.8% of females (n=58). Scoring in the marginal health literacy range was 19.4% of the males (n=22) and 27.1% of the females (n=114).

Health status was measured using four questions and is shown in Figures 1, 2, 3, and 4. For the first health status question, "Would you say that in general your health is: Excellent, Very Good, Good, Fair, Poor?" Survey participants circled the appropriate response. Using the "Excellent" response as five and the "Poor" response as one, the means score was 3.2. As shown in Figure 1, only 5.4% (n=29) reported poor health and 13.9% (n=74) reported fair health. There were 48.8% (n=260) reporting good health, 24.2% (n=120) reported very good health and 7.7% (n=41) reported excellent health.

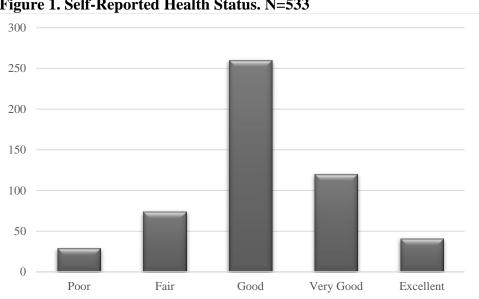


Figure 1. Self-Reported Health Status. N=533

For the second health status question, "Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" As shown in Figure 2, the majority of participants experienced either zero or one day of poor physical health. The mean number of days of poor physical health out of the last thirty days was 4.4 (SD=7.28) and 42.2% (n=225)

participants reported zero days of limited physical health, 8.6% (n=46) reported one day of limited health, 9% (n=48) reported two days of limited physical health, 5.4% (n=29) reported three days, 9.4% (n=50) reported four days, and 5.4% (n=29) reported five days of limited physical health. Another 7% (n=10) reported limited physical health for six days, 1.9% (n=10) limited physical health for seven days36% (n=31) reported poor physical health for eight days, 1.5% (n=8) reported poor physical health for nine, 3.4% (n=18) reported poor physical health for ten days, and 3.8% (n=20) reported poor physical health for thirty days out of the last thirty days.

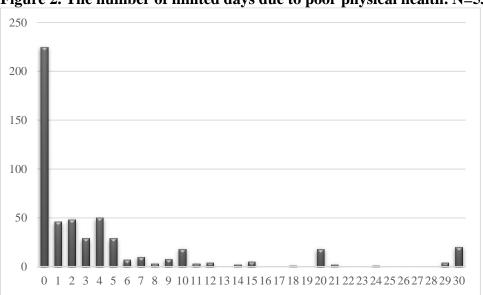


Figure 2. The number of limited days due to poor physical health. N=533

On the third question, "Now thinking about your mental health, which includes stress, depression and problems with emotions, for how many days during the past <u>30</u> <u>days</u>, was your mental health not good?" As shown in Figure 3, the majority of participants reported good mental health every day for the last thirty days. The mean

number of days of poor mental health out of the last thirty days was 3.3 (SD=6) and 58.9% (n=314) reported that their mental health was good every day, 3.8% reported poor mental health for one day, 3.8% (n=20). 8.8% (n=45) reported poor mental health for two days, 3.6% (n=19) reported poor mental health for three days, and 3.8% (n=20) reported poor mental health for four days, 1.5% (n=8) reported poor mental health for five days, 1.7% (n=15) reported poor mental health for seven days, 1.1% (n=6) reported poor mental health for eight days, 1.9% (n=10) reported poor mental health for nine days, 2.6% (n=14) reported poor mental health for ten days, and 1.3% (n=7) reported poor mental health for thirty days in the past thirty days,.

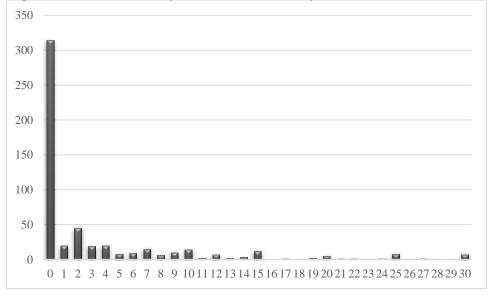


Figure 3. Number of Days of Limited Activity Due to Poor Mental Health. N=533

The mean number of days of limited activities was 3 (SD=6) but the majority (64.7%, n=345) stated that they missed zero days of activity due to poor physical or mental health on the fourth question asking about health status, "During the past <u>30</u>

days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work or recreation?" As shown in Figure 4, the majority of participants reported no limited activity due to poor physical or mental health in the past thirty days. 64.7% (n=345) participants reported missing zero days of activity, 4.1% (22) reported missing one day of activity, 7.5% (n=40) missed two days, 2.1% (n=11) missed three days, 5.4% (n=29) missed four days, 1.5% (n=8) missed five days, 2.1% (n=11) missed six days, .4% (n=2) missed seven days, .6% (n=3) missed eight days, .9% (n=5) missed nine days, 3.8% (n=20) missed ten days and 1.7% (n=9) had limited activities due to poor physical or mental health for 30 days out of the last thirty days.

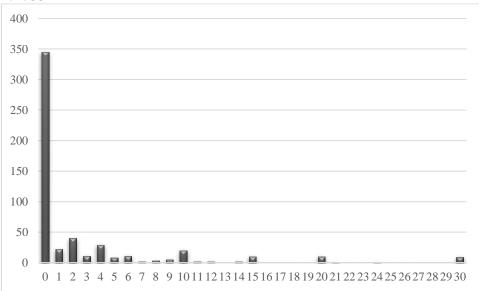


Figure 4. Number of days of limited activity due to poor physical or mental health N=533

A comparison of participants' self-reported health status responses for questions two, three, and four can be found in Table 7.

| Ľ              | Question 2 <sup>a</sup> | Question 3 <sup>b</sup> | Question 4 <sup>c</sup> |
|----------------|-------------------------|-------------------------|-------------------------|
|                | Physical Health         | Mental Health           | General Health          |
| Number of Days | n (%)                   | n (%)                   | n (%)                   |
| 0              | 225 (42.2)              | 314 (58.9)              | 345 (64.7)              |
| 1              | 46 (8.6)                | 20 (3.8)                | 22 (4.1)                |
| 2              | 48 (9)                  | 45 (8.4)                | 40 (7.5)                |
| 3              | 29 (5.4)                | 19 (3.6)                | 11 (2.1)                |
| 4              | 50 (9.4)                | 20 (3.8)                | 29 (5.4)                |
| 5              | 29 (5.4)                | 8 (1.5                  | 8 (1.5)                 |
| 6              | 7 (1.3)                 | 9 (1.7)                 | 11 (2.1)                |
| 7              | 10 (1.9)                | 15 (2.8)                | 2 (.4)                  |
| 8              | 3 (.6)                  | 6 (1.1)                 | 3 (.6)                  |
| 9              | 8 (1.5)                 | 10 (1.9)                | 5 (.9)                  |
| 10             | 18 (3.4)                | 14 (2.6)                | 20 (3.8)                |
| 11             | 3 (.6)                  | 2 (.4)                  | 2 (.4)                  |
| 12             | 4 (.8)                  | 7 (1.3)                 | 2 (.4)                  |
| 13             | 0                       | 2 (.4)                  | 0                       |
| 14             | 2 (.4)                  | 3 (.6)                  | 2 (.4)                  |
| 15             | 5 (.9)                  | 12 (2.3)                | 10 (1.9)                |
| 16             | 0                       | 0                       | 0                       |
| 17             | 0                       | 1 (.2)                  | 0                       |
| 18             | 1 (.2)                  | 0                       | 0                       |
| 19             | 0                       | 2 (.4)                  | 0                       |
| 20             | 18 (3.4)                | 5 (.9)                  | 10 (1.9)                |
| 21             | 2 (.4)                  | 1 (.2)                  | 1 (.2)                  |
| 22             | 0                       | 1 (.2)                  | 0                       |
| 23             | 0                       | 0                       | 0                       |
| 24             | 1 (.2)                  | 1 (.2)                  | 1 (.2)                  |
| 25             | 0                       | 8 (1.5)                 | 0                       |
| 26             | 0                       | 0                       | 0                       |
| 27             | 0                       | 1 (.2)                  | 0                       |
| 28             | 0                       | 0                       | 0                       |
| 29             | 4 (.8)                  | 0                       | 0                       |
| 30             | 20 (3.8)                | 7 (1.3)                 | 9 (1.7)                 |

 Table 7. Study Participants' Self-Reported Answers to Questions 2, 3, & 4 (N=533)

<sup>a</sup>Question 2: Now thinking about your physical health, which includes physical illness and injury, for how many days during the past <u>30 days</u> was your physical health not good? <sup>b</sup>Question 3: Now thinking about your mental health, which includes tress, depression and problems with emotions, for how many days during the past <u>30 days</u>, was your mental health not good?

<sup>c</sup>Question 4: During the past <u>30 days</u>, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work or recreation?

A further question asking them to identify any chronic conditions they had was included in the survey. This question said, "Please indicate which chronic conditions you have: (please check all that apply)". Choices were Diabetes, heart disease, hypertension (high blood pressure), lung disease (asthma, emphysema, bronchitis), Arthritis/rheumatic disease, cancer, and other chronic disease. For this analysis, the number of diseases was then totaled. The mean number of total diseases was 2.27, the mode was 2, and the standards deviation was 1.3. Only 9.8% (52) participants reported having no chronic disease and 19.7% (105). 30% (n=160) reported having two chronic disease, 17.6% (n=94) reported four chronic diseases as shown in Figure 5.

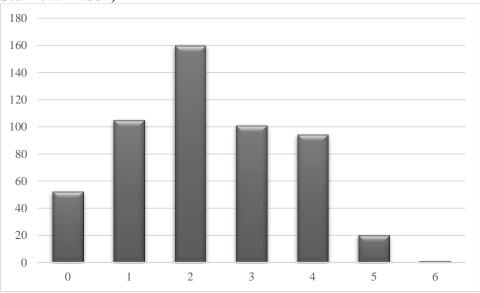


Figure 5. Total Number of Chronic Diseases (N=533, Mean = 2.27, Std Dev. = 1.334)

Multivariate linear regression models were used to examine the relationship between health literacy and health status, patient activation and health status and to examine whether or not there is an interaction between health literacy and patient activation on health status (Table 8). Using the self-assessed health status question as the dependent variable and controlling for sociodemographic factors (race, age, sex, education, and income), the interaction between health literacy and patient activation was not statistically significant ( $\beta$ =-.071, p=.156). There was a statistical significant relationship between higher patient activation and better self-reported health ( $\beta$ =.234, p<.000). Thus, patient activation and health literacy together did not have a joint effect on self-reported general health.

Multivariate linear regression examining the relationship between the dependent variable of limited days of physical health and controlling for sociodemographic factors (race, age, sex, education, and income), showed no statistically significant relationship between either health literacy and limited days of physical health (p=.361) and between patient activation and limited days of physical health (p=.801). There was a statistically significant relationship between limited days of physical health and an interaction of health literacy and patient activation ( $\beta$ =.994, p<.000).

Multivariate linear regression examining the relationship between the dependent variable concerning the number of days of poor mental health and health literacy and controlling for sociodemographic factors (race, age, sex, education, and income), showed that the higher the health literacy, the fewer days of activity missed due to poor mental health ( $\beta$ =-.191, *p*<.000). Examining the relationship between this dependent

variable and patient activation yielded no statistically significant relationship (p=.938) and there was no statistically significant relationship between limited number of days due to poor mental health and the interaction of patient activation and health literacy (p=.502).

Multivariate linear regression using the dependent variable of limited days and controlling for sociodemographic factors (race, age, sex, and income) determined that participants with higher health literacy had fewer days of limited activity than those with lower health literacy ( $\beta$ =-.123, p=.019) and participants with higher patient activation scores had fewer days of limited activity due to poor physical or mental health ( $\beta$ =-.159, p=.001). Further analysis showed no statistically significance between the number of days of limited activities due to poor physical or mental health and the interaction between health literacy and patient activation (p=.209).

Further investigation using multivariate analysis controlling for sociodemographic factors (race, age, sex, education, and income) concerning total number of chronic diseases and its relationship between health literacy yielded no statistically significant results (p=.809). The same held true for no statistically significant relationship between patient activation and number of chronic diseases (p=.387) and the relationship between the number of chronic diseases and the interaction between health literacy and patient activation (p=.299).

Given the limited nature of the four questions concerning health status, those four variables were standardized and then aggregated along with the number of diseases to form one variable. This was then used as the dependent variable in a multivariate analysis of health literacy, patient activation, and the interaction between health literacy and patient activation. There was a statistically significant relationship between higher patient activation and better health status ( $\beta$ =.251, *p*<.000) but no statistically significant relationships between health literacy and health status (*p*=.528) or between the interaction of health status and the interaction of health literacy and patient activation (*p*=.781).

 Table 8: Linear Regression Coefficients for Health Literacy, Patient Activation,

 and Health Literacy and Patient Activation Interaction Variable and Health Status

| Variables               | Health Literacy ( $\beta$ ) | Patient Activation | Interaction ( $\beta$ ) |
|-------------------------|-----------------------------|--------------------|-------------------------|
|                         |                             | (β)                |                         |
| Question 1 <sup>a</sup> | 017                         | .234*              | 049                     |
| Question 2 <sup>b</sup> | 048                         | 252                | .994*                   |
| Question 3 <sup>c</sup> | 191*                        | 004                | .189                    |
| Question 4 <sup>d</sup> | 123**                       | 159***             | .352                    |
| Total Diseases          | .012                        | .043               | .362                    |
| Standardized Health     | 631                         | .251*              | 028                     |
| Status <sup>e</sup>     |                             |                    |                         |

p < .000, \*\*p = .019, \*\*\*p - .001

<sup>a</sup>Question 1: Would you say that in general your health is: Excellent, Very Good, Good, Fair, Poor

<sup>b</sup>Question 2: Now thinking about your physical health, which includes physical illness and injury, for how many days during the past <u>30 days</u> was your physical health not good?

<sup>c</sup>Question 3: Now thinking about your mental health, which includes tress, depression and problems with emotions, for how many days during the past <u>30 days</u>, was your mental health not good?

<sup>d</sup>Question 4: During the past <u>30 days</u>, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work or recreation?

<sup>e</sup>The standardized health status is an aggregate variable created from Questions 1, 2, 3, and 4 plus the total number of diseases.

## Discussion

A large proportion of the participants assessed in this study scored with higher health literacy than other populations studied. Only 14.9% (n=79) tested in the inadequate health literacy range, 25.5% (n=136) had marginal health literacy and 59.7% (n=318) scored in the adequate health literacy range. The few previous studies on older adults and health literacy clearly put the majority of older adults in the inadequate or marginal health literacy ranges (Gazmararian et al., 1999). This may be because they studied patients and the population studied here were individuals who were active in their communities as demonstrated by their attendance of senior center programs and church functions.

The difference may also be linked to instrument validity because the screening question chosen may be a poor measure of health literacy in older populations. Previous studies using it were conducted with Medicare patients who were recruited from insurance and clinic patient records. While it may be a good measure for screening clinic patients, it does not appear to discriminate in this age group. This group of active older adults may also be more literate than those studied earlier as 34% of them finished high school and 29% had some college or vocational school. If health literacy were assessed in a more meaningful manner, then there may have been a statistically significant interaction between health literacy and patient activation in lower literacy groups.

Prior studies also may not have taken into account time limitations of other instruments. When measuring health literacy in older adults, other studies used the timed

Shortened Test of Functional Health Literacy in Adults (S-TOFHLA) developed by Baker et al. (1999). People given this assessment are given only twelve minutes to complete the exam, but Salthouse (1996) noted that older adults' ability to quickly perform cognitive tasks declines with. Their longer information processing time may have influenced their lower scores on the instrument in that situation. Participants in this study were given adequate time to complete the surveys and so were not rushed to perform. The lack of a statistically significant relationship could have been either been we did not assess it in a meaningful manner or there may in fact be no relationship there.

While self-reported health status has been demonstrated to be a valid measure of actual health status in other populations, it may not be a valid measure of health status in this population. Schuz et al. (2011) demonstrated that "good" health means different things to different people. Participants in this study were older adults who were active in their communities. They may have believed their health was as good as or better than others. Older adults who manage their chronic diseases may believe they are in better health than those who are not feeling good that day. If they believe they are in poor health, are not managing their chronic illnesses, or do not feel good, then they may be more likely to stay at home instead of attending community activities so there is the possibility of an attendance/participation bias in the sample. Additionally, a more accurate measure may be to access participants' medical records and develop an algorithm to determine health status. Use of the number of doctor visits or hospitalizations data might be considered, but is also fraught with limitations related to access and affordability.

This study did have some limitations. The participants were recruited from senior centers, aging programs and churches thus resulting in self-selection bias. Older adults who participate in these activities may be more healthy, active, and outgoing than older adults who stay home. The social support that they receive may motivate them to take better care of their health thereby making them a more activated patient. Also, 78.8% of the participants were female. According to the U. S. Census Bureau in 2012, approximately 55% of the population of the United States of 65 years of age and older are female, so this adds to the lack of ability to generalize the results.

Another limitation may be that while the surveys were administered and collected in a confidential manner, they were in a group setting and may have influenced the way participants answered survey items. For instance, they may have seen someone who they considered in worse health and thereby rated their health higher. If the survey administrator gave the surveys in private conditions, their answers may have been different.

A Further limitation of this study would be the ordinal nature of the question asking participants to self-rate their health. The first question, "Would you say that in general your health is: Excellent, Very Good, Good, Fair, Poor?" was poorly worded in the choices given for answers. There was no neutral position and the analysis assumed equal spacing between responses options. For example, "poor" was the only negative response available because "fair" has positive connotations, the response categories were conceptually skewed toward positive responses. A possible more accurate approach might have used a numbered Likert scale with "5" being excellent health and "1" being very poor health thereby turning this item from an ordinal to a nominal measure.

A further limitation may have been the lack of normality in the responses to the questions asking about the number of days of limited physical activity. The data for the three questions about the number of days included a skewness from 2.4 to 3.0. This may have some influence on the multivariate regression model.

Weaknesses aside, however, there were a few statistically significant results that merit further study. Higher health literacy was related to fewer days of missed activity due to poor mental health. This may have been because study participants with lower health literacy have a lower social support for coping with mental health issues (Lee et al., 2009), the most common being depression among this population (Corcoran et al., 2013). Ware, Kosinski, & Keller, (1996) that in participants with low health literacy, low social support was associated with poorer mental health. More research into why poor health literacy is associated with poorer mental health is needed. A good research question would address how is health literacy related to poor social support and what role that plays in mental health?"

Higher health literacy was also statistically significantly related to fewer days of limited activity due to poor physical or mental health. Those with higher health literacy may have a better set of skills to better manage their chronic diseases than those without functional health literacy (Nutbeam, 2000) thereby feeling better to participate in daily living activities. Further research into how to improve the self-care skills of persons with lower health literacy is needed. Higher patient activation was associated with better self-reported health, fewer days of limited activity due to poor physical or mental health, and the standardized variable of better health status. This may be because study participants who actively manage their disease and health issues tend to have better health outcomes (Greene and Hibbard, 2010).

The interaction of health literacy and patient activation was only statistically significantly related to the limited number of days of physical health. This interaction may not have been statistically significant with the other dependent variables due to the poor measurement of functional health literacy.

## **Summary**

The United States is experiencing a large rise in the population over 65 and that population will continue to grow (Committee on the Future Health Care Workforce of Older Americans, 2008). This population will be better educated, wealthier, more racially and ethnically diverse and have fewer children to care for them. As the population ages, there will be more chronic diseases and other infirmities associated with aging to tax health care resources. It is imperative that more research be done to assess the attributes and needs of this population. Earlier research demonstrated that higher health literacy was related to better health status as well as higher patient activation was related to better health status. Functional health literacy plays an important role in the health status of older adults, but there is no current evidence as to the role health literacy plays. The relationship may be due to many factors including, demographics, preventive health behaviors and daily living activities, cognitive abilities, knowledge, belief and culture or higher health literacy may be due to health status. Other factors relating to functional health literacy in older adults may be communication styles, social support, and health care access. Further, the ability to measure functional health literacy in older adults may be difficult due to instrument limitations and cognitive abilities of an aging population. Future research should include:

- Develop an accurate measure of health literacy in older adults.
- Establish new strategies for studying health literacy such as:
  - What role health literacy plays in managing chronic diseases and activities of daily living,
  - What psychometrics are involved in understanding basic health information,

This set of studies was an attempt to explore the relationship between health literacy and patient activation in regard to the health status of older adults. The interaction between the two proved to be statistically significant only when related to the limited number of days of good physical health. Further research is needed to create a combined tactic to study health literacy and patient activation such as a more practical and accurate approach and to assess the relationship between skills sets and mind sets and between skills sets, mind sets, and health status.

Until then, researchers should continue to explore the relationships between health literacy and patient activation and health care providers and behavioral scientists should consider these issues when working with older adults.

#### CONCLUSIONS

With the growth in the population of people over sixty years of age, it becomes imperative to examine health literacy and older adults not only to improve the health of the population but to keep our health care system from being overburdened. Few studies have been done to assess health literacy and the health status of older adults. Most of the data come from one large study where the data was collected fifteen years ago.

There is sufficient evidence that a relationship between health literacy and health status exists, as well as a relationship between health literacy and demographics such as race, education, socioeconomic status, and age. More whites had functional health literacy than African Americans and other minority racial groups. Further examination of the data showed that health literacy was more likely to decline with age and individuals with higher levels of education had higher levels of health literacy. The data in the third study show that health literacy is also related to physical health and daily living activities. The data showed that the higher level of health literacy, the better the physical health, and lower health literacy was related to poorer physical health. Individuals with lower health literacy were less likely to perform activities of daily living than those with higher health literacy. Further research has demonstrated that health literacy was related to cognitive abilities, knowledge, beliefs, reading abilities, communication skills, social support, healthcare access, preventive care behaviors such as vaccinations, mammograms and Papanicolaou smears, and hospitalizations. While evidence exists that there is a relationship between health literacy and health status in older adults, few studies have been conducted. Not much is known about that relationship in older adults and in older adults who are active in their communities. As the baby boomers age, it is imperative that more research is conducted to assess the attributes and needs of this population.

Paper 1 provided evidence from the literature that health literacy plays a role in the health status of older adults, and the second paper explored the evolution of instruments measuring health literacy. Measuring functional health literacy has proved to be difficult, and existing instruments do not measure the broad spectrum of functional health literacy.

There are some limitations in using the instruments and methods developed for testing functional health literacy. Most importantly, most instruments assess reading skills and medical terminology word recognition, thus measuring familiarity with the language of the instrument. If functional health literacy is the ability to understand and use health information to promote and maintain good health, then there are still no effective instruments to measure this concept. The ability to read and/or a higher level of education do not guarantee functional health literacy. Both the REALM and the TOFHLA were developed around word recognition and the TOFHLA measures word recognition around a specific type of medical/clinical encounter. A person can have adequate health literacy and not be acquainted with specific medical terms used in a clinical setting. In the same way, one can have the ability to read difficult clinical material but have no understanding of the information. An attempt to shorten the instruments so as not to require long periods of time resulted in instruments created from earlier versions. They, too, examined word recognition and reading skills.

The validity of all the current questions is questionable. Most instruments were compared to standardized reading exams or to each other. The MART was developed directly from the WRAT and was not tested for validity (Hanson-Divers, 1997). The researchers assumed that since it was designed from the WRAT and used the same format, the proven content validity of the WRAT would apply to the MART.

Generalizability is difficult because current instruments do not address age, education, or cultural differences. Older adults bring different experiences into the testing arena than younger adults. They may have more familiarity with some procedures because of medical history or, as Rosen (1980) reported, they may have delayed recall thereby scoring lower on current examinations. On the other hand, younger adults may have more education or exposure to medical terminology due to experience with the Internet. Also, cultural differences may influence scores, as demonstrated in the lower scores on the REALM for African Americans than Whites even though their academic achievements were the same.

Further, since functional health literacy is situational, there are no means to measure how health literacy changes with the situation. For example, a person may be very knowledgeable about arthritis, but know very little about diabetes. He or she may not understand basic instructions about diabetes prevention or care but need very little instruction about caring for his or her arthritis. While the clinical aspect is important, most people make decisions based on their personal experience as well as knowledge and do not spend the majority of their time in their physician's office. Personal and self-care/management have become even more important as health care costs continue to escalate while the number of uninsured increases. By measuring one's level of health literacy, interventions and health literature will be more successful when developed around those levels because it is more likely to reach people in meaningful ways. Developing measures for health literacy for personal asset as well as clinical measures should make programs and communications more successful thus improving health outcomes.

The third part of the study examined the research question, "In older adults, do functional health literacy and patient activation relate to health status when controlling for demographics?" Using one of the newer instruments to measure health literacy, a one question assessment by Wallace et al. (2006) was used to assess health literacy in older adults in south central Texas. Health status was assessed using the CDC HRQOL 14 "Healthy Days Measure" along with a Patient Activation Measure. The study established a relationship between health literacy and mental health, and between health literacy and overall general health.

Further, this study demonstrated a statistically significant relationship between patient activation and self-reported health status, overall general health, and a standardized aggregate health status variable. The only statically significant relationship between an interaction of health literacy and patient activation was with the number of days of poor physical health. There are some challenges that may impact further research. Measuring health literacy may be difficult in older adults due to instrument limitations, cognitive functioning and time needed for processing information. While there is some information available, there is still much to be done. Further research should include:

- assessing the role health literacy plays on health outcomes and mortality of older adults;
- observing cultural differences and health literacy. This topic could include immigration factors as well as the differences in baby boomers and their parents;
- exploring the relationship of health literacy to health care delivery in older adults;
- examining the relationship between Medicare policies and practice and health literacy;
- assessing the relationship between clinical and personal asset health literacy;
- developing an instrument to accurately assess health literacy in older adults; and
- developing successful health literacy interventions for older adults.

As the population of the United States ages, research in health literacy and older adults increases in significance to older adults, researchers, healthcare providers, healthcare service providers, and legislative powers. Now is the time to start addressing these issues.

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