Health Literacy and Quality: Focus on Chronic Illness Care and Patient Safety

abstract

Despite a heightened focus on improving quality, recent studies have suggested that children only receive half of the indicated preventive, acute, or chronic care. Two major areas in need of improvement are chronic illness care and prevention of medical errors. Recently, health literacy has been identified as an important and potentially ameliorable factor for improving quality of care. Studies of adults have documented that lower health literacy is independently associated with poorer understanding of prescriptions and other medical information and worse chronic disease knowledge, self-management behaviors, and clinical outcomes. There is also growing evidence to suggest that health literacy is important in pediatric safety and chronic illness care. Adult studies have suggested that addressing literacy can lead to improved patient knowledge, behaviors, and outcomes. Early studies in the field of pediatrics have shown similar promise. There are significant opportunities to evaluate and demonstrate the importance of health literacy in improving pediatric quality of care. Efforts to address health literacy should be made to apply the 6 Institute of Medicine aims for quality-care that is safe, effective, patient centered, timely, efficient, and equitable. Efforts should also be made to consider the distinct nature of pediatric care and address the “4 D’s” unique to child health: the developmental change of children over time; dependency on parents or adults; differential epidemiology of child health; and the different demographic patterns of children and their families. Pediatrics 2009;124:S315–S326
Improving the quality of health care for children and adults in the United States has been a major priority over the past 2 decades. Despite these efforts, gaps in quality continue to be significant. Studies have demonstrated that the quality of preventive, acute and chronic care for both children and adults remains suboptimal, with both populations only receiving approximately one half of the recommended preventive, acute, or chronic care. Among the factors that contribute to the suboptimal quality of care in this country, health literacy was recently identified as an important and potentially ameliorable factor. According to the 2003 National Assessment of Adult Literacy, ~90 million Americans have basic or below-basic literacy skills, and 110 million have basic or poor quantitative (numeracy) skills. Lower health literacy and numeracy skills have been independently associated with poorer health knowledge, poorer health behaviors, and worse clinical outcomes. Although health literacy research has focused primarily on adult health, a growing body of knowledge is revealing a similar detrimental impact of low health literacy in pediatrics. Caregivers of young children and adolescents with limited literacy skills can have difficulty navigating complex health systems, understanding medical instructions and recommendations, performing child and self-care tasks, and understanding issues related to consent, medical authorization, and risk communication.

In 2001, the Institute of Medicine (IOM) released the report *Crossing the Quality Chasm,* which focused on ways in which the health care system should be redesigned to improve care. The report outlined 6 major aims for quality improvement to provide care that is (1) safe, (2) effective, (3) patient centered, (4) timely, (5) efficient, and (6) equitable. These goals are listed in Table 1 with specific examples of opportunities to address health literacy to improve quality of care. In this article we examine the role of health literacy in pediatric quality of care, with a specific focus on 2 important areas: improving chronic illness care and promoting patient safety. We also review efforts to demonstrate the importance of health literacy and health communication in chronic illness care and patient safety and suggest opportunities for addressing health literacy to improve child health and safety.

**TABLE 1 Six Aims for Quality Health Care**

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<th>AIm</th>
<th>Description</th>
<th>Opportunities to Address Literacy</th>
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<tr>
<td>Safety</td>
<td>Addresses safety in hospital and outpatient care, prescription medication usage, and OTC medication usage, prevention, and other areas</td>
<td>Ensure that educational materials and medical instructions are clear and at the appropriate level for caregivers and patients. Examine opportunities to improve communication by using color coding, teach-back, clear communication principles, and other techniques to promote patient safety.</td>
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<td>Effectiveness</td>
<td>Provide services based on the best available scientific knowledge (avoid underuse, overuse, misuse)</td>
<td>Examine health care provider understanding of medical evidence and training in how to communicate this evidence effectively to families to improve family understanding, behaviors, and outcomes. Examine opportunities to improve communication by using teach-back, video and other electronic media, clear communication principles, and other techniques to promote patient understanding of medical recommendations.</td>
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<tr>
<td>Patient centered</td>
<td>Ensure that patient values and preferences are included in the decision-making process</td>
<td>Examine opportunities to improve communication by using clear communication principles. Examine the role of patient-centered communication, shared decision-making, and shared goal-setting approaches.</td>
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<td>Timely</td>
<td>Reduce wait times and possibly harmful delays in care</td>
<td>Examine opportunities for more efficient delivery of health information to best promote health-related knowledge and behavior among families. Examine the role of information kiosks, internet portals, point-of-care, and mobile technology to improve timeliness.</td>
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<td>Efficient</td>
<td>Avoid waste, including waste of equipment, supplies, ideas, and energy</td>
<td>Examine opportunities for more efficient delivery of health information to best promote health-related knowledge and behavior among families. Examine the role of non–health providers, electronic media, and other venues for the delivery of health information.</td>
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<td>Equitable</td>
<td>Provide care that does not vary in quality according to gender, ethnicity, race, socioeconomic status, or other issues</td>
<td>Examine the role of literacy as a mediator to health disparities. Examine the impact of addressing health literacy to help alleviate disparities.</td>
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**THE ROLE OF HEALTH LITERACY IN CHRONIC ILLNESS CARE AND PATIENT SAFETY**

**Chronic Illness Care**

More than 130 million Americans have a chronic illness, and by 2030, this number is expected to increase to 170 million. The vast majority of health care costs are now devoted to treat-
ment of chronic illness. Up to 20% of the pediatric population now has a chronic illness. The rapid rise in the number of children with chronic disease is likely a result of (1) better treatments for congenital and acquired diseases, which let children survive into adulthood, (2) advances in the diagnosis of pediatric conditions, and (3) a rise in "adult diseases" in childhood (eg, type 2 diabetes).

Comprehensive chronic disease management programs and the patient-centered medical home have been innovative approaches to improving chronic illness care. Disease management has been referred to as "a systematic, population-based approach to identify persons at risk, intervene with specific programs of care, and measure clinical and other outcomes." In contrast to traditional care models, which are often designed to address acute problems, disease management is meant to create an "organized system tailored to the less urgent problems of chronic illness." The chronic care model, elucidated by Wagner, is a common comprehensive approach to addressing chronic illness care that includes improvements at the health system and community level to improve interactions between a prepared proactive health care team and an informed, activated patient to improve health outcomes (see Fig 1). Chronic care programs are typically characterized by the use of (1) integrated delivery of services with multidisciplinary teams that can include physicians, nurses, case managers, psychologists, educators, dieticians, and pharmacists, (2) use of care algorithms that are based on the best available evidence, (3) information systems that allow proactive, population-based monitoring and adjustment of treatments, and (4) mechanisms to address social barriers.

Approaches that apply principles of the chronic care model or the patient-centered medical home provide an opportunity to apply effective, evidence-based practices to reduce morbidity while also improving efficiency and quality of care. Studies of adults have demonstrated that chronic disease management programs can improve care for patients with diabetes, heart failure, asthma, and other chronic illness. Research has demonstrated that disease management programs can often be implemented with modest cost or be cost-saving. To date, there have only been a few studies that have examined the role of disease management or patient-centered medical home programs to address child illness. Chronic illness care interventions have improved attention-deficit/hyperactivity disorder management and had mixed effects on improving pediatric asthma care.

Recent studies have examined the role of literacy in chronic illness care in adults. Research has linked lower health literacy to worse chronic disease knowledge, behaviors, and outcomes. In diabetes, for example, lower health literacy has been independently associated with worse diabetes knowledge, self-management, and glycemic control (A1c). One study revealed that 55% of patients with diabetes had inadequate literacy. Of those with inadequate literacy, 50% did not know the symptoms of hypoglycemia, 62% did not know how to treat hypoglycemia, and 42% did not know the normal blood glucose range, despite the fact that 73% of the patients had participated in previous diabetes education. The importance of numeracy (math skills) in diabetes and other chronic illness care was also elucidated recently. Poor numeracy is common in patients with diabetes and is significantly associated with worse self-management, self-efficacy, and A1c levels. Lower numeracy has also been associated with greater difficulty understanding food labels, poorer anticoagulation management, and worse asthma management.

The identification of health literacy or numeracy as barriers to health is important, because they are factors that are potentially modifiable by improving underlying literacy skills or by providing accommodations to help those with lower skills. Several studies have demonstrated that providing low-literacy materials or low-literacy
forms of communication can improve comprehension for patients across literacy levels. In one study, Schillinger et al. suggested that doctors who used the “teach-back” form of communication with their patients with diabetes had higher odds of having patients with better glycemic control. A randomized, controlled trial of an adult literacy education program conducted by Weiss et al. suggested that intensive literacy training may reduce depressive symptoms. A study by DeWalt et al. suggested that addressing literacy among patients with heart failure by using a simplified self-management program could lead to improved outcomes, including reduced hospitalization rates.

The importance of literacy was demonstrated recently in a randomized, controlled trial of a comprehensive diabetes disease management intervention. Patients in the intervention group received education and medical management from a team of midlevel providers in conjunction with the primary care provider, application of evidence-based treatment algorithms, use of an electronic registry to proactively manage patients and provide intervisit contact, and the use of care coordinators to help address barriers to care. Literacy was addressed by use of clear communication and the teach-back technique, use of low-literacy materials, and a focus on key behaviors and actions for patient self-management. The study demonstrated that literacy was a significant factor in predicting patients’ improvement in glycemic control, and the authors suggested that addressing literacy could lead to improved glycemic control. In addition, another study recently tested a novel Diabetes Literacy and Numeracy Education Toolkit (DLNET). The DLNET uses color-coded measuring devices, picture-based materials, and other tools to aid education of patients with diabetes of all literacy levels, but particularly for those with poor literacy or numeracy skills. Results have suggested that this approach may lead to improvements in glycemic control.

In another study, a low-literacy-oriented education guide developed for the American College of Physicians (Living With Diabetes Guide), when used by physicians trained in motivational interviewing, resulted in 71% of the patients reaching their target behavior goal at 2 weeks and 59% of the patients sustaining the goal at 12 weeks. Results did not differ according to literacy level. There have been very few studies to date that have examined the importance of health literacy in childhood chronic illness. A few recent studies have linked lower caregiver literacy or numeracy with poorer control of asthma, type 1 diabetes, and higher BMI. One recent pilot study suggested that addressing literacy and asthma self-management skills could lead to reduced emergency department visits by and hospitalization rates in children with asthma.

### Patient Safety and Medication Errors

Medication errors have received significant national attention since the release of the pivotal IOM report “To Err Is Human: Building a Safer Health System.” Although much of the initial national focus has been on the prevention of error in the inpatient setting, there is growing recognition that medications are most frequently used within the outpatient setting and managed by patients, parents, and other lay caregivers. More than half a million medication errors take place in the outpatient setting each year. Medication errors may worsen as the number of chronically ill children grows.

A recent study revealed that 70% of preventable adverse drug events are attributable to errors in medication administration, which highlights the critical role that health literacy can play in appropriate medication management. Outside of the hospital, patients and caregivers must take responsibility for the implementation of medication instructions, monitoring of medication effects, and decisions regarding when to seek care for adverse effects. Patients and caregivers with lower health literacy disproportionately struggle with these issues.

Although patients and their families may receive counseling from their health provider regarding their medication regimens, studies have found that clear details are often not provided from physicians and pharmacists regarding medication dosing, frequency, and length of treatment. The availability of liquid medications in different concentrations, instructions given using different units of measurement (e.g., ml, teaspoon, tablespoon), and the wide variety of dosing instruments also contribute to parent confusion with provider instructions.

The literacy demands placed on patients and caregivers as they seek to follow medication instructions are formidable. Previous research has demonstrated that many adults, particularly those with lower literacy skills, struggle to understand prescription drug labels. Confusion arises when difficult language, graphics, numerical concepts, and distracting marketing information are encountered. Overall, poorly designed labeling has been deemed to be a contributor to one third of medication errors evaluated by the US Pharmacopeia. Furthermore, accompanying written drug information given to patients and caregivers, including consumer medication information leaflets, package
inserts, and US Food and Drug Administration (FDA) medication guides, is typically at a ≥10th-grade reading level,96,97 which is too high for the majority of the US population.95,98,99 Nonprescription, or over-the-counter (OTC), medications pose additional problems, because patients and caregivers must distinguish from an array of available medicines those that meet the desired health indication and determine how to appropriately dose that medication. Misdosing of OTC medicines is multifactorial, and includes misinterpretation of dosing charts, problems in measurement, and lack of recognition that the same ingredient present in an OTC medication may also be present in other medications being taken simultaneously. Many OTC medication product labels contain a high volume of textual information, which may be confusing to parents, particularly those with limited literacy and numeracy skills. The “drug facts” panel, the FDA-regulated section of the label that addresses usage and warning information, is complex and can be challenging for parents to understand. OTC products marketed for children also frequently include pictures of small children or childlike graphics and other marketing claims that can be misleading. In a recent study of OTC cold and cough medications, graphics and other language on the front of the label adversely influenced caregivers’ perceptions of the appropriateness of OTC cold and cough medications for young children.100 More than 80% of caregivers of infants stated that they would use OTC cold and cough medications in a child <2 years of age despite the dosage instructions on the label recommending consultation with a physician before usage.100 The interpretation of weight- and age-based dosing charts for OTC medicines is particularly difficult for caregivers with limited literacy or numeracy skills.101–104 In 1 study of >180 parents of infant children, approximately half of the parents could not accurately interpret a medication dosing table for acetaminophen, with parent performance on this task significantly correlated with underlying literacy and numeracy skills.104

The role of health literacy in medication safety has received considerable attention recently, with statements issued by the Agency for Healthcare Research and Quality,13 the IOM,10,105 and the Joint Commission.90 In 2007, a task force convened by the American College of Physicians106 presented recommendations to the IOM and called for (1) an evidence-based set of practices to guide medication-label content and format, (2) standardization of language used to convey medication instructions for improved patient understanding, and (3) the development of an integrated system of patient information, including improvements in accompanying written information. Unfortunately, standards that regulate drug labeling and associated written materials are currently minimal.90,97 Pictorial-enhanced written materials have been shown to improve comprehension, adherence, and dosing accuracy,83,88,107–110 particularly for patients with low literacy skills.111–114 The use of illustrated schedules to assist patients with medication self-management108,115 can be especially beneficial for patients who take multiple medications. These picture-based scheduling tools seem to aid in the integration of dose and time information,108 have been well accepted by patients, and are particularly beneficial for those with limited literacy or decreased cognitive function.115 Use of photographs and audiovisual and multimedia aids is another potential strategy for improving patient/caregiver understanding of medication instructions, particularly when medication regimens are complex, such as those for children with chronic diseases. Sufficient testing and evaluation of these approaches are needed before implementation.

Increased availability and standardization of dosing instruments is another important strategy for improving pediatric dosing accuracy. The use of nonstandardized instruments is associated with dosing errors.85,87,116–118 The provision of standardized instruments significantly improves dosing accuracy.86,110 Despite American Academy of Pediatrics recommendations endorsing their use,119 standardized dosing instruments are not typically provided by clinicians, and a significant proportion of caregivers continue to use a nonstandardized spoon for administering liquid medications.13,32,86,87 In fact, caregivers with lower literacy may be at increased risk of using nonstandardized dosing instruments.105 Use of color-coded information accompanied by color-coded dosing instruments for OTC medications is another strategy that has been associated with improved caregiver ability to determine a correct dose and measure accurately.90 Additional study is needed to determine how to best simplify medication measurement for patients and caregivers, including how to standardize dosing instruments, given the range of interinstrument and intrument variability.

Training of health providers in health literacy and effective medication-counseling techniques represents another important strategy for decreasing medication error and improving child safety. A study of a structured medication-counseling approach in a pediatric emergency department setting, which included the provision of patient- and medication-specific plain-language, pictogram-based medication instruction sheets, teach-back,
and provision of a standardized dosing instrument, resulted in fewer dosing errors compared with usual practice (5.4% vs 47.8%; \( P < .001 \)) and decreased rates of nonadherence (9.3% vs 38.0%; \( P = .002 \)).

**OPPORTUNITIES TO FURTHER ADDRESS THE ROLE OF LITERACY IN CHILD HEALTH QUALITY**

Significant opportunities exist to further explore and define the role of health literacy in quality of care. Any efforts to address health literacy must acknowledge the unique challenges in examining health care quality and outcomes for children and their families. Forrest et al\(^{120} \) have suggested the “4D model” for the unique attributes that should be considered in child-related research or quality improvement (see Table 2). The 4 D’s include developmental change, dependency, differential epidemiology, and demographic patterns.

1. **Developmental change:** Any examination of health literacy should consider the cognitive level of the child and the literacy level of the caregiver for infants and young children. There is a need for the development and validation of health literacy-assessment scales for older children. These measurement tools would provide information that would help further understand health literacy’s impact on child health and the effectiveness of developed interventions.

2. **Dependency:** A thorough examination of when health communication should be provided toward the child, the caregiver, or both is needed. Literacy assessment and support tools aimed at caregivers need to be developed and evaluated. In addition, the importance of transitional issues as adolescents’ transition into adulthood should be considered. These issues include how adolescents and young adults navigate from the pediatric health system to the adult system as they obtain their own health insurance and become independent in the management of health issues.

3. **Differential epidemiology of health and illness in children compared with adults:** An examination of how the timing of disease occurrence may affect cognitive development and health literacy skills is needed, as well as an examination of the psychosocial impact of disease development at different age groups and how health communication may need to be tailored for different age groups and different diseases. Developing health literacy interventions that can benefit a wide range of children with chronic illness, including those with rare conditions, special health needs, and other issues, is also needed.

4. **Demographics of child health:** Current disparities according to social, racial/ethnic, and other factors and their relationship to health literacy should be further explored. Better literacy-assessment skills for non–English-speaking patients should be developed, as well as culturally and linguistically sensitive interventions for these children and their families.

Specific opportunities to further address health literacy to improve chronic illness care and child safety should be considered in 4 key areas of the pediatric health care environment: the health care system, the community/family level, the provider level, and the patient/caregiver level.

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<th><strong>TABLE 2 The 4 D’s and Issues Related to Health Care Quality and Health Literacy</strong></th>
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<td><strong>Issue</strong></td>
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<tr>
<td>Developmental change</td>
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<td>Differential epidemiology</td>
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<td>Demographic patterns</td>
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(see Fig 2). Many approaches may cross multiple levels of the health care environment.

1. Health system level

- Explore the role of health literacy in designing and assessing quality metrics, which could include examining how health systems are determining health literacy in their patient/family population and what systems are in place to address low literacy.

- Determine how patient assessments of care can be best used to measure and improve the quality of care given by providers to patients and families of low literacy.

- Study the role of rapid health-literacy screening tools to assess literacy for large populations and determine if this type of screening approach is effective in improving quality of care.

- Examine the written materials used in health systems, including administrative forms, consent forms, patient-education materials, medication labels, and other electronic and print media, to ensure that the materials are written at an appropriate literacy level for all caregivers and older pediatric patients and are created by using the principles of plain language and clear communication. Examine the effect of newly created literacy-sensitive materials on improving child health outcomes.

- Examine the system-level implementation of electronic media and health information technology to support self-management and improve communication between the health system and families, which can include exploring the role of patient/family personal health records and Web portals into health systems, the use of the Internet, e-mail, mobile messaging, or other information technology for chronic disease management and medication monitoring. Study the effect of these technologies on child health outcomes and the differential use of technology according to family health-literacy level.

- Explore the role of different care teams to deliver literacy-sensitive chronic disease care, including the use of midlevel providers, health educators, and lay health workers to interact with children and their families, and to examine how family literacy level may affect child outcomes. Examine the role of patient navigators or advocates to aid families with low literacy skills.

- Work with the FDA, drug manufacturers, pharmacies and other organizations to examine the optimal way to design drug labels and drug-measuring devices and improve health communication to ensure patient and family understanding and safe usage.

- Use quality-improvement science methods (eg, plan-do-study [or check]-act [PDSA], tests of change, and statistical process control) to explore how to best integrate health literacy strategies and tools into practice.

- Explore the impact of health-literacy initiatives on efficiency and cost-effectiveness of patient care. Examine the role of including health literacy assessment or applying clear health communication principles in a pay-for-performance model.

2. Community/family level

- Examine relevant community- and family-level moderators of the relationship between literacy and self-management behaviors.

- Promote and explore the value of community-based interven-
tions (churches, community centers, day care centers, etc) that address health literacy to improve chronic illness care and patient safety.

- Collaborate with and evaluate the role of community adult literacy and basic education programs to improve adult literacy and child health.
- Examine the role of school-based interventions to improve health literacy of children and their parents and its impact on health.
- Examine means to improve literacy in adolescent populations and how adolescents may act as change agents for family and peer systems.
- Determine the most efficacious level for health literacy interventions to impact pediatric outcomes. For example, compare family, individual, and combined approaches within a pediatric chronic illness.

3. Health care provider level

Improving health provider communication skills is a logical approach to optimizing patient understanding, promoting shared decision-making, and enhancing patient self-management behaviors. Many health providers report low self-efficacy for self-management.125–127 Improving the communication skills of health providers so they may effectively use plain language, the teach-back approach, and low-literacy education128–133 could promote improved quality and safety. Specific opportunities include:

- Further exploring the quality of current provider-patient/caregiver communication, including level of “patient-centeredness,” amount of jargon use, shared decision-making, and shared goal setting, and its impact on pediatric quality and safety.
- Examining the impact of training health providers in improved health communication skills on improving patient/family knowledge, behaviors, satisfaction, safety, and clinical outcomes.
- Exploring different methods of training health providers in clear health communication principles.

4. Patient/caregiver level

- Examine the impact of patient and caregiver literacy and numeracy skills on disease-specific knowledge, self-efficacy, self-management behaviors, and clinical outcomes.
- Examine the relationship between language barriers/limited English proficiency and literacy skills and how it may affect health care and health outcomes. Develop and test interventions customized to limited-English-proficiency and culturally diverse parents, parents/caregivers, and families.
- Examine usability of electronic tools to flexibly accommodate for lower literacy and numeracy of patients/caregivers, including the use of mobile technology, Web-based interventions, and video instruction. Examine the role of interactions that occur by using “just-in-time” technology as the provider is interacting with the patient (ie, point-of-care approach).

CONCLUSIONS

Health literacy plays an important role in both adult and child health. There is currently a significant need for more research to better assess and define the importance of health literacy in pediatric chronic illness care and child safety. There are tremendous opportunities to address health literacy to develop new interventions and quality metrics to improve child and family health. Anyone designing new approaches should consider the 6 IOM aims of quality improvement, the 4 Ds of child-related research, and the components of the chronic illness care or medical home model. Interventions need to include evaluation of the importance of addressing literacy to improve care, but they also need to be practical, sustainable, and cost-effective.134 We encourage clinicians, educators, researchers, and policy makers to further advance collaborative work on health literacy and opportunities to improve child health outcomes in the context of family, community, and health systems.

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/content/124/Supplement_3/S315.full.html