Fall 1-8-2016

Health Literacy in High-Risk Populations

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Health Literacy in High-Risk Populations

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Dissertation Prepared for the Degree of

DOCTOR OF PHILOSOPHY

GEORGIA STATE UNIVERSITY

SCHOOL OF PUBLIC HEALTH

November 17, 2015

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Acknowledgements

I would like to thank the members of my committee for their guidance and wisdom during my time in this PhD program, and in particular my committee chair, Dan Whitaker, for his patience, advice, and support during the writing of this dissertation.

Special thanks and love to Bruce for always believing in me and never expecting anything but the best.
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Chapter 1: Introduction to Health Literacy

Background

Health Literacy is a concept that is complex and dynamic, and takes into account how people access, understand and use health information and health care in everyday life and in medical situations. The term “health literacy” was introduced in the 1970s and describes a set of skills that people use to function effectively when accessing and using health information and services (Baker, 2006; Parker, Williams et al., 1999; Sorenson et al., 2012). Literacy (reading ability) was identified early on as a key health literacy skill. As the field has developed, however, other characteristics of health literacy have emerged, providing a more dynamic understanding of its complexity (Baker, 2006; Benjamin, 2010; Frisch, Camerini, Diviana & Schulz, 2011; Martin, et al., 2009; Zarcadoolas, Pleasant & Greer, 2005). For example, the field of health literacy now includes numeracy, information seeking, oral interactions between patient and provider, digital skills, and the role played by providers of health information.

There is also an increased recognition of the contextual nature of health literacy, and how risk factors across the social ecology can affect health literacy. For example, individual health literacy behaviors and skills are impacted by a continuum of factors ranging from individual (e.g., age, education, race, biology, genetics) to societal (e.g., health disparities, social norms, public policy, the built environment) (Anker, Reinhart, & Feeley, 2011; Berkman, et al., 2011; Dutta-Bergman, 2004). Additionally, health needs change across the lifetime, as does health literacy, and thus health literacy skills and behaviors should be considered in the context of development (Manafo & Wong, 2012; Nutbeam, 1999; Sambamoorthi & McAlpine, 2003).
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Health literacy is now understood as interplay between individuals’ literacy skills and the demands of their environment. When individuals can effectively access, understand, and use health-related information (i.e., have high health literacy) their short- and long-term health outcomes improve (Baker, 2007; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Paasche-Orlow & Wolf, 2007). However, health professionals must also provide accessible, understandable, and meaningful information in order for people to use that information, navigate the health system, and better control their health outcomes (Berkman, et al., 2011; DeWalt, et al., 2004; Parnell, 2014). Thus, the purpose of this dissertation is to examine the gap between the health literacy demands of consumers and the provision of health information by health education and health care professionals.

Definition of Health Literacy

One of the fundamental issues facing health literacy researchers is that there is no clear, authoritative definition of health literacy. The definitions that currently guide health literacy research, practice, and policy run the gamut from individual skills and characteristics, for example, reading, to the social process of interactivity between patient and health care provider. The most widely used definition is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Institute of Medicine, 2004, p. 10). This broad definition describes health literacy as an individual capacity, and is comprised of an individual’s proficiencies in accessing content.
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knowledge, reading, writing, numeracy, digital skills as well as the interactive skills of speaking, listening, interpreting, and acting on health information (Nutbeam, 2008; Paasche-Orlow & Wolf, 2007; Speros, 2005; Peerson & Saunders, 2009). However, health literacy is also defined as being two-sided and interactive, and is dependent on how lay and professional people navigate differences in communication skills, knowledge, and culture (Berkman, Davis, & McCormack 2010; Betancourt, Green, & Carrillo, 2002; Nutbeam, 2008; Paasche-Orlow & Wolf, 2007; Peerson & Saunders, 2009; Von Wagner, Steptoe, Wolf & Wardle, 2009). Interactive health literacy occurs in real time and can be viewed as a dynamic, situational activity (Baker, et al., 1996; Frisch, et al., 2011; Parnell, 2014; Rubin, 2014; Zarcadoolas et al., 2005). The need for health literacy evolves and changes depending on different situations across the lifespan including states of illness and wellness, age, care for self or others, and management of chronic or emergent illnesses (Kerka, 2003; Nutbeam, 1999; Peerson & Saunders, 2009). This further suggests that health literacy involves skills for applying new and old information in differing and novel situations and contexts (Kutner, Greenberg, Jin, & Paulsen, 2006; Roter, 2011; Rubin, 2014; Office of Surgeon General, 2006; Zarcadoolas et al., 2005).

Prevalence of Low Health Literacy

Low health literacy (HL) can affect people regardless of age, race, socioeconomic status or educational attainment (IOM, 2004; Kutner, et al., 2006; Nutbeam, 2009; Rudd, Kirsch, & Yamamoto, 2004). Low HL is a stronger predictor of a person’s health than individual demographic variables (Berkman, et al., 2011, Parker, et al., 1999). The National Association of Adult Literacy Skills (NAALS), a literacy survey completed in 2003, was the first population-
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based measurement of health literacy in the United States, and included measures based on three literacy scales (prose, document, and quantitative) in three different health domains (clinical, prevention, and navigation of the health care system) (Kutner, et al., 2006). Results from the NAALS indicate that 77 million people in 2003 - over one-third of the entire population - did not have the written or numeracy skills necessary to complete a patient form, seek or follow guidelines for age-appropriate preventive health services, nor were they able to share personal medical information, navigate the healthcare system, understand and communicate symptoms to a health care provider, or make appropriate health decisions (Kutner, et al., 2006). The study indicated that low HL affects all racial and ethnic groups; however, Hispanics had the largest percentage of people at Basic and Below Basic (65%), followed by Blacks (57%), Asian American and Other (44%), and White (28%). (Kutner, et al., 2006)

The latest population-based study to measure literacy - the Program for the International Assessment of Adult Competencies (PIAAC) - was completed in 2012. The PIAAC measured literacy, numeracy, and problem-solving in technology rich environments; however, unlike the NAALS study, there was no direct health literacy measure. The PIAAC surveyed representative samples of at least 5,000 adults between the ages of 16 and 65 in each of the 24 participating countries (OECD, 2013), and scored proficiency in 6 levels (Below Level 1, Levels 1-5). Fifty-two percent of Americans scored below Level 3 in literacy and 64% scored below Level 3 in numeracy, which indicates a limited ability to engage with text and work with numbers. A large portion of those scoring in these low categories did not have a high school education (National Center for Education Statistics, 2013).
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One in six U.S. adults read at elementary levels (National Center for Education Statistics, 2013), therefore, it is not surprising that they fare poorly on tests that measure health literacy as reading. In addition, studies suggest that low HL is also highly prevalent among those of minority racial and ethnic status and low socioeconomic status (SES) who are also the most likely to have low levels of reading literacy (Baker, 2006; Berkman, et al., 2010; Kutner, et al., 2006; Martin, et al., 2009; Peterson, Garbers, et al., 2007; Weiss, Hart, et al., 2005). There is a strong association between low reading skills and poor health outcomes (Baker, Parker, et al., 1997; Braveman, Egerter, & Williams, 2011; DeWalt, et al., 2004; Ross, 1995). Measures of health literacy such as the Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Assessment of Literacy Levels (REALM), and the Newest Vital Sign (NVS) (Parker, et al., 1999; Davis, Long, et al., 1993; Rothman, Housam, et al., 2005) are primarily reading-based, and measure constructs related to reading such as word recognition, pronunciation of medical terms, and reading skills (Baker 2006; Frisch, et al., 2011; Hernandez, 2009; Sorenson, Van den Broucke, et al., 2012). Therefore, it is not surprising that such measures are strongly correlated with grade equivalent reading levels. In addition, systematic reviews of health literacy studies using reading and non-reading based measures support this notion that low HL is commonly associated with low education levels, and related to ethnicity and age as well (Paasche-Orlow, Parker, et al., 2005).

How Health Literacy Impacts Health

Low HL has been linked to reduced use of health care services and poor health outcomes in emergent, preventive, and chronic disease care (Berkman, et al., 2011; Paasche-Orlow &
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Wolf, 2007; Weiss, et al., 2005). Studies of mammography use, cervical cancer screening, emergency department discharge instructions, heart health knowledge, and informed consent all demonstrate a statistically significant association between lower literacy levels, health knowledge, and use of health care services (Baker, 2007; Berkman, et al., 2011; Peerson & Saunders, 2009; Sambamoorthi & McAlpine, 2003; Von Wagner, et al., 2009). People with low HL report poorer health than those with adequate health literacy (IOM, 2004; Martin, et al., 2009; Speros, 2005). They are also less likely to be able to manage chronic health conditions such as diabetes, high blood pressure, and asthma due to less disease knowledge and lack of understanding self-management requirements (Berkman, et al., 2011; IOM, 2014; Kutner et al., 2006; Martin, et al., 2009; Paasche-Orlow & Wolf, 2005; Sorenson, et al., 2012; Weiss et al., 2005). Adults with low HL are less likely to know about both preventive measures and management of sick behaviors, are less likely to seek health information, and more likely to miscommunicate with their health providers (Aguilera, Dailey, & Perez, 2008; Bennett, Chen, Sorouei, & White, 2009; Manafo & Wong 2012; McCray, 2005). Studies indicate a direct association between low HL and poor health (Benjamin 2012, Egbert & Nanna, 2009; Paasche-Orlow & Wolf, 2007; Weiss, et al., 2005).

Socio-Ecological Model of Health Literacy

Because of the complex and multifaceted nature of health literacy, and the evidence that individual processes and social context act in some combination to explain health literacy (Frisch, et al., 2011; Zarcadoolas, et al., 2005), it is important to consider the entire social ecological system in which health literacy occurs. The social ecological model (SEM) is often
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used in the field of Public Health; in addition to aligning individual factors, the SEM can also help frame a deeper understanding of how society, community, and neighborhood factors impact outcomes such as health literacy (Richard, Gauvin, & Raine, 2011). This model has discrete rectangles to indicate different levels of factors, however, they are not meant to be static; rather there is a fluid interplay between the factors, which can affect health literacy as it is used in different contexts or situations.
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The foundational level of the SEM is intrapersonal, and includes factors that are both nonmodifiable (i.e., biology and genetics) and modifiable. Individuals have biological and genetic traits such as race, gender, or genetically determined diseases that can affect how they accumulate and use information through their lifespan. For example, women may interact more with the health system than men (Berkmann, DeWalt, Pignon, et al., 2004); older adults have highest demand for health care services of any age group (Butler, Talley, et al., 2011; Lyons, Dunson-Strane, & Sherman, 2014; Manafo & Wong, 2012); and, African-Americans have a higher incidence of heart disease than other races (Aguilera, et al., 2008; Butler, et al., 2011). Other factors include language, culture, educational attainment, literacy level, SES, and the beliefs, values, attitudes and experiences that stem from them. Over 50.2 million people in the US speak a language other than English at home in 2013, representing 15.9% of the population (Gonzalez-Barrera & Lopez, 2013). In addition to speaking a different language, people who are native English speakers commonly use nuanced language that non-natives may not understand; for example, the use of negatives in sentences is common (“You don’t want to have to go to the hospital, do you?”) which non-native English speakers may find difficult to translate and comprehend. Both native and non-native English speakers with low literacy describe significant communication problems with their healthcare providers (Andrulis & Bach, 2007; Baker et al., 1996, Berkman et al, 2011; Ownby, Waldrop-Valverde, & Taha, 2012) that has a negative impact on health care access, quality of care, and quality of life (Brach, Fraser, & Paez, 2005; Fortier & Bishop, 2004; Nutbeam, 2000). Even those who are competent in other areas of
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communication can find themselves at a communication loss when they are dealing with unfamiliar and stressful situations such as seeking health care (Kerka, 2003).

Educational attainment is relevant for health literacy through individual health knowledge and behaviors, literacy levels, and a variety of other social and psychological factors (Collins, Bryant, & Rocco, 2014; Egerter & Nanna, 2009; Hill, 2011; Levy, Ubel, Dillard, Weir & Fagerlin, 2014; Prins & Mooney, 2014). There is a positive relationship between education and health; those who are better educated report healthier behaviors including less drinking, smoking, and illegal drug use, greater household safety, and use of preventive health measures (Driscoll & Benstein, 2012; Egerter, et al., 2009). In addition, individuals with higher education levels are more likely to have overall higher literacy levels, more stable employment, higher income, better health insurance, and easier access to health care (Adler & Stewart, 2007; Baum, Ma, & Payea, 2013; Eide & Showalter, 2011; Egerter, et al., 2009, North Carolina Institute of medicine Task Force on Prevention, 2009). With regard to low literacy, 1 in 6 adults read at elementary levels (OECD, 2013); studies indicate that a majority of medical-related documents are written between the 11th and 14th grade level (Leroy, Helmreich, Cowie, Miller & Zheng, 2008).

The next level of the SEM is interpersonal which focuses on relationships with close others. Social support from family, partners, and close friends has both a direct and indirect relationship with how individuals view health information (Aguileara, et al., 2008; Andrulis & Brach, 2007; Keller, Vega-Lopez, et al., 2012; Lee, Arozullah, & Cho, 2004; Ogden, 2012). The PIAAC data suggest that 70% of individuals ages 20-65 rely on friends and family for health information (Feinberg, et al., 2015). When patients with low literacy do not rely on a trusted
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confidant, they are not inclined to ask for help that may be needed to take medication correctly (Johnson, Jacobson, Gazmararian, & Blake, 2010). Positive tangible support such as assistance finding and understanding health information or communicating with a healthcare provider, may help individuals with low HL overcome certain limitations in seeking and using health services (Gallant, 2003; Johnson, et al., 2010). Family and social support can act as a mediator between health literacy skills and health outcomes by either providing positive support (providing emotional and tangible support in seeking health information or services) or negative support (social pressure to ignore health messaging) (Richmond, Ross, & Egeland, 2007; Lee, et al., 2004).

The third level of the socio-ecological model is the community, which includes opportunities for employment and education. Employment is important for health literacy because adults who are employed are more likely to be able to afford medical care and prescriptions, hence interacting much more often with health information and the health system (Driscoll & Bernstein, 2012). Employers often provide health insurance and wellness programs to their employees; this can serve to increase health literacy through acquired knowledge and use of preventive services. The value to employers accrues in lowered sick day costs, lower insurance costs, and enhanced productivity (Loeppke, Edington, Bender, & Reynolds, 2013; Musich, McCalister, Wang, & Hawkins, 2015). Formal and informal education can also help augment the acquisition, understanding, and use of both general and health literacy skills (Altendag, Cannonier, & Mocan, 2011; Eide & Showalter, 2011; Hill, 2011; Nutbeam, 2000).
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People with lower education demonstrate lower health literacy skills when compared to people with higher education (Nutbeam, 2008; Paasche-Orlow et al., 2005; Rudd, 2007).

With regard to culture, individuals are affected by their own cultural histories and values; culture shapes the way people communicate and present themselves in all aspects of life (Healthy People 2010; Parker, et al., 1995; Peerson & Saunders, 2009). Cultural and social norms can have a great impact on how individuals view health, health information, and health care. Some cultural beliefs that interfere with how health information is accessed and understood are centered on how the body works and what causes illness and wellness (Betancourt et al., 2003; Galambos, 2003; Lie et al., 2012; Koh, Garcia, & Alvarez, 2014; Whaley, 2000). For example, many individuals from Eastern cultures believe that illness is the result of the supernatural, which is in direct conflict with how Western industrialized societies present disease as a result of natural scientific phenomena (Aguilera et al., 2008; Langer, 2008; Whaley, 2000; Yeo, 2009). Religious beliefs also play a role in how health information impacts health behaviors. For example, the African American culture has a heightened sense of religious belief relating to illness (God as healer) (Whaley, 2000). This could lead to ignoring health messaging (e.g., mammography screening) which may further cause a delay in seeking treatment or taking individual control over health behaviors (Levin, Chatters, & Taylor, 2005; Whaley, 2000). Cultural and social norms of some peer affiliation groups do not encourage collaboration; for example, the U.S. military has cultural and social norm of organization, rules, and performing behaviors without question (Hus 2010, Koenig et al., 2014). Studies of military veterans show...
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that they have great difficulty in integrating civilian and military identities, which can directly affect interactive health literacy and participation in healthcare encounters. (Koenig, et al, 2014).

Societal factors are at the most distal level of the SEM, including laws and the health care system itself. There are federal initiatives that focus on improving health literacy, however, few are mandated or funded. The National Action Plan to Improve Health Literacy is a federal initiative that provides guidelines to decrease barriers to health care access and improve informed decision-making by encouraging the use of evidence-based health literacy research in all areas to inform change (Office of Disease Prevention and Health Promotion, 2010). The Plain Writing Act of 2010 requires federal agencies to use plain language for documents that provide information about federal services, including health information (Public Law 111-274). The US Department of Health and Human Services developed the Culturally and Linguistically Appropriate Services (CLAS) in their 2011 Action Plan to Reduce Racial and Ethnic Health Disparities (Koh, et al., 2014). CLAS provides a framework for health providers to enhance their services to be the most responsive to cultural health beliefs and practices, preferred languages, health literacy levels, and other communication needs (Koh, et al., 2014).

Policies regarding education and training of healthcare providers are another source of outer level influences on health literacy. There are 134 accredited US medical schools that graduate approximately 18,000 new physicians every year (Association of American Medical Colleges, 2011) and census statistics indicate that there are approximately 3.5 million practicing LPNs, RNs, and advanced RNs (Bureau of Labor Statistics) as well as 275,000 licensed pharmacists (University of Florida). These and other allied healthcare professionals (e.g.,
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physical therapists, certified nursing assistants, pharmacy techs) are a primary source of health care and health information. There is little systematic training on issues of health literacy for these professionals, however. In most professions, health literacy is not offered as a stand-alone class, but communication skills may be integrated in many other classes and practice experiences (Flores, Gee, & Kastner, 2000; Koh, et al., 2014). In addition, as part of Continuing Medical Education accreditation, many private and public organizations offer cultural and linguistic sensitivity courses for physicians, nurses, pharmacists, physical therapists, and other health care providers through workshops, online training, and resources for materials development (Center for Linguistic and Cultural Competence in Health Care). Appropriate education for health professionals can increase the awareness of the effects of low HL, and can play a critical role in improving patient health literacy across diverse communities. Thus, there is a strong need for addressing health literacy policies toward increasing provider health literacy skills and creating new resources to promote health literacy within the health professions (Brown, Ludwig, et al., 2004).

At-Risk Populations Affected by Low Health Literacy

Certain populations are more likely to have poor health outcomes, and to be affected by low HL. Health disparities are a type of health difference closely linked with economic, social, and/or environmental disadvantage (Braveman, et al., 2011). Health disparities strongly affect people of racial and ethnic minorities, but can also exist based on people’s age, gender, religion, disability status, mental health, sexual orientation, and geographic location.
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Enhancing health literacy may be an important step on the pathway to reducing health disparities (Bennett, et al., 2009; Braveman, et al., 2011; PrinsSaha, 2006; Prins & Mooney, 2014). Health literacy may play an important role in health disparities either because a population may have poorer health literacy (e.g., low SES), or because a population has greater health care needs (e.g., elderly, people with disabilities) and thus greater demands to be health literate. For example, people of minority status, individuals with less than a high-school education, and people living in poverty are much more likely than others to have low literacy and also have higher mortality rates (Adler & Stewart, 2007; Bennett, et al., 2009; Braveman, et al., 2011; DeWalt, et al., 2004; Sambamorthi & McAlpine, 2003). The elderly have greater healthcare needs than the non-elderly, and thus are more greatly challenged regarding health literacy in that there is so much more to understand and use when navigating the health care system (Ownby et al., 2012).

Older Adults

Older adults are a segment of the population with an extensive need for health care services, and the number of older adults in the U.S. will double to 72 million by 2030. According to the 2003 NAALS, adults 65 and older had the lowest health literacy scores of any age bracket (Kutner, et al., 2006). Health literacy among the elderly is particularly complex and important for several reasons. Older adults often have highly complex health needs. Health literacy in older adults may be affected by the physical effects of aging combined with cognitive declines in memory, reaction time, and executive functioning (Aguilera, et al., 2008; Butler, et al., 2011; Langer, 2008; Speros, 2005). Older adults may also have specific challenges in
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learning due to age-related cognitive and physical difficulties (e.g., memory loss, hearing loss) as well as the social issues that older adults face including loss of independence, ageism, and reduction in socioeconomic status. Healthcare decisions can be overwhelming for older adults who may need to manage several health conditions and several healthcare providers simultaneously (Logan et al., 2015; Ownby, et al., 2012; Speros, 2005). For older adults, managing health may also mean including a caregiver who may not be health literate himself or herself. With the growing population of older adults, and the lack of health literacy among older adults, there is a critical need for research to examine health literacy processes among older adults.

Individuals with Low Socio-Economic Status

Population-based studies indicate that low HL can affect all people regardless socioeconomic status (Kutner, et al., 2006; Nutbeam 2008; Rudd, et al., 2004). There is, however, a strong and positive correlation between SES and health and between SES and health literacy (Adler & Newman, 2002; Mechanic, 2002). SES is broadly defined as a measure of economic and social position based on income, education, and occupation. Adults with low SES bear the burden of entrenched healthcare disparities and are at a greater risk for increased morbidity and mortality (Adler & Stewart, 2007; Braveman, et al., 2011; DeWalt, et al., 2004; Sambamorthi & McApline, 2003). Additionally, individuals with low SES may have more trouble communicating their health history to health care providers, may not understand the link between behaviors and outcomes, and may need more help understanding and navigating both their complex health needs and the health care system than those with moderate or high SES.
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(Adler & Stewart, 2007; Baker, et al., 1997; Sambamorthi & McApline, 2003). Low SES individuals may also live in communities with built environments that are not conducive to healthy behaviors (Adler & Stewart, 2007; Collins, Bryant & Rocco, 2014; Prins & Mooney, 2014); for example, walking as a means of exercise for diabetes patients is often encouraged but if the neighborhood has broken sidewalks and unsafe street corners, people may not be able to practice this health behavior. In addition, low SES individuals are more likely to have less social support and fewer economic and educational opportunities (Adler & Stewart, 2007; Collins, et al., 2014; Prins & Mooney, 2014) which can support health literacy.

Communication Challenges between Providers and Consumers of Health Information

An important aspect of health literacy is that it is social, interactional and contextual. Within this definition, there is both information supplied by providers (i.e., health information that is created, written, spoken, and delivered by health and health care providers and educators) and information used by consumers who access their health literacy when acquiring, understanding, and using that health information. There is often a significant mismatch between the complexity of health information and the understandability/usability of that same information (Rowlands, Protheroe, et al., 2014).

The Provision of Health Information

The proclivity of the health industry to use a direct communication style replete with medical jargon, and idiomatic English increases the health literacy demand on patients (Epstein, Franket, et al., 2005; Fagerlin, Zikmund-Fisher, & Ubel, 2011). Regulatory requirements, legal protectionism, institutional/provider choice, and medical training add layers of complexity to the
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use of medical language. The health industry includes those that deliver direct care (physicians, nurses, other personnel, hospitals, clinics, community health centers, pharmacies, etc.) and others from the medical industry such as insurance providers and pharmaceutical manufacturers. The healthcare field has its own formal, technical, idiomatic, and exact register. Patients often have a difficult time understanding a health care provider’s words and intentions even without language barriers, due to heightened anxiety when dealing with a medical situation (Kutner et al., 2006). Even the simplest questions such as “are you running a fever?” or “did you catch a cold?” can create problems for adults with low literacy as they attempt to decode the meaning and intent of the question. Issues of style (direct vs. indirect), conflict avoidance, self-advocating, or cultural preference for gender may affect delivery of health information (Ngoh, 2003; Safeer & Keenan, 2005). Written health information has a number of different lexical and linguistic features including difficulty level of vocabulary, grade level readability and understandability, pragmatic and idiomatic phrases, visual features, and medical terminology. Although there are methods to evaluate the readability and visual formatting of written health information (Baker 2006; Baker, Parker, Williams, Clark, & Nurss, 1997; Berkman et al., 2011; Hernandez 2009; Leroy, Helmreich, Cowie, Miller, & Zheng, 2008), aside from lowering readability levels, there is little consensus on what constitutes clear and meaningful health-related documents.

Health providers are often encouraged to use interactive communication methods to help increase health literacy, including the interactive communication loop, a method that highlights the dyadic interpersonal and interactive nature of communication, and allows for question asking, request making, clarification, and supportive speech (Street & Millay, 2001). Health
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providers are trained in different communication styles, as they need to gather factual information that is relevant, meaningful, and descriptive to the health situation at hand; in order to diagnose and treat disease, they must be able to objectify and quantify symptoms, often at the expense of conversational niceties. Health providers share evidence-based, scientific information that affects the lives of patients and consumers; however, research shows that fewer than 40% of people said their health provider clearly explained this information (Alston & McCabe, 2012). In addition to minimal communication training, many health providers have little opportunity for feedback on their patient interaction skills (Ngoh, 2003; Safeer & Keenan, 2005).

Consumer and Patient Acquisition of Health Information

People seek and use different types and amounts of health information depending on their motivation, skills and abilities, and health or illness needs (Lambert & Loiselle, 2007). A complexity of factors influence where and how people seek health information, including a varying combination of background, health-related behaviors, and literacy skills (Lambert and Louise 2007).

Health Information Seeking Behavior (HISB) refers to how people seek health information through print, graphic, or oral media; health information can also be learned actively or passively through different media channels such as searching the internet or listening to the radio (Lee 2010; Longo, et al., 2010). Studies indicate the importance of seeking health information, as those who do seek health information report better health than those who do not seek health information (Feinberg, et al., 2015). Additionally, those who actively seek health
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information are more likely to be active participants in their health care outcomes, a key construct in high quality healthcare (Case, 2012; Lambert & Loiselle, 2007).

Individuals who have low literacy are more likely to use oral sources of health information (Radio/TV, Friends/Family/Co-Workers, Health Professionals) than written sources (Print Media, Internet) (Feinberg, et al., 2015). Written health information is often dense, complex, and scientific, even when presented in an easier to read format (Brown et al., 2011; Dutta-Bergman, 2003; Hibbard, Peters, Dixon & Tusler, 2007). Those who have low HL skills have trouble navigating complex written text and applying the highly cognitive multi-step processes that are needed to understand and use even simple health materials (National Center for Education Statistics, 2013). Health information is often replete with both text and numbers; therefore, it is not surprising to see that sources with written information are the ones least used by adults with these low literacy and numeracy skills (Feinberg, et al., 2015).

People typically use multiple sources of health information; the Internet is most often combined with use of Print Media and Radio/TV while use of Friends/Family/Co-Workers was most often combined with Health Professionals (Feinberg, et al., 2015). HISB, then, is not necessarily driven by comfort with or availability of one source or another, but rather by multiple sources through various modalities. Individuals may understand different aspects of that health information differently, depending on whether it is media-related, people-related, actively sought, or passively sought (Anker et al., 2011; Salwen & Stacks, 2009; U.S. Department of Education, 2013; Wakefield et al., 2010). The increase of health information on the Internet contributes to challenges in seeking health information because the high literacy, numeracy, and
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Computer-skill demands of health-related websites create problems for those who have low literacy, numeracy, or computer skills (Birru, et al., 2004).

With regard to patient-provider interactions, patients of all health literacy levels ask more questions, share more information, and participate in decision making when health providers engage in interactive communication patterns, that is, providers listen to patients, discuss patient health concerns and health goals, explain patient options, and ensure the patient’s understanding of what was both said and meant (Safeer & Keenan, 2005; Street & Millay, 2001; Von Wagner, et al., 2009). Patients with low HL may have limitations in communicating health information; they may have language difficulties (both non-concordant language and lack of vocabulary) or cultural differences that result in lessened abilities to ask or challenge their health provider. Patients may not know how to ask questions, which questions to ask, or on which symptoms to report due to a deficit in health and wellness knowledge. Adults with low HL may be ashamed to ask the provider to repeat or explain as well as to report non-adherence to medication and discharge instructions; often adults with low literacy are unable or simply do not want to bring a supportive family member or caregiver to help them understand how to be adherent (Lyons, et al., 2014; Ngoh, 2003; Safeer & Keenan, 2005). Patients with low HL have challenges seeking, understanding, and using health information; there is often a mismatch between how health information is supplied and the abilities of those who need that information (Rowlands, et al., 2015).
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Manuscripts

This dissertation will focus on aspects of health literacy among high-risk populations including provider-patient communication and consumer health information seeking behaviors. The papers will attempt to add to the understanding of how the health literacy demands of health information users and the health information supply from providers are at different literacy levels, and why this mismatch between consumer/patient and provider affects individuals with poor health literacy and great health needs (i.e., those with low SES and the elderly).

Manuscript #1 - Health Information Seeking Behaviors

Manuscript 1, through a secondary analysis of the PIAAC data, addresses how adults of different characteristics who have below average literacy, numeracy, and problem solving skills seek health information. Patient-centered care (PCC), in which patients and their providers work together to make decisions about health care and disease management, is considered one of the key components of high-quality healthcare (IOM, 2013). For patients to participate in their care, they must be able to first access and identify health information that can then be used for the more complex and situational demands of health care. The specific aim of this paper is to analyze the PIAAC data to understand how adults with low literacy seek health information. Questions addressed are: What sources do individuals use when seeking health information? Do different demographics, health behaviors, and facilities in English predict different health information sources for people with low skills in literacy, numeracy, and problem solving?

Key findings are as follows:
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- Health information seeking behaviors are both complex and subtle, and depend on a multitude of factors. One size does not fit all as evidenced by varying combinations of background, health behaviors, and facilities in English. People with low level literacy, numeracy, and problem solving who seek health information report having better health status.

- Oral sources of communication (Radio/TV, Friends/Family/Co-Workers, and Health Professionals) are used more often than written sources (Print Media/Internet). Those with low literacy and numeracy seek health information from Radio/TV most often while those with low problem solving use the Internet and Health Professionals. Written health information is often complex, even when presented at lower reading levels (Brown et al., 2011; Dutta-Bergman, 2004; Hibbard, Peters, Dixon & Tusler, 2007). In addition, health information is often replete with both text and numbers; therefore, it is not surprising to see that sources with written information are the least used by adults with these low level skills.

- Having a high facility in writing English is a significant predictor of using the Internet and Health Professionals as a source of health information. This is true for people with low-level literacy, numeracy, and problem solving.

- Over 80% of adults with low-level literacy, numeracy, and problem solving have a high school diploma. Adults who have a high school diploma, regardless of their literacy levels, are more likely to use the Internet or Print Media for health information. However, their low-level literacy scores may indicate a problem in using higher-level skills to interpret and use that health information. Education and literacy levels are both strongly linked to health outcomes (Egerter, et al., 2009; OECD, 2013).
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Overall, the PIAAC data suggest that adults with low skill levels practice varying kinds of health information seeking behaviors from multiple sources. Different stakeholders have unique roles to play in increasing health information seeking behaviors. Health professionals could develop more focus and skills in oral participatory care with patients and caregivers. The health care industry (pharmaceutical, hospital systems, insurance companies) could simplify and standardize forms and written materials, policy-makers could include health literacy at appropriate funding levels for K-12 and Adult Basic Education curricula, and health educators and researchers must develop interventions to address health information seeking behaviors through differing skill levels in multiple modalities.

Manuscript #2 - Cultural Competence and Health Literacy for Older Adults

Manuscript 2 is a literature review with the specific aim of understanding the intersection of health literacy and culture as it relates to older adults. A broad and overarching goal of improving health literacy is to improve the health and quality of life for all groups of people across all cultures and all life stages (Centers for Disease Control and Prevention, 2015). In 2008, more than 33% of the U.S. population identified as belonging to a racial or ethnic minority population, 51% of the U.S. population were women, 23% of the population lived in rural areas, and 20% spoke a language other than English at home (CDC 2015; U.S. Census Bureau).

In addition, according to the National Association of Adult Literacy study in 2003, adults 65 and older had the lowest health literacy scores of any age bracket (Kutner, et al., 2006). The number of older people in the U.S. is expected to double to 72 million people by 2030; by 2050, one in four older adults is projected to be from one of the four populations designated as
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minority: African American, Asian, Hispanic, and Other (U.S. Census Bureau). Thus, the United States will have a large older adult segment of the population that combines the highest demand for health care services of any age group, the lowest health literacy scores, and many who will belong to racial and ethnic minorities. Thus, it is critical to understand and summarize the literature on health literacy needs of diverse older needs, and what interventions seem to work for this group.

Manuscript #3 - Oral Interactions between Healthcare Providers and low-SES Patients in an Inner City Diabetes Clinic

The third manuscript will provide an analysis of how providers and patients communicate in their clinical encounters in an inner city public hospital diabetes clinic. Oral communication barriers between patient and health care provider have a negative impact on health literacy and health outcomes (Brach, et al, 2005; Fortier & Bishop, 2004). Patients who have low education levels may not have the linguistic or cognitive skills to actively participate in their healthcare encounters. The specific aim of this study is to evaluate oral communication between diabetes patients with low education levels and their health providers to determine what communication strategies are used – or not used - in clinical encounters. It is hypothesized that, in this setting, health care providers do not use interactive oral communication strategies that have been shown to be helpful to patients with low education levels. In addition, it is hypothesized that nurses have more interactive encounters with patients than they do with physicians and that patients who are adherent to taking blood sugar measures at home will have more interactive encounters overall. In addition, it is hypothesized that patients can be assigned
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to adherent or non-adherent groups based on their use of first- or second- person pronouns as possible linguistic markers of adherence. Manuscript 3 was a Georgia State University and Emory University IRB-approved study conducted at the Grady Diabetes Center with 17 patients and 10 health providers between September and December 2011. Basic demographic information was obtained, and the clinical encounters between patient and health provider were audio taped. The tapes were transcribed and downloaded into NVivo, and subsequently analyzed for two different communication methods - the Interactive Communication Loop and Active Patient Participation. Two researchers coded the transcriptions reliably. The focus of Manuscript 3 will be on summarizing characteristics of patient-provider interactions from these data.

Coding methodology from Schillinger, et al., was used to assess provider interactivity by checking for lapses in recall, understanding, and use of the “teach-back” method (2003). The “teach-back” method is a communication process in which the health providers ask the patient to explain what he/she said; if the patient understands, he/she will be able to accurately explain the information and teach it back to the provider. Specific codes are delivery of new concepts (medication and non-medication), request patient recall of new concepts, clarification of information based on patient response and request patient recall of clarified information (Schillinger, et al., 2003). The number of times the “teach-back” method was used to assess patient recall was also analyzed because that is a clearly recognized method of engaging in interactive communication (Rudd, 2010). Active Patient Participation was analyzed by assessment of three (3) patient measures (asks questions, makes an assertive utterance, and expresses concerns) and two (2) provider measures (participates in partnership building and
engages in small talk) according to schemata developed by Street and Millay (2001). Additional analysis was performed to identify use of first and second pronouns in patient talk and to determine if patient talk could be profiled according to adherence to taking blood sugar measures at home.
Understanding Health Information Seeking Behaviors of Adults with Low Literacy, Numeracy, and Problem Solving Skills: Results from the 2012 US PIAAC Study

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This paper has been commissioned by American Institutes for Research, funded through a contract with the National Center for Education Statistics (NCES).
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Abstract

Literacy, numeracy, and problem solving in technology-rich environments (LNPS) skills are important for health – LNPS is linked with health through accessing, interpreting, and using health information which leads to increased health knowledge and further impact on health behaviors. In order for adults to participate in their health care, they must have adequate functional health literacy, which is driven by the ability to seek and then use health information. There is limited understanding about health information seeking behaviors (HISB) for adults with low LNPS. The purpose of this study is to gain an understanding about which demographic, health behavior, and facilities in English factors influence health information seeking behaviors (HISB) in adults 16-65 who have low-level LNPS.

Methods and Data Source: We ran several sets of analyses on the 2012 US PIAAC Data using SAS v. 9.1.3 (Cary, NC). Our population was stratified into 3 specific domains – Literacy, Numeracy, and Problem Solving – with low-level proficiency levels based on OECD convention. Outcome variables are sources of health information – Print Media, Internet, Radio/TV, Family/Friends/Co-Workers, and Health Professionals. Predictor variables are Gender, Age, Race, Educational Attainment, Health status, Use of Preventive Health Measures and Facilities in Reading, Writing, Speaking, and Understanding Spoken English. All appropriate weighting and imputation macros derived by the OECD were utilized, and frequencies and logistic regressions were conducted.
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**Results:** Within the Literacy and Numeracy domains, our study population used oral communication sources (Radio/TV, Health Professionals, Friends/Family/Co-Workers) more often than printed communication sources (Print Media, Internet). Those in the Problem Solving domain used the Internet more than those in the Literacy and Numeracy domains. Varying combinations of demographic, health behavior, and facilities in English were significant for each source of health information depending on the cognitive domain. However, there was no predictive consistent pattern across domains or across health information sources.

**Significance:** People with low-level LNPS who seek health information report better health than those who do not seek health information, regardless of information source. HISB is also complex and individualized. There are differences in HISBs among those with low level Literacy, Numeracy, and Problem Solving proficiency levels based on both sources used and different demographic, health behavior, and facilities in English variables. People also use multiple sources for health information. Those who actively seek health information are more likely to be active participants in their health care outcomes, a key construct in high quality health care. Understanding the multifaceted nature of HISB can help researchers and practitioners develop targeted and sustainable interventions to increase HISB.
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Introduction

Patient-centered care (PCC), in which patients and their providers work together to make decisions about health care and disease management, is considered one of the key components of high-quality healthcare (IOM, 2013). For patients to participate in their care, they must have adequate functional health literacy, which enables them to use health information in this dyadic communication framework (Rubin, 2014; Parker et al., 1995). A critical first step in having functional health literacy is the ability to access and identify information that can be used for the more complex and situational demands of health care (Rubin, 2014, IOM, 2013; Alharbi, Ekman, Olsson, Kudas & Calsrom, 2012).

Studies indicate that there are many predisposing characteristics to individual health literacy, including age, education level, literacy level, pre-existing health conditions, and race (Dutta-Bergman, 2004; Berkman et al., 2011; Anker, Reinhart, & Feeley, 2011). Women, for example, interact more often with the health care system than men (Berkmann, DeWalt, Pignonette, et al., 2004), yet those with low literacy levels are less likely to use preventive health services (National Women’s Health Resource Center, 2004). Older adults and those with less than a high school diploma are less likely to be knowledgeable about both preventive measures and management of sick behaviors because they are less likely to seek health information and more likely to miscommunicate with their health providers (McCray, 2005). Results from the 2003 NAALS study indicate that adults who were White or Asian/Pacific Islander had higher average health literacy levels than Blacks, Hispanics, American Indians, and Multiracial adults.
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(2006). These individual factors and characteristics are important to study in a holistic manner since they each affect health outcomes in a different way.

Adults with lower literacy and numeracy skills have significantly lower health literacy and poorer health outcomes (Koo, Krass, & Aslani, 2006; Birru et al., 2004; Berkman et al., 2011). Adults of all literacy and numeracy levels face challenges in making choices about their health behaviors. For example, knowledge, motivation, self-efficacy and self-regulation are some personal characteristics that can enhance or impede behavior change (Mann, deRidder & Fujito, 2013). In addition to these personal factors, adults who have low level literacy and numeracy levels may have difficulty accessing, understanding, and communicating important health information (Berkman, et al., 2011), which further inhibits their ability to make health changes or participate in their health care.

The implications of low health literacy have come to the attention of the healthcare community over the last 20 years, and as a result increasing attention has been paid to the readability levels of printed materials (Berkman et al., 2011). The simultaneous increase of health information on the Internet confounds this advance because the high literacy, numeracy, and computer skill demands of health-related websites create problems for those who have low literacy, numeracy, or computer skills (Birru et al., 2004). Challenges in oral communication exist as well; the complexity of medical language, discordance between language and literacy skills of patients and providers, and intercultural communication issues add to the difficulty adults with low levels of literacy have in participating fully in their health care (McCray 2005, Roter, 2011). Numeracy creates different challenges as adults struggle to understand medical
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statistics, medication dosage requirements, and basic health concepts such as daily nutritional values (Berkman et al., 2011; Parker et al., 1995; Rothman et al., 2006). Multiple health information sources are also used, often simultaneously, which can create conflicting reliability, relevance, and information overload.

The Program for the International Assessment in Adult Competencies (PIAAC) data present a unique opportunity to understand how directly assessed skills in the cognitive domain areas of literacy, numeracy, and problem solving in technology rich environments (LNPS) interact with background and demographic factors that may inform how individuals function in society. The PIAAC is an international survey conducted under the auspices of the Organization for Economic Cooperation and Development (OECD). Representative (minimum) samples of 5,000 adults between the ages of 16 and 65 were surveyed in each of the 24 participating countries (OECD, 2013). Each domain (Literacy, Numeracy, and Problem Solving in Technology Rich Environments) is divided into proficiency levels; adults at each proficiency level have a 67% chance of completing all test items located at that score cut point (OECD, 2013). Literacy and Numeracy proficiency levels are reported in 5 levels (Below Level 1, Level 1, Level 2, Level 3, and Level 4/5) and Problem Solving in Technology Rich Environments is reported in 4 levels (Below Level 1, Level 1, Level2, and Level 3), each on a 500-point scale.

Each country was allowed to add 5 minutes of questions to their background questionnaire. The United States included questions relating to health status, health information seeking behaviors, and use of preventive health measures. This broad look at self-reported health
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behaviors allows us to consider differences across demographic factors, educational attainment, self-reported facilities in reading, writing, and speaking/understanding spoken English and specific cognitive domain skills. This may provide important data to inform targeted interventions within each domain for health promotion, health education, and participatory health decision-making. These differences also help us understand how to help adults become more health literate which can lead to better health outcomes through improved integration and application of written and oral educational and promotional materials, health directives, and communication with health providers (U.S. Department of Health and Human Services, 2010).

Health literacy is an interactive and iterative process, with a key tenet of matching the literacy content of health information with the literacy skill level of the individual. Numeracy is also a critical component of health information, since adults with low numeracy skills may not be able to process and understand numbers and statistics in a health context such as dosing information on prescription labels (Brown et al., 2011; Goodman, Finnegan, Mohadjer, Kenzke & Hogan, 2013). The growth of the Internet as a source of health information has been exponential (Manyika & Roxburgh, 2011; Fox, Duggan & Purcell, 2013). Adults with low problem solving skills in technology rich environments may not be able to access information or navigate through electronic sources of health information (OECD, 2013). We use the PIAAC proficiency levels to understand the health information seeking behavior of people with low-level LNPS. Acquiring this knowledge can generate important opportunities for those who create and deliver health information, education, and messaging because it enables them to more successfully match the LNPS content in the supply of health information and health education to
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the LNPS demands of health information users (Baker, 2007; Rothman et al., 2006; Hibbard, Peters, Dixon & Tusler, 2007; Rubin, 2014). Decreasing the gap between what is written and said and what is read, heard and understood helps reduce knowledge barriers and may enhance positive health outcomes for adults with low LNPS (Rubin, 2014; Rothman et al., 2006; Epstein et al., 2005; Parker et al., 1995).

The United States spent $2.6 trillion on health care in 2010 (Emanuel, 2011); it is estimated that 40% of that amount, almost $1 trillion, is wasted. Overtesting, lack of patient compliance, hospital readmissions, and unnecessary emergency room visits are four of the top contributors to this inefficiency (Kavilanz, 2009). Poor communication and understanding contribute to all of these. Adults who have low LNPS have difficulty accessing, understanding, and communicating important health information (Berkman et al., 2011). These barriers impact access to health care, health outcomes, patient safety, engagement and participation in society, and the development of individual and family potential (NCES, 2013). Few studies have assessed how individuals varying in LNPS levels engage in health information seeking behaviors (HISB). Knowing how adults with low LNPS engage in HISB is important because those who actively seek health information from a variety of sources are likely to be more cognitively and psycho-socially prepared to engage in medical decision-making and with the medical system (Lambert & Loiselle; 2007; Case, 2012). The PIAAC data present a unique opportunity to understand how a holistic set of demographic traits, self-reported background questions, and cognitive skills measured by direct assessments in literacy, numeracy, and problem solving relate to the choices that adults make in seeking health information.
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To this end, we explored how individuals with low-level LNPS seek health information by asking the following research questions:

Research Question 1: “What sources do people with low level LNPS utilize when seeking health information?”

Research Question 2: “When looking at Gender, Age, Race, Educational Attainment, Health Status, Use of Preventive Measures and Facilities in Reading, Writing, and Speaking/Understanding Spoken English, which of these factors predict different health information sources for people with low level LNPS?”

Methods

Study Population

Data for this study were acquired from the 2012 PIAAC dataset using the United States country-specific background questionnaire administered to a representative sample of 5,000 adults between the ages of 16 and 65. The background questionnaire was given in both English and Spanish depending on the respondent’s language.

Eligibility

Our sample (n= 2,270 for Literacy, n=2,810 for Numeracy, and n=2,270 for Problem Solving) included all PIAAC participants who scored at Literacy and Numeracy proficiency levels of Below Level 1, Level 1, Level 2 and who scored at Problem Solving proficiency levels
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of Below Level 1 and Level 1. Our proficiency level groupings followed the OECD reporting convention (OECD, 2013). Literacy, Numeracy, and Problem Solving skill proficiency levels were defined according to the classifications by the United States Department of Education at Below Level 1 (scores of 0-175), Level 1 (176-225), and Level 2 (226-275) for Literacy and Numeracy, and Below Level 1 (scores of 0-240), and Level 1 (241-290) for Problem Solving (OECD, 2013). We further combined Below Level 1, Level 1, and Level 2 within the Literacy and Numeracy domains; these groupings are called “Low level Literacy” and “Low level Numeracy”. We combined Below Level 1, and Level 1 within the Problem Solving domain and called the grouping “Low level Problem Solving”.

The above described proficiency levels were created for each imputation of the PIAAC as recommended by the PIAAC analytic staff. In this study, participants were only included only if there was no missing data in any of the dependent and independent variables under study in order to avoid separation of the data. We evaluated each domain independently, however, participants may have had some combination of low level Literacy, Numeracy and Problem Solving; we did not study those who had only low Literacy, only low Numeracy or only low Problem Solving.

Variables

Dependent Variables

Sources of health information were our outcome variables. Participants were asked, “How much information about health issues do you get from…” The responses, “A lot”, “Some”, “A Little”, and “None” were coded on a Likert Scale from 1-4..There were eight
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different outcome source variables – newspapers, magazines, Internet, radio, television, books or brochures, family members/friends/co-workers, and health professionals. Individuals in our sample answered each survey question independently; each individual could have selected from 0 to 8 sources of health information. The variables were collapsed into five outcome categories: Print Media (newspapers, magazines, books or brochures), Internet, Radio/TV (radio, television), Family Members/Friends/Co-Workers, and Health Professionals. We created dichotomous variables from the Likert Scale responses: “A Lot” or “Some” were coded as “Uses This Source” and “A Little” or “None” were coded as “Does Not Use This Source”. Participants who selected “A Lot” or “Some” in any of the original variables for Print Media (newspapers, magazines, books or brochures) were considered as “Uses This Source” while those who selected “A Little” or “None” in any of the original variables were considered as “Does Not Use This Source”; the same is true for any of the dichotomous variables that were collapsed from multiple questions in the background questionnaire. We considered retaining “A Lot” and “None” as separate categories, however, the frequency of those categories was too low and the analysis would not have been informative or broadly generalizable.

Independent Variables

We were interested in several demographic variables (Gender, Age, Race, Educational Attainment), self-reported health variables (Health Status, Use of Preventive Health Measures) and self-reported facilities in English (Reading, Writing, Speaking/Understanding Spoken English).
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Demographic:

Gender was determined using the PIAAC variable GENDER_R. With regard to Age, we utilized the PIAAC AGE10LF variable code, which breaks age groups into 24 and under, 25-34, 35-44, 45-54, and 55-65. We used the PIAAC RACETHN_4CAT race variable with 4 categories: White, Black, Hispanic, and Asian/Other. For Educational Attainment, we were interested in those with and without a high school diploma, and used the PIAAC B_Q01aUS_C variable to make that determination, creating a dichotomous variable to indicate whether or not a person had a high school diploma.

Self-Reported Health Variables:

We were interested in self-reported health status and use of preventive health measures. Self-reported Health Status was reported as “Excellent”, “Very Good”, “Good”, “Fair” and “Poor” on a Likert Scale from 1-5; we created dichotomous variables from these responses, coded as “Excellent/Very Good/Good” and “Fair/Poor”. We considered only analyzing Excellent and Poor, however, the frequency of those categories was too low and the analysis would not have been informative. Additionally, while this may have provided empirically sound data, we felt that this would generalize the results to a population that is too heterogeneous, i.e., inclusive of a range from those whose health status may have ranged from Fair to Excellent at any time in the present or past.

The other variable was Use of Preventive Health Measures. There were a series of questions relative to preventive measures to which participants answered either “Yes” or “No” (“In the past year have you had a…” flu shot, mammogram, pap smear, screen for colon cancer,
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dental visit, vision check, screen for prostate cancer, screen for osteoporosis). We measured “Any” versus “None”; if a participant had used any of the preventive measures, they were coded as “Any Preventive Measure”; otherwise if they had no preventive measures, they were coded as “No Preventive Measures”. We felt that this accommodated for preventive measures that may have been directed toward women only (e.g., pap smear), men only (e.g., prostate cancer screen), or those of a certain age only (e.g., osteoporosis screen).

Self-Reported Facilities in English

We used three broad measures of self-reported facilities in English - Reading Writing, and Speaking/Understanding Spoken English. These variables represent different cognitive and affective constructs. Adults who have low LNPS may have strengths or weaknesses in any or all of them, which may further inhibit or enhance their HISB. Self-reported Facility in Reading English was reported as “Very Well”, “Well”, “Not Well”, “Not at All” on a Likert Scale from 1-4; we created dichotomous variables from these responses with “Very Well” or “Well” as “High” and “Not Well” or “Not at All” as “Low”. We used the same scoring for writing in English. There were two oral variables in the PIAAC dataset – Speaking and Understanding Spoken English. With regard to these facilities, we determined a high correlation between speaking and understanding spoken English (ϕ=.85, p<.001), so we created a single variable, Facility in Spoken English, to measure this construct. If Self-reported Facility in Speaking or Understanding Spoken English was reported as “Very Well” or “Well”, we considered the response as “High”; if reported as “Not Well” or “Not at All”, we considered the response as “Low”.
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Statistical Analyses

We ran several sets of analyses using SAS v. 9.1.3 (Cary, NC) after downloading the PIAAC U.S. Public Use File Number 2014045 from the National Center for Education Statistics and creating the abovementioned variables (SAS, 2002-2004; U.S Department of Education, 2013). All appropriate weighting macros derived by PIAAC were utilized in order to provide population-level results adjusted for the sampling methods used in the study. By using random selection methods at each stage of sampling, this four-stage stratified area probability sample provided reliable statistics for the US population from the sampled data (OECD, 2013).

The proficiency scoring categories were created for each imputation of the PIAAC as recommended by the PIAAC analytic staff. In addition, according to NCES Statistical Standards and IES Data Security’s rules, sample frequencies were rounded up to the nearest 10s. Weighted frequencies and binary univariate logistic regressions were conducted. The regression models produced by SAS provided estimated odds ratios (ORs) with confidence interval of 95% as well as significance ($p \leq .05$).

Results

Before specific research questions are addressed, we looked at characteristics of our sample. Frequencies are stratified according to each domain - Literacy, Numeracy, and Problem Solving and are listed in Appendix Table 1.

Significant differences in population distribution were generally found in all variables between Literacy and Problem Solving and Numeracy and Problem Solving. Significant differences in population distributions between Literacy and Numeracy were found in Gender
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(more men in Low Level Literacy and more women in Low Level Numeracy, \( \chi^2 = 4.1 (1), p \leq .05 \)). Age was also a variable with statistical significance in distribution between Literacy and Numeracy \( \chi^2 = 14.1(4), p \leq .05 \). Adults ages 55-65 were more likely to be in the low level Literacy domain than adults 24 and younger while a higher proportion of adults ages 24 and younger were in the low level Numeracy domain. Differences in sample distribution between all variables within the 3 domains are shown in Appendix Table 2.

**Research question 1 asks** ‘What sources do people with low level LNPS utilize when seeking health information?’ To answer this question, we consider weighted frequencies and odds ratios.

Table 1 shows the frequencies of utilization of health information source by cognitive domains. Radio/TV were the most used source for those with low level Literacy and Numeracy and the Internet and Health Professionals were the most used sources for those with low level Problem Solving. Overall, Radio/TV was the most frequently used source and Print Media was the least.
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Table 1. Use of Health Information Sources by Cognitive Domain

<table>
<thead>
<tr>
<th></th>
<th>LITERACY</th>
<th>NUMERACY</th>
<th>PROBLEM SOLVING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Media</td>
<td>68%</td>
<td>70%</td>
<td>72%</td>
</tr>
<tr>
<td>Internet</td>
<td>65%</td>
<td>68%</td>
<td>79%*</td>
</tr>
<tr>
<td>Radio/TV</td>
<td>80%*</td>
<td>79%*</td>
<td>78%</td>
</tr>
<tr>
<td>Friends/Family/Co-Workers</td>
<td>75%</td>
<td>70%</td>
<td>71%</td>
</tr>
<tr>
<td>Health Professionals</td>
<td>68%</td>
<td>77%</td>
<td>79%*</td>
</tr>
</tbody>
</table>

*Most used source/sources of health information

Figure 1 highlights the use of difference health information sources by cognitive domain.

There is a correlation among all of the health information sources (Print Media, Internet, Radio/TV, Family/Friends/Co-Workers and Health Professionals), and they are all significantly associated as shown in Appendix Table 3.

Figure 1. Use of Health Information Sources by Cognitive Domain
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Participants used multiple health information sources. Within the Literacy domain, for example, Radio/TV was used most often (Table 1, Figure 1). According to results shown in Table 2, that means that those who are in low level Literacy and who use Radio/TV are 3.5 times more likely to use Print Media as their secondary source of health information while those in low level Problem Solving are only 2.8 times more likely. All of these relationships are significant as shown in Appendix Table 3.

<table>
<thead>
<tr>
<th>Source of Health Information</th>
<th>Most Likely Additional Source of Health Information</th>
<th>Domain Odds Ratios</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print Media</td>
<td>Internet</td>
<td>Literacy 3.6*</td>
</tr>
<tr>
<td>Internet</td>
<td>Print Media</td>
<td>Literacy 3.6*</td>
</tr>
<tr>
<td>Radio/TV</td>
<td>Print Media</td>
<td>Literacy 3.5*</td>
</tr>
<tr>
<td>Friends/Family/Co-Workers</td>
<td>Health Professionals</td>
<td>Literacy 2.6*</td>
</tr>
<tr>
<td>Health Professionals</td>
<td>Internet</td>
<td>Literacy 3.4*</td>
</tr>
</tbody>
</table>

*Significance at p<.05

Figures 2 – 6 illustrate the likelihood of using multiple sources in addition to an individual source. All of the results are significant (p<.05) except for the Problem Solving domain interaction between Health Professionals and Radio/TV.
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Figure 2. Likelihood of Using Different Health Information Sources in Addition to PRINT MEDIA

Figure 3. Likelihood of Using Different Health Information Sources in Addition to INTERNET
Health Literacy in High-Risk Populations

Figure 4. Likelihood of Using Different Health Information Sources in Addition to RADIO/TV

Figure 5. Likelihood of Using Different Health Information Sources in Addition to FRIENDS/FAMILY/CO-WORKERS
Health Literacy in High-Risk Populations

Figure 6. Likelihood of Using Different Health Information Sources in Addition to HEALTH PROFESSIONALS

*Research Question 2* asks: “When looking at Gender, Age, Race, Educational Attainment, Health Status, Use of Preventive Measures and Facilities in Reading, Writing, and Speaking/Understanding Spoken English, which of these factors predict different health information sources for people with low level LNPS?” Key findings at $p \leq .05$ are discussed herein, and detailed Odds Ratios are shown in the Appendix, Table 4 with a summary shown below in Table 3.
### Table 3. Significant Factors Predicting Use of Health Information Source, Domains with Significant Findings (Noted as L=Literacy, N=Numeracy, PS=Problem Solving)

<table>
<thead>
<tr>
<th></th>
<th>Print Media</th>
<th>Internet</th>
<th>Radio/TV</th>
<th>Friends/ Family/Co-Workers</th>
<th>Health Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong> (referent= male)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (L,N,PS)</td>
<td>Female (L,N,PS)</td>
<td>Female (PS)</td>
<td>--</td>
<td>Female (L,N,PS)</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong> (referent=24 and younger)</td>
<td>55-65 (L, N, PS)</td>
<td>24 and younger vs 35-65 (L,N)</td>
<td>35-54(L) 45-54(N) 35-65 (PS)</td>
<td>--</td>
<td>55-65 vs 24 and younger (L, N, PS)</td>
</tr>
<tr>
<td>Black, Hispanic, Asian/Other vs non-Black, Hispanic, Asian/Other (L,N,PS)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic, Asian/Other vs non-Hispanic, Asian/Other (L)</td>
<td>Black vs Non-Blacks (L,N,PS) Hispanics vs non-Hispanics (L) Asian/Other vs Non-Asian/Other (N)</td>
<td>--</td>
<td></td>
<td>Blacks vs Non-Blacks (L,N,PS)</td>
<td></td>
</tr>
<tr>
<td><strong>Educational Attainment</strong></td>
<td>High School Diploma (L,N,PS)</td>
<td>High School Diploma (L,N,PS)</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td><strong>Health Status</strong> (Good vs Poor)</td>
<td>Good (L,N)</td>
<td>Good (L,N,PS)</td>
<td>Good (L,N,PS)</td>
<td>Good (L,N,PS)</td>
<td>Good (N, PS)</td>
</tr>
<tr>
<td><strong>Preventive Measures</strong></td>
<td>Use of Preventive Measures (L,N,PS)</td>
<td>Use of Preventive Measures (L,N,PS)</td>
<td>--</td>
<td>Use of Preventive Measures (L/N,PS)</td>
<td>Use of Preventive Measures (L/N,PS)</td>
</tr>
<tr>
<td><strong>Facility in Reading English</strong></td>
<td>High (L,N)</td>
<td>High (N)</td>
<td>High (N)</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td><strong>Facility in Writing English</strong></td>
<td>--</td>
<td>High (L,N,PS)</td>
<td>--</td>
<td>High (N)</td>
<td>High (L,N,PS)</td>
</tr>
</tbody>
</table>
Discussion

Health Information Seeking Behavior (HISB) is a complex process (Lambert & Loiselle, 2007). Our research demonstrated that for people with low-level LNPS, HISB is determined by varying combinations of a person’s background, health related behaviors, and perceived skills in English. Our study identified the sources that adults with low LNPS used when searching for health information. In addition, we identified what factors might individually or in combination predict the use of certain health information sources. Taken together, these findings provide guidance to those involved in health education, health promotion, and the delivery of health care, and shed light on the complex role HISB plays in health literacy and health behaviors.

Individuals at low-level Literacy/Numeracy proficiency levels were more likely to use oral sources of health information (Radio/TV, Friends/Family/Co-Workers, Health Professionals) than written sources (Print Media, Internet). Written health information is often dense, complex, and scientific, even when presented in an easier to read format (Hibbard, Peters, Dixon & Tusler, 2007; Dutta-Bergman, 2004; Brown et al., 2011). Those who have weak skills in navigating complex written text and in applying multi-step processes to understand, evaluate, and apply what is read may have difficulty even accessing printed health materials (OECD, 2013). Health information is often replete with both text and numbers; therefore, it is not surprising to see that sources with written information are the least used by adults with these low level skills. Adults with such limitations may only be able to identify basic vocabulary, determine sentence meaning, perform the most basic mathematical operations, and identify
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simple graphical elements according to directly assessed testing done in the PIAAC study (National Center for Education Statistics, 2013). On the other hand, one of the most commonly used health information sources for adults with low level Problem Solving is the Internet. Even though the tasks they can accomplish may be simple or one-dimensional according to directly assessed PIAAC testing, the ability to use available and familiar technology such as web browsers may lead to ease in finding information on a digital platform such as the Internet (National Center for Education Statistics, 2013).

Multiple Sources of Health Information

We demonstrated that individuals use multiple sources of health information, and those who do tend to report better Health Status. The Internet was most often combined with use of Print Media and Radio/TV while use of Friends/Family/Co-Workers was most often combined with Health Professionals. HISB, then, is not necessarily driven by comfort with or availability of one source or another, but rather by multiple sources through various modalities.

Understanding how information sources and adults with low level LNPS interact with each other in HISB will provide a more comprehensive and holistic understanding of information acquisition. Individuals may understand different aspects of that health information differently, depending on whether it is media-related, people-related, actively sought, or passively sought (Anker et al., 2011; U.S. Department of Education, 2013; Wakefield et al., 2010; Salwen & Stacks, 2009).
Print Media

Although the use of print media as a source of health information has fallen since 2007 (Tu, 2011), written materials are the most common source of health information, are widely and easily available, and are often distributed to patients who utilize the health care system. Our study found that use of printed materials has the broadest group of significant predictors of any health information source (see Appendix Table 4) – Gender, Age, Race, Health Status, Use of Preventive Measures, and Facility in Reading English. This indicates the importance of printed materials for adults across all low LNPS domains (Ryan et al, 2014).

We also demonstrated that adults who report good Health Status and Use of Preventive Measures in the low level Literacy and Numeracy domains were more likely to use Print Media. A variety of tools such as the CDC’s Clear Communication Index and the AHQR’s Health Literacy Toolkit have been developed to assess the readability and suitability of printed materials for adults with low literacy levels. Regardless of LNPS level, printed materials that are clear, concise, in plain language, and use simple graphics increase patient uptake and utilization of information (Hibbard, Peters, Dixon & Tusler, 2007; Parker et al., 1995, Rothman et al., 2006). In addition, printed materials are often kept for future reference, can be shared with those who may have a higher level of understanding, are used as teaching or reinforcement tools, and share information about available health services (Shieh & Hosei, 2008).

Hispanics and Asians favored Print Media and this may be because print materials are widely available in multiple languages (Sarkar, Schillinger, Lopez, & Sudore, 2010; Ye, Mack, Fry-Johnson, & Parker, 2012). This broad availability may inform this finding since the PIAAC
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survey question did not specify which language the health information was in. Older adults across LNPS domains also rely on Print Media for health information. Health professionals such as physicians, nurses, and pharmacists often provide health materials as part of providing health care (Schloman, 2014). Research suggests that health professionals are the most trusted source of health information; therefore, receiving printed materials from a trusted source may make them more credible (Dutta-Bergman, 2003; Health Information National Trend Survey, 2010). This is also consistent with our findings that people ages 55-65 are more likely to use Health Professionals as a source of information.

The Internet

The Internet is considered the fastest growing source of health information (Manyika & Roxburgh, 2011; Fox, Duggan & Purcell, 2013); however, our results showed that only 2/3 of adults with low level Literacy/Numeracy use the Internet as a source of health information. The high literacy demands of health-related websites may create problems in understanding and application of information even for those who have a high school diploma (Birru, Monaco, Charles, Drew, Njie, Bierria, Detlefseon & Steinman, 2004). According to the directly assessed Literacy and Numeracy PIAAC testing, adults with low literacy and numeracy proficiencies are more likely to only be able to access and identify rather than integrate and apply information (OECD, 2013). The knowledge and use gap further created by the introduction of digital resources exacerbates challenges faced by those with low LNPS who may also have low digital literacy skills (Birru et al., 2004; Dutta-Berman, 2004; Fox, Duggan, & Purcell, 2013). In addition, health information that people acquire from the Internet is often neither complete nor
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accurate. Those with low LNPS may have difficulty interpreting information correctly as well as determining the validity and accuracy of what they read.

   Adults with low LNPS may have difficulty searching for health information on the Internet for the following reasons: difficulty generating effective search terms, an aversion to using links on web pages, access to computers, and difficulty understanding how to use the information obtained (Fox, Duggan, & Purcell, 2013). Our finding that a high Facility in Reading English did not have significance in use of the Internet across all three domains is surprising since information on the Internet is largely text-based and must be read. This may be because many health-related websites and source materials have been translated into multiple languages and, at least for Hispanics and Asians in our study, reading in English does not matter.

   Interestingly, a high Facility in Writing English was significant in using the Internet across all 3 domains. Writing skills, including spelling and typing, are critical for digital literacy, and enhance use of the computer to access the Internet (Graham, MacArthur & Fitzgerald, 2013). It is also possible that those who are non-native English speakers have a low facility in writing English whereas their abilities to read in English are higher. They might not use the Internet because they cannot yet write confidently in English.

Radio/TV

   Television and radio are ubiquitous sources of passive information and widely accessible to most Americans. Within these media, health information is shared through different modalities including public service announcements, paid advertisements, educational entertainment, and documentaries (Cutilli, 2010; Redmond, Baer, Clark, Lipsitz & Hicks, 2010). Our study suggests
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that Blacks with low-level proficiency levels across all domains use Radio/TV as a health information source. This is not surprising since, according to the Nielson Company, Black Americans watch significantly more television than any other racial group (2013). Hispanics with low level Literacy /Numeracy skills also cite Radio/TV as a source of information. Because the PIAAC survey did not ask about source language, it is difficult to assess whether Hispanics used Spanish or English language Radio/TV as their source of information. In general, adults passively acquire health information from Radio/TV as an unintentional result of simply leaving the radio or television on during the day (Longo et al., 2010), or they may turn to specific educational entertainment shows that specifically focus on health related topics. Studies indicate that passive acquisition of health information from Radio/TV may ebb and wane depending on disease state, amount of prior health knowledge, source credibility, and clarity of the information (Longo et al, 2010).

**Friends/Family/Co-Workers**

The only significant findings regarding the immediate social context was that those who report better Health Status and Use of Preventive Measures use Friends/Family/Co-Workers as a source of health information. This is true across all LNPS domains, and the percentage of use is also fairly consistent within domains (75% Literacy, 71% Numeracy, 70% Problem Solving). According to Redmond et al. (2010), interpersonal sources of health information are often associated with self-reported health behaviors. Social influence may be partially responsible for eliciting healthy behaviors because interpersonal communication can create shared norms around health behaviors (Lee, 2010).
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Health Professionals

Our results indicate that people ages 55-65 are more likely than those 24 and younger to use Health Professionals as a source of information. Older individuals tend to have more chronic diseases, which facilitates the need for interaction with Health Professionals. Following from this, it is not surprising that those who report Use of Preventive Measures consider Health Professionals as a source of health information since health professionals are most likely to promote and/or provide these preventatives. Health Professionals can include physicians, nurses, allied health professionals, pharmacists, and others. They provide the majority of oral health communication with patients. Research indicates that healthcare professionals are the most trusted source of health information (Paradise & Garfield, 2013). Using health professionals as a source of information indicates that people are also utilizing some resources of the health care system, an important variable in having better health outcomes (Paradise & Garfield, 2013).

An interesting finding is that adults with low-level LNPS who report having a high Facility in Writing English report using Health Professionals as a source of information. Past studies have shown that adults with poor writing skills cannot adequately fill out medical forms, apply for health insurance, or miss appointments (i.e., because they do not write them down) and therefore do not access the health care system as readily as those with adequate writing skills (Baker, 2007; Berkman, 2011; IOM, 2013; Parker et al., 1995; Schloman, 2004; Safeer & Keenan, 2005). Blacks are the only racial group with greater usage of Health Professionals. Prior studies have conflicting findings: some indicate that Blacks have less trust in the health care system which is further associated with less doctor-patient interaction (Musa, Schulz, Harris,
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Silverman & Thomas, 2009), while others indicate that Blacks seek more health information from physicians and nurses because they are more trustworthy and credible than other sources (Agada 1999, Powe, Caburnay, Cooper, & Cameron, 2013).

Implications

It is evident from this study that Health Information Seeking Behaviors (HISB) are both complex and subtle, and depend on a multitude of factors. One size doesn’t fit all as was evidenced by the varying combinations of a person’s background, health related behaviors, and perceived skills in English as well as the use of multiple information sources as found in our study. This does not mean that continuing efforts to create health materials in appropriate readability levels should not continue. However, efforts must go beyond this.

Researchers and clinicians need to consider varying combinations of factors when developing health promotion and education interventions and materials for adults with low level LNPS. Materials should be developed at appropriate readability levels; however, additional focus must be placed on the health professionals themselves. Our study finds that people with low level LNPS who use health professionals as a source of information report better health status. It is challenging for health professionals to gain a patient’s trust, reduce their anxiety, exchange appropriate information, manage uncertainty and enhance their participation in decision making during a brief health care visit. Health literacy and cultural sensitivity training should be included as part of all health professional training, whether as a discrete curricular objective or as a component of continuous and on going training with evaluation criteria to measure outcomes. While one obstacle lies in training, another lies in time. The current system leverages high
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volume throughput over quality interaction between patients and providers. Changes could be made in how health care professionals are reimbursed for evaluation and management of patients because the amount of time required to engage in participatory decision making may exceed the amount of time required for a physical exam, diagnosis and development of a treatment plan. Other resources like para-professionals or physician extenders could help address this need, and should be considered as a complementary solution.

Patients and caregivers seek different types and amounts of information depending on their specific contexts and needs (Lambert & Loiselle, 2007). Health needs also change over the course of a lifetime and it may be valuable to consider HISB as a continuum of information seeking rather than a discretely occurring behavior. Our results show differences in ages relating to use of different health information sources. In particular, those who are older and have low LNPS do not use the Internet as much as those who are young; they face a critical gap in accessing health information as more health professionals and consumer organizations and agencies rely on its use. Digital literacy includes both use of physical technology and having the literacy skills to search and access information including medical communication such as medical forms, insurance forms, Internet search terms, and screening guidelines. It is unlikely that older individuals with low LNPS will become proficient technology users. Health information must be provided through modalities that are useful for older adults with low LNPS such as print media and oral communication with health providers.

Many basic and often repeated forms are filled with medical jargon that is meaningless to consumers. The health care industry – pharmaceutical companies, hospital, medical systems,
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and insurance companies – creates these documents, and has the ability to find ways to standardize and simplify information needs. While both reading and writing skills are important in seeking health information, our study shows that writing is significant when seeking information from two of the most common sources of health information – the Internet and Health Professionals. Medical history forms, insurance forms, informed consent forms, and other documents that contain blank spaces that are required to be filled in by the user are difficult for adults with low LNPS to fill out (Cornett, 2009). The health care industry could improve the meaning and usability of these documents by simplifying them and/or by providing assistance to those who may have difficulty filling out the forms. This might require additional sensitivity or cultural training for those who need to have medical forms filled in accurately and completely. Additionally, accessing this information on the Internet requires basic typing skills. Adults with low skill levels may not have had exposure to computer keyboards, or may have difficulty in spelling that inhibits their writing. While attention to digital literacy skills in all educational, vocational, or extra-curricular settings (such as libraries) can help increase use of the Internet by those who may be inhibited by their low facilities in writing, the medical industry can find ways to simplify the documentation to begin with.

Those who are involved in Adult Basic Education (ABE) may be able to find ways to increase participation in HISBs. For example, curricular modifications could be made to enhance writing skills in a health-related context since our study finds they are significantly associated with use of the Internet and Health Professionals. Educational attainment is a significant factor for those who use the Internet and Print Media as sources of health information, but so are self-
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reported Facilities in Reading English and Writing English. While some ABE classes only cover reading, many others do try to cover other skills and topics such as computer skills, math, writing, health literacy, and financial literacy. There is, however, very little curricular guidance, professional development, and overall funding provided to ABE (Greenberg, 2008). Within this reality, teachers could still be encouraged to incorporate those skills that lead to increased use and understanding of health content and information. Increasing access to and comfort with computers can also be encouraged by also providing information to adult learners about using computers at public libraries. Reading, writing, and digital literacy may be remediable skills for adults in ABE programs; enhancing skill level and self-efficacy in these direct skill areas could enhance how adults with low LNPS seek health information. Additionally, as functional skill levels in reading, writing, and computer use increase, these adults may also be more able to acquire higher-level skills and move from low-level LNPS levels to higher, more complex proficiency levels. Policy makers should consider enhanced funding for ABE in order to assist these adults with greater opportunities to engage in participatory health care.

Those with high school diplomas may be able to find health information, however their inability to use higher-level skills may inhibit interpretation and use of that health information. Ultimately, higher levels of engagement in health care and better health outcomes stem from this more complex use of health information. Educational ability matters for health – studies show that education is linked with health through health knowledge and behaviors, literacy levels, employment status, insurance status and a variety of social and psychological factors (Egerter, Braveman, Sadegh-Nobari, Grossman-Kahn, & Dekker, M., 2009; OECD, 2013). Results from
our study indicate that over 80% of adults in low-level LNPS have a high school diploma. The goal of accessing health information is eventually using that information to make informed health decisions and lead to better health outcomes, however, if students are not taught health literacy as part of the K-12 curriculum, there will never be a health literate adult population. Teaching children health content, how to seek information to answer health questions, and how to engage in healthy behaviors could have a maximal impact on their success in not only health, but in life and work as well. Policy makers in K-12 education must consider health literacy as an integral part of an educational system’s responsibilities to developing academic and life skills in their students.

Health information can be made simpler, more streamlined, more accessible, and more meaningful for adults with low LNPS. As shown through this analysis of the PIAAC data, there are a myriad of opportunities to be addressed. All stakeholders – researchers, clinicians, patients, caregivers, the health care industry, ABE and K-12 education policy makers – have a role to play in improving the health of individuals and society.

Limitations and Future Research

One limitation to this study is that we considered adults within each cognitive domain separately, i.e., we did not assess those who had any combination of low level literacy, numeracy and/or problem solving skills. We also dichotomized the outcome measures and only studied use vs non-use of a health information source. Measures of Health Status and Use of Preventive Measures were self-reported as were measures of Facility in Reading, Writing and Spoken English. We also were not able to discern if health information sources were in English or any
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other language. Our study also did not evaluate insurance-related access to the health care system, which could have created bias in participant responses. We did not consider native language status in our analysis as well. Additionally, the findings in this study addressed how adults source health information, not whether they understand and act on health information. Finally, we did not study how our sample population compares to those who have higher-level LNPS proficiency skills.

It is also possible that people who are deficient in all three domains have different outcomes than people with low skills in only one domain, therefore, future research in understanding how people with deficiencies in just one, two, or all of the three PIAAC cognitive domains source health information could inform more targeted HISB interventions. Although the PIAAC data only provided self-reports of health status and preventive measures usage, it may be valuable to corroborate some of these findings with directly assessed health data such as that found in the CDC NHANES dataset and others. Self-reported facilities in reading, writing and spoken English do not align themselves with educational attainment; it would be valuable to understand where these discrepancies lie and perhaps uncover how other sources of learning that are reported in the PIAAC data affect HISB. Evaluating native-language statuses as well as language of written and oral health information are other opportunities to add to the body of health communications research specifically targeted at the non-native English speaking population. Further questions about how individuals use health information provides a rich area for additional research since simply accessing health information does not always lead to positive changes in health outcomes. Finally, since HISB are not limited to adults with low level
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LNPS skills only, evaluation of adults with higher-level LNPS as directly assessed by the PIAAC data can help researchers frame targeted and sustainable changes in development of health education as well as the delivery of health information and health promotion by health professionals, health education and promotion practitioners, and the health care system.
### Table 1
General Population Characteristics and Weighted Frequencies, 2012 US PIAAC DATA
Low Level Literacy, Numeracy, and Problem Solving Proficiency Levels

<table>
<thead>
<tr>
<th>Variable</th>
<th>Low level Literacy</th>
<th>Low level Numeracy</th>
<th>Low level Problem Solving</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n*</td>
<td>Weighted %</td>
<td>SE</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1040</td>
<td>47.9%</td>
<td>0.9</td>
</tr>
<tr>
<td>Female</td>
<td>1230</td>
<td>52.1%</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under Age 24</td>
<td>230</td>
<td>10.3%</td>
<td>0.9</td>
</tr>
<tr>
<td>25-34</td>
<td>460</td>
<td>20.4%</td>
<td>0.9</td>
</tr>
<tr>
<td>35-44</td>
<td>450</td>
<td>21.0%</td>
<td>0.9</td>
</tr>
<tr>
<td>45-54</td>
<td>550</td>
<td>25.0%</td>
<td>0.9</td>
</tr>
<tr>
<td>55-65</td>
<td>580</td>
<td>23.4%</td>
<td>0.7</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1300</td>
<td>53.8%</td>
<td>1.2</td>
</tr>
<tr>
<td>Black</td>
<td>430</td>
<td>17.9%</td>
<td>0.6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>380</td>
<td>20.7%</td>
<td>0.9</td>
</tr>
<tr>
<td>Asian/Other</td>
<td>170</td>
<td>7.6%</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>High School Diploma</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>390</td>
<td>18.4%</td>
<td>0.6</td>
</tr>
<tr>
<td>Yes</td>
<td>1880</td>
<td>81.6%</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Health Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fair/Poor</td>
<td>530</td>
<td>22.0%</td>
<td>1.1</td>
</tr>
<tr>
<td>Excellent/Very Good</td>
<td>1740</td>
<td>78.0%</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Use of Any Preventive Health Measure</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't Use</td>
<td>440</td>
<td>20.5%</td>
<td>1.1</td>
</tr>
<tr>
<td>Use</td>
<td>1830</td>
<td>79.5%</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Facility in Reading English</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>190</td>
<td>10.6%</td>
<td>0.9</td>
</tr>
<tr>
<td>High</td>
<td>2080</td>
<td>89.4%</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Facility in Spoken English</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>110</td>
<td>6.5%</td>
<td>0.8</td>
</tr>
<tr>
<td>High</td>
<td>2160</td>
<td>93.5%</td>
<td>0.8</td>
</tr>
</tbody>
</table>
### Health Literacy in High-Risk Populations

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>High</th>
<th></th>
<th></th>
<th></th>
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<th></th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>250</td>
<td>2020</td>
<td>260</td>
<td>2560</td>
<td>80</td>
<td>2200</td>
<td>4.2%</td>
<td>95.8%</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td>13.9%</td>
<td>86.1%</td>
<td>11.5%</td>
<td>88.5%</td>
<td>0.8</td>
<td>0.8</td>
<td>0.9</td>
<td>0.8</td>
<td>0.5</td>
</tr>
<tr>
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*rounded to tens according to NCES Statistical Standards and IES Data Security Rules
Table 2: Differences between LNPS Domains for Gender, Age, Race, Educational Attainment, Health Status, Use of Preventive Measures, Facilities in Reading, Writing and Spoken English, Using Chi-Square Goodness of Fit Tests, df=1

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<th>Literacy to Problem Solving</th>
<th>Numeracy to Problem Solving</th>
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<td>$\chi^2$ (df)</td>
<td>$\chi^2$ (df)</td>
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<td>17.3(1)*</td>
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<td>Health Status</td>
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<td>Use of Preventive Measures</td>
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<td>20.3(1)*</td>
<td>4.8(1)*</td>
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<td>550.6(1)*</td>
<td>443.8(1)*</td>
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<td>Facility in Spoken English</td>
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<td>335.3(1)*</td>
<td>238.2(1)*</td>
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<tr>
<td>Facility in Writing English</td>
<td>.5(1)</td>
<td>260.2(1)*</td>
<td>175.4(1)*</td>
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* $p \leq .05$
# Health Literacy in High-Risk Populations

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<th>Friends/Family/Co-Workers</th>
<th>Health Professionals</th>
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<td>OR (CI)</td>
<td>OR (CI)</td>
<td>OR (CI)</td>
<td>OR (CI)</td>
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<td>3.5 (2.8, 4.5)*</td>
<td>1.9 (1.6, 2.3)*</td>
<td>3.4 (2.7, 4.2)*</td>
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<td>1.9 (1.6, 2.4)*</td>
<td>1.5 (1.3, 1.8)*</td>
<td>2.6 (2.0, 3.4)*</td>
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<td>1.6 (1.2, 2.1)*</td>
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<td>1.5 (1.3, 1.8)*</td>
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<td>2.6 (2.1, 3.2)*</td>
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<td>2.6 (2.0, 3.4)*</td>
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<td>2.6 (2.1, 3.2)*</td>
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<td>3.3 (2.6, 4.1)*</td>
<td>2.0 (1.7, 2.4)*</td>
<td>2.0 (1.7, 2.4)*</td>
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<td>3.7 (3.1, 4.5)*</td>
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<td>1.6 (1.3, 1.9)*</td>
<td>1.5 (1.3, 1.8)*</td>
<td>2.6 (2.1, 3.3)*</td>
</tr>
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<td>1.6 (1.3, 1.9)*</td>
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<td>2.0 (1.7, 2.4)*</td>
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<td>2.7 (2.2, 3.3)*</td>
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<th>Radio/TV</th>
<th>Friends/Family/Co-Workers</th>
<th>Health Professionals</th>
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<td>2.8 (2.2, 3.5)*</td>
<td>1.9 (1.6, 2.3)*</td>
<td>3.2 (2.5, 4.0)*</td>
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<td>2.1 (1.6, 2.8)*</td>
<td>1.4 (1.1, 1.8)*</td>
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<tr>
<td>Radio/TV</td>
<td>2.8 (2.2, 3.5)*</td>
<td>2.1 (1.6, 2.8)*</td>
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<td>1.3 (0.9, 1.8)</td>
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<td>1.4 (1.1, 1.8)*</td>
<td>1.8 (1.5, 2.3)*</td>
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<td>2.1 (1.7, 2.7)*</td>
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<td>2.4 (1.8, 2.3)*</td>
<td>1.3 (0.9, 1.8)</td>
<td>2.1 (1.7, 2.7)*</td>
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* Significance at p<0.05
## Table 4

**Odds Ratios (OR) for Gender, Age, Race, Educational Attainment, Health Behaviors, and Facilities in English on Sources of Health Information**

2012 US PIAAC Data, Low level Literacy, Numeracy, and Problem Solving Proficiency Levels

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<th>NUMERACY</th>
<th>PROBLEM SOLVING</th>
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<td>p</td>
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<td>1.3, 2.9</td>
<td>&lt;.05*</td>
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<tr>
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<td>.45</td>
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<tr>
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<td>.25</td>
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<td>1.3, 2.9</td>
<td>&lt;.05*</td>
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<tr>
<td>Black vs Non-Black</td>
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<td>1.0, 2.0</td>
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<tr>
<td>Hispanic vs Non-Hispanic</td>
<td>2.1</td>
<td>1.6, 2.8</td>
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<td>1.2, 3.1</td>
<td>&lt;.05*</td>
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<td>1.1, 1.9</td>
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<th>PROBLEM SOLVING</th>
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# Health Literacy in High-Risk Populations

## Hispanic

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<th>95% CI</th>
<th>p</th>
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<td>2.8, 2.1, 3.9</td>
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<td>2.1, 4.3, 3.0</td>
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<td>1.8, 1.4, 2.2</td>
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<td>1.4, 1.1, 1.9</td>
<td>&lt;.05*</td>
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<td>1.5, 1.2, 2.0</td>
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<td>1.6, 1.2, 2.2</td>
<td>&lt;.05*</td>
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## Radio/TV Literacy

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<th>p</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
<th>OR</th>
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<td>0.21</td>
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<tr>
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<td>1.3, 3.2</td>
<td>&lt;.05*</td>
<td>1.6</td>
<td>1.1, 2.2</td>
<td>*</td>
<td>2.2</td>
<td>1.2, 2.2</td>
<td>&lt;.05*</td>
</tr>
<tr>
<td>55-65 vs under 24</td>
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<td>0.9, 2.4</td>
<td>0.15</td>
<td>1.4</td>
<td>0.9, 2.1</td>
<td>0.13</td>
<td>2.5</td>
<td>1.0, 2.5</td>
<td>&lt;.05*</td>
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## Feminine/Family/Co-Workers Literacy

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<th>p</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
<th>OR</th>
<th>95% CI</th>
<th>p</th>
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*Note: CI = Confidence Interval, p = Probability*
## Health Literacy in High-Risk Populations

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<th>Odds Ratio (95% CI)</th>
<th>p Value</th>
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<td>0.19</td>
</tr>
<tr>
<td>35-44 vs under 24</td>
<td>0.8 (0.5, 1.2)</td>
<td>0.27</td>
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*Significance at p<.05
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from


Chapter 3: Manuscript Two

Cultural Competency in Health Literacy for Older Adults

Iris Feinberg, MA MBA
Daphne Greenberg, PhD
Amani Talwar, BA
Health Literacy in High-Risk Populations

A broad and overarching goal of health care delivery, health promotion, and health education is to improve the health and quality of life for all groups of people across all cultures and all life stages (Centers for Disease Control and Prevention [CDC], 2015a). In 2008, more than 33% of the U.S. population identified as belonging to a racial or ethnic minority population, 51% of the U.S. population were women, 23% of the population lived in rural areas, and 20% spoke a language other than English at home (CDC 2015a, 2015b; U.S. Census Bureau).

Acknowledging cultural differences in health care and health education is important, because culture forms one’s perspectives on health, wellness, disease, and treatment, and these perspectives can be vastly different within individuals, groups, and populations. It is essential, therefore, for health care and health education providers to understand how culture and health are intertwined. This chapter will discuss the intersection of health literacy and culture as they relate to older adults.

Health literacy is typically defined as the ability to obtain, read, understand, and use health care information to make meaningful health decisions and follow instructions for prevention and treatment (Kindig, Panzer, & Nielsen-Bohlman, 2004; Osborne, 2012; Parker et al., 1999; Speros, 2009). According to the National Association of Adult Literacy study in 2003, individuals aged 65 and older had the lowest health literacy scores of any age bracket (Kutner, Greenberg, Jin, & Paulsen, 2006). The number of older people in the U.S. is expected to double to 72 million people by 2030; additionally, by 2050, one in four older adults is projected to be from one of the four populations designated as minority: African American, Asian, Hispanic, and Other (U.S. Census Bureau). Thus, the United States will have a large older adult segment of the
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population that combines the highest demand for health care services of any age group, the lowest health literacy scores, and many who will belong to racial and ethnic minorities.

The move to patient-centered care and shared decision making as standard of care puts patients in the difficult position of needing to acquire disease knowledge and complex self-care skills through written and verbal instructions (Logan et al., 2015; Ownby, Waldrop-Valverde, & Taha, 2012; Speros, 2009). Older adults from marginalized groups who have low background health knowledge and low reading skills may be too uncomfortable to ask questions of their health provider (Findley, 2015; Speros, 2009). If information is not conveyed in a culturally and literacy-level appropriate way, it will not be understood or acted upon. A fundamental goal of health literacy for older adults is to improve their access to health information and help them use it effectively to make informed choices and exert greater control over their lives (Bennett, Chen, Soroui, & White, 2009; Findley, 2015; Fortiere & Bishop, 2004; Kutob et al., 2013; Lyons, Dunson-Strane, & Sherman, 2014; Purdie & McCrindle, 2002; Ziegahn & Ton, 2011). This interactive health literacy happens when individuals acquire and apply both disease knowledge and practical knowledge in reading and numeracy as well as communicate well with health providers, learn how to problem solve, and make meaningful health-related decisions (Aguilera, Dailey, & Perez, 2008; Manafo & Wong, 2012; Osborne, 2012; Rubin, 2014; Zamora & Clingerman, 2011).

Culturally competent health literacy for older adults integrates issues relating to aging with language differences, cultural differences, and an awareness of differences in health beliefs and behaviors. Common elements that individuals use to form their cultural identities include
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language, customs, beliefs, values, actions, and institutions; often specific to racial, ethnic, socio-economic, religious, social, peer, and/or geographic groups, culture influences the way people communicate and present themselves in all aspects of life (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Galambos, 2003; National Center for Cultural Competence [NCCC]). Internal to each culture are patterns and core values, and, as such, cultural boundaries are created organically (Galambos, 2003; NCCC; Yeo, 2009). People also have their own cultural histories, biases, ideas, and values, which can create language barriers and cultural mismatches (Aguilera et al., 2008; Guy, 1999; Lie, Carter-Pokras, Braun, & Coleman, 2012; Office of Minority Health [OMH]; Yeo, 2009). Oftentimes, these cultural boundaries are not clear, because each individual belongs to more than one cultural group, which causes the intersection and interaction of different cultural values within each of us. Cross-cultural communication, the ability to appropriately and effectively communicate across those boundaries, is a critical skill as there are few instances where people interact solely with others in their own culture (Langer, 2008; NCCC; Yeo, 2009).

Culture also plays a critical role in how individuals view health, health care, and health systems. Inherent in these views are the systems of beliefs that govern what causes illness and wellness, how the body works, how diseases are treated or cured, and who should participate in the delivery of health care and health-related services (Betancourt et al., 2003; Galambos, 2003; Lie et al., 2012; Koh, Garcia, & Alvarez, 2014; Whaley, 2000). For example, many groups within Western industrialized societies see disease as a result of natural scientific phenomena, while many groups within Eastern societies believe that illness is the result of the supernatural
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(Aguilera et al., 2008; Langer, 2008; Whaley, 2000; Yeo, 2009). Cultural beliefs play a role in how patient education is perceived, what kinds of compliance measures are likely to be adhered to, and why health promotion interventions may work for some but not for others (Aguilera et al., 2008; Betancourt et al., 2003; Langer, 2008; NCCC; Yeo, 2009). For example, military veterans, who are part of a culture that emphasizes discipline and hierarchy, may have a very difficult time questioning authority, even if those questions are simply to access more information (Hsu, 2010). In order to cross these and other linguistic and cultural boundaries, health care and health education providers must develop cultural competence, which is the ability to relate to and interact with people of different cultures in a respectful and responsive manner.

There are many challenges inherent in providing literacy level-appropriate health education while also considering culturally distinguishing features. For instance, a culturally distinguishing feature is peer affiliation, which can influence one’s cultural norms. Studies of military veterans show an organizational culture replete with certain behavioral norms and expectations, which can create difficulty integrating civilian and military identities (Koenig, Maguen, Monroy, Mayott, & Seal, 2014). In particular, there is a norm of organization, rules, and performing behaviors without question (Koenig et al., 2014). As another example, African American culture values strong kinship bonds, informal support networks (family, church, and community), and a strong sense of self-sufficiency and pride (Whaley, 2000). Other strong cultural values are a heightened sense of religious belief relating to illness (God as healer) that may cause a delay in seeking treatment or taking individual control over health behaviors (Levin, Chatters, & Taylor, 2005; Whaley, 2000). Geography can also play a role in how health
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education is delivered and received; rural citizens may have greater access to community-level care than to medical clinics and hospitals due to a wider geographic distribution of health providers. Their health problems may be more serious by the time they are diagnosed or by the time they are treated (Bolin & Bellamy, 2011; Meit, 2004) because their access to health care may be restricted due to distance.

Latino culture values “respeto” (respect), “la familia” (family), and “personalismo” (trust of others by developing personal relationships) (Freeman, 2002; Whaley, 2000). These values directly inform how health messages are received as they guide such behaviors as being deferential toward others, which may lead to not getting clarification, expecting family members to provide explanations and support. Belief in these values may also lead to a lack of trust in health providers who speak directly and do not develop a personal relationship with a patient (Keller et al., 2012; Whaley, 2000). Many Asian cultures hold beliefs such as a collectivist orientation (group needs are greater than individual needs), an indirect communication style (expecting others to understand what is meant instead of what is directly said), face maintenance (not wanting to impose on others), and shame orientation (a concern about behaviors that bring embarrassment), all of which are very different than normative Western behaviors (Whaley, 2000).

Finally, there are linguistic challenges to consider. For example, Spanish speakers may understand and use the English language, but there may be different meanings and connotations in even everyday words. One simple example is the word “once” which English speakers know to mean one time. Spanish speakers may read “once” as “on-say” in Spanish, which means the
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number 11; this could drastically change the number of pills one takes or the number of times one does something. Another linguistic challenge is the common use in English of negatives, e.g., “You don’t want to be sick, do you?” which may be difficult for non-native English speakers to translate and comprehend.

A perusal of the literature points to very few examples of health literacy intervention studies on older adults with a focus on cultural differences. Highlighted here are a few examples that depict how culture is important to consider when designing health literacy interventions. The selected studies represent a variety of different cultural aspects – language, ethnicity, and geography. Although these studies were not primarily focused on cultural competency, cultural awareness issues are highlighted and are reflected in each study.

Valle et al. (2006) examined the health education impact of a fotonovela (photo novel) about Alzheimer’s disease with 111 older Spanish-speaking adults. The fotonovela was delivered by a facilitator in a guided educational session and then left with the participants. Prior knowledge of and experience with dementia and Alzheimer’s disease was measured both pre- and post-intervention; results showed a significant increase in knowledge on five out of the six study questions. Researchers also evaluated whether the participants liked the fotonovela, found it informative, and/or found it understandable. The young older group of participants (age range 55-64) and women in all age cohorts (55-64, 65-74, 75 plus) found the fotonovela more informative than others. A high rate of study participants (41%) also shared the fotonovela with others who were not part of the study.
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This study shows that providing health information in an individual’s first language and in a format that is culturally sensitive and meaningful can increase individual health knowledge (Guy, 1999; Koh et al., 2014; Langer, 2008; Orem, 2005; Osborne, 2012; Whaley, 2000; Yeo, 2009). The Latino culture values using education/entertainment as a way to combine factual and emotional information that can assist in decision making (Castaneda, Organista, Rodriguez, & Check, 2013; Tufte, 2009; Valle et al., 2006). The delivery modality of health education materials – for example, using a fotonovela format for a Hispanic audience – increases the likelihood that an individual will be able to retain the information presented (Castaneda et al., 2013; Tufte, 2009; Valle et al., 2006). Popular culture fotonovelas are often recirculated through the Hispanic community; this educational fotonovela was also shared, indicating a common cultural phenomenon (Flora, 1980; Valle et al., 2006).

Fitzpatrick et al. (2012) studied older Asian adults who provided their perspectives on cardiovascular health through the use of Photovoice, a qualitative methodology using photographs taken by participants. The participants were Chinese, Vietnamese, and Korean older adults, with mean age 71.6 years (n=23). Bilingual facilitators were trained in the Photovoice methodology (one in Cantonese, one in Vietnamese, and one in Korean), and all written materials were translated into these languages as well. The facilitators explained the Photovoice methodology to participants, including how to use the camera and take good pictures. At the second session, participants presented their photographs; facilitators led the group discussion based on themes of what heart health is, what helps and hurts your heart, and barriers to care and education. This study revealed commonalities and differences in perspectives of
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heart disease held by different Asian groups. For example, all three groups were concerned with stress; however, while the Chinese and Vietnamese participants felt that stress was induced by external factors that cause fear or anxiety, a Korean perspective was that the internal factor of loneliness precipitated by stress.

This creative study methodology was acceptable to participants, and helped give voice to the beliefs, needs, and knowledge of these vulnerable Chinese, Vietnamese, and Korean older adults. Using visual images rather than direct language was a way to value the indirect communication style favored by Asians (Whaley, 2000), and gave voice to both ideas about health and a way to learn what these individuals knew about health and health care. Another highlight of the study was that care was taken to honor the three different groups within the Asian culture, each of which may have very different belief structures and knowledge about health and health care, rather than combining the three into one generalized group (Galambos, 2003; Koh et al., 2014; Langer, 2008)

A multi-faceted program, “Health Enhancement for Rural Elderly”, was conducted with older rural adults in Montana by Young, Weinert and Spring (2012). One intervention was the delivery of Health Information Webinars, which had 152 participants (no mean age provided). Health Information Webinars consisted of five monthly health information webinars broadcast to four rural communities. The intent of the webinars was to increase health literacy skills with a central theme of how to obtain, evaluate, and use Web-based information. Senior community centers were provided with necessary equipment to host these webinars.
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Health education is often difficult to deliver in rural areas because of the vast distances between people and communities; therefore, the use of computer technology to share and provide health information seems like a natural fit. The participants found the information useful and a majority indicated that they would recommend the webinars to others. The participants indicated that the Internet was a valuable source of health information; however, only about half of the participants had Internet access at home, which limits the usability and sustainability of a program like this (Butler et al., 2011). Therefore, being able to access the webinars in the community centers shows the importance of providing public access to individuals in rural areas. Providing the webinars in a public setting such as a community center or library helps develop this concept into a broader community-wide model where older adults, their families, and their caregivers could attend together, which may be important in sustaining and enhancing health education (Bolin & Bellamy, 2011; Butler et al., 2011; Horrell, Stephens, & Breheny, 2014; Meit, 2004).

There are various federal policy initiatives to enhance cultural competence in health care, including the 2010 National Action Plan to Improve Health Literacy. This plan focuses on decreasing barriers to health care access and improving informed decision-making by encouraging the use of evidence-based health literacy research in all areas, including cultural competency, to inform change (Office of Disease Prevention and Health Promotion). The Plain Writing Act of 2010, another federal initiative, requires federal agencies to use plain language in any document that provides information about federal benefits or services, including health information (Plain Writing Act, 2010). Plain language helps individuals who have low literacy
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from different cultures understand health care messages in ways that may be more meaningful to them. The 2011 Health and Human Services Strategic Action Plan to Reduce Racial and Ethnic Health Disparities includes updating and disseminating national standards on linguistically and culturally appropriate health care services (OMH). These standards, known as Culturally and Linguistically Appropriate Services (CLAS), are broken into three thematic sections and provide a framework within which health care providers can enhance their services to be the most responsive to cultural health beliefs and practices, preferred languages, health literacy levels, and other communication needs (OMH). The first section is Governance, Leadership, and Workforce and provides a blueprint for building culturally and linguistically health literate organizations. The second section, Communication and Language Assistance, specifies standards for appropriate and timely health-related language assistance as well as easy-to-understand health organization signage and materials. The final section is Engagement, Continuous Improvement, and Accountability, and provides guidelines for quality improvement, evaluation, and community engagement in health organizations. While not mandated by law, the CLAS standards have been adopted by many organizations for consideration and implementation at the highest levels (board and governance) through day-to-day activities (language assistance, community engagement, and education) (Koh et al., 2014).

Because health care workers are the ones who deliver a majority of health information, it is essential that cultural and linguistic sensitivity is included in their training. Approximately 18,000 new physicians graduate every year from 134 accredited U.S. medical schools; all are trained in the science and art of practicing medicine and have learned how to make appropriate
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life or death decisions in situations that are often fraught with risk, high emotions, and chaos (Association of American Medical Colleges, 2011). Cultural sensitivity training is offered either as a stand-alone class or is integrated into existing lectures in many medical, nursing, and pharmaceutical schools (Flores, Gee, & Kastner, 2000; Koh et al., 2014). One of the most important components to providing effective health care is learning how to communicate with an increasingly varied cultural, ethnic, and linguistic population so that people get the care they deserve and need, regardless of background.

In addition to what may be offered as part of the medical school curriculum, many private and public organizations offer courses in cultural and linguistic sensitivity as part of Continuing Medical Education accreditation. Their goal is to enable physicians and other clinical staff to broaden attitudes and understanding about their diverse patient populations (Betancourt, Green, & Carrillo, 2002; Betancourt & Green, 2010) by increasing knowledge about sociocultural diversity and hands-on skills. Organizations like the U.S. Department of Health and Human Services also offer health literacy and intercultural training and education for health care professionals including workshops, online training, guidance on creating a health literacy plan for medical organizations, and resources for material development (Center for Linguistic and Cultural Competence in Health Care [CLCCHC]). There is also continued recognition and implementation of mandated and continuing education offerings in cultural sensitivity and health literacy training for pharmacists, nurses, physical therapists, and other health care providers (Betancourt et al., 2002; Betancourt & Green, 2010; Koh et al., 2014; CLCCHC).

Conclusion
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While the literature describes the great need for cultural competence in health care delivery and health education, it is difficult to identify health literacy research interventions that specifically study cultural issues for older adults. This is unfortunate because individuals define health and illness through the lens of their own cultural backgrounds, which is made even more complicated by the intersection of their many different cultural affiliations. For example, a person could be female, Hispanic, 65, an immigrant, and live in a rural community, or a person could be a male African American military veteran from a Caribbean background. This interaction of cultures affects choice of health provider, description of symptoms, consideration of treatment options, and whether treatment will be adhered to (Andrulis & Brack, 2007), and it is difficult, if not impossible, to know which cultural position may have the strongest impact. While this chapter focuses on patients, culture also affects the health care provider, staff, institution, industry, and caregiver; health care providers and health care systems need interventions that can cut across cultural and linguistic boundaries. These population-specific differences are often responsible for not only poor health quality outcomes, but also for a lack of efficiency within the health care system; according to a study by the Joint Center for Political and Economic studies, elimination of these social disparities would have reduced direct medical care expenditures by $229.4 billion between 2003 and 2006 (LaViest, Gaskin, & Richard, 2009). Creating culturally competent health care and health education delivery can increase quality of life outcomes, decrease health disparities, and act as a business strategy for the medical industry to increase their market share (Betancourt et al., 2002). In their seminal 2002 field report, Betancourt, Green and Carrillo discussed opportunities to develop three different types of...
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cultural competence in the health care delivery system – organizational (within the health care workforce), systemic (within the systems of care like hospitals and clinics), and clinical (within the provider community). Reducing cultural dissonance and increasing culturally competent communication values differences in cultural experiences, and addresses those differences in the delivery of education, care, and services
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Chapter 4: Manuscript Three

Oral Discourse between Healthcare Providers and Patients in an Inner City Diabetes Clinic

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This study was funded by a 2011 Centers for Disease Control and Prevention and Georgia State University Seed Grant for Social and Behavioral Science Research. The author acknowledges and thanks the efforts of Sara Weigle, PhD (GSU), Judith McDivitt, PhD (CDC) and David Ziemer, MD (Emory/Grady Healthcare Systems)
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Abstract

Background: Oral communication between healthcare providers (HCP) and patients impacts how patients participate in their health care, adhere to medication and discharge instructions, and obtain and share health information. Patients who have low education levels may not have the linguistic, cognitive skills, or communication skills to participate in their healthcare encounters. The specific aim of this study is to evaluate oral discourse between diabetes patients with low education levels and their HCPs and to evaluate communication strategies used by patients and HCPs.

Methods: Between September and December 2012, 17 patients and 10 HCPs in an inner city hospital diabetes clinic participated in a study yielding 24 distinct clinical encounters. All encounters were audio taped, transcribed, and analyzed. Two different methods, Interactive Communication Loop and Active Patient Participation, were used to analyze provider and patient oral communication behavior. A corpus-based linguistic analysis of first person and second person pronouns used by patients was also performed.

Results: With regard to the Interactive Communication Loop, there was only one instance where the HCP asked a patient to recall information. Active Patient Participation was low as patients used fewer than 10% of their conversational turns to actively participate with HCPs; within the same interactions, HCPs were less likely to interact in supportive talk or partnership building with the patients. Patients were more likely to actively engage with nurses. Patients
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who were adherent to taking blood sugar measures at home used more first person pronouns than those who were non-adherent.

Conclusions: HCPs in this setting did not employ interactive communication methods to ensure that patients understand and can recall important health data. Nurses are more likely than physicians to engage with patients in active communication. Patients who are adherent to taking blood sugar measures may be more likely to demonstrate self-confidence and involvement in care by using first person pronouns in their discourse with HCPs. Further research is needed to identify how to facilitate interactive and participatory conversation between HCP and patient and to further measure patient discourse to evaluate language use and its impact on health behavior.
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**Background**

Adults of many backgrounds and education levels may have low health literacy (HL); however, low HL is most prevalent among those with low education levels, low socioeconomic status, and non-majority race, culture, and language (Baker, 2007; Beacom & Newman, 2010; Freman, 2006). These individuals may have a lower ability to seek, understand, and use health information as well as a lessened ability to communicate with healthcare providers (HCPs) (Beacom & Newman, 2010; Brown, Stewart, & Ryan, 2003; Parker et al., 1999; Rothman et al., 2005). Successful self-management of diseases such as diabetes requires that patients participate in self-care and adherence to medication and discharge instructions; a lack of adherence increases the likelihood of disease complications such as kidney failure, blurred vision/blindness, and nerve damage (Feldman, 2011; Jin, Sklar, Min Sen Oh, & Chuen, 2008). Diabetes management is complicated; it involves daily blood sugar testing, medication titration, dietary restrictions and exercise. A critical component to self-management for patients with low HL is the information flow between patient and HCP, which must be clear and complete so that detailed instructions and expectations are understood, and manageable self-care plans are developed. Most patients with low HL do not initiate interactive dialogue with HCPs, thus, HCP communication skills are a critical factor in engaging patients and educating them about their health and health care regimens (Hawk & Evans, 2013; Ishikaway & Yano, 2008; James, 2013; McCaffrey, Smith & Wolf, 2010; Roter, 2011; Street, Gordon, Ward, Krupat & Kravitz, 2005). In addition, patients who are more adherent to certain health management behaviors are
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also more likely to have higher self-confidence in performing those measures (Salager-Meyer, Ariza & Zambrano, 2003).

**Health Literacy of Patients and Providers**

Health literacy is the ability of individuals to use health-related information to make appropriate health decisions (Institute of Medicine, 2004). In order to obtain health-related information, individuals must be able to orally communicate with HCPs, read health care related documents, and use basic numeracy skills. HL is a multi-faceted and context-dependent construct, and depends on the individual patient’s ability to acquire and use new information, the health care situation, and communication skills of the patient, HCP, and health system (Baker, 2006). Many adults who are low SES have poor communication and HL skills and may not understand the severity of their illness, the control they have over making changes, and the recommended behaviors for health improvement (Freeman, 2006). Patients with low HL comprise a significant and rising percentage of the urban population; addressing their health-related communication needs is a critical part of improving health outcomes (Paasche-Orlow, Parker, Gazmararian, Neilsen-Bohlman, & Rudd, 2005).

However, the patient’s skill set is only one part of the equation; another part is the HCP communication skills. HCPs and healthcare systems present health information in ways that are challenging to patients at all literacy levels (Rudd, 2010). HCPs also bring their individual communication skills into the clinic setting which generally fall into one of two dimensions – patient-centered (open-ended questions, offering support) or provider-centered (closed-ended questions, giving instructions, maintaining control of the encounter) (Roter, 2011; Roter &
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Hall, 1988; Salmon & Young, 2011). In addition, HCPs are trained to collect subjective and objective patient information to make assessments and treatment plans; they are not trained, however, in conversation that is participatory and culturally competent, or that considers the health literacy of the patient (Hamilton & Woodward-Kron, 2010; Harper, Cook,& Makoul, 2007; Street, Gordon, et al., 2005). Thus, there is often a mismatch in communication skills between patient and HCP that can affect how information is transmitted, understood, and acted upon.

HCPs and patients play different roles in provider-patient communication because they have different responsibilities in the exchange, and they may not share a common understanding of health terminology. In addition, power differences can affect the interaction; patients may not be comfortable asking question or challenging their HCP. This role ambiguity can lead to patient hesitancy in sharing health concerns, asking questions, or even knowing what to expect from their HCP (Beacom & Newman, 2010; Parker et al., 1995; Roter, 2011; Roter & Hall, 1988; White, 1987). Patients often play a submissive role in the communication relationship; those with low levels of education and low HL may find themselves at loss because they may not understand the HCP’s words (Andrulis & Brack, 2007; Beacom & Newman, 2010; Schillinger, Piette, et al., 2003). This can be particularly challenging in developing specific plans health management strategies, because “patients with low levels of functional health literacy are especially likely to have difficulty recalling and comprehending medical information” (Schillinger, 2003, p. 83). Physicians and patients may also cut off dialogue or veer from the topic at hand (Street, 2013). Further, there may be a difference in
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self-confidence and involvement in health management by patients based on their collocational use of first and second pronouns used in health care discourse (Cortes, 2015).

**Measuring Patient/Provider Health Care Exchanges**

The health care system has begun to focus on the need for clear communication between patients and HCPs (Sudore & Schillinger, 2009); this move toward patient-centered care means that providers and patients need to work together to enhance communication and understanding. For example, providers who ask patients if they recall new information employ an interactive educational strategy known as an *Interactive Communication Loop* that helps patients to remember and understand information (Schillinger et al., 2003). Part of this strategy is using a method called “teach back” which ensures that the patient can explain what was just said to him/her to the satisfaction of the HCP. This is a well-studied active-learning methodology that can significantly enhance the quality of patient/provider communication and lead to more positive health outcomes for patients (Harper et al., 2007; Kountz, 2009; Sudore & Schillinger 2009). Improved clinical outcomes come from these types of enhanced patient-provider relationships where patient understanding and involvement are a focus of the health care interaction (Shue, O’Hara, Marini, McKenzie & Schreiner, 2010, Cegela & Broz, 2003). Roett and Wessel (2012) showed that diabetes patients were almost nine times more likely to achieve Hemoglobin blood test (HbA1C) targets when HCPs assessed their recall or comprehension of new concepts.

A successful model of health care communication is both patient- and provider-centered. This type of interactive framework allows for request making, clarification,
supportive talk, and the understanding of different speech codes by both parties (Bylund, Peterson, & Cameron, 2012). Additionally, negative patient emotions such as anxiety can be diminished when they are encouraged to ask for, and then receive clear and helpful information (Brown, Stewart, Ryan, 2003). Using an interactive communication framework, the HCP would have an opportunity to evaluate a patient’s understanding and clarify information (Schillinger et al., 2003). In addition, patients who ask questions, assert themselves, and express their concerns allow HCPs to respond by partnership building or supportive talk (Street & Millay, 2001). Most patient/provider communication involves seeking, providing, and verifying information (Cegala & Broz, 2003).

Finally, one must take into account how patients talk and if their choice of words informs their engagement with HCPs and/or their adherence to medication/discharge instructions and self-management behaviors. In diabetes management, those behaviors include taking blood sugar measures at home, taking medications correctly, and maintaining a diabetic diet. Greater adherence to self-management is related to higher levels of self-confidence and self-efficacy (Mann, Ponieman, Leventhal, & Halm, 2009). According to Bandura (1982), self-efficacy precedes agency, which is the ability of a person to make choices and act on those choices. In his seminal work of 1989, Fulford describes the use of first person pronoun and its association with agentic aspects of illness and recovery; more recent studies in psychotherapy and psychiatry indicate that semantic use of pronouns in the course of treatment can mark recovery (Van Staden & Fulford, 2014). Thus, counts and comparisons of pronoun use could shed light on outcomes that require agency to accomplish.
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The present study

This study aimed to explore the discourse between HCPs and patients in order to discover communication patterns and profiles. These communication tendencies can be further examined as they relate to patient engagement in health care; an increase in engagement may lead to increased HL and positive changes in health behavior. The study setting is a diabetes clinic in an inner city hospital in Atlanta, Georgia. This is a crucial setting in which to examine communication as such environments are often challenging to both HCPs and patients because of funding, overcrowding, and a patient population that is low-SES, poorly educated, and highly culturally diverse. Examined here are audiotaped health care encounters to understand the basic communication behaviors of HCPs and patients in a diabetes clinic. The research questions were:

RQ1: Do HCPs use interactive oral communication strategies that have been shown to be helpful to patients with low education levels?

RQ2: Do HCPs and patients engage in active patient participation during healthcare encounters?

RQ3: Do patients actively engage in health care discourse more with nurses or with physicians? Are patients who are adherent to taking blood sugar measures at home more likely to actively engage in health care discourse?

RQ4: Does adherence to taking blood sugar measures at home relate to use of first and second pronouns in discourse with HCPs?
Methods

The data were collected between September and December 2012 at an inner-city public hospital outpatient diabetes clinic where a team of nurse providers, certified diabetes educators, nutritionists, podiatrists and physicians collaborate to evaluate and manage patient care. This clinic treats predominantly African American patients who are either uninsured or who have Medicaid, and who come from the surrounding low-income neighborhoods. Each clinical encounter was audiotaped, transcribed and analyzed. Georgia State University and Emory University Institutional Review Boards approved the study.

Study Sample

Potential patient participants were approached in the clinic waiting room by researchers according to the approved patient recruitment plan; 30 patients were approached and 17 agreed to participate in the study. Patient demographic data were self-reported and included age, gender, educational level attained, and native language. The HCPs were recruited during two separate meetings and included certified diabetes educators, endocrinologists, a podiatrist, and nurses. Five endocrinologists, one podiatrist and four nurses/certified diabetes educators agreed to participate. HCP demographic data was self-reported and included age, gender, and native language. Demographic data of all participants is shown in Table 1.
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Procedures

Patients were approached in the clinic waiting room by the senior author and asked if they were interested in being part of a study that would involve being audiotaped during their doctor and/or nurse visit. They were told that the reason for the study was to learn more about how physicians and patients communicate during their healthcare visits. Patients were told they would be paid $25 for their participation. If a patient indicated interest, he/she went to a private area in the waiting room with either the senior author or a graduate research assistant from the Applied Linguistics Department at Georgia State University to review the IRB-approved informed consent document, which the research read out loud to the patient. Once the patient consented to be part of the study, basic demographic data were obtained. One of the researchers then accompanied each patient into his/her appointments with the HCP (who had previously signed an informed consent), sat on a chair in the corner of the room, and audiotaped the encounter.

A professional transcription company then developed a set of transcriptions from the audiotaped medical encounters between patients and HCPs. Transcription was narrow, and included interactional phenomena such as pauses, backchanneling (“uh huh”), and overlapping talk. The same researchers who obtained the audiotapes reviewed the verbatim transcripts and replaced names with agreed-upon codes in order to ensure patient and provider confidentiality. The researchers loaded the transcripts into NVivo 10, a computer assisted data analysis software, for coding. Two researchers and Principal Investigator reviewed and discussed the coding for the Interactive Communication Loop and Patient
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Activation to ensure clarity prior to coding the transcriptions. The two researchers then coded the same set of 3 files and the results were reviewed by the Principal Investigator to determine inter-rater reliability; coding by each researcher was compared to both the coding standards and to each other, and there were no discrepancies yielding 100% reliability. The researchers completed the coding.

In order to capture both patient active engagement and the use of first and second pronoun usage by patients and then determine if their use was related to adherent behaviors, one researcher reviewed the transcripts to determine self-reported adherence to taking blood sugar measures at home. It was determined that 17 transcriptions contained references to taking blood sugar measures at home. If a patient indicated he or she did not take his/her blood sugar measure, that patient was coded as non-adherent, and if they did indicate they took it, they were coded adherent there were 7 non-adherent and 10 adherent patients. The files were then scanned for use of patient first person (I, my, mine, myself, we, our ours, ourselves) and second person (you, your, yours, yourself, yourselves) use. Pronouns used as discourse markers (e.g., “you know” or “you know what I mean”) were not included in the analysis.

Methodology

For Research Question 1, coding methodology from Schillinger et al., was used to assess provider interactivity of audiotaped and transcribed clinical encounters; this “interactive communication loop” checks for patient lapses in recall and understanding but can also “uncover health beliefs, help providers reinforce and tailor health messages, and activate
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patients by opening a dialogue” (2003, p. 83). Researchers focused on provider speech related behaviors in four specific areas: (1) delivery of new concepts (medication and non-medications); (2) request patient recall of new concepts; (3) clarification of information based on patient response; and, (4) request patient recall of clarified information (Schillinger et al., 2003). In addition, the number of times the “teach-back” method was used to assess patient recall was analyzed since that is a clearly recognized method of engaging in interactive communication (Rudd, 2010). Item descriptions and coding scheme are: HCP introduces a new concept (I’d like to start you on a new medicine), asks patient for recall of that concept (So what’s the new medicine called?), HCP clarifies information (No, you take it twice a day not once), HCP asks patient for recall of clarified information (So tell me, how many times a day will you be taking the new medicine?). Mean per encounter was measured.

For Research Questions 2 and 3, an additional set of coding analyzed the construct of active participation in dialogue by both providers and patients (Street & Millay, 2001). There are three patient measures (asks questions, makes an assertive utterance, and expresses concerns) and two provider measures (participates in partnership building and engages in small talk). Analysis was performed on the oral interactions between HCPs and patients since these verbal activities create meaning and understanding (Tsai, Lu & Frankel, 2013). Item descriptions and coding scheme are: Patient asks question (Is that heart rate bad?), Patient makes assertive utterance (I don’t want to go to surgery), Patient expresses concern (I’m concerned about my foot tingling), HCP participates in partnership building (HCP: What do you think? Patient: It sounds like a plan. HCP: Don’t be afraid of going up
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on insulin if you need to do it. Patient: I can do that), and HCP engages in supportive talk
(Patient: And the hand right now, it’s moving good. HCP: That’s very good). A t-test was
conducted to determine if there was a significant difference between active patient
engagement with physicians versus with nurses. Patients were divided into two groups
according to whether or not they reported being adherent to taking blood sugar measures at
home, a key self-management behavior. Patients who were adherent to taking blood sugar
measures at home were considered to be more likely actively engaged with their HCP, and
a t-test was conducted to determine if there was significance between those who were and
who were not adherent.

For Research Question 4, a corpus of the written texts was created in order to
measure tendencies of first and second person pronouns in patient talk. Patient first person
(I, my, mine, myself, we, our ours, ourselves) and second person (you, your, yours,
yourself, yourselves) usage was highlighted in the transcription, and counted for frequency.
Discourse markers such as “I know what you mean” were not included in the analysis;
results of pronoun use were further analyzed by adherent and non-adherent groups.
Statistical analysis was performed to determine significance between groups and to measure
pronoun tendencies between those who were adherent and those who were not. T-tests and
the Mann-Whitney U test were used to compare means of the samples and determine
significance.
Results

Results for RQ1 show that over the course of 24 independent clinical encounters (range 3 to 41 minutes, mean = 20.5, sd=8.1), the mean of new information presented was 5.17 (sd=1.99); the mean of asking for patient recall using the “teach-back” method was .04 (sd=.20). Results are shown in Table 2. The only teach-back episode was when a HCP introduced the concept of titrating the amount of sugar in the patient’s coffee according to her insulin levels; the conversation was as follows (specific recall request in bold italics):

*Physician: I’m gonna stretch the truth a little. But let’s say you put 10 packets of sugar in there [coffee].*

Patient: Right.

*Physician: What do you think would have happened to your sugar?*

Patient: It probably would have gone up. I mean, it was 106 when she checked it today.

*Physician: Right.*

Patient: And that was after the coffee.

Non-interactive communication (not coded) was more typical as shown in the following excerpt between HCP and patient. For example, in the following text the HCP did not ask the patient to confirm what she had said; rather, she asked the patient if he had any questions (in bold italic).

*Nurse: Bring the meter. I think you’re going to like that meter...you do need to walk, okay? Because she had a very, very nerve transmission, but you didn’t have as
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much. You’re a little low. And the only way to assure you’re going to have transmission and circulation is walking... You need to get it to the foot, to the toes, okay? After breakfast and after dinner, especially after dinner. Walk 30 minutes twice a day. And you can return here in about two months and a half, something like that. Okay, right now, stand for me. Keep updating your record. Any questions, sir?

Patient: No.

Nurse: You’re understanding everything? Okay. The cholesterol now is 40, and I see [inaudible] is at 40. We can make some changes, um, you’re not taking the water pill, and the Toprol 100 twice a day. 100 is twice a day.

Active patient and provider participation were analyzed according to the Active Patient Participation method. With regard to RQ2, HCPs made partnership building comments and supportive talk in response to patients’ activation per encounter an average of 3.25 (sd=2.42) and 1.92 (sd=1.71) times per encounter, respectively. HCPs used 5.1% of their conversational turns in partnership building and supportive talk. The mean number of times per encounter that patients asked questions was 5.96 (sd=2.11); mean patient expressions of concern and assertions were 1.54 (se=1.15) and 1.46 (sd=1.38), respectively. Patients asked questions, expressed concerns, or asserted themselves 9% of coded encounters. The remainder of the patient talk time was used to answer questions, affirm what the HCP said, and provide
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additional subjective information such as answering questions like “how are you feeling now?” Results are shown in Table 2.

INSERT TABLE 2 HERE

Active patient engagement is measured by the number of times patients asked questions, made utterances, and expressed concerns. Patients actively engaged with physicians an average of 7.6 ($sd = 3.7$) times in 14 encounters (range 0-13), and engaged with nurses an average of 10.8 ($sd = 3.4$) times in 10 encounters (range 6-16). There were 24 HCP:patient dyadic encounters, therefore, an independent samples t-test was conducted to compare active patient engagement with physicians versus nurses and showed that patients actively engaged more with nurses than physicians, $t (22) = 2.14$, $p < .05$. Because some of the observations were not independent in that the same patients saw both a physician and a nurse and contributed two observations, analyses were conducted using the full sample ($n = 24$) and reduced sample ($n = 17$) in which the effect of the dependency by eliminated by removing the patient’s second appointment. In the reduced sample, similar results were obtained in that patients engaged on average more with nurses than with physicians ($M = 12.1$, $sd = 6.4$ versus $M =5.1$, $sd=3.4$), and a independent samples t-test showed that this was significant, $t (15) = 5.23$, $p < .05$.

With regard to patient talk and adherence to taking blood sugar measures, we evaluated both the full ($n = 17$) and reduced ($n = 12$) sample of those patients who had adherence discourse in their interactions. Patients who were adherent to taking blood sugar measures at home were no more likely to actively engage in total with HCPs than those who were not for both sample sizes
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(full sample $t (15) = .51, p > .05$ and reduced sample $t (10) = .46, p > .05$). Results are show in Table 3.

With regard to patient talk and use of first or second person pronouns as they relate to self-reported adherence in taking blood sugar measures at home, we again evaluated both samples. For the full sample size, the mean number of first person references for the adherent and non-adherent samples were 85.8 and 58.4, respectively, and the means for the adherent and non-adherent samples for speaking in second person were 20.8 and 29.7, respectively. For the full sample, differences between the groups for both first and second pronoun use were statistically significant, (adherent at $t (18) = 8.75, p < .05$ and non-adherent at $t (12) = 4.75, p < .05$.) When analyzing the reduced sample, both sets of means were similarly significantly different, (adherent at $t (10) = 2.12, p < .05$ and non-adherent at $t (10) = 2.59, p < .05$).

INSERT TABLE 3 HERE

Discussion

We studied the oral communication behaviors of HCPs and patients with low education levels in an inner-city public hospital diabetes clinic in order to explore provider and patient communication strategies during clinical discourse. Use of interactive communication using the ‘teach-back” method and active patient participation was examined; our analysis showed that use of those strategies by patients and HCPs was uncommon. HCPs used the “teach back” method only once out of 124 opportunities. The “teach-back” method has the potential to help patients achieve healthier outcomes by directly addressing the specifics and details of care
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instructions and assuring the patients are clear on what those instructions are and how to implement them (Baker, Dewalt, Schillinger et al., 2011; Roett & Wessel, 2012).

Research indicates that HCPs often direct patients to a specific topic by asking closed-ended questions, which do not lend themselves to building dialogue (Marvel, Epstein, Flowers & Beckman, 1999; Tsai, Lu & Frankel, 2013). Patients who speak up in clinical encounters are more likely to receive patient-centered care, have better understanding of self-management, and have better control over their health outcomes (Street & Millay, 2001). The use of questions, assertions, and concerns by patients has been identified as “essential and observable features of patient participation in medical encounter” (Street & Millay, 2001, p. 63), and can influence responses and conversation with providers. In this study, patients used fewer than 10% of their conversational turns to participate actively in the healthcare dialogue; there is limited data as to the significance or clinical importance of this amount of engagement, however, other methods of discourse analysis indicate that patients must introduce and share relevant information in order to actively participate in healthcare dialogue (Eggly, Harper, et.a.l, 2011; Galiher, Post, et al., 2010; Rost, Carter & Inui, 1989). Patients who engage actively in health care dialogue with HCPs are more likely to be satisfied with their healthcare and with their health provider (Eggly, Harper, et al., 2011; Venetis, Robinson & Kearney, 2013.

Patients engaged more actively in conversation discourse with nurses than with physicians. Research indicates that nurse conversation is often mediated by a patient’s contribution to the conversation while physicians are more likely to direct the medical
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discourse (Collins, 2005). Additionally, patients often express worry about upsetting or angering their physicians and are more likely to share information with nurses because physicians often appeared to be rushed and not seeming to be interested in collaborating in decisions about care (Collins 2005; Frosch, May, Rendle, Tietbohl & Elwyn, 2013). Rather than acting authoritative, physicians often acted authoritarian while nurses were more likely to listen and engage patients in conversation (Frosch, et al., 2013).

Patients who were adherent to blood sugar testing at home used more first person pronouns than those who were non-adherent. Although use of first person pronouns can mean a variety of things, in this exploratory investigation the conversation marker was used to explore group membership. Understanding how patients self-refer may provide HCPs with an indication of group membership in terms of adherence. Patients who are more adherent may have more self-efficacy and agency, and thus may be more involved in their healthcare (Salage-Meyer, et al., 2003; Van Staden & Fulford, 2004). Understanding this group membership by observing patient talk could help HCPs better assess the meaning of what is disclosed by patients (Connor, Anton, et al., 2012; Van Staden & Fulford, 2004). We found no relationship between patient active engagement and adherence to taking blood sugar measures at home.

Limitations and Areas for Future Study

This study investigated and described communication patterns of interactivity and participation between diabetes patients and their HCPs. One of the study’s limitations was the small sample size of audio recordings (n=24); additionally, the participants were selected
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using a convenience sampling method that is appropriate for this type of pilot study, but limits
the generalizability of the findings. While there were 24 independent dyadic patient:HCP
encounters, 7 of the 17 patients saw both a nurse and a doctor and 5 of the HCPs saw more
than one patient. Future discourse studies should be designed to determine a priori how to
handle patients who see multiple HCPs. Patients were not tested for their health literacy level;
rather, a low health literacy level was assumed based on education and SES level. Future
studies should specifically test patients for general and diabetes specific health literacy levels
using previously established scales such as the Literacy Assessment for Diabetes (Nath,
Sylvester, Yasek & Gunel, 2001) and the Spoken Knowledge in Low Literacy in Diabetes
Scale (Rothman, et al., 2005). Another potential limitation was the Hawthorne effect, wherein
the presence of the researcher in the exam room during the clinical encounter might have
affected the communication behavior of the provider and/or patient due to being observed
(Fernald, Coombs, DeAlleaume, West, & Parnes, 2012). Additionally, because audio rather
than videotaping was used, this study did not address nonverbal behaviors of HCPs or patients
during the encounter, which could have an impact on communication processes. The coding
methodology chosen measured only one type of patient engagement, and all evaluation was
done in one setting type only.

Corpus-based study of health discourse is an emerging and exploratory research
process (Cortes, 2015; Zimmerman, Wolf, Bock, Peham, & Benecke, 2013). Linguistic
features used by adherent and non-adherent patients could be used to develop a profile of
patients who are more or less likely to be adherent. This small sample size does not allow for
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generalizability to other studies, nor is there enough data to conclusively support the findings that one can be assigned group membership based on self-referencing pronoun use; there are few medical discourse corpora available for analysis. Further research should collect more oral discourse between HCPs and patients and analyze the use of many different grammatical speech functions that may describe psychosocial constructs such as agency or control orientation, both of which are important in understanding patient self-management behaviors (Connor, Anton et al., 2012). In addition, this corpus may help profile patients by their language use so that HCPs could be more aware of which patients may need additional health education or management based on group membership (adherent vs non-adherent).

Opportunities exist to develop interactive communication interventions and training for providers; implementation and tracking of results in a controlled research setting could help researchers ascertain which provider behavior patterns are indeed changeable and what their impact is on patient recall and subsequent health status. A larger scale study of this type could focus on the communication behavioral differences between non-native English speakers and native English speakers including use of and interpreters and translators. This larger scale research could include issues of gender differences, age preferences, HCP language, nurse vs doctor, and illness/wellness behavior. Practical relevance and usability of any communication intervention should be included in any study to ensure that HCPs can incorporate communication changes in their care patterns; systemic and organizational evaluation should also occur to ensure that HCP change will be facilitated and encouraged. Patient communication behaviors could also be studied in a more multidimensional way;
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understanding patients’ communities of care and lifestyles could expand providers’ perceptions and methods of delivering messages based on patient defined needs. Additional study could be taken in the area of patient/HCP discourse and technology use as many HCPs use electronic medical records on a computer in the exam room and this may or may not have an effect on HCP discourse or patient talk.
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Table 1

*Patient and HCP Demographic Data*

<table>
<thead>
<tr>
<th></th>
<th>Patient (n=17)</th>
<th>Physicians (n=6)</th>
<th>Nurses (n=4)</th>
<th>TOTAL HCPs (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td></td>
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<td></td>
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<tr>
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<td>n/a</td>
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<td>n/a</td>
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<td><strong>Native English Speaker</strong></td>
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<td>1</td>
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### Table 2

Interactive Communication Loop and Active Patient Participation (*n=24 encounters*)

<table>
<thead>
<tr>
<th>Interactive Communication Loop</th>
<th>frequency in discourse</th>
<th>mean per encounter</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCP introduces a new concept</td>
<td>124</td>
<td>5.17</td>
<td>1.99</td>
</tr>
<tr>
<td>HCP asks patient for recall of new concept</td>
<td>1</td>
<td>.04</td>
<td>.20</td>
</tr>
<tr>
<td>HCP clarifies information</td>
<td>1</td>
<td>0.04</td>
<td>.20</td>
</tr>
<tr>
<td>HCP asks patient for recall of clarified concept</td>
<td>0</td>
<td>0.00</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Active Patient Participation</th>
<th>frequency in discourse</th>
<th>mean per encounter</th>
<th>percentage of turns</th>
<th>sd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversational Turns</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients</td>
<td></td>
<td>2384</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCPs</td>
<td></td>
<td>2403</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PATIENT asks questions</td>
<td>143</td>
<td>5.96</td>
<td>6%</td>
<td>2.11</td>
</tr>
<tr>
<td>PATIENT makes assertive utterance</td>
<td>37</td>
<td>1.54</td>
<td>1.6%</td>
<td>1.15</td>
</tr>
<tr>
<td>PATIENT expresses concern</td>
<td>35</td>
<td>1.46</td>
<td>1.5%</td>
<td>1.38</td>
</tr>
<tr>
<td>HCP participates in partnership building</td>
<td>78</td>
<td>3.25</td>
<td>3.2%</td>
<td>2.42</td>
</tr>
<tr>
<td>HCP engages in supportive talk</td>
<td>46</td>
<td>1.92</td>
<td>1.9%</td>
<td>1.71</td>
</tr>
</tbody>
</table>
## Table 3

**Patient Talk Analysis:**

<table>
<thead>
<tr>
<th></th>
<th>ACTIVE PATIENT PARTICIPATION (n=17)</th>
<th>ACTIVE PATIENT PARTICIPATION (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td>Adherent</td>
<td>8.9*</td>
<td>0-16</td>
</tr>
<tr>
<td>Non-Adherent</td>
<td>9.9*</td>
<td>7-14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>FIRST PERSON PRONOUN USE (n=17)</th>
<th>FIRST PERSON PRONOUN USE (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td>Adherent</td>
<td>85.8**</td>
<td>48-119</td>
</tr>
<tr>
<td>Non-Adherent</td>
<td>58.4**</td>
<td>36-75</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>SECOND PERSON PRONOUN USE (n=17)</th>
<th>SECOND PERSON PRONOUN USE (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Range</td>
</tr>
<tr>
<td>Adherent</td>
<td>20.8**</td>
<td>9-30</td>
</tr>
<tr>
<td>Non-Adherent</td>
<td>29.7**</td>
<td>20-43</td>
</tr>
</tbody>
</table>

* non-significant
** significant at p<.05
Chapter 5: Summary

The manuscripts presented in this dissertation focus on different facets of health literacy in two high-risk populations: older adults and adults with low SES. As previously discussed, these are priority populations for health literacy research in order to effectively address health disparities and the growing burden of health care on the elderly.

The goals of the papers were: (1) to understand how individuals access information through HISB; (2) to examine how culture can affect the way in which older adults understand and use health information; and, (3) to assess the levels of specific communications between providers and patients during a health care exchange. Results from the first manuscript indicate that people with low literacy, numeracy, and problem solving skills are more likely to use oral sources than print sources when seeking health information. In addition, among people with low literacy, those who sought health information were more likely to report better health than those who did not. The second manuscript reviewed issues at the intersection of health literacy, older adults and culture. Results from the extant literature show that even though there is a great need for cultural competence in health care delivery and health education, there are very few health literacy research interventions that specifically study how health literacy is affected by cultural issues for older adults. The third manuscript explored communication between HCPs and patients in oral exchanges in an inner-city public diabetes clinic using three measures, the Interactive Communication Loop, Patient Activation Measure, and a corpus-based linguistic analysis. Findings suggest that even though HCPs provided an average of five pieces of new
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information per interaction, they rarely used interactive communication methods to ensure that patients understood that information. Other findings from this manuscript indicate that patients in this study who were adherent to taking blood sugar measures at home were more likely to use first person pronouns rather than second person pronouns; this group membership could indicate greater feelings of self-efficacy and agency in self-managing their disease. The findings from these three manuscripts shed light on the complex nature of health literacy, and further add to the understanding of how health information is accessed, understood, and used by individuals with low health literacy and by those providing health education and health care services.

Implications for Future Research

Much of the extant health literacy literature focuses on developing written health promotion and education materials that are less complex, in plain language, more visually appealing, and often translated into languages other than English (Andrulis & Brach, 2007; Berkman et al., 2011; Betancourt & Carillo, 2002; DeWalt, Berkman, et al., 2004; Manfo & Wong, 2012; Rowlands et al., 2014; Wakefield, Loken & Homik, 2010). This move toward simpler and more culturally competent written health information is critical, as data suggest that individuals seek health information from multiple sources including print media and the Internet (Feinberg, Frijter, & Greenberg, 2015). Use of native language and reduced complexity in written documents is supported by analysis of existing literature on adults and cultural competence as well (Andrulis & Brach, 2007; Betancourt & Carillo, 2012; Fortier & Bishop, 2004; Langer, 2008; Office of the Surgeon General, 2006), therefore, these print-based
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Interventions may help reduce health literacy barriers caused by written information for adults with low health literacy.

The PIAAC data also suggest, however, that individuals with low literacy levels are more likely to seek health information from oral sources than written sources (Feinberg, Frijter, & Greenberg, 2015). As with written message content, health information that is orally delivered must be in plain language and less complex in order to ensure understanding by adults of all ages and all cultures who have low health literacy levels (Baker, et al. 1996; Roter, 2011; Safer & Keenan, 2005; Street & Millay, 2001). Oral communication remains the most common way health and healthcare information is disseminated (Fox, 2011), therefore, it is critical that health education and healthcare professionals are trained in issues of health literacy, plain language, interactive communication techniques, and cultural competency. The findings from Study 3 showed that, at least in a small pilot conducted in an inner city hospital, the use of effective patient-provider communication was very low. Thus, this dissertation affirms a need to further examine the ways in which individuals seek, understand, and use health information in conjunction with the way in which health information is delivered.

**Future Research Directions**

**Employing the Cognitive Skill Levels of Adults with Low Literacy and Numeracy**

The PIAAC data provide an in-depth understanding of directly measured literacy, numeracy, and problem solving levels that correlate directly to specific tasks. For example, 14% of US adults scored at Level 1 in literacy which correlates with the ability to read short continuous or non-continuous print, locate a single piece of information, and complete simple
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forms with basic vocabulary, but not with the ability to compare or contrast information or make inferences (OECD, 2013). There are tools available (e.g., the Clear Communication Index or the Plain Language Toolkit) that can guide those who develop materials, however, it is not clear if these guides help create materials based on literacy levels, on knowledge acquisition, or on developing competence in the use of health care materials. It would be valuable to develop a Task Level Content Analysis tool to utilize in conjunction with or instead of existing tools. This task-based tool could help researchers develop techniques to understand the significance and usability of content and determine its appropriateness for users at different skill levels (Krippendorf, 2012). Additional content analysis could lead to systematically codifying the meaning and intent of health care terms within certain sets of task competencies (Krippendorf, 2012); for example, if adults who have low literacy do not have good inference skills and only basic health-related vocabularies, materials for them could be standardized to only have similar and straightforward terms and content.

The PIAAC data also show that having a high school diploma is not an indication of one’s ability to read and do math at a 12th grade level; rather, many individuals with a high school diploma scored at the basic and below-basic level of reading and numeracy and 1 in 6 adults in the US read at elementary levels (OECD, 2013). Researchers use educational attainment as a benchmark in health literacy research, often because it is easy to obtain and it is a historical standard, however, education level merely measures grade level completion, not skill attainment or performance abilities (Altindag, Cannonier, & Mocan, 2011; OECD, 2013). Health literacy research for development of materials or interventions should include a direct
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assessment of literacy and numeracy skill levels using standard tests that are normed for adults; it would also be important to include content knowledge, as individuals with low literacy may have high disease-specific knowledge if they or a family member have been diagnosed with a certain disease (Berkman, et al., 2011; Cardin, Sisler, Newlin, Smith & Godder, 2015). Research should also seek to understand how literacy and numeracy skills are related to use of the Internet as a health information source, which can further leading to curricular development in health information-related digital literacy skills. Digital literacy skills are critical in accessing accurate and reliable health information and decreasing the digital divide between those who have adequate digital literacy skills and those who do not (Birru, et al., 2004; Hibbard, Peters, Dixon, & Tusler, 2007; Neter & Brainin, 2012; Percheski & Hargittai, 2011; Stellefson et al., 2015).

Developing an Ecological View of Older Adults, Cultural Competence, and Health Literacy

There is a paucity of research on health literacy as it relates to older adults and cultural competence. One type of research could be conducted at the patient level to understand how to better measure the health literacy environment of the older patient (Boyle, Yu et al., 2013; Gallant, 2003; Manafo & Wong, 2012). For example, if the patient has any kind of assistance (e.g., informal or formal caregiver, Meals on Wheels delivery, or group meetings), medical information may come to them through all of these channels, and there may be a great deal of inconsistency in how health information is interpreted and delivered (Johnson, Jacobson, Gazmararian & Blake, 2010; Rubin, Parmer, Freimuth, Kaley, & Okundaye, 2011). Research studies could lead to a better understanding of how to evaluate an older patient in an ecological context and, further, what types of support and assistance that patient and his/her support system
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may need (Aguilera, Dailey & Perez, 2008; Butler et al., 2011; Langer, 2008; Lee, Arozullah & Cho, 2004).

Medical provider education is also an ideal setting within which to develop interventions. Providers treat diverse populations that present with various beliefs and behaviors, as well as differing linguistic and cognitive abilities, all of which combine to influence health care decision making, compliance, and outcomes (Betancourt, 2003; Betancourt, Green & Carillo, 2002; Flores, Gee & Kastner, 2000). Research into the development and testing of curricular competency measures could ensure that the dual goals of changing providers’ communication skills and positively impacting patient health education and healthcare outcomes are reached (Langer, 2008; Lie, Carter-Pokras, Braun & Coleman, 2012). This research could yield standardized and high quality medical professional and para-professional educational interventions with measurable outcomes for competency in cultural issues and/or dealing with older adults (Lie, Carter-Pokras, Braun & Coleman, 2012). Research could also support the development and testing of appropriate decision-supported tools, for example, an electronic medical record system that prompts the provider with specific questions when dealing with a cross-cultural or language-related challenge (Rasmussen, Thompson et al., 2014). Input from patients should be included in any research effort since their compliance with health education and healthcare directives depend, at a minimum, on their ability to understand them (Carman, Dardass et al., 2012).

Exploring Oral Discourse between Health Providers and Patients
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Real-world oral discourse between patients and health care providers should continue to be collected and analyzed to study where lack of understanding caused by medical terminology, idiomatic expressions, pragmatic utterances and formal and informal stylistic speaking features occurs (Nouri & Rudd, 2015; Roter, 2011; Rubin, 2014). Oral discourse could be analyzed for different kinds of provider communication styles such as direct, open, inquisitive, or co-dependent (Opel, Robinson, Heritage, Korfiatis, Taylor & Mangione-Smith, 2012; Roter, 2011; Rubin, 2014). Once understood, interventions could be developed to help HCPs enhance their communication skills with patients by providing HCPs practical guidance on both how their communication style is interpreted and how to adjust their style to patient needs. Further, understanding how patients communicate and being sensitive to those communication cues may also help HCPs increase their communication competency with patients (Street, 2013; Street & Millay, 2001; Wright, Sparks & O’Hair, 2012). Creating datasets of oral discourse used in the health education and healthcare setting can help identify areas where the specific uses and structures of language and communication techniques create discordance between patients and providers (Cortes, 2015). Analysis of this data could enhance the specific understanding of where language and communication challenges may occur.

Another critical area for research study is patient communication skills. A critical patient skill when communicating with a health professional is the ability to ask questions. However, some patients may have limited skills with regard to verbally interacting with a health care provider, for example, how to have a conversation, ask when there is a lack of understanding, and participate in developing an executable plan of care (Roter, 2011; Street, 2013). One
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research idea for patients who use smartphone applications is the development of a patient-level, theory-driven application that directly models best practices in question asking and ensuring patient understanding of what the HCP says (Buolos, Wheeler, Tavares & Jones, 2011; Kreuter, Farrell, Olevitch, & Brennan, 2013). Direct measurement of skill acquisition could be measured by audio or video taping the actual health care interaction between patient and health provider to determine skills uptake and retention. Research into other communication aids could include creating videos that help patients know that it is okay to ask questions as well as which questions to ask; these videos could be delivered through a variety of modalities including YouTube, sent electronically with patient materials when patients make appointments, delivered through others such as Meals on Wheels volunteers, and in the clinician’s office via Ipad or other hand-held device upon check in for an appointment (Buolos, Wheeler, Tavares, & Jones, 2011; Rubin, Freimuth, Johnson, Kaley, & Parmer, 2013; Street, 2013). A greater emphasis could also be placed on teaching health literacy skills in settings where older adults and adults with low health literacy already congregate such as adult basic education classes or community centers. The content should not only be directed at basic knowledge of health and health care, but could also include standard practices and processes within the medical system such as learning how to describe symptoms to a HCP, fill out medical forms, and have interactive conversations with HCPs which may lead to increased critical thinking skills (Cutler & Lleras-Muney, 2006; Hibbard, Peters, Dixon & Tusler, 2007; Kerka, 2003; Zarcadoolas, Pleasant & Greer, 2005).

**Putting People First - Using Old and New Technologies**
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The digital divide, that is the social and economic disparity regarding accessing, using, or being impacted by information and technologies, plays a significant role in how technology can be harnessed for health in vulnerable populations. There is a seductiveness to using digital health technologies to understand, measure, report, and help people lead healthier lives, yet there are problems with equity, access, cost, development, evaluation and measurement (IOM, 2015). According to Orlow, health technologies “will drive an increase in disparities because the most avid users are the wealthy, worried, and well” (IOM, 2015). Individual may be able to acquire a smartphone or other device does not mean that they know how to use the technology for health. Issues such as limited health literacy, low reading ability, personal economic and social stability, cost of connectivity, and designs that are not user-centered can exacerbate disparities in technology use, however, limited information exists about how vulnerable populations access, understand, and use health technology to change health behaviors and health outcomes (Bauer, Thielke, Katon, Unutzer, & Arean, 2014; Czaja, 2015; IOM, 2015).

Design of health technology must be based on what users want and what they will use, regardless of whether the final product is old (e.g., video) or new (e.g., wearable monitoring devices). To that end, rigorous participatory research that is user-centered must be used in developing health technologies such as the one utilized by Schnall et al. that began with focus groups of end users prior to the develop/build/evaluate phases that most technology development begins with (Czaja, 2015; IOM, 2015; Taha, Czaja, Tarit & Morrow, 2013). Design must be intuitive to the end user, not only to the developer, and the technology must be useful, available,
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and usable, particularly for adults who may have limited health literacy and limited digital literacy.

**Conclusion**

There has been a conceptual shift in healthcare that moves the responsibility for relationships, information gathering, and decision making solely from those in the healthcare system toward a cooperative and participatory relationship between healthcare systems and patients (Alston et al., 2012; Carman et al., 2012; Fagerlin, Zikmund-Fisher, & Ubel, 2011; Ishikawa & Yano, 2008). Researchers understand the relationship between health literacy and health outcomes, how to measure health literacy, the need for higher health literacy in order to participate in health-related decisions, and what socio-economic determinants are most likely correlated with low health literacy (Berkman et al., 2011). Building on this prior work, researchers can now focus on interventions that advance the understanding of how to improve health literacy at the intersection of those using information, those providing information, and those who are members of vulnerable populations. It is this work for both individuals and within health systems that may lead to increased health literacy levels with the ultimate goal of improving health outcomes.
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