Perspective in AE — Building a Culture of Health Literacy during COVID-19

Iris Feinberg

One in five Americans reads at elementary school levels (U.S. Department of Education et al., 2020). These low literacy skills include the technical part of reading (phonemic awareness, phonics, fluency) and the essential component of comprehension, the cognitive process readers use to understand what they have read. This means over 66 million people cannot read or understand most of the health materials that are currently written about COVID-19. If people do not understand what is being said, whether due to technical reading skills or poor comprehension, they will not be able to follow guidelines and instructions, know when to contact their health provider, or how to protect themselves and their families during this pandemic. We have learned that protective COVID-19 behaviors like wearing a mask and social distancing protect both the individual and the community. Adults who read at elementary levels (low literacy) are also likely to have low health literacy which are the skills that allow one to access, understand, and use health information. If we allow adults with low literacy to fail at COVID-19 safeguards and inadvertently share this illness broadly throughout communities, we will all fail. The link between adult education and health literacy is a critical component of improving health outcomes for adults with low literacy. Individual skills such as reading, understanding numeracy issues like risk or probability, locating health information, and verbal communication skills are fundamental to improving health literacy, and can be successfully taught in adult education and English as a second language classes.

In the rush to find the latest smart pill with embedded microtechnology that can be tracked through your body with GPS technology, harness big data, or reverse the trend of this COVID-19 pandemic, the fundamentals of healthcare and well-being are often missed. Our healthcare system – education, insurance, pharmaceutical, clinical care, and population health – was not designed to serve individuals and communities in terms of cultural competence, language, and literacy standards, yet there is a clarion call for patient participation and shared decision-making in healthcare today (Richard et al., 2017). The gap between what and how health information is provided and what information patients, caregivers, and health consumers can access,
Low health literacy can affect everyone and techniques used to improve the content and delivery of health communication should be universal (Liang & Brach, 2017). Individual health literacy is also contextual and situational – many of us, even highly-skilled readers, are struggling with the barrage of information, misinformation, and conflicting information about COVID-19. Generally, however, low health literacy is highly correlated with lower levels of educational attainment, being a minority, limited English proficiency, having low reading skills and other measures of lower socio-economic status (Kutner et al., 2006). Research tells us that individuals with lower health literacy also tend to have lower digital skills and less access to the internet (Feinberg et al., 2015), which is incredibly problematic when so much COVID-19 information is disseminated online. Individuals who tend to have low health literacy are struggling with caring for themselves and their families during this crisis because they cannot access, understand, or use COVID-19 health information.

The social ecological model is often used to describe how individual, relational, community, and societal factors all interact to affect peoples’ health and well-being. For example, people who have higher literacy skills (individual) are likely to hold better paying jobs (community) and may be more able to afford insurance and medical care (societal healthcare system), and thus know more about health-related issues like COVID-19 (Driscoll & Bernstein, 2012). Also called social determinants of health (SDOH), these factors can have either positive or negative influence on a person’s well-being. We have seen how COVID-19 has taken a terrible toll on African Americans who live in lower resourced communities with poor SDOH (Centers for Disease Control and Prevention, 2020). Adding to the underlying injustice that many people in lower resourced communities are deemed essential workers and do not have a choice of not going to work, they also may not be able to read or understand the health warnings and instructions that have been created to protect individuals and communities in this crucial time.

Immigrant, migrant, and refugee populations face other barriers and challenges including language, culture, trusting the sender of the message, and the health system itself (National Academies of Sciences, Engineering and Medicine [NASEM], 2017). Our recent study in Clarkston GA, a community where more than 17,000 refugees who speak 60 different languages have been settled since 2004, demonstrates that 41% have poor health, only 30% have health insurance, 60% have transportation problems and 76% have high stress, yet the primary barrier to health care access is language, both limited English, inadequate translation services, and the technical language of health and healthcare (Feinberg et al., 2020). Other studies indicate that the combination of English proficiency, culture, and health literacy is complex, and create significant challenges to engage individuals and provide care to communities (NASEM, 2017).

We can do better. Creating a culture of health literacy means not only paying attention to the fundamentals of improving equitable quality of care, it also means being prepared so when flu season arrives or new viruses rear their ugly heads, the large portion of low-skilled readers in America are protected at the beginning of the cycle, not sometime later on when health literacy and literacy specialists start creating materials to respond. An example of reaching people where they are when they need information is a project called Text4Baby; originally an SMS-based system and now including an app, Text4Baby helps low-SES pregnant women get critical COVID-19 health information during their pregnancy and for a few months afterwards (Whitaker et al., 2012). Available in English and Spanish, evaluation shows that 90% of participants found the messages easy to read and useful; another study showed that 92% of users regularly read Text4Baby messages (Whitaker, et al., 2012). Perhaps more important are the behavior changes that are associated with receiving health information that is easy to access and understand – various studies show improved appointment attendance, improved glycemic control, lower postpartum alcohol consumption and improved rates of influenza vaccination (Evans et al., 2015; Grabosch et al., 2014; Martinez & Úekusa, 2013). Text4Baby shows that improving prenatal and postnatal beliefs, knowledge, and behaviors in an appropriately delivered and health literate program has a positive impact on maternal and child wellbeing, both key indicators of improved family, social, and educational circumstance (Federal Interagency Forum on Child and Family Statistics, 2015). We know that many communities, particularly those that are marginalized and have low literacy or English skills, are still struggling with the barrage of Coronavirus and COVID-19 information. Providers of COVID-19 information should consider the success of this texting program that provided scientifically accurate yet easy to understand health information delivered in a timely and accessible format.
Partnership plans need to be in place with community leadership before disasters and emergencies strike so people can look to their own trusted sources for accurate information. Adult educators, community organizations, and health clinics all serve the same population that may struggle with not only literacy issues, but with concerns about source credibility (Chen et al., 2018). Getting information that is trustworthy and easy to understand and use into people’s hands without delay is a key element of caring for people in a crisis. There are several examples of cross-organization collaboration that build this kind of trust and access. One is the Florida Health Literacy Initiative, a statewide program between the Florida Literacy Coalition and various literacy, English language, and family literacy programs that helps local literacy providers build robust health literacy projects (Florida Literacy Coalition, 2015). A key component of their work is collaborating with health centers and community partners to provide health care screenings, exercise classes, presentations by health providers, and visits to hospitals, fire stations, and health centers. Another program is the Literacy Assistance Center of New York City which developed partnerships between 75 adult education programs and 35 health facilities; more than 3,000 adult learners and 175 teachers improved their health-related knowledge, increased understanding of the medical system, and have healthier practices in dietary habits and use of preventive screenings. In times of crisis, stronger partnerships and coordinated efforts between community-level organizations that serve similar populations can help disseminate trustworthy information to benefit adults with low literacy in a timely manner (Drew et al., 2019). People who live in more vulnerable communities tend to trust those they know, that is, a community organizer, their pastor, or an adult education teacher (Chen et al., 2018). Providers of health information like doctors, the CDC, and health systems can help get critical COVID-19 information out to communities by partnering with these trusted sources.

Public health agencies who are tasked with health promotion can be better prepared by anticipating and planning alternatives to print information for the tens of millions have low literacy and who struggle with COVID-19; our analysis of data from the Programme for the International Assessment of Adult Competencies (PIAAC) tells that adults with low literacy rely on television and radio more often than on print information or the internet (Feinberg et al., 2015). Further, PIAAC data tell us how people read, write, and use numeracy skills in order to accomplish daily tasks; those with low literacy and numeracy skills may have more difficulty than others in performing health-related tasks like filling out forms in a doctor’s office, understanding health insurance information, or reading a prescription label, all indications of low individual health literacy (Goodman et al., 2013). Simple messaging modalities, like Public Service Announcements (PSA), remove many of the complications that adults with low literacy skills have in accessing important health messages. PSAs are verbal and/or visual messages created to raise awareness and change attitudes and behavior toward an issue, most commonly on health and safety issues, and are often shown on television, radio, or billboards so that many people can hear/see the same message at the same time. One example is the “Talk Until They Hear You” campaign by Substance Abuse and Mental Health Service Administration (SAMHSA) that addressed parental influence in stopping underage drinking; PSAs were featured on TV, radio, newspaper, and billboards in both English and Spanish. One of the most successful public health PSA campaigns is the Anti-Smoking campaign that began in 2000 in North Carolina; aimed primarily at teens, analysis in 2005 showed that there were substantial declines in youth smoking that were associated with this campaign. The idea of PSAs and other mass media campaigns is to reach people where they are with messages that are clear, easily understandable, and meaningful. Current COVID-19 PSAs are primarily online (YouTube, Facebook, and organization websites) and may not be accessible by adults with low digital access and/or skills who may rely on television and radio for health information.

The background information and science behind the Coronavirus and COVID-19 is important and interesting, but it’s not much use to struggling readers who simply need to know what to do in times of emergency to take care of themselves and their loved ones. Plain language guidelines focus on writing so readers can find what they need, understand what they find, and act on what they find (Plain Language Action and Information Network, nd). When health promotion materials contain concrete, short action statements and are focused on answering the question “what should I do”, individuals understand what their behaviors should be (Barton et al., 2018; Mayer & Villaire, 2007). Using plain language, non-technical terms, and including appropriate visuals can help individuals with low reading skills understand what steps to take to improve their health and well-being (Batterman et al., 2016). At the Adult Literacy Research Center, we have created a library of high interest/low literacy COVID-19 documents that adult educators, community organizations, and health providers can access to share with adults who are low-skilled readers. As part of our collaboration with the School of Public Health CDC-funded Prevention Research Center at Georgia State University, we have also created a flip book
for adults who have low reading skills that addresses many of the COVID-19 related myths that our local refugee communities struggle with. Both can be accessed at https://education.gsu.edu/research-outreach/alrc/. We decided to organize and release all of these materials even though they have not been tested with our intended audience, a process that is vital to producing health literate materials. As experts in the field of health literacy and adult literacy, we called on our past experience and skills in developing materials for adults with low reading skills because people need this information now in the midst of this pandemic. Now that the English version has been disseminated, we have begun a study to determine if there is a change in knowledge after reading the flipbook. We have also been asked to translate the flipbook into five other languages to disseminate in the community.

We find ourselves faced with a public and individual health crisis that requires all of us to practice the same health protections in the same way to create and maintain healthy communities. Structural racism, economic disparities, and health inequities are related in many ways and are inexorably inter-related. Adults from marginalized communities with poor education are likely to have low-paying jobs which affects not only income, but housing, food security, and availability of health insurance. As a society, we have institutionalized policies surrounding educational and social opportunities for minority communities, and although COVID-19 is but one of many crises facing these communities, we can take this opportunity to do better. Adults with low literacy skills are left out of the critical communication chain that describes those health protections which is more than simply unfortunate. It is part of a structured social injustice that we can address by improving the health and wellbeing of vulnerable populations. Dealing with COVID-19 requires equitable and universal dissemination of culturally and linguistically appropriate health information. There has never been a more important time to build a culture of health literacy for all Americans.

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