# Health Literacy in the Inpatient Setting



### **Implications for Patient Care and Patient Safety**

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#### **KEYWORDS**

- Health literacy Communication Patient safety Patient- and family-centered care
- Pediatrics Inpatient care Bedside rounds Discharge

#### **KEY POINTS**

- Health literacy plays a role in the events leading up to children's hospitalizations, during hospital admission, and after discharge.
- Hospitals and providers should use a universal precautions approach and routinely incorporate health-literacy-informed strategies in communicating with all patients and families to ensure that they can understand health information, follow medical instructions, participate actively in their own/their child's care, and successfully navigate the health care system.
- Interventions that incorporate health-literacy-informed strategies and that target patients/ families and health care systems should be implemented to improve patient outcomes and patient-centered and family-centered care.

#### HEALTH LITERACY CHALLENGES RELATED TO HOSPITALIZATION

Each year, more than 1.5 million children are hospitalized. Families face many challenges during their child's hospitalization, as well as at the time of hospital discharge. They are tasked with the responsibility of describing their child's symptoms and

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providing a coherent, detailed history, and are presented with possible diagnoses by health care providers. Families must choose to accept or reject possible treatments, weighing risks and benefits. They are asked to learn how to take care of their child when it is time to go home and what they should watch out for that would warrant renewed medical attention.

Health literacy skills impact the ability of families to handle the hospital demands placed on them. Health literacy has been traditionally defined as "the ability to obtain, process, understand, and use basic health information and services needed to make appropriate health decisions." There is, however, growing support of the construct that health literacy is a product of both the skills and abilities of individuals, and the complexity of health information and health care tasks presented to families by those in the health care system. How effectively families are able to participate in their child's care during and after a hospitalization therefore depends largely on how easy the hospital makes it for them to understand and act on information, and navigate the health care system.

Without realizing it, hospitals frequently make the hospitalization experience difficult for families. Clinicians and other staff use specialized medical terminology that is effectively shorthand among themselves but frequently is incomprehensible to others. <sup>4,5</sup> Members of the hospital staff often provide families with too much information at one time and do not check whether they understood it. <sup>6</sup> They send families home with prescriptions for medicines without determining whether families are able to fill them or know how to administer medicines correctly. <sup>7</sup> Families are often sent home with confusing discharge instructions, without an assessment by hospital staff to ensure that they are able to follow them properly. <sup>8</sup> Providers also make referrals for additional tests and care without providing assistance in making the follow-up appointments or taking into consideration transportation barriers. <sup>9,10</sup> Lack of attention to these health literacy issues creates a patient safety risk. Each time an instruction is misunderstood, a medicine is not taken, or an appointment is not kept is a patient safety event, that is, an event that has the potential to lead to a worse patient outcome.

#### **EPIDEMIOLOGY**

According to the most recent health literacy data, 77 million adults, or 36% of adults in the United States, are categorized as having limited health literacy, indicating that they have no more than the most simple and concrete literacy skills 11,12; this includes nearly 21 million parents (29% of US parents). Notably, only 12% of adults are considered to have "proficient" health literacy skills, which means that the vast majority of individuals experience health literacy challenges. In addition, only 8% of US adults have "proficient" numeracy skills; such skills are often needed in health-related decision-making, including tasks such as understanding the relative risks and benefits of treatment options, and correct administration of medications (amount, frequency, duration). Those from low socioeconomic status backgrounds, low educational attainment, racial/ethnic minority groups, and non-English speakers, are disproportionately affected by limited health literacy. A growing body of research indicates that health literacy is an important contributing factor to income-associated and race/ethnicity-associated health disparities.

Although an individual's overall health literacy skill level is important, another issue to consider is the dynamic nature of health literacy, and the impact of anxiety and stress on an individual's ability to process and act on health information. <sup>15</sup> For example, parents who believe their child is in pain are less likely to understand information provided during encounters with the health care team. <sup>16</sup> Throughout the

hospitalization and at the time of hospital discharge, parents are often sleep deprived and are experiencing high levels of stress and fear related to their child's prognosis, which can interfere with their ability to function at their normal level of health literacy. Given that health literacy is dynamic and not static, a "state" rather than a "trait," health care providers should consider *all* individuals to be at risk for limited health literacy. Experts therefore recommend following health literacy universal precautions: assuming that all patients may have difficulty comprehending health information and accessing health services. <sup>17</sup>

Measuring individuals' health literacy is not recommended as part of clinical practice. This is because not only is health literacy dynamic, but all patients benefit from clear communication. Measuring health literacy can be important at the population level, however, and is essential for research purposes. Researchers have used a wide variety of measures to assess individuals' health literacy. Tools used to assess health literacy include both objective measures (eg, Short Test of Functional Health Literacy in Adults, <sup>18</sup> Newest Vital Sign, <sup>19</sup> Parental Health Literacy Activities Test<sup>20</sup>) and subjective measures, focusing on an individual's self-reported ability to understand health information (eg, Single Item Literacy Screener<sup>21</sup>) or work with numbers (Subjective Numeracy Scale<sup>22</sup>). The Health Literacy Toolshed Web site houses a comprehensive listing of health literacy measures (https://healthliteracy.bu.edu).<sup>23</sup>

#### **HEALTH-LITERACY-INFORMED COMMUNICATION STRATEGIES**

The Joint Commission has asserted that unaddressed health literacy issues undermine the safety of patients and the ability of health care organizations to comply with accreditation standards, which require hospitals to identify and meet patients' oral and written communication needs.<sup>24</sup> Adopting health literacy universal precautions is a way of meeting those needs that benefits everyone, regardless of their education or literacy level. One of the most important components of health literacy universal precautions is the teach-back method, also known as the teach-to-goal method. In the context of provider-parent communication, providers ask parents to describe the information they have been given using their own words. If the parent teaches back the information inaccurately, or repeats the provider's exact words, the provider re-teaches the information in a different way and again asks for a teach-back of the information. This is repeated until the parent can describe the information correctly in his or her own words. The Agency for Healthcare Research and Quality and the National Quality Forum declared teach-back to be a Safe Practice for informed consent<sup>25,26</sup>; "Always Use Teach-back" is a key component in the Institute for Healthcare Improvement's recommended discharge process.<sup>27</sup> Research studies show that teach-back can increase comprehension, reduce medication errors, and reduce readmissions.<sup>28-30</sup> Best practice calls for using the "chunk-and-check" strategy, whereby teach-back is performed intermittently in a discussion so that each set of information is digested before another is introduced. If the information is an instruction about how to use a medication or equipment, such as how to use an inhaler or administer a medication via a feeding tube, the "Show Me" or "Show-Back" method, in which a provider asks for a demonstration rather than a spoken teach-back (often after first demonstrating the steps of a task), is more effective at detecting misunderstanding than teach-back.<sup>30</sup>

Teach-back is just one of a number of health-literacy-informed strategies for spoken communication. One of the strategies that health care providers find difficult to implement is limiting the amount of information presented at one time. Prioritizing 2 or 3 most important messages requires distinguishing between "need-to-know" and "nice-to-

know" information. With large quantities of "need-to-know" information, it is optimal if educators can begin to provide teaching at the beginning of the hospital stay, recognizing that multiple teaching sessions might be needed to ensure learning. Other strategies include speaking distinctly, at a moderate pace, and using common, everyday language, that is, plain language that is free of medical jargon. Listening without interrupting is a highly effective and undervalued skill. Encouraging questions by asking "What questions do you have for me?" recognizes that families are likely to have questions; this strategy is preferred over asking "Do you have any questions?" which is more likely to lead to a response of "no" even when families do have questions. Communication must also be culturally and linguistically competent, showing respect for diverse cultures, customs, and beliefs. Only qualified interpreters should be used when there are language barriers (See Jennifer K. O'Toole and colleagues' article, "Communication with Diverse Patients: Addressing Culture and Language," in this issue).

Use of written information to supplement what is discussed verbally is known to help reduce cognitive load (or the amount of information that working memory can hold and process at one time), making it easier for families to understand and act on the information provided.<sup>31</sup> It is best to use materials that incorporate plain language principles, include simple visual aids, make their purpose evident, focus on a limited number of messages, sequence information logically, break-up information into sections with informative titles, break-up actions into manageable steps and make numbers easy to understand and do not require calculations. Referring to written materials as part of verbal counseling is considered to be especially effective. The American Academy of Pediatrics' Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics is one example of educational materials that are easy to understand and can complement a verbal explanation of many common diagnoses.<sup>32</sup> It is important to keep in mind, however, that many individuals have poor reading skills; 18% of the US adult population scored at the lowest level of an international literacy assessment. 11,12 Others may not learn well by reading. Still others may lack time or concentration to read materials. Technology, such as talking touchscreens or audiovisual presentations, can sometimes overcome literacy barriers; providers could use this as part of verbal counseling to reinforce concepts, but should not assume that the families they care for have access to such technologies for home education. Written handouts are still important memory aids and reference documents. When it comes to written materials, experts give the following advice:

- Choose materials that are easy to understand and act on. You can evaluate materials by using an assessment tool such as the Patient Education Materials
   Assessment Tool (PEMAT) (note that there is a PEMAT-AV as well, which is helpful for assessing audiovisual information).<sup>33</sup>
- Provide materials in languages your patients read<sup>34</sup> (see Communication with Diverse Patients: Addressing Language and Culture).
- Never assume people are going to read what you give them. Review written materials together. Personalize and highlight important information (eg, circle, underline, star important concepts).<sup>35</sup>
- When reviewing written information, use easy-to-understand words, organized in a logical fashion, and focus on key action items.<sup>36</sup>
- Use of pictures or drawings to support the text is linked to improved understanding and ability to act on medical instructions.<sup>37,38</sup>
- Even when written materials are given to families, teach-back, and show-back should still be used whenever possible to confirm understanding.<sup>7,32</sup>

 To create written materials that are understood by the target audience follow guidance such as that outlined in the Toolkit for Making Written Materials Clear and Effective.<sup>39</sup>

A summary of health-literacy-informed verbal and written communication strategies is presented in **Table 1**.

### IMPACT OF HEALTH LITERACY ON MANAGEMENT OF CHRONIC CONDITIONS THAT CAN LEAD TO HOSPITALIZATION

Limited health literacy is associated with poor chronic disease management, contributing to emergency department (ED) visits and hospitalizations. Most of the pediatric research to date has been related to asthma and diabetes. Parents with limited health

#### Table 1 Health literacy communication strategies and resources

### Health Literacy Strategies for Spoken Communication

- Use a private, quiet space
- Sit down and be at the patient's eye level
- Make good eye contact
- Ask the patient/family to invite others they want to be part of the conversation
- Limit discussion to 2–3 main points
- · Listen without interrupting
- Speak distinctly and at a moderate pace
- Use every day, familiar words
- Use medical terms only if it is important for the patient to become familiar with a medical term; be sure to explain what the term means and check understanding
- Show pictures or use models
- Use the teach-back method (Example of provider statement: "I want to make sure I did a good job explaining how to give Carlos the medicine. Can you tell me how much medication you will give each time?"); try to "chunk-and-check" so that teach-back focuses on one topic at a time
- Demonstrate how it is done (eg, exercises, taking medicine) and have the patient or family member "show-back" how they would do it; encourage questions and elicit concerns and priorities
- Repeat key points
- Respect diverse cultures, customs, and beliefs (see Communication with Diverse Patients: Addressing Language and Culture)
- Use only qualified interpreters when there are language barriers (See Communication with Diverse Patients: Addressing Language and Culture)
- Teach trainees to explain information to families in words they can understand
- Speak to and involve the child as appropriate

#### Health Literacy Strategies for Written Materials

- Make purpose evident
- Focus on a limited number of messages
- Sequence information logically
- Break-up information into sections with informative titles
- Use plain language
- Make numbers easy to understand and do not require calculations
- Provide clear instructions (eg, Uniform Medication Schedule – UMS; "give medicine in the morning and in the evening" more explicit than "give 2 times a day")
- Use simple visuals that enhance understanding rather than distract
- Use large font size, bulleted text, and short sentences
- Make use of alternatives to print, including talking touch screens, audiovisual, and multimedia materials.
- Break-up actions into manageable steps
- Review print information verbally, personalizing it by using strategies such as highlighting, circling, starring, and underlining, to draw attention to key information

literacy have poor asthma knowledge and have difficulty following their child's asthma action plan. 40,41 With respect to understanding and management of diabetes mellitus, parents with lower health literacy scores have worse adherence to complex insulin regimens compared with those with adequate health literacy. 42 Children of parents with low numeracy scores have poorer diabetes control as reflected by higher hemo-

Limited health literacy is frequently associated with increased health care utilization. ED visits<sup>41,44</sup> and hospitalizations<sup>45</sup> are more likely in children with asthma whose parents have limited health literacy. In addition, children whose parents had limited health literacy have more ED visits overall.<sup>46</sup>

### IMPACT OF HEALTH LITERACY ACROSS THE HOSPITALIZATION AND BEYOND: EVIDENCE FOR HEALTH-LITERACY-INFORMED COMMUNICATION STRATEGIES

A patient or parent's health literacy is relevant across the course of a hospitalization, beginning at the time of admission and continuing through discharge. In this section, we review key timepoints during a hospitalization using a health literacy perspective, incorporating information from the pediatric inpatient literature when possible and expanding to other settings and adult literature when relevant. These are summarized in **Table 2**. Pertinent interventions that may help overcome the effects of limited health literacy in the inpatient setting also are discussed.

#### Taking Complete and Accurate History

Health literacy skills affect the ability of caregivers and patients to report a thorough, accurate, and coherent history. Individuals often do not have a good understanding of their children's chronic medical problems, \$^{40,41,47}\$ which can make it challenging to give detailed information about past medical history and medications. One study found that two-thirds of patients had a poor understanding of their home medications. Several studies have focused on an individual's understanding of their family history; between 20% and 60% of adults inaccurately report their family history of cancer. The manner in which the history is taken should be taken into consideration; for example, those with limited health literacy struggle when written screening tools are used to elicit the history of a symptom. \$^{51}

Improving parental understanding of a child's chronic diseases and overall history is important for a parent to be able to report this information on admission. One intervention that targeted parents of children with asthma used low literacy, pictogram-based and photograph-based asthma action plans; parents receiving the low literacy plan were more likely to understand which medications to give every day and when sick; they also made fewer errors regarding spacer use. <sup>52</sup> Although education to improve parent understanding of their child's chronic disease management regimen may begin in the outpatient setting, this teaching should continue during the hospital stay so families can become more comfortable with this information.

Just as families struggle to convey information on a child's medical history, provider history-taking techniques have also been found to be suboptimal. Some studies have shown that more than half of providers use jargon during their initial encounter with families, and many ask lengthy and complex questions. <sup>4,5</sup> If providers use confusing language and do not effectively ask questions that guide patients through the history-taking process, they may not obtain a complete and accurate picture, and diagnosis and treatment may be delayed.

Use of health-literacy-informed communication strategies can improve the likelihood that providers elucidate a clear history. Providers should ask simple questions

Table 2 Health literacy–related challenges for families across the hospitalization and ways to optimize this process <sup>a</sup>			
Challenges for Family	Ways Provider/System Can Optimize This Process		
Reporting an accurate history  Chronic medical problems/past medical history  Medications  Reporting symptoms  Family history	<ul> <li>Acknowledge that what you are asking the parent to do is difficult. They are likely tired or stressed because their child is sick; you may need to return at a later time to clarify key points, especially if you're taking a history in the middle of the night.</li> <li>Stay clear of distractions (eg, looking at computers/ tablets, noisy environments)</li> <li>Take a clear and thorough history         <ul> <li>Start with open-ended questions</li> <li>Progress to more focused questions when needed</li> <li>Ask clarifying questions</li> <li>Ask questions in multiple different ways if families are having trouble (eg, history of medical problems, prior hospitalizations, types of doctors child is being followed by)</li> <li>Use clear language the family can understand</li> <li>Ask one question at a time</li> <li>Summarize the history</li> <li>Take history as a team or share history among the team to eliminate the need for parents to repeat a history multiple times</li> </ul> </li> <li>Do not use screening tools that are difficult for parents to navigate</li> </ul>		
Provider to parent communication at admission <ul><li>Diagnosis</li><li>Reason for admission</li></ul>	<ul> <li>Ensure that families understand their chronic and other medical conditions at the point of diagnosis</li> <li>Use written or audiovisual materials that use health-literacy-informed strategies to supplement verbal counseling on diagnosis</li> <li>May need to explain information again if family members are tired, in pain, or experiencing stress/anxiety</li> </ul>		
Plan of care: tests, treatments, procedures, and informed consent	<ul> <li>Explain risks, harms, and benefits of choices, including the choice to not have a test, procedure, or treatment</li> <li>Use high-quality decision aids to elicit goals and values</li> <li>Use easy-to-understand consent documents</li> <li>Use whiteboards, easy-to-understand written materials, or easy-to-access patient portals to supplement verbal counseling on plan of care</li> <li>Update the family throughout the hospitalization</li> <li>Use easy-to-access patient portal to share easy-to-understand explanations of results</li> <li>Provide written information summarizing results in a way the family can understand</li> <li>Ensure providers are on the same page, providing one centralized message throughout the hospital stay</li> </ul>		
Bedside rounds	Start with the family's concerns first Review the child's health status in the context of the hospital stay Summarize what is new and what has changed Summarize the plan for the day Discuss things that might happen/change and what family members can do to help and watch out for Provide an easy-to-understand written summary of the plan for the day  (continued on next page)		

Table 2 (continued)	
Challenges for Family	Ways Provider/System Can Optimize This Process
Challenges for Family Discharge	Start education at the beginning of the hospital stay Use shared decision-making strategies for reaching an agreement about discharge goals and postdischarge treatment  Use health-literacy-informed verbal communication strategies (eg, plain language, teach-back, limit information, encourage questions)  Use health-literacy-informed written communication strategies (eg, 6th-8th-grade level, understandable and actionable)  Make sure verbal and written instructions include all key domains of care  Medications (including changes to medication regimen, dosing, side effects) Appointments Return precautions Diet, activity, bathing restrictions Information on return to school/daycare Equipment Additional postdischarge imaging/testing needed Information on who to contact with questions or if problems arise  Navigation assistance Make appointments at a convenient time for the family and establish that they have a plan to get to appointments Set up delivery of equipment and ensure family knows how to use it Delivery of medications to bedside if possible, ascertain how medicines will be obtained in the future, and whether financial assistance is needed Postdischarge Send the discharge summary to the outpatient clinician the day of discharge as many children will have appointments the next day. This ensures the outpatient clinician has the information at the follow-up visit and does not have to rely on the parent Conduct a follow-up phone call 2–3 days after discharge to check on the child, ensure instructions have been followed, and that no additional issues have come up Staff and provide a phone number for families to call
	with questions after discharge

<sup>&</sup>lt;sup>a</sup> This table contains a list of strategies to use during specific parts of the hospitalization. The general health-literacy-informed strategies mentioned in Table 1 should be incorporated at every point throughout the hospitalization.

one at a time and ask clarifying questions to obtain all of the necessary details. The interview should start with open-ended questions, followed by more focused questions. The interviewer should also summarize the patient's history to confirm that the health care team has accurately understood the information conveyed. Although self-administered written screening tools can be confusing and difficult to navigate, an intervention that used a multimedia version of such a tool (incorporating color coding,

written questions, and a video of someone reading the questions with ability to have the question repeated) led to improved ability to answer the questions in patients across all literacy levels.<sup>51</sup>

#### Communication of the Diagnosis and Reason for Admission

Discussion of potential diagnoses and plans of care takes place after the initial history and physical and throughout the hospitalization. As part of these conversations, providers must explain the most likely diagnosis, other potential diagnoses being considered, the rationale for hospitalization (for admission or the need for continued inpatient care), and the plan for care of the hospitalized child.

Families frequently misunderstand information related to the diagnosis and reason for admission. Approximately 25% of parents are unable to state their child's diagnosis in the ED, and complex admissions associated with multiple diagnoses are even more confusing. <sup>54</sup> Other studies have shown that up to 50% of individuals misunderstand the reason for admission. <sup>16</sup>

A number of provider behaviors have been identified as contributing to poor understanding of the diagnosis by patients and their families. Physicians often leave out key information related to diagnoses<sup>55</sup> and include jargon in these descriptions.<sup>56</sup> Complaints that physicians do not give enough information about medical conditions are especially common among patients with limited health literacy.<sup>57</sup> These studies highlight the need for provider use of health-literacy-informed communication strategies such as teach-back with patients and families to confirm understanding. Several health-literacy-informed interventions have been developed to improve understanding of the reason for admission. One intervention focused on use of bedside huddles with the nurse, physician, and parents for the 2 most medically active patients on the unit; written update sheets with the plan of care were given to these families. The intervention led to parents' reporting better communication with overnight doctors, improvement in shared understanding between the parent and nurse, and a trend toward improvement in concordance between the reason for admission reported by the parents and what was documented in the written signout.58

### Understanding the Plan of Care: Tests, Treatment, Procedures, and Informed Consent

Another domain of inpatient care in which health literacy plays a role and in which parent misunderstanding is common is the plan of care, including treatments provided, as well as tests and procedures to be performed. One study found that only one-third of parents completely understood the plan of care, including treatment and potential tests or procedures.<sup>59</sup> Another study found that 38% of patients were unaware of all the tests planned for a given day, and 10% were unaware of planned procedures. 60 Complex plans are more likely to be associated with a lack of shared understanding between the provider and parent. 61 Parents have particular difficulty understanding postoperative pain management plans, with up to one-third having no understanding of risks associated with their child's pain management regimen.<sup>62</sup> In general, patients with limited health literacy are also less likely to ask physicians questions about therapeutic regimens, 63 which may further contribute to poor understanding. Much of the lack of parental understanding may be due to poor communication from the inpatient team. One study by Khan and colleagues<sup>64</sup> have shown that information given to families by providers during the inpatient stay is often conflicting, delayed, or erroneous. Patients with limited health literacy are more likely to rate inpatient communication as poor.<sup>65</sup>

Studies examining patient and family ability to understand care delivered in hospitals indicate that consent, if obtained at all, was frequently not adequately informed. For example, one study found that 76% of parents of children undergoing an endoscopy did not understand alternatives to the procedure and only 14% had a complete understanding of the entire informed consent discussion. Incomplete provider counseling was a key barrier. Even when information is provided to parents, they often misunderstand the risks associated with surgical procedures and anesthesia.

The inpatient team should strive to present clear and timely information to families to ensure understanding of this information. Providing a clear written and verbal summary of events occurring during the hospital course can help. In one study of an intervention that used patient white boards to assist with communication, a greater proportion of patients knew their goals for admission, and nearly all patients wanted the white boards to list upcoming tests and studies.<sup>69</sup> In another intervention, providers wrote patient-directed letters describing the events of the hospitalization. The provider read the letter to the patient and allowed the patient to ask questions. After the intervention, patients had better understanding of the reasons for hospitalization, tests performed in the hospital, and treatments received. 70 However, this after-thefact communication does not comport with the principles of informed consent, which requires understanding of information about tests, treatment, and procedures before they are administered. The informed consent process can be improved in several ways, including use of supplemental written information, audiovisual materials, and teach-back.<sup>71</sup> Hospitals can use the Agency for Healthcare Research and Quality's Making Informed Consent an Informed Choice: Training Module for Health Care Professionals to help providers learn how to use clear communication strategies. 72 Even when formal written informed consent is not required, providers should use these strategies when explaining the plan of care to ensure a shared understanding with the patient and family. There is also a second module designed for hospital leadership; the purpose of the module is to ensure that informed consent policies are complete and unambiguous and infrastructure supports are in place.

#### **Conducting Bedside Rounds**

One of the most important contexts for communication in the inpatient setting is bedside or family-centered rounds. Unfortunately, providers often use complex language on rounds without providing plain language explanations. <sup>73</sup> In addition, key content, such as information about discharge timing and medications, may not be presented on rounds. <sup>74</sup> Unsurprisingly, families often do not understand the information presented on rounds. One study found that only 40% of parents could accurately report the full plan discussed on rounds, and 1 in 4 were unaware of the diagnosis discussed on rounds.

Provider use of health-literacy-informed communication strategies can improve a family's understanding of the information presented on bedside rounds. The Patient and Family-Centered I-PASS model,<sup>76</sup> designed using health literacy principles, gives providers a standard communication framework for rounds to ensure that important domains are covered. It is recommended that families are engaged from the very beginning of rounds, where family concerns are elicited and a shared understanding of the reason for admission and continued hospitalization is achieved. This is followed by information presented in "chunks," including (1) reviewing the child's health status in the context of the hospital stay (I = illness severity), (2) summary of the interval history (P = patient summary), (3) plan for the day (A = action list), and (4) things that might happen/change and what family members can help watch out for (S = situational awareness and contingency planning). All the while, providers use

health-literacy-informed strategies (eg, chunk-and-check and simple, clear language). The parents can later synthesize the information (ie, teach-back). A written "rounds report" (on paper or on a white board) that uses health-literacy-informed strategies is provided. This gives parents the ability to more easily digest the information provided on rounds and allows them to have something to reference throughout the day and share with other family members.

Families often find rounds to be intimidating and may not understand what their role is on rounds. Providers can "set the stage" early in the admission to empower families to be actively engaged on rounds, emphasizing the important role that families play in describing concerns, asking questions, and helping to formulate the plan for the day. At admission, the health care team can designate a staff person to discuss this important role with families, and members of the health care team can reinforce this daily before rounds; an easy-to-understand pamphlet or handout clearly describing the rounds process, the family's role, and the role of each team member, can be helpful to supplement the verbal information conveyed by the team. This strategy has been used as part of the Patient and Family-Centered I-PASS model<sup>76</sup> (See Jennifer Baird and colleagues' article, "Interprofessional Teams: Current Trends and Future Directions," in this issue).

#### Preparing for Discharge

Families eagerly await discharge and do not always understand why the patient is still in the hospital and not yet discharged. One example from the pediatric emergency medicine literature found that one-third of families were not completely aware of the reasons they were still in the ED. Families with lower educational attainment were more likely to have answers discordant from those of the physicians. When the time for discharge arrives, and most children are being prepared to go home, it is often chaotic. Parents are presented with a great deal of information, often right before leaving the hospital, about how to manage their child's care at home. Discharge instructions cover a wide range of domains including medications, appointments, return precautions (the signs and symptoms that must be monitored for at home), restrictions (eg, diet, activity-related), and equipment; these instructions are often confusing for families.

Understanding of medication instructions can be particularly challenging for parents, especially those with limited health literacy, <sup>78</sup> posing a major threat to patient safety. Comprehension of medication duration, frequency, and indication is often poor. <sup>77</sup> More than 40% of parents do not understand medication side effects <sup>79</sup> and dose liquid medications incorrectly. <sup>7</sup> One intervention designed to improve parent ability to understand and follow medication instructions focused on use of health-literacy-informed communication strategies (teach-back, demonstration, medication instruction sheets with a pictographic representation of the amount of medication to be given, dosing tool provision). This intervention led to a reduction in dosing error rates for short-course prescribed medications (eg, antibiotics, steroids) from 48% to 5%, in addition to improvements in medication adherence. <sup>7</sup>

Parents also commonly misunderstand instructions related to their child's follow-up appointments, <sup>79,80</sup> return precautions, <sup>81</sup> activity restrictions, <sup>82</sup> medical equipment, <sup>83</sup> and testing needed after discharge. <sup>84</sup> Overall, patients with limited health literacy are less likely to understand and adhere to discharge instructions. <sup>85</sup>

Although health literacy has been linked to several aspects of postdischarge care, associations with postdischarge hospital utilization are mixed. One study found that patients with limited health literacy were almost twice as likely to have a readmission or ED visit within 30 days of discharge compared with those with adequate health

literacy. <sup>86</sup> Although some studies have shown that limited health literacy is associated with readmissions, <sup>87,88</sup> this association was not found in all studies. <sup>89,90</sup>

Studies have found that providers often do not use health-literacy-informed communication strategies to ensure that patients and families understand their discharge instructions. In one study, use of medical terminology in verbal counseling was the factor most likely to contribute to poor understanding. 91 Few providers use health-literacy-informed communication strategies as part of discharge counseling; teach-back, for example, is used less than half of the time.<sup>36</sup> Adult studies have found an increased length of stay in patients with limited health literacy even after controlling for other factors including illness severity92; families with limited health literacy may require additional time for discharge counseling and coordination of postdischarge care, which may account for this increased length of stay. This would make sense in the context of patients with limited health literacy having lower scores on readiness for discharge scales. 93 Hospital systems should start discharge education at the beginning of the hospital stay so that families have more time to learn this information. Health-literacy-informed communication techniques such as teach-back can lead to significant improvements in understanding of discharge instructions,<sup>28</sup> and should therefore be incorporated into regular discharge counseling practices.

Another challenge is that families are often provided with suboptimal written instructions. Discharge instructions at one large academic referral center had a mean readability level of 10th grade, had poor understandability scores, and were missing key content (eg, diagnosis, signs and symptoms to watch for). One national study of asthma action plans found that 70% of plans studied were written above the sixth grade level, and many used unsuitable layout and typography or failed to use graphics. Hospital-wide initiatives are needed to prioritize the provision of health-literacy-informed, easy-to-understand written discharge instructions. Health literacy impacts a patient's ability to interact with written information related to their home care. For example, individuals with limited health literacy are more than 3 times as likely to misunderstand warnings on medication bottle labels. For optimal learning by patients and families, it is helpful for written discharge instructions to be referenced as part of verbal counseling, providing a framework for standardized, organized counseling. This will increase the likelihood that parents are aware of the tasks they are responsible for taking care of at home.

Use of technology-based strategies can also be helpful. For example, implementation of video discharge instructions with content at or below the eighth grade reading level improved understandability of discharge instructions for pediatric fever and closed head injury in the ED.<sup>97</sup>

It is also important to keep in mind that families with limited health literacy may have difficulty navigating the health care system. Strategies to make this process easier for families include making appointments before the family leaves the hospital, working with the family to identify convenient times for them, having medications filled and brought to the hospital for review before discharge or ensuring medications are easy to obtain at a pharmacy close to the child's home, and making sure equipment and services are set up appropriately before discharge. Finally, "closing the loop" of communication by quickly sending discharge information to the child's outpatient providers, including the primary care provider within a child's medical home, as well as subspecialists and other caregivers such as home care providers, will limit the information that the family will need to transmit and reduce errors in understanding by the provider team who will take on the child's care after hospital discharge.

A variety of comprehensive health-literacy-informed interventions have been developed with aims to reduce postdischarge hospital use. These interventions

include components that both help families understand health information and navigate the health care system. One intervention, RED (Re-Engineered Discharge), uses a discharge educator during the hospital stay to provide patient education, confirm understanding using teach-back, coordinate postdischarge appointments and equipment, and quickly transmit the discharge summary to the outpatient clinician; the patient is provided with an after-hospital care plan and a postdischarge phone call. In a randomized controlled trial, rehospitalization and ED visit rates were lower in the group receiving the intervention. 98 One pediatric-focused intervention known as Project IMPACT included counseling using teach-back, implementation of a transition checklist, a postdischarge phone call, and timely and complete communication with the outpatient pediatrician. Initial pilot data established feasibility and showed improved rates of teach-back, patients being discharged with medications in-hand, and patient satisfaction with education about medication side effects; however, it did not lead to an improvement in hospital utilization rates (eg, readmissions, ED visits, urgent clinic visits). 99 Several other health-literacyinformed resources have been developed that focus on various aspects of the discharge process, ranging from engaging patients and families in discharge planning, to improving communication, to promoting ability to manage discharge instructions. 27,100-102

## PROMOTING SYSTEM-WIDE IMPLEMENTATION OF HEALTH-LITERACY-INFORMED COMMUNICATION STRATEGIES

Adoption of health-literacy-informed strategies will not happen without concerted organizational effort. Health systems often start by conducting health literacy organizational assessments, focusing on written and spoken communication, that can be used to document problems and build support for change. Internal advocates can make arguments for addressing deficiencies by pointing to how health-literacy-informed strategies can help the hospital achieve its goals, such as reducing readmission. Often they start with a quality improvement project, then gradually spread the intervention to the entire hospital and expand it to encompass additional health-literacy-informed strategies.

Training has to be central to any implementation effort. Training should be a recurrent activity that can take the form of online modules augmented by practice sessions, orientation and in-service training, in situ training at bedside, and other methods. Hospitals, however, also need to think through a range of system actions if they are to make the use of health-literacy-informed strategies normative. For example, organizations have used the following policies and standardized processes to reinforce the use of teach-back:

- The charge nurse joins rounds with nurses and ensures the nurses are using the teach-back method correctly.
- Educational information is assigned in the electronic medical record and it is not marked as completed until educators attest to a successful teach-back.
- Daily huddles, e-mails, and posters are used to remind staff to use teach-back.
- Facilities report monthly on observed teach-back for the first 6 months of implementation.
- Members of the care team are designated to follow-up with parents who have difficulty teaching back information during rounds to continue to re-teach and confirm understanding.
- Staff members are required to sign a pledge committing themselves to use teach-back.

Table 3 Health literacy resources	
Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit <sup>17</sup>	A set of 21 tools to increase patient understanding of health information and enhance support for patients of all health literacy levels.
AHRQ Pharmacy Health Literacy Center <sup>104</sup>	A Web site that contains medication-related health literacy tools, including evidence-based prescription medicine instructions.
AHRQ's Making Informed Consent an Informed Choice: Training for Health Care Leaders and Professionals <sup>72</sup>	Two interactive training modules that teach health- literacy-informed strategies that health care organizations and clinical teams can use to ensure that people understand their choices.
Always Use Teach-back! 105	Interactive training to help health care providers learn to use teach-back, every time it is indicated, to support patients and families throughout the care continuum.
American Academy of Pediatrics Resources (Health Literacy and Pediatrics) <sup>106</sup>	A list of resources compiled by the American Academy of Pediatrics, including a Pedialink Continuing Medical Education Course, a webinar, and conference materials.
Building Health Literate Organizations: A Guidebook to Achieving Organizational Change <sup>107</sup>	A resource that helps health care organizations of any size engage in organizational change to become health literate.
Clear Communication Index (CCI) <sup>108</sup>	An assessment tool that provides a set of research-based criteria to develop and assess public communication products.
The Health Literacy Environment of Hospitals and Health Centers <sup>109</sup>	A guide to analyzing literacy-related barriers to health care access and navigation and using the results to create an action plan.
Health Literacy Maintenance of Certification (MOC) Modules	Pediatricians and family physicians taking the Health Literacy Knowledge Self-Assessment Module (MOC Part 2) or Improve Health Literacy Performance Improvement Modules (MOC Part 4) through the American Board of Pediatrics or the American Academy of Family Physicians can earn credit for recertification.
Health Literacy Online <sup>110</sup>	A guide to writing and designing easy-to-use health Web sites.
HELPix Medication Sheets <sup>111</sup>	Plain language, pictogram-based medication instruction sheets to support medication counseling for parents with low literacy and limited English proficiency.
How-to Guide: Improving Transitions from the Hospital to Community Settings to Reduce Avoidable Rehospitalizations <sup>9</sup>	A guide to support inpatient teams and community partners in collaborating in the design and implementation of processes to ensure optimal transitions of care after hospital discharge.
IDEAL Discharge Planning from the Guide to Patient and Family Engagement in Hospital Quality and Safety <sup>23</sup>	Summary of key components for ideal discharge planning and how to implement them.
	(continued on next page)

Table 3 (continued)	
Patient Education and Materials Assessment Tool (PEMAT) <sup>33</sup>	A systematic method to evaluate and compare the understandability and actionability of print and audiovisual patient education materials.
Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics <sup>32</sup>	A guide for using plain language communication strategies, including 25 bilingual (English/Spanish) patient education handouts.
Re-Engineered (RED) Discharge Toolkit <sup>112</sup>	A set of tools to help hospitals re-design the discharge process, particularly hospitals that serve diverse populations, to reduce readmissions and post-hospital emergency department visits.
The SHARE Approach <sup>25</sup>	A train-the-trainer curriculum that supports the training of health care professionals on how to engage patients in their health care decision making.
Taking Care of Myself: A Guide for When I Leave the Hospital <sup>24</sup>	A fillable PDF that allows patients to record information they need to remember about appointments and medicines and how to care for themselves when they get home.
Ten Attributes of Health Literate Health Care Organizations <sup>3</sup>	A set of 10 attributes that health-literate health care organizations can adopt and invest in to help everyone benefit fully from the nation's health care systems.
Toolkit for Clear and Effective Written Materials <sup>39</sup>	A resource that provides a detailed and comprehensive set of tools to help make written materials easier for people to read, understand, and use.

- Hospital policy requires teach-back of benefits, harms, risks, and other information about tests, procedures, and medicines as part of obtaining informed consent.
- Patients are not discharged until successful teach-back of discharge instructions is documented in the medical record.

For hospitals to adopt health literacy universal precautions, champions are needed at every level of the organization, from executive sponsors to frontline staff, to lead the required quality improvement efforts. It also means allocating resources to create supports, such as easy-to-understand patient education and informed consent materials. Hospitals that aim to become health literate go even further. They integrate health literacy into planning, evaluation measures, patient safety, and quality improvement. They include the populations they serve in the design, implementation, and evaluation of health information and services. They provide easy access to health information and services and navigation assistance. They systematically hardwire the hospital to make it easy for people to navigate, understand, and use information and services to take care of their health. The resources listed in **Table 3** can help hospitals along their health literacy improvement journey.

#### **SUMMARY**

Health literacy has implications for patients and families in the events leading up to hospitalization, during the hospital stay, and post-discharge. Hospitals and providers

should use a universal precautions approach and routinely incorporate health-literacy-informed strategies in communicating with all patients and families to ensure that they can understand health information, follow medical instructions, participate actively in their own/their child's care, and successfully navigate the health care system. Interventions that go beyond the individual provider level are essential to keep patients safe from harm. Addressing the problem of health literacy necessitates health care systems matching the demands they place on individuals with those individuals' skills and abilities. Future work should focus on studying the effects of limited health literacy in pediatric inpatients and their parents as much of the work in this field has come from the adult literature. Additional strategies to provide education to providers and trainees about health literacy should be developed and implemented.

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