WHAT WE HAVE HERE IS A FAILURE TO COMMUNICATE

The Ethical Dimension of Health Literacy

As health care itself has become more complex, the inability of patients to understand medical terms and concepts has become more problematic. At the same time, patient involvement in health care decisions has become even more crucial. Both the Joint Commission and the National Committee for Quality Assurance have adopted guidelines aimed at ensuring better communication between patient and provider so that patients can understand their consent forms, care instructions and other medical information.[1]

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Professionals who address health literacy usually place the issue in the context of patient safety, better clinical outcomes or less litigation, because "lack of understanding can lead to medication errors, missed appointments, adverse medical outcomes, and even malpractice lawsuits."[2] I would like to suggest, however, that for those in Catholic health care, health literacy is also — and perhaps even primarily — an ethical issue involving the dignity of the patient and the very integrity of health care itself.

The U.S. Department of Health and Human Services has defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[3] By some accounts, more than a third of American adults lack sufficient health literacy "to effectively undertake and execute needed medical treatments and preventive health care."[4]

To be more specific, according to a recent study, only 12 percent of American adults have attained what researchers have called proficient health literacy. About half of American adults — 53 percent — can be termed intermediate in health literacy, 22 percent have basic health literacy and 14 percent are below basic.[5]

Health care tasks at the below-basic level generally require only that the patient find relatively simple information in short texts or forms. At the basic level, the patient is able to find more complex information in texts and documents that are somewhat longer and may contain longer words.

At the intermediate health literacy level, patients are able to move beyond simply searching documents for information; they are able to interpret or apply the information they find. Finally, those at the proficient level are able to draw rather abstract inferences from multiple pieces of information within complex texts and apply the information they have retrieved to their medical situation.

Patients who are at the basic or below-basic levels — roughly a third of all adult patients — are less likely than others to ask the health care professional any questions, yet 26 percent of those patients could not understand when they were supposed to come in for their next appointment. Almost half of them could not understand the instruction to "take medication on an empty stomach."[6]

Even well-educated patients have reported difficulties understanding information provided by a health care professional because the vocabulary was unfamiliar. Furthermore, a high percentage of

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individuals explain that their primary sources for health care information are magazines, television and family members, friends or co-workers.[7]

It is easy to see why health literacy is an issue in terms of successful patient outcomes and safety. Why, however, should Catholic health care regard it as an ethical issue, as well?

The answer is in the Introduction to Part Three of the *Ethical and Religious Directives for Catholic Health Care Services,* which describes the ideal relation between the patient and the health care provider: "A person in need of health care and the professional health care provider who accepts that person as a patient enter into a relationship that requires, among other things, mutual respect, trust, honesty, and appropriate confidentiality."

It goes on to say that the health care professional must avoid "manipulation, intimidation, or condescension."[8] Going further, the first numbered directive in this section, Directive *23*, emphasizes that "the inherent dignity of the human person must be respected and protected regardless of the nature of the person's health problem or social status."

In contrast to dominant attitudes in medicine and law that strongly emphasize patient autonomy, the *Directives* maintain that neither patient nor health care professional acts independently of the other. Rather, both need to work together, each with her or his own personal responsibility: "The health care professional has the knowledge and experience to pursue the goals of healing, the maintenance of health, and the compassionate care of the dying, taking into account the patient's convictions and spiritual needs, and the moral responsibilities of all concerned. The person in need of health care depends on the skill of the health care provider to assist in preserving life and promoting health of body, mind and spirit. The patient, in turn, has a responsibility to use these physical and mental resources in the service of moral and spiritual goals to the best of his or her ability."[9]

These last words place health literacy in a moral and spiritual context of expanding the ability of the patient to participate more fully in a holistic healing process. The thrust of Part Three of the *Directives*, therefore, describes the co-responsibility of patient and health care provider. A patient's lack of health literacy becomes an obstacle to such co-responsibility. Removing these obstacles becomes the health care professional's ethical responsibility because of both the dignity of the patient and the nature of the professional-patient relationship itself.

Regarding the dignity of the patient, Daniel Sulmasy, OFM, MD, PhD, professor of medicine at the University of Chicago, has suggested: "The persons who are most vulnerable, particularly in a health care system, are those whose dignity already has been called into question by society before they ever enter the office, clinic, or emergency room — homeless persons, those living with HIV, injection drug users, retarded persons, demented persons, undocumented aliens, and others. Anyone whose worth has been ascribed to anything other than being a member of the human community is vulnerable. Those whose attributed dignity has been assaulted are most at risk for believing that their own intrinsic dignity has been vanquished. This risk applies, above all, to the sick, frail and dying."[10]

Persons whose dignity has been called into question by the larger society are precisely the persons with limited health literacy who may be most intimidated by the health care setting.

Persons whose dignity has been called into question by the larger society are precisely the persons with limited health literacy who may be most intimidated by the health care setting. We already have seen that patients who are at the basic or below-basic health literacy level are less likely to ask physicians questions than their counterparts who are at the intermediate or proficient level. They also are more likely to misinterpret the language — or jargon — typically used in health care.

Within the appropriate context, medical terms and wording articulate precise meanings to those in the health care professions. For many patients, however, technical words and usage can create confusion or outright misunderstanding. For example, a patient may not understand that hypertension refers to blood pressure, not emotional stress, or that in health care usage, a lab test result that comes back "negative" is probably good

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news, while "positive" usually is not.

The American Medical Association recently has reported that appropriate communication between health care provider and patient lowers the rate of medical errors.[11] The Catholic health care tradition also acknowledges effective communication as part of the respect due to patients because of their inherent dignity.

What's more, the relationship between the patient and the health care professional necessarily entails a difference in power. The power of the health care professional can be used to enhance the dignity of the patient or contribute to his or her denigration. Even in the best of circumstances, a patient can feel intimidated, no matter what the health care professional does.

Mindful of this, John Abbott Worthley, while professor of public administration at Seton Hall University in South Orange, N.J., stated straightforwardly that in health care, "attitudes and the tone and flavor of official behavior are morally significant."[12]

He goes on to suggest that the health care professional must go beyond doing his or her job professionally. Although one needs to be clinically skilled, one also must become aware whether and how one's words and actions contribute to the patient feeling more vulnerable and intimidated or, on the other hand, respected.

Understanding the culture of the people served by the health care organization, securing language assistance for those who do not speak English well, speaking in ordinary language to all patients, providing easy-to-understand instructions, confirming the patient's understanding — all of these aid health literacy. In doing so, they also show respect for the dignity of the patient and contribute to the healing relationship. This should be a hallmark of Catholic health care.

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NOTES

1. Barry D. Weiss, *Health Literacy and Patient Safety: Help Patients Understand, Manual for Clinicians*, 2nd ed. (Chicago: American Medical Association Foundation, 2007), 15.
2. Weiss, 6.
3. See, for example, Mark Kutner, et al., *The Health Literacy of America's Adults* (Washington, D.C.: National Center for Education Statistics, 2006), iii. Kutner, in turn, is quoting from the 2000 U. S. Department of Health and Human Services document, *Healthy People 2010: Understanding and Improving Health* and from the 2004 Institute of Medicine document, *Health Literacy: A Prescription to End Confusion*.
4. Weiss, 7.
5. Kutner, 10.
6. Weiss, 12.
7. Kutner, v.
8. United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, D.C.: USCCB Publishing, 2009), Introduction to Part Three.
9. *Directives*, Introduction to Part Three.
10. Daniel P. Sulmasy, *The Rebirth of the Clinic: An Introduction to Spirituality in Health Care* (Washington, D.C.: Georgetown University Press, 2006), 34.
11. *JAMA*, "Multifaceted Program to Improve Patient Continuity of Care in Hospitals Associated with Reduction in Medical Errors," news release, Dec. 3, 2013.
12. John Abbott Worthley, *The Ethics of the Ordinary in Healthcare* (Chicago: Health Administration Press, 1997), 69.

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