REVIEW

# Health literacy: What we know and don't know - A literature perspective

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#### ABSTRACT

Health literacy has become an important topic to discuss in the US healthcare system. Almost nine out of ten adults in the United States lack the knowledge and skills required to manage their health and prevent disease. While studies have shown the importance of health literacy, not may have explored its' history and conceptual roots. Hence, the purpose of this study is to address the gap in the literature by reviewing studies related to the past, present, and the effect of health literacy. The results have shown that inadequate health literacy does affect patients' general health and performance of the US healthcare system.

Key Words: Health literacy, Past, Present, Effect on society

### **1. INTRODUCTION**

According to the Institute of Medicine, health literacy is defined as "the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services needed to make appropriate decisions for the better of his or her health".<sup>[1]</sup> A study from the National Assessment of Adult Literacy shows that only 12 percent of adults in the United States have proficient levels of health literacy while 14 percent of adults, which accounts for about 30 million people, have below basic health literacy levels.<sup>[2]</sup> More specifically, almost nine out of ten adults may lack the knowledge and skills needed to prevent disease and manage their health.<sup>[3]</sup> The primary issue with health literacy is that patients do not understand the complex medical communication used in the delivery of care, which can cause a wide-range of negative consequences affecting disparities, care quality, and costs.<sup>[4]</sup>

While studies have shown the importance of health literacy, not many have explored its' history and conceptual roots. As it is important to know why and how major healthcare enactments, such as Medicare and Medicaid and the Affordable Care Act, have transpired, it can be equally important to find out the history, current status, and the effect of health literacy. Especially with COVID-19 impacting diverse patient popu-

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lation and healthcare systems, the topic of health literacy has become more crucial for researchers to understand. While diverse studies have examined the effect of health literacy in specific medical fields, limited number of studies have conducted a review on the past, present, and the effect of health literacy on general society. Hence, the purpose of this study is to address the gap in the literature by reviewing studies related to the past, present, and the effect of health literacy.

#### 2. HISTORY OF HEALTH LITERACY

The term "health literacy" is a relatively new term. It is derived from the umbrella term of "literacy", which is defined as: "The ability to use printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential."<sup>[4]</sup> Literacy became an emerging topic in the late 19th century because it was believed that nearly 20% of the American people were illiterate.<sup>[4]</sup> The US congress passed the National Literacy Act of 1991 as an attempt to increase the literacy levels of American adults and defined the term "literacy" as "Individual's ability to read, write, speak in English, compute and solve problems at a level of proficiency necessary to function on the job and in society, to achieve one's goals and to develop one's knowledge and potential".<sup>[4]</sup>

After the enactment of the law, diverse definitions and measurements of literacy started to appear in civilian and military work-forces as these two sectors required their employers to be able to read and write appropriately in order for them to function in their jobs.<sup>[4]</sup> Hence, the term "functional literacy" was coined.<sup>[4]</sup> The advent of this term brought a wave of educational reforms in the United States. Throughout the 20th century, the way literacy was measured was relative to people's educational level and increasing demands of more complex jobs.<sup>[5]</sup> For example, the US Census Bureau defined functional literacy as having at least a sixth-grade education in the 1980s, and most recently to a postsecondary education in the 2000s.<sup>[5]</sup>

In the 1980s, two leading literacy researchers published a study "Toward a Literate Society", which highlighted the fact that despite steadily increasing literacy levels, many Americans continued to suffer severely from deficient levels of comprehension and reading ability.<sup>[6]</sup> In order for researchers to accurately accrue information in regard to people's literacy level, different organizations recognized the importance of developing a precise measure of literacy before implementing any future assistance programs addressing literacy.<sup>[5]</sup> In 1985, the US Department of Education initiated a program called National Assessment of Educational Programs (NAEP), which was drafted to collect literacy data for Amer-

ican adults in the age range between 21 and 25.<sup>[7]</sup> In 1990, the US Department of Labor published a questionnaire and an assessment called "Literacy Proficiencies of Job Seekers". The purpose of this questionnaire was to better comprehend how working adults were understanding different forms of text.<sup>[7]</sup> In 2003, the Department of Education introduced the National Assessment of Adult Literacy (NAAL) to specifically target the measurement of adults with limited literacy levels, who would need further education.<sup>[7]</sup> NAAL is still regarded as an important milestone for the field of health literacy because it was the very first national assessment that specifically included a section to measure health literacy for all American adults.<sup>[7]</sup>

The advancement of health literacy followed similar steps as literacy. With the focus of the medical field shifting from treating medical conditions to preventing the conditions in the 1960s, which overlaps with the 1964 Surgeon General's report on smoking, the term "health literacy" was born.<sup>[8]</sup> The emergence of health literacy allowed the focus of public health initiatives to change from modifying the generally poor working and living conditions of the industrial revolution to improving individual's health behaviors.<sup>[8]</sup> This transition represented the importance of basic health and hygiene education and how it assisted the prevention of disease spread and promotion of better lifestyles for people residing in developed nations during the 1960s and 1970s.<sup>[9]</sup>

It became clear that researchers simply introducing assessment tools and providing large amounts of information, without considering the varying levels of socioeconomic status of people, was not helping the cause of increasing people's health literacy levels.<sup>[9]</sup> Studies have shown that the majority of the health initiatives of the 1970s were only impactful to those with higher socioeconomic status who previously had exposure to education.<sup>[9,10]</sup> Since then, many health literacy studies have identified factors such as economic, environmental, and social conditions and various policies as determinants of health.<sup>[10]</sup> The Ottawa Charter for Health Promotion, which was held in 1986, showed this change by focusing its' meeting on the necessity of organization's commitment to health promotion.<sup>[11]</sup> In this meeting, the term "good health" was defined as "a state of well-being that ideally should be achieved by all", instead of it being just a lifestyle choice.<sup>[11]</sup>

Since then, abundant studies focused on health literacy have presented enhanced definitions of health literacy and various interventions that could improve health literacy levels for patients with low health literacy levels.<sup>[12–14]</sup> Similar to literacy, many researchers focusing their attention on developing studies and tools to be able to accurately assess patients' health literacy levels. While there are more than jha.sciedupress.com

133 validated instruments measuring health literacy,<sup>[15]</sup> the three assessment tools that are most widely used are: Test of Functional Health Literacy in Adults (TOFHLA), Rapid Estimate of Adult Literacy in Medicine (REALM), and Brief Health Literacy Screen (BRIEF).<sup>[16]</sup>

#### **3.** CURRENT STATUS OF HEALTH LITERACY

The importance of health literacy has caught the attention of many healthcare researchers and organizations. Health literacy is now included as one of the measures of Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, and other organizations and agencies such as the Joint Commission, American Medical Association, and the Department of Health and Human Services have listed health literacy as an important component for healthcare quality and patient safety.<sup>[17]</sup>

Despite the fact that different healthcare organizations recognize the importance of health literacy, studies have demonstrated that the general population's health literacy levels are still low and limited.<sup>[18]</sup> In a study conducted by Pleasant et al.,<sup>[18]</sup> a global survey was sent out to 300 researchers who primarily focused their research on health literacy. Even though the majority of the researchers did agree with the notion that health literacy was a topic requiring attention. almost half of those very researchers also stated that they believed the public's awareness of, and attention to, health literacy was still quite lacking. One of the main reasons is because the term "health literacy" does not have a set-instone definition. The American Medical Association's Ad Hoc Committee noted the term "health literacy" had existed for at least 30 years in a number of health-related literatures, without having a singularly clear definition.<sup>[9]</sup> As a newer construct, it is not surprising that the definition of health literacy continues to evolve<sup>[9]</sup> and that the term has been incorrectly used across several studies.<sup>[11]</sup> Guyz et al.<sup>[11]</sup> noted that this lack of consistency might be because health literacy is comprised of multiple attributes, which allows different people and researchers to prioritize certain attributes over others. One peer-reviewed article found out that of 17 health literacy studies published from 1999 to 2010, 13 used different definitions of health literacy.<sup>[4]</sup> Of all the diverse definitions of health literacy, the definition from a 2004 Institute of Medicine report is the most commonly used throughout studies post-2010, which defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services to make appropriate health decisions".<sup>[4]</sup> While the definition of health literacy is becoming clearer, translating and comparing the meaning of health literacy in different languages is difficult since the conceptual comprehension of the term goes further than literal translation of words "health" and "literacy".<sup>[19]</sup> In other words, because the words "health", and "literacy" can have different meanings in different languages, comparing the meaning of health literacy in other languages becomes increasingly problematic.

Despite advancements, low health literacy remains problematic in the United States. According to a report from the Annals of Internal Medicine in 2011, nearly 80 million adults in the US are believed to have inadequate health literacy levels.<sup>[13]</sup> The impact of low health literacy is well documented. While research has shown that improving health literacy levels can enhance disease management behaviors,<sup>[20]</sup> low levels of health literacy, on the other hand, can act as a barrier to communication, which can diminish patients' understanding of physicians' instructions.<sup>[21]</sup> Low health literacy was defined as patients' inability to understand information in regards to managing disease.<sup>[21]</sup> The lowered level of patient-physician communication, due to low level of health literacy, can lead to additional issues such as perceived intimidation,<sup>[22]</sup> lessened patient engagement in their healthcare,<sup>[23]</sup> or provider mistrust.<sup>[24]</sup> All of these factors can lead patients with low health literacy to feel embarrassed when talking with physicians.<sup>[25]</sup> This can bring negative consequences for an individual patient such as refusing to accept that he or she has a health problem or impeding them from asking questions in regard to their health.<sup>[25]</sup> Additional studies have found that patients with low health literacy have experienced decreased levels of satisfaction at time of discharge.<sup>[26]</sup> Moreover, patients with low health literacy have a difficult time deciphering medical discharge instructions or prescription labels<sup>[27]</sup> and filling out forms necessary to obtain services, such as medication and insurance.<sup>[28]</sup>

# 4. EFFECT OF LOW HEALTH LITERACY ON SOCIETY

Understanding the epidemiology of low health literacy before understanding the actual effect of low health literacy levels in healthcare is imperative.<sup>[29]</sup> Socioeconomic and racial determinants of health literacy are crucial to more clearly understand the complexity of health literacy that can affect demographically diverse groups.<sup>[29]</sup> For example, a researcher cannot develop an intervention and state that it is going to be beneficial for people with different racial and ethnic backgrounds because the results of interventions may produce varying outcomes depending on race and ethnic background.<sup>[30]</sup> This is demonstrated in numerous studies, which have observed an association between epidemiological factors and low health literacy levels.<sup>[29,30]</sup>

Four of the most commonly studied epidemiological factors

are education, racial differences, age and physical impairments. There have been mixed results in terms of the association between health literacy and education, age and physical impairments. In terms of the association between education and low health literacy levels, Martin et al.,<sup>[29]</sup> reported that out of nine variables tested, low education level came out as the strongest predictor of inadequate health literacy levels. However, both Baker et al.,<sup>[31]</sup> and Taha, Sharit, & Czaia<sup>[32]</sup> stated in their studies that lower educational levels were not significantly associated with low health literacy levels. Similar trends are seen for age and impairments as well.<sup>[33]</sup> Both Kobayashi et al.,<sup>[34]</sup> and Bostock and Steptoe<sup>[33]</sup> reported increasing age and slowing in cognitive capabilities as strong indicators of limited health literacy levels. Furthermore, Shea et al.,<sup>[35]</sup> suggested that increasing age can be a strong predictor of low health literacy levels, but only when controlling for patients' educational levels. This proposes that age alone cannot be appropriate indicator of patients' health literacy levels. Out of the three epidemiological factors that have been most heavily researched, race is the only predictor studies have consistently reported to be a strong predictor of limited health literacy. Unfortunately, researchers have not discussed other possible predictors such as ethnic or cultural origins in this particular study. Chaudry et al.<sup>[36]</sup> noted that there as a strong association between being African American and having inadequate health literacy. A similar result was obtained by Martin et al.,<sup>[29]</sup> who found Hispanics and African Americans had lower health literacy levels than non-Hispanic whites.

Previous studies examined how inadequate health literacy can affect patients' general health and performance of the US healthcare system. Inadequate health literacy levels have been associated with numerous health issues such as lower overall health,<sup>[37]</sup> increased rate of obesity,<sup>[38]</sup> worse management for HIV/AIDS patients,<sup>[13]</sup> and increased use of health services.<sup>[37]</sup> One specific aspect of low health literacy related to all of these phenomena is patients' inability to comport with a healthy lifestyle. By not being able to adhere to a positive lifestyle, patients will be more likely to engage in unhealthy eating habits, resulting in patients having a higher than average body mass index (BMI). James and colleagues<sup>[38]</sup> found an association between limited health literacy levels and high BMI in a population of African American females who had a difficult time comprehending nutritional information. A similar result was observed within HIV/AIDS patients. HIV/AIDS patients with low health literacy levels were shown to have higher risk of medication nonadherence and worse self-reported health.<sup>[39]</sup>

Not only does limited health literacy level have an association with increased use of health services, it is also significantly associated with lower utilization of preventative health services such as immunizations and an inability to adhere to a recommended medication and treatment.<sup>[13]</sup> In other words, patients' limited health literacy levels can potentially have a negative impact on the US healthcare system. According to the National Institute of Health and Friedland's modeling assumptions,<sup>[40]</sup> it was estimated that the effect of low health literacy cost the US healthcare system \$1.6 trillion to \$3.6 trillion,<sup>[41]</sup> due to medical complications and readmissions.

## 5. CONCLUSIONS

The purpose of this review was to explore the literature related to the past, present, and the effect of health literacy. With COVID-19 affecting a huge number of population and its effect overwhelming the healthcare system, the role of health literacy and health education has become even more imperative. Unfortunately, even though the topic of healthcare quality improvement has been thoroughly studied for a long period of time, health literacy has rarely been thought of. Part of a reason for this phenomenon could be because the field and definition of health literacy is still evolving.<sup>[9]</sup> However, the primary issue with health literacy is that at least half of Americans adults may not understand the complex medical communication used in the delivery of care, causing a wide-range of negative consequences such as disparities, costs, and care quality.<sup>[1]</sup> Furthermore, studies have shown that patients' limited health literacy levels can cause patients to have longer length of stay in a hospital, higher chance of being readmitted, and higher chance of getting complications post-surgery.[26,42]

Hence, the direction of future research can be to create and observe the impact of health literacy interventions. A number of health literacy interventions exist, such as the teach-back method, eHealth intervention, and simplifying health information in educational materials. Future research can compare individual interventions to one another and see which are most effective. On the other hand, a new intervention can be generated to observe if it improves patients' health outcomes or observe how these interventions can impact overall quality improvement and financial status of their organizations. For example, a study conducted by Barad et al.<sup>[43]</sup> showed that the decrease in average length of stay from 2.0 to 1.3 days resulted in \$3,245 of savings per patient in 2014 for a healthcare organization. Furthermore, additional study has shown that reduction in readmission rates have resulted in decrease in operating expenses for healthcare organizations.<sup>[44]</sup>

#### **CONFLICTS OF INTEREST DISCLOSURE**

The authors declare they have no conflicts of interest.

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