Health Literacy, Communication, and Treatment Decision-Making in Older Cancer Patients

April 13, 2009
By Sunil Amalraj, MD [1], Chelsea Starkweather, MPH [2], and Arash Naeim, MD, PhD [3]

The authors review the current trends in health literacy, patient-physician communication, and the medical treatment decision process, focusing attention on the older cancer patient population.

Literature from the past 2 decades widely acknowledges both inadequate health literacy and poor physician-patient communication as major health-care challenges. Deficient health literacy contributes to poor treatment compliance, uncontrolled chronic disease, and high health-care costs.[1,2] Similarly, quality of physician-patient communication correlates strongly with patient satisfaction and positive health outcomes.[3] Patient health literacy, through its influence on physician-patient communication, has profound impact on the effectiveness and quality of medical treatment decisions, especially in the older cancer patient.[4]

Several major health-care policy organizations in the United States have made addressing these issues a high priority. For example, a 2004 report by the Agency for Healthcare Research and Quality found “confidence in the conclusion that low reading skills and poor health are clearly related.”[5] Furthermore, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has added health-care benchmarks for hospitals to achieve and improve health literacy as one of the Department of Health and Human Services’ Healthy People 2010 goals.[6] Correspondingly, the Institute of Medicine of the National Academy of Sciences recently added health literacy to its list of areas for quality improvement.[1]

In regard to physician-patient communication, JCAHO annually releases National Patient Safety Goals that include recommendations for improving patient communication and autonomy in treatment decisions.[7] Moreover, the Liaison Committee on Medical Education (LCME) and the Accreditation Council for Graduate Medical Education (ACGME) recognize interpersonal and communication skills as a core competency for medical trainees in medical education.[8] However, despite the significant amount of attention these topics receive in relation to the general population, they remain relatively unstudied in subpopulations of patients that may in fact have the poorest health literacy and be subject to the least effective communication. One such subpopulation is comprised of elderly cancer patients.[9] These individuals face increasingly complex cancer management options and may be hindered by issues such as impaired memory, language deficits, and intergenerational and cultural barriers.[10] As such, we review the current trends in health literacy, patient-physician communication, and the medical treatment decision process, focusing attention on the older cancer patient population.

Health Literacy

Definition of Health Literacy

The American Medical Association defined health literacy in 1999 as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.”[11] A patient’s health literacy level, which includes such skills as the ability to comprehend prescription bottle labels, follow written and oral health instructions, and understand physician dialogue, may be significantly lower than their general literacy level.[12] Health literacy level in today’s complicated medical environment can be conceptualized 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.[13]
Epidemiology of Health Literacy

Most health-care material is written at a 10th grade reading level or higher and most adults read between the 8th and 9th grade levels.[14] The National Adult Health Literacy Survey (NALS) published in 1993 reported that almost 50% of the US population was either functionally illiterate or possessed marginal literacy skills. Almost 25% of adults read at the lowest level, approximately 5th grade or lower.[14] The 2003 National Assessment of Adult Literacy (NAAL) conducted by the US Department of Education found no significant improvement in the percentage of adults with below basic or basic literacy ability.[15]

Furthermore, these health literacy statistics are subject to disparities based on sociodemographic characteristics such as race, income, education, language, and age. Specifically, black race, low income, low rate of high school completion, Spanish language, and advancing age are all associated with lower levels of literacy.[16,17] The problem of inadequate health literacy is especially significant in older patients. The majority of patients over 60 years of age perform at the lowest levels of literacy, and 80% have poor document literacy, limiting their ability to complete basic health forms employed by many physicians.[9]

Impact of Inadequate Health Literacy

The negative effects of low health literacy can be found on many levels when a patient attempts to access and utilize the health-care system. Literacy deficits can inhibit a patient’s ability to attend appointments, follow prescription directions, and make informed decisions about their treatment plan. The largest study of health literacy conducted to date in the United States found that 30% of patients at two public hospitals could not read or comprehend basic health-related materials. In addition, 42% failed to understand directions for taking medications, 60% could not comprehend a routine consent form, and 26% did not understand the information written on an appointment slip.[2]

Patients with inadequate health literacy have difficulty controlling chronic illness and are more likely to be hospitalized, resulting in an additional $69 billion in health-care costs annually.[1,18] These patients are also less likely to participate in disease prevention programs. Female patients with poor literacy skills have been found to have difficulty understanding commonly recommended cancer screening tests such as Pap smears and mammograms.[19,20] The effect of health literacy on patient morbidity and mortality, especially in the elderly, has become clearer over the past decade.[2] A 1997 prospective cohort study of 3,260 Medicare managed-care enrollees in four US metropolitan areas found that inadequate health literacy, as measured by reading fluency, independently predicted all-cause mortality and cardiovascular death among community-dwelling elderly persons.[21]

Inadequate Health Literacy and Cancer Patients

It is common for oncologists and other health-care providers to use information about rates,
percentages, and proportions when discussing treatment and prognosis. An important component of health literacy in the context of cancer treatment is the patient’s ability to understand these basic probability and numeric concepts. Health numeracy can be defined as the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numeric, quantitative, graphic, biostatistical, and probabilistic health information needed to make effective health decisions.[22] Recent studies have found inadequate numeracy skills in the general patient population, and especially in older adults.[9] Although there is a correlation between prose or print literacy and numeracy, many patients have adequate literacy but poor quantitative skills. A cross-sectional study of 200 primary care patients tested numeracy and comprehension of basic food labels. While 75% of patients reported at least a high school education and 77% had 9th grade literacy skills, only 37% had 9th grade math skills. Only 37% of patients could calculate the number of carbohydrates consumed from a 20-oz bottle of soda that contained 2.5 servings.[23] Decreased numeracy competency in cancer patients may have an impact on their ability to accurately assess their own health risks. Studies have shown that cancer patients regularly overestimate their survival rates. For instance, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)—a prospective cohort study of outcomes and decision-making in hospitalized patients with serious illnesses including late stage colon and lung cancer—found that 82% of patients’ survival estimates were more optimistic than physician’s estimates.[24,25] These differences in survival estimates may be correlated with lower health numeracy given that numeracy has been shown to already affect patient comprehension of colorectal cancer risk.[22] In a study of 254 women aged 40 to 85 years, researchers analyzed lifetime and 5-year breast cancer risk perceptions and found subjects had a mean estimation error for lifetime and 5-year risk of 29.5% and 24.8%, respectively. [26] These estimation errors were significantly correlated with lower numeracy rates. The prevalence of deficient numeracy may have a significant impact on quality-of-life instruments that are often used in medical oncology to analyze alternative treatments that have equivalent survival rates. A study of newly diagnosed head and neck cancer patients showed that 50% had poor numeracy ability. Furthermore, the patient’s lack of facility with numeric expressions impaired their ability to provide meaningful data on quality-of-life assessment performed with utility instruments.[27]

**Inadequate Health Literacy and Older Cancer Patients**

More than 60% of new cancers and 70% of cancer deaths occur in people over the age of 65 years.[28] Older adults diagnosed with cancer are especially vulnerable to the effects of poor health literacy and are at the greatest risk for poor communication with health professionals. Rapidly expanding treatment options and overall complexity of cancer management require higher involvement of patients in decision-making.[10]

A limited number of studies have focused on the prevalence and impact of health literacy in geriatric cancer patients. A survey of Medicare enrollees between June and December 2007 demonstrated that 34% of English-speaking and 50% of Spanish-speaking respondents had inadequate or marginal health literacy. Reading ability declined dramatically with age, even after adjusting for years of school and cognitive impairment.[29] One study in newly diagnosed prostate cancer patients with a mean age of 67 demonstrated that low health literacy limited patient understanding of complex information regarding treatment and quality-of-life issues.[30]

**Physician-Patient Communication**

Physician-patient communication is a process by which information is exchanged between a physician and patient through a common system of symbols, signs, and behaviors.[31] Communication is a core clinical skill in the practice of medical oncology, and health literacy has a central role in cancer patients’ ability to discuss their disease and prognosis with their oncologist in a meaningful way. The average clinical career of an oncologist is approximately 40 years and can involve up to 200,000 consultations with patients and their families. As with the general population, effective communication has many positive effects on cancer patients’ adjustment to the disease and its treatment, whereas poor communication has negative consequences for both health-care professionals and patients.[32,33]

Effective communication between health-care professionals and patients is essential for the delivery of high-quality health care. Communication issues are often a critical factor in litigation.[34] Research has suggested that effective communication during medical encounters positively influences patient recovery, pain control, adherence to treatment, satisfaction, and psychological
functioning.[3,35] Due to the threat of mortality from the diagnosis of cancer, uncertainty of therapy efficacy, and the physical and emotional stress of undergoing chemotherapy, patients must obtain a high level of complex information during communications with their treating physician.[36,37] Older adults diagnosed with cancer are the population group considered to be at highest risk for poor communication with health professionals. The older patient is less likely to be assertive and ask in-depth questions. Overall physician responsiveness (ie, the quality of questions, informing, and support) is better with younger patients than with older patients, and there is less concordance on the major goals and topics of the visit between physicians and older patients than between physicians and younger patients.[38,39]

Physician-Patient Communication and Oral Literacy Demand The underpinning of effective verbal communication in the medical encounter is the interaction between a patient’s health literacy level and the quality of dialogue between patient and physician. “Oral literacy demand” can be defined as the aspects of dialogue that challenge patients with low literacy skills.[40] During conversations, the general language complexity increases with the greater number of sentences in the passive voice and faster dialogue pacing, both of which have negative effects on comprehension.[40] The use of technical terminology is an important component of oral literacy demand. Research done on adult literacy of genetic information presented during genetic counseling sessions suggests that literacy demand was proportional to the use of technical terms.[41] A doctor’s choice of vocabulary can affect patient satisfaction immediately after a general practice consultation, and if the doctor uses the same vocabulary as the patient, patient outcomes improve.[42] In addition, studies have found increased “dialogue density”—or the duration of uninterrupted speech by a physician—correlates with greater oral literacy demand.[43] A review 152 prenatal and cancer pretest genetic counseling sessions with simulated clients found that the higher use of technical terms, and the more dense and less interactive the dialogue, the less satisfied the simulated clients were and the lower their ratings were of counselors’ nonverbal effectiveness.

In addition, patients with low health literacy are less likely to ask their physician to slow down the dialogue and repeat information when their understanding is compromised.[44] Interventions to modify health-care provider use of technical terms, general language complexity, and structural characteristics of dialogue can enhance overall communication by decreasing patient oral literacy demand.[40]

Communication Barriers in the Elderly

The literature suggests that evaluating such factors as memory decline and sensory deficits are essential in geriatric patient medical visits. These common age-related communication barriers are often overlooked in the oncology consultation and frequently compromise the quality of communications. There is a broad range of cognitive loss among individuals with dementia, and unless the physician is trained to uncover this problem, it can be missed in patients with mild or even moderate loss.[45] For example, the 1999–2001 National Health Interview Surveys (NHIS) indicate that 2.3 million (7.1%) community dwelling people aged 65 and over are limited by memory impairment or confusion, while 800,000 (2.4%) are limited by senility and dementia.[46] In addition to cognition, hearing and vision are important components of communication. Presbycusis, or decreased hearing of higher frequency sounds, is one of the most common and significant sensory changes that affect elderly people. The incidence of sensorineural hearing loss increases each decade so that by the 7th and 8th decades, 35% to 50% of older adults have hearing impairment.[47] Vision loss also has a significant impact on physician-patient interaction because visual cues are vital in interaction. After age 65 there is a decrease in visual acuity, contrast sensitivity, glare intolerance, and visual fields. Based on the 1997–2002 NHIS, 15% to 25% of older adults had visual impairment.[47] The combination of both hearing and visual impairment among elders aged 65 to 79 was 7% and increased to 17% for individuals aged 80 and over.[47] Physician visits for elderly patients with these functional impairments may be so difficult to coordinate that they result in frequently missed appointments. When these frail older patients finally do see the physician, the visits may be emotionally and physically stressful for them, limiting effective communication.[10,39]

Decision-Making

Low levels of health literacy present challenges to any decision-making paradigm,[48,49] especially in the case of complex cancer treatment decisions in the elderly. Complexity in the cancer treatment decision process originates from the fact that selection of therapy is unique to every patient. Typically, several treatment options are possible and the oncologist and patient must together carefully weigh the risk of toxicity against potential benefit. Patient preferences, quality of life, and social responsibilities must be considered along with the stage of disease, biologic characteristics of
the tumor, and comorbid illnesses.

Cancer Treatment Decisions and Self-Efficacy One important factor in decision-making is "self-efficacy," or confidence in one’s ability to understand and communicate with physicians. Patients with high self-efficacy have been found to have fewer episodes of depression and develop more realistic goals. An important aspect of self-efficacy is the sense of control and involvement in the treatment, which has been associated with several desirable outcomes including greater patient satisfaction, increased adherence to treatment, and positive treatment outcomes in elderly patients. Evidence suggests that cancer patients who report greater self-efficacy are better adjusted and experience greater quality of life than those with low self-efficacy.[50]

Older patients are often less assertive in communicating with physicians, less likely to ask questions, and less inclined to take a controlling role in their health-care decision-making.[51] Self-efficacy is a predictor of how the patient perceives and reacts to the encounter with the physician.[4] Studies in older breast cancer patients have shown that patients with higher self-efficacy are more likely to report that discussions with their physicians are helpful.[52] Caregivers/Companions and Treatment Decisions in Older Cancer Patients The effect of family caregivers and companions on cancer treatment decisions is a frequently overlooked, yet significant influence. An estimated 20% to 50% of geriatric patients are accompanied by a family caregiver or companion during their routine medical visits.[53] Most cancer patients share their diagnosis and current condition with a family member or companion. These members of the patient’s “social support network” are often highly motivated to help the patient manage information related to their cancer treatment.[54] They play key roles in interpretations of medical diagnosis, offering explanations, and encouraging patients to comply with their treatment plan. Their level of health literacy and actions during the medical visit are critical to defining these roles. Patients with lower health literacy are likely to be more influenced by a caregiver or companion.[55] Specifically directed physician interactions with these individuals, including assessing their level of health literacy and providing them with appropriate written cancer information during the oncology visit, are important opportunities to optimize communication and medical decision-making.[56] The consequences of companion behavior on patient autonomy and its impact on the decision-making process during the medical visit are important areas of investigation. Several studies have found definite benefits when a family member is present, such as an increase in the amount of medical information provided.[57] Other researchers have determined a negative, intrusive effect of a third party on patient autonomy during a medical visit.[58] A study of 93 patients and companions during geriatric primary care visits found more autonomy-enhancing behaviors (facilitating patient understanding, patient involvement, and doctor understanding) than autonomy-detracting behaviors (controlling the patient and building alliances with the physician). They also found that while nonspousal companions are not as active in decision-making, they are more likely to facilitate patient involvement in the visit than spouses.[53]

**Degree of Shared Treatment Decision-Making in Older Cancer Patients**

The “shared decision model” has gained consensus as the preferred method of making treatment decisions, especially in the situation where many different therapeutic strategies are equivalent. Patient autonomy is prioritized and the physician’s obligation is to provide factual information and execute the patient’s selected intervention.[59,60] A systematic review of studies has shown variability in a older patient’s desire to actively participate in their cancer treatment.[61,62] One study looking specifically at an older individual’s participation in medication-related decision-making identified perceived lack of knowledge, low self-efficacy, and fear as the major impediments to shared decision-making.[63] Moreover, a very recent study demonstrated that statistical illiteracy (understanding the meaning of numbers) impeded both risk communication and shared decision-making, and that interventions directed at changing the way information is presented could be helpful.[64]

These findings suggest that the elderly patient may view their involvement in treatment decisions differently than younger patients who are more homogeneous in their preference of the shared decision-making model. A study of hospitalized patients with advanced cancer and a palliative treatment goal demonstrated that younger age and higher Karnofsky index were significantly associated with active involvement in making treatment decisions.[65] Furthermore, research in patients 70 years and older with a recent diagnosis of metastatic colorectal cancer found relatively few (44%) wanted information about expected survival when they made a treatment decision, and 52% preferred a passive role in the treatment decision-making process.[66] For older patients with advanced cancer, preferences for prognostic information and for an active
role in treatment decision-making are not easily predicted. Many factors including lower health literacy, socialized belief in the “traditional patient” role, and age bias among physicians who view older patients as passive participants can contribute to older patients assuming this passive role. Also, there may be a natural developmental tendency for older patients to want less responsibility for medical decisions and to rely on the expertise of others.[50] Explicit communication about decision-making preferences and the desire for specific facts such as prognostic information will help the oncologist distinguish which patients would benefit most from the shared decision-making model.[60, 67]

**Assessment of Health Literacy and Communication**

In the Institute of Medicine report, Health Literacy: A Prescription to End Confusion, health literacy is divided into health-related oral literacy and health-related print literacy.[1] Conceptualizing general health literacy in this way is useful in trying to understand the most efficient methods to identify deficiencies and formulate interventions. However the practicality of analyzing them separately is problematic. Both of these domains are tightly interwoven and each dependent on an individual’s overall cognitive ability to process health information and build new knowledge. Comprehension of spoken health-related information is critically important to functioning in the health-care environment; however, there is currently no established standardized instrument for its discrete evaluation.[68] Further research is needed to determine whether the ability to understand medical spoken communication independently predicts patient knowledge, behavior, and health outcomes.

**Health Literacy Instruments**

Several health literacy tools based on reading comprehension are available. The most commonly used are the Rapid Estimate of Adult Literacy in Medicine (REALM), Wide Range Achievement Test-Revised (WRAT-R), and the Test of Functional Health Literacy in Adults (TOFHLA), as well as its recently developed short form (S-TOFHLA). The REALM and the WRAT-R are word recognition tests validated as instruments of reading ability and are highly correlated with other traditional reading assessments such as the Adult Basic Learning Examination (ABLE).[16] The TOFHLA measures written health literacy and consists of a reading comprehension section with reading passages in which every fifth to seventh word is deleted and a numeracy section that assesses an individual’s ability to read and understand numeric information used on actual hospital documents and labeled prescription bottles.[69]

**Communication Analysis**

The Roter Interaction Analysis System (RIAS) is the most widely used measure for assessing provider-patient communication during routine face-to-face consultations. The RIAS, which describes and categorizes communication behaviors from audio or videotape, is used to quantify communication events, that can then be correlated with patient, provider, and system characteristics and health outcomes.[70]

In the RIAS, the variables describing medical encounter communication are grouped into discrete categories of patient and physician behaviors: instrumental behaviors (information giving/seeking), affective behaviors (positive/negative talk), partnership building, and social conversation.[71,72] Not only is verbal literacy burden taken into account, but the tonal qualities of the conversation are assessed. These tonal qualities give the interaction an emotional context and an affective impression for both the patient and the physician, coding for anger, anxiety, dominance, friendliness, and interest. The RIAS is able to give as complete of an assessment as possible of provider-patient communication.

**Conclusions**

Older cancer patients are especially vulnerable to poor health literacy and suboptimal communication. There is a need for additional research looking at how health literacy, patient-physician communication, and the presence of companions interact to affect outcomes such as patient self-efficacy, risk communication, and shared decision-making. The conceptual model outlined in Figure 1 provides a broad framework with which to organize future research and locates promising areas for intervention. The issues are relevant not only to cancer patients making routine treatment decisions, but to those who are undergoing procedures or participating in clinical trials where informed consent of the older cancer patient is required.

Although cancer represents one of the most complicated areas in medical decision-making, the issues and framework discussed in this review are applicable to a wide variety of other medical situations. As the baby boomers grow into the next generation of older individuals, the need for effective and efficient means of communicating complex information will be critical.
Financial Disclosure: The authors have no significant financial interest or other relationship with the manufacturers of any products or providers of any service mentioned in this article.

9. Literacy of Older Adults in America Results From the National Adult Literacy Survey. Washington, DC; National Center for Education Statistics/US Department of Education; 1996.
2005.


Links: