Functional Health Illiteracy

Ethical Concerns

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Functional health illiteracy is a silent disability demanding the attention of healthcare professionals because it affects millions of people in the United States. Patients are reluctant to disclose this problem because they fear discrimination and stigmatization. Inadequate health literacy raises ethical questions because it is a barrier to healthcare and results in poor health outcomes. The purposes of this article are to provide an overview of functional health illiteracy, identify related ethical concerns, and discuss selected, relevant nursing implications. Nurses are in a unique position to identify gaps in their patients’ understanding of their health needs and also to serve as advocates, mediators, and translators for their patients who are functionally illiterate.

Health disparities continue to attract considerable attention in healthcare delivery and clinical research. Healthy People 2010 calls for reducing health disparities as one of its goals (U.S. Department of Health and Human Services, 2000). A recent article by the author called for healthcare providers to recognize and become sensitive to differences within their patient populations (Erlen, 2003). Functional health illiteracy is one example of a difference that demands the attention of health professionals. Health illiteracy can result in a lack of patient-provider communication. Unless health professionals recognize health illiteracy as an issue requiring attention, the lack of communication that results between patients and their providers will widen the chasm of health disparities.

This lack of communication has significant implications for patient outcomes. When patients do not understand the treatment regimen and cannot read the directions, their level of adherence will be less than optimal. Patients will not follow the regimen and/or return for follow-up care. Morbidity and mortality rates will increase (Buka, 2002). In addition, the nature of the communication that occurs and the care that patients receive may be based on the providers’ erroneous assumptions about the patients, because the health professionals are not sensitive to the issues that are raised when patients are functionally illiterate regarding their health.

The purposes of this article are to provide an overview of the problem of inadequate functional health literacy and consider ethical concerns that may arise when nurses care for patients who are unable to understand healthcare information. Selected, relevant nursing implications are discussed. Nurses are in a unique position to identify gaps in their patients’ understanding of their health needs and also to serve as advocates, mediators, and translators for patients.

Functional Health Illiteracy

The magnitude of functional illiteracy cannot be ignored. The National Health Literacy Survey conducted approximately 10 years ago showed that among adults in the United States, there were between 40 and 44 million who were functionally illiterate. In addition, an even greater number of persons, 50 million, are marginally literate (Williams et al., 1995). Low literacy levels are more often found among minority populations, those who are indigent, and the elderly (Davis et al., 1991; Gazmararian et al., 1999).

Completed level of education does not serve as an adequate indicator of literacy. Reports show that reading levels of patients cared for at large public facilities may be up to five grade levels lower than the grade level that these individuals complete (Davis, Crouch, Wills, Miller, & Abdelhou, 1990). Researchers have shown that the results on the Mini-mental State Examination have a stronger association with reading level than educational level (Mayeaux et al., 1995). Functional health illiteracy may be the reason pa-
tients do not perform well on an assessment tool; provide an accurate or complete health history, particularly if they are doing it alone; or follow written instructions regarding their treatment regimen. Unless they assess reading level, providers may judge patients to be cognitively impaired. Another important consideration based on the findings in their study of health literacy in persons 65 years of age and older by Gazmararian and colleagues is “that reading ability declines with age” (1999, p. 550).

Functional health illiteracy is a silent and hidden disability and a significant barrier to healthcare. Patients are unable to read and understand health information (Williams et al., 1995). They may be uncooperative; they may be unable to make health related decisions. In addition, the health-related decisions that they do make may negatively affect their health and healthcare costs, as these individuals may engage in none or few preventive health practices, seek more care in emergency rooms, and require more frequent and lengthier hospitalizations (Blackshear, 2002).

### Ethical Concerns

Social factors, such as functional health illiteracy, are even more important than access to healthcare in relation to the contributions they make to a person’s overall health. Blackshear (2002) stresses that “chronic socioeconomic deprivation can undermine the development of capacities constitutive to moral agency” (p. 456).

Individuals who are functionally illiterate may feel oppressed by those persons who have power; these other people are in control and are making decisions. Persons who are illiterate may feel devalued and experience stigma, prejudice, and discrimination. They may be marginalized by society, thus limiting their ability to access healthcare services (Volbrecht, 2002).

#### Lack of Respect for Autonomy

Functional health illiteracy can threaten respect for one’s autonomy. Being functionally illiterate can decrease a person’s self-worth and self-respect. Individuals are reluctant to admit their inadequacy and may feel ashamed of their inability to read and understand. They may not want to ask too many questions because they fear that their disability will become known.

The contributions they make to society lack the knowledge and understanding to be self-determining. The choices that they make are constrained by what they seemingly understand. Their decision making is impaired because they are functionally health illiterate.

They are vulnerable to the control of others because they do not understand what they are reading or what is being said. Health professionals may make assumptions that because these individuals have completed high school they understand the various options that are available to them. Yet, health literacy and level of education are not necessarily equivalent.

The language used in the documents that they are being asked to read, such as informed consent documents, patient education materials, and prescription or diagnostic test instructions, is at a level beyond their comprehension. Thus, although they may sign a form or nod their head indicating “yes” when the healthcare provider asks if they understand, in fact, they do not. Actually, they have not given informed consent; they have only signed a form.

#### Potential for Harm

Providing ethically appropriate healthcare requires that providers act so that they prevent harm, not harm, and promote good in their patients (Beauchamp & Childress, 1994). Because persons with functional health illiteracy can be classified as belonging to a vulnerable group, they may be in need of special protection to prevent them from harm or injury. The potential harm may exist because of the inadequacies of the patient, a mistrust of healthcare providers, or inappropriate care that is provided by the healthcare team.

Functional health illiteracy needs to be recognized as a problem that can negatively affect patients’ health outcomes. Because of the silent nature of this problem, healthcare providers may not know that their patients do not understand what has been said. The result is that patients may not adhere to treatment protocols, thereby reducing the effectiveness of the prescribed regimen. There is a potential for harm that needs to be recognized so that maximum health benefits are realized.

Some ethicists and healthcare professionals argue that patients have a right to choose whether to follow a planned treatment regimen; however, others argue that healthcare professionals have a duty to protect patients. On balance, the patient’s right to decide can only be exercised within a context of knowledge and understanding (Beauchamp & Childress, 1994). Unless vulnerable patients like those with functional health illiteracy are afforded this protection, they have the potential to put themselves at risk for poor health outcomes.

#### Allocation of Healthcare Resources

The problem of inadequate functional health literacy can limit a person’s access to healthcare resources and increase healthcare costs. Society espouses goals of equal access, quality care, and cost containment in relation to the healthcare needs of its people (Beauchamp & Childress, 1994). Using the ethical principle of justice, ethicists and healthcare providers attempt to achieve a balance in these relevant healthcare areas and also address the issues of the most vulnerable within the society.

Beauchamp and Childress (1994) argue that “persons with functional disabilities lack capacity and need health care to gain a higher level of function and have a fair chance in life” (pp. 342–343). If functional health illiteracy is viewed as a disability for which the person is not responsible, then additional resources may need to be allocated to address this reason for healthcare disparities.

The problem becomes what resources and how much of these resources should be allocated to those who have functional health illiteracy. Finding the appropriate balance is difficult because there are competing interests. The functionally health illiterate are not the only vulnerable group deserving attention; others can also claim the need for some special treatment.

#### Implications for Nurses

Nurses apply ethics in their practice (Volbrecht, 2002). Because of the amount of time they spend with patients,
nurses are able to view the context in which ethical questions arise. In their interactions with patients, nurses have an excellent opportunity to begin to address the problems faced by persons who are functionally health illiterate. The nurse as mediator, advocate, and translator can help patients develop their voice and address their concerns.

Increase Awareness of the Problem
Patient-provider communication is a concern when patients and providers speak different languages. Unlike functional health illiteracy, the issues related to communication are readily apparent. Health professionals will seek an interpreter. However, this same level of awareness of a communication gap is not seen when patients have a low health literacy level because of the hidden nature of this disability.

Therefore, nurses need to help raise the awareness of this problem. Nurses need to engage in a dialogue with other healthcare professionals. Staff can be directed to research articles and to measures that assess level of health literacy. These materials can form the basis of interdisciplinary conferences. Experts can be invited to address the issue.

Develop a Literacy Assessment Protocol
When health professionals have a greater understanding of the magnitude and the implications of functional health illiteracy, they will recognize that there is a need to assess patients’ literacy level. This information will help health professionals develop and choose educational materials and clinical interventions that are appropriate for particular patients (Davis et al., 1998).

Developing a protocol for the healthcare agency is one way to ensure that patients are assessed early in their care. If all patients are assessed, then no one will feel as if they are being singled out and treated differently. However, assessing only whether someone can read or what grade they last completed in school may be insufficient (Davis et al., 1998).

Because there are various instruments that can be used to assess health literacy, agency staff will need to decide what aspects are to be assessed and how much time can be allotted for this assessment. Is the focus on word recognition or comprehension? Examples of tests designed to assess word recognition are the Wide Range Achievement Test (WRAT-3), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Slosson Oral Reading Test-Revised (SORT-R). Examples of tests that assess comprehension are the Test of Functional Health Literacy in Adults (TOFHLA) and the Cloze technique, in which readers have to fill in the omitted word in a sentence. The TOFHLA is also available in Spanish. The length of time for these tests varies from 2 to 22 minutes (Davis et al., 1998).

Develop and Evaluate Health Education Materials
Health education materials are frequently written at a sixth-grade or seventh-grade reading level. In addition, these materials often contain few pictures or diagrams. However, when patients are functionally illiterate, this reading level is too high and many words are beyond their comprehension.

When nurses know that they provide care to many patients who are functionally health illiterate, then educational materials and instructions need to be written clearly and concisely. Nurses must consult with patient health educators when preparing these materials. Rather than use a lot of words, there should be accompanying colorful pictures and diagrams that show the patients what to do. The words need to be carefully selected so that they convey the message simply without being too technical. Patients will respond better to materials that are attractive and that they can understand.

These educational materials must be evaluated by healthcare professionals to ensure that they are accurate and patient health educators to ensure that the reading level is appropriate. In addition, patients who are being asked to use the materials also need to evaluate them. It is also possible to evaluate the effectiveness of the materials by assessing whether patients return for clinic visits, get their prescriptions refilled, and have improved clinical outcomes.

Facilitate Decision Making
When patients are not functionally health literate, nurses need to help them to make their own choices. These patients need protection so that others do not coerce them or bias their decision making. As advocates for their patients, nurses can translate the technical language into language that patients understand. Nurses need to offer explanations that include words and pictures or diagrams. The words need to be carefully selected so that they do not demean patients.

In addition, nurses must review the instructions regarding the treatment regimen or the prescribed medication with their patients. Ascertaining that patients understand by having them repeat the instructions and by helping them to solve real-life problems involving implementing the treatment plan or taking the medication will help patients as they try to adhere to the regimen. Facilitating decision making and assessing understanding demonstrate that nurses respect the autonomy of their patients and help to build a relationship that is based on trust.

REFERENCES


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**Calendar**

**NAON Educational Activities**


**NAON Chapter Educational Activities**

**April 1–2, 2004.** Springfield, MO. Greater Ozark Chapter. 15th Annual Orthopaedic Nursing Symposium. Contact: Angeline Susan Epperson at 417-767-4478 or paulepperson647@hotmail.com.

**April 3, 2004.** Southbury, CT. Connecticut Chapter. Hands and Feet—Orthopaed’s Treat. Contact: Simplicia Sanvicente at 203-357-0124, 203-675-9237, or DimpleSanv@aol.com.

**April 13, 2004.** Coralville, IA. Hawkeye Chapter and University of Iowa Department of Nursing. Upper Extremity Conditions: Armed with Knowledge. Contact: Melody Machula at 319-848-3043 or mmachul@pcofiowa.com.

**April 24, 2004.** Spokane, WA. Inland Northwest Chapter. Orthopaedics: More than Broken Bones. Contact: Brenda Elliff at 208-765-5730 or belliff@my180.net.

**Regional Continuing Education**

**April 16–17, 2004.** Cincinnati, OH. Cincinnati Children’s Hospital Medical Center. Cincinnati Children’s 4th Annual Sports Medicine Symposium. Contact: Becky West at 513-636-6732 or 800-344-2462, Ext 6732.