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HEALTH LITERACY AND CANCER PREVENTION: A QUALITATIVE
EXPLORATION OF THE HEALTH COMMUNICATION NEEDS OF HISPANICS
RESIDING IN NORTHEAST TEXAS

by

JESSICA R. HYDE, BS, CHES

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Health Sciences
Department of Health and Kinesiology

Cheryl Cooper, PhD, Committee Chair

College of Nursing and Health Sciences

The University of Texas at Tyler
May 2014


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Tyler, Texas

This is to certify that the Master's Thesis of

JESSICA R. HYDE

has been approved for the thesis requirement on
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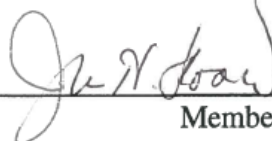
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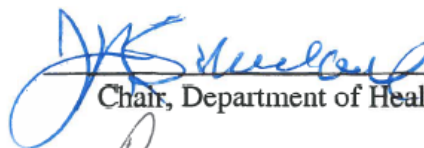
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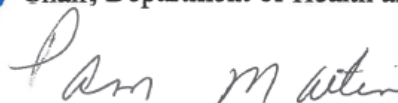
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ABSTRACT

HEALTH LITERACY AND CANCER PREVENTION: A QUALITATIVE EXPLORATION OF THE HEALTH COMMUNICATION NEEDS OF HISPANICS RESIDING IN NORTHEAST TEXAS

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The University of Texas at Tyler
May 2014

Introduction: Limited health literacy can impede adherence to cancer screening guidelines. This problem transcends sociocultural boundaries; however, Hispanics are more likely to have limited health literacy than other racial/ethnic groups in the U.S. The purpose of this study is to explore health literacy at a conceptual level in Hispanic adults residing in Northeast Texas in order to better understand this population's communication needs related to cancer prevention.

Methods: Focus group methodology and the Spanish-language version of the Newest Vital Sign (NVS-S) were used to gather data.

Results: Of the 18 individuals who sat for the NVS-S, 6 were classified as having a high likelihood of limited literacy, 4 as possibly having limited literacy, and the other 8 as having adequate literacy. The participants had limited cancer-specific knowledge and marginal numeracy skills, both of which play an integral role in understanding cancer prevention materials. Engagement in preventive behaviors may be negatively associated with attitudes of cancer fatalism and external locus of control.

Conclusion: Generalized public health messages or clinical information may not be adequate to motivate individuals of this population to engage in cancer prevention. Therefore, addressing all of the components of health literacy via targeted communication that is developed with their health literacy skills in mind in both the clinical and public health arenas could benefit local Hispanics through their increased engagement in cancer prevention behavior and subsequently better health outcomes.

CHAPTER ONE: INTRODUCTION

Background & Significance

Limited health literacy is prevalent in the United States, with almost 9 out of every 10 adults having difficulty understanding routine health information (Kutner, Greenberg, Jin, & Paulsen, 2006). This represents a significant problem for the health of the population of the U.S., and it is an expensive problem, costing the economy \$106-238 billion each year (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). Individuals with limited health literacy are more likely to avoid seeking primary and/or preventive care (Scott, Gazmararian, Williams, & Baker, 2002), including cancer screenings, and to have higher rates of preventable hospitalizations and utilization of urgent care facilities (Baker, Parker, Williams, & Clark, 1998). These individuals are also more likely to misunderstand and be non-adherent to treatment plans (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004).

Having limited health literacy, particularly suboptimal numeracy skills and reduced contextual knowledge, places one at greater risk for misunderstanding health information provided by healthcare professionals, such as diagnoses, risk communication, instructions for self-care, or displayed on prescription and nutrition labels (Schapira et al., 2008). While having a low degree of health literacy is a problem that transcends sociocultural boundaries, Hispanics, especially those who are less acculturated and have little or no English proficiency, are more likely to have limited health literacy

than other racial and ethnic groups in the U.S. (Koskan, Friedman, & Hilfinger-Messias, 2010).

Purpose of Study

Careful study of a population's culture and increased understanding of their communication needs can enable health professionals to develop and deliver culturally and linguistically appropriate health messages. Removing barriers that decrease access to and utilization of care is vital to not only reduce cancer health disparities, but also to increase individual empowerment and quality of life. The purpose of this study is to use focus group methodology to explore health literacy and numeracy at the conceptual level in Hispanic adults residing in Northeast Texas in an effort to inform the local medical and public health community of this population's communication needs related to cancer prevention.

Research Questions

- 1) What do Hispanic adults residing in Northeast Texas understand conceptually about health, specifically about cancer, including the words and numbers used in their communications with their healthcare provider?
- 2) What are the communication and education needs of the local community of Hispanic adults, and are these needs being met?
- 3) What specific barriers do Hispanic adults face when accessing the healthcare system?
- 4) How do culture, language, experiential knowledge, and sources of health information impact attitudes and behaviors regarding cancer prevention in Hispanic adults?

CHAPTER TWO: LITERATURE REVIEW

Overview of Health Literacy

According to *Health Literacy: A Prescription to End Confusion*, commissioned by the Institute of Medicine, health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer, & Kindig, 2004). The narrative of the 2010 Patient Protection and Affordable Care Act expands the definition of health literacy to include an individual’s ability to communicate and interact with healthcare providers (Somers & Mahadevan, 2010). This set of skills constitutes a complex, context-specific ability of an individual to effectively and efficiently engage in health-seeking behavior. “Thus, true health literacy is not just a matter of understanding what one is told: health literacy also encompasses the ability to independently formulate questions and to initiate interactions with health care providers...to secure necessary information” (Rosenbaum, Shin, & DeBuono, 2007, p. 3).

Health literacy is divided into four domains: 1) cultural and conceptual knowledge, 2) oral literacy, 3) print literacy, and 4) numeracy, as illustrated in Figure 1 (Nielsen-Bohlman et al., 2004). Within the context of the first domain, cultural and conceptual knowledge, health literacy is a skill set which can grow through increased exposure to health-related education and experience. Gaining this knowledge is dependent upon personal learning capabilities, the drive to learn, and the system-wide

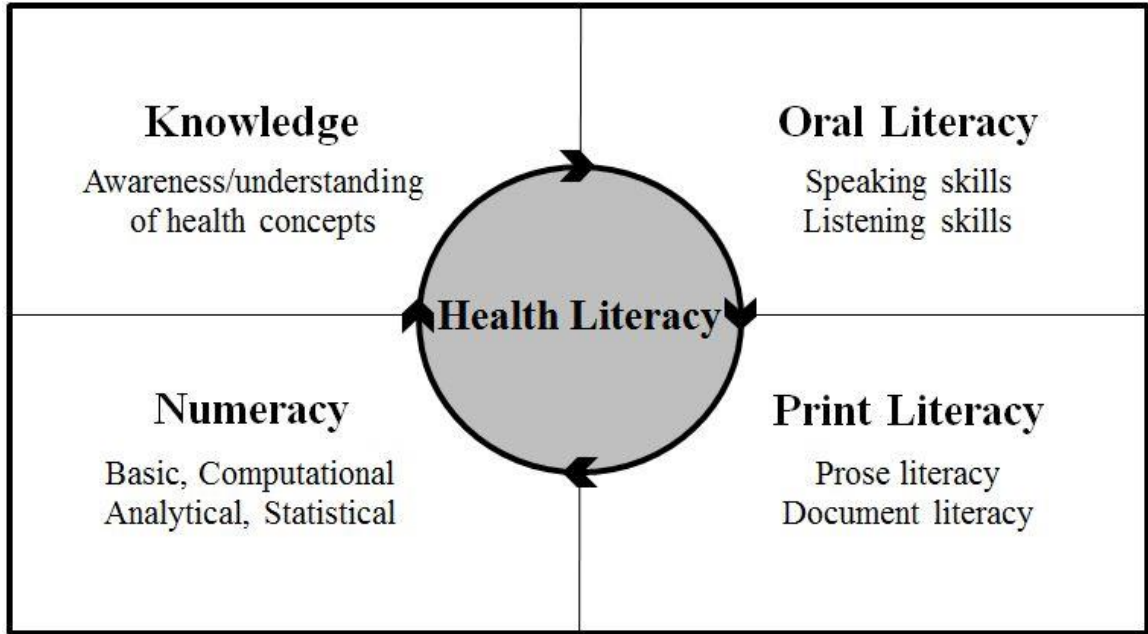


Figure 1. An interpretive conceptual model of the four domains of health literacy.
Constructed by Jessica Hyde.

capabilities of the health care setting to support an educational environment (Baker, 2006). The second domain, oral literacy, refers to the ability to understand and participate in two-way verbal communication (Baker). The third domain, print literacy, is comprised of the skill sets most commonly associated with general literacy: reading and writing. The subcategories of print literacy are prose literacy – the ability to read and comprehend information contained in text, and document literacy – the ability to find and put textual information to use (Baker). The fourth domain, numeracy, is defined as the capacity to carry out calculations and understand health-related quantitative information (Baker; Kirsch, Jungeblut, Jenkins, & Kolstad, 2002). All of these parts are equally important to the whole of health literacy. If any one component is missing or underdeveloped, an individual may then have suboptimal contextual health literacy.

Why is health literacy an important issue? Individuals with low health literacy are more likely to have poorer self-reported health status (Baker, Parker, Williams, Clark, &

Nurss, 1997), are less likely to seek preventive healthcare services (Scott et al., 2002), and are more likely to delay treatment (Bennett, Chen, Soroui, & White, 2009), to use emergency services, and to have higher in-patient hospitalization rates (Baker et al., 1998). Low health literacy is also associated with depression and poorer social networking among the chronically ill (Kalichman & Rompa, 2000) and with poorer self-reported health-related quality of life in cancer survivors (Song et al., 2012). Those with literacy difficulties are also less likely to adhere to medication instructions or treatment plans. For example, a study of patients undergoing anticoagulant therapy found that the clotting times of patients with lower literacy ($p=0.009$) and numeracy ($p=0.004$) were more erratic than patients with higher literacy and numeracy skills, indicating that the latter patients had increased control of their condition by taking medications as directed (Estrada et al., 2004). Limited health literacy is also associated with decreased management of chronic diseases, such as hypertension or diabetes. It has been shown that diabetic patients with marginal health literacy skills are more likely to have an insufficient knowledge base regarding their condition (Gazmararian, Williams, Peel, & Baker, 2003). Diabetics with poor health literacy are also less likely to have control over blood glucose levels (Schillinger, Bindman, Wang, Stewart, & Piette, 2004; Schillinger et al., 2002) and are at increased risk of diabetes-related complications (Schillinger et al., 2003). Those with suboptimal health literacy skills are also more likely to use nonstandard measurement tools, such as kitchen spoons, when measuring doses of liquid medications and are less likely to understand how to accurately dose medication based on weight (Yin, Dreyer, Foltin, van Schaick, & Mendelsohn, 2007). Parker, Ratzan, & Lurie offer a more dramatic example of the effects of poor health literacy:

A two-year-old is diagnosed with an inner ear infection and prescribed an antibiotic. Her mother understands that her daughter should take the prescribed medication twice a day. After carefully studying the label on the bottle and deciding that it doesn't tell how to take the medicine, she fills a teaspoon and pours the antibiotic into her daughter's painful ear (2003, p. 147).

This scenario makes it clear that an individual's level of health literacy has the potential to impact not only her personal health, but also the health of those in her care.

Conceptual Knowledge Component

The focus of this thesis is on the left half of the conceptual model, illustrated in Figure 1, which encompasses conceptual knowledge and numeracy. These two components have received relatively scant attention in research as compared to health-related print and oral literacy, but they are equally important. It is vital that we gain an in-depth understanding of what individuals understand conceptually about health and illness and utilize that knowledge to develop more effective health communication tools. "Ignorance of how patients conceptualize and label ill-health can lead to misinterpretation," (Helman, 1994, p. 140), as well as inadequate patient-provider communication. The decreased amount of time spent face-to-face between patients and providers requires individuals to have the ability to understand health information quickly and accurately, to which an adequate knowledge domain is essential (Osborne, 2005). In relation to cancer prevention, "the ability to understand cancer information is an essential health care skill and allows individuals to engage in meaningful conversation with providers to assess their risk of disease and agree on best practices appropriate to the determined risk" (Donelle, Arocha, & Hoffman-Goetz, 2008, p. 1). An individual's print

and oral health literacy – the components of the right half of the conceptual model (Figure 1) – depend heavily upon that individual’s familiarity with and comprehension of health-related terms and concepts that are presented (Baker, 2006).

Several studies have shown that patients with low health literacy often misunderstand disease-specific terminology commonly used in the clinical setting (Gibbs, Gibbs, & Henrich, 1987; Hadlow & Pitts, 1991), including cancer-related vocabulary (Davis et al., 2001; Samora, Saunders, & Larson, 1961). A recent pilot study conducted with a small group of Hispanic women in Northeast Texas corroborated these findings and revealed gaps in conceptual knowledge of health-related topics, including cancer, such as the meaning of a negative test result (Hyde & Cooper, 2013). A study of 445 women in a Louisiana public hospital found that 25% of the women who claimed to know what a mammogram is in fact did not, and they often confused mammograms with pap smears. Additionally, it was revealed that women who did have accurate knowledge about mammograms were significantly more likely to have had the cancer screening performed within the six months prior to the study (Davis et al., 1996).

In a 2001 study by Davis et al., focus groups exploring lay knowledge of colorectal cancer uncovered gaps in conceptual understanding of early detection. Some respondents reported they did not feel vulnerable to colorectal cancer because they currently felt well, indicating a misunderstanding of the idea that cancer has stages or series of progression, or that a disease can be silent. Similar results were found in focus groups covering the topic of breast cancer. The women in the group indicated that they did not feel at risk for the disease if they felt well, if their breasts looked good or had no palpable lumps, or if their breasts were small in size (Davis et al., 1996). This suggests

that individuals with low health literacy may not fully comprehend the importance of following cancer screening guidelines or that early detection and treatment of cancer can give them better odds of survival, especially if they do not adequately understand how the disease can progress.

Numeracy Component

As is the case with health literacy, health numeracy has many definitions, but lacks a standard definition agreed upon by experts in the field. The most comprehensive definition to date is similar to that of health literacy: “The degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005, p. 375). In addition, Golbeck et al. provide the following subcategories of health numeracy: 1) basic health numeracy – the ability to correctly identify numbers and make sense of numerical information that does not require any calculations, 2) computational health numeracy – the ability to perform simple one-step calculations and other simple numerical manipulations, such as counting, 3) analytical health numeracy, which requires higher level critical thinking, involving inferences, ratios, estimations, percentages, frequencies, etc., as well as assimilating information from multiple sources, and 4) statistical health numeracy, which involves probability, risk assessments, and comparing information (2005). Many in the U.S. struggle with understanding and manipulating numerical information. According to a 2003 national education survey, approximately two-thirds of fourth- and eighth-grade students lacked proficiency in arithmetic skills associated with their respective grade levels (Braswell, 2005). Americans particularly

struggle with ratio concepts, such as fractions, percentages, proportions, etc. (Reyna & Brainerd, 2007). In a study of individuals with higher levels of formal education than the general population, approximately 40% had difficulty answering basic probability questions (Lipkus, Samsa, & Rimer, 2001). These are troublesome statistics, as cancer prevention and risk communications often include the use of numbers, specifically ratios and percentages.

Individuals with limited numeracy skills are less likely to accurately personalize and understand the concept of health risks (Donelle et al., 2008). For instance, studies have found that women with limited health numeracy were more likely to overestimate their risk of death from breast cancer and misjudge the risk-reducing capabilities of breast cancer screenings (Black, Nease, & Tosteson, 1995; Fagerlin, Ubel, Smith, & Zikmund-Fisher, 2007; Schwartz, Woloshin, Black, & Welch, 1997). A study of cancer patients showed that those who struggle with health-related numerical concepts were significantly more likely to overestimate the benefits of experimental clinical trials and have higher expectations than those with adequate numeracy skills (Weinfurt et al., 2003). Low context-specific health numeracy is also associated with reduced quality of life in asthmatics, as well as reduced control over their condition in minority populations (Apter et al., 2009). As is the case with limited health literacy, individuals with suboptimal numeracy skills also have increased rates of visits to acute care facilities. Health numeracy may be a more useful predictor of poorer health outcomes and of decreased management of chronic conditions than general reading comprehension. One study found that emergency room patients, especially those belonging to a racial/ethnic

minority, tended to have lower numeracy than the general populace (Ginde, Clark, Goldstein, & Camargo, 2008).

Hispanic Health

Substantial disparities exist in health literacy¹ levels between majority and minority populations in the U.S. Between 62-65% of Hispanic adults have basic health literacy or below compared with 28-35% of non-Hispanic white adults (HHS, 2008; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005; Williams et al., 1995). Many factors mediate the relationship between race/ethnicity and health literacy levels, including language barriers. About 21% of the U.S. population over the age of 5 speaks a language other than English in the home (Ryan, 2013), including 34% of Texas residents (Johnson, Rios, Drewery, Ennis, & Myoung, 2010). As many as of 20% of Spanish-speaking U.S. citizens and residents have reported that they avoid or delay seeking help from a healthcare provider because of language barriers (Russell, 2010). Even with the availability of cancer-related materials written in Spanish, some knowledge of the English language is required of patients in order to successfully navigate the healthcare system.

Hispanics are more likely than other races and ethnicities to lack a regular healthcare provider (AHRQ, 2005; Nelson, Chapko, Reiber, & Boyko, 2005). According to a report from the Robert Wood Johnson Foundation, about 67% of Mexican-Americans do not have a medical home (RWJF, 2009). This subsequently increases dependence upon emergency services for acute needs. Having a regular source of health care is also important for the receipt of accurate health information. In the Hispanic

¹From this point forward, *health literacy* will act as an umbrella term for all four domains of health literacy unless otherwise specified.

culture, individuals often rely upon the advice of friends, family, or other persons labeled as lay experts with either direct or indirect experiential knowledge as sources of health information (Bowen et al., 2013; Helman, 1994). This may in turn increase the risk of receiving misinformation regarding an illness and condition, especially if these sought out individuals have low health literacy as well (Bevan & Pecchioni, 2008).

As previously mentioned, individuals with low health literacy are less likely to seek preventive care, such as cancer screenings and early diagnostic procedures, and are thus more likely to be diagnosed at later cancer stages (Davis, Williams, Marin, Parker, & Glass, 2002). Cancer was the leading cause of death for Hispanics in the U.S. in 2009 (CDC, 2013). According to the National Cancer Institute, minority groups and non-Hispanic whites of low socioeconomic status tend to have higher incidence and mortality rates for specific cancer sites (NCI, 2008). For instance, Hispanic females had the highest rate of cervical cancer incidence of any racial or ethnic group in the U.S., 13.8 per 100,000 compared with 8.5 per 100,000 in non-Hispanic white females, from 2000 to 2004 (NCI).

In Texas Health Service Region (HSR) 4, which represents Northeast Texas, all-site cancer *incidence* in Hispanics from 2007-2010 was among the lowest in the state (Figure 2); however, HSR 4, along with HSR 2, had the highest rates of all-site cancer *mortality* among Hispanics (Figure 3) (DSHS, 2013). According to the 2010 data available through the Texas Behavioral Risk Factor Surveillance System, Hispanics statewide were less likely to engage in cancer prevention practices than non-Hispanic whites (Figure 4) (CHS, 2012). While the Hispanic rates for pap smears and

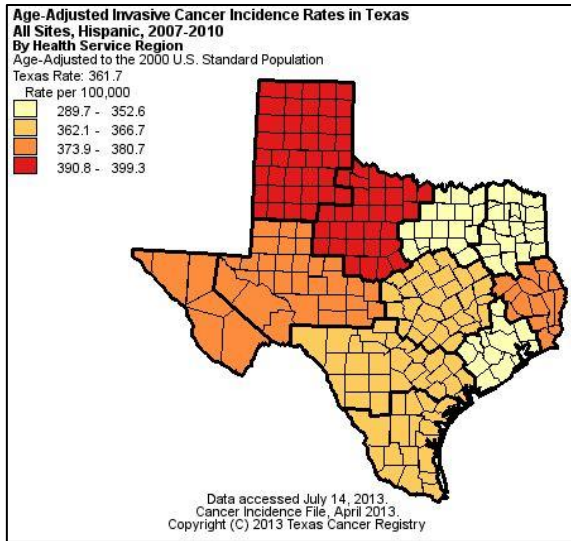


Figure 2. Texas Cancer Registry map divided by Public Health Service Region detailing the age-adjusted all-site cancer incidence rates in Hispanics in 2007-2010.²

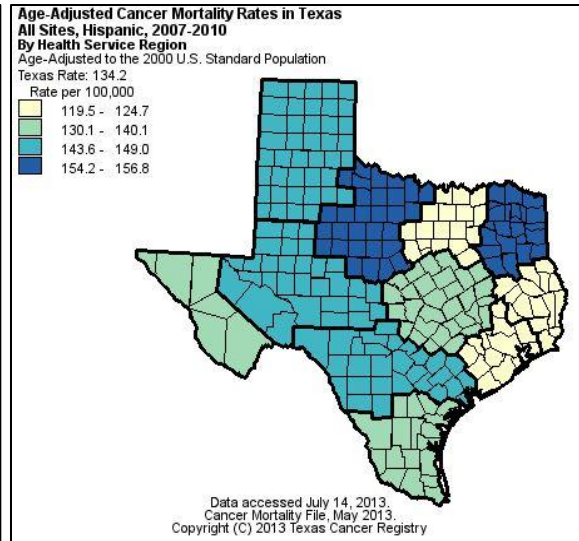


Figure 3. Texas Cancer Registry map divided by Public Health Service Region detailing the age-adjusted all-site cancer mortality rates in Hispanics in 2007-2010.²

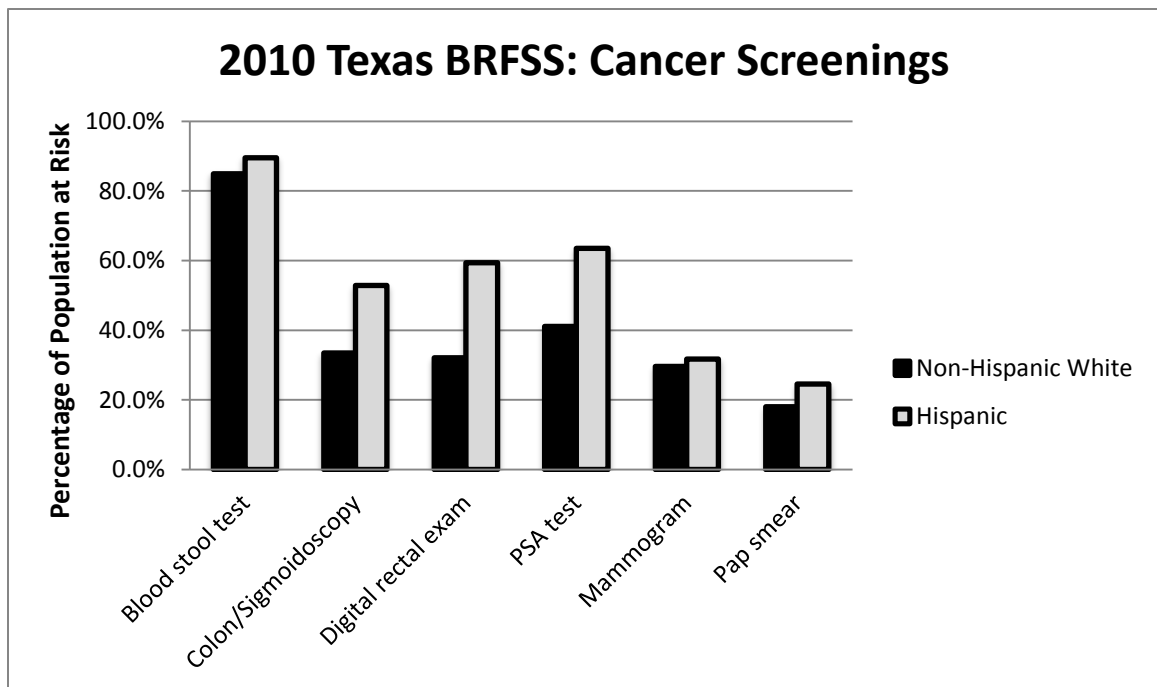


Figure 4. Texas Behavioral Risk Factor Surveillance System data from 2010. The following survey items are represented: 1) individuals 50+ years of age who reported not having a blood stool test in 2 years, 2) individuals 50+ years of age who reported never having a colon/sigmoidoscopy, 3) males 40+ years of age who reported not having a digital rectal exam in the past 5 years, 4) males 40+ years of age who reported not having a PSA test in the past 2 years, 5) females 40+ years of age who reported not having a mammogram in the past 2 years, and 6) females 18+ years of age who reported not having a pap smear in the past 3 years.

²Cancer data have been provided by the Texas Cancer Registry, Cancer Epidemiology and Surveillance Branch, Texas Department of State Health Services, 211 E. 7th Street, Suite 325, Austin, TX 78701, <http://www.dshs.state.tx.us/tcr/default.shtm>, or (512) 305-8506.

mammograms were relatively close to that of non-Hispanic whites, narrative from local community outreach staff indicated that the problem often lies in attrition between screening and diagnosis. For instance, one community health worker stated that Hispanic women often do not comprehend what a doctor says when he or she calls with abnormal test results from a pap smear, nor do they understand the recommended next steps, such as colposcopies or biopsies. They think these procedures are surgeries which they are hesitant to undergo. The staff interviewed suggested that cervical cancer receives less promotion than other cancer sites, such as breast cancer, and that lack of awareness and education about a health issue has direct impact on behavior post-diagnosis (A. Farias, S. Taylor, personal communication, July 5, 2013), an assumption that is also backed up by the literature (Bowen et al., 2013).

Culture can also have an impact on health-seeking behaviors in that it acts as a lens that colors interpretation of symptoms and the meanings connected to them (Bishop & Yardley, 2010; Coffman, Norton, & Beene, 2012). One study uncovered a common misunderstanding among diabetic Mexican-American women that a lack of noticeable symptoms meant the disease was well-managed or even nonexistent (Phinney & Wallhagen, 2003), a misconception that could influence attitudes toward cancer prevention and/or management. Some may also ignore symptoms if they lack sufficient understanding or knowledge about the signs and symptoms (Coffman et al., 2012) or anatomy relative to cancer (Davis et al., 2002).

Why should health professionals focus on Hispanic health communication? In 2011, over 16% of the total Texas population was comprised of foreign-born individuals, 71.5% of whom emigrated from Latin America (Migration Policy Institute, 2013). These

individuals may be from countries where English is not the primary language, or where education is neither compulsory nor free (Taylor, Nicolle, & Maguire, 2013). In a recent press release from the U.S. Census Bureau, the acting director, Thomas L. Mesenbourg, was quoted as saying, “The next half-century marks key points in continuing trends – the U.S. will become a plurality nation, where the non-Hispanic white population remains the single largest group, but no group is in the majority” (2012). The Hispanic population is expected to double, with 1 in 3 residents being of Hispanic origin by the year 2060 (U.S. Census Bureau). With the U.S. population becoming increasingly diverse, increased focus will be required on minority health and the context in which *health* happens – economic, social, and cultural – in order to fully achieve cancer control goals and objectives (Davis et al., 2002), such as those outlined in the Texas Cancer Plan and Healthy People 2020.

The Stigma of Cancer

Even with advances in technology and treatment options, as well as increases in survival rates, cancer is still the diagnosis that Americans fear most above all other illnesses (Barker & Jordan, 2003). The word cancer provokes fear (Trumbo, McComas, & Kannaovakun, 2007), stirring up images of suffering, pain, possible disfigurement, and social stigmatization (Berman & Wandersman, 1990). Those afflicted with a form of this dreaded disease are sometimes avoided because they invoke increased levels of personal vulnerability in others (Katz et al., 1987). To many, cancer is equated to a death sentence (Block, 2008; Moser et al., 2013; Petrie & Weinman, 1997). A survey conducted through the American Association for Cancer Research found that 73% of respondents had a family member or close friend die from cancer, while only 45% knew a cancer survivor

(Barker & Jordan). It should not be surprising, then, that many develop a sense of fatalism (Dent & Goulston, 1982) after watching friends and loved ones endure ongoing suffering at the hands of cancer (Petrie & Weinman).

The feeling that one has no control over an outcome, especially related to cancer, could lead to negative attitudes toward screening: “Emotions are well known for their powerful ability to alter the course of rational thought” (Petrie & Weinman, 1997, p. 292-293). Individuals with low health literacy often rely upon the experiential knowledge of others, such as friends and/or family, for health information. Their perceptions of cancer could especially be influenced by members of their social networks chose to avoid or delay screening themselves and were subsequently diagnosed with cancer at later, more terminal stages, which could exacerbate feelings of hopelessness and fatalism.

Gaps in Literature

Further research is needed to clear up the ambiguity inherent in the concept of health literacy. As a relatively new concept, there is still much to learn about the topic, and even more so about even newer ideas such as health numeracy. Additional research and review is needed to establish a standard definition of health numeracy in order to more accurately develop and validate numeracy assessments and “investigate the relationship between health prose and numeracy skills with all age cohorts, pertaining to various chronic illnesses and among diverse ethnic groups” (Donelle et al., 2008, p. 6). Only two articles to date are available through PubMed that focus on health numeracy in Hispanics specifically.

The relationship between health literacy and the effectiveness of cancer communication has received relatively little research attention. There are sizable

differences between the amounts of literature pertaining to general health literacy and what is available related to context- and/or disease-specific health literacy. Further research on the latter subject is suggested in numerous manuscripts (Bynum et al., 2013; Diviani & Schulz, 2012; Hepburn, 2012). “Health literacy studies should embrace the complexity of disease specific healthcare information, and the effect of race, ethnicity, socioeconomic status, education, linguistics, and accessibility to healthcare information, to the ability to navigate the health care system” (Hepburn, p. 230). The problem of health illiteracy has been often overlooked in cancer and cancer-specific communication (Davis et al., 2002; Diviani & Schulz, 2011). A review of cancer prevention materials found that the average reading levels of newer educational brochures and pamphlets were comparable to those expected of late junior high and high school students, and only about half were culturally sensitive (Guidry, Fagan, & Walker, 1998), suggesting a need for informed development of more culturally and linguistically appropriate written communication.

Little is known about the conceptual understanding of health and illness in general among Hispanics in the Northeast Texas area or about specific topics such as cancer. In order to establish areas of improvement, a baseline must first be established in terms of this population’s working knowledge of health topics (Britigan, Murnan, & Rojas-Guyler, 2009; Diviani & Schulz, 2011). The culture of local Hispanics and how their values and beliefs impact health-seeking behaviors also remain relatively unknown. As cancer is a leading cause of preventable death in Hispanics (CDC, 2013), it is imperative that future research focus on the psychosocial and cultural contexts in which health and illness, specifically cancer, occur (Bowen et al., 2013).

CHAPTER THREE: METHODS

Study Design

To date, there is no standard comprehensive measure of health literacy, with consideration of health numeracy and conceptual knowledge. Until such a measurement has been developed and validated, the appropriate method depends upon perspective:

If health literacy is a capacity of a person, measures of an individual's reading ability and vocabulary are appropriate. In contrast, if health literacy depends on the relationship between individual communication capacities, the health care system, and the broader society, measures at the individual level are clearly inadequate. If knowledge is part of the definition of health literacy, this too must be measured (Baker, 2006, p. 878).

Health literacy assessments that are currently available tend to measure only reading ability and basic math skills; therefore, they do not thoroughly assess health literacy comprehensively. These measurements “cannot differentiate among (a) reading ability, (b) lack of background knowledge in health-related domains..., (c) lack of familiarity with language and types of materials, or (d) cultural differences in approaches to health and health care” (Nielsen-Bohlman et al., 2004, p. 6). The Rapid Estimate of Adult Literacy in Medicine (REALM) measures only word recognition and the ability to accurately pronounce a list of increasingly difficult health-related terminology (Thompson, Dorsey, Parrott, & Miller, 2003). The Test of Functional Health Literacy in Adults (TOFHLA) measures reading comprehension and some numeracy skills by testing

a patient's ability to correctly fill in the blanks in health-related prose passages, given a multiple choice list for each blank (Thompson et al., 2003). These tests focus on superficial knowledge, not conceptual knowledge, with disproportionate emphasis on reading skills, and thus do not measure health literacy thoroughly. Two individuals may have very similar skills in reading, writing, listening, and speaking, but vary greatly in their ability to comprehend health information. This can be caused by variations in their culture, experience, and health-related vocabulary and conceptual knowledge (Baker). If these individuals were to take a health literacy assessment such as the Short Test of Functional Health Literacy in Adults (S-TOFHLA) that focuses on reading ability only, they may produce similar scores; however, they could possibly have very dissimilar health communication needs.

In order to establish a more comprehensive method of measuring health literacy and numeracy, researchers must first get to the core of what the target audience understands about health-related topics in order to understand their learning abilities, communication needs, and language and culture (Osborne, 2005). This first requires a qualitative approach from which quantitative measures can be developed, which when informed by thorough and rigorous qualitative methods, are more likely to be effective. Qualitative methodology also gives the respondents an opportunity to have a voice and can be an empowering experience through an increase in critical consciousness and awareness (Freire, 1970). Few studies have used qualitative methods, such as focus groups and interviews, to explore health literacy and numeracy in the context of conceptual understanding of health information, and no such research has been done with this population and in this geographic location to date.

Sampling & Recruitment

All adults living in Texas HSR 4 who self-identified as Hispanic, indicated their primary language as Spanish, had never been diagnosed with cancer, and were capable of verbally responding to a set of semi-structured health-related questions were eligible to participate. The purpose of these inclusion criteria was to ensure a more homogenous cultural group with similar levels of acculturation, as well as educational histories. Recruitment efforts were focused on individuals who were non-professionals and who did not hold college degrees; however, individuals were not excluded based on educational attainment. After obtaining approval from the Institutional Review Board at the University of Texas at Tyler (Appendix A), participants were recruited via word-of-mouth communication by administration and staff at the Literacy Council of Tyler. Two focus groups were conducted during English as a Second Language (ESL) class sessions at the Family Learning Center and Douglas Elementary School in Tyler, Texas. Recruiting from these ESL classes helped to ensure that the participants met the language inclusion criterion and also increased the response rate, as these groups had a predetermined meeting time in venues to which the potential participants were already accustomed.

Focus Group Protocol

The focus groups were conducted by a graduate student researcher with experience in all aspects of this qualitative methodology, including moderating, documenting, analyzing, and triangulating. All documents given to the participants were written in Spanish and were back-translated to English by a bilingual case worker from a local community outreach center with about 10 years of experience working with this

population to prevent any meanings from being lost in translation. Each participant was asked to sign an informed consent document that was read aloud at the beginning of each focus group session. The participants were assured that their involvement was voluntary and there would be no personal identifiers collected at the time of sampling. Participants were asked to refrain from using names or other identifiers during the focus group session. To mitigate the use of names, the participants were assigned numbers. The groups verbally assented to the discussions being recorded via audiotape.

Participants were given a written demographic questionnaire followed by the Spanish version of a health literacy assessment known as the Newest Vital Sign (NVS) (Appendices B & C). The assessment was developed as a screening tool to be used in clinical settings to quickly identify patients with limited document and prose literacy, as well as suboptimal numeracy. This assessment consists of six questions that are to be presented verbally to participants as they look at a nutrition label from a container of ice cream, which is available in both English (NVS-E) and Spanish (NVS-S) (Weiss et al., 2005). NVS-E was shown to have good internal consistency (Cronbach $\alpha=0.76$) and criterion validity ($r=0.59$, $p<0.001$) and had high sensitivity for classifying individuals with limited health literacy skills during performance testing (Weiss et al.). NVS-S was also shown to have good reliability (Cronbach $\alpha=0.69$) and significant correlation with the full version of the TOFHLA ($r=0.49$, $p<0.001$) (Osborn et al., 2007). Both versions are easy and quick to administer, taking only 2 to 3 minutes, as compared to other commonly used health literacy assessments such as the S-TOFHLA, which takes about 8 minutes to complete (Osborn et al.).

Participants were then requested to respond verbally to a set of semi-structured questions asked by the researcher, who acted as moderator. A translator was available during both sessions to interpret the questions and responses as necessary; however, most dialogue was transacted in English. Participants were repeatedly reminded before and during the session that they could communicate to the researcher in whichever language

Table 1
Focus Group Question Set

Question	Component Addressed
1. When you visit with your doctor or nurse, how well do you feel you understand the words they use when they talk to you about your health?	Oral literacy
2. When you visit with your doctor or nurse, how well do you feel you understand the numbers they use when they talk to you about your health?	Numeracy
3. When you go to the doctor's office, do you go by yourself or have someone with you? Who? For what purpose?	Oral/Print literacy
4. In general, are you able to fill out medical forms by yourself, or do you sometimes need help with understanding the paperwork?	Print literacy
5. What do you think it means to be healthy?	Knowledge
6. Why do you think people get sick, in general?	Knowledge
7. What disease do you fear getting the most?	Knowledge
8. Do you have a sibling or parent who has cancer? What about anyone else in your family? How likely do you think it is that you will get cancer?	Knowledge
9. How/why do you think people get cancer?	Knowledge
10. If you wanted to get information about cancer, where (from whom) would you get that information?	Print literacy/Knowledge
11. Suppose you had a test for cancer and the doctor told you the results were negative. What does that mean?	Knowledge
12. How do doctors decide whether someone has cancer?	Knowledge
13. What is cancer? What happens inside the body when a person has cancer?	Knowledge
14. If a doctor or nurse told you that you had a high risk for getting a disease such as lung cancer or diabetes, what does that mean? What about low risk?	Numeracy/knowledge
15. If a doctor told you that lung cancer affects 2.3 per 1,000 people and colon cancer affects 6.8 per 1,000 people, which cancer is less common?	Numeracy
16. If a doctor told you that lung cancer affects 1 in 426 people and colon cancer B affects 1 in 104 people, which cancer is less common?	Numeracy
17. If your doctor told you that you have a 50% chance of getting lung cancer, and a 70% chance of getting colon cancer, which cancer would you be more likely to get?	Numeracy
18. Jar analogy	Numeracy

they felt most comfortable. When a participant expressed him- or herself in Spanish, the translator interpreted their response for the moderator. Note takers were present during both focus group sessions to document nonverbal cues and behaviors. The participants' answers were summarized at the end of each question for audience verification. The question set, along with a description of the literacy component assessed by each item, is available in Table 1. The question, "How confident are you in filling out medical forms by yourself?" was selected for use as it has been validated as a single-question screening tool that is predictive of inadequate health literacy in the clinical setting (Chew, Bradley, & Boyko, 2004; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). The latter questions were developed from questions asked in other related focus group studies previously conducted by the researcher and her faculty mentor (Cooper, Hyde, & Miller, 2013; Hyde & Cooper, 2013).

Analysis

Once the focus groups were completed, the audio recordings were transcribed by the researcher and analyzed using constant comparison analysis. This method of analysis, developed by Glaser and Strauss, consists of three steps: 1) open coding – separating the data into small bits and attaching a code, 2) axial coding – grouping the coded data into categories, and 3) selective coding – developing themes based on the collected groupings (Doody, Slevin, & Taggart, 2013). Constant comparison analysis is particularly useful when conducting multiple focus groups within one research study, allowing the researcher to evaluate whether or not themes from one group correlate with those from the others (Doody et al.). The transcripts and audio were carefully and

repeatedly reviewed by the researcher, an undergraduate bilingual research assistant, and one of the note takers to ensure that themes were extracted to the point of saturation.

CHAPTER FOUR: RESULTS

Population Sample

Ten participants were initially present for the first focus group session. One participant left immediately after the NVS-S was administered before the discussion questions began, and three others had to leave the session around the midway point due to conflicting obligations. Nine participants were present for second focus group session,

Table 2
Participant Demographics

Age in years (%)	
18-24	2 (11)
25-34	3 (16)
35-44	8 (41)
45-54	3 (16)
55-64	0 (0)
65 or older	1 (5)
Preferred not to answer	2 (11)
Sex (%)	
Male	6 (32)
Female	13 (68)
Race (%)	
Hispanic	19(100)
Other	0 (0)
Education (%)	
Less than high school	10 (53)
High school	5 (25)
More than high school	2 (11)
Preferred not to answer	2 (11)
Self-reported English Proficiency (%)	
None	0 (0)
Not very well	9 (47)
Well (more or less)	8 (42)
Very well	0 (0)
Preferred not to answer	2 (11)

though one participant arrived late and thus did not sit for the NVS-S with the rest of the group. A total of 19 participants were present to be introduced to the study and to sign

informed consent documents, 18 took the NVS-S, and 18 participated in the group discussions, at least in part. Demographics for the participants are presented in Table 2.

Health Literacy Assessment

The Spanish version of the Newest Vital Sign (NVS-S) was used to gather quantifiable estimates of the participants' levels of health literacy. As discussed previously, the NVS-S has been shown to be a reliable tool that correlated well with other longer measures of health literacy, such as the TOFHLA (Osborn, 2007); however, use of the NVS-S in this study showed the tool to be linguistically biased against Spanish-speakers. The fourth question on the instrument on the English version (NVS-E) reads as follows: "If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?" while the Spanish version roughly translates to "If you normally eat 2,500 calories, what will you consume if a portion is eaten?" The only correct answer is in the form of a percentage, which Spanish-speakers are not instructed to calculate. Only one participant responded with the correct answer of 10% because she requested that the question be explained to her, at which point the researcher read the question to her in English from the NVS-E. To adjust for this issue, the researcher developed a new scoring system similar to the original; however, the new scale is based on a five-question scale, due to the exclusion of Question 4. The adjustment is outlined in Table 3. For this study, the adjusted scale did *not* have an impact on the participants' final literacy classification. Of the eighteen individuals who sat for the NVS-S, six were classified as having a high likelihood of limited literacy, four as possibly having limited literacy, and the other eight as having adequate literacy. The

adjustment did not affect the mean score of the two groups, which was 2.8, indicating that overall the group possibly has limited literacy skills.

Table 3
NVS-S Adjusted Scale

NVS-S Original Scale	NVS-S Adjusted Scale	Literacy Classification
0-1 (0-16.7% correct)	0-1 (0-20% correct)	Indicates high likelihood of limited literacy
2-3 (33.3-50% correct)	2-3 (40-60% correct)	Indicates possibility of limited literacy
4-6 (66.7-100% correct)	4-5 (80-100% correct)	Indicates adequate literacy

Focus Group Discussions

The responses chosen for discussion are the ones that were the most salient to the focus of the study. The participants were oriented toward answering cancer-specific questions by discussing more general health topics first. The initial questions prompted the participants to discuss their comfort levels with the words and numbers used when communicating with their healthcare provider. The majority (72%) stated that they were uncomfortable or nervous when visiting with their doctor, the most common reason being communication barriers, such as unfulfilled translation needs. Those who had an easier time interacting with their healthcare provider also reported having a regular source of care with whom they had established a good relationship. Perceived differences between the healthcare systems of Mexico and the United States could also have been a source of the participants' discomfort, as exemplified by one participant's statement:

It is very different in Mexico and the United States, because in Mexico, doctors are pediatricians, oncologists, all of them, general doctor. There were no specialties. For me, it is very problematic because here if the doctor is not familiar with [the condition] he will send me to someone else. I get sent from one doctor

to another. We only need one person instead of all of them. Of course, in Mexico, there is not that many people, and you know the doctors and they listen. And you know by word of mouth how he is, if he's a good doctor or not.

Other participants reaffirmed her discomfort with the U.S. healthcare system, explaining to the researcher that it was easier to communicate and establish relationships with doctors in Mexico. There, according to the participants, language issues for Spanish-speakers are not a barrier to access, and only one doctor is seen for all problems. This potentially allows for doctors to develop more personal relationships with their patients. It was a complaint among multiple participants that doctors in the U.S. often do not take the time to listen or talk to their patients, leaving some of their problems unaddressed. All but two of the participants indicated that they had difficulty understanding the numbers that are commonly used in the clinical setting. Some (22%) reported having to ask the doctor about the numbers, such as blood pressure or lab results, to get a more specific explanation than 'good' or 'you are okay.' Except for the two oldest participants in the groups, the groups indicated that they would search the Internet if they needed more health information beyond what was given to them by their healthcare provider.

The participants were then asked about their confidence in filling out medical forms without assistance. As mentioned previously, this question has been validated as a one-question clinical assessment that is predictive of health literacy levels (Chew et al., 2004; Wallace et al., 2006). All but one of the participants expressed that they have never needed help when filling out paperwork, which would indicate that the majority of the participants (94%) are likely to have adequate health literacy; however, these results

do not corroborate those from the NVS-S, which identified more than half of the group as potentially having limited health literacy skills.

Next, the participants were asked to express their thoughts on what it means to be healthy. The most common answers were lifestyle-focused, such as eating a balanced diet (67%), being physically active (44%), achieving a healthy weight (11%), and getting an adequate amount of sleep (11%). One-third of the participants related the state of being healthy to ‘feeling good’ or being asymptomatic, which is troublesome as many conditions, such as the early stages of some cancers, are considered ‘silent’ and may not have readily perceivable symptoms. To others, being healthy meant feeling energetic (11%) and maintaining functionality (6%). One of the younger respondents mentioned that someone who is healthy would not partake in illicit drug use.

Similarly, the participants’ answers to the subsequent question regarding why people get sick, in general, were those most commonly associated with an individual’s lifestyle, such as unhealthy diets (78%), physical inactivity (11%), stress (11%), inadequate sleep (5%), and poor hygiene (5%). Some also mentioned factors that are outside of an individual’s control, such as family history of a particular disease (22%), exposure to harmful substances (17%), allergies (5%), and a change in the weather (5%). Being around others who are ill was also brought up by one participant, indicating there is at least some understanding of the concept of communicability.

When asked what disease or condition they feared developing the most, cancer (56%) and diabetes (39%) were at the top of the list. Five of the participants shared stories of friends or family who died from cancer, two of whom died very quickly after a cancer diagnosis. Yet, when those with a family history of cancer (39%) were asked to

share their beliefs regarding their personal risk of developing cancer, they reported having a low to medium risk, or at least expressed a desire to think their risk was low. The only participant who perceived herself to be at high risk of developing cancer had no known family history of the disease. A later question was asked to assess the participants' understanding of the concept of risk. Of the participants still present to respond, most (67%) understood that if a doctor told them that they were at high risk of developing a disease that it meant they have a possibility of getting the disease in the future; however, the other 33% of the participants were unsure or reported that receiving such a message from a provider would mean "bad news" or that "there is a big chance that you have the disease" which would need medical attention soon, "or you will die young."

Next, the participants were asked why or how people get cancer. Of those who provided a response (67%), most identified risk factors for cancer that are beyond personal control, such as exposure to harmful substances (46%) – chemicals, pesticides, or radiation – or family history (20%). Only one participant mentioned a behavioral risk factor, that diet plays a role in the development of cancer. In both focus groups, participants mentioned that people get cancer because they do not go to the doctor (13%), which seems to indicate a mindset that seeing a healthcare provider can prevent cancer rather than diagnose it in an earlier, more manageable stage.

The groups were then asked to explain what cancer is and what happens inside the body when someone has cancer. The majority of the participants were unsure of how to answer (53%). One of the participants hesitated when it was her turn to respond and explained that she was scared. She did not want to think about cancer or know what it is. Among the participants who attempted to answer, 71% stated that cancer is a group of

damaged cells (71%), “bad cells in our bodies that are killing people.” One participant explained that cancer is “a virus inside the body that starts eating some parts of the body...,” while another was able to explain that cancer cells can reproduce and attack other healthy cells. The latter was the only one to provide an explanation that indicated a basic understanding of the concept of metastasis.

Table 4
Assessment of Numerical Concepts

Probe	Number Correct (%)	Number Incorrect (%)
2.3 per 1,000 (lung) vs. 6.8 per 1,000 (colon) ----- Which cancer is <i>less</i> common?	11 (73%) [lung]	4 (27%) [colon]
1 in 426 (lung) vs. 1 in 104 (colon) ----- Which cancer is <i>less</i> common?	8 (53%) [lung]	7 (47%) [colon/unsure]
50% chance (lung) vs. 70% chance (colon) ----- Which cancer has the <i>greatest</i> chance of developing?	13 (87%) [colon]	2 (13%) [lung]
1 black in 10 total vs. 10 black in 100 total ----- Which jar gives you the greatest odds of choosing a black marble?	5 (33%) [same odds]	10 (67%) [10/100 or unsure]

The final set of questions focused on the participants’ understanding of numerical information, specifically ratios and percentages, the results from which are reported in Table 4. First, the groups were shown a set of two large flashcards that displayed the numerical information from the following scenario: “If your doctor told you that lung cancer affects 2.3 per 1,000 people, and colon cancer affects 6.8 per 1,000 people, which cancer is *less* common?” Of the 15 still present at this point in the discussion, 11 (73%) of the participants chose lung cancer (the correct answer) as being less common, and the other 4 (27%) chose colon cancer. Next, the groups were shown flashcards and given information in a different numerical format: “If your doctor told you that lung cancer affects 1 in 426 people, and colon cancer affects 1 in 104, which cancer is *less* common?”

Eight (53%) of the participants selected the correct answer, lung cancer, and the other 7 (47%) chose colon cancer or were unsure.

Next, the groups were given the following scenario orally, *without* flashcards displayed: “If your doctor told you that you have a 50% chance of getting lung cancer or a 70% chance of getting colon cancer, which cancer would you have the greatest chance of getting?” Most of the participants (87%) were able to respond correctly by choosing colon cancer, while the other 13% selected lung cancer. The groups were then shown two jars filled with marbles. Both jars had the same proportion of black to clear marbles. One jar had 1 black marble and 9 clear ones, for a total of 10 marbles, while the other had 10 black marbles and 90 clear ones, for a total of 100 marbles. The participants were then asked to indicate which jar they thought would give them the greatest odds of choosing a black marble while blindfolded. The majority of the participants (67%) chose incorrectly by selecting the jar with 10 black marbles or by not making a selection due to being unsure of which jar to choose. Only 5 (33%) expressed an understanding that both jars carried the same odds of picking a black marble.

CHAPTER FIVE: DISCUSSION

Cancer Fatalism

The most striking theme to emerge from the focus group responses was a lack of perceived control among the participants regarding cancer causality. When asked why people get sick in general, both groups were quick to respond with risk factors that are typically within an individual's scope of control, such as poor diet, physical inactivity, or lack of sleep; however, when the participants were asked why people develop cancer, the reasons reported were mostly those beyond personal control, such as family history or exposure to harmful substances – such as chemicals or pesticides – or radiation. Throughout the discussions it was made evident that cancer is stigmatized as a dreaded disease, something to be viewed as a death sentence. Cancer was the most frequently cited disease that the participants feared developing above all others.

The thought that nothing can be done to prevent cancer or subsequent death may steer individuals away from following screening guidelines (Baron-Epel, Friedman, & Lernau, 2009). This stigma is related to the concept of *cancer fatalism*, “the belief that death is inevitable when cancer is present” (Powe & Finnie, 2003, p. 454) or that the development of cancer is beyond personal control (Straughan & Seow, 2000). Multiple studies have shown there to be an inverse relationship between cancer fatalism and performance of protective behaviors, such as receipt of mammograms and colorectal cancer screenings (Gorin, 2005; Liang et al., 2008; Mayo, Ureda, & Parker, 2001; Powe, 1995; Spurlock & Cullins, 2006; Straughan & Seow). This view about cancer may be

influenced by cultural beliefs, as African Americans and Hispanics are more likely to harbor such an attitude than Caucasians (Facione, Miaskowski, Dodd, & Paul, 2002; Russell, Perkins, Zollinger, & Champion, 2006). Cancer fatalism is also associated with a lack of cancer-specific knowledge (Powe & Finnie), and could therefore be considered a contextual health literacy issue. Such lack of knowledge was demonstrated in both groups by the participants' responses to the cancer-specific and risk related probes.

External Locus of Control

Fatalism is very similar to external locus of control, a construct that emerged from the discipline of psychology in Rotter's Social Learning Theory (1966). As it is related to health, external locus of control is defined as an "individual's characteristic attributions of responsibility for their health" (Williams-Piehota, Schneider, Pizarro, Mowad, & Salovey, 2004, p. 408) and is associated with feelings of helplessness. Individuals with an internal health locus of control tend to perceive greater personal control of their health, while those with an external locus believe that fate, luck, chance, or 'powerful others,' such as doctors or other healthcare providers, are in charge of their health (Wallston, Wallston, & DeVellis, 1978). Participants in both focus groups reported a belief that people get cancer because they do not visit their doctor regularly, as if seeing their provider prevents cancer from developing. This lends support to the notion that those with limited cancer-specific knowledge may indeed exhibit a more external health locus of control, which could exacerbate fatalistic tendencies.

Lay Epidemiology

These beliefs about personal helplessness and lack of perceived control are also intensified when individuals witness late diagnoses followed by 'sudden' cancer-related

deaths within their social spheres (Powe & Finnie, 2003). A number of participants (28%) in this study shared personal stories of a friend or family member dying of cancer, some of whom died suddenly after receiving a cancer diagnosis. Such anecdotal evidence plays a key role in the process of lay epidemiology, “a scheme in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and in the public arena” (Frankel, Davison, & Smith, 1991, p. 428). Lay epidemiology influences an individual’s decision-making related to her personal risk and what actions might be taken to decrease the risk. The Extended Parallel Process Model (Witte, 1992) is a framework that outlines the cognitive processes an individual undergoes to make a decision about performing a particular protective behavior when confronted with a health threat (Figure 5).

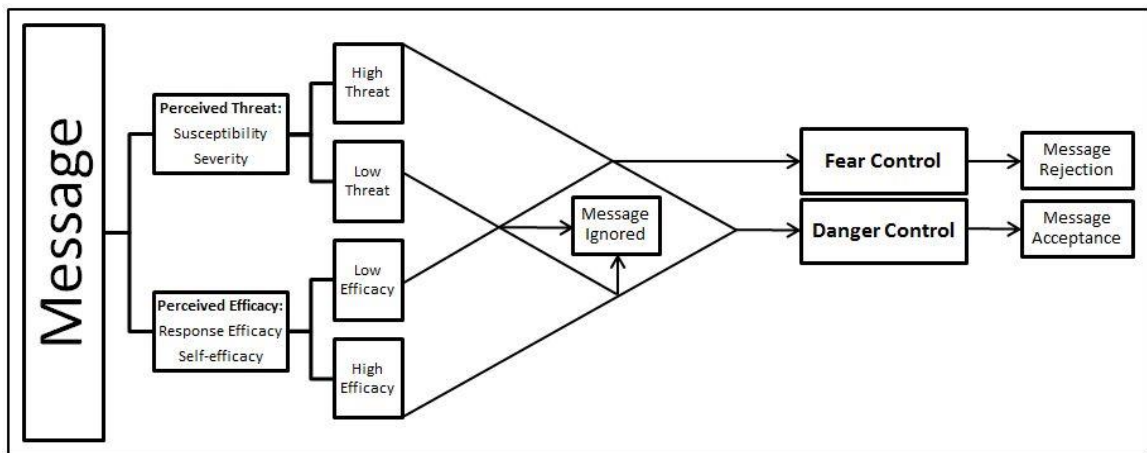


Figure 5. Interpretive diagram of Dr. Kim Witte’s Extended Parallel Process Model (Hyde, Sorensen, & Njororai, 2014).

If cancer is perceived as a serious enough threat to which someone feels vulnerable, the individual who is knowledgeable about cancer screenings would evaluate if she is capable of carrying out the recommended action (self-efficacy) and if that action will work to reduce the severity of the health threat (response efficacy) (Witte, 1992). If response efficacy of cancer screenings is diminished due to the effects of anecdotal

evidence, the individual may proceed with fear control processes rather than follow prevention guidelines. Individuals may employ such cognitive processes as denial, avoidance, or wishful thinking in order to minimize the threat through coping with the induced fear (Rippetoe & Rogers, 1987). The participants in this study made light of their use of wishful thinking, including those who had shared the previously described anecdotes, often making statements such as, “I want to think low” when asked about their beliefs regarding their personal risk of developing cancer in the future. Cancer fatalism and external locus of control may therefore play a significant role in the reduced uptake of cancer screenings that is seen in Hispanics across the state of Texas if stories of unfavorable screening outcomes have become widespread through dissemination into social narrative.

Limited Understanding of Numerical Concepts

Another variable that can skew an individual’s risk beliefs is limited health numeracy. As mentioned previously, all but two of the participants indicated that they had trouble understanding the numbers that healthcare providers use in the clinical setting. Some of the participants reported that their doctor does not provide a detailed explanation of what the numbers mean, simply a vague “Your blood pressure is good,” or “You are okay.” More than half of the questions on the NVS-S are numeracy related, the results from which also suggest that several of the respondents may have difficulty processing numerical information. Some participants’ limited health numeracy skills came to light when questions were asked that directly assessed their understanding of numerical concepts. The groups were asked to interpret four different kinds of number sets: one in which the numerator was the variable of comparison (2.3/1,000 vs.

6.8/1,000), another in which the denominator was different (1/426 vs. 1/104), one that required comparison between sets with different numerators *and* denominators (1/10 vs. 10/100), and a percentage comparison (50% vs. 70%), given specific scenarios (Table 4).

The participants seemed to fare better on simpler questions that did not require as much mental processing, such as numerator and percentage comparisons. When the denominator stays the same between two number sets (i.e. 2.3/1,000 vs. 6.8/1,000), all that is required is a simple look at the numerator to see which one is lesser or greater than the other. The same goes for comparing two percentages. However, number sets in which it is the denominator that changes (i.e. 1 in 426 vs. 1 in 104) or both the numerator and denominator are different (i.e. 1/10 vs. 10/100) requires an understanding of fractions and proportions, concepts that many people struggle with regardless of educational status (Reyna & Brainerd, 2007). In light of these findings, thought should be given to numerical representations people may or may not understand when preparing information for cancer prevention and guideline materials.

Insufficient Patient-Provider Communication

As mentioned in previously, many of the focus group respondents reported that their doctor does not provide clear explanations to their patients about vital signs or other health information. Those who reported a regular source of health care indicated having fewer difficulties than other participants with communicating in the clinical setting. Most of the participants, especially those who admitted to getting very nervous about conversing with their provider, reported that they needed a translator to interact successfully. Some of these individuals also stated that if a translator were unavailable that they would just try to understand their doctor to the best of their personal ability.

This is especially troublesome, as “poor communication is often cited as the main underlying and remediable factor behind medical errors, adverse events, and the readmissions that commonly occur after hospital discharge” (Kripalani et al., 2010, p. 6). Others reported leaving an office visit feeling that some of their problems or symptoms were not addressed and thus did not feel satisfied with the care that they received. Insufficient patient-provider communication, including a lack of available interpreters, could serve as a potential barrier for patients in establishing a relationship with their healthcare provider. The relationship between patient and provider is instrumental for patients to find a source of care they deem to be trustworthy, where they are likely to visit again in the future.

Concentrating on this relationship is where patient-centered medical homes (PCMH) will find their success. The PCMH is a model of health care that is based on collaborative efforts of the patient and her healthcare provider(s) and support staff, with the ultimate goal of helping the patient play a more active role in the development of their treatment/care plan (Zajac, 2014), to which effective communication plays a key role. Organizations such as the Joint Commission (Murphy-Knoll, 2007) and the Robert Wood Johnson Foundation (RWJF) (Berenson, Devers, & Burton, 2011) are proponents of the PCMH model. The RWJF particularly supports the idea of the “flipped visit” (Figure 6). During a traditional office visit, patients are subjected to the provider’s questions with little chance to express their feelings, concerns, or ask their own questions. These patients often leave the visit unsatisfied, as was reported among the focus group participants. The “flipped visit” involves patients entering their provider’s office with a

question and leaving with answers that empower them to take responsibility for their health (Goetz, 2013).

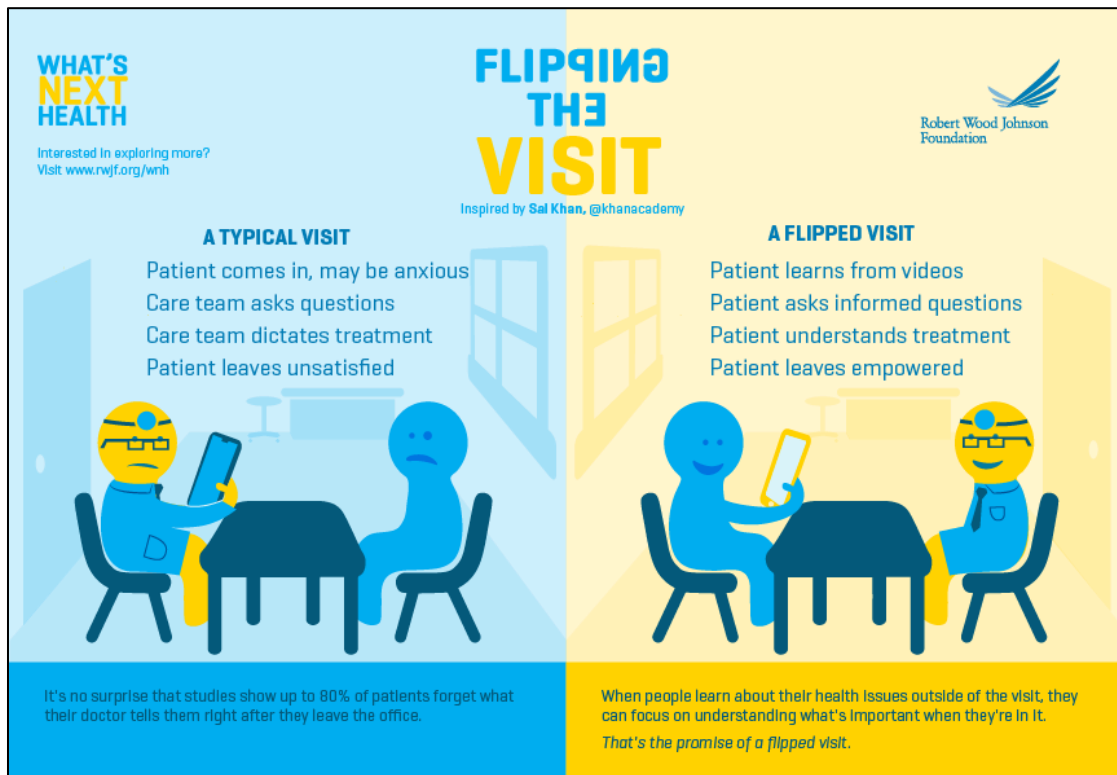


Figure 6. The benefits of a flipped visit.

When patients do not leave an office visit with the answers they need or want, they are more likely to turn to other sources of information. The majority of this study's participants reported using the Internet if they wanted to get information about health topics, including cancer. Health information that is available in English and Spanish on the Web is often of poor quality, incomplete, or unreliable, and requires a higher reading ability than what is seen in the general population (Berland et al., 2001). In a report commissioned by the California HealthCare Foundation (Appendix D), of all of the websites containing health information, 100% of English- and 86% of Spanish-language sites require individuals to read at a high school level or greater to be comprehensible (RAND, 2001). This is a troubling statistic, given that 78% of this study's population

sample had not completed high school. The commissioned report goes on further to explain that using English keyword searches about health topics gives Internet users a 20% chance of finding relevant information, while those who use Spanish search engines only have a 1 in 8 chance of receiving pertinent results. Information accessible to Spanish-speakers is also less likely to be as accurate or comprehensive as what is available in English (Berland et al.).

Such limited access to timely, comprehensive, and accurate information outside of an office visit lends support to the idea of providers and their practices becoming PCMHs. There patients can feel free to communicate with healthcare staff and educate themselves with information directly from a licensed professional rather than comb the Web for answers. The PCMH model also provides an opportunity for providers to advance health literacy on systemic and individual levels by adopting communication best practices, improving patient access to care, collaborating with patients and agreeing

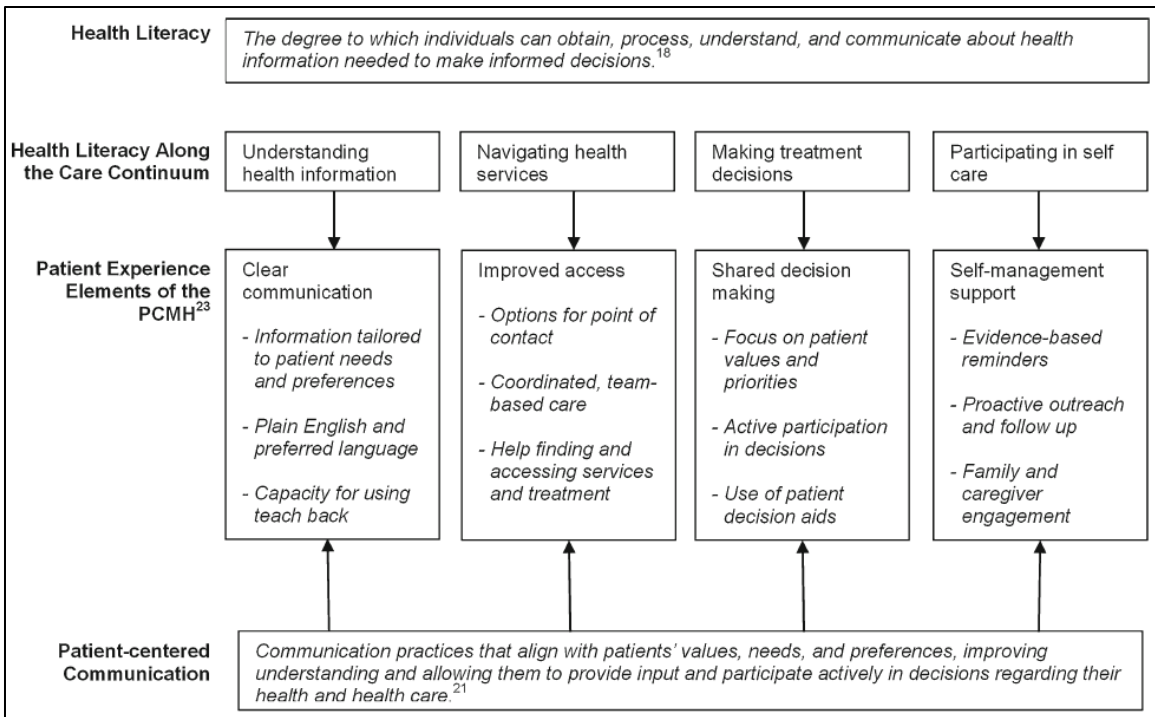


Figure 7. How adopting the PCMH model can advance health literacy in patients (Ridpath et al., 2011).

on a care plan, and enabling patients to better care for themselves (Figure 7) (Ridpath, Larson, & Greene, 2011).

Study Limitations

Due to convenience sampling and the nature of qualitative research, the conclusions drawn from this study may or may not be generalizable to the population of interest as a whole; however, the concepts that are revealed in the process are useful for the development of instruments that are able to generate generalizable information. As with any form of research, there are a number of limitations inherent in qualitative studies. First, it is difficult to confirm the results through replication of the study due to the fickle nature of self-reported and anecdotal data. Second, because of the characteristic interactivity of focus groups, the responses of the participants may have been influenced by the answers provided by their peers. Third, while many of the discussion questions and probes had been used in previous studies, there may have been some items that did not carry the same meaning for the respondents as they did for the researcher. The questions were translated into Spanish and back-translated into English again by nonparticipating members of the priority population to avoid any meanings being lost in translation; however, several things could have influenced responses, including the paralanguage – facial expressions, body language, and vocal tone and inflection – of the researcher. Also, the discussions primarily took place in English at the request of the participants, who were repeatedly encouraged by the research team to express themselves in their native language. Their desire to make use of their English skills could have potentially affected the intended meanings of their responses. To mitigate any cultural biases on the part of the researcher during analysis, the audio

recordings and transcripts were reviewed with the aid of a Hispanic undergraduate student with personal connection and experience with the target population.

The quantitative portion of this study was not free of limitations, either. The health literacy assessment (NVS-S) was designed to be administered orally, preferably by a nurse, on an individual basis. For the purpose of simultaneous administration of the assessment in a group setting, the questions from the NVS-S were given to the participants in a written format. Talking among the participants occurred, albeit briefly, while the NVS-S was being administered, which might have potentially skewed their results. Most importantly, the NVS-S, as discussed in the results, proved itself to be biased against Spanish-speakers. An improperly worded question, when translated, did not have the same meaning as the corresponding question on the NVS-E. Further studies should investigate whether or not other instruments against which the NVS-S was tested for reliability also share similar biases.

CHAPTER SIX: CONCLUSION

The underdeveloped cancer-specific knowledge domain and the marginal numeracy skills seen in this sample of the Hispanic population of Northeast Texas may impede adherence to cancer screening guidelines. The issue of limited health literacy is not only economically expensive, but it is taxing on individual health and the health of the patient-provider relationship. The inability to adequately communicate creates a frustrating experience for patients (Baker et al., 1996), as well as for healthcare professionals and support staff in their charge. Outside of the clinical environment, it is important that health professionals develop materials that are not only linguistically appropriate, but also developed with the target population's cultural beliefs – such as cancer fatalism – and health literacy levels in mind. 'Blanket' public health messages or information provided at a provider's office, clinic, or hospital may not be adequate to motivate individuals of this population to engage in cancer prevention. Therefore, addressing all of the components of health literacy via improved, targeted communication and education in both the clinical and public health arenas has the potential to benefit local Hispanics through their increased engagement in cancer prevention behavior and subsequently better health outcomes.

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APPENDIX A: Institutional Review Board Approval

The University of Texas at Tyler

Institutional Review Board

September 11, 2013

Dear Ms. Hyde,

Your request to conduct the study entitled: *Health Literacy and Cancer Prevention: A Qualitative Exploration of the Health Communication Needs of Hispanics Residing in Northeast Texas*, IRB #F2013-08 is approved by The University of Texas at Tyler Institutional Review Board under the terms of the UT Centralized IRB Review Reciprocity Agreement initiated by UT Health Science Center at Houston. This approval includes written informed consents for any interviews conducted. There must be assurance prior to participation that participants understand all procedures, risks, and that participation is strictly voluntary. In addition, ensure that any research assistants or co-investigators have completed human protection training, and have forwarded their certificates to the IRB office (G. Duke).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- This approval is for one year, as of the date of the approval letter
- Request for Continuing Review must be completed for projects extending past one year
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- **Any adverse event or unanticipated event MUST be reported promptly to academic administration (chair/dean), and to the IRB.**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,



Gloria Duke, PhD, RN

Chair, UT Tyler IRB

Appendix B: Newest Vital Sign - English



Dear Healthcare Professional:

Thank you for your interest in the Newest Vital Sign (NVS), the first tool available to assess health literacy in English and Spanish.

Research shows that patients with low health literacy are less likely to comply with prescribed treatment and medical instructions from their physician. Identifying patients who are at risk for low health literacy allows physicians to apply specific clear health communication techniques that may enhance understanding. The Newest Vital Sign is a simple and fast way to identify those patients. The tool, which tests literacy skills for both numbers and words*, has been validated against a previously validated measure of health literacy (the TOFHLA), and has been shown to take approximately three minutes to administer.

In addition to the NVS tool, we are also including information to help enhance patient-provider communication. In this folder you will find the following materials:

- NVS Tool (nutrition label and scoring sheet tear-off pad, both two-sided in English/Spanish)
- NVS Implementation Guide
- *Ask Me 3* (fact sheet on free educational materials from the non-profit Partnership for Clear Health Communication)
- *Help Your Patients Succeed* (tips for improving communication with your patients)
- *Why Does An Ice Cream Label Work . . .* (fact sheet explaining the design of the NVS)

The Newest Vital Sign is Pfizer Inc's most recent contribution to the health literacy movement. For more than nine years, Pfizer has been committed to raising awareness of developing solutions for low health literacy. The overall goal of our Clear Health Communication Initiative is to positively impact the health care system by enhancing patient-provider communication to increase compliance and improve patient health outcomes.

The Newest Vital Sign and companion materials are available to medical and public health providers at no cost. To learn more about our efforts to improve health literacy, please visit www.pfizerhealthliteracy.com.

Sincerely,

Richard C. Hubbard, M.D.
Senior Director, External Medical Affairs
Pfizer Inc

*Literacy is defined as the understanding and application of words (prose), numbers (numeracy), and forms, etc. (document).



Implementation Guide for the Newest Vital Sign

Health literacy— the ability to read, understand and act upon health information — is now known to be vital to good patient care and positive health outcomes. According to the Institute of Medicine’s groundbreaking report on health literacy, nearly half of all American adults — 90 million people — have difficulty understanding and using health information. When patients lack the ability to understand and act upon medical information, it can put their health at risk.

The Newest Vital Sign is a new tool designed to quickly and simply assess a patient’s health literacy skills. It can be administered in only 3 minutes and is available in English and Spanish. The patient is given a specially designed ice cream nutrition label to review and is asked a series of questions about it. Based on the number of correct answers, health care providers can assess the patient’s health literacy level and adjust the way they communicate to ensure patient understanding.

There are many ways to integrate the Newest Vital Sign (NVS) into a private practice or clinic setting to improve communication with patients. Improved communication can help increase your patients’ ability to understand and act upon the information you provide; ultimately improving patient satisfaction and health outcomes.

How To Use the Newest Vital Sign

1. **Who and when to administer the Newest Vital Sign.**
 - A nurse (or other trained clinic staff) is the preferred administrator of the Newest Vital Sign.
 - Administer at the same time that other vital signs are being taken.
2. **Ask the patient to participate.**

A useful way to ask the patient is an explanation similar to this:

“We are asking our patients to help us learn how well patients can understand the medical information that doctors give them. Would you be willing to help us by looking at some health information and then answering a few questions about that information? Your answers will help our doctors learn how to provide medical information in ways that patients will understand. It will only take about 3 minutes.”
3. **Hand the nutrition label to the patient.**

The patient can and should retain the nutrition label throughout administration of the Newest Vital Sign. The patient can refer to the label as often as desired.

More...

Appendix B Continued

4. **Start Asking the 6 questions, one by one, giving the patient as much time as needed to refer to the nutrition label to answer the questions.**
 - There is no maximum time allowed to answer the questions. The average time needed to complete all 6 questions is about 3 minutes. However, if a patient is still struggling with the first or second question after 2 or 3 minutes, the likelihood is that the patient has limited literacy and you can stop the assessment.
 - Ask the questions in sequence. Continue even if the patient gets the first few questions wrong. However, if question 5 is answered incorrectly, do not ask question 6.
 - You can stop asking questions if a patient gets the first four correct. With four correct responses, the patient almost certainly has adequate literacy.
 - Do not prompt patients who are unable to answer a question. Prompting may jeopardize the accuracy of the test. Just say, "Well, then let's go on to the next question."
 - Do not show the score sheet to patients. If they ask to see it, tell them that "I can't show it to you because it contains the answers, and showing you the answers spoils the whole point of asking you the questions."
 - Do not tell patients if they have answered correctly or incorrectly. If patients ask, say something like: "I can't show you the answers till you are finished, but for now you are doing fine. Now let's go on to the next question."
5. **Score by giving 1 point for each correct answer (maximum 6 points).**
 - Score of 0-1 suggests high likelihood (50% or more) of limited literacy.
 - Score of 2-3 indicates the possibility of limited literacy.
 - Score of 4-6 almost always indicates adequate literacy.

Record the NVS score in the patient's medical record, preferably near other vital sign measures.

Best Practices for Implementation: Summary

- A nurse (or other trained clinic staff) is the preferred administrator of the Newest Vital Sign.
- Administer the NVS at the same time that the patient's other vital signs are being taken.
- Record the NVS score in the patient's chart, preferably near other vital sign measures.
- Tailor communication to ensure patient understanding.

Appendix B Continued



Why Does an Ice Cream Label Work as a Predictor of the Ability To Understand Medical Instructions?

A patient's ability to read and analyze any kind of nutrition label requires the same analytical and conceptual skills that are needed to understand and follow a provider's medical instructions. The skills, which are known as *health literacy*, are defined as the understanding and application of words (prose), numbers (numeracy), and forms (documents).

The use of an ice cream label is especially relevant as recent research in the *American Journal of Preventive Medicine* (November 2006) has shown that poor comprehension of food labels correlated highly with low-level literacy and numeracy skills. However, the study found that even patients with better reading skills could have difficulties interpreting the labels.

Whether reading a food label or following medical instructions, patients need to:

- remember numbers and make mathematical calculations.
- identify and be mindful of different ingredients that could be potentially harmful to them.
- make decisions about their actions based on the given information.

PROSE LITERACY:

Clinical example: The patient has scheduled some blood tests and is instructed in writing to fast the night before the tests. The skill needed to follow this instruction is **Prose Literacy**.

Ice cream label example: The patient needs this skill to read the label and determine if he can eat the ice cream if he is allergic to peanuts.

NUMERACY:

Clinical example: A patient is given a prescription for a new medication that needs to be taken at a certain dosage twice a day. The skill needed to take the medication properly is **Numeracy**.

Ice cream label example: The patient needs this same skill to calculate how many calories are in a serving of ice cream.

DOCUMENT LITERACY:

Clinical example: The patient is told to buy a glucose meter and use it 30 minutes before each meal and before going to bed. If the number is higher than 200, he should call the office. The skill needed to follow this instruction is **Document Literacy**.

Ice cream label example: The patient needs this skill to identify the amount of saturated fat in a serving of ice cream and how it will affect his daily diet if he doesn't eat it.



Appendix B Continued

Nutrition Facts

Serving Size ½ cup
 Servings per container 4

Amount per serving
 Calories 250 Fat Cal 120

%DV

Total Fat 13g 20%

Sat Fat 9g 40%

Cholesterol 28mg 12%

Sodium 55mg 2%

Total Carbohydrate 30g 12%

Dietary Fiber 2g

Sugars 23g

Protein 4g 8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

Appendix B Continued



Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT:

This information is on the back of a container of a point of ice cream.

1. If you eat the entire container, how many calories will you eat?
Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl?"

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
Answer: 33 is the only correct answer

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
Answer: 10% is the only correct answer

READ TO SUBJECT:

Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?
Answer: Because it has peanut oil.

ANSWER CORRECT?

yes	no

Number of correct answers:

Interpretation

Score of 0-1 suggests high likelihood (50% or more) of limited literacy.
 Score of 2-3 indicates the possibility of limited literacy.
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APPENDIX C: Newest Vital Sign – Spanish



Dear Healthcare Professional:

Thank you for your interest in the Newest Vital Sign (NVS), the first tool available to assess health literacy in English and Spanish.

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More...

Appendix C Continued

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Ice cream label example: The patient needs this skill to identify the amount of saturated fat in a serving of ice cream and how it will affect his daily diet if he doesn't eat it.



Appendix C Continued

Información Nutricional

Tamaño de la Porción ½ taza
 Porciones por envase 4

Cantidad por porción

Calorías 250 Cal Grasa 120

%DV

Grasa Total 13g 20%

Grasas Sat 9g 40%

Colesterol 28mg 12%

Sodio 55mg 2%

Total Carbohidratos 30g 12%

Fibras Dietéticas 2g

Azúcares 23g

Proteína 4g 8%

*Porcentaje de Valores Diarios (DV) se basan en una dieta de 2.000 calorías. Sus valores diarios pueden ser mayores o menores dependiendo de las calorías que usted necesite.

Ingredientes: Crema, Leche Descremada, Azúcar Líquida, Agua, Yemas de Huevo, Azúcar Morena, Aceite de Cacahuete (Maní), Azúcar, Mantequilla, Sal, Carragenina, Extracto de Vainilla.



Hoja de Resultados para el Nuevo Signo Vital Preguntas y Respuestas

LEA AL PACIENTE:

Esta información aparece en el reverso de un envase de helado.

1. Si usted se come todo el helado en el envase, ¿cuántas calorías habrá consumido?
Respuesta: 1,000

2. Si a usted le recomendaron consumir 60 gramos de carbohidratos en la merienda, ¿cuánto helado puede comer?
Respuesta: Cualquiera de: Hasta un máximo de una taza, una taza, la mitad del envase. Nota: si el paciente responde "dos porciones," pregunte "¿Qué cantidad de helado sería si lo sirviera en un tazón?"

3. Su médico le aconseja reducir la cantidad de grasas saturadas en su dieta. Usted normalmente consume 42 gramos de grasa saturada al día, que incluye una porción de helado. Si deja de comer helado, ¿cuántos gramos de grasa saturada consumiría cada día?
Respuesta: 33 gramos

4. Si usted normalmente come 2500 calorías habrá consumido si se come una porción?
Respuesta: 10%

LEA AL PACIENTE:

Imagine que es alérgico/a a las siguientes sustancias: Penicilina, cacahuete (maní), guantes de latex y picaduras de abeja.

5. ¿Puede comer este helado con seguridad?
Respuesta: No

6. (Solamente si responde "no" a pregunta 5): ¿Por qué no?
Respuesta: Porque tiene aceite de cacahuete (maní)

¿RESPUESTA CORRECTA?

sí	no

Número de respuestas correctas:

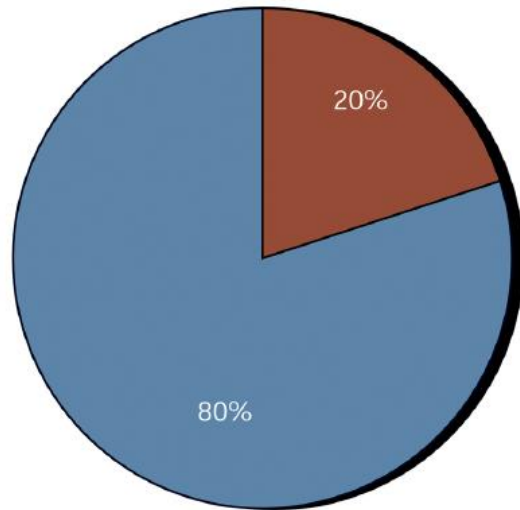
Interpretación

Resultado de 0-1 sugiere alta probabilidad (50% o más) de alfabetización limitada.
Resultado de 2-3 indica la posibilidad de alfabetización limitada. Resultado de 4-6 casi siempre indica alfabetización adecuada.



APPENDIX D: *Proceed with Caution* Chart Pack

How Helpful are English-Language Search Engines?

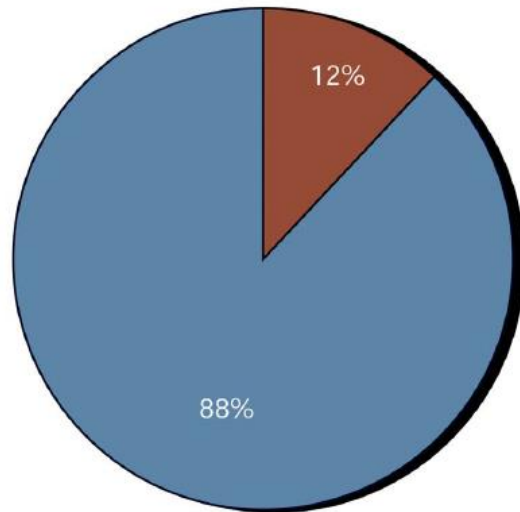


The majority of English-language links provided by search engines do not lead to relevant content.

- Percentage of links leading to relevant health information
- Percentage of links not leading to relevant health information

Source: Berland, G., et al., "Proceed with Caution: A Report on the Quality of Health Information on the Internet," California HealthCare Foundation and RAND Health, May 2001.

How Helpful are Spanish-Language Search Engines?

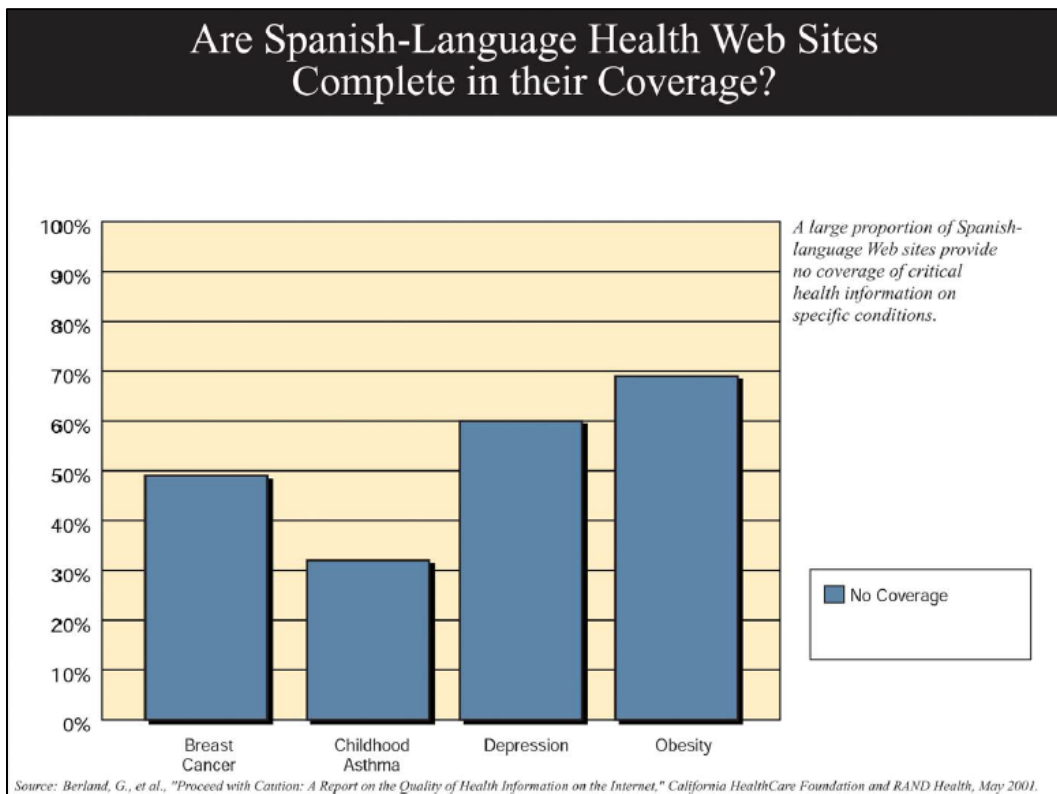
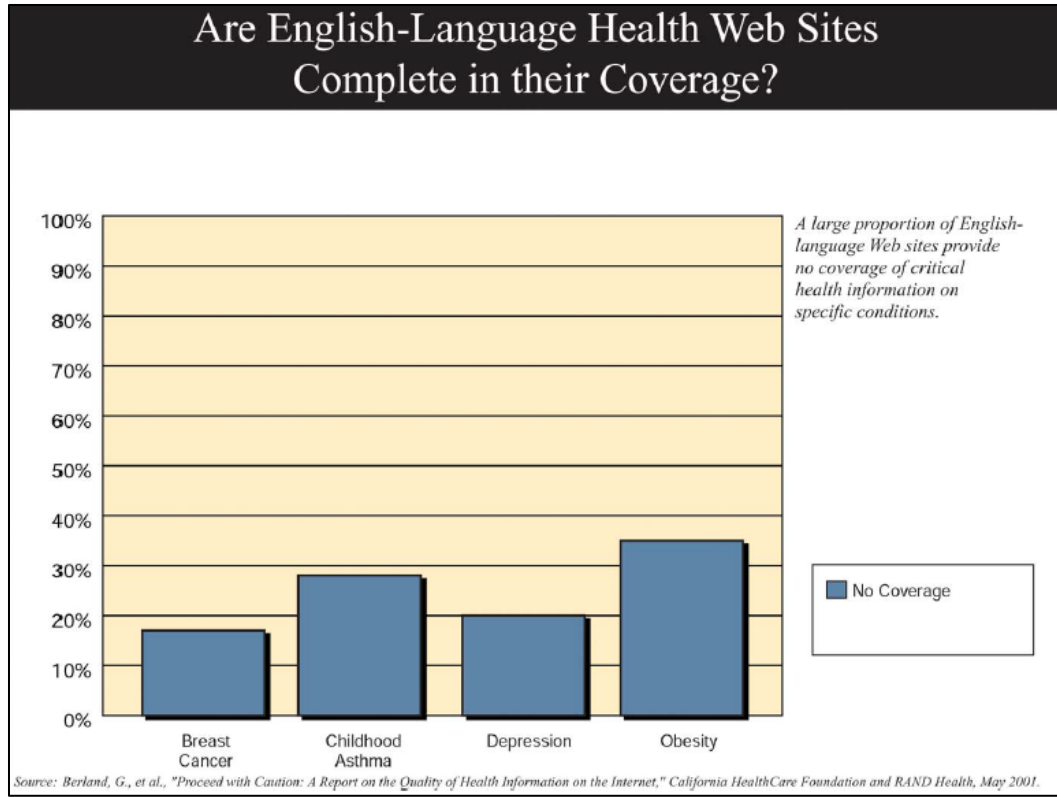


The majority of Spanish-language links provided by search engines do not lead to relevant content.

- Percentage of links leading to relevant health information
- Percentage of links not leading to relevant health information

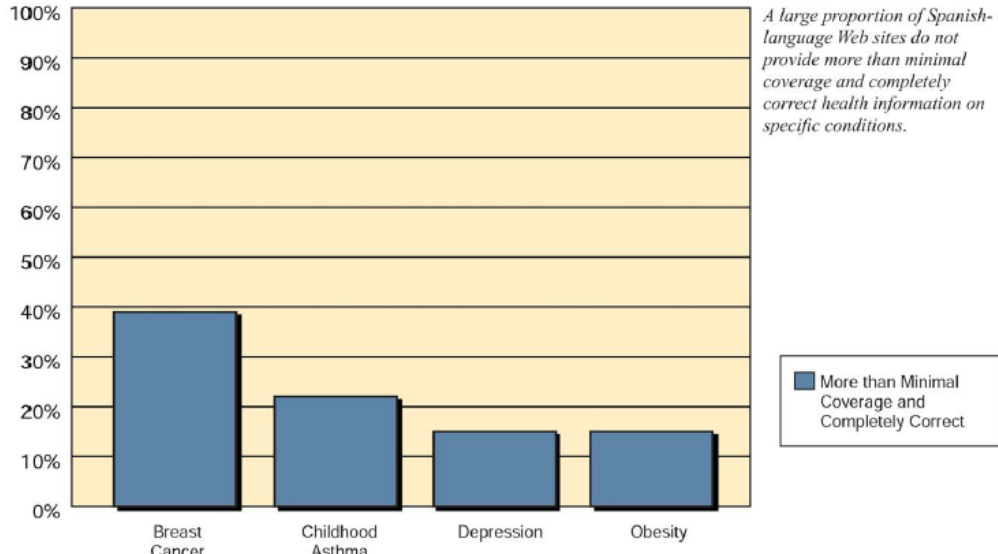
Source: Berland, G., et al., "Proceed with Caution: A Report on the Quality of Health Information on the Internet," California HealthCare Foundation and RAND Health, May 2001.

Appendix D Continued



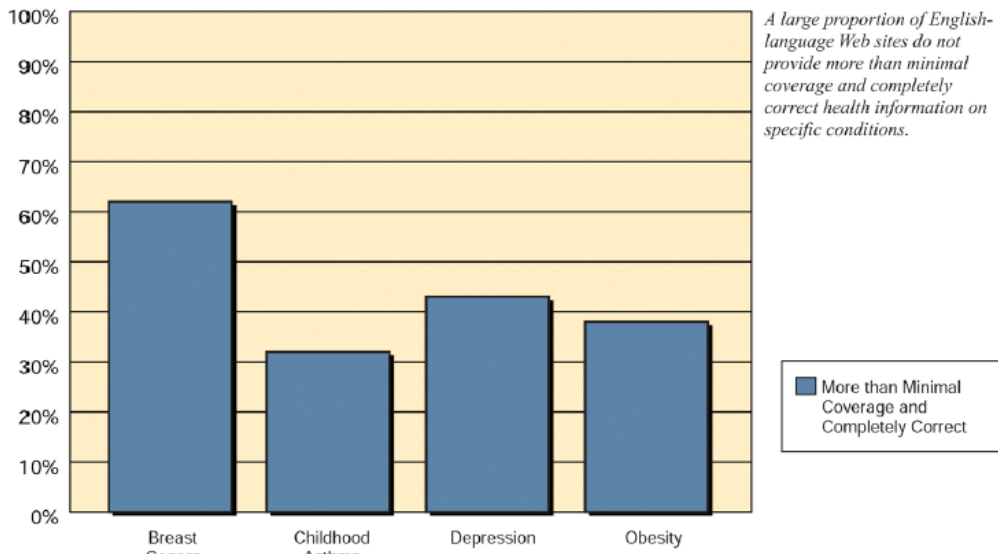
Appendix D Continued

Are Spanish-Language Health Web Sites Complete and Correct in their Coverage?



Source: Berland, G., et al., "Proceed with Caution: The Quality of Health Information on the Internet," California HealthCare Foundation and RAND Health, January 15, 2001.

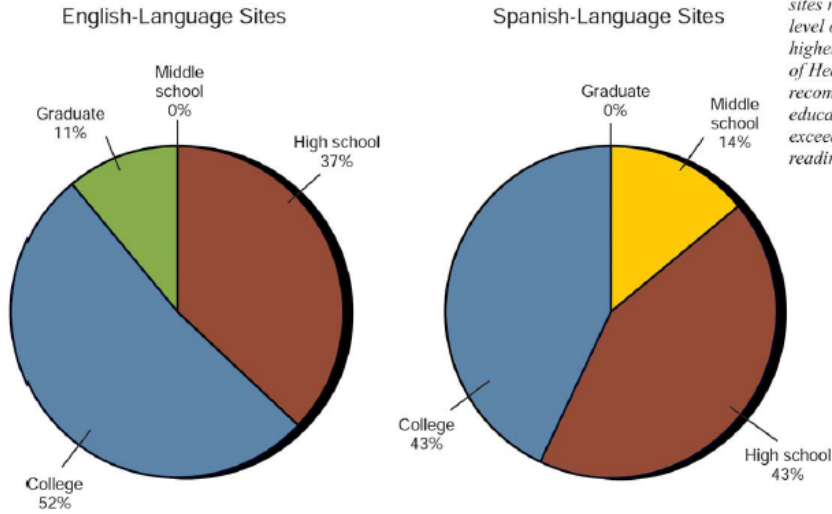
Are English-Language Health Web Sites Complete and Correct in their Coverage?



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Appendix D Continued

What is the Readability of Health Information on the Internet?



Research shows that 100% of English-language sites and 86% of Spanish-language sites require a high-school level of reading ability or higher. The U.S. Department of Health and Human Services recommends that patient education materials not exceed a 6th grade reading level.

Source: Berland, G., et al., "Proceed with Caution: A Report on the Quality of Health Information on the Internet," California HealthCare Foundation and RAND Health, May 2001.