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# Considerations of Low Health Literacy during the COVID-19Pandemic

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***Abstract:*** The Coronavirus (COVID–19) pandemic has had devastating effects throughout the United States and the world. Recent numbers indicate that approximately 250,000 people in the United States have died from COVID-19, while over 150,000 new cases are announced each day. The numbers of people affected, and the latest Covid research findings have been reported several times a day. Despite the reports, directions, mandates, and recommendations of public health officials, the number of people with COVID-19 continues to climb. Medical information has been reported by the media, medical officials, press briefings, social media, and through social interactions, but that information has often been confusing, conflicting, misleading, and fear inducing for many. Individuals with low health literacy may be impacted by COVID–19 more heavily and more frequently than individuals with proficient health literacy levels due to their inability to understand and carry out health safety recommendations.

***Keywords:*** literacy, low health literacy, medical terminology, coronavirus, , pandemic

## CONSIDERATIONS OF LOW HEALTH LITERACY DURING THE PANDEMIC

The United States (U.S.) is facing the debilitating and deadly impact of the Coronavirus (COVID–19) with 262,673 deaths, and more than 150,000 new cases added each day (Elflein, 2020).Daily news reports relay numbers of cases and the dire state of the nation's hospitals' capacity to take new COVID cases. Government, public health, and medical officials have been reporting the status of the COVID virus while offering suggestions regarding self-protection since March of 2020. Yet, new cases of the virus continue to be identified, mortality rates continue to climb, and families are left to deal with the loss of loved ones. There must be other variables that are driving new cases of the virus despite official recommendations to wear masks, wash hands, and socially distance. Some of those variables include problems with low health literacy, communication difficulties created from the use of medical terminology and jargon, comorbidities, issues of demographics and social influences, understanding the unique factors involved in educating patients, and infodemics. While the COVID-19 pandemic alone is creating devastating health problems, the combination of COVID–19 and low health literacy is elevating the medical crisis to frightening and potentially catastrophic levels.

## THE DISCONNECT OF MESSAGE VERSUS UNDERSTANDING

There is a possible disconnect between what public health officials are saying and what the public understands. Part of the problem is low / poor health literacy, or the inability to understand medical information that is being stated or read. Low health literacy impacts an individual's ability to make appropriate health decisions and has a potential result of more frequent hospitalizations, poorer health outcomes, higher mortality rates, suboptimal quality of life issues, and more expensive healthcare utilization (Haun etal., 2015). In 2013, Mahadevan estimated that close to 36 percent of United States (U.S.) residents had low health literacy which includes the categories of basic and below basic health literacy leading to approximately $236 billion in health care costs each year. Furthermore, a study by Davis et al. (2020) concurred with the 36 percent basic or below basic health literacy finding, while noting that only 12 percent of U.S. residents had a proficient health literacy, or the ability to perform difficult and demanding health care skills.

## LITERACY BY GRADE LEVEL

This may be easier to understand when one considers literacy compared to school grade levels, according to Mahdevan(2013) the average American reads at a fifth-grade level (Fact Sheet #4).While this information represents the literacy of approximately one-half of American adults, it indicates that a large proportion of residents will potentially have health literacy difficulties. To confound the health literacy issue, most health care information is written at the 10-grade level (Safeer & Keenan, 2005; Mahdevan).This discrepancy in reading ability versus the reading level at which health literature is written will prevent individuals with low health literacy from being able to review and comprehend medical directions that may lead to medication errors, missed appointments, or worsening health conditions.

## HEALTH LITERACY DEFINED

Health literacy is defined as an individual's ability to access, use, and comprehend health guidance, knowledge, services, or instructions (Davis et al., 2020); the skills needed to carry out health care responsibilities (Berkman, Davis, & McCormack, 2010); and the capacity to carry out fundamental reading and math calculations related to health care needs (Egbert & Nanna, 2009).There are four literacy

performance levels, below basic, basic, intermediate and proficient. Each level is determined by specific key abilities such as searching, comprehending, using, calculating and identifying certain health information (Kutner, Greenberg, Jin, & Paulsen, 2007).Each performance level includes health tasks in three areas. Those areas are 1) prose, or the ability to obtain information from written text, 2) document literacy, which requires being able to locate, understand, and use specific information found in a document, and 3) quantitative skills, or the skills needed to abstract and apply numerical information (Kutner et al., 2007).A patient who receives an appointment card for a return appointment and can look at the reminder card and find the date and time of the next appointment would be exhibiting the ability to obtain information, or prose. A patient who is given a prescription for an antibiotic and is able to look at the medication label and locate, read, and correctly follow the directions in order to take the right amount of medication at the right time exhibits literacy. A patient who reads the label and is directed to take two tablets twice a day with meals, and is able to apply that knowledge and takes the correct number of tablets twice a day at mealtime rather than taking two tablets an hour apart, is exhibiting the skill of quantitative health literacy. However, individuals with low health literacy may have difficulty with one or all of these types of skills.

## HEALTH LITERACY REQUIRED ABILITIES

However, according to Mahdevan (2013), health literacy goes beyond the ability to read, comprehend, locate, understand, follow, or calculate (Fact Sheet #2). When it comes to personal health care, health literacy involves the ability to recognize health problems, locate and access a source of healthcare, relay the health problem to a medical professional, comprehend what directions are received to treat the problem, and obtain, read and take medication, among other necessary tasks. An individual who can carry out any of the abilities related to health care can potentially prevent, slow, or eliminatea healthcare problem. Delayed healthcare makes treatment more difficult ,or in the example of COVID-19, very difficult to treat successfully. Early recognition, detection, treatment and participation in one's healthcare leads to better health outcomes. In the case of COVID–19, many people choose to ignore the signs and symptoms of the virus, choosing instead to believe that it is an allergy, cold, or the flu. Granted, there may be some similarities, but rather than contact a healthcare provider, a COVID-19 telephone hotline, or seek a COVID–19 test, they choose to deny the possibility of having the virus, lessen the veracity of their symptoms, and not seek medical treatment until the virus has advanced to a dangerous and potentially untreatable level. In addition to the health related skills listed, individuals need to successfully understand medical terms.

Patients often run into the problem of medical jargon, also called MedSpeak or medical shorthand,which is a communication style used by medical personnel (Killian &Coletti, 2017).In addition, laypersons tend to have a healthcare vocabulary or medical understandings that may mean something to the person, but not to medical professionals. This language confusion can lead to misinterpretation that may interfere with healthcare diagnosis and treatment (Zeng & Tse,2006).COVID terms such as virus, herd immunity, social distancing, and contagion have different meanings to different people. For example, colds are caused by a virus, yet people don't usually die from a cold, so colds are not considered dangerous. Herd immunity sounds like something having to do with cattle or placing people together in one place, which may seem illogical for good health. Social distancing conjures thoughts of emotional separation as in a bad relationship rather than physical distancing, and morbidity tends to make one think of something or someone who is gloomy or obese. In other words, these terms do not convey the COVID-19 meaning to all people.

In the case of the COVID-19pandemic, news and public health reports continually mentioned higher risks of contracting related to the comorbidities of hypertension, diabetes, obesity, cardiovascular disease, cancer, chronic obstructive pulmonary disease, cerebrovascular accident and chronic kidney disease (Singh, & Misra, 2020). The names of the comorbid conditions alone, could cause confusion as many people do not refer to the conditions by those terms. For instance, hypertension is often referred to as high blood pressure or, simply, blood pressure; diabetes may be called sugar or blood sugar; cardiovascular disease is often called simply heart disease, and so on(Zeng & Tse, 2006). The misinterpretation and misunderstanding of these medical terms and their effects could lead to failure to be concerned up to complete panic. The term comorbid can easily be confused with mortaland could easily be interpreted as having to do with death or dying. The thought of death can create such a level of fear that some people no longer hear anything that is said to them which can be disastrous when working with patients who have or may have COVID-19.

## POOR HEALTH OUTCOMESRELATED TO LOW HEALTH LITERACY

The inability to understand medical terms is a problem across the literacy spectrum and is not limited only to individuals with low health literacy. Graham and Brookey (2008) noted that lower health literacy skills carry a higher level of poor health outcomes, and patients with low health literacy tend to have less understanding of their chronic illnesses, and how to manage those illnesses. Poor physical condition, pain, sedation from medication, and the inability to differentiate trustworthy information may all contribute to difficulty understanding medical information and healthcare directions. Furthermore, Graham and Brookey referred topoor health literacy is an unseen epidemic that involves individuals who do not understand written or verbal directions and are unable to navigate the healthcare system without difficulty. In 2011, Peterson et al. conducted a surveyof heart failure patients that had 1547 respondents. Of the survey respondents, 262, or 17.5%, were considered to have low health literacy and by comparison to other responders, had a higher mortality rate of 17.6 % compared to 6.3% (Peterson et al., 2011). Peterson et al. concluded that low health literacy was notably affiliated to higher mortality.

## DEMOGRAPHICS OF LOW HEALTH LITERACY

Certain demographic groups have been identified as having higher numbers of individuals with low health literacy including individuals with lower socioeconomic status (SES), lower than a high school education, and those who were older chronologically (Peterson et al., 2011). In addition, Kutner, et al. (2006) found that men, Blacks, Hispanics, American Indians/Alaska Natives, and Multiracial adults, and English as a second language learners had a lower health literacy. Hickey et al. (2018), included individuals with chronic health conditions in their low health literacy list, while Christy et al. (2017) included lack of employment, being unable to work, lack of health insurance or primary care doctor, social influence and religious stance as variables with low health literacy indications. These demographic groups have higher than average numbers of individuals stricken by COVID-19, with 58% of hospitalized COVID patients being Black or Hispanic and 53% of those dying from the COVID–19 (Rodriguez, 2020).

In many cases, individuals with low health literacy have several demographic factors that tend to increase health literacy problems. Factors such as being unemployed, a member of certain minority groups, or lower levels of education, which are often seen together,may interfere with one's ability to attain and afford healthcare, while lower reading skills may make completing basic medical paperwork or making and keeping appointments more difficult. Friends and family and social media may interfere or sway an individual's decision making in ways that conflict with medical recommendations. Rural and underserved areas tend to have residents who do not have regular or easily accessible healthcare providers, and lower SES that make healthcare logistically and financially problematic.

## SOCIAL INFLUENCES ON HEALTH CARE DECISION MAKING

The inability to fully comprehend the need for preventative services and health screenings, such as COVID-19 testing, may contribute to the failure to detect health problems until the disease or condition is well advanced. Christy et al. (2017), in a study of Colorectal (CRC) screening patients, found that many patients lacked understanding of the need for screening and preventive health services even though they were in populations with greater risk of and mortality from CRC. However, Christy et al., found that participants in theCRC study with lower health literacy placed a greater reliance on opinions and directions of influential individuals, such as medical personnel or family, and would comply with medical screening when directed by the influential person to do so. In other words, rather than the study participants understanding the need for healthcare screening, they tended to follow the directions of others which indicated an inability to make healthcare decisions autonomously. Furthermore, a patient who cannot make an autonomous, informed decision may be easily convinced to do something that is harmful or not in their best interest.

Furthermore, individuals who relied on the opinions of others for decision making were less inclined to seek medical information online or in written form (Christy et al., 2017). This could indicate an unfamiliarity with technology or trustworthy written information, or it could be related to uncertainty about one's ability to comprehend the material, and a desire to avoid feeling incompetent. However, seeking direction from others does not indicate that a person will develop an understanding of the medical issue nor does it show the ability to make sound medical decisions. In addition, many individuals with low health literacy tend to look to religion for healthcare direction. Christy et al. noted that increased dependence on religious beliefs was frequently an indicator of lower health literacy due to coping styles related to religious beliefs. During the COVID-19 pandemic, many religious groups denied the need for facial masks for protection, citing belief in the protection of a higher power. Unfortunately, the failure to practice safe self-care has led many religious groups to be the cause of COVID-19 super spreader events.

## SOCIAL MEDIA AND HEALTH CARE LITERACY

While many individuals with health literacy issues have looked to medical professionals, family, and religious influences for help with comprehension and directions related to medical issues, other individuals across the health literacy spectrum have turned to social media (Mokhtari & Mirzaei, 2020). Nowhere is this more evident than in the case of COVID-19with the rapid increase in complex information related to the causes, symptoms, mortality, treatments, and control of the disease, much of which has been false, misleading, and unreliable, or written at a level that most Americans cannot adequately understand. (Mokhtari & Mirzaei). Given the $10^{th}$ grade level at which much of the information is written, combined with the questionable reliability, the lack of veracity, and the fear and anxiety inducing topic, it is logical that many individuals would find the articles confusing, frightening, and misleading. In addition, misinterpretation or implementation of false instructions or suggestions may lead to disastrous and possibly deadly results (Mokhtari & Mirsaei). Indeed, the social media situation has grown so rapidly in relation to COVID-19, that in February 2020, the director of the World Health Organization (WHO) declared the widespread misinformation an "infodemic" (Zarea Gavgani, 2020, p. 1; Katella, 2020).

## INFODEMIC DEFINED

Infodemic is defined as an exorbitant amount of information that is often incorrect, misleading, has a rapid spread, and does not improve a problem or lead to a solution. Katella (2020) described infodemic information as conflicting, staggering, of questionable reliability, and fluctuating. Some opinions offered on social media have denied the existence of the pandemic, made claims that the COVID–19 pandemic is actually the yearly flu, and that the source of the pandemic was a planned biochemical release. Personal rights about the need to wear a mask have been argued in social media, while a range of home remedies for curing COVID–19 have been abundant.

Social media has frequently used medical terms such as presumptive, presumably recovered, micro epidemics, epicenter, and flattening the curve which can be confusing,

create stress and lead to more questions across the health literacy spectrum. Furthermore, an individual's choice of social media may present inherent factual problems. One who considers Facebook, Twitter, or Instagram more reliable than reports from the WHO, or peer reviewed scientific journals may find information that is dangerously unsafe and unreliable (Katella). Individuals with and without health literacy issues may not be able to determine whether the author of health information is citing fact based information or a third or fourth hand reinterpretation of a report.

In today's fast paced society, the desire for quick information may lead an individual to internet websites that are compensated by advertisements and encourage visits with shocking information rather than true and factual information (Mokhtari & Mirzaei, 2020). Furthermore, Mokhtari and Mirzaei stated the acceptance of information without possessing basic health literacy can lead to increased mental stress and uncertainty. Misleading health information is not limited to social media or the internet. Many often repeated and dangerously misleading ideas and suggestions can be heard during press briefings and news reports as noted by Evanega et al.,(2020). In an article about coronavirus misinformation, Evanega et al. analyzed 38 million pieces of media information over a five month period in early 2020 and found the over 1.1 million news articles reported misleading or incorrect information about the pandemic.

Of the misleading information found in the Evanega et al. (2020) study, President Trump is indicated in 37.9% of the reviewed articles and was deemed the greatest force behind Covid-19 misinformation. For individuals with low health literacy who look to authorities for direction in health matters, this abundance of misinformation including disinfectants used internally and promotion of drugs such as hydroxychloroquine could lead to serious health outcomes. Evanega et al, concluded that information presented by infodemic requires increased attempts to fight the misinformation in order to protect the public by citing the HIV/AIDS pandemic in South Africa, where incorrect and misleading information led to more than 300,000 extra deaths. The goals of combating misinformation and improving health outcomes return the focus of health care to remedies for low health literacy.

## IDENTIFYING BEHAVIORS OF INDIVIDUALS WITH LOW OR POOR HEALTH LITERACY

Much has been written about low health literacy and methods to identify individuals with literacy issues and methods of improving communication, understanding, and health outcomes. Mahdevan (2013) stated that low health literacy may be hidden and difficult to identify due to the patient's embarrassment, but it is often present (Fact Sheet #2). Aside from the demographic identifiers of lower SES, culture, race, gender, culture, employment, lower education level, or social or religious affiliations, Mahdevan listed other potential indicators of low health literacy. Behaviors such as missing appointments; difficulty or inability filling out forms; inability to state names of medications, their purpose or dose; looking at pills to identify them instead of reading the label; difficulty relaying a logical medical history; failure to complete tests or referrals; or frequently offering excuses for not being able to read textual materials.

## QUESTIONS PROVIDERS CAN USE TO DETERMINE PROBLEMS OF LOW HEALTH LITERACY

During an appointment, health care providers can ask questions about a patient's ability to read prescription bottles, complete forms, use health related items or materials or if the person gets help with these items or actions. In addition, a provider can ask if the patient has problems reading and recalling healthcare information; what the patient likes to read; and where they get their information about health matters (Mahdevan, 2013, Fact Sheet #2). Providers can also obtain online formal assessments that identify low health literacy including REALM/D, SAHLSA and TOFHLA available on the AHRQ Literacy Tools website (2019).

## ENCOUNTER CONSIDERATIONS FOR HEALTH LITERACY

Major considerations when speaking with any patient, but especially individuals who may have issues with health literacy, include whether the patient seems reluctant to share that they have problems understanding the medical information said to them, appears to be too uncomfortable with the information to ask questions, or that they may not be able to understand medical language, or Medspeak (Killian & Coletti, 2017). Mahdevan (2013) suggests that medical providers try to provide an environment that feels comfortable and accepting of the patient; use language that is slow, clear, and easy to understand; avoid medical jargon or Medspeak and abbreviations; involve the patient by using visual aids such as pictures, models, and videos to describe the medical issue; and ask for teach back which has the patient repeat to the provider what they were told (Fact Sheet #5). Another important consideration for medical providers is the issue of magical thinking across all levels of the health literacy spectrum. Magical thinking, according to Miro (2020), is the belief that some individuals hold that they are different and, therefore, invincible or unable to catch or fall victim to a disease, in this case COVID-19. The error of magical thinking is that the failure to follow prescribed medical directions such as handwashing, social distancing, and wearing masks creates a potential for the spread of the virus especially if an individual has COVID-19 but is asymptomatic. In addition, a magical thinking may be an indication of low health literacy and the inability tograsp health the severity of health issues.That lack of understanding could explainwhy an individual does not protect himself or follow health safety measures.

## PATIENT RIGHTS

Ideally health care should engender shared decision making which involves patients and medical providers making informed decisions for health care and positive outcomes (Killian & Coletti, 2017). To that end, according the American Medical Association (AMA, 2020), patients have certain health care rights including the right to dignity, autonomy, respect, to receive and discuss information, to ask questions, to make decisions, to have privacy and confidentiality, to have copies of the records, to get a second

opinion, to be made aware of conflicts of interest regarding their care, and to have continuity of care To that end, Killian and Coletti (2017) recommend the use of Health Literacy Universal Precautions (HLUP), a toolkit created by the Agency for Healthcare Research and Quality (AHRQ), to improve patient's grasp of what they can expect during a healthcare visit.

The HLUP provides free online tools that providers can use to foster communication with individuals and their families across the health literacy spectrum (Killian & Coletti, 2017). The tools cover a range of questions, literacy level prepared materials, and directions for having the patient "teach-back," or explain, their grasp of what they have been told (Killian & Coletti). Furthermore, Killian and Coletti stated, the HLUP recommends that medical providers operate from the viewpoint that all patients may have low health literacy.

## HEALTH CARE APPROACH TO HEALTH LITERACY

While medical providers should assume that all patients have low health literacy, Koch-Weser et al. (2009) found that 79% of doctors in a study did not translate or clarify medical terms that they used when speaking with patients. In addition, Koch-Weser et al., found that patients did not react in ways that indicated they understood the complex terms, and medical terms were usually not repeated during the current or subsequent encounters to allow for clarification or inquiry by the patient. Given the lack of clarity or explanation, the potential for misunderstanding, misinterpretation or harm was possible. Koch-Weser et al. used the common term drugs as an example of potential miscommunication. While the doctor might be using drugs to mean prescribed medications, a patient could comprehend the term drugs to mean illegal substances. Another common question such as "Have you had anything to drink today?" could mean the intake of water, milk, coffee, etc. to one patient but might be taken to mean drinking alcohol to another patient. Communication needs to be clear, concise with the potential meaning or comprehension for the listener taken into consideration.

In conclusion, the COVID–19 crisis has placed the issue of health literacy front and center. More than at any recent time, the pandemic has shown that individuals need to be able to respond to health issues quickly, accurately, and responsibly (Paakkair&Okan 2020) But the rising numbers of new COVID-19 cases and the rising death toll indicate that people are not making appropriate health decisions, and they are suffering the consequences from those poor decisions. Indeed, individuals who are in low health literacy demographic groups are dying at far greater numbers than groups that do not have health literacy issues. This is not the time to disseminate health information that is misleading, unclear, or difficult to understand. Health care providers need to determine the health literacy of patients and provide clear, understandable directions that the patient can "teach back" to the provider. News reports and press briefings should be basedon factual, scientifically based informationthat is easy to understandat a fifth grade reading level to educate the public of the risks of this deadly disease. Health information needs to be simple, straightforward, logical, and medically accurate, and it needs to provide understandable direction to everyone across the health literacy spectrum while emphasizing the need for social responsibility (Paakkari&Okan). To do otherwise allows the COVID-19pandemic to continue to destroy lives, families and societies.

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