Health Literacy and Patient Safety Events

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ABSTRACT

Structuring and presenting healthcare information that aligns with a patient's level of understanding can help patients achieve optimal outcomes. The Pennsylvania Patient Safety Authority is participating in a statewide health literacy initiative focused on providing strategies to healthcare providers that help patients understand and engage in their medical care. A search of the Pennsylvania Patient Safety Reporting System identified 265 potential health literacy-related event reports in which patients misunderstood or did not comprehend healthcare instructions provided to them by healthcare clinicians. The most frequent outcomes of patients misunderstanding instructions or information were delayed or cancelled procedures, surgeries, treatments, or tests; or patients leaving without being seen. Verbal communication strategies such as "teach back" and "Ask Me 3®" programs and written strategies address opportunities identified in the event reports and may help improve patient understanding and engagement in their care. (Pa Patient Saf Advis 2016 Jun; 13[2]:58-65.)



Scan this code with your mobile device's QR reader to access the Authority's toolkit on this topic.

INTRODUCTION

Helping patients understand healthcare information and instructions is pivotal to engaging patients to improve their own health and safety. The challenge in communicating complicated and sometimes evolving healthcare information is in the presenter's ability to deliver the information in a clear yet concise manner. Learning to read and speak healthcare terminology is akin to learning a foreign language. Acronyms, abbreviations, and Latin-based words are often used to represent complex concepts. Individuals unfamiliar with medical terms frequently struggle to understand and make decisions based on information presented to them. Analysts from the Pennsylvania Patient Safety Authority identified event reports in which the patient's misunderstanding of healthcare instructions or information adversely impacted the patient's care.

Communication gaps are not new to healthcare and can contribute to Serious Events, including permanent loss of function and even death. Health literacy, the ability to comprehend healthcare information, goes beyond reading and writing, and includes listening, speaking, and numeracy (i.e., use of math skills and reasoning for decision-making in everyday situations) in order to make informed healthcare choices. ²

In 2010, the Health Care Improvement Foundation and Thomas Jefferson University and Hospitals started a health literacy initiative funded by the Pennsylvania Department of Health. This program, Southeastern Pennsylvania Regional Enhancements Addressing Disconnects in Cardiovascular Health Communication (SEPA-READS), began as a regional effort in Southeastern Pennsylvania and initially focused on older adults, age 50 or older, with cardiovascular disease. The SEPA-READS program has since expanded across the Commonwealth and helped spur the formation of the Pennsylvania Health Literacy Coalition.³ In December 2015, Authority staff attended a train-the-trainer program, "Communicating to Connect: Strategies to Improve Health Literacy." This program taught Authority staff about health literacy principles and provided methods to disseminate this information among Pennsylvania healthcare facilities to improve patient comprehension of healthcare information. To better understand the impact of health literacy on patient care in Pennsylvania, Authority analysts searched the Pennsylvania Patient Safety Reporting System (PA-PSRS) database to identify potential health literacy-related event reports.

METHODS

Analysts queried the PA-PSRS database, searching the event narratives and recommendation data fields using the following keywords and phrases: "misunderstood," "misunderstand," "comprehend," "did not understand," and "did not follow directions;" the query was for the 10-year time period of January 2005 through December 2014. Analysts read event report narratives to identify potential health literacy-related event reports (i.e., situations in which patients either misunderstood or did not comprehend healthcare instructions or information provided to them by healthcare clinicians). Situations in which healthcare workers misunderstood instructions or orders were excluded.

Potential health literacy-related event reports were analyzed according to patient age and harm score.*

Event report narratives and PA-PSRS data fields labeled "contributing factors" (e.g., patient not understanding) and "remedy factors" (i.e., what was done to remedy the

^{*} The Pennsylvania Patient Safety Authority Harm Score Taxonomy is available online at http://patientsafetyauthority.org/ADVISORIES/AdvisoryLibrary/2015/mar;12(1)/PublishingImages/taxonomy.pdf.

situation) were further analyzed to identify patient outcomes, event explanations (e.g., preoperative instructions not followed), contributing factors, and remedies.

Event reports describing patients with cognitive impairment were also found and analyzed separately to identify outcomes specific to this subgroup.

RESULTS

Patient-Related Event Reports

Analysts identified 265 potential health literacy-related event reports in which patients misunderstood or failed to understand instructions or information provided by healthcare clinicians.

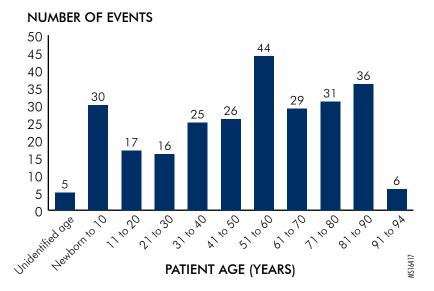
Patient age. The largest number of event reports (16.6%, n = 44 of 265) involved patients 51 to 60 years old. See Figure 1 for the age distribution from newborns to 94 years.

Harm score. Ten (3.8%) events were reported as Serious Events; harm scores were E and F. There were no event reports with the harm scores G, H, or I. The

majority of events (48.3%, n = 128 of 265) were reported as a harm score C followed by the next harm score category D (27.9%, n = 74).

Outcomes, explanations, contributing factors, and remedies. Seven outcomes, five explanations, four patient-related contributing factors, and one patientrelated remedy were identified (Table 1). Outcomes were identified in all but one report. The most frequently reported outcome was a delayed or cancelled procedure/surgery/treatment/test or the patient leaving without being seen (33.7%, n = 89 of 265), followed by patient falls (30.7%, n = 81). Fewer than half of the event reports identified an explanation (35.8%, n = 95 of 265), contributing factor (29.0%, n =77), or remedy (26.8%, n = 71).* Patients not following preoperative instructions (54.6%, n = 53 of 97) was the

Figure 1. Potential Health Literacy–Related Events Involving Patient Misunderstanding as reported through Pennsylvania Patient Safety Reporting System, By Patient Age (Years), 2005 through 2014 (N=265)



most frequently reported explanation for a misunderstanding. The most frequently reported contributing factor was patient not understanding (80.5%, n = 62 of 77); lack of patient compliance, the second most frequently reported contributing factor, often results from lack of patient understanding.⁴ Talking to the patient/family was the only patient-related remedy identified (n = 71).

Cognitive impairment. A subgroup of 75 event reports (28.3%) was identified that described patients who were confused, had cognitive disorders (e.g., Alzheimer's disease, dementia), psychiatric disorders, or an inability to comprehend instructions (e.g., traumatic brain injuries). Patients in this subgroup experienced the outcomes shown in Table 2.

Examples of Patient Misunderstandings

The following are de-identified PA-PSRS event narratives.[†]

Delayed or Cancelled Procedure/Surgery/ Treatment/Test

Even though the patient had preop instructions explained to her
yesterday, she obviously did not
understand. The nurse explained the
instructions several times and the
patient's husband said he could stay
and would be able to take a taxi
home with his wife, the patient. This
[action] did not transpire and the
patient's procedure had to be cancelled on the day of surgery.

Patient was to have an outpatient MRI with sedation. The patient had concerns about sedation. Investigation with involved staff revealed that detailed explanations were given to the patient. The patient was extremely anxious about the

^{*} Several event reports identified more than one explanation or contributing factor for patients not following a healthcare worker's directions.

[†] The details of the PA-PSRS event narratives in this article have been modified to preserve confidentiality.

procedure. The patient left without sedation or the test being performed.

Falls

The patient had been to the bathroom without assistance. The patient at times did not understand what was being said. Just prior to being admitted to the floor, and after family had left, the patient staggered out of the room and fell in the hallway. No injury noted. The patient was immediately raised up to his feet and assisted back into his room.

Patient stated several times that she wanted to get into bed. She was told that her physician ordered her to sit in a chair. The patient did not understand what was told to her. Patient was found by staff in the bathroom.

Patient has right hemiparesis. Patient was instructed not to get up without assist. Patient dropped her glasses on the floor, and in an attempt to get them, she fell.

Table 1. Potential Health Literacy-Related Event Outcomes, Explanations, Contributing Factors, and Remedies, as Reported through Pennsylvania Patient Safety Reporting System, January 2005 through December 2014 (N = 265)

OUTCOMES	NO. OF EVENT REPORTS	% OF EVENT REPORTS
Delayed or cancelled procedure/surgery/treatment/test or patient left before being seen	89	33.7
Fall	81	30.7
Medication error	31	11.7
Premature removal of pulmonary, gastric, or peripheral central catheters	19	7.2
Aggression by patient or family	11	4.2
Wrong procedure/site	4	1.5
Miscellaneous (e.g., skin tears, patients leaving unit, removed dressing)	29	11.0
Total	264*	100
EXPLANATIONS [†]		
Preoperative instructions not followed	53	55.8
Language barrier	15	15.8
Discharge instructions not followed	13	13.7
Consent issue	9	9.5
Change in mental/medical status	8	8.4
Total	95§	100
CONTRIBUTING FACTORS [†]		
Lack of patient understanding	62	80.5
Lack of patient compliance [‡]	37	48.1
Lack of family cooperation	7	9.1
Language barrier	4	5.2
Total	77 §	100
REMEDIES		
Information or explanation provided to patient or family	71	100
Total	71	100

^{*} One event report did not identify an outcome.

[†] Explanations and contributing factors not reported on all reports.

[‡] Lack of patient compliance is often a result of lack of patient understanding.⁴

[§] More than one explanation or contributing factor was described in some reports.

Table 2. Cognitive Impairment-Related Outcomes, as reported through the Pennsylvania Patient Safety Reporting System, January 2005 through December 2014 (n = 264*)

	EVENT REPORTS SPECIFYING COGNITIVE IMPAIRMENT
OUTCOMES	(NO. OF EVENT REPORTS/TOTAL NO. OF EVENTS)
Aggression-related incidents by patients or family	81.8% (9 of 11)
Unplanned removal of tracheostomy, nasogastric, and gastric tubes	73.7% (14 of 19)
Falls	44.4% (36 of 81)
Miscellaneous issues (e.g., pressure ulcers)	20.7% (6 of 29)
Delays or cancellations in procedures, surgery, treatments, or tests	9.0% (8 of 89)
Medication errors	6.5% (2 of 31)
Wrong procedure or site	0% (0 of 4)

^{*} One event report did not identify an outcome.

Preoperative Instructions Not Followed

The patient told the doctor that he had taken his [medication] for the past 3 days. The prescription was written for postoperative use. The patient misunderstood. The doctor explained to the patient the risk of continuing with the surgery due to the fact that he had been taking the [medication]. The patient and surgeon agreed to cancel the surgery and surgery will be rescheduled. The patient was re-educated to not take any medication prior to surgery.

The patient arrived for endoscopy. The patient misunderstood instructions and ate a sandwich two hours prior to arriving for the procedure.

The patient had a snack at 5:45 am. The parent misunderstood the NPO [nothing by mouth] instruction to stop solid food at midnight. The surgery was delayed.

Consent Issues

Consent form for trigger finger release was blank on front page. [Staff] filled in trigger finger release for patient to read but was unable to obtain permission. Patient not sure of procedure to

be done, did not understand physician explanations... will have to wait until tomorrow.

Extubations

Patient found pulling her [nasogastric] tube out. Patient repositioned and order received to replace tube. Patient unable to comprehend the need to leave the tubes alone.

Patient was sitting up in the chair. When family entered the room, they noted the [patient's] Foley catheter was completely removed. The patient was in no distress... Patient in wrist restraints due to mentally...unable to comprehend reason for tubes.

DISCUSSION

In the PA-PSRS events, oral communication issues, such as misunderstanding oral instructions for preventing falls or preoperative instructions, and written communication issues, such as obtaining a consent for procedures or surgery, are challenges faced by patients and healthcare staff. A person's level of health literacy is based on word recognition, reading comprehension, and numeracy.² Some aspects of health literacy are not

easily measured, such as oral and written communication skills, reading ability, and familiarity with language, as well as background knowledge, such as biology, and different cultural approaches to health care.⁵

Almost one third (28.3%, n = 75 of 265) of reported events in Pennsylvania involved patients with a cognitive impairment, and more than half (55.3%, n = 146 of 264) were patients age 51 or older. Many factors influence a person's ability to process and understand health care information. Individual factors may include culture, language, emotion, age, medications, previous exposure to the health care system, cognitive impairment, and general literacy, as well as acute stresses such as fatigue and illness.^{2,5,6,7} Healthcare system factors include the complex and often-contradictory nature of health care information, complicated technology, diverse manners of presentation (e.g., signs, directions,) and time constraints.5 Although certain groups of patients (e.g., older adults, non-native English speaking people) are at greater risk of having a lower level of health literacy, it is difficult to determine a person's level of health literacy by observation of how they look or speak.^{5,8}

The 2003 National Assessment of Adult Literacy (NAAL) categorized health literacy into four levels based on standardized test scores. The NAAL health literacy results showed that 12% of adults had proficient health literacy, 53% of adults had an intermediate health literacy level, 22% of adults had a basic health literacy level, and 14% had a below basic health literacy level.9 See "Health Literacy Level Descriptions" for further information. The NAAL has been replaced by the Program for the International Assessment of Adult Competencies (PIAAC). The PIAAC was last administered in 2012 and yielded results similar to the NAAL, indicating that health literacy is relatively static at the population level.¹⁰

The NAAL assessed patient age, gender, race and ethnicity, language spoken before starting school, highest level of education, and poverty level. The results showed that, in general, women have a slightly higher level of health literacy than men; more adults age 65 or older had lower levels of health literacy than adults in any of the younger age groups; Hispanic adults had lower average health literacy than adults in any other race or ethnic group; adults who did not speak English before starting school had the lowest average health literacy level; and adults below the poverty level had lower average health literacy than adults living above the poverty threshold.9

Effects of Low Levels of Health Literacy

Inadequate health literacy has been associated with poorer health outcomes. ¹¹⁻¹⁴ Implementing plain language descriptions (e.g., replacing medical or technical terms with words that people use in everyday conversations) during clinical encounters and in healthcare documents can help patients understand the complex language used in healthcare. ^{8,15,16} A plain language agenda has been developed by the Centers for Disease Control and Prevention and the federal government; however, application of plain language

HEALTH LITERACY LEVEL DESCRIPTIONS

Below Basic—indicates no more than the most simple and concrete literacy skills, such as not being literate in English or not locating easily identifiable information in simple documents (e.g., charts or forms).

Basic—indicates skills necessary to perform simple and everyday literacy activities, such as reading and understanding information in simple documents.

Intermediate—indicates skills necessary to perform moderately challenging literacy activities, such as locating information in dense, complex documents and making simple inferences about the information.

Proficient—indicates skills necessary to perform more complex and challenging literacy activities such as integrating, synthesizing, and analyzing multiple pieces of information located in complex documents.

Source: Kutner M, Greenberg E, Jin Y, Paulsen C. The health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy (NCES 2006–483) [online]. 2006 [cited 2016 Feb 26] Washington, DC: U.S. Department of Education, National Center for Education; p. 5. http://nces.ed.gov/pubs2006/2006483.pdf

into everyday documents, such as consent forms, and educational programs requires time to develop, test, and implement. 16-18 Obtaining informed consent involves more than obtaining a patient's signature on a written consent form. It is an interactive process between a patient and physician that has two major elements: a patient's awareness and understanding of a healthcare situation and treatment options, and their voluntary choice to act upon this information.¹⁹ A patient's signature on a consent form does not necessarily confirm that the patient understands the type of treatment he or she has authorized. Studies have shown that up to half of patients did not correctly recall the risks of surgery and one third did not correctly recall the alternatives to the procedures after providing informed consent.20-23

Determining Health Literacy

Before implementing any health literacy strategies with patients, the first step is to ensure that the universal health literacy precautions are in place.²⁴ Then staff can proceed to identify whether a patient has a medical or mental health condition that will impinge on the patient's ability to

understand instructions. Next, determine whether patients with limited decision-making capacity are incapable of making their own decisions (e.g., giving informed consent) or whether there are periods when they are lucid and able to actively participate in their care. ^{25,26} A patient's overall decision-making capacity will drive the type of risk-reduction strategies selected by healthcare staff. The following risk-reduction strategies are useful to institute in patients who are unable to comprehend instructions due to medical or mental health conditions. ^{7,25,31}

Risk Reduction Strategies for Patients with Impaired Decision-Making Capabilities

The following strategies can be used with patients who have impaired decision-making capability:

- Screen patients for cognitive impairment
- Engage family members or surrogate decision-makers in the patient's care
- Incorporate shared decision-making with other healthcare professionals who have cared for the patient

Recognizing Low Levels of Health Literacy

Testing patients to determine their level of health literacy can lead to shame and alienation.^{11,32-34} The literature suggests close observation and asking certain types of questions that can help identify individuals with limited reading and comprehension skills.³⁵ Patients with low health literacy may exhibit the following behaviors:^{8,35,36}

- Make excuses when asked to read or fill out forms, such as "I don't have my glasses" or "I'll read this when I get home"
- Lift text close to their eyes, point to the text with a finger while reading, or visually wander over the page without finding a central focus
- Provide incomplete medical history or check items as "no" to avoid follow-up questions
- Listen carefully and take instructions literally to avoid mistakes
- Identify medications based on color, size, and shape
- Fail to comply with medication regimens
- Frequently miss appointments
- Show signs of nervousness, confusion, frustration, and even indifference
- Avoid situations or withdraw when complex learning is required
- Give incorrect answers when questioned about what they have read

Keep in mind that if patients do not exhibit any of these behaviors, it is not confirmation that they are health literate.^{5,8}

Addressing Health Literacy

The majority of PA-PSRS events involved patients with the capacity to make health-care decisions. Yet these patients were faced with challenges in understanding oral and or written communication instructions and are the focus of the risk-reductions strategies. Oral communication methods and programs such as the "teach back" method

and the National Patient Safety Foundation (NPSF) Ask Me 3® program can provide feedback to healthcare clinicians about the patient's level of understanding.^{37,38} Written communication strategies are divided according to common themes used to create the forms or instructions intended to inform patients.

Risk Reduction Strategies Oral Communication

The following risk reduction strategies can be implemented when communicating verbally with a patient:

Verbal Communication Techniques

- Use teach back (or show me)
 method, which allows providers to
 confirm understanding by asking the
 patient to demonstrate or explain, in
 their own words, what they need to
 do.^{6,8,15,35-37}
- Encourage patients and families to ask questions and engage in their care. NPSF's Ask Me 3® program is an example of a patient education campaign that focuses on asking questions, as follows: (1) What is my main problem? (2) What do I need to do? and (3) Why is it important for me to do this?^{8,15,35,38}
- Ask patients open-ended questions instead of questions that can be answered with a yes or no (e.g., "What questions do you have? instead of "Do you have any questions?" or "Do you understand?")^{15,35}

Verbal Communication Skills

- Talk slowly, use plain language.^{8,15-18,24,35-37,39}
- Avoid medical jargon.^{8,15,18,24,35,37,39}
- Use a trained medical interpreter for patients who have limited English proficiency.^{6,24,36}
- Use videos, interactive computer programs, or pictures to accommodate different learning styles. 8,24,35,36,40
- Keep number of points to three or less to focus on what the person

- needs to know and needs to do (i.e., action oriented).^{8,15,24,35,39}
- Communicate as if talking to a friend to show genuine interest.^{8,16,37}

Non-Verbal Communication Skills

 Face the patient when talking with him or her, make direct eye contact, and use relaxed body language. 15,24,35,37,39

Written Communication

Written communication approaches can focus on principles that simplify written instructions and forms that include:

Document Suitability

- Use assessment tools to evaluate the overall suitability of materials, such as the Plain Language Grade level, Relevance, Interest, and Design (Plain Language GRID), Suitability of Assessment Materials (SAM), Patient Education Materials Assessment Tool (PEMAT), and the Clear Communication Index (CCI).^{15,16,24,39,42}
- Explain the purpose of documents and keep the description simple (e.g., one to two key objectives).^{8,35,40}
- Provide clear messages; give the most important information first, describe what actions to take, and explain their importance.³⁵
- Emphasize desired behaviors.^{35,40}
- Highlight the positive message.³⁵
- Pretest materials for the intended audience. 8,16,40,43

Document Content

- Write at a grade 4 to 6 level; use readability calculators such as the Simple Measure of Gobbledygook (SMOG), Fry Graph Readability Formula, and Flesch-Kincaid readability tests (which is available in Microsoft Word).^{6,8,15,35,40,44,45}
- Write in short, brief sentences (no more than 10 to 15 words).^{8,18,40}
- Limit paragraphs to three to five sentences. 8,16,18

- Use the word "must" to indicate requirements.^{6,18}
- Use active voice.^{8,16,18,24,40}
- Use plain language and words with one or two syllables.^{8,15,18,35,36,39,40}
- Avoid medical jargon, technical, or scientific language, and unnecessary abbreviations and acronyms; if a complex term cannot be avoided, clearly define what it means. ^{6,8,15,16,18,35,39}
- Use audience-appropriate images and diagrams to highlight key messages. 18,35

Document Format

- Keep design simple, with sharp contrast between text color and background paper color.⁴⁶
- Include ample white space, use appropriate space between lines of text (e.g., 1.2 to 1.5 spacing, and leave at least ½ inch to 1 inch of white space around the margins and between columns).^{8,16,18,40,46}

- Leave right margin ragged so readers can easily track their location within the text. ^{16,18,40,46}
- Create short lists (i.e., three to seven items) with bullets, not commas.¹⁶
- Use no smaller than 12 point font, ideally 14 point font; avoid italics. 8,15-18,35,40,46
- Use a simple, clear font style; a sans serif font is generally recommended for viewing on screens and devices.^{16,40}

LIMITATIONS

This retrospective review of reported events is limited by the information reported through PA-PSRS, including the event descriptions and explanations. PA-PSRS does not have structured data fields that identify health literacy events; and the search terms used may not have encompassed all of the relevant descriptions used in reported events. It is also possible that limited health literacy may

have contributed to events in ways that were not recognized by staff.

CONCLUSION

Limited healthcare literacy can contribute to delays or errors in treatment that can lead to poor healthcare outcomes. The complexity of healthcare information that healthcare clinicians use every day can be overwhelming for patients to comprehend and assimilate. Clear communication of healthcare information between healthcare clinicians and patients can improve patient understanding of the benefits and risks and improve adherence with medical interventions, thereby increasing the chance of better healthcare outcomes. Achieving effective patient communication requires implementation of universal precautions in a manner that meets the health literacy needs of all patients. The written and verbal strategies identified in this article provide some initial steps that can help bridge communication gaps between clinicians and patients and lead to better informed patients.

NOTES

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