

HEALTH LITERACY'S EFFECT ON EMERGENCY DEPARTMENT
UTILIZATION: A SMARTPHONE-BASED INTERVENTION

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

by

Julia Burger, MD
December 2018

Thesis Approvals:

Kathleen Reeves, Thesis Advisor, Center for Bioethics, Urban Health, and Policy

ABSTRACT

Health literacy is not only the ability to read, but also the ability of an individual to obtain, process, and understand the basic health information needed to make appropriate health decisions. Over time the concept of health literacy has evolved from considering it a risk factor to be managed to considering it an asset which can be continually built upon. With this in mind health professionals should continue to communicate in simple language, but should also provide their patients with high-quality educational materials and aid them in making the best choices about their health. One way to do this could be with the use of symptom-checking and decision-aiding smartphone apps. In this study, the primary caretakers of children aged 30 months and younger with publicly funded health insurance will be randomized to receive a pediatric symptom-checking smartphone app or a developmental milestone smartphone app. Caretaker health literacy will be measured, and data will be collected on emergency department and primary care office sick visits. It is hypothesized that the use of the pediatric symptom-checking smartphone app will decrease non-urgent visits to the pediatric emergency department.

TABLE OF CONTENTS

ABSTRACT.....	II
LIST OF FIGURES	IV
CHAPTER 1: INTRODUCTION AND SCOPE OF PROBLEM.....	1
CHAPTER 2: EFFECTS OF HEALTH LITERACY.....	6
CHAPTER 3: CONCEPTUAL MODELS OF HEALTH LITERACY	12
Health Literacy as a Clinical Problem	12
Health Literacy as a Public Health Issue	17
HEALTH LITERACY AND VISITS TO THE PEDIATRIC EMERGENCY	
DEPARTMENT.....	22
CONCLUSION.....	29
BIBLIOGRAPHY.....	30

LIST OF FIGURES

1. Causal Pathways Between Limited Health Literacy And Health Outcomes	7
2. Conceptual Model of Health Literacy as a Risk Factor.....	12
3. Conceptual Model of Health Literacy as an Asset.....	18
4. The Health Literacy Continuum.....	19

CHAPTER 1: INTRODUCTION AND SCOPE OF PROBLEM

Health literacy is a complicated concept at the intersection of health and education. It is defined by the Institute of Medicine as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Institute of Medicine (US) Committee on Health Literacy, 2004). More recent definitions have begun to consider "health literacy as an interaction between the demands of the health system and the skills of individuals." Others have modified this to highlight the skills of all parties involved in communication, providers included (Sorensen et al., 2012).

The term "health literacy" was first used in 1974 in a discussion of health education as a social policy (Simonds, 1974). While poor health education in the school curriculum may contribute to low health literacy, the difficulties that many Americans face cannot be blamed solely on the educational system. As technology has progressed, health information has become more complex. Simultaneously the American health care system has evolved into a many-layered maze. A large portion of the population, disproportionately including the most vulnerable among us, has been unable to keep up. These are the people with low health literacy.

Literacy, the ability to read, is not the same as health literacy. Health literacy is much more complicated. According to the Department of Health and Human Services, “health literacy is a complex phenomenon that involves skills, knowledge, and the expectations that health professionals have of the public’s interest in and understanding of health information and services” (U.S. Department of Health and Human Services,

Office of Disease Prevention and Health Promotion, 2010). Health literacy consists of conventional literacy skills as well as other skills. Conventional literacy skills include prose literacy, document literacy, and numeracy. Prose literacy is the ability gather, understand and use information from written text. In health-related situations, prose literacy is required for reading physician-provided documents like discharge instructions, as well as learning about one's condition from outside sources like the internet.

Document literacy is the ability to understand and fill out forms, for example enrolling in health insurance. Numeracy (also called computational or quantitative literacy) is the ability to perform basic math skills, like that required to calculate a dose of medicine (Kutner, Greenberg, Jin, & Paulsen, 2006).

Other components of health literacy include oral language skills, navigational literacy, and cultural and conceptual knowledge. Oral language skills consist of speaking and listening, and are important for the exchange of information during a visit with a healthcare provider. Navigational literacy refers to the ability to navigate the complicated American healthcare system. It spans from basic skills, like reading hospital signs, to complicated tasks like understanding what services insurance providers do and do not cover. Cultural and conceptual knowledge are the preexisting facts and ideas that one brings with them to a health care setting. Present day Americans get health information from friends and family, TV, websites, social media, product labels, doctors, nurses, pharmacists, and dentists, just to name a few. The information can be different, incomplete, and conflicting, resulting in an overwhelming and confusing barrage of facts received daily.

The health literacy of Americans was assessed for the first time in 2003 with a nationwide survey of more than 19,000 adults aged 16 years and over. The U.S. Department of Education National Assessment of Adult Literacy (NAAL) measured prose, document, and computational literacy. To try to assess the other components of health literacy, questions were asked in scenarios with different types of health content. The health content fell into three domains: clinical, preventative, and navigational. The clinical domain encompassed tasks that would be encountered in a doctor's office visit, like filling out a new patient form and understanding medication dosing. The preventative domain included following guidelines for age-appropriate screenings and understanding how diet and exercise can impact health. The navigational domain included tasks like determining what insurance will and will not pay for and being able to provide informed consent. The NAAL did not test knowledge of specialized medical terms.

The NAAL found that 12% of adults had the highest level of health literacy, termed proficient. A person with proficient health literacy would be able to find the information to define a medical term by searching through a complex medical text or be able to calculate an employee's share of health insurance costs using tables that show how cost varies based on income and family size. The majority of adults, 53%, had intermediate health literacy. A person with intermediate health literacy would be able to interpret a childhood vaccination chart or determine substances that may interact with a drug based on the drug label. Twenty-two percent of adults had basic health literacy. A person with basic health literacy be able to explain why it is important to know if they have a specific medical condition based on a brief article about the condition. Fourteen

percent of adults have below basic health literacy. A person with below basic health literacy would range from being illiterate in English, to being able to locate an appointment date on an appointment slip, to being able to determine how often a test is needed based on a simple brochure (Institute of Medicine (US) Committee on Health Literacy, 2004).

Overall, women had slightly higher health literacy than men. White and Asian/Pacific Islander adults had higher average health literacy than other racial/ethnic groups and multiracial adults. Hispanic adults had the lower average health literacy than other racial/ethnic groups. Adults who spoke English alone before entering school had higher average health literacy than those who spoke another language or lived in a multi-lingual household. Adults over 65 had lower average health literacy than adults in younger age groups. Of adults who did not complete high school, 49% had below basic health literacy, whereas 15% of those with a high school diploma and 3% of those with a bachelor's degree fall into this category. Finally, adults in poverty had lower average health literacy than those living about the poverty threshold(Kutner, Greenberg, Jin, & Paulsen, 2006).

Health literacy levels vary by type of insurance coverage. Among adults who receive Medicaid 30% had below basic health literacy, whereas among adults with employer-provided coverage only 7% had below basic health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). As health literacy increases, so does overall level of health by self-assessment. Of people who rate their health as poor, 42% have below basic health literacy and 3% have proficient health literacy. Of people who rate their

health as excellent, 8% have below basic health literacy and 19% have proficient health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006).

CHAPTER 2: EFFECTS OF HEALTH LITERACY

Unsurprisingly, health literacy level affects health outcomes. A 2011 systematic review found association between low health literacy and limited health-related knowledge and comprehension. Low health literacy is also associated with decreased mammography screening and influenza immunizations, and increased emergency care visits and hospitalization rate. Elderly persons with low health literacy have higher mortality rates (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

In addition to contributing to poor patient outcomes, low health literacy is responsible for increased healthcare expenditures. According to a 2007 report by Vernon and colleagues, "low health literacy is a major source of economic inefficiency in the U.S. health care system" (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). The report estimates that the cost of low health literacy to the U.S. economy is between \$106 billion to \$238 billion annually. To put this into perspective, the National Library of Medicine website estimates that the above stated cost represents an amount equal to the cost of insuring every one of the more than 47 million people who lacked coverage in the United States in at the time the report was written (Health Literacy, NLM website). In 2015 a study estimated a similar annual cost to low health literacy, \$215.5 billion (Rasu, Bawa, Suminski, Snella, & Warady, 2015). The researchers went further and looked at the effect of low health literacy on different types of healthcare expenditures. Interestingly 80% of the increased cost was attributed to prescription medications, 18.4% to office visits, and 1.6% to emergency department visits (Rasu, Bawa, Suminski, Snella, & Warady, 2015). The authors feel that possible explanations for the prescription costs could include greater

severity of disease (especially in the 65 and above age group which exerted about a 56% influence on the prescription medication expenditures) and/or a greater reliance on prescription therapy instead preventative health care.

Clearly limited health literacy is associated with worse outcomes, but understanding the causal pathways is more difficult, especially because literacy is also associated with socioeconomic indicators such as ethnicity, age, and educational attainment. Orlow and Wolf suggested the model represented in Figure 1. The model suggests that there are three critical points where health literacy can affect care and outcomes: access and utilization, patient-provider relationships, and self-care (Paasche-Orlow & Wolf, 2007).

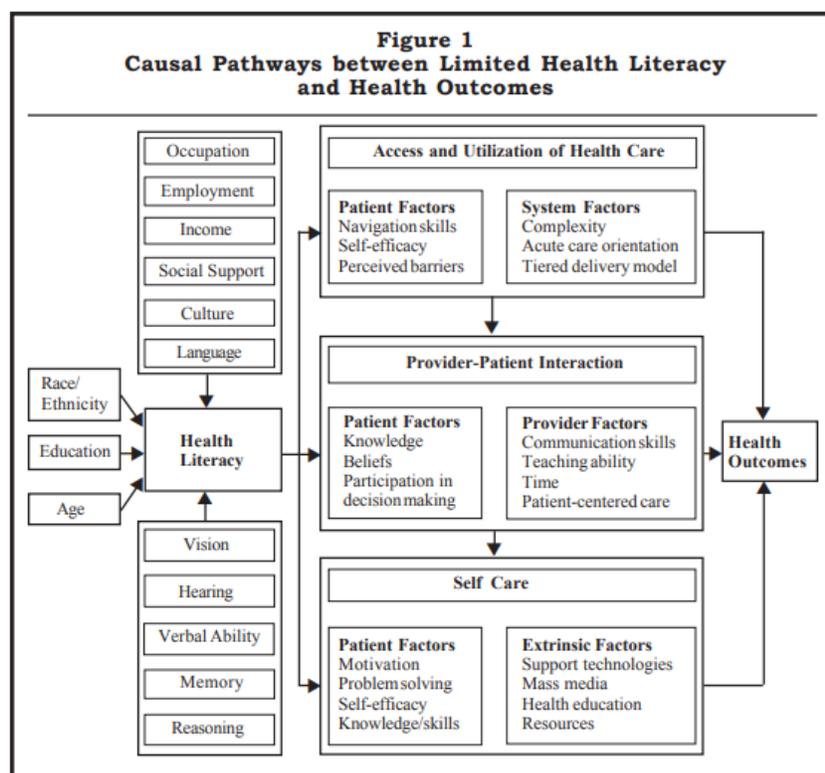


Figure 1: Causal Pathways Between Limited Health Literacy and Health Outcomes (Paasche-Orlow and Wolf, 2007).

Barriers to access and utilization of health care occur at both the patient end and the system end. From the patient standpoint, people with limited health literacy may delay seeking care due to not understanding the importance of preventative measures, or knowing signs and symptoms of disease. As for the health care system, the mix of payers, lack of universal healthcare record sharing, and constantly changing policies have made the American health care delivery system hard to navigate.

Limited health literacy also affects patient-provider interactions. There are several ways in which this happens. Having less knowledge about a disease may mean that one simply doesn't know which questions to ask. It also may affect how a person feels about herself and this may change patient-provider interactions.

Patients with low health literacy may be reluctant to reveal their limitations as to do so would require them to declare their own inadequacies (Perrin, 1998). Decreased literacy carries a stigma and may lead to feelings of low self-esteem and fear. A 1996 study showed that of patients found to have low health literacy on a screening tool, only 67.4% admitted to having trouble reading and 39.7% admitted to feeling ashamed. Many people were reluctant to disclose that they had trouble reading: 67.2% had never told their spouse, 53.4% had never told their children, and 19% hadn't told anyone at all (Parikh, Parker, Nurss, Baker, & Williams, 1996). Feelings of shame seem to increase as literacy level decreases. Almost half (47.8%) of patients with reading levels at or below the third-grade level admitted to feeling shame about reading difficulties, compared to 19.2% of patients reading at the fourth- to sixth grade level and 6.5% reading at the seventh- to eighth-grade level (Wolf et al., 2007). Sadly, those experiencing the most difficulties may be the least likely to ask for help.

Feelings of shame may contribute to low self-esteem, and patients with low self-esteem may be hesitant to ask questions of and express their opinions to their physician for fear that it may reveal their limited understanding. A 2006 study showed that patients with low health literacy asked significantly fewer questions about key aspects of their medical care, especially questions regarding lifestyle modifications. The questions they did ask were more likely to be requesting repetition or clarification (Katz, Jacobson, Veledar, & Kripalani, 2007).

A group of researchers sought to learn more about the experiences of patients with low health literacy in a qualitative study published in 1996. They found that registering for care and completing forms seemed to be the most difficult and embarrassing task for patients with low health literacy. One patient stated "I've had a lot of illnesses, but I preferred to stay home, until I get better by taking anything I can. Because being asked to fill this out, to fill that out, I feel embarrassed to ask for help, to ask them to fill it out for me. They might get upset or they would say 'This lazy lady, she never learned to read,' that's how I think." Another theme that emerged was difficulty following medication instructions. One woman recounted how she took birth control pills incorrectly after delivering a child and quickly became pregnant again (Baker et al., 1996).

Patients with low health literacy may try to hide it from providers. The most common coping strategy is to bring someone who can read to appointments with them. Disturbingly, when asked about coping strategies, 62.8% of patients with low health literacy said they would never ask for help (Katz, Jacobson, Veledar, & Kripalani, 2007). This may be because they have had negative experiences with this in the past. One

patient stated "What I feel, in my case, if there could be a person that could talk like us, and be kinder, and to ask us if we can read, or offer to fill it out, and with a smile, so we feel the person supports us. But if we see their hard faces, how could we ask for help to fill out the form?" (Baker et al., 1996).

These compensatory behaviors may lead physicians to overestimate patient's health literacy. A study of resident physicians showed that they inaccurately assessed health literacy in 34% of their patients, and 95% of these incorrect assessments were overestimations of literacy level (Bass, Wilson, Griffith, & Barnett, 2002). Experienced physicians did not do any better. Primary care physicians with an average of 15 years' experience misjudged patients' literacy levels 40% of the time, with overestimations outnumbering underestimations 2:1. Overestimations were more frequent in racial/ethnic minority patients. (Kelly & Haidet, 2007). Nurses also overestimate health literacy. In a 2013 study, nurses estimated 19% of patients having high likelihood of limited health literacy, but a screening tool found that 63% of patients actually had limited health literacy (Dickens, Lambert, Cromwell, & Piano, 2013).

The last causal pathway between health literacy and health outcomes suggested by Paasch-Orlow is self-care. Knowledge and certain skills are required for health maintenance and for managing minor health conditions at home. One example of this is medication dosing. Two studies by a group of researchers showed that parents with low health literacy were about twice as likely as likely to make liquid medication dosing errors as parents with adequate health literacy (Yin et al., 2010; Harris et al., 2016). Similar results were found in adults. Although 70.7% of patients with low literacy correctly stated the instructions, "Take two tablets by mouth twice daily," only 34.7%

could demonstrate the number of pills to be taken daily. With confounding variables controlled for, again people with low health literacy were twice as likely to make dosing mistakes (Davis, Wolf, Bass, et al, 2006).

Knowledge is also required for basic injury prevention techniques. In a cross-sectional study of nearly 18,000 children researchers found that parents with low health literacy less likely than parents with adequate health literacy to practice injury prevention techniques such as having working smoke detectors and setting water heaters to below 120 degrees. They were also less likely have first-aid knowledge of what to do in the event of choking or burns (Cheng, Bauer, Downs, & Sanders, 2016).

The previous sections have discussed the definition and scope of low health literacy and explained how it may affect health outcomes. In the next section I will discuss different conceptual models of health literacy. Understanding conceptual models is important because they help identify opportunities for intervention.

CHAPTER 3: CONCEPTUAL MODELS OF HEALTH LITERACY

Two models of health literacy were proposed in 2008 by Dr. Don Nutbeam. Dr. Nutbeam is a Professor of Public Health at the University of Sydney, Australia and former Head of Public Health in the United Kingdom Department of Health.

Health Literacy as a Clinical Problem

Given the enormous costs of limited health literacy on economics and outcomes, it isn't enough to simply address health literacy by changing our communication practices, we must also screen for health literacy levels and provide tailored education (Figure 2). When health literacy is thought of as a clinical problem, it essentially becomes a risk factor for poor outcomes. Therefore, we would screen for it as we screen for other risk factors, like high blood pressure.



Figure 2: Conceptual Model of Health Literacy as Risk Factor (Nutbeam, 2008)

In this model, health literacy would be routinely assessed. Health care providers and office staff members would become more sensitive to health literacy and would tailor communication and interactions with patients according to their needs.

Multiple instruments exist for screening for health literacy. Two of the screening tools that have been used the longest are the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM). Newer screening tools are the Newest Vital Sign (NVS) and the Single Item Literacy Screen (SILS).

The TOFHLA consists of two sections, a 50-question reading comprehension section and a 17-question numeracy section. The reading comprehension section asks patients to fill in blanks in passages taken from actual hospital documents written at varying grade levels. The numeracy section asks patients to interpret directions for quantitative tasks such as taking medications and obtaining financial assistance based on actual hospital instructions (Parker, Baker, Williams, & Nurss, 1995). As this can be time consuming averaging 22 minutes to complete, the developers created a shortened version, the S-TOFHLA. The S-TOFHLA consists of 17 prose and 4 numeracy items and can be completed in less than 12 minutes. (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Both versions of the TOHFLA are available in English and Spanish.

The REALM is a reading recognition test that measures a person's ability to pronounce 66 common medical terms. The patient is provided with lists of words that they are asked to read out loud. The test can be completed in 2-3 minutes (Murphy, Davis, Long, Jackson, & Decker, 1993). A drawback of the REALM is that it is only available in English.

The NVS screens for difficulties in prose literacy, document literacy, and numeracy. It is a series of six questions based on a fictitious ice cream label. The NVS can be administered in 2-3 minutes. It is reliable and correlates with the TOFHLA. The NVS has a high sensitivity and a moderate specificity meaning that it may over classify patients as having limited health literacy. It is available in English and in Spanish (Weiss et al., 2005).

The SILS can be administered by asking only three questions. The questions are: 1) "How often do you have problems learning about your medical condition because of difficulty understanding written information?"; 2) "How often do you have someone help you read hospital materials?"; and 3) "How confident are you filling out medical forms by yourself?" Each question can be answered with one of 5 scaled responses (always, often, sometimes, etc). Benefits of the single question are the ease of use and limited time commitment. It has been suggested by some authors that this screening method may be less embarrassing for patients. However, these questions may fail to pick up patient with marginal health literacy (Chew, Bradley, & Boyko, 2004; Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). They are also vulnerable to being answered in a way that prioritizes pleasing the screener over honesty, especially if they are not asked in a sensitive way.

The SILS questions can also be asked individually and still be predictive of limited health literacy. In this case they are referred to as a "validated screening question" rather than SILS. This method of screening does not perform as well as test that evaluates reading and shares the same drawbacks as the SILS mentioned above (Wallace et al., 2006).

In a 2015 study, researchers administered all the above health literacy screens and another less frequently used screen, the Medical Term Recognition Test (METER), to 400 patients in an emergency department. The S-TOFHLA classified the fewest patient as having limited health literacy and the NVS classified the most patients as having limited health literacy. Despite the difference in instruments, lower scores on all of the tools was correlated with lower self-reported health status (Kiechle et al., 2015).

It is understandable that providers may be hesitant about administering health literacy screens if they feel that they may be embarrassing their patients. Therefore, there have been several studies to gauge acceptance of health literacy screens by patients. One study found that more than 98% of patients in public and private practices were willing to undergo literacy screening (NVS) at a routine visit. Administering the NVS did not affect patient satisfaction scores (Ryan et al., 2008). Another study of the NVS showed that only 3.5% of patients were upset about having to complete the assessment. More than 98% of patients reported that the NVS did not cause them to feel shame. When asked if they would recommend the NVS screening if it "could help doctors improve care", 97% of respondents answered affirmatively (VanGeest, Welch, & Weiner, 2010).

Wolf et al found that 47.8% of patients at or below a third-grade reading level acknowledged having felt shame or embarrassment about their difficulties reading. These patients were screened with the REALM tool. They were not specifically asked if the REALM screening caused them to feel shameful, but the authors inferred that it did. Despite this, 95% of the patients if the patients felt that it would be helpful for their doctor to know about their difficulty reading, and 83.7% were willing to have a note placed in their chart documenting that they have difficulty understanding medical words

(Wolf et al., 2007). In a study of patient given the S-TOFHLA, 96% felt that the health literacy screening was useful. Patients in this study were not asked about how the health literacy screening made them feel (Seligman et al., 2005).

Taken all together, it seems that while experiences and feelings may vary depending on the health literacy screen used, overall patients agree that screening is helpful. The NVS may feel more acceptable to patients because it is task based and doesn't require the patient to directly reveal reading troubles (VanGeest et al., 2010). The REALM may be less acceptable because it requires reading out loud. Possibly it is less embarrassing to have reading difficulties revealed on a questionnaire because it feels less personal.

Giving merit to Nutbeam's health literacy as a risk factor model, one study did find that screening for health literacy could change physician communication practices. When physicians were randomized to be notified of patient's low health literacy, intervention physicians were more likely to use management strategies intended for patients with low health literacy. They felt that the literacy screening was useful 64% of the time. However, physicians felt less satisfied with the visits. Hemoglobin A1c, a marker of diabetic control, was lower in patients whose physician was notified of their low health literacy 2-9 months after their visit, though not to a statistically significant level. It is important to note that the physicians in this study did not receive any training on communicating with patients with low health literacy, yet they were still able to modify management strategies. With adequate physician training interventions may have been more frequent and possibly more successful (Seligman et al., 2005).

Despite this, some experts feel that exposing patients to the potential stigma and shame of low health literacy outweighs the benefit of screening. They argue for a “universal precautions” approach, because all patients can benefit from information that is easier to understand (Paasche-Orlow & Wolf, 2007). While I agree that easy-to-read handouts and jargon-free conversations should be the norm, I would argue that other more time-consuming techniques should be reserved for those who can benefit the most from them. For example, for patients identified as having low health literacy, office staff can help by asking questions such as "Some people find these forms confusing, would you like some help filling it out?" and "Would you like some help scheduling the test that your doctor just ordered?". Physicians could use the effective but time consuming teach back technique with the patients at the highest risk. In the teach back technique, the health care provider asks a patient to repeat instructions back to them by asking questions such as "We've just gone over a lot of information, and I want to make sure I haven't missed anything. Can you remind me how you will know if Johnny needs to use his inhaler?"

Health Literacy as a Public Health Issue

As opposed to viewing health literacy as a clinical risk factor to be screened for and managed, Nutbeam has also looked at health literacy from a public health standpoint (Figure 3). In this model health literacy is now considered an asset that can be built upon—like a diet that can be made healthier. In the public health model health literacy is "a means to enabling individuals to exert greater control over their health and the range of personal, social, and environmental determinants of health" (Nutbeam, 2008). The public

health model also starts with health literacy assessment but differs in the way low health literacy is dealt with. The focus of the healthcare provider now shifts from only modifying communication to also helping patients develop knowledge and skills in multiple areas that affect health. It allows for a broader range of interventions, including outside of the clinical setting. This is very important as only a very small portion of a person's health behaviors take place in the presence of a health care professional.

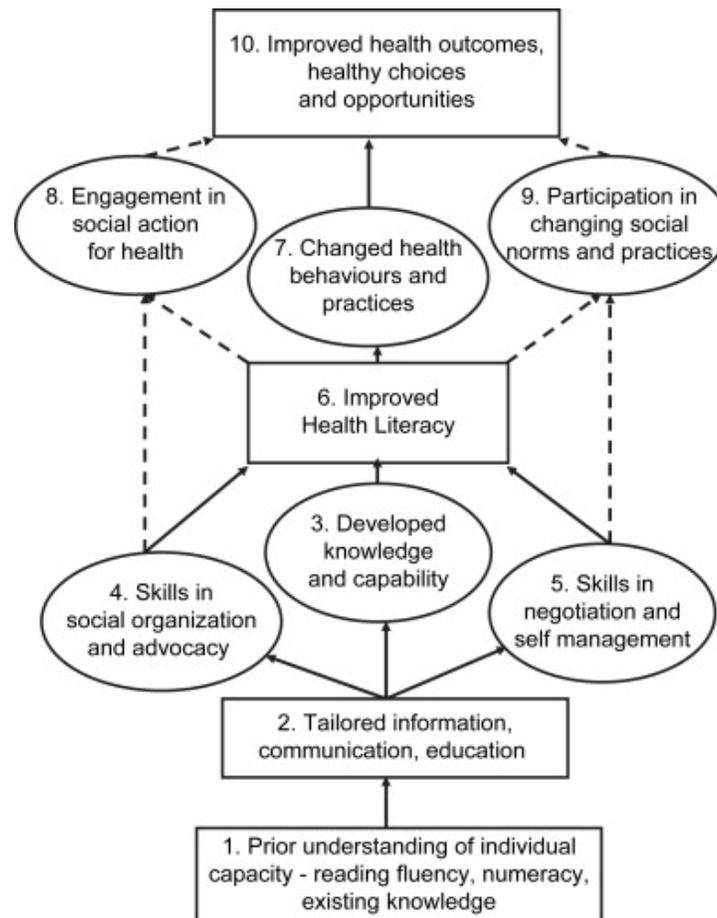


Figure 3: Conceptual Model of Health Literacy as an Asset (Nutbeam, 2008)

Now, the patient is no longer just the passive recipient of tailored communication but is an active participant in developing knowledge and skills for self-management and advocacy.

Porr et al have expanded this model by describing where along the health literacy continuum this skill building should be incorporated (Figure 4). The model was developed for teaching parenting skills to low-income mothers but could be applied and many other situations (Porr, Drummond, & Richter, 2006).

First, rather than classifying health literacy as below basic, basic, intermediate, and proficient the categories are shifted to functional, interactive, and critical- a move which was first suggested by Nutbeam. These terms identify types of literacy more in terms of what it is that literacy enables a person to do (Nutbeam, 2000).

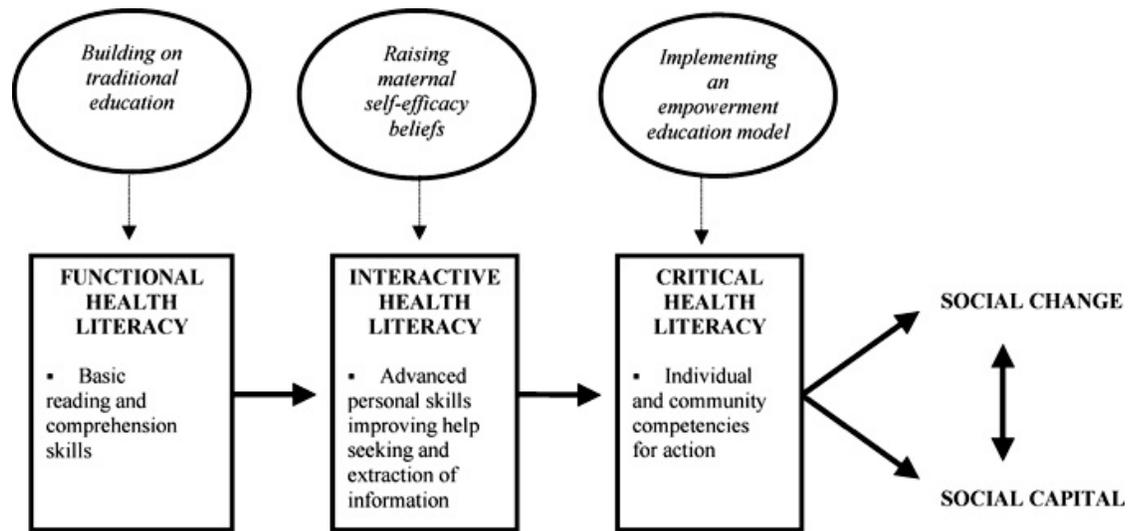


Figure 4: The Health Literacy Continuum (Poor, Drummond, & Richter, 2006)

Functional health literacy is the outcome of traditional education, where the focus has been to understand health risks and comply with prescribed treatments. It is the goal

of patient education materials provided by most health care providers, and do not foster skills or autonomy.

Moving along the health literacy continuum is interactive health literacy.

Interventions here would focus on improving capacity to act independently on medical knowledge and improve motivation and self-confidence to act on medical advice. In this stage, Porr et al suggest using the social cognitive theory developed by Albert Bandura and stress the importance of improving self-efficacy as a part of health literacy. Self-efficacy is the belief in one's capabilities to produce desired results by one's actions, it is critical because it is what gives people incentive to act. As people with low health literacy are more likely to be members of groups who have suffered long standing oppression and discrimination, they may feel powerless and devalued. While healthcare professionals may not be able to change a patient's prior experiences, they can practice empowerment strategies such as engaging in mutual goal setting and problem solving to encourage self-efficacy.

Critical health literacy is the highest level of literacy in this model. It includes skills that support not only individual action but can also be oriented towards supporting effective social and political actions (Nutbeam, 2000). A person's physical environment itself may not be related to literacy. But, when confidence and competence in decision making are encouraged, people may feel more encouraged to modify their circumstances, and eventually extend this to their communities as well (Porr, Drummond, & Richter, 2006; Perrin 1998). In this way improving health literacy can be thought of as a mediator for other social determinants of health and can be a path leading to social change.

A longitudinal study of sociodemographic risk factors in childhood asthma found that race-based disparities in quality of life and asthma knowledge could be partially explained by caregiver health literacy level and educational attainment, and that health literacy was independent of education. The authors feel that this is important because health literacy is modifiable, and that improving health literacy could be used as a tool to alleviate race-based asthma disparities as well as to empower care givers to better advocate for themselves (Washington, Curtis, Waite, Wolf, & Paasche-Orlow, 2017).

If health literacy is modifiable, as suggested in the public health model, how do we modify it? I'd suggest that a good place to start would be by improving "interactive" health literacy. According to Porr, this would involve "improving help-seeking and extraction of information." As previously discussed, in present-day America there are many sources of health information, often conflicting, and this can be overwhelming—especially for a person with low health literacy. Providing patients with a reliable source of medical information, and coupling this with a decision-making aid, could potentially improve a person's health literacy. Simultaneous to this it could improve their self-efficacy and therefore empower them to take better control of their health. This has been the focus of my research, and in the next section I will discuss my current project: the effect of a pediatric health information and symptom checking smartphone app on emergency department utilization.

HEALTH LITERACY AND VISITS TO THE PEDIATRIC EMERGENCY DEPARTMENT

In 2006, American children aged 17 years and younger made more than 25 million visits to EDs, which averages to nearly 69,000 visits per day. It is estimated that between 58% and 82% of these visits were for non-urgent reasons. A non-urgent complaint is defined as one where the patient could "safely wait 2-3 hours or be seen by their regular doctor the next day" by the National Hospital Ambulatory Medical Care Survey (Fieldston, Alpern, Nadel, Shea, & Alessandrini, 2012).

Parents of children presenting to the PED for a non-urgent complaint of more likely than average to have a low health literacy level. In a yearlong study the NVS was administered to parents presenting to a PED in Milwaukee. The researchers found that 55.7% of parents were classified as having low health literacy (Morrison, Schapira, Hoffmann, & Brousseau, 2014) compared to 26% of parents nationally (Yin et al., 2009). Low health literacy was associated with a 50% increase in PED visits (Morrison et al., 2014).

One reason that parents may bring their children to the emergency department is that they overestimate the degree of illness. When parents whose children were determined by nurses to have non-urgent complaints in a Los Angeles PED were surveyed 63% of them stated that their children had "very" or "extremely" urgent conditions (Kubicek et al., 2012). In a Canadian study, 36% of parents whose children were determined to have non-urgent complaints felt that the emergency department was the most appropriate setting to treat their child's problem (Farion et al., 2015).

A 2017 qualitative study linked health literacy to overestimation of illness. Parents seeking care for children with acute complaints in the clinic and parents of children with non-urgent complaints in the PED were interviewed and given the NVS health literacy screen. The authors found that parents with low health literacy tended to seek expedient care for a diagnosis and recommendations for treatment. In support of the earlier studies, all parents with low health literacy interviewed in the ED identified their child's illness as severe. One parent stated "It's very hard to make decisions when he's sick. Because I want to be able to do everything I need to do for him to feel better, and if I can't do it, I'm going to take him to the hospital to see if a doctor or somebody can help me." Another parent worried that "I would wake up and ...he'll be gone or something." The same study found that parents with adequate health literacy were more likely to initiate care at home, seek information from resources (internet or print), and engage in active problem solving than low health literacy parents. One parent said "It depends on the situation...If he would've fell and cut his hand...then I probably would've taken him to the emergency because he would've needed more extensive care" (May et al., 2017).

If parents with low health literacy tend to overestimate their children's degree of illness and this leads to increased PED visits, then education surrounding minor pediatric illnesses could be a potential intervention. Unnecessary PED visits overtax a system meant for emergency use, lead to long wait times, and lead to increased healthcare expenditures. They also disrupt the medical home, a model of care in which a provider delivers comprehensive and continuous medical care to patients with a goal of obtaining the most optimal outcomes. Several studies have shown that educational interventions can be effective.

In two studies, Herman and colleagues gave a children's health information book written at a 3rd-5th grade level to parents. When the book was given to parents in the PED waiting room along with 5-10 minutes of instruction on how to use it, parents reported a 30% decrease in ED use 6 months later (Herman, Young, Espitia, Fu, & Farshidi, 2009). When the same book was given to parents of children enrolled in 55 Head Start sites in 35 different states and paired with 2 hours of related skill development, it resulted in a 58% decrease in PED visits. It also decreased parental missed workdays by 42% and child missed schooldays by 29%. The authors calculated that this saved \$554 per family per year, while the book and training only cost \$60 per family (Herman & Jackson, 2010). Another study based in Head Start sites provided three 1.5-hour education modules focusing on upper respiratory infections and use of over-the-counter medications. Compared to control families, those who underwent training were less likely to visit the PED when their children were ill (8.2% vs 15.7%) (Stockwell et al., 2014). In a clinic based intervention, nurses provided 5-10 minutes of education on ear pain along with written information and a prescription for analgesic medication. One year later, children involved in the intervention had 80% fewer ED visits for ear pain.

I hypothesize that similar results could be achieved with the use of an educational symptom-checking smartphone application (app). The benefits to a smartphone app are that it is more readily available for use, as people tend to carry their phones but may leave print materials at home. Apps are also less expensive than books and can be updated regularly. The app I have developed for my research is OwlCare4Kids.

OwlCare4Kids is a medical decision-making tool for families. The content is owned by a company called Self Care Decisions and is reviewed and updated at least

yearly. Content is written by Dr. Barton Schmitt, Professor of Pediatrics at the University of Colorado. The Schmitt-Thompson protocols are used by 90% of medical nurse advice lines and more than 90% of pediatric practices nationally for triaging patients and providing advice. The symptom checking app offers the same advice on a mobile device platform that is written for caregivers on a 6th grade level per CMS standards. It includes 235 symptom care guides to help families make decisions about what level of care is needed (for example, emergency department vs. pediatrician office). It offers first aid advice, with illustration, on 55 topics. There is also advice on 145 specific wellness and behavior topics.

The OwlCare4Kids app uses the content described above and has been customized for the North Philadelphia community. It lists resources such as breastfeeding support and local food banks. It also has a mapping feature to locate the nearest emergency department or urgent care center. 911 can be dialed directly through the app, as can a mental health crisis line.

Self Care Decisions has customized its content for a number of organizations, including but not limited to Children's Hospital of Pittsburgh, Children's Hospital of Wisconsin, Children's Hospital of Colorado, Children's Hospital of St. Louis, and the American Academy of Pediatrics, as well as numerous private pediatric practices. Therefore, the content is already widely in use. These customized apps are commercially available for prices ranging from free to \$1.99 per download. The OwlCare4Kids would be provided at no cost to study participants in the intervention arm, and eventually made available for free to all Temple Pediatric Care patients.

OwlCare4Kids contains a great deal more information than the standard discharge instructions provided by Temple Pediatric Care. Currently the practice provides age-specific anticipatory guidance on development and behavior, as well as limited sick care instructions. As described above, OwlCare4Kids provides a large amount of searchable data that would be impossible to provide on paper.

Information about an illness can be found in an alphabetical index, by clicking on a body part in a diagram, or by keyword search. Once a topic has been selected, the app helps a family make a decision about what level of care to seek based on what other symptoms may be present. The app also helps families by allowing them to store and directly dial their child's pediatric office, as well as directly dial 911, Poison Control, and a mental health crisis line. It will also help find the nearest Temple ReadyCare urgent care center or Emergency Department location.

In addition to emergency information, the OwlCare4Kids app offers advice on common pediatric topics to serve as a reference for families between well-child visits. It also links to web sites for local community organizations that may be of interest to families with young children.

Participants not randomized to receive the OwlCare4Kids app will receive a "placebo" app. The placebo app is called GROW and it is developed and maintained by Fisher Price. GROW is an open source, free smartphone app that gives information about developmental milestones for ages 1 month through 5 years. It also offers age appropriate tips for helping children develop new skills. The app has no implications for medical care of the child, and no usage data will be collected for the app.

Eligible patients will be identified at their well child visits to Temple Pediatric Care, consented in their preferred language (English or Spanish), and randomized to receive either the OwlCare4Kids app or the GROW developmental milestones app. Patients will be assisted with downloading their app. After download no internet connection is required. No knowledge beyond ability to use a smartphone is required of the participants. The entire content of both apps is available in both English and Spanish and will be displayed in whichever language has been selected as preferred in the phone settings.

There are three outcomes of interest in this study. First, I will measure the effect of a symptom checking smartphone app on ED utilization. This will be achieved by tracking the number of ED visits and associated billing diagnoses in the control and intervention groups for 6 months after enrollment has ended. Second, I will look at the acceptance and use of a pediatric symptom checking smartphone app in the North Philadelphia community. Acceptance will be measured by using a survey to determine parent satisfaction with the app provided by asking a) if they referred to the app and how often and b) if the app was helpful. App usage will be measured by Google Analytics which will collect de-identified data on the number of times each component of the app is accessed. Third, I will study the health literacy level of primary care givers and see how it relates to both ED utilization and app utilization and satisfaction. We will administer the Newest Vital Sign (NVS) survey to help determine the level of health literacy of the primary care giver of our enrolled patients.

So far little research has been done to understand the utility and accuracy of symptom checking apps. In a recently published Danish study adult and pediatric

patients were provided with a symptom checking app. Of all users, 87% rated the information provided in the app as “neutral” to “very clear.” Sixty-five percent of users said that they intended to follow the advice. When app use was followed up with a nurse phone call, the advice given by the app and the nurse were in agreement 81% of the time (Verzantvoort, Teunis, Verheij, & van der Velden, A W, 2018). In an audit of 23 different symptom checking apps, Harvard researchers found that overall triage advice was appropriate in 57% of scenarios they created. However, symptom checkers using Schmitt Thompson nurse triage protocols, like OwlCare4Kids, made appropriate triage decisions 72% of the time (Semigran, Linder, Gidengil, & Mehrotra, 2015). Taken together, these two studies show that symptom checking smartphone apps can be useful.

With my research I hope to begin to understand how people of varying levels of health literacy use a symptom checking smartphone app, and how this affects the use of the emergency department for non-urgent illnesses and injuries. Most obviously this is important because it represents a potential tool for decreasing unnecessary health care expenditures. It is also important because knowing how people of different health literacy levels use a health information app could help improve the content of such apps in the future. The empowerment potential of a smartphone app would be difficult to measure, but self-efficacy scales do exist and could potentially be modified for the purpose of studying this in the future.

CONCLUSION

Health literacy is a complicated phenomenon consisting of conventional literacy skills, numeracy, health system navigation, and pre-existing knowledge and beliefs. Low health literacy is common, and it impacts the American healthcare system by increasing costs and impacts patients by negatively affecting health outcomes. In order to mitigate these negative impacts, health care providers must not only improve their communication skills, but they should also provide their patients with the tools they need to start making better health decisions. From an ethical standpoint, this supports a person's agency, or capacity to act independently and make free choices. The more a person understands different options available to them, the better able they are to make a choice for themselves. Empowering people to make good choices can contribute to health equity. Why should some people be able to be healthier than others because they are fluent in a particular language, or have had a particular educational experience? Meeting a person where they are on their own literacy level, and then providing them with appropriate educational materials in a way that encourages them to make the healthiest decisions possible could be one step toward overcoming health disparities. It is my hope that a symptom-checking smartphone app will prove to be a useful tool for achieving this goal.

BIBLIOGRAPHY

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., et al. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, 5(6), 329-334.

Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, 38(1), 33-42. doi: S0738-3991(98)00116-5 [pii]

Bass, P. F., Wilson, J. F., Griffith, C. H., & Barnett, D. R. (2002). Residents' ability to identify patients with poor literacy skills. *Academic Medicine: Journal of the Association of American Medical Colleges*, 77(10), 1039-1041.

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155(2), 97-107. doi:10.7326/0003-4819-155-2-201107190-00005 [doi]

Cheng, E. R., Bauer, N. S., Downs, S. M., & Sanders, L. M. (2016). Parent health literacy, depression, and risk for pediatric injury. *Pediatrics*, 138(1), 10.1542/peds.2016-0025. Epub 2016 Jun 7. doi:10.1542/peds.2016-0025 [doi]

Chew, L. D., Bradley, K. A., & Boyko, E. J. (2004). Brief questions to identify patients with inadequate health literacy. *Family Medicine*, 36(8), 588-594.

Davis, T. C., Wolf, M. S., Bass, P. F., III, & et, a. (2006). Literacy and misunderstanding prescription drug labels. *Annals of Internal Medicine*, 145(12) 887-94. doi:10.7326/0003-4819-145-12-200612190-00144 [doi]

Dickens, C., Lambert, B. L., Cromwell, T., & Piano, M. R. (2013). Nurse overestimation of patients' health literacy. *Journal of Health Communication*, 18 Suppl 1, 62-69. doi:10.1080/10810730.2013.825670 [doi]

Farion, K. J., Wright, M., Zemek, R., Neto, G., Karwowska, A., Tse, S., et al. (2015). Understanding low-acuity visits to the pediatric emergency department, *PloS One*, 10(6), e0128927. doi:10.1371/journal.pone.0128927 [doi]

Fieldston, E. S., Alpern, E. R., Nadel, F. M., Shea, J. A., & Alessandrini, E. A. (2012). A qualitative assessment of reasons for nonurgent visits to the emergency department: Parent and health professional opinions. *Pediatric Emergency Care*, 28(3), 220-225. doi:10.1097/PEC.0b013e318248b431 [doi]

Harris, L. M., Dreyer, B. P., Mendelsohn, A. L., Bailey, S. C., Sanders, L. M., Wolf, M. S., et al. (2017). Liquid medication dosing errors by Hispanic parents: role of

health literacy and English proficiency. *Academic Pediatrics*. 17(4)403-410.

doi://doi.org/10.1016/j.acap.2016.10.001

Health literacy. Retrieved August 20, 2018, from

<https://nmlm.gov/initiatives/topics/health-literacy>

Herman, A., & Jackson, P. (2010). Empowering low-income parents with skills to reduce excess pediatric emergency room and clinic visits through a tailored low literacy training intervention. *Journal of Health Communication*, 15(8), 895-910.

doi:10.1080/10810730.2010.522228 [doi]

Herman, A., Young, K. D., Espitia, D., Fu, N., & Farshidi, A. (2009). Impact of a health literacy intervention on pediatric emergency department use. *Pediatric Emergency Care*, 25(7), 434-438. doi:10.1097/PEC.0b013e3181ab78c7 [doi]

Institute of Medicine (US) Committee on Health Literacy; Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. *Health Literacy: A Prescription to End Confusion*. Washington (DC): National Academies Press (US); 2004. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK216032/> doi: 10.17226/10883

Katz, M. G., Jacobson, T. A., Veledar, E., & Kripalani, S. (2007). Patient literacy and question-asking behavior during the medical encounter: A mixed-methods analysis. *Journal of General Internal Medicine*, 22(6), 782-786. doi:184 [pii]

Kelly, P. A., & Haidet, P. (2007) Physician overestimation of patient literacy: A potential source of health care disparities. *Patient Education and Counseling*. 66(1), 119-122. doi://doi.org/10.1016/j.pec.2006.10.007

Kiechle, E. S., Hnat, A. T., Norman, K. E., Viera, A. J., DeWalt, D. A., & Brice, J. H. (2015). Comparison of brief health literacy screens in the emergency department. *Journal of Health Communication*, 20(5), 539-545. doi:10.1080/10810730.2014.999893 [doi]

Kubicek, K., Liu, D., Beaudin, C., Supan, J., Weiss, G., Lu, Y., et al. (2012). A profile of nonurgent emergency department use in an urban pediatric hospital. *Pediatric Emergency Care*, 28(10), 977-984. doi:10.1097/PEC.0b013e31826c9aab [doi]

Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy (NCES 2006-483 ed.)*. Washington, DC: National Center for Education Statistics, U.S. Department of Education.

May, M., Brousseau, D. C., Nelson, D. A., Flynn, K. E., Wolf, M. S., Lepley, B., et al. (2017). Why parents seek care for acute illness in the clinic or the ED: The role of health literacy. *Academic Pediatrics*, doi:S1876-2859(17)30369-8 [pii]

Morrison, A. K., Schapira, M. M., Hoffmann, R. G., & Brousseau, D. C. (2014). Measuring health literacy in caregivers of children: A comparison of the newest vital sign and S-TOFHLA. *Clinical Pediatrics*, 53(13), 1264-1270. doi:10.1177/0009922814541674 [doi]

Murphy, P. W., Davis, T. C., Long, S. W., Jackson, R. H., & Decker, B. C. (1993). Rapid estimate of adult literacy in medicine (REALM): A quick reading test for patients. *Journal of Reading*, 37(2), 124-130. Retrieved from JSTOR database. Retrieved from <http://www.jstor.org/stable/40033408>

Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health.Promotion International*, 15(3), 259-267. doi:10.1093/heapro/15.3.259 [doi]

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine* (1982), 67(12), 2072-2078. doi:10.1016/j.socscimed.2008.09.050 [doi]

Paasche-Orlow, M. K., & Wolf, M. S. (2007). The causal pathways linking health literacy to health outcomes. *American Journal of Health Behavior*, 31 Suppl 1, S19-26. doi:10.5555/ajhb.2007.31.supp.S19 [doi]

Parikh, N. S., Parker, R. M., Nurss, J. R., Baker, D. W., & Williams, M. V. (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling*, 27(1), 33-39. doi:0738-3991(95)00787-3 [pii]

Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10(10), 537-541.

Perrin, B. (1998). How does literacy affect the health of Canadians?: A profile paper. Ottawa, Ontario, Canada: Minister of Public Works and Government Services Canada.

Porr, C., Drummond, J., & Richter, S. (2006). Health literacy as an empowerment tool for low-income mothers. *Family & Community Health*, 29(4), 328-335. doi:00003727-200610000-00011 [pii]

Rasu, R. S., Bawa, W. A., Suminski, R., Snella, K., & Warady, B. (2015). Health literacy impact on national healthcare utilization and expenditure. *International Journal of Health Policy and Management*, 4(11), 747-755. doi:10.15171/ijhpm.2015.151 [doi]

Ryan, J. G., Leguen, F., Weiss, B. D., Albury, S., Jennings, T., Velez, F., et al. (2008). Will patients agree to have their literacy skills assessed in clinical practice? *Health Education Research*, 23(4), 603-611. doi:cym051 [pii]

Seligman, H. K., Wang, F. F., Palacios, J. L., Wilson, C. C., Daher, C., Piette, J. D., et al. (2005). Physician notification of their diabetes patients' limited health literacy. A randomized, controlled trial. *Journal of General Internal Medicine*, 20(11), 1001-1007. doi:JGI189 [pii]

Semigran, H. L., Linder, J. A., Gidengil, C., & Mehrotra, A. (2015). Evaluation of symptom checkers for self diagnosis and triage: Audit study. *BMJ*, 351 doi:10.1136/bmj.h3480

Simonds, S. (1974). Health education as social policy. *Health Education and Behavior*, 2(1), 1. doi:10.1177/10901981740020S102

Sorensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., et al. (2012). Health literacy and public health: A systematic review and integration of definitions and models. *BMC Public Health*, 12, 80-2458. doi:10.1186/1471-2458-12-80 [doi]

Stockwell, M. S., Catalozzi, M., Larson, E., Rodriguez, C., Subramony, A., Andres Martinez, R., et al. (2014). Effect of a URI-related educational intervention in early head start on ED visits. *Pediatrics*, 133(5), e1233-40. doi:10.1542/peds.2013-2350 [doi]

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). National action plan to improve health literacy. Washington, DC.

VanGeest, J. B., Welch, V. L., & Weiner, S. J. (2010). Patients' perceptions of screening for health literacy: Reactions to the newest vital sign. *Journal of Health Communication, 15*(4), 402-412. doi:10.1080/10810731003753117 [doi]

Vernon, J. A., Trujillo, A., Rosenbaum, S. J., & DeBuono, B. (2007). Low health literacy: Implications for national health policy. Washington, DC: Department of Health Policy, School of Public Health and Health Services, The George Washington University.

Verzantvoort, N. C. M., Teunis, T., Verheij, T. J. M., & van der Velden, A W. (2018). Self-triage for acute primary care via a smartphone application: Practical, safe and efficient? *PloS One, 13*(6), e0199284. doi:10.1371/journal.pone.0199284 [doi]

Wallace, L. S., Rogers, E. S., Roskos, S. E., Holiday, D. B., & Weiss, B. D. (2006). Brief report: Screening items to identify patients with limited health literacy skills. *Journal of General Internal Medicine, 21*(8), 874-877. doi:JGI532 [pii]

Washington, D. M., Curtis, L. M., Waite, K., Wolf, M. S., & Paasche-Orlow, M. K. (2017). Sociodemographic factors mediate race and ethnicity-associated childhood

asthma health disparities: A longitudinal analysis. *Journal of Racial and Ethnic Health Disparities*, doi:10.1007/s40615-017-0441-2 [doi]

Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., et al. (2005). Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*, 3(6), 514-522. doi:3/6/514 [pii]

Wolf, M. S., Williams, M. V., Parker, R. M., Parikh, N. S., Nowlan, A. W., & Baker, D. W. (2007). Patients' shame and attitudes toward discussing the results of literacy screening. *Journal of Health Communication*, 12(8), 721-732. doi:786442306 [pii]

Yin, H. S., Johnson, M., Mendelsohn, A. L., Abrams, M. A., Sanders, L. M., & Dreyer, B. P. (2009). The health literacy of parents in the united states: A nationally representative study. *Pediatrics*, 124 Suppl 3, S289-98. doi:10.1542/peds.2009-1162E [doi]

Yin, H. S., Mendelsohn, A. L., Wolf, M. S., Parker, R. M., Fierman, A., Van Schaick, L., et al. (2010). Parents' medication administration errors: Role of dosing instruments and health literacy. *Archives of Pediatrics and Adolescent Medicine*, 164(2), 181-186. doi:10.1001/archpediatrics.2009.269