# Chapter 19
# Health Literacy


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## 19.1 Definition

Health literacy is a crucial component for population-based health promotion and disease prevention initiatives. Although it is widely acknowledged that health literacy skills are necessary for individuals to navigate health contexts, there is little consensus about the definition of health literacy. Some definitions emphasize individual capacity to acquire and use new information that is impacted by both innate potential and an individual's sociocultural context, while others emphasize healthcare knowledge and the dynamic nature of the healthcare context as impacting an individual's health literacy skills (Baker, 2006). Health literacy then has historically been defined as, "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate decisions" (Ratzan & Parker, 2000, p. ix). This definition emphasizes:

1. *Individual capacity*: includes reading fluency, vocabulary, and listening and speaking skills. Reading fluency refers to an individual's ability to read, write, and understand written information, ability to locate and use information in documents, and numeracy (e.g., ability to understand probabilities and percentages and apply arithmetic operations) (Baker, 2006). Vocabulary includes characteristics of individuals (familiarity with the health concepts presented) and the larger healthcare system (complexity of the language or jargon utilized to communicate health concepts). Listening and effective communication skills are neces-

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W. O'Donohue, M. Zimmermann (eds.), *Handbook of Evidence-Based Prevention of Behavioral Disorders in Integrated Care*,
https://doi.org/10.1007/978-3-030-83469-2_19

sary components of an individual's capacity to convey symptoms accurately, ask appropriate questions, understand medical advice or directions, and engage in shared decision-making.
2. *Healthcare knowledge*: includes an individual's prior knowledge of maintaining good health, risk factors, health beliefs, the organization and functioning of healthcare systems, and knowledge and understanding of billing and insurance processes.

Although this definition is widely utilized in public health initiatives and clinical and research settings, it maintains a focus on the characteristics and prior abilities of individuals while largely neglecting the role of health systems. To more comprehensively capture the complexity of health literacy, *Healthy People 2030* has redefined the concept to incorporate the complex role of health systems and organizations in increasing health literacy and emphasize individual ability to *apply* health information to make well-informed decisions instead of simply understanding it to make appropriate decisions (ODPHP, 2020). To this end, health literacy is comprised of *personal health literacy*, which refers to an individual's ability to find, understand, and use information to make healthcare decisions, and *organizational health literacy*, which refers to the degree to which organizations facilitate individuals to find, understand, and use information to make healthcare decisions.

Thus, shared decision-making is an essential component of behavioral health literacy.

Willis and O'Donohue (2018) have created an integrated model of behavioral health literacy that incorporates shared decision-making and patient-centered care as interconnected concepts. They define behavioral health literacy as the ability to:

1. Obtain behavioral health information that is valid and relevant in consultation with healthcare professionals
2. Evaluate and integrate behavioral health information
3. Make informed behavioral healthcare decisions utilizing this information for both treatment of disease and wellness
4. Understand factors that contribute to prevention of disease and the promotion of overall wellness

Behavioral health literacy is essential for shared decision-making and patient-centered care. Shared decision-making can be defined as an ongoing process of collaboration and discussion between the patient and provider wherein the provider actively creates and maintains rapport, evaluates a patient's preference for information and role in decision-making, and incorporates the patient's ideas, concerns, and expectations into decision-making, discussion of available option, and mutual selection of treatment course (Willis & O'Donohue, 2018). Patient-centered care can be defined as a spectrum of care that increases access to and knowledge and utilization of behavioral healthcare by incorporating the use of staff effective interpersonal skills, materials and handouts, and quality improvement (Willis & O'Donohue, 2018).

The authors propose that shared decision-making impacts behavioral health literacy and patient-centered care, in that providers ought to supply patients with

accurate and complete information regarding evidence-based treatment options for their individual difficulties for patients to be active participants in their care (Willis & O'Donohue, 2018). This is particularly important as it has the potential to address the inherent dynamic and malleable nature of health literacy as a concept. The substantiative knowledge of a patient with cardiovascular disease may be vastly different than someone coping with a cancer diagnosis. Although there may be a general knowledge of health literacy domain (e.g., healthy diet and exercise), providing patients with disease-specific information and treatment options can impact their level of engagement in decision-making. This creates a need for healthcare providers to be knowledgeable about a range of behavioral health conditions, insurance policies, and evidence-based treatments. In turn, patients may feel empowered to make informed decisions, which further impacts shared decision-making and patient-centered care. Thus, health literacy is determined by individual and healthcare variables. It is a dynamic and malleable concept that represents a constellation of skills across various domains.

## 19.2 Prevalence

In a National Adult Literacy Study, 90 million American adults fell in the lower two levels of a five-level scale assessing the degree of proficiency needed to function in American society, and more than 40 million were categorized as functionally illiterate (Kirsch et al., 1993). Individuals with low literacy encounter challenges in reading, understanding, and integrating written information with accuracy (Nielsen-Bohlman et al., 2004). The inability to interpret written information accurately and consistently complicates skills needed to function in American society, including the demands of the healthcare system such as understanding consent forms and prescription medication information inserts.

In a review of 85 studies, the weighted prevalence of low health literacy was 26%, and that of marginal health literacy was 20% (Paasche-Orlow et al., 2005). When assessing the 85 studies individually, the reported prevalence of low health literacy ranged from 0% to 68%. The prevalence of low health literacy was significantly associated with level of education, age, and ethnicity (Paasche-Orlow et al., 2005). Specifically, the rate of high school completion was significantly associated with literacy levels. American adults with higher levels of education have higher average proficiencies (Kirsch et al., 2002). There is a positive relationship between literacy and years of education. Age also appears to have a significant association with health literacy. Paasche-Orlow et al. (2005) noted that the studies with the lowest average age had the lowest prevalence of low literacy at 15.9%, and studies in which the average age was over 50 years old had a prevalence of low literacy of 37.9%.

In addition to education and age, ethnicity and race disproportionately impact literacy. White and Asian/Pacific Islander adults have higher average health literacy than adults identifying with other ethnic and racial minorities, such as Black,

Hispanic, American Indian/Alaskan Native, and Multiracial (Kutner et al., 2006). Fourteen percent of adults that participated in the 2003 National Assessment of Adult Literacy fell in the *Below Basic* health literacy level. Twenty-four percent of Black adults and 41% of Hispanic adults were in the *Below Basic* health literacy category, compared to 9% of White and 13% of Asian/Pacific Islander adults. Hispanic adults had a higher prevalence of low health literacy than adults in any other racial and ethnic group. Furthermore, studies with higher numbers of Black participants had the highest levels of low literacy (Kutner et al., 2006; Paasche-Orlow et al., 2005).

Despite the growing number of Americans that speak a language other than English at home, research studies often exclude participants who are not Native English speakers (Paasche-Orlow et al., 2005). By excluding the non-Native English-speaking portion of the population, studies may be underestimating the prevalence of low health literacy in the United States. Paasche-Orlow et al. (2005) assessed non-Native English speakers separately. Results indicated that participants tested in Spanish had significantly higher rates of low literacy (44%) compared to participants tested in English (26%), which could be an indication that language is an important factor to consider in health literacy.

## 19.3 Risk Factors

Low health literacy is associated with a number of outcomes at the individual and societal levels. The estimated yearly cost of low literacy in the United States ranges from $106 to $238 billion (Liechty, 2011). Lower health literacy is associated with increased risk of hospitalization (Baker et al., 2002), higher rates of hospitalizations (Nielsen-Bohlman et al., 2004; Paasche-Orlow et al., 2005), longer hospital stays (Findley, 2015), greater emergency department visits (Mitty & Flores, 2008), and higher rates of ambulance transport (Findley, 2015). Individuals with low literacy levels tend to have higher healthcare utilization leading to increased costs.

In addition to societal costs, there are a number of costs at the individual level associated with low health literacy. Low literacy is linked to poor socioeconomic conditions (Nutbeam, 2008). Poor socioeconomic conditions are in turn linked to negative health effects. Kim (2009) indicated that individuals with low health literacy have a lower subjective sense of health and happiness and significantly higher rates of pain, arthritis, hypertension, and limitations in activity. Adults with low health literacy are also at greater risk for additional potential adverse health outcomes including high systolic blood pressure (Findley, 2015), higher mortality rates (Baker et al., 2007), and poorer health status upon presentation to treatment (Findley, 2015). Thus, health literacy poses a risk for an individual's mental and physical health.

With higher rates of chronic diseases and hospitalizations, individuals with low literacy have to navigate the healthcare system. It is well documented that the majority of healthcare materials exceed the comprehension abilities of most of the

American population (Rudd et al., 1999). American adults with low literacy encounter many challenges with navigating the healthcare system, which range from difficulty filling out forms in a medical office to comprehending and adhering to treatment plans. The absence of guidelines in plain language is associated with multiple healthcare disparities, chronic illness management, and failure to engage in healthy lifestyles (Mitty & Flores, 2008). If people do not understand guidelines and directions, then they will not be able to adequately manage their own health. Individuals with limited health literacy have less knowledge of disease management, lower rates of health promotion behaviors (Nielsen-Bohlman et al., 2004), decreased use of preventative services (DeWalt et al., 2004; Findley, 2015; Nielsen-Bohlman et al., 2004). Consequently, poorer self-management leads to worsening medical health and an increase in hospitalizations and emergency care utilization.

Providing health-related education for individuals with inadequate health literacy can be challenging. Williams et al. (1998) noted a significant relationship of functional health literacy to patients' knowledge of their chronic diseases and improper use of medical devices. This relationship has been supported by an additional study associating better reading ability to increased knowledge of health services (DeWalt et al., 2004). Providers who serve populations with low health literacy described their education and treatment efforts as challenging and exasperating (Liechty, 2011). The perceived resistance or difficulty has the potential to damage patient-provider rapport, which in turn may increase the discomfort felt by patients with low literacy and maintenance of the existing health disparity.

## 19.4 Effective Screening

It is imperative for health organizations to efficiently identify patients at risk for negative health outcomes through screening for low health literacy as this can facilitate prevention, early intervention, and treatment. Leading healthcare organizations have provided guidelines, recommendations, and toolkits to raise awareness of health literacy and improve patient-provider communication. For instance, the 2004 Institute of Medicine (IOM) report on health literacy indicated that "health literacy assessment should be a part of healthcare information systems and quality data collection" (IOM, 2004, p. 16). A 2013 workshop convened by IOM's Roundtable on Health Literacy further noted, "what gets measured gets managed" (IOM, 2014, p. 93), suggesting that the development of metrics to measure health literacy as part of existing programs and services may encourage health organizations to screen for health literacy status. The Joint Commission requires that hospitals attend to health literacy issues, such as providing written information in plain language and in a manner that patients can understand, encouraging patients to use information to make healthcare decisions, and engaging patients in shared decision-making (JCO, 2012). Despite public health efforts, there is no consensus about the most cost-effective, practical, and best approach to routine screening.

Screening for low health literacy has generally taken one of two approaches: a universal precautions or a hybrid approach that integrates universal precautions with targeted assistance. From a health literacy universal precautions paradigm, healthcare providers assume that all patients may experience difficulties with accessing health services and comprehending health information (Brega et al., 2015). The overarching goals of health literacy universal precautions are to make healthcare systems easier to navigate, simplify communication, and support patients in their efforts for health improvement (Brega et al., 2015). The Agency for Healthcare Research and Quality (AHRQ) developed the *Health Literacy Universal Precautions Toolkit 2.0* to assist healthcare organizations in implementing systems-level changes to address low health literacy. The toolkit offers guidance for conducting organizational assessments, developing plans to address health literacy and strategies to increase health literacy (e.g., Teach-Back method), medication management, and designing written materials and tools to help coordinate care between disciplines and improve the likelihood that patients will follow through with referrals.

The feasibility of scaling universal precautions across healthcare systems has not yet been demonstrated. In a study of 12 primary care practices that implemented specific tools from the toolkit over a period of 6 months, participating practices reported implementation barriers in the form of limited support from leadership, bureaucratic and technological challenges, competing demands and staff capacity, and limited quality improvement experiences (Mabachi et al., 2016). In an examination of whether health literacy universal precautions recommendations are being followed, only 17% of the population was offered help with forms, 29% reported their providers used the Teach-Back method to assess comprehension, and 70% always received easy-to-understand instructions from their providers (Liang & Brach, 2017). In order to achieve health literacy universal precautions, healthcare systems need to redesign workflows to integrate health literacy practices into existing services, which is an ambitious and resource-intensive undertaking.

An alternative to health literacy universal precautions is a hybrid approach that operates from a universal precautions lens and identifies patients with risk factors for low health literacy to maximize resource allocation (Hadden & Kripalani, 2019). Within this model, systems-wide screening and documentation in electronic health records (EHR) are implemented to identify patients for whom evidence-based prevention or intervention strategies can likely improve specific health outcomes. A hybrid approach incorporates some elements from the universal precautions model, namely, some resource allocation in the form of staff training in the use of the Teach-Back method, plain language with all patients, and time for data collection in addition to screening (Hadden & Kripalani, 2019). Health literacy data can present a number of opportunities for prevention and intervention strategies. These data can be accessed in real time in the patient's EHR, and providers can tailor their approach, instructions, and education to improve patients' experience. Health literacy data can also be utilized in quality improvement efforts and population based-health strategies to allocate resources for patients who are most likely to benefit from health literacy prevention and intervention strategies. This approach may be particularly

beneficial given the high degree of shame associated with low health literacy or illiteracy (Parikh et al., 1996; Wolf et al., 2007).

Incorporating routine screening as part of a comprehensive health history in combination with the Teach-Back method can alleviate potential discomfort and normalize discussions of health literacy. In fact, patients are generally supportive of measures that assess and inform their medical providers of their healthy literacy level (Farrell et al., 2008; Seligman et al., 2005). There are promising findings from the last decade that have demonstrated the acceptability and feasibility of brief health literacy screening (Cawthon et al., 2014; Kindig et al., 2004). For instance, in a dissemination and implementation study of a three-item health literacy assessment tool in a hospital setting, Cawthon et al. (2014) found that the completion rate was 91.8% for inpatient admissions and 66.6% for outpatient visits. The authors identified leadership support and integration into existing workflows and infrastructure as key facilitators of rapid adoption of the screening tool.

Despite the lack of consensus regarding the most effective approach to the implementation of health literacy screening, there is overwhelming support from medical providers and patients for providers to know if patients experience difficulties with health literacy (Farrell et al., 2008; Seligman et al., 2005). There are several self-report questionnaires that have been validated and well established for use in integrated care settings that are easy to administer and provide useful information. The most common measures include (see Table 19.1).

- *Rapid Estimate of Adult Literacy in Medicine, Revised* (REALM-R; Bass et al., 2003): The REALM-R is an 11-item word recognition test utilized to identify patients at risk of low health literacy. Eleven common medical words are printed

**Table 19.1** Health literacy screening tools

| Name | Number of items | Time to administer | Cutoff | Language |
|---|---|---|---|---|
| REALM-R | 11 | < 2 minutes | ≤ 6 = at risk of low health literacy | English |
| BHLS | 3 | 1 minute | Total scores:<br>3–9 = lower health literacy;<br>10–15 = higher health literacy | English |
| BRIEF | 4 | < 2 minutes | Total scores: 4–12 = inadequate;<br>13–16 = marginal; 17–20 = adequate health literacy | English |
| S-TOFHLA | 36 | 7 minutes | Total scores: 0–16 = inadequate;<br>17–22 = marginal; 23–36 = adequate literacy | English |
| SAHLSA | 50 | 4–5 minutes | Total scores:<br>0–37 = inadequate health literacy | Spanish |
| NVS | 6 | 3 minutes | Total scores:<br>0–1 = high likelihood of limited literacy;<br>2–3 = possibility of limited literacy;<br>4–6 = adequate literacy | English |
| SILS | 1 | <1 minute | ≥ 2 | English |

in 18-point font, and patients are asked to read each word aloud with a time limit of 5 s per word. The first three words, "fat," "flu," and "pill" are not scored and are only administered to increase confidence and decrease anxiety. The REALM-R does not assess comprehension.

- *Brief Health Literacy Screen* (BHLS; Chew et al., 2004): The BHLS is a three-item self-report questionnaire that has been validated in outpatient, inpatient, and emergency department settings and administered by nurses during routine clinical care. Each question on the BHLS is scored on a 5-point scale that is summed, and total scores can range from 3 to15, with higher scores indicating higher health literacy levels. The three questions are: (1) "How often do you have someone help you read hospital materials?" (2) "How confident are you filling out medical forms by yourself?" and (3) How often do you have problems learning about your medical condition because of difficulty understanding written information?"
- *Brief Health Literacy Screening Tool* (BRIEF; Haun et al., 2009): The BRIEF is a four-item self-report questionnaire that incorporates the three questions from the BHLS in addition to a fourth question, "How often do you have a problem understanding what is told to you about your medical condition?" to assess difficulties with auditory health information. Scores on all four questions are summed and can range from 4 to 20.
- *Short Test of Functional Health Literacy in Adults* (S-TOFHLA; Baker et al., 1999): The S-TOFHLA is a shortened version of the TOFHLA, which is a written prose test comprised of 67 items that takes approximately 20–25 minutes to administer. The S-TOFHLA is a 36-item questionnaire from the reading comprehension subsection of the full TOFHLA that is scored on a scale of 0–36 and only takes 7 min to administer. It is as valid and reliable as the full version but much less burdensome.
- *Short Assessment of Health Literacy for Spanish Adults* (SAHLSA; Lee et al., 2006): The SAHLSA is a health literacy assessment based on the REALM test that is comprised of 50 items designed to assess a Spanish-speaking patient's ability to read and understand common medical terms.
- *Newest Vital Sign* (NVS; Powers et al., 2010): The NVS is a brief screening tool that utilizes a nutrition label from an ice cream container. Patients are provided with the label and asked six questions about the label. Patients should refer to the label while answering the questions.
- *Single-Item Literacy Screener* (SILS; Morris et al., 2006): The SILS is a single-item question designed to identify adults who experience difficulties with understanding printed health materials. The SILS asks, "How often do you need to have someone help you read instructions, pamphlets, or other written material from your doctor or pharmacy?" The SILS utilizes a Likert scale from 1 *Never* to 5 *Always*. Scores greater than 2 indicate some difficulty with reading health-related print material.

In addition to these instruments, there are many other full-length assessments, such as the REALM and TOFHLA, that are considered to be "gold standards" for

measuring health literacy but are likely not feasible for implementation in integrated care settings due to their length and time needed for administration. This likely is largely dependent on the clinical setting and population of interest. The measures listed above and many others can be accessed via several repositories, including AHRQ's *Toolkit 2.0* (https://www.ahrq.gov/health-literacy/research/tools/index.html) or the *Health Literacy Tool Shed* (https://healthliteracy.bu.edu), which is the culmination of a collaboration between Boston University, RTI, and CommunicateHealth, Inc. The choice of instrument is largely dependent on clinical need, patient population, provider preference, time availability, and patient acceptability.

## 19.5 Evidence-Based Prevention

Promoting health literacy is a global public health goal. The relationship between low health literacy and poorer health outcomes, including higher rates of mortality and hospitalization (Baker et al., 2004; Baker et al., 2007), lower use of preventive services (White et al., 2008), poorer medication adherence (Kripalani et al., 2010), and higher use of emergency services (Baker et al., 2004), is well established. Improving the health literacy of individuals then can improve understanding of preventive care information, access to preventive care services, and improve health outcomes. Health literacy then can serve as preventive action against the onset or exacerbation of disease. Prevention efforts can be primary, secondary, or tertiary:

- *Primary prevention*: The aim of primary prevention is to prevent disease before it occurs by modifying unhealthy behaviors, increasing resistance to disease, or preventing exposure to disease. Immunizations and community-based screening initiatives are examples of primary prevention.
- *Secondary prevention*: The focus of secondary prevention is early disease detection via screening efforts. Examples include screening for high blood pressure, breast self-examinations, or Pap smears.
- *Tertiary prevention*: The aim of tertiary prevention is to mitigate the impact of an already-existing disease or prevent the onset of other severe diseases by helping patients manage complex health problems and alleviate suffering. Examples include interventions to reduce dropout rates in cardiac rehabilitation to prevent further coronary events and provision of prostheses and medical devices to improve quality of life.

There is a plethora of health literacy initiatives to create information, recommendations, and guidelines, but fewer evidence-based prevention efforts, particularly primary prevention. Emerging and evidence-based health literacy primary prevention efforts include the Black Barbershop Health Outreach Program (BBHOP), which is a partnership between medical professionals, community health volunteers, and African American-owned barbershops (Releford et al., 2013). The aim of BBHOP is to educate, screen, identify, and refer African American men at risk for

diabetes and hypertension for early intervention. BBHOP developed culturally sensitive educational materials and incorporates self-administered surveys to understand the factors that prevent African American men from engaging in health-promoting behaviors. BBHOP has screened over 7000 African American men in 300 barbershops in over 20 cities across 6 states (Releford et al., 2013). Additional successful primary prevention programs include the Health Literacy Screening (HEALS) study outlined by Cawthon et al. (2014) that incorporated a brief health literacy screen into the electronic medical record in the emergency department, three primary care clinics, and all adult outpatient clinics at a large academic medical center. A systematic review of community-based programs yielded seven other studies that examined the effects of health literacy interventions that served a primary prevention function (e.g., understand food labels; Nutbeam et al., 2018).

More common than primary prevention strategies are health literacy secondary and tertiary health prevention programs. The extent to which greater health literacy can prevent the onset of disease is highly debated. Emerging evidence suggests that improving health literacy can improve comorbidities rather than preventing the first chronic disease (Liu et al., 2020). This suggests that health literacy can be a protective factor in the development of chronic diseases. A suggested theoretical pathway is that health literacy impacts health outcomes by affecting health behaviors, knowledge about health concepts, self-efficacy, and health-related perceptions (Baker, 2006; Speros, 2005; von Wagner et al., 2009). Empirical studies have yielded promising results for this proposed framework.

For instance, Fernandez et al. (2016) examined the relationship between health literacy and health perceptions and behaviors in a subsample of the Health and Retirement Study (HRS). The authors found that participants with adequate health literacy were more likely to report engaging in moderate physical activity two or more times weekly, more likely to report having a mammogram within the last 2 years, more likely to provide a correct response to a question regarding whether colon cancer screening reduces the risk of dying from colon cancer, and less likely to report current tobacco use. Interestingly, in women, 49.4% with adequate objective health literacy reported conducting monthly breast self-examinations (BSE) in comparison with 72% of those with inadequate objective health literacy (Fernandez et al., 2016). This finding is surprising and possibly related to patients' knowledge of evidence-based preventative measures. The World Health Organization does not recommend BSE (WHO, 2016) as a breast cancer screening method, and it is possible that women with higher levels of health literacy may have greater knowledge about the breast cancer guidelines and recommendations, whereas women with lower levels of health literacy may utilize BSE as a replacement to mammography for a variety of reasons (Fernandez et al., 2016; Nielsen-Bohlman et al., 2004). Similar results have been found for health literacy when assessed for specific diseases such as diabetes and HIV. Mancuso (2010) examined health literacy as a predictor of glycemic control in a sample of patients with diabetes recruited from two primary care clinics and found a strong correlation between health literacy and diabetes knowledge, such that an inadequate understanding of diabetes explained the

differences found in HbA1c levels. Mancuso (2010) also found that trust in the provider was the most significant factor that impacted HbA1c levels, suggesting that the interaction with healthcare providers can influence patients' health outcomes. Although further research is necessary to elucidate the underlying mechanisms, extant evidence suggests that health literacy can be a key factor across the spectrum from prevention to treatment.

It is also possible for healthcare systems to develop programs across the spectrum of prevention. For instance, an example of a comprehensive health literacy prevention initiative can be found in the Southeastern Pennsylvania Regional Enhancements Addressing Disconnects (SEPA-READS) collaborative (Simmons et al., 2017). Nine hospitals in Southeastern Pennsylvania collaborated with several institutes and foundations to develop easy-to-read educational material on a broad range of cancer topics, plain language text messages to reduce no-show rates on the mobile mammography unit, a text messaging intervention for low-income pregnant women smokers, a comic-book-style photonovel on breast cancer from an intergenerational perspective for Chinese-Americans, and healthcare provider trainings on strategies for enhancing health literacy during patient-provider encounters (Simmons et al., 2017). Given the complexity of health literacy and the variety of extant prevention strategies, what ought prevention initiatives include? Common to many of the prevention efforts outlined here and elsewhere are the following components:

- Easy-to-understand printed and electronic materials that are newly developed or have been redesigned with a specific focus on plain language
- The use of plain language during patient encounters
- Incorporation of the Teach-Back method
- Staff training
- Support from organizational leadership and champions
- Continuous program evaluation and development

It is evident that primary, secondary, and tertiary prevention programs can positively impact the rates of identifying patients at risk of developing specific diseases (e.g., hypertension, diabetes), improve health behaviors and health knowledge, and affect the healthcare provider-patient relationship.

## 19.6 Intervention

In 2010, the US Department of Health and Human Services published the *National Action Plan to Improve Health Literacy*. They proposed developing a society-wide health response to health literacy targeting multiple areas, including communication skills of health professionals, clarity and accuracy of health information, cultural and linguistic adaptation of health information, and systemic changes to healthcare. Nonetheless, research on health literacy interventions has been relatively scarce (Kelly et al., 2007), and most of the existing models have focused on identifying associations between health literacy and its outcomes (Geboers et al., 2018) as

opposed to identifying interventions to improve health literacy. Interventions are key, as improvements in health literacy can lead to prevention of the outcomes often associated with health literacy. Improvements in health literacy are associated with better health outcomes, such as reduced reported disease severity, greater awareness of risks for chronic diseases, and a decrease in unplanned emergency department visits and hospitalizations (Nutbeam et al., 2018). Hence, health literacy interventions can be viewed as preventative.

Healthcare providers and healthcare systems contribute to the maintenance of poor health literacy in a variety of ways, including insufficient patient education, language barriers, differing expectations between providers and patients, overuse of medical terminology, and overly technical forms/instructions (US Department of Health and Human Services, 2010). This problem begins during health professionals' training. Only a small portion of US medical schools and internal-medicine residency programs are teaching about health literacy, yet 48% of healthcare providers (physicians and nonphysicians) overestimate their understanding of health literacy issues (Coleman & Fromer, 2015). Given that health literacy is a critical factor in communication between healthcare providers and patients in their care, interventions targeting provider health literacy competency should be considered. Coleman and Fromer (2015) provided a 70-minute didactic overview of health literacy for physicians and nonphysicians. The didactic covered information on the definition of health literacy, health literacy-related outcomes, best practices for communication with patients, self-management and empowerment, and effective use of patients' social support systems. Study participants reported improved self-perceived knowledge, skills, and planned behaviors about health literacy following the didactic. The newly acquired knowledge can help providers approach patients with low health literacy in a more understanding way, provide simpler explanations of health conditions, and create a shame-free environment, in turn improving the patient-provider relationship. Despite the evidence that literacy training for healthcare providers is an important factor of health literacy intervention, more research is needed on identification and development of instructional strategies.

There are also concerns with the use of existing healthcare models, like the Stepped Care Prevention Approach, to improve health literacy. In a traditional stepped care model, healthcare professionals provide evidence-based psychological treatments in different steps (Franx et al., 2012; Ho et al., 2016). A stepped care approach typically begins with less intensive treatments, which can then be graduated to more intensive treatments if patients do not respond to prior steps. Less intensive treatments include watchful waiting, psychoeducation, and bibliotherapy. Care can then progress to individual or group therapy, as well as pharmacological treatment. Each step relies on individuals' ability to process information provided by healthcare professionals, read healthcare or self-help materials, and possess awareness of medical or mental health disorders. When more than 40 million Americans are categorized as functionality illiterate (Kirsch et al., 1993) and the reading age of some of the most popularly used self-help materials is 12.6–15.4 (Martinez et al., 2008), this is going to be a challenge. Therefore, intervention is an important area of focus within health literacy.

Researchers have approached interventions of health literacy in a variety of ways. Some researchers have attempted to identify broad categories for intervention, while others have focused on the identification of specific strategies. Nutbeam et al. (2018) postulated that health literacy can be improved through dissemination of information, effective communication, and structured education. Four broad methods of targeting mental health literacy in youth are through disseminating information in whole-of-community campaigns and community campaigns, education-based interventions, and training programs for intervention during mental health crises (Kelly et al., 2007). Examples of interventions within these four target areas are:

- *Whole-of-community intervention*: Pamphlet and poster distribution, psychoeducational website, television advertising, and educational videos
- *Community campaigns targeting youth*: Cinema, printed materials, and radio
- *Education-based interventions*: Curriculum support materials, visits to schools by health professionals, mental health information sessions, and resilience enhancement programs
- *Training programs for interventions during mental health crisis*: Course teaching recognition of risk factors for mental health disorders, applied-intervention skills training, presentations by school counseling services, and written material.

In efforts to identify more specific target areas, Brainard et al. (2016) reviewed various studies that had implemented health literacy interventions, the majority of which were delivered via interactions with healthcare professionals, with adult participants. The interventions in these studies focused on psychoeducation, skill building, behavioral change, strengthening contextual support, individual involvement at the systems live, individualization of health literacy interventions, and changes in social or cultural environments for enhancement of health literacy interventions. Health literacy interventions have been associated with increased post-intervention knowledge (Kelly et al., 2007) and significant improvements in certain health literacy aspects, including skills, self-efficiency, health knowledge, quality of life, and communication with healthcare providers (Brainard et al., 2016). Hence, it is imperative to develop specific interventions to improve health literacy.

Awareness of target areas has contributed to a shift in health literacy research with a greater focus in the development of interventions. Geboers et al. (2018) proposed a comprehensive health literacy intervention model in which outcomes are determined by the collaboration between individuals and health providers, as well as their broader social contexts. On the individual level, it is important to consider patients' interpersonal relationships, and for healthcare providers the model should also consider the entirety of the healthcare system. It is imperative to also consider the broader systemic contexts, as these include factors that can perpetuate poor health literacy. According to the proposed model, interventions targeting a combination of its five factors can improve health literacy. The five factors identified by the Geboers et al. (2018) as potential targets are:

- Context of individual

- Individuals with low health literacy
- Individual characteristics and healthcare system interactions
- Healthcare professionals
- Communication and accessibility of healthcare systems

Geboers et al. (2018) identified specific interventions such as strengthening social support systems, empowering individuals with low health literacy, improving communication between individuals and healthcare providers, skill-building (communication, awareness or health conditions), and policy change. The specific interventions are designed to target a combination of the five factors in the comprehensive health literacy intervention model.

Improvement in health literacy does not solely rest on individuals but on the collaboration of healthcare professionals, healthcare systems, and community support/engagement. A comprehensive health literacy intervention model provides multiple target areas while incorporating individuals' larger contexts. It makes both individuals and healthcare providers key players in the improvement of health literacy, contributing to the establishment of more collaborative relationships.

## 19.7 Role of Primary Care Providers and Behavioral Care Providers

The primary care team is uniquely situated to screen, assess, and implement strategies to enhance patients' health literacy. Typically, a patient's first point of contact with a healthcare practitioner is during the annual primary care visit. Healthcare teams can triage patients based on need by first incorporating a single item screener such as "How often do you need to have someone help you read instructions, pamphlets, or other written material from your doctor or pharmacy?" during the initial visit with a medical assistant or nursing provider. If the screen is positive, the PCP and BCP can then intervene in a number of ways:

- *Use plain language*: Using plain language means conveying information in a simple and clear way using common terms that are free of medical jargon both in written and oral communication (e.g., using "cut" instead of "abrasion," "breast health test" instead of "mammogram," etc.). Elements of plain language include using active voice instead of passive voice, breaking complex information into small chunks, organizing information so that the most important points come first, and asking open-ended questions. Plain language resources can be found at: https://www.cdc.gov/healthliteracy/developmaterials/plainlanguage.html.
- *Use the Teach-Back method*: The Teach-Back method is a simple approach for confirming that patients understand what has been communicated during a medical visit and provides an opportunity to answer questions and provide corrective information. Primary care providers can begin by asking, "We covered a lot today and I want to make sure that I explained things clearly. Let's review what

we discussed. Please describe the three things you agreed to do to help you prevent and reduce the risk of cancer" (Simmons et al., 2017).

- *Use visual aids*: The use of graphic displays of health information can help patients gain a better understanding of their medical conditions. This can be a powerful tool that can augment the oral information provided. Visual aids can also facilitate shared decision-making. Visual aid tools can be found at: http://www.vizhealth.org and https://visualsonline.cancer.gov.
- *Use and recommend technological health aids*: Actively encourage patients to use patient portals to access their health information and communicate with their providers, recommend the use of mobile applications, and telehealth options. Mobile apps provide an opportunity for self-management and tracking symptoms and can provide health information.
- *Practice culturally competent care*: Avoid making assumptions about patients' educational attainment, socioeconomic status, or the beliefs they hold about health. Promote a welcoming environment that invites patients to involve any family members or friends who are important members of their social network and can aid in decision-making.
- *Develop printed materials that promote health literacy*: Ensure that the information included in written materials is at a fifth or sixth grade level; include generous white space; integrate graphics, photographs, and conversation bubbles; and approach health literacy from a culturally sensitive lens (Simmons et al., 2017).

*Attend to disease-specific and general health literacy*: Ensure that handouts, brochures, or other written/digital materials include information regarding ways to maintain good health and minimize risk factors while also including separate materials that target individual diagnoses or disease processes (e.g., lifestyle modifications for diabetes management). Although time is limited during medical visits, PCPs can start this process by ensuring the use of plain language and the Teach-Back method with all patients. Providers can then engage in a "warm hand off" with a behavioral care provider who can provide targeted and brief interventions and incorporate some of the same strategies as PCPs. This can increase collaboration between various members of the integrated care team and normalize discussions of health literacy.

## 19.8 Lessons Learned/Implementation

A successful response to limited health literacy requires multidisciplinary collaboration and communication, coordination, and quality improvement. A systematic approach is necessary to improve the health literacy environment of a healthcare system and increase individual health literacy. To address health literacy in a coordinated and comprehensive way, several "lessons" can be considered:

- *Embed health literacy into existing systems*. Sustainable health literacy initiatives require development and implementation of health literacy procedures at an

organizational level. This might require allocation of monetary funds for a designated health literacy coordinator or administrator, implementing policies that prioritize health literacy efforts, or identifying funding mechanisms that can finance staff training, development of materials, or quality improvement (ACSQHC, 2014; Simmons et al., 2017).

- *Actively and consistently update materials*. An inherent challenge is the dynamic and malleable nature of health literacy as a construct. Individuals may have a high health literacy in the general healthcare knowledge domain, in that they have a good understanding of how to maintain good health (e.g., regular physical exercise, reduce sedentary behaviors, healthy diet, minimize substance use, etc.) but may have a low health literacy regarding diabetes management, such as knowledge of medications, glucose monitoring, or lifestyle modifications that are needed to self-manage. Ensure that materials include information regarding general health literacy and disease-specific health literacy.
- *Identify leaders and champions*. Identify and support providers, administrators, or staff who can facilitate and nurture interagency relationships, advocate for health literacy policies at an organizational level, and lead development and implementation efforts.
- *Develop effective partnerships*. Action to improve health literacy can begin in one department and can flourish in collaboration with community partners and collaborators at the local, state, regional, and national levels.
- *Engage in on-going quality improvement*. Given the complexity of healthcare systems and extant gaps in research evidence for the most effective prevention and intervention programs, providers and organizations can incorporate evaluations of cost, efficiency, satisfaction, and other domains as needed into existing systems. QI efforts are likely to vary based on an organization's goals and priorities, resources, and clinical setting.

These are long-term considerations and strategies that can provide an initial framework to implement change at the organizational level. There are a number of tools that have been identified here that can provide extra assistance in the development of health literacy initiatives, including sample forms, worksheets, PowerPoint presentations, and quality improvement planning tools. Increasing the health literacy of individuals, families, and communities can have a long-standing effect throughout the medical community. Health literacy is critical for health promotion and disease prevention.

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