Breaking Down Barriers to Health Information: An Analysis of the Relationship between Health Literacy, Health Equity, and Patient-Provider Communication

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Abstract
This thesis examines the relationship between health literacy and patient-provider communication and how improvements in both help mitigate health disparities. A literature review was completed to examine (1) health literacy concepts, (2) health literacy disparities among minorities, individuals with low socioeconomic status (SES), the elderly, and those with communication disorders, and (3) health literacy interventions that focus on patient-provider communication. Improving the communication quality in health care may help address the overall low health literacy skills of people in the United States. Some approaches to improve patient-provider communication include using plain language, multimodal communication, a communication book, and the teach back method. As experts in communication, speech-language pathologists are in a unique position to help health care providers improve health literacy and communication quality. Improving communication quality is especially crucial considering the negative health outcomes that are associated with low health literacy.

Keywords: communication disorders, health literacy, patient-provider communication, health disparities, health outcomes
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A typical visit to the doctor’s office begins with checking-in with the receptionist and filling out what seems to be a copious amount of paperwork. The first form that is usually given is a medical history form in which questions about the patient’s general health, medical conditions, and medications are asked. Next, the patient must provide their health insurance information and read through and sign a privacy form. After filling out this paperwork, the physician examines the patient and discusses their health, medical conditions, test results, medications, and recommendations. This process is similar when interacting with other allied health professionals, such as physical therapists, occupational therapists, and speech-language pathologists (SLPs). Unique to these rehabilitation professionals is the opportunity to provide more long-term patient education about the patient’s diagnosis, treatment, and goals (Levasseuur & Carrier, 2010). In addition, these professionals provide detailed clinical reports for their clients regarding assessment results and treatment goals. Understanding these reports is an important prerequisite to being an active participant in one’s therapy. All the activities mentioned, from filling out paperwork and receiving patient education to understanding written reports and interacting with the health care professional, require that the patient has adequate health literacy.

**Defining Health Literacy and Its Impact on Health Outcomes**

**Definition of Health Literacy**

According to Ratzan and Parker (2000), health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. vi). This definition has been adopted by many organizations, including the Institute of Medicine (IOM), the National Library of
Medicine, and Healthy People, the nationwide health promotion and disease prevention agenda organized by the U.S. Department of Health and Human Services. As a whole, health literacy comprises of the skills of reading, writing, basic numeracy, speaking, and auditory comprehension as it is related to health information (IOM, 2004). The ability to obtain, process, and understand health information is important when interacting with providers in the health care system. Adequate health literacy is needed when discussing health information with health care providers, reading health information, interpreting test results, making personal or familial health care decisions, calculating timing or dosage of medicine, and voting on health care issues (IOM, 2004).

Don Nutbeam (2008), a professor of public health at the University of Sydney, posits an alternate to Ratzan and Parker’s (2000) widely used definition of health literacy, which has been adopted by the World Health Organization (WHO). According to Nutbeam (2008), health literacy comprises of “the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” (p. 2074). In his definition, Nutbeam (2008) emphasizes cognitive and social skills because he argues that health literacy goes beyond reading and writing abilities. Furthermore, Nutbeam (2008) asserts that health literacy is a personal asset to be built. In this regard, health literacy focuses on the achievement of a level of knowledge, personal skills, and confidence that allows an individual to improve personal and community health. In other words, Nutbeam (2008) views the role of health literacy as enabling and empowering individuals to exert greater control over their health and determinants of health. Consistent with this view, increased levels of literacy have been found to be associated with higher levels of empowerment, better decision-making skills, and a more active role in treatment (Visscher et al., 2018).
Nutbeam (2000) also devised a three-level model of health literacy that elaborates on his definition. It is helpful to think of the three health literacy levels as increasing from a micro to a macro level approach to health literacy. The first level is functional health literacy which is based on the communication of factual information and how to use the health care system. The goal of this level is to improve knowledge of health risks and health services and compliance with health care recommendations. Examples of functional health literacy include distributing pamphlets and informing patients about their condition and the available services (Hester & Stevens-Ratchford, 2009). The second level is communicative/interactive health literacy. This level focuses on the development of personal skills in a supportive environment so that individuals are better able to act independently on their health care. Communicative/interactive health literacy can involve making appointments, interacting with the health care provider, and understanding assessment findings (Hester & Stevens-Ratchford, 2009). The third level is critical health literacy which reflects the cognitive and social skills needed to support effective social, individual, and political action. This tier has a more macro-level approach to health literacy since it focuses on achieving policy and organizational change as it relates to personal and public health. In this thesis, the focus will be on functional and communicative/interactive health literacy since it aligns more closely with the goal of improving health literacy through better-quality patient-provider communication.

Nutbeam (2008) argues that Ratzan and Parker’s (2000) competing definition of health literacy follows a clinical risk model in which health literacy focuses on a set of individual capacities that are intended to lead to compliance with recommended clinical care. Instead, Nutbeam (2008) asserts that the goal of health literacy is more than compliance and the transmission of health information; the goal of health literacy is to empower individuals to be
active participants in their health care. Nutbeam (2008) makes a strong argument that the ultimate goal of health literacy should be to empower people in their health care. However, the capacity to understand health information and compliance with recommended treatment are still needed to ensure positive health outcomes. Thus, the concept of health literacy should be viewed as an intersection between the definitions that Nutbeam (2008) and Ratzan and Parker (2000) have established. By combining these two definitions, the concept of health literacy encompasses the reading, writing, speaking, listening, and social skills needed to access and understand health information in order to confidently and actively make appropriate health decisions. These skills will ultimately lead to empowerment and compliance among health care recipients so that better health is attained.

Assessments of Health Literacy

To measure people’s level of health literacy, different types of assessments have been created. Assessments most frequently used by researchers and are recommended for physicians to utilize include the Test of Functional Health Literacy in Adults (TOFLHA) (Parker, Baker, Williams, & Nurss, 1995), the Short Test of Functional Health Literacy (s-TOFLHA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991). The TOFLHA consists of a 17-item test of numerical ability and a 50-item test of reading comprehension (IOM, 2004). It draws on materials commonly used in medical settings at the time the test was developed. For example, the reading passages that were selected to assess reading comprehension came from the instructions used to prepare for an upper gastrointestinal series, the patient “Rights and Responsibilities” section of a Medicaid application, and a standard informed consent form (IOM, 2004). The other section of the TOFLHA that focuses on numeracy assesses the person’s ability to understand monitoring
blood glucose, keep a clinic appointment, obtain financial assistance, and understand directions for taking medication using a real pill bottle (IOM, 2004). Since the TOFLHA takes up to 22 minutes to administer, the s-TOFLHA, an abbreviated version that takes at most 12 minutes to administer, was developed.

Unlike the TOFLHA and the s-TOFLHA, the REALM is a medical-word recognition and pronunciation test that screens the reading ability of adults in medical settings. Adults are instructed to read from a list of 66 common medical terms. These three assessments, while to some degree useful, have limitations. According to the IOM (2004), these tests do not assess the full complexity of health literacy since they focus solely on print literacy and health-related terms. By concentrating only on print literacy, speaking and listening skills are not evaluated even though they fall on the spectrum of health literacy. Furthermore, the REALM does not test numeracy skills and is only available in English.

In light of these limitations, researchers have advocated for more comprehensive and multidimensional assessments that go beyond word recognition, text comprehension, and numeracy skills. Batterham, Hawkins, Collins, Buchbinder, and Osborne (2016) suggest the use of the Health Literacy Questionnaire (HLQ), which is based on Nutbeam’s definition of health literacy. This questionnaire identifies nine separate health literacy scales that are used to identify an individual’s specific strengths and limitations in health literacy (WHO, 2014). The nine areas of health literacy it examines are the following: (1) feeling understood and supported by healthcare providers, (2) having sufficient information to manage my health, (3) actively managing my health, (4) social support for health, (5) appraisal of health information, (6) ability to actively engage with healthcare providers, (7) navigating the healthcare system (8) ability to find good health information, and (9) understanding health information well enough to know
what to do (Debussche et al., 2018). The items in the first five areas are scored on a 4-point Likert scale (strongly disagree, disagree, agree, strongly disagree), and the items in the last four areas are scored on a 5-point Likert scale that focuses on difficulty (cannot do or always difficult, usually difficult, sometimes difficult, usually easy, always easy) (Debussche et al., 2018). The advantages of the HLQ are that it is thorough, reliable, and available in several languages (Debussche et al., 2018; WHO, 2014).

Another assessment that is considered more comprehensive than the TOFLHA, s-TOFLHA, and the REALM but is used less frequently is the Health Activities Literacy Scale (HALS). The HALS includes 191 health-related literacy tasks that cover reading and using prose, reading and using documents, and use of quantitative skills (Educational Testing Service [ETS], 2004). These tasks are designed to be representative of the texts and processes associated with five health activities: health promotion, health protection, disease prevention, health care and maintenance, and systems navigation (ETS, 2004). The tasks connected with each text also vary in difficulty, ranging from relatively basic, moderately difficult, to quite hard (ETS, 2004). An example of a text included in the HALS is a pediatric dosage chart. Tasks associated with this chart include underlining the sentence that indicates how often the medication should be administered and determining how much of the medicine is recommended for a child who is 10 years old and weighs 50 pounds. Although the HALS is comprehensive, Nutbeam (2008) acknowledges that an abbreviated version is needed for it to be used regularly.

**The Impact of Health Literacy on Health Outcomes**

Without adequate health literacy, navigating the health care system and taking charge of one’s health becomes a challenge. It may also have an adverse impact on one’s health. Numerous studies have actually shown that low health literacy is associated with negative health outcomes.
In a report about health literacy, the Ad Hoc Committee on Health Literacy for the Council of Scientific Affairs (1999) found that those with low health literacy report worse health status (poorer physical and psychological health) and have less understanding about their medical condition and treatment than those with better literacy skills. The latter is especially troubling when it comes to the management of chronic conditions, such as asthma and diabetes. Since those with poor health literacy are less likely to understand and remember medical recommendations, it makes it more difficult to manage chronic conditions. The Ad Hoc Committee (1999) also indicated that patients with low health literacy have higher health care costs. Health issues that arise from poor management of health conditions and higher rates of hospitalizations may result in increased health care costs among individuals with low health literacy (Ad Hoc Committee, 1999; Kutner, Greenberg, Jin, Paulsen, 2006).

In addition to worse health outcomes, poor understanding of medical conditions and treatments, poor management of chronic conditions, and increased health care costs, low health literacy has been found to be an independent risk factor for hospital admissions (Baker et al., 2002). Specifically, those with inadequate and marginal health literacy were at a higher risk for hospital admission than individuals with adequate health literacy. This study used the s-TOFLHA to measure health literacy, which is scored on a scale of 0 to 100. Scores falling in the 0 and 55 range are in the inadequate health literacy level, and scores in the range of 56 to 66 fall in the marginal health literacy level. In the adequate health literacy level, scores range from 67 to 100 (Baker et al., 2002). Participants with inadequate health literacy often misread materials with basic information, including prescription bottles and appointment slips (Baker et al., 2002). In contrast, participants with adequate health literacy were able to complete most of the reading tasks required in a health care setting (Baker et al., 2002). In an updated systematic review about
the relationship between low health literacy and health outcomes, researchers discovered that low health literacy was consistently associated with more hospitalizations, greater use of emergency care, and decreased use of mammography screenings and influenza immunizations (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Berkman et al. (2011) also found that low health literacy was correlated with decreased ability in taking medications appropriately and interpreting labels and health messages.

Low health literacy has also been shown to be associated with negative health outcomes in older adults (Wolf, Gazmarian, & Baker, 2005; Berkman et al., 2011). Specifically, Wolf et al. (2005) found that older adults with inadequate health literacy report significantly poorer physical and mental health functioning and greater limitations in routine activities (Wolf et al., 2005). In another study, Berkman et al. (2011) discovered that older adults with low health literacy had poorer overall health status and higher mortality rates. These findings show that health care providers must especially consider the health literacy needs of older adults.

**Disparities in Health Literacy**

**Description of the 2003 National Assessment of Adult Literacy**

The 2003 National Assessment of Adult Literacy (NAAL) was conducted to assess adult English literacy in the U.S. The NAAL is currently the most comprehensive measure of adult literacy in the U.S. and is widely cited in research (National Center for Education Statistics [NCES], n.d.). The NAAL was administered to more than 19,000 adults ages 16 years or older who were living in households and prisons (Kutner et al., 2006). The 2003 NAAL is different from other assessments of adult literacy in that it is the first large-scale national assessment in the U.S. that included a health literacy component (NCES, n.d.). Health literacy was measured directly through tasks that were drawn from actual health-related texts and documents, such as
insurance and preventative care information and medication directions. In addition to including information about adult literacy, the NAAL also provided information about related demographic characteristics that researchers, practitioners, and policymakers are concerned about (NCES, n.d.). Demographic characteristics are important to examine because various social factors, such as native language, socioeconomic status (SES), gender, race, and ethnicity may impact health literacy. (IOM, 2004).

On the NAAL, each health task that was used to assess health literacy was designed to fit one of three scales: prose literacy scale, document literacy scale, and quantitative scale. The prose literacy scale measured the knowledge and skills that are needed for searching, comprehending, and using information from texts that are organized in sentences or paragraphs (Kutner et al., 2006). An example of a prose task is understanding health-related brochures and instructional material. The document literacy scale is like the prose literacy scale, except that it involves noncontinuous texts in various formats. Noncontinuous texts do not have a continuous organization, and examples are lists, tables, graphs, diagrams, and schedules (UNESCO Institute of Statistics, n.d.). Examples of document tasks are filling out information on a form and understanding drug labels. Different from the previous scales is the quantitative scale which measured the knowledge and skills required for identifying and performing computations using numbers found in printed materials (Kutner et al., 2006). These health literacy scales and the health literacy tasks associated with them focus on print literacy and reflect Ratzan and Parker’s (2000) narrower, clinical risk-focused definition of health literacy. The focus on print literacy is a limitation of the 2003 NAAL because health literacy also involves listening and speaking skills, not just reading and writing abilities.
The health tasks included in the NAAL are related to three domains of health and health care information and services: clinical, prevention, and navigation of the health system (Kutner et al., 2006). The clinical domain includes activities associated with patient-provider interaction, diagnosis and treatment of illness, and medication (Kutner et al., 2006). Examples of activities in the clinical domain are filling out a patient information form, understanding dosing instruction for medication, and following a health care provider’s recommendation for a diagnostic test. On the other hand, the prevention domain involves activities related to preventing disease and engaging in self-care and self-management of illness (Kutner et al., 2006). Examples are following guidelines for preventative health services, identifying signs and symptoms of health problems, and understanding how eating and exercise habits decrease risks for developing serious illness. Lastly, the domain regarding the navigation of the health care system covers the activities related to understanding how the health care system works. The activities in this domain include the understanding of what a health insurance provider will and will not cover, determining eligibility for public insurance or assistance programs, and being able to give informed consent for a health care service.

The results of the NAAL were reported using four literacy levels: below basic, basic, intermediate, and proficient. From below basic to proficient, these levels move from the least demanding to the most advanced literacy skills. The below basic level refers to no more than the most basic and concrete literacy skills, such as locating easily identifiable information in short prose texts and following instructions in basic documents (Kutner et al., 2006). Adults in the below basic level range from being nonliterate in English to having the abilities mentioned previously. Following this degree of health literacy is the basic level which comprises of the abilities that are needed to perform everyday literacy activities, such as reading and
understanding information in short, commonplace prose texts and basic documents (Kutner et al., 2006). Next, the intermediate level encompasses the skills related to performing moderately challenging literacy activities, such as reading and understanding less commonplace prose texts and locating information in complex documents. At the very top is the proficient level which includes the necessary skills needed to perform more complex and challenging literacy activities, such as reading and synthesizing complicated and abstract information in prose and document texts.

**Results of the 2003 NAAL and Group Differences in Health Literacy**

The 2003 NAAL found that most adults (53%) had intermediate health literacy (Kutner et al., 2006). At the two ends of the spectrum, 12% of the respondents had proficient health literacy, while 14% had below basic health literacy (Kutner et al., 2006). Above the below basic level, 22% of the participants had basic health literacy (Kutner et al., 2006). These findings show that over a third of the respondents had limited health literacy (basic or below basic health literacy). The results from the NAAL also indicate clear disparities in health literacy among different groups, characterized by gender, race and ethnicity, first language, age, and socioeconomic status (income and educational attainment). This thesis will focus on the last four demographics since these are considered the main factors that influence health literacy (Stormacq, Van den Broucke, Wosinski, 2018; Paasche-Orlow, Parker, Gazmarian, Nielsen-Bohlman, Rudd, 2004).

**Race and Health Literacy.** The NAAL categorized the participants into six racial groups: White, Black, Hispanic, Asian/Pacific Islander, American Indian/Alaskan Native, and Multiracial. The results from the NAAL found that White and Asian/Pacific Islander adults had the highest average health literacy (Kutner et al., 2006). In comparison, Hispanic adults had the
lowest average health literacy skills (Kutner et al., 2006). Adults categorized as Multiracial, American Indian/Alaskan Native, and Black had health literacy scores in the middle, with Multiracial adults scoring below the Asian/Pacific Islander respondents, and Black adults scoring above the Hispanic respondents (Kutner et al., 2006). American Indian/Alaskan Native adults scored below the Multiracial respondents and above the Black participants.

Researchers re-analyzing the results from the 2003 NAAL found that African Americans and foreign-born and native-born Hispanics/Latinos had significantly lower health literacy scores than the scores of Whites (Rikard, Thompson, McKinney, Beauchamp, 2016). In addition, Asian/Pacific Islanders, Native Americans, and Multiracial respondents were found to have lower health literacy compared to Whites (Rikard et al., 2016). Even with the same educational attainment, income, gender, and age, results showed that racial minorities had consistently lower health literacy than white respondents. This finding is significant in that it suggests that race is a considerable social determinant of health literacy.

The research literature also substantiates that Black patients are especially vulnerable to having low health literacy. The systematic review conducted by Paasche-Orlow et al. (2004) found that the rate of Black participants was significantly associated with the rate of low health literacy, meaning that studies with the highest quartile of Black participants had the highest prevalence of low health literacy. This finding was corroborated by a more recent review by Stomacq et al. (2018) who determined that African Americans/Blacks and Latinos/Hispanics were more likely to have higher chances of limited health literacy. Moreover, in a study of Black patients with heart failure, Chaundhry et al. (2011) found that Black patients were significantly more likely than White patients to have poor health literacy. As in the study of Rikard et al. (2016), Chaundhry et al. (2011) concluded that race continued to be strongly associated with low
health literacy, even when potential mediators, such as educational attainment, income, and insurance status were controlled.

**English proficiency and health literacy.** In the research literature, English proficiency is often discussed when explaining racial/ethnic disparities in health literacy. Although the 2003 NAAL did not include a measure of English proficiency, it did describe differences in health literacy among respondents who spoke other languages besides English. The results of the NAAL showed that adults who spoke only English before starting school had higher health literacy skills than adults who spoke another language alone or in addition to English (Kutner et al., 2006). Specifically, adults who spoke only Spanish before starting school had the lowest average health literacy and only had skills in the below basic level (Kutner et al., 2006). Even though English proficiency was not explicitly expressed or measured, these results may suggest that proficiency in English can affect health literacy.

In a study by Sentell and Braun (2012), low health literacy was found to be prevalent among Latino, Chinese, Korean, Vietnamese, and White respondents with limited English proficiency (LEP) who were living in California. Chinese respondents with LEP had the highest prevalence of low health literacy, while White respondents with LEP had the lowest prevalence of low health literacy. Sentell and Braun (2012) also discovered that individuals with LEP and low health literacy had the highest prevalence of poor health status. They also found that adults with only LEP appeared more vulnerable to poor health outcomes than adults with just low health literacy. Mantwill, Monestel-Umaña, and Schulz (2015) also suggested that LEP was a more important predictor of poor health outcomes than health literacy but that the combination of LEP and poor health literacy had the highest odds for poor health status. Overall, these studies
show that LEP can negatively impact health literacy and that a combination of both LEP and health literacy is associated with poorer health outcomes.

**SES and health literacy.** Socioeconomic status (SES) is the social standing of an individual, and it is often measured as a combination of education, income, and occupation (American Psychological Association, n.d.). To measure the respondents’ SES, the NAAL considered their educational attainment and income. In terms of income, the NAAL found that adults living below the poverty level had lower average health literacy than those living above the poverty level (Kutner et al., 2006). According to Rikard et al. (2015), health literacy scores on the NAAL also increased by a quarter of a point for every additional thousand dollars in median household income earned. Additionally, health literacy scores increased by six points with each additional monetary source of income from savings and investments.

On the NAAL, average health literacy increased with each additional level of education attained beginning with adults who graduated from high school or obtained a GED through adults with a graduate degree. Among adults who never attended or did not complete high school, 49% had below basic health literacy. Of the adults whose highest level of education was a high school diploma, 15% had below basic health literacy. In contrast, only 3% of adults with a bachelor’s degree had below basic health literacy. A recent systematic review by Stormacq et al. (2018) also found a significant independent association between educational level and health literacy. Specifically, this study discovered that individuals with low educational attainment were more likely to have poor health literacy.

**Age and health literacy.** According to the NAAL, older adults who were 65 years or older had lower average health literacy skills than younger adults. There was also a higher percentage of older adults who had below basic or basic health literacy skills (59%) compared to
younger age groups. Older adults may have lower health literacy as a result of the physical and cognitive changes that occur as a result of aging. For example, older adults experience reduced processing speed, increased tendency to be distracted, reduced capacity to process and remember new information, and problems with vision and hearing (Centers for Disease Control and Prevention [CDC], n.d.). These physical and cognitive challenges that come with aging may very well impact how older adults are able to obtain, process, and understand health information.

**Communication disorders and health literacy.** A group that was not accounted for in the NAAL but whose health literacy needs to be considered are people with communication disorders. According to the American Speech-Language-Hearing Association (ASHA) (1993), a communication disorder is “an impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal, and graphic symbol systems” (para. 2). When individuals have difficulty understanding or expressing information due to a communication disorder, they may also encounter challenges when faced with health information. Thus, people with communication disorders may be at risk for low health literacy (Hester & Benitez-McCrary, 2006).

Among those with communication disorders, a specific population that may be at considerable risk for low health literacy are people with aphasia. Aphasia is an acquired neurogenic language disorder that results from an injury to the brain, such as a stroke (ASHA, n.d.b). Individuals with aphasia may have impairments in spoken language expression, spoken language comprehension, written expression, and reading comprehension (ASHA, n.d.b). They may also experience speech disorders, such as dysarthria and apraxia of speech. Dysarthria is a speech disorder that is caused by muscle weakness and results in slurred speech that can be difficult to understand (ASHA, n.d.c). Like dysarthria, apraxia of speech makes it challenging to
speak and be understood by others. However, it is characterized as a motor speech disorder that affects the motor planning component of speech (ASHA, n.d.a). These communication challenges that are associated with aphasia can have a direct effect on health literacy since they impact a person’s ability to understand and express health information and interact with health care providers. Patients with communication disorders also report that their difficulties in communicating with medical professionals result in stressful and difficult experiences (Hemsley & Balandin, 2014).

**Understanding health literacy disparities as a whole.** According to the nationwide health promotion and disease prevention agenda known as Healthy People 2020 (n.d.), a health disparity is a type of health difference that is closely linked with social, economic, and/or environmental disadvantage and adversely affects groups of people who have systematically experienced greater obstacles to health based on race, religion, socioeconomic status, gender, age, disability, sexual orientation, or other characteristics that are linked to discrimination or exclusion. The differences in health literacy that were seen in the results of the NAAL affect groups of people who have systematically experienced barriers to health. Low health literacy among these groups may contribute to even greater health disparities. Additionally, the social categories that the NAAL examined should not be viewed in isolation since race, SES, and age intersect and shape the inequalities found in health outcomes. Since the results from various studies suggest a strong association between health literacy and health outcomes, it is imperative that health care providers and policymakers develop approaches to improve health literacy, especially among those who are at risk for low health literacy. Improving health literacy may consequently lead to better health outcomes and reduce health disparities.

**Improving Patient-Provider Communication to Counter Limited Health Literacy**
Health Literacy and the Right to Accessible Health Information

As several studies have shown, limited health literacy is associated with negative health outcomes and lower levels of empowerment (Ad Hoc Committee, 1999; Visscher et al., 2018). It may also contribute to greater health disparities among minorities, individuals with low SES, and those with communication disorders. These consequences of limited health literacy are alarming and indicate the need to develop strategies to improve health literacy. It is the responsibility of health care providers to lessen the burden of low health literacy on their patients. Medical professionals can achieve this by ensuring that the transmission of health information is accessible. Accessibility to health information is defined as the “the right to seek, receive, and impart health-related information in an accessible format (for all, including persons with disabilities)” (United Nations Office of High Commissioner for Human Rights, n.d., p. 4). There are several communication strategies that health care providers can use to make the transmission of health information accessible to people with limited health literacy. However, these strategies should be used with all patients since everyone can benefit from improved health communication.

Communication Strategies

Sudore and Schillinger (2009) developed a framework that summarizes the most commonly suggested communication techniques to help individuals with low health literacy. The strategies concerning patient-provider communication include patient-centered communication, clear health communication, confirmation of understanding, and reinforcement. Patient-centered communication refers to communication that is tailored to the individual patient and is respectful and responsive to individual patient preferences, needs, and values (Sudore & Schillinger, 2009; Altin & Stock, 2016). Health care professionals can provide patient-centered
communication by first asking patients what they already know or believe (Sudore & Schillinger, 2009). By asking this question, the health care provider will know what kind of information to share, clarify, and add. Other elements of patient-centered communication include eliciting the patient’s perspectives, understanding their psychosocial contexts, ensuring they understand their medical problems and treatment options, and involving them in the decision-making process (Morris, Clayman, Peters, Leppin, LeBlanc, 2015). Providing patient-centered communication is important because it meets patients where they are, empowers them, and increases their satisfaction with their health care (Altin & Stock, 2016).

The second communication strategy is employing clear health communication techniques. These techniques include slowing down speech, using plain language, matching the patient’s vocabulary, and limiting the number of key points to no more than three (Sudore & Schillinger, 2009). Plain language is clear, concise, well-organized, and appropriate for the patient (Plain Language Action and Information Network, n.d.). When using plain language, it is important to avoid jargon. If technical terms are used, it is best to explain them. Using plain language is imperative because it helps with accurate recall and understanding (Kurtz, Silverman, & Draper, 2005). The Calgary-Cambridge Process Skills Guides also offer other techniques that may contribute to clear communication and aid accurate recall and understanding (Kurtz et al., 2005). These include using explicit categorization (e.g., There are three important things that I’d like to discuss. First…) and utilizing repetition and summaries to reinforce information.

The third communication strategy is to confirm the understanding of the patient. A way to do this is by using the teach back method in which the health care professional asks the patient to restate the message or demonstrate the knowledge or technique being taught (Sudore &
Schillinger, 2009). For example, the health care provider can say “I’ve just said a lot of things. To make sure I did a good job and explained things clearly, can you describe to me…?” (Schillinger, Piette, & Grumback, 2003). Importantly, the teach back method has been shown to improve patients’ self-management of diabetes (Schillinger et al., 2003). Expanding on the teach back method is the chunks and checks technique, which involves the health care professional dividing information into manageable chunks or portions and checking for understanding (Kurtz et al., 2005). The patient’s response is then used as a guide on how to proceed with the information.

The fourth communication strategy that Sudore and Schillinger (2009) recommend is reinforcement. This refers to using multimodal teaching aids, such as pictures or graphs to reinforce verbal instruction (Sudore & Schillinger, 2009). Barnard (2001) explains that providing visual aids, such as diagrams, drawings, and gestures, increases comprehension, retention, and compliance. In addition, he (2011) states that offering written instructions and recommendations in the form of a chart, calendar, or list is particularly beneficial for elderly patients. When providing written instructions for older adults, Sudore and Schillinger (2009) suggest using 14-point nonserif fonts (e.g., Arial, Helvetica) and nonglossy paper with bright contrasting colors.

**Communication Strategies for Patients with Communication Disorders**

The recommendations that Sudore and Schillinger (2009) outline are similar to the communication strategies that speech-language pathologists suggest that medical professionals use when interacting with individuals with communication disorders. Speech-language pathologists at the University of Washington designed the FRAME framework to teach medical students how to communicate with patients with communication deficits (Burns, Baylor, Morris, McNalley, Yorkston, 2012). FRAME stands for familiarize (figure out how the patient best
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communicates), reduce rate (slow down speaking rate, ask one thing at a time, and allow extra time for patient to respond), assist with message construction (acknowledge what information you have understood and assist patient when communication breaks down), mix communication modalities (incorporate writing, drawing, pictures, gestures, and eye contact), and engage the patient (keep the focus on the patient and use caregivers and interpreters when needed). Patients with communication impairments also find it helpful when health care providers write down key words and rephrase messages they cannot understand (Morris et al., 2015; Hemsley & Balandin, 2014). Although these techniques are specific to those with communication disorders, they can also be helpful for patients with low health literacy.

The FRAME framework builds upon a well-established communication method known as Supported Conversation for Adults with Aphasia (SCA). SCA is based on the idea that the individual’s communication partner should act as a resource and actively share the communication load (Kagan, 1998). In order for communication partners to actively share the communication load and facilitate communication with an individual with speech and language disabilities, they can use various SCA techniques. For example, they can use spoken and written keywords, body language and gestures, hand drawings, and detailed pictographs (Kagan, 1998; Aphasia Institute, n.d.).

These communication techniques aim to achieve two goals: acknowledgement of competence and revealing competence. Acknowledgement of competence refers to recognizing the fact that the individual with a communication disorder is a competent communication partner. This can be achieved by using an appropriate tone of voice that is natural and verbally acknowledging that the individual knows what they want to say, e.g., “I know that you know” (Kagan, 1998; Aphasia Institute, n.d.). On the other hand, revealing competence involves the
following: (1) ensuring comprehension by using gestures, written key words, or drawings, (2) ensuring that the individual can respond by using yes/no or fixed-choice questions and providing enough time to respond, and (3) verifying responses by reflecting, expanding, or summarizing what the individual has communicated (Kagan, 1998).

It is imperative that speech-language pathologists train health care providers to use SCA and the FRAME framework when they are working with individuals with communication disorders. Not only will these communication methods facilitate conversations with the patient and provider, using these techniques may contribute to better understanding of health information and improved health literacy. Since SCA and the FRAME framework share many commonalities with the communication strategies specifically recommended to improve health literacy, speech-language pathologists can also teach health care professionals how to use the communication techniques that are recommended by Sudore and Schillinger (2009). As experts in communication, speech-language pathologist will be equipped to train health care professionals on how to use these various communication tools.

Creating a Health Communication Book

The last tool that may improve patient-provider communication and health literacy is a portable health communication book that is used primarily by the patient. This book should be individualized for the patient and contain several visuals that can aid communication and clarify the medical information that is being shared. Speech-language pathologist should collaborate with other health care providers in creating this book. The beginning of the book can include a brief written description of the patient’s health history, current health problems, and their preferred mode of communication (Burns et al., 2012). Other sections can include pictures of the patient, their family, and medical providers, summaries and explanations of their medical tests.
and procedures, important information about the health care setting (e.g., contact information), and future medical appointments (Lee et al., 2016). Health care providers can also use the pictures in the book as communication tools when the patient has difficulty communicating and as visual aids to reinforce the health information and instructions that they are sharing. To encourage questions and prepare the patient to communicate with their medical provider, it may also be helpful to have a section that begins with “My top three concerns/questions are…” The patient can complete this section prior to their appointment.

For Spanish-speaking families whose children were hospitalized, the use of a health communication book, known in Lee et al.’s study (2016) as a passport book, contributed to the families feeling more confident and motivated to participate in their child’s health care (Lee et al., 2016). Moreover, being able to write things down in the passport book helped the families better remember medical information. This retention of medical information led to the families feeling more empowered to ask questions. Access to Spanish-speaking interpreters and the passport book being written in Spanish also increased the families’ understanding of laboratory results and medical records. This increased understanding can be considered an improvement in their health literacy. As evidenced by Lee et al.’s study (2016), it is important to create communication tools that consider the patient’s primary language and to use interpreters when needed. The use of an individualized health communication book and the communication strategies described previously may lead to improved health literacy, higher levels of empowerment, and better-quality health care.

**Conclusion**

The concept of health literacy comprises of the reading, writing, speaking, listening, and social skills needed to access and understand health information in order to confidently and
actively make appropriate health decisions. These skills will ultimately lead to the empowerment of health care recipients and compliance with health care recommendations so that better health can be attained. In the U.S., over a third of the population has limited health literacy. According to the NAAL, groups at risk for low health literacy include racial minorities, those with low SES, and the elderly. With the nature of communication disorders, individuals with speech and language disabilities are also at risk for low health literacy. However, further research studies should directly assess the health literacy of adults with communication disorders and examine how their health literacy affects their health outcomes.

Inadequate health literacy is concerning because it is associated with negative health outcomes, poor understanding of medical conditions and treatment, poor management of chronic conditions, and increased health care costs. Low health literacy may also further contribute to health disparities among vulnerable groups. As such, it is important to develop strategies to improve health literacy.

A feasible way to improve health literacy is to enhance patient-provider communication. Health care providers should improve their communication with their patients by drawing on available communication tools and applying them across populations at risk for low health literacy. For example, it is imperative that medical providers utilize patient-centered communication strategies, clear health communication techniques, the teach back method, the chunks and checks method, and multimodal teaching aids. With their knowledge of and experience using communication tools, speech-language pathologists should also teach health care providers how to use these communication techniques during in-services in various medical settings. Furthermore, they should train health care professionals to utilize the FRAME framework and SCA strategies with their patients who have communication disorders. By
utilizing these various communication strategies, the objectives are to help patients better understand health information so that they can make appropriate health decisions and better manage their health and to reduce health disparities among vulnerable groups.
References


https://doi.org/10.3109/07434618.2014.955614

https://doi.org/10.1044/leader.FTR2.11172006.33

https://doi.org/10.1044/1058-0360(2009/08-0005)


https://doi.org/10.1177/0269215509360752

http://dx.doi.org/10.1016/j.dho.2014.09.007


Rikard, R.V., Thompson, M.S., McKinney, J., Beauchamp, A. (2016). Examining health literacy
disparities in the United States: A third look at the National Assessment of Adult literacy.


