

Overcoming Low Health Literacy

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Abstract:

Low health literacy is so widespread among patients in outpatient settings, some authors have called it a silent epidemic.[1] Research continues to show that many patients don't understand the recommendations given to them by their healthcare providers.[2,3] Because of this lack of understanding, these patients can't follow directions to adopt healthful lifestyle behaviors, make wise healthcare decisions, actively participate in their plan of care, manage medication regimens, and follow their healthcare providers' treatment advice.

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Article:

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Low health literacy is so widespread among patients in outpatient settings, some authors have called it a silent epidemic.¹ Research continues to show that many patients don't understand the recommendations given to them by their healthcare providers.^{2,3} Because of this lack of understanding, these patients can't follow directions to adopt healthful lifestyle behaviors, make wise healthcare decisions, actively participate in their plan of care, manage medication regimens, and follow their healthcare providers' treatment advice.

Every critical care nurse has cared for a patient or family who just doesn't seem to understand what's happening. One family member appears to believe nothing is wrong. Another patient or family member doesn't see that the patient's outcome isn't going to be good. Another seems incapable of making a decision.

To date, however, only a few authors have addressed low health literacy in critical care. Mattox recently addressed the fundamental challenges of low health literacy and critical care.⁴ This article describes a model or framework for critical care nurses to use when addressing low health literacy, and shows through two scenarios how addressing low health literacy can dramatically improve outcomes for the patient and family. Finally, we suggest some practical strategies that you can use to address low health literacy in critical care areas.

Defining health literacy

Health literacy is a person's capacity to obtain, process, and understand basic health information and services needed to make appropriate health-related decisions.^{5,6} Someone with adequate health literacy has the skills to access healthcare information and make informed healthcare decisions.⁷ Not knowing ICU information is different from low health literacy. Even patients and families who read and write well may not understand what's happening in the ICU, nor what's expected of them.^{1,2,5,6}

Patients with low literacy skills face additional challenges maneuvering within the healthcare system. They often face difficulties in completing healthcare forms, understanding their healthcare instructions, keeping appointments and scheduling follow-up care, and self-administering their medications. The National Assessment of Adult Literacy report indicates that about 50% of the U.S. population has low literacy levels.⁸ Having low literacy levels equates to low health literacy levels. Patients with low health literacy are prone to make potentially fatal mistakes or not comply with their healthcare plan because of inability to obtain, process, and analyze basic health information.⁹

A model of health literacy

Baker's model of health literacy (see *A model of health literacy*) provides a framework for critical care nurses to assess health literacy when educating patients and their families on complex healthcare issues.¹⁰ The model focuses on a person's individual capacity, the complexity of health-related messages, and how other factors such as cultural norms and self-efficacy affect health outcomes. (Self-efficacy is the belief that one has the ability to do what needs to be done to take care of oneself. The complexity of illnesses that lead to ICU admission may greatly reduce self-efficacy.)

Individual capacity refers to the skills needed to maneuver through the healthcare system effectively, such as the ability to read, previous healthcare knowledge, and ability to understand and apply the skills to access healthcare information. Simply stated, people can more easily read and understand information if the terms used are those they find familiar. Health literacy is determined by a person's characteristics and by environmental influences, including the healthcare system used by the person. Several other factors may also be important, including cultural considerations, acquired knowledge, and behavior change. In the paragraphs below, this model is applied to two critical care scenarios in which poor decisions were made because of low

health literacy. In these cases, the staff overcame the patient's or family's low literacy to improve outcomes for their patients.

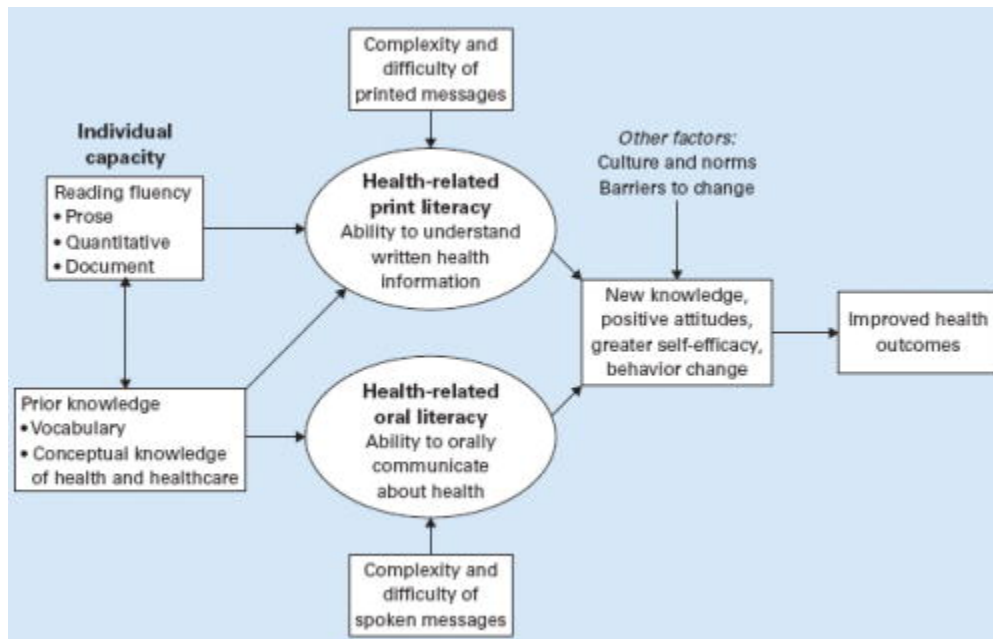


Figure. A model of health literacy

Taking it to the streets

JK, 19, had lived on the street as long as he could remember, and had no family, no known address, and no steady employment. Based on their interactions with JK, the ICU staff believed he couldn't read. He was admitted to the ICU with multiple trauma sustained during a motorcycle crash. His right leg and arm were in casts due to fractures. He had a chest tube and closed chest drainage system for a hemothorax and a negative pressure wound therapy system for an open abdominal wound. JK said he'd never been to a hospital or a physician's office. He openly feared the staff and cursed and swore much of the time. He developed compartment syndrome of his right thigh, and his abdominal wound needed to be debrided, but he refused to give consent for anesthesia and the needed procedures.

JK's team met to develop a plan to ensure that he understood his need for surgery and to help him become a more active participant in his care. Using Baker's model, the team saw that JK's individual capacity was severely impaired because he had no knowledge of healthcare and might not be able to read. He also had very limited ability to communicate about his health needs. RO, a 24-year-old monitor technician who'd spent a few years living on the street as a teen, offered to help when a nurse and physician went to talk to JK. RO knew the lingo of the ICU, and had an uncanny ability to explain complex health problems and procedures in simple terms.

RO and one of the nurses whom JK seemed to trust more than the others approached him after he appeared to have rested. They explained that JK's broken arm and leg and belly wound would heal in about 2 months, and the tube in his chest would come out in 2 or 3 days. JK visibly relaxed. They answered many more of his questions, and he fell asleep, obviously exhausted. When he woke up after an hour, RO, the nurse, and a physician explained that the pain in JK's right leg meant there was too much swelling and the doctors needed to make a cut to let the pressure out. They also said the doctors needed to get more gravel and infection out of his belly wound.

JK consented to surgery, which was performed that afternoon. Each day, he continued to improve, and he was transferred to a medical unit on the same floor as the ICU. Over the next 3 weeks, RO and JK developed a close friendship. JK had additional complications including pneumonia and *Clostridium difficile*-associated disease. However, through the ongoing efforts of RO and the staff, JK actively participated in his care, routinely made decisions, understood his prognosis, and at discharge, was independent in caring for all his wounds and performing his therapy.

JK confided to RO that this was the first time in his life that he saw that he had a future. Getting around in his wheelchair was a breeze for JK, and he frequently ran errands for staff, getting snacks, showing visitors how to get to other hospital departments, and delivering supplies from one floor to another. The social worker was able to arrange for JK to live in a group home until the casts came off and his wounds healed. JK was referred to vocational rehabilitation for an assessment.

Although the initial efforts with JK were time-consuming and taxing, the outcomes achieved were worth it. JK's self-efficacy increased dramatically, and by RO connecting with JK on his level, what could have been a disastrous ICU stay turned out to be a success for JK and the staff.

The big picture

A lack of formal education and poor reading ability aren't the only causes of low health literacy.

JU was a concert violinist in her mid-40s. One day, she developed a severe headache and was admitted to the hospital with a subarachnoid hemorrhage secondary to a ruptured cerebral aneurysm. Even though they were able to clip the aneurysm and stop much of the bleeding, JU's brain damage was so severe that the surgeons anticipated she'd remain in a vegetative state. Two weeks after the initial bleed, JU remained minimally responsive on the ventilator in the ICU. Complications included ventilator-associated pneumonia but she was now infection-free. The physicians asked her husband, BL, for permission to wean her from the ventilator, but he refused. BL was also in his 40s and played oboe in the same orchestra as JU. Both had master's degrees in music performance, but had limited healthcare knowledge because they'd never been hospitalized. They had no children, and had written advance directives a few years earlier, after BL's father developed Alzheimer disease.

In their advance directives, JU and BL agreed that they didn't want to be kept alive when there was little hope of recovery, as most of the joy in their life came from playing music. They also decided that they didn't want to be organ donors.

One afternoon, the clinical nurse specialist (CNS) sat down with BL in a quiet, private room and told him that she heard him and JU play last year in concert, and was especially moved by JU's violin solo in one of the featured pieces. They discussed JU's music. The CNS then asked BL to tell her how he thought JU was doing, and found that he was focusing on the nurses' reports of the day-to-day lab results. The infections were now cleared up. The recent removal of the intracranial pressure monitoring catheter led BL to believe JU was "out of the woods." He did, however, acknowledge his understanding that if she was going to improve cognitively, her improvement should have started before now.

With the CNS's assistance, they explained JU's prognosis. The next morning, BL agreed to take JU off the ventilator. While JU was listening to her favorite violin concerto, the endotracheal tube was removed and she died a peaceful death, with BL by her side, and the CNS close by.

The CNS knew that BL would respond much better if their discussion was structured following Osborne's health literacy guidelines.¹¹ (Osborne's practical guide describes how practitioners can effectively explain many procedures, diseases, and treatments to patients and families.) She found a private place to talk, away from distractions and interruptions; made eye contact; and sat down with him—showing that she had time to listen to him. She established rapport and a supportive environment with BL by talking about JU's music, then bringing up the end-of-life discussion. These strategies also created a shame-free environment, letting BL know that it was all right that he was focusing on the day-to-day rather than JU's long-term prognosis. The CNS listened to BL's frustration and anger, sat with him while he cried, and let him express for himself that JU was being needlessly kept alive. BL was then ready to make the hard decisions he needed to make, and took control by ensuring that the last things JU experienced were the music she loved and his touch.

In both of these scenarios, the nurses and the healthcare team met the patient and family on their own terms. The strategies they used helped patients and family members make more informed healthcare decisions. The time and energy invested in doing this prevented unnecessary suffering by the patient and family, optimized the care provided by the nurses, and saved thousands of dollars.

Common health literacy problems

When a patient is admitted to a CCU, the family may not understand what's happening to their loved one. Consider these elements before attempting to educate the patient and family:

* *The family's ability to read and comprehend healthcare information.* If some family members have low literacy levels and limited exposure to healthcare, you'll have to work harder to convey

information in a “health literacy-friendly” manner. However, keeping the family informed and helping families and patients to understand and manage their care will lead to better decisions on their part, and may lead to improved outcomes.

** The patient's and family's understanding of why the patient is in a critical care environment.*

The seriousness of the critical care environment may not make sense to patients and families with limited healthcare knowledge. They may not comprehend which noises or alarms require an immediate response from the nursing staff or why their loved ones are “hooked up to so many tubes and wires.” Explain the situation to the patient and family members. Provide a full explanation of what's happening, to help relieve patient and family anxiety.

The Joint Commission (TJC) notes that effective communication between healthcare professionals and patients is key to improving outcomes.¹² Printed patient education materials or handouts should be prepared at or below the fifth grade reading level, per the TJC, include pictures as appropriate, and be sensitive to a variety of cultures whenever possible. Avoid medical jargon and complex healthcare terms if possible, in both printed and verbal healthcare information.

Nurses may not have the time to educate CCU visitors. However, this education should become a required part of the patient's care; that is, someone from the nursing staff should be required to educate patients, their family members, or their loved ones and document this within 24 hours of the patient's ICU admission. If this education session doesn't occur, the nurse responsible for caring for the patient should be required to document the reason in the patient's medical record. For example, if a family member or loved one isn't present, this should be documented in the patient's medical record, showing that the nursing staff had a desire to communicate effectively with patients and their family. The education session should provide more information on the patient's healthcare status and possibly improve patient and family health literacy.

A patient's willingness and ability to understand discharge instructions are important because understanding typically leads to adherence. A positive attitude is generally associated with behavioral change. Barriers to understanding and applying healthcare knowledge to daily life, such as cultural norms that deviate from Western medicine, are also a factor.¹²

Critical care nurses must balance the care they provide with efforts to ensure that the patient and family understand what's happening to them. An ICU setting has so many inherent distractions that patients and their families may not be able to listen and understand, yet they may also be too sick to read. Although following Osborne's practical ways to communicate health messages takes extra time, you're likely to find these techniques effective when communicating information that's hard for families to hear, as the CNS did with BL. By conducting surveys and monitoring outcomes, you can determine which approaches are most effective. Patients' and families' lives may depend on this research, which may also help to increase the satisfaction of nurses providing care.

Toward better understanding

Addressing low health literacy in critical care patients and their families may not be seen as a priority for critical care nurses. However, taking the time to establish rapport, listening—uninterrupted—to the patient and family, effectively educating them about what is happening, and providing appropriate printed educational materials may be essential to help some patients and families understand what's happening and make appropriate decisions. Not doing so may lead to disastrous outcomes for the patient, the family, and the healthcare team.

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