

# Health Literacy: Implications for Child Health

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## Practice Gaps

Health literacy plays a critical role in the health of pediatric patients, with effects across the continuum of care (ie, preventive, acute, and chronic care). Although the use of health literacy–informed communication strategies and interventions can improve pediatric health outcomes and reduce health disparities, few providers receive training in health literacy principles, and few routinely incorporate health literacy–informed communication strategies into their daily practice.

## Objectives

After completing this article, readers should be able to:

1. Understand how health literacy is a critical health concern for pediatric medicine.
2. Describe how low health literacy affects knowledge, behaviors, and health outcomes for parents, children, and adolescents in preventive, acute, and chronic care.
3. Recognize key strategies and interventions to improve communication and care in preventive, acute, and chronic care.

## Abstract

Health literacy is an important issue to consider in the provision of health-care to children. Similar to the adult population, most parents face health literacy challenges. Of particular concern, 1 in 4 parents have low health literacy, greatly affecting their ability to use health information to make health decisions for their child. High expectations are placed on parents and children to achieve effective disease management and positive health outcomes in the context of complex health-care systems and disease treatment regimens. Low health literacy affects parent acquisition of knowledge, attitudes, and behaviors, as well as child health outcomes across the domains of disease prevention, acute illness care, and chronic illness care. The effect of low health literacy is wide ranging, including 1) poor nutrition knowledge and behaviors, 2) higher obesity rates, 3) more medication errors, 4) more emergency department use, and 5) poor asthma knowledge, behaviors, and outcomes. Health-care providers can

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### ABBREVIATIONS

AHRQ Agency for Healthcare Research and Quality  
CDC Centers for Disease Control and Prevention  
ED emergency department  
OTC over-the-counter

mitigate the effects of health literacy by seeking to align health-care demands with the health literacy skills of families. Effective health literacy-informed interventions provide insights into methods that can be used by providers and health systems to improve health outcomes. Health literacy-informed communication strategies should be used with all families in a “universal precautions approach” because all parents likely benefit from clear communication. As scientific advances are made in disease prevention and management, unless families understand how to follow provider recommendations, the benefit of these advances will not be realized and disparities in outcomes will be exacerbated.

## INTRODUCTION

Health literacy is a key safety and quality issue to consider in the delivery of high-quality health-care by national organizations, including the Centers for Disease Control and Prevention (CDC), the Joint Commission, and the American Academy of Pediatrics. (1)(2)(3)(4)(5)(6) Health literacy, beyond the ability to read, is most commonly defined 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.” (4) Health literacy encompasses a complex set of skills, including knowledge, oral communication, written communication, quantitative ability, and navigation and information seeking (Table 1). (2)(7)(8)(9)(10) Every health-care encounter on the continuum from entry into the system to self-management at home requires health literacy skills. (11)

Health literacy issues are central to the interaction between individuals’ capacities and the demands and complexities of the tasks placed before individuals by the health-care system. (12) Health literacy is, thus, not simply a description of one person’s skills but also reflects the ability of a health system to meet the needs of consumers. There is a national movement toward establishing “health literate” organizations that take responsibility for making it “easy for people to navigate, understand, and use information and services to take care of their health.” (12)

Individuals who possess limited health literacy skills, or who have low health literacy, have difficulty performing tasks necessary to maintain their health. For example, someone with low health literacy likely struggles with filling in basic information on medical forms, understanding diagnoses, taking medications correctly, adhering to recommended behaviors, and assessing the validity of and interpreting the content of health information presented via media channels. (2)(9)(13)(14) Research in adults has shown

that individuals with low health literacy are less likely to use preventive services, have less knowledge of chronic illnesses and their management, have more preventable hospital visits, have more admissions and use of emergency services, are more likely to report their health status as poor, and have higher mortality rates. (2)(15)(16)(17)(18)(19)(20)(21)(22)(23)(24)(25)(26)(27) The construct of health literacy is linked to knowledge, self-efficacy, attitudes, health behaviors, and health outcomes (Fig). Although research findings related to children and adolescents who manage their own care is not as robust as that in adults, a growing body of literature suggests that children and adolescents who have low health literacy face similar problems as adults with low health literacy and may, additionally, be at a developmental disadvantage. (28)

It is important for providers to recognize that one cannot identify an individual as having low health literacy by appearance, although there are sometimes signs to suggest that an individual has low literacy (eg, incomplete intake forms, frequently missed appointments, not giving medications correctly, inability to give a coherent sequential history, or asks few questions to providers). (2) In addition, when considering the health literacy level of patients or parents, it is important to understand that health literacy is not a “fixed” trait. Factors such as stress and sleep deprivation can have a detrimental effect on an individual’s health literacy, making communication and comprehension more difficult. Given provider difficulties in reliably judging an individual’s health literacy level by appearance, as well as the potential fluctuation in skills based on circumstances, providers should use recommended communication strategies with all patients or parents, often referred to as a “universal precautions” communication approach. (29)(30)(31)

In this article, health literacy levels are described using the common terminology of low, marginal, and adequate. There are differences in how health literacy levels are

TABLE 1. **Domains of Health Literacy and Examples of Health Literacy Skills (2)(7)(8)**

SKILLS DOMAIN	EXAMPLES OF HEALTH LITERACY SKILLS <sup>a</sup>	EXAMPLES OF TASKS
Knowledge	Disease-specific knowledge Conceptual knowledge of health Vocabulary	Albuterol is an inhaled asthma medicine that is used for the quick relief of symptoms Fever is a body temperature elevated from normal Understanding words during oral or written communication enough to comprehend topic
Oral communication (listening, speaking)	Communicate history of illness or medical history Listen and comprehend Discuss risks, choices, treatments, and decisions regarding health Ask for clarification and ask questions	Give an accurate history of an acute problem or past medical problems Understand the choices when spoken to about them Participate in shared decision making regarding an upcoming procedure Having the knowledge and skills to actively participate in conversations with a health-care provider
Written communication (reading and writing)	Reading and understanding written information Interpreting and applying information needed to make health decisions Understand and give consent Interpreting a health-care document	Brochures, facts sheets, booklets, or information using full sentences in paragraph form Understanding a brochure with a graph about body mass index and placing child's weight in a category and understanding meaning Comprehend required informed consent documents before procedure Interpreting a food label to determine how many calories are in a food item
Quantitative	Interpreting and applying meaning of numbers (numeracy) Dosing medications (especially liquid medications, using inhaled medications, understanding timing)	Understanding the normal range of a test Understand how to measure out the correct amount of medication and give it at the right times in the course of a day
Navigation and information seeking	Make, plan for, and get to appointments Finding appropriate health-care providers Navigate insurance system Finding information (online, print) needed to make health decisions	Finding the way around the medical complex to get to a subspecialist's office Navigate insurance and hospital systems to find the right doctor for child's problem Call for prior authorization before procedure Being able to find pertinent and correct information about a health condition on the Internet, or in periodicals, books, or the media

<sup>a</sup>This table is not an all-inclusive list of skills; illustrative examples of the concepts of health literacy skills are presented.

described depending on the measure used, but we sought to interpret the health literacy levels in a consistent manner when presenting data.

## EPIDEMIOLOGY

In the most recent report from the US Department of Education and the National Center for Education Statistics, 77 million adults, or 35% of the adult population, have low health literacy, (32) including 28% of US parents (>21 million). (9) It is important to note, however, that only 15% are categorized as having the highest level of health literacy skills, indicating that most individuals face some

health literacy challenges. (9) Even more startling, only 8% of adults are categorized as having the highest level of health numeracy skills, or the ability to use numeric information to make health decisions. (33)

In the pediatric emergency department (ED) setting, the prevalence of parents and caregivers with low health literacy may be higher, with rates of up to 70%. (34)(35) This increased prevalence may be an indication of lack of health-care access due to poverty, language, or educational status, characteristics also associated with low health literacy.

Older adults, racial and ethnic minorities, people with low income levels, people with lower educational attainment, and nonnative speakers are among the

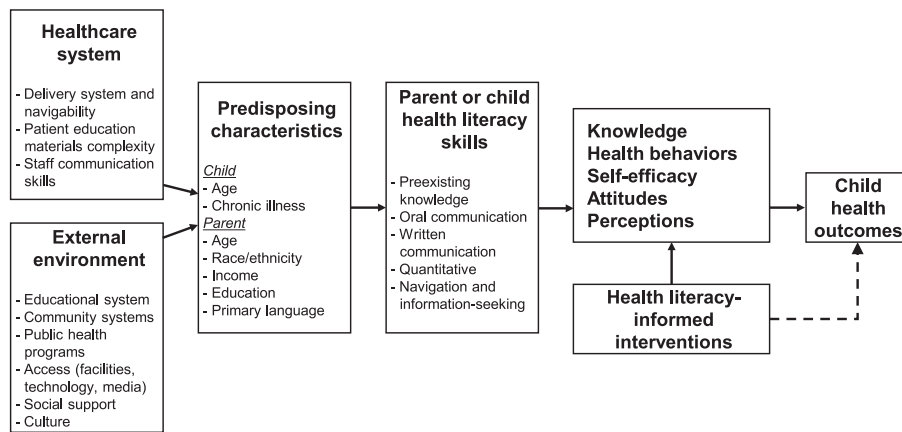


Figure. External factors, predisposing characteristics, and individual health literacy skills linked to knowledge, behavior, and health outcomes. (7)(8)(12)(36)

groups most likely to have low health literacy, (2)(37) and research suggests that health literacy is a likely mediator of income- and race/ethnicity-associated health disparities. (9)(38)

### MEASURING HEALTH LITERACY

Rather than measure health literacy by screening individuals before care delivery, there is a general consensus that health systems should use a universal precautions approach to health literacy; this is championed by the Agency for Healthcare Research and Quality (AHRQ). (29) Universal precautions for health literacy advocate for communicating with all people as if they have low health literacy. Nearly all people benefit from strategies designed for those with low health literacy because health literacy skills can vary based on stress, sleep deprivation, pain, or disease-/context-specific knowledge.

In some instances, however, a clinician or researcher may desire to measure health literacy. Numerous assessment tools have been designed and are available to measure an individual's health literacy level (Table 2). To be suitable in a clinical environment, administration time must be short and content must be complex enough to accurately measure health literacy across the range of skills. The Health Literacy Toolshed is a comprehensive resource for health literacy measures (<https://healthliteracy.bu.edu/>).

### COST

The estimated annual cost of low health literacy to the US economy is \$106 billion to \$238 billion, equal to 7% to 17% of personal health-care expenses. (39) In an analysis of nationally representative estimates, individuals with low

health literacy spent an average of \$500 more on office visits, \$50 more on ED visits, and \$2,600 more on prescriptions compared with those with adequate health literacy. (40) Another study found that patients with low literacy have higher annual costs (\$8,000 higher, of which \$6,000 reflect inpatient costs) than those with higher literacy, even after considering age, ethnic/racial group, and health status. (41)

The following sections discuss how health literacy affects knowledge, behaviors, and outcomes related to pediatric preventive care, acute care, and chronic conditions (summarized in Table 3).

### PREVENTIVE CARE

Disease prevention by primary, secondary, or tertiary prevention strategies has transformed pediatric health. However, health system and public health efforts to prevent injury and disease require effective communication. Despite provider efforts and public health campaigns focused on preventive behaviors, many parents with low health literacy do not follow these recommendations, contributing to poor health outcomes.

#### Knowledge

Low health literacy has been associated with less injury prevention knowledge, including less knowledge on how to treat choking or what to do for a child if he or she is burned (2× the odds). (42) Expecting parents with lower health literacy faced with questions about prenatal screening for genetic defects had less knowledge of test availability and less understanding of test results than those with adequate health literacy. (43)

TABLE 2. Health Literacy Measures and Characteristics

MEASURE	MEASUREMENT DOMAINS	ITEM EXAMPLE	NO. OF ITEMS AND AVERAGE ADMINISTRATION TIME
Newest Vital Sign (44)	Written communication Quantitative	"If you eat the entire container, how many calories will you eat?" – referring to a nutrition label.	6 items, 3 min
Parental Health Literacy Activities Test (45)	Written communication Quantitative	"Using the instructions provided on the Enfamil powder formula, how much water and formula would you add to make a 4-oz bottle?" – referring to a label provided.	20 items, 21 min <i>Parental Health Literacy Activities Test 10:</i> 10 items, 13 min
Rapid Estimate of Adult Learning in Medicine (46)	Vocabulary knowledge Oral and written communication	Pronounce medical terms on a list correctly, eg, <i>flu, caffeine, menopause, osteoporosis, impetigo</i>	66 items, 2–3 min <i>Short form:</i> 7 items, 1 min <i>Teen form:</i> 66 items, 2–3 min
Single Item Literacy Screener (47)	Written communication	"How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"	1 item, 1 min
Test of Functional Health Literacy in Adults (48)	Written communication Quantitative	"If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it?" – referring to a medication label	67 items, 20 min <i>Short form:</i> 40 items, 7 min

### Behaviors

Parents with low health literacy have less optimal health behaviors for injury prevention, including firearm safety-related measures (keeping a gun unloaded and locked in a safe place, discussing firearm safety). (42) Low health literacy is also related to other safety behaviors, including not having a working smoke detector (3× the odds), allowing a child to play alone near water (2× the odds), and having harmful household products and matches within reach (2× the odds). (42)

Several studies have found that parents with low health literacy have less optimal behaviors related to proper feeding and nutrition. Mothers with low health literacy exclusively breastfeed 20% less during the first 2 months of life (49) and have 2× the odds of feeding more formula than human milk. (50) Mothers with low health literacy have 2× the odds of feeding immediately when their child cries (rather than investigating other reasons for crying) and propping the bottle while their child feeds. (50) Low parent health literacy is also associated with 35% fewer parents using healthy weight behaviors with their child, such as increasing fruit/vegetable consumption, increasing physical activity, and decreasing fat intake. (51) Parents with lower numeracy skills have worse portion-size estimation skills, growth chart interpretation abilities, and nutrition label comprehension.

(52) Parents with low health literacy also have fewer optimal physical activity-related behaviors, (42) including more infant television time and less tummy time. (42)(53) Sports participation is lower among adolescents with low health literacy. (54)

Low health literacy in parents or adolescents is associated with worse tobacco and alcohol-related behaviors. Children of parents with low health literacy have higher levels of salivary nicotine and air nicotine in the home. (55) Low health literacy was found to be a key predictor of tobacco use for adolescents (4× the odds). (56) In adolescent boys, low health literacy was associated with 2× the odds of consuming alcohol. (56)

Low health literacy in adolescents is significantly associated with increased violent behaviors. Specifically, after adjusting for sex, race, and age, those who have low health literacy have a significantly higher odds of carrying a weapon (2× the odds), carrying a gun (3× the odds), being in a physical fight at school (3× the odds), being in a fight that resulted in injuries requiring treatment (3× the odds), being threatened by a weapon at school (2× the odds), and missing school because of feeling unsafe (2× the odds). (57) Adolescents with low health literacy are more likely to be both the aggressor and the victim and less likely to only be a victim. (57)

**TABLE 3. Low Health Literacy and Relationship with Pediatric Health-Related Knowledge, Behaviors, and Outcomes**

CATEGORY OF ISSUE AFFECTED BY LOW HEALTH LITERACY		DETAILS OF IMPACT OF LOW HEALTH LITERACY
Knowledge	Less topic-related knowledge	<p><b>Medication:</b> ↑ knowledge about use of cough/cold medications in a child &lt;2 y, ↓ knowledge of weight-based dosing, ↓ medication label understanding</p> <p><b>Asthma:</b> ↓ general asthma knowledge, ↓ knowledge of asthma treatment regimen and triggers, ↓ confidence in ability to manage asthma, ↑ perceived need for asthma medicine</p> <p><b>Injury:</b> ↓ knowledge of choking treatment, ↓ knowledge of treating burns</p> <p><b>Sickle cell disease:</b> ↓ sickle cell disease knowledge</p> <p><b>Genetic screening:</b> ↓ knowledge of test availability and understanding of test results for prenatal screening for genetic defects</p>
	Perceive child to be more ill	Perceive child to be sicker during mild acute illness
Behaviors	Worse safety behaviors	<p><b>Firearms:</b> ↓ safe firearm storage, ↓ discussion about firearm safety with child</p> <p><b>Home safety:</b> ↓ safe water heater setting, ↓ working smoke detector, ↑ harmful household products and matches within reach, ↑ allow child to play alone near water</p>
	Worse feeding, nutrition, healthy weight, and activity behaviors	<p><b>Nutrition and feeding:</b> ↑ formula-feeding (versus breastfeeding), ↓ feeding based on satiety cues (immediately feeds when child cries, ↑ bottle propping), ↓ portion size estimation, ↓ nutrition label comprehension, ↓ ability to assess portion size</p> <p><b>Healthy weight:</b> ↓ ability to interpret growth charts, ↓ use of weight loss strategies (increasing fruits/vegetables, increasing physical activity, or decreasing fat intake)</p>
	Worse tobacco and alcohol behaviors	<b>Activity (parents):</b> ↑ child television viewing, ↓ adequate tummy time
	Increased violent behavior	<b>Activity (adolescents):</b> ↓ sports participation
Behaviors	Incorrect medication use	<p><b>Children:</b> ↑ exposure to second-hand smoke</p> <p><b>Adolescents:</b> ↑ tobacco use, ↑ alcohol consumption (adolescent boys)</p> <p><b>Adolescents:</b> ↑ violent behaviors, ↑ weapon carrying, ↑ history of physical fights, ↑ likelihood of being aggressor and victim</p> <p><b>Over-the-counter medications:</b> ↑ difficulty understanding ↓ medication labels, ↑ errors in decision making based on age of use, ability to use active ingredient information in decision making</p> <p><b>Prescription medications:</b> ↓ medication adherence (in general, epilepsy medication, glaucoma eye drops)</p> <p><b>Liquid medications:</b> ↑ dosing errors (liquid medication), ↑ overdosing with dosing cup or dosing spoon</p>
	Worse disease management	<p><b>Asthma:</b> ↓ likelihood of being seen by an asthma specialist, ↓ ability to use asthma action plan (eg, determine what zone asthma in, determine proper management)</p> <p><b>Diabetes:</b> ↓ adherence to diabetes management (eg, insulin management, blood sugar monitoring, diet)</p>
	Greater prevalence of disease	<p><b>Obesity:</b> ↑ child obesity if parent with low health literacy; ↑ obesity if adolescent has low health literacy</p> <p><b>Depression:</b> ↑ depression rate (worse child school readiness if parent has low health literacy and depression)</p> <p><b>Behavior:</b> ↑ behavior problems</p> <p><b>Asthma:</b> ↑ school days missed, ↓ asthma control</p> <p><b>Diabetes:</b> ↓ glycemic control</p> <p><b>Epilepsy:</b> ↑ seizure frequency</p> <p><b>Nephrotic Syndrome:</b> ↑ relapse rate, ↓ complete remission rates</p> <p><b>General population:</b> ↑ ED visits, ↑ nonurgent ED visits (among children without chronic illness)</p>
Outcomes	Worse child disease-specific outcomes	<p><b>Asthma:</b> ↑ ED visits and ↑ hospitalizations in children with asthma, ↓ rates of child health insurance</p>
Outcomes	Greater health-care utilization	
	Worse health-care access	

ED=emergency department.



## Outcomes

Given worse knowledge and less advantageous behaviors, it translates that children of parents with low health literacy have worse health outcomes related to disease prevention. Health outcomes sensitive to health literacy include depression, school readiness, and having health insurance. Parents with low health literacy are more likely to have depression. (42) In a study of preschool-aged children, mothers with depressive symptoms and low health literacy were more likely to have children with worse school readiness and more behavior problems. (58) A child has 2.5× the odds of not having health insurance if a parent has low health literacy. (9)

Interestingly, if a parent has higher health literacy, their child is less likely to be vaccinated. (59) Parents with higher health literacy have more antivaccine attitudes and also perceive unofficial information sources to be more reliable if those sources oppose vaccines.

## Interventions

To date, interventions using health literacy-informed strategies have improved care in 3 areas in preventive health: vaccine knowledge, child injury prevention knowledge, and obesity prevention. Health literacy-informed strategies incorporated by interventions include low grade-level readability, plain language, instructional graphics, bullet points, emphasis on key points, and clear layout. (60)(61)(62)

One study compared a vaccine information statement from the CDC and an easy-to-read intervention pamphlet and found that the pamphlet was preferred, was considered more readable, and was more easily understood. (60) Parents were able to comprehend only one-third to one-half of what they read despite most completing the 12th grade. The Safety in Seconds study, conducted with low-income, urban families, involved a computer kiosk placed in the waiting room of a pediatric ED, with intervention group parents receiving a customized child injury prevention report and control group parents receiving general child health information. (62) Participants with higher health literacy scores receiving the intervention were significantly more likely to have higher knowledge score improvements in poison storage and smoke alarms compared with those with lower health literacy levels. Although these strategies are meant to aid those with low literacy, these aforementioned studies found that the knowledge gains were greater in those with higher health literacy levels. (60)(62)

An obesity prevention study in low-income Hispanic families included in-person counseling in addition to the use of health literacy-informed print materials. (61) The intervention consisted of 1) individual nutrition and

breastfeeding counseling, 2) support groups coordinated with well-child visits, and 3) plain language handouts using images and action-oriented, positive messages. Early findings include more floor tummy time and more unrestrained floor time in the intervention group. Study findings support the use of verbal counseling reinforced by consistent messaging in print materials as a more effective strategy than handouts alone.

## ACUTE CARE

In pediatrics, where chronic illness occurs with a much lower prevalence than in the adult population, the health literacy challenges faced by parents in caring for their child's health needs often occur sporadically in the context of acute self-limited illnesses. Parents with low health literacy have a poorer understanding of acute illnesses and are less likely to search for information to guide their child's care. Parental decision making in the context of a knowledge-poor environment affects health-care utilization choices, including when and where to seek care, as well as appropriate medication use.

## Knowledge

Parents with low health literacy have less knowledge of medications used during acute illness. Parents with low health literacy are more likely to report having difficulty understanding over-the-counter (OTC) medication instructions (3× the odds). (9) Parents with low numeracy skills are more likely to misinterpret OTC cough/cold medication labels and incorrectly decide that cough/cold medications can be used in a child younger than 2 years. (63) Parents with low health literacy are less likely to know that the dosing of a child's medication should be based on weight rather than age, increasing the likelihood of dosing errors. (64)(65)(66)

Furthermore, health literacy affects parents' ability to understand and interpret symptoms to make a health decision while their child is ill. Parents with low health literacy perceive that their child is sicker than parents with adequate health literacy during a mild acute illness. (67) Misinterpretation of child illness severity likely contributes to more ED visits during acute illnesses.

## Behaviors

Frequently, OTC medications are used to symptomatically treat acute illness in children. Low health literacy limits parent ability to safely/effectively use these medications. Many parents, but especially those with low health literacy, do not use active ingredient information as part of decision making related to administering multiple medications, increasing the risk of multifold overdose. (68)

Low health literacy is associated with the use of non-standard dosing tools (eg, kitchen spoons) and more parent dosing errors. (65) Parents with low health literacy made more large (>40% deviation) and small (20%–40% deviation) dosing errors compared with parents with adequate health literacy. (66) Parents with low health literacy also made more overdosing errors when using a dosing cup or dosing spoon. (66) Having both low health literacy and low English proficiency results in an even greater risk of dosing errors. (69)

Health literacy also affects how parents prefer to dose medications. Parents with lower health literacy prefer to use teaspoon units over milliliter units (3× the odds) and believe that a move to dosing in milliliters only (now recommended by the American Academy of Pediatrics) will be difficult (14× the odds). (70)(71)

### Outcomes

Parent health literacy–related caregiving skills, including illness assessment and treatment skills, understanding of illness severity, and health system navigation, influence how parents with low health literacy seek care for their child during acute illness. (72) A child has 50% more ED visits if his or her parent has low health literacy, regardless of whether the child has a chronic illness. (34) Of children without a chronic illness, those whose parents had low health literacy had more than 3× the odds of presenting to the ED for a nonurgent visit, such as for a cold or a rash. (34) Also, children older than 2 years presenting to the ED with fever were more likely to have a nonurgent visit if their parent had low health literacy. (35)

### Interventions

Acute care interventions have focused primarily on 2 key areas: medication dosing and ED use. Redesigning the process of provider medication counseling from a health literacy perspective has been found to decrease dosing error rates. Use of the HELPix intervention, which includes low-literacy pictographic patient- and medication-specific instruction sheets, along with optimized provider counseling (demonstration, teach-back/show-back) and provision of an oral syringe, was found to reduce liquid medication dosing error rates (control versus intervention: 48% versus 5% for daily-dose medications; 40% versus 16% for as-needed medications), in a randomized trial with a number needed to treat of 2.4. (73) The instruction sheets included a pictographic dosing diagram that visually showed the amount to measure in a recommended dosing tool. Several studies have demonstrated that medication labels with pictographic versus text-only instructions are more effective

in reducing dosing errors. (73)(74)(75) Other considerations for dosing liquid medications include units of measurement and the size and type of dosing tools provided; a randomized study found that parents had fewer errors with milliliter-only instructions, that parents dosed more accurately with oral syringes (especially for smaller dose volumes), and that using a dosing tool size that more closely matched the dose volume prescribed led to fewer errors. (75) Provision of an optimized dosing tool benefited parents across health literacy levels, but especially those with low health literacy.

To reduce ED utilization, 2 studies used low literacy, easy-to-read health aid books that provided information on more than 50 common childhood medical problems. (76)(77) Parents participated in a 4-hour educational program on how to use the book and were given a copy to take home. In a primarily low-income minority population, there was a 30% reduction in ED use during a 6-month period, and in a Head Start population there was a 58% reduction in ED visits per child per year. (76) In another study designed to reduce ED use, intervention clinic patients who used a low-literacy health aid book were found to have fewer ED visits after implementation. (78)

## CHRONIC DISEASES

Low parent health literacy has been linked to poor management and outcomes related to a child's chronic conditions. Many chronic childhood illnesses require that medications are taken daily, and these instructions can be difficult to follow, especially when titration of doses is needed to optimize care regimens. Children with chronic conditions may require frequent follow-up with their primary care provider or specialists, have specific dietary restrictions, or have other complex routines. The effect of low health literacy has been examined in the context of several common pediatric chronic conditions, including asthma, diabetes, obesity, and sickle cell disease.

### Knowledge

Much of the work examining health literacy's impact on improving knowledge of chronic pediatric diseases has focused on asthma and sickle cell disease. Composite asthma knowledge scores (including information on asthma in general, treatment, and triggers) are lower for parents with low health literacy. (79)(80)(81) Parents with low health literacy are less confident in their ability to manage their child's asthma. (82) Low parent health literacy is also associated with increased worry about asthma and greater perceived need for asthma medicines. (83) One study



also found lower sickle cell disease-specific knowledge in parents with lower scores on health literacy measures. (84)

### Behaviors

Several studies have examined the relationship between health literacy and behaviors in parents whose children have chronic illnesses, including asthma. Children whose parents have low health literacy are less likely to receive care from an asthma specialist. (80) In 1 study, parents with low health literacy had more difficulty using asthma action plans to identify the level of control of a child's asthma (ie, which action plan color-coded zone the child was in) and determine appropriate management when given standard vignettes. (85)

Other studies have examined parental behaviors related to medication dosing and adherence for several chronic diseases. Parents with lower scores on a human immunodeficiency virus-specific health literacy assessment were more likely to make errors in dosing liquid zidovudine. (86) For parents managing complicated diabetes regimens, low health literacy is associated with low scores on a composite adherence measure (including insulin management, blood sugar monitoring, and diet). (87) Low parent health literacy is also associated with poor adherence to prescribed eye drops for glaucoma and epilepsy medications. (88)(89)

### Outcomes

Children with chronic conditions whose parents have low health literacy have worse disease-specific outcomes and increased health-care utilization compared with those with adequate health literacy. Asthmatic children whose parents have low health literacy and numeracy scores have been shown to be more likely to be hospitalized (>4-fold adjusted incidence rate ratio). (81)(90) Asthma-related ED visits were more likely in parents with low health literacy in several studies (as high as 1.7× increased odds). (80)(81)(90) Low parent health literacy is associated with worse asthma control (both provider-reported and a validated parent-reported measure) (79) as well as more missed school days in asthmatic children (adjusted incidence rate ratio, 2.8). (81)

Studies assessing the relationship between parental health literacy and glycemic control in their type 1 diabetic children have shown mixed results. Lower scores on numeracy measures (91) and on the Newest Vital Sign health literacy assessment (92) are significantly associated with higher hemoglobin A<sub>1c</sub> levels. In other studies, print literacy skills were not associated with glycemic control. (91)(93)

Both parent and child health literacy have been found to be related to weight outcomes. Parental low health literacy increases the likelihood of abnormal body weight in children. (94) Parents with low numeracy are more likely to have either underweight or overweight children. (52) Children and adolescents with low health literacy have a higher odds of obesity (up to a 5-fold increased odds) and increased body mass index Z score. (94)(95)

The relationship between health literacy and outcomes for several other diagnoses have also been studied. Seizures were more frequent in the setting of low parent health literacy in 1 study. (88) In children with nephrotic syndrome, higher health literacy scores were associated with a lower risk of first relapse (hazard ratio, 0.67) and higher odds of complete remission (2× the odds) in a clinic with standardized nurse-delivered medication. (96)

### Interventions

Interventions geared toward improving outcomes in children with chronic diseases whose parents have low health literacy have focused on 2 primary health issues: asthma and obesity. One study assessed overall asthma knowledge scores in parents whose asthmatic children presented to the ED for evaluation of respiratory symptoms before and after they had received educational materials in video or written form. Absolute knowledge scores increased by 40% in parents with low literacy whether they received written or video education, whereas those with adequate health literacy had improved knowledge scores with video education only. (80) Others have studied the impact of a low literacy, photograph- and pictogram-based asthma action plan on parent asthma knowledge and provider counseling in hypothetical asthma counseling scenarios. Parents who received the low literacy plan were less likely to make errors in knowledge of medications to take every day and when sick (0.5× the odds) and errors regarding spacer use (0.1× the odds). (97) Physicians who counseled families with a low literacy plan provided more detailed and higher-quality counseling. (98)

Other recent literature has focused on health literacy-informed interventions to improve obesity-related outcomes. One quasi-experimental study, which focused on a community-based intervention applying universal health literacy precautions, led to improvements in child body mass index Z scores in obese children. (99)

## COMMUNICATION STRATEGIES FOR PROVIDERS

Providers can mitigate the disparities in health knowledge, behaviors, and outcomes associated with low parent health

literacy by using health literacy–informed counseling strategies as part of verbal and written communication with patients and families; such strategies are beneficial for individuals across health literacy levels. In this section, we discuss the theory and evidence behind several of these strategies, including data from adult studies (given that much of the evidence comes from the adult literature). A summary of health literacy–informed communication strategies is presented in Table 4.

### Simplifying and Organizing Information

An overarching strategy to ensure that families understand information is to simplify the content as much as possible and organize it in a logical manner to reduce the cognitive load. The cognitive load, or the amount of mental demand that medical information presents, can affect how well an individual can process and understand this information. (100)(101) Per cognitive load theory, information that is too complex may not be fully processed or incorporated into working memory; use of more simple information can help reduce demand. (102)(103) Specific strategies are described in the following subsections.

**Limiting Information.** Limiting information presented to 3 messages (or the single most important message if possible) can make information easier to retain. Adults who are presented with shorter amounts of information that highlight key points and eliminate unnecessary information have better comprehension. (104)(105) Parents of children who are discharged home with more complex instructions (eg, multiple medications) have worse knowledge of their child’s diagnoses, medication administration information, and appointments. (106) Complex instructions are also associated with failure to pick up prescriptions and attend appointments. (107)(108)

Focusing on key messages can help ensure that parents finish an encounter understanding the most essential information. (109) The “Ask Me 3” strategy does this by encouraging parents to ask “What is my main problem?” “What do I need to do?” and “Why is it important for me to do this?” In general, parents should be encouraged to ask questions to ensure that they understand the information presented.

**Explicit and Action-Oriented Instructions.** Focusing on specific behaviors can improve understanding. For example, the AHRQ-recommended Universal Medication Schedule provides actionable medication instructions in the context of 4 standard periods per day (eg, morning, noon, evening, and bedtime) instead of vague frequency information (eg, 2×, 4× per day). (110) Use of the Universal Medication Schedule has led to improved medication adherence, (111) and is preferred by patients. (112)

The best instructions also provide information salient to taking an action; excessive background information or explanations may be distracting. (113) Patients prefer more action-oriented instructions (114) and find them to be more understandable. (115)

**Chunking.** Chunking information into small, manageable pieces can help overcome the limits of working memory and reduces demand when there is a lot of information that must be learned. (116) Parents also prefer information to be broken down into pieces that are easy to understand, including for conditions such as diabetes when there are complex insulin regimens. (117)

### Plain Language Verbal Counseling

Plain language verbal counseling refers to using simple words in short, simple sentences. Lay terms should be used, with minimal medical jargon. When jargon must be used, a full explanation in plain language terms should be included. Use of jargon and unfamiliar language contributes to misunderstanding or disregarding of advice. (116) Parents prefer that providers use plain language and avoid using jargon. (118)(119) Jargon can interfere with the communication process (120); for example, common diabetes jargon, such as “honeymoon period” and “peaks of insulin,” were noted to be confusing for parents in 1 study, with parents with low health literacy disproportionately affected. (117)

### Demonstration

Dual coding theory suggests that humans process verbal and visual information through separate channels, (100) so using both verbal communication and demonstration in providing instructions results in easier and quicker learning. (102)(103) Parents prefer demonstration of diabetes information over simple verbal instructions; this is especially true for parents with low health literacy. (117) Demonstrating how to dose liquid medications can lead to improved dosing accuracy. (121) Use of demonstration has also been incorporated into interventions that can improve proper dosing accuracy of liquid medications, as well as use of inhalers in asthmatic patients. (73)(122)(123)

### Teach-back/Show-back

Because many families are not aware that they do not understand physician instructions, (124)(125) it is important to ensure that learning has occurred before ending the counseling encounter. One method of doing so is teach-back, where patients/caregivers state information that was taught to them in their own words. (29) Teach-back is considered a top safety practice by the AHRQ. (126) One

TABLE 4. Health Literacy-Informed Communication Strategies

STRATEGY	DEFINITION	RATIONALE	EXAMPLES OF STRATEGY
Simplifying and organizing information			
Limiting information	Providing only the minimal amount of information necessary	Per cognitive load theory, information that is too complex may not be fully processed into working memory	For a patient with multiple issues, counseling on single topic and emphasizing the key points during a clinic visit
Explicit and action-oriented information	Providing specific and nonambiguous instructions related to taking a particular action	Puts less strain on cognitive processes	Instructions stating to give medication "in the morning and in the evening" (as opposed to "twice per day")
Chunking	Breaking down information into segments that are easy to understand	More information can be stored in working memory when organized and sorted into chunks	A list of warning signs is grouped into 3 organ system chunks: 1) nausea, vomiting, diarrhea; 2) cough, trouble breathing; 3) pain, swelling, redness to make them easier to remember. Bullet points can be used to chunk written information
Plain language verbal counseling	Language that is clear, concise, well organized, and easy to understand for the intended audience	>40% of adults are categorized as having the lowest levels of health literacy. Many do not understand complicated medical terminology.	Discharge counseling incorporates simple terms such as <i>fast breathing</i> and <i>throwing up</i> (as opposed to <i>tachypnea</i> and <i>emesis</i> )
Demonstration	Showing a patient how to perform a certain task	Dual coding theory suggests that humans process verbal/visual information through separate processes; presenting information in a visual way makes verbal counseling more efficient	Showing a patient how to use an asthma inhaler with spacer
Teach-back	Having a patient summarize instructions in their own words	Restating small pieces of information leads to improved recall	Giving a patient medication instructions and having them say in their own words how they would measure out the medication
Show-back	Having a patient demonstrate how they would follow instructions you have explained	There is improved recall of information when you are asked to show how you would perform task. Provides opportunity for additional teaching if patient not able to demonstrate task.	Giving a patient medication instructions and having them show you how they would measure a dose using an oral syringe
Written information	Supplementing verbal counseling with written instructions to reinforce concepts	Using written materials can offset having too much information in working memory at a given time	Verbally discussing return to play guidelines after a concussion while also providing a written instruction sheet with the same information. These instructions should be written in plain language and in active voice, have a clear layout, and be written at a 6th grade or lower level. The written materials should have an evident purpose and use headers, captions, a font size of ≥12 points, and typographic cues (eg, bolding).

Continued

TABLE 4. (Continued)

STRATEGY	DEFINITION	RATIONALE	EXAMPLES OF STRATEGY
Pictographic and video instructions	Use of pictures or drawings to supplement written material	Dual coding theory suggests that humans process verbal/visual information through separate processes; multimedia theory suggests that some concepts are easily understood through visual compared with verbal/text-based instruction	A video or instruction sheet with step-by-step pictographic and verbal information to show a parent how to measure out a liquid medication.

helpful strategy to use when conducting teach-back is to create a shame-free environment by putting the responsibility of learning on the clinician. For example, "I want to make sure I did a good job of explaining how to give the asthma medication. Can you tell me how you would give Jennifer the medicine at home?" Cognitive science studies have shown that restating short amounts of information can lead to improved recall. (127)(128) In adult studies, use of teach-back has been associated with better glycemic control in diabetic patients (24) and improved understanding of discharge instructions. (129)(130)

Pediatric studies have found that families and providers believe that teach-back is effective, can improve communication, can confirm learning, and should be used as a communication technique. (131)(132)(133) Despite this, teach-back is not standard practice, with only 23% of physicians reporting that they routinely use this technique; barriers include limited time and volume of information to be communicated. (134)

Several interventions have been developed that include teach-back as part of a bundle of elements to improve outcomes. These intervention bundles led to improvements in rates of surgical site infections after spinal fusion procedures (135) and reductions in readmission rates. (136)

Another strategy that goes 1 step beyond teach-back is show-back, or having a patient demonstrate how they would follow physician instructions; in 1 study, more than 70% of patients with low literacy were able to teach-back medication instructions, but only approximately half of those were found to understand instructions correctly with show-back. (137) Another study showed that when providers asked children to show them how they would use an inhaler, the child was more likely to have a higher percentage of inhaler use steps performed correctly 1 month later. (138)

### Written Information

It is well-established that supplementing verbal counseling with written instructions can help reinforce concepts. Written information should be up-to-date and reflect the

language used during verbal counseling. The addition of written information may help overcome the limits of working memory; rather than having patients focus on trying to memorize multiple pieces of information at once, provision of written materials may help reduce the cognitive load. (139)

Studies have shown that parents who receive verbal and written instructions, compared with only one of these modalities, had higher levels of understanding of medication instructions and of the signs and symptoms associated with gastroenteritis. (140)(141)(142)

Although simply providing written instructions can help ensure learning, use of plain language written materials can further increase the effectiveness of communication. Plain language materials should include lay language and easy-to-understand terms, with action-oriented information written in short, simple sentences. Greater amount of white space and a clear organizational structure are also helpful for readers with low literacy. (143)(144) Although more than 40% of adults in the United States have the lowest levels of health literacy, (145) a large proportion of printed health information is written at a level higher than the average patient can understand. (147)(147) Experts recommend the use of educational materials written at a sixth-grade level or lower to ensure understanding, especially in low literacy populations. (116)

Interventions incorporating plain language written materials have been shown to improve parental understanding of medication instructions, reduce medication dosing errors, and ensure that parents are giving the prescribed number of medication doses. (73) Providers can get guidance on how to evaluate or develop low literacy materials using tools such as Doak and Doak's Suitability Assessment of Materials checklist (116) or the AHRQ's Patient Education Materials Assessment Tool. (148)

### Pictographic and Video Instructions

Visually showing a patient or caregiver how to follow instructions is another beneficial communication strategy, which can be accomplished through the use of pictographic or video instructions. Multimedia or interactive modules

should use the same language as provided in the written information. In addition to incorporating the concepts of dual coding theory mentioned previously, multimedia theory suggests that some concepts are too difficult to depict using text and verbal information alone and are most easily represented using multiple types of instructions, including visual representations, such as pictures and videos. (149) In adult studies, the use of pictographic instructions has led to improved understanding of instructions related to the care of lacerations, (150)(151) understanding of several aspects of medication labels, (152)(153)(154) and adherence to medications. (153)

Pictographic instructions have been shown to improve parent knowledge related to medication administration, understanding of asthma management, medication dosing and adherence, and instructions on preparation of oral rehydration solution. (73)(75)(97)(155) Diagrams and graphics incorporating key, limited amounts of information are easier to understand than more detailed diagrams. (156)(157)

Video instructions take the benefits of pictographic instructions 1 step further by giving step-by-step visual and verbal information. Demonstration of instructions can be provided in a standardized way and can be played back multiple times, without adding provider time burden. The use of educational videos can improve knowledge of asthma-related triggers and proper inhaler technique, and the understanding of several ED diagnoses. (158)(159)(160)(161)(162)(163)(164)

## Summary

- Based on expert opinion, health literacy is defined 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.” (4)
- Based on quality observational studies, few US parents are categorized as having proficient health literacy, indicating that most parents encounter at least some health literacy challenges. (9)
- Based on quality observational studies on prevention, parents with low health literacy are less likely to observe injury prevention practices and follow recommended behaviors related to feeding and nutrition. Adolescents with low health literacy have worse tobacco- and alcohol-related behaviors and increased violent behaviors. (49)(51)(52)(53)(56)(57)
- Based on quality randomized controlled trials and observational studies on acute care, parents with low health literacy have worse knowledge related to medication use during an acute illness, make more medication errors, and are more likely to take their child to the emergency department. (9)(59)(60)(61)(62)(63)(64)(65)(66)(67)(68)(69)(70)(71)

- Based on quality observational studies on chronic care, parents with low health literacy have worse knowledge, health behaviors, and outcomes related to a variety of chronic illnesses, including asthma, diabetes, and obesity. (52)(79)(80)(81)(83)(84)(85)(86)(87)(88)(89)(90)(91)(92)(93)(94)(95)
- Based on quality randomized controlled trials, observational studies, and expert opinion, providers should consider use of the following evidence-based, health literacy–informed strategies to improve parent and patient outcomes: limiting information, explicit and action-oriented instructions, chunking, plain language verbal counseling, demonstration, teach-back/show-back, supplementing counseling with written information, and pictographic and multimedia materials. These health literacy–informed communication strategies should be used with all families in a universal precautions approach because all parents likely benefit from clear communication. (24)(29)(73)(75)(96)(103)(104)(105)(106)(107)(108)(109)(110)(111)(112)(113)(114)(115)(116)(119)(120)(121)(122)(123)(124)(125)(126)(127)(128)(129)(130)(133)(134)(135)(142)(143)(144)(145)(146)(147)(148)(149)(151)(152)(153)(154)(155)(156)(157)(158)(159)(160)(161)(162)(163)(164)

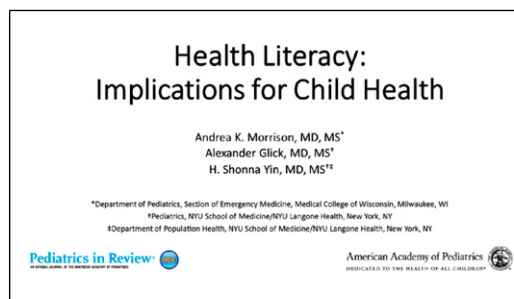
## ADDITIONAL RESOURCES FOR PEDIATRICIANS

AAP Resources: Health Literacy and Pediatrics: <https://www.aap.org/en-us/professional-resources/Research/research-resources/pages/Health-Literacy-and-Pediatrics.aspx>

AAP Resources: Literacy and Health Literacy: Culturally Effective Care Toolkit – Chapter 6: <https://www.aap.org/en-us/professional-resources/practice-transformation/managing-patients/Pages/chapter-6.aspx>

MOC Health Literacy Activities Open Lines of Communication: <https://www.abp.org/news/moc-health-literacy-activities-open-lines-communication>

To view teaching slides that accompany this article, visit <http://pedsinreview.aappublications.org/content/40/6/263>.



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1. A hospital has adopted "becoming a health literate organization" as the central component of its safety and quality improvement programs. In considering the scope of its intervention strategy and to be most effective, hospital interventions should target which of the following patient populations or settings?
  - A. All patients/parents (ie, universal precautions).
  - B. Chronic care patients.
  - C. Non-English-speaking patients.
  - D. Suspected high-risk patients based on appearance.
  - E. Preventive services/settings.
2. You discuss with a group of medical students the importance of health literacy and its correlation with health-care quality and safety. A medical student inquires about the reasons why institutions are placing such a heavy focus on health literacy. You explain to the student that based on the available evidence, higher health literacy rates have been associated with which of the following outcomes?
  - A. Feeling unsafe at school.
  - B. Higher health-care utilization costs.
  - C. Higher rates of emergency department (ED) use.
  - D. Higher risk of first relapse of nephrotic syndrome.
  - E. Fewer hospitalizations in children with asthma.
3. In studying postdischarge ED visits and readmissions, a hospital quality and safety review committee identified medication dosing errors as a major cause in a significant percentage of these ED returns and readmissions. The committee started an initiative to address these dosing errors after discharge. Drug administration instructions provided at discharge in which of the following formats is expected to be the most effective evidence-based mitigating strategy that will lead to significant reduction in these medication administration errors?
  - A. Based on total doses per day.
  - B. Only provided in English language.
  - C. Detailed instructions that are comprehensive in nature.
  - D. Using a kitchen teaspoon for dose measurement.
  - E. Using the Universal Medication Schedule strategy.
4. A 12-year-old boy newly diagnosed as having asthma is being discharged from the hospital after being admitted with asthma exacerbation. His medical history is significant for a few previous admissions for "bronchitis" and "pneumonia." No family history of asthma. On the day of discharge, the resident caring for the patient is explaining to him and his parents the discharge medications, which include an albuterol meter-dose inhaler to be used with an aerochamber and a mouthpiece and 2 more days of oral corticosteroids once a day. The patient has never used an inhaler before. Which of the following is the most effective method to use in providing this patient with instructions on the proper use of an inhaler?
  - A. Develop a 7- to 10-task/step "to do" list for the family.
  - B. Provide handouts with pictures.
  - C. Provide only written handouts.
  - D. Use of demonstration as part of verbal counseling, supplemented by written handouts with pictures.
  - E. Use only verbal instruction.

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5. You are preparing a new information pamphlet on routine immunization for your practice. Considering the principles of health literacy, at which of the following maximum reading levels should this material be prepared to ensure understanding by all parents?
- A. 6th grade.
  - B. 8th grade.
  - C. 10th grade.
  - D. 12th grade.
  - E. College level.
-

**Health Literacy: Implications for Child Health**  
Andrea K. Morrison, Alexander Glick and H. Shonna Yin  
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