

When the Patient and Family Just Do Not Get It: Overcoming Low Health Literacy in Critical Care

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Abstract:

Low health literacy in patients and families has been called a silent epidemic. Although there is a great deal of literature to assist nurses to address health literacy problems, little has focused on overcoming low health literacy in critical care. This article provides a definition of health literacy, explores how Baker's health literacy model can be applied to the critical care environment using Osborne's practical strategies, and presents 2 patient scenarios in which addressing low health literacy changed the outcomes for the patient and family. The article concludes with recommendations for critical care nurses to overcome low health literacy of patients and their families.

Keywords: Baker's health literacy model | Critical care | Low health literacy

Article:

Low health literacy has been shown to be one of the greatest problems of patients in outpatient settings. The problem is so widespread that some authors have called low health literacy a silent epidemic.¹ Research continues to show that patients simply do not understand the recommendations given to them by their providers.^{2,3} Without understanding, patients are unable to follow directions in adopting healthy lifestyle behaviors, make wise health care decisions, actively participate in their plan of care, manage medication regimens, and follow the treatment advice of their physicians, nurses, and other members of the health care team. Methods of addressing low health literacy have been suggested for nurses providing outpatient care. However, low health literacy is also a problem for critical care patients, their families, and the nurses who care for them. Every critical care nurse has cared for a patient or family who just do

not seem to “get it.” They appear clueless about what is happening. One family member appears to believe nothing is wrong. Another patient or family member does not see that the outcome for the patient is not going to be good. Another seems incapable of making a decision.

One family member appears to believe nothing is wrong.

To date, however, only a few authors have addressed low health literacy in critical care. Ott and Hardie⁴ looked at the readability of critical care patient education materials, and Riley et al¹ addressed the fundamental challenges of low health literacy and critical care. This article updates this prior work, provides a model or framework for critical care nurses to use when addressing low health literacy, and shows through 2 scenarios how addressing low health literacy can dramatically improve outcomes for the patient and family. Finally, the article suggests some practical strategies for critical care nurses to address low health literacy in critical care areas.

HEALTH LITERACY

Health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”^{5,6} McCabe⁷ describes persons with adequate health literacy as having a combination of skills that enable them to access health care information and equip them to make informed health care decisions. Patients with low literacy face numerous challenges in maneuvering within the health care system. They often face difficulties in completing health care forms, understanding their health care instructions, keeping appointments and follow-up care, and self-administering their medications. The National Assessment of Adult Literacy⁸ report indicates that approximately 50% of the US population have low literacy levels. Having low literacy levels equates to low health literacy levels. Patients with low health literacy are at a disadvantage because they are prone to make potentially fatal mistakes or be nonadherent to their health care plan because of inability to obtain, process, and analyze basic health information.⁹

A MODEL OF HEALTH LITERACY

Baker’s¹⁰ model of health literacy provides a framework to guide critical care nurses in making certain that the determinants of health literacy are considered when educating patients and their families on complex health care issues (Figure). The model serves as a framework to focus on a person’s individual capacity, the complexity of health-related messages, and the ways in which other factors such as cultural norms and self-efficacy affect health outcomes. Individual capacity reflects the skills that a person has to maneuver through health care effectively, such as ability to read, previous health care knowledge, and ability to understand and apply the skills to access health care information. Simply stated, persons can more easily read and understand information if the terms used are those they find familiar. Health literacy is determined by the characteristics of a person and by environmental influences, including the health care 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 2 critical care

scenarios in which poor decisions were made because of low health literacy and the staff overcame the low literacy to improve outcomes for their patients.

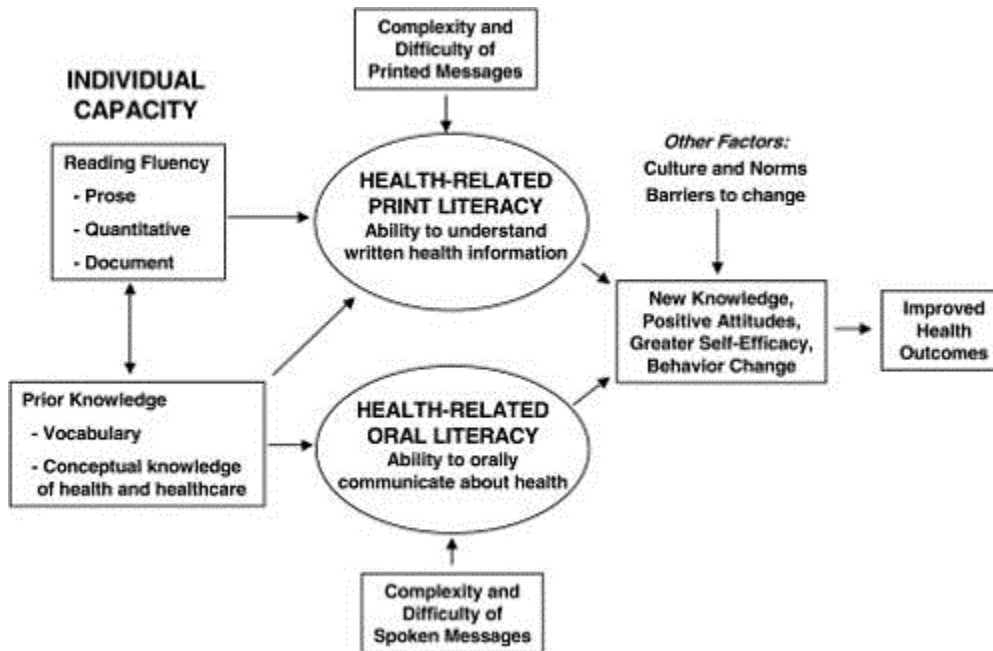


Figure. Baker’s 10 model of individual capacities, health literacy, and health outcomes.

Jack, a 19-year-old, had “lived on the street” overcoming low literacy in critical care ever since he could remember. Based on their interactions with Jack, intensive care unit (ICU) staff believed he could not read. He had no family, no known address, and no steady employment and he had been admitted to the ICU with multiple traumas sustained during a crash on a motorcycle he apparently had stolen. His right leg and arm were in casts due to fractures. He had a chest tube for a hemothorax and a pleuravac on an open abdominal wound. Jack said he had never been to a hospital or a physician’s office. He openly feared the staff and cursed and swore much of the time. It appeared that he was developing compartment syndrome in his right thigh, and he also needed his abdominal wound debrided again to remove more of the “road rash” and necrotic infected tissue in and around the wound. He was refusing to give consent for anesthesia and the surgeries needed.

Jack’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 his individual capacity was severely impaired because he had no knowledge of health care and might not be able to read. His oral health literacy was also impaired; he had very limited ability to communicate about his health needs. A 24-year-old monitor technician named Rocky who had spent a few years in his teens living on the street offered to help when a nurse and physician went to talk to Jack. Rocky had been hired and trained after becoming a paraplegic 3 years earlier. In addition to becoming a valued team member, he called the ICU his “second home” and referred to some of the staff as “family.” Through his job, Rocky had learned the lingo of the

ICU, and he has an uncanny ability to explain complex health problems and procedures in simple terms. Rocky and one of the nurses that Jack seemed to trust more than the others approached him after he appeared to have rested. They explained that Jack's broken arms and legs and belly wound would heal in 2 months, and the tube in his chest would come out in 2 or 3 days. Jack visibly relaxed. They answered many more of his questions, and he fell asleep, obviously exhausted. When he woke up after an hour, Rocky, the nurse and a doctor explained that the pain in his 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." He 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, Rocky and Jack developed a close friendship. Jack had additional complications of pneumonia, 1 episode of sepsis, and a bout of c-diff diarrhea. However, through the ongoing efforts of Rocky and the staff, Jack actively participated in his care, routinely made decisions, understood his prognosis, and at discharge, was independent in caring for all his dressings and performing his therapy. Jack confided to Rocky 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 Jack, 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 Jack to live in a group home until the casts came off and his wounds healed. Jack was referred to vocational rehabilitation for an assessment. Although the initial efforts with Jack were time-consuming and taxing, the outcomes achieved were worth it. Jack's self-efficacy increased dramatically, and by connecting with Jack on his level, what could have been a disastrous ICU stay turned out to be a success for Jack and the staff. However, as is shown in the scenario below, a lack of formal education and poor reading ability are not the only causes of low health literacy.

Over the next 3 weeks, Rocky and Jack developed a close friendship.

Judy was a concert violinist in her mid-40s. One day, she developed the "worst headache she had ever had" and was admitted to the hospital with a severe subarachnoid bleed. The neurosurgeons determined that she had a ruptured cerebral aneurysm. Even though they were able to clip the aneurysm and stop much of the bleeding, the brain damage was so severe that they anticipated that Judy would remain in a vegetative state. Two weeks after the initial bleed, Judy remained minimally responsive on the ventilator in the ICU. She had experienced a bout of ventilator-assisted pneumonia and a severe urinary tract infection but was now infection free. The physicians approached her husband Bill to wean her from the ventilator, but he refused. Bill was also in his 40s and played oboe in the same orchestra as Judy. Both Judy and Bill had master's degrees in music performance. Although they both were well educated in music theory, Bill admitted to having limited health care knowledge because neither he nor Judy had ever been hospitalized. They had no children. Both Judy and Bill had written living wills a few years ago, after Bill's father developed Alzheimer disease, and "lived long past any meaningful existence."

Both Judy and Bill agreed that they did not 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 did not want to be organ donors. Even with their experiences, they both admitted knowing little information about critical care but probably knew and understood more about the system than others did.

One afternoon, the clinical nurse specialist, Akia, sat down with Bill in a quiet, private room. Akia told Bill that she saw them play last year in concert, and she was especially moved by Judy's violin solo in one of the featured pieces. They discussed Judy's music. Akia then asked Bill to tell her how he thought Judy was doing. It became apparent that Bill was focusing on the nurses' reports of the day-to-day laboratory results. The infections were now cleared up. The recent removal of the intracranial pressure catheter led Judy to believe Bill 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. Over the next 60 minutes, Akia and Bill continued their heart-to-heart talk. Bill broke down several times as it hit him that Judy would never play the violin again. After expressing his anger and regret that Judy would not be able to play again, Bill relayed that he now saw that there is little hope for Judy, and she was being kept alive against her wishes. Bill and Akia went to talk with the neurosurgeons. With Akia's assistance, they used simple health care terms and avoided complex medical jargon as much as possible to explain Judy's prognosis. The next morning, Bill agreed to take her off the ventilator. While Judy was listening to her favorite violin concerto on the headphones, the endotracheal tube was removed and Judy died a peaceful death, with Bill by her side, and Akia close by.

Akia knew that Bill would respond much better if she followed Osborne's¹¹ health literate guidelines for talking and listening as a way to deal with health literacy issues. She found a private place to talk, away from distractions and interruptions; made eye contact; and sat down with him—showing that she had "all the time in the world, just for him." She established rapport and a supportive environment with Bill by talking about Judy's music, then bringing up the end-of-life discussion. These strategies also created a shame-free environment, letting Bill know that it was all right that he was focusing on the day to day rather than Judy's long-term prognosis. She listened to Bill's frustration and anger, sat with him while he cried, and let him express for himself that Judy was being needlessly kept alive. He was then ready to make the hard decisions he needed to make, and Bill took control by ensuring that the last things Judy experienced were the music she loved and his touch.

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

COMMON HEALTH LITERACY PROBLEMS IN CRITICAL CARE

When a patient and family member(s) are admitted to a critical care unit, the family may not understand what is happening to their loved one. Nurses should attempt to educate but must consider some critical elements before doing so. The family's ability to read and comprehend health care information is critical. If there are family members with low literacy levels and limited exposure to health care information and environments, the health care provider, including nurses, has to work at getting information across in a "health literacy-friendly" manner. Keeping the family informed and equipping families and patients with the ability to understand and manage their care will lead to better decisions on their part and improved health care outcomes, as shown in the scenarios with Jack and Bill.

Patients and their family members often do not understand the need to be in a critical care environment. If they have limited health care knowledge, the seriousness of the critical care environment may not make sense to them. They may not comprehend why there are limited visitation hours and why the machines are making all of those noises and which noises or alarms are necessary for the nursing staff to respond to right away. They also may not understand why their loved ones are hooked up to so many tubes. Instead of explaining the situation to the family members and to the patients who are alert and able to talk, the nursing staff typically ask the family members to leave or simply direct the patient to follow a set of instructions without a full explanation as to what is occurring. This causes anxiety for both patients and families.

When a client is in another unit of a health care facility, generally, visitors are allowed at variable hours and restrictions are minimal. In critical care units, however, there may be strict regulations and guidelines that are not clear to patients and their loved ones. Loved ones become upset when they are asked to leave and they are more likely to associate being asked to leave or step out of the area with some type of personal negativity. Nurses should take the time to explain what the patient is encountering and introduce the guidelines to family members.

The Joint Commission on the Accreditation of Health Care Organizations¹² notes that effective communication must occur between health care professionals and patients to promote improved health care outcomes. Written material or handouts that are prepared at or below the eighth grade reading level are encouraged to keep the family and patient informed at a level that they can understand. Medical jargon and complex health care terms should be avoided if possible, in both written and verbal health care information. The complexity of medical jargon confuses the family and creates an environment of frustration. Printed and verbal materials must also be created in a manner that does not offend and must be sensitive to a variety of cultures whenever possible. Nurses should strive to develop handouts that are written at low literacy levels, with a balance of pictorials and simple wording that addresses issues relevant and appropriate to family members.¹²

Nurses may not have the time to educate those who come to visit patients in critical care environments. 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 admission to ICU. If this education session does not occur, the nurse responsible for caring for the patient should be required to document this in the patient's chart. For example, if a client is on a ventilator, information regarding the specifics associated with the ventilator should be explained to the patient and/or family members. If there is not a family member or loved one present, this should be documented in the patient's chart, showing that the nursing staff had a desire to communicate effectively with clients and their family. This education session should provide more information on the health care status and possibly improve health literacy.

Patients and their family members do not always understand what is supposed to happen after they have been discharged from a critical care unit, and thus, they have difficulty adhering to their instructions. For example, if a patient is on a diet restriction or a fluid restriction, this may be perceived as punishment.

A patient's willingness and ability to understand health care instruction are important in a critical care environment. Understanding typically leads to compliance. A positive attitude is generally associated with behavioral change. Barriers to understanding and applying health care knowledge to daily life, such as cultural norms that deviate from Western medicine, are also a factor.

Critical care nurses must balance the care they provide, with efforts to ensure that the patient and family understand what is 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 it will take extra time, critical care nurses are likely to find Osborne's recommendations effective when communicating information that is hard to hear, as Akia did with Bill.

Patients and their families often do not understand the need to be in a critical care environment.

These recommendations need to be studied to determine which are most effective for patients in a critical care area. Whereas it is unethical to conduct randomized controlled trials to test such interventions, there are many opportunities for nurses to conduct surveys and to monitor outcomes to determine which approaches are most effective. Every day, critical care nurses document in patient records the strategies they are implementing with patients and families. These nurses are documenting the outcomes of their interventions. They can simply retrieve and analyze these data to see which interventions are most effective. Patients' and families' lives may depend on this research, and the research may also help to increase the satisfaction of nurses providing care.

CONCLUSIONS

In summary, although addressing low health literacy in critical care patients and their families may not be seen as a priority for critical care nurses, there are times when this may be essential. Taking the time to establish rapport, listening—uninterrupted—to the patient and family, effectively educating them about what is happening, and providing appropriate written educational materials may be essential to help some patients and families understand what is happening and make appropriate decisions. Not doing so may lead to disastrous outcomes for the patient, the family, and the health care team. Moreover, we must remember that not knowing ICU information is different from low health literacy.

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