AN OVERVIEW OF MEDICAL AND PUBLIC HEALTH LITERATURE ADDRESSING LITERACY ISSUES: AN ANNOTATED BIBLIOGRAPHY

by

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EXECUTIVE SUMMARY

The numerous explorations of the links between literacy and health, and of the importance of literacy to health, are of interest to practitioners and researchers in adult education and in health education. Researchers in adult education are interested in the impact of health on learning and retention. In addition, recent studies indicate that teachers value health as a subject of study that draws learners' interest and as a vehicle for teaching basic skills. Research findings are offering insight into literacy skills needed for navigating health care environments and for managing health problems. Such findings may enrich curriculum development efforts for adult learners. At the same time, research findings may lead to modifications in patient protocols, educational materials, and health related forms.

Increasingly, limited literacy is being cited as an inhibiting factor in accessing health information such as patient education materials, informed consent, discharge documents, and directions for self-care or medication. This report presents results from a computer assisted search of the medical and public health literature addressing literacy issues in health care and in health promotion education published between 1990 and 1999. Following a brief introduction on the subject of health and literacy, the literature search methods are described and the choice of citation categories is discussed. Finally, an annotated bibliography is presented for articles meeting the inclusion requirements.

This bibliography includes 241 citations which are arranged in the following categorical groups:

- Links between literacy and health;
- Literacy levels of patients, clients, or program participants;
- Match between reading ability and written materials;
- Functional literacy and institutional settings;
- Materials assessments:
- Research tools for assessing health literacy;
- Program descriptions; and
- Guidelines for practice.

AN OVERVIEW OF MEDICAL AND PUBLIC HEALTH LITERATURE ADDRESSING LITERACY ISSUES: AN ANNOTATED BIBLIOGRAPHY

INTRODUCTION

The findings of the 1992 *National Adult Literacy Survey* (NALS) indicate that those adults performing in the lowest two literacy levels were more likely than those performing at the higher levels to be poor and to report having a physical, mental, or other health condition that kept them from full participation in work, home, or school activities. Older adults were more likely than middleaged or younger adults to demonstrate limited literacy skills. In addition, members of minority populations, and most especially those for whom English is a second language, were more likely to perform in the lowest two literacy levels. Black, American Indian/Alaska Native, Hispanic, and Asian/Pacific Islander adults were more likely than White adults to have limited literacy skills. Overall, however, NALS findings indicate that almost half of adults in the United States have limited or extremely limited reading and quantitative skills.

Education, according to *Healthy People 2000*, is a key determinant of access to health services and to health promotion activities. People living in poverty are often exposed to greater environmental and occupational exposures and face educational, housing, and employment opportunities that are often limited or substandard. In addition, those living in poverty have limited access to health promotion and disease prevention programs, as well as to curative services. Consequently, many adults in our society face triple jeopardy because of minority status, poverty, and communication barriers.

Those with limited reading and quantitative skills cannot fully participate in a society such as ours where, increasingly, adults are expected to read and understand a wide variety of written materials in everyday settings. Limited literacy skills inhibit the ability to access information, including much of the currently available health promotion and patient education materials, patient rights and informed consent documents, materials describing insurance or health care plan options, as well as directions for self care or medication. Commonly held expectations about reading ability and social approbation that often follow discovery of literacy limitations may serve to inhibit disclosure, silence patients, and further discourage efforts to seek information or request assistance. An understanding of patient perceptions and needs is vital for informing and shaping communication protocols.

A search of the current literature related to literacy in the medical and public health fields indicates a growing recognition of vital communication barriers within the health field.

Search Methods

The Med-Line database was searched for articles addressing literacy issues in health care and in health promotion/education between 1990 and 1999. The search was conducted using text words in titles and abstracts. In order to identify literature that addresses a broad range of literacy issues, the following text words were used: **literacy, illiteracy, illiterate, readability, educational status,** and **communication barriers.** The final two terms, *educational status* and *communication barriers*, were included in order to find those articles related to, but not directly mentioning, literacy. The search was then limited to those articles in the English language and to those published since 1990.

The yield was then restricted to a set including only articles concerned with patients, health education, the specific materials used with patients, and those materials used for general health education. Another set of text words was used to generate a cross-listing of articles. This set included: **patient**, **health education**, **materials**, **health services**, and **health**. The search was again limited to those articles in the English language and those published since 1990. The resulting literacy set was then crossed with the patient set.

The abstracts of these articles were then read in order to eliminate unrelated topics, such as provider education/literacy and educational status as a control variable. International studies conducted in developing countries and non-English-speaking countries were also eliminated; studies from Canada, Britain, and Australia were included. The final yield was 241 articles. These articles were collected and reviewed. The main focus of the articles and, when appropriate, key findings are briefly noted. A small number of articles were not available. These articles are listed without annotation.

This literature search extends and augments foundation work prepared by Sujata Bose, Sc.M., and Susan Koch-Weser Sc.M., whose contributions are acknowledged. Dr. Rudd and Ms. Bose prepared the *Annotated Bibliography on Health and Literacy* for the World Education and National Institute for Literacy June 1995 Conference, *Ideas in Action: A Conference on Health and Literacy*, Medford, Massachusetts.

Citation Categories

The 241 citations were reviewed and grouped into the following broad categories. Each citation was limited to one category.

- 1. Links Between Literacy and Health (12)
 - 1A. Studies (20)
 - 1B. Editorials and Letters (23)
- 2. Literacy Levels of Patients, Clients, or Program Participants (21)
- 3. Match Between Reading Ability and Written Materials (22)
- 4. Functional Literacy and Institutional Settings (9)
 - 4A. Consent Forms (14)
 - 4B. Emergency Department Discharge Information (7)
- **5.** Materials Assessment (33)
- **6.** Research Tools for Assessing Health Literacy (9)
 - 6A. Health Instruments: Readability Considered (11)
 - 6B. Health Instruments: Validity Issues (5)
- 7. Program Descriptions
 - 7A. Literacy Noted as Key Issue (17)
 - 7B. Literacy Noted (7)
- 8. Guidelines for Practice
 - 8A. Materials/Readability (16)
 - 8B. Patient/Health Education (15)

OVERVIEW OF CITATION CATEGORIES

1. Links Between Literacy and Health (12)

Healthy People 2000, a description of the national health promotion and disease prevention objectives set forth by the Department of Health and Human Services (1990), is cited as a key publication in the field of public health. The National Adult Literacy Survey (Kirsch et al., 1993), conducted by the Department of Education, is cited as a key publication in the field of adult education.

Rudd et al. provides a review of health and literacy in the medical and public health literature of the last three decades in an extensive chapter for an annual review. An ad hoc committee for the AMA highlights literacy studies and health outcomes and issues of low literacy in health care settings. Other review articles include: a discussion of communication with patients who have limited literacy (Anon, 1998); a round table dialogue of the challenge of health literacy (Pfizer, 1998); a discussion of patient education for low literacy populations (Mayeaux et al., 1996); an overview of maternal and child health materials (National Center for Education in MCH, 1994); a publication of selected literacy and health annotations from the CDC (1991); and an overview of the general relationship between literacy and health in the United States (Weiss et al., 1991).

1A. Studies (20)

Articles in this citation category describe specific health outcomes that may be directly linked to limited literacy skills. Baker et al. (1998) reports that those patients with inadequate literacy skills seeking emergency treatment for non-life threatening conditions were twice as likely to be hospitalized as were those patients with adequate skills and (1997) that patients with inadequate functional health literacy were more likely to report poor health. Bennett et al. (1998) found that men with low literacy skills were more likely than men with higher skills to present with more advanced stages of prostate cancer at screening. Baker et al. (1998) reports that patients with inadequate functional health literacy were more likely to report poor health than were patients with adequate reading skills. Davis et al. (1996) concludes that limited literacy skills made a considerable contribution to the under-utilization of mammograms in low-income, low-literacy women. Weiss et al. (1992) finds a significant relationship between reading level and physical health among persons with extremely low reading levels.

Other studies include: a study of the relationship between literacy and chronic disease management (Williams et al., 1998); an examination of alternative

communication methods for patients with limited literacy (Lasater & Mehler, 1998); a study of the relationship between functional health literacy and contraceptive knowledge (Parker et al., 1996); and a study of the relationship between literacy and the cost of providing care to Medicaid recipients (Weiss et al., 1994).

1B. Editorials and Letters (23)

A number of editorials focus on the importance of literacy in health settings. Issues include: access barriers (Roter et al., 1998); health outcomes (Baker, 1999); language (Gordon, 1996); readability of materials (Johnson et al., 1997); reaching illiterate populations (a concern in cancer care and prevention and mental health care [Grace & Christensen, 1998]); the need for plain language in the medical setting (Weiss & Coyne, 1997); and the concept of a "hard to reach" audience (Freimuth & Mettger, 1990).

Letters to the editor address: health and literacy (Elson, 1993), inadequate functional health literacy in patient populations (Gottesman & Kelly, 1996), and readability.

2. Literacy Levels of Patients, Clients, or Program Participants (21)

Citations in this category focus on literacy levels of a variety of patients, clients, or program participants. Gazmararian et al. (1999) examines literacy skills of Medicare enrollees and found that more than one third had inadequate or marginal health literacy. Christensen et al (1999) discusses the prevalence of low literacy in a psychiatric population and Fisher (1999) discusses implications of low literacy for patient education. Literacy levels are assessed for nutrition education program participants (Anderson, 1994; Hartman et al., 1994; TenHave et al., 1997); minority patients (Francis, 1991; Nurss et al., 1997); parents at child clinics (Fredrickson et al., 1995); the elderly (Jackson et al., 1994; Murphy et al., 1993; Weiss et al., 1995); and cancer patients (Jubelirer et al., 1994). Two articles suggest that limited literacy skills function as an important barrier to the health care system and that educational level may not always be an accurate predictor of reading level (Wilson, 1995; Wilson & McLemore, 1997). One article explores the perspectives of educators and health providers for nutrition education (Macario et al., 1998).

3. Match Between Reading Ability and Written Materials (22)

The articles in this citation category compare the readability of patient education materials with the reading levels of the audience for which they were intended. In nearly every case, large discrepancies were found between the two. One review article cited in this category focuses on readability of patient education materials and implications for clinical practice (Albright et al., 1996); another on the gap between comprehension and readability of materials (Davis et al., 1990). Other articles address medical topics of concern such as: cancer (Cooley et al., 1995; Foltz & Sullivan, 1996; Guidry et al., 1998; Meade et al., 1994; Michielutte et al., 1992); substance abuse (Davis et al., 1993); pediatric medicine (Davis et al., 1994); and chronic diseases (Hearth-Holmes et al., 1997; Hosey et al., 1990; Overland et al., 1993; Siminerio & Frith, 1993).

4. Functional Literacy and Institutional Settings (9)

Articles in this category focus on literacy skills needed in health care settings and on the literacy demands of the health care sector. In general, these literacy skills include the ability to understand medication instructions, appointment slips, informed consent documents, health education materials, discharge instructions, and health care providers. One study examines how parental literacy level affects ability to follow prescribed therapy for one's child (Moon et al., 1998). Two studies highlight the issue of navigating the health institution and suggest that demands including forms and hospital signage as well as attitudes and assumptions of employees must be considered (Baker et al., 1996; Williams et al., 1995). One study conducted in Mexico (Dexter et al., 1998) suggests that limited literacy affects reading ability as well as listening and speaking abilities and that decontextualized medical language may be difficult for people who are poorly educated. Two studies (Brez & Taylor, 1997; Parikh et al., 1996) address the connections between shame and limited literacy skills and discuss ways in which this connection may influence interaction with the health care system.

4A. Consent Forms (14)

The articles in this category suggest that informed consent documents are too often incomprehensible for a majority of the patient population. The articles focus on informed consent procedures forms for clinical trials (Hopper et al., 1995), university-sponsored research (Goldstein et al., 1996), the Institutional Review Board (Hammerschmidt & Keane, 1992), cancer treatment protocols (Jubelirer, 1991), and consent procedures for pediatric biomedical research (Tarnowski et al., 1990). Several articles in this category offer suggestions for assessing and improving the readability of informed consent documents (Meade & Howser, 1992). Three offer findings of patient satisfaction with standard versus simplified forms (Agre et al., 1997; Davis et al., 1998; Montgomery & Sneyd, 1998).

4B. Emergency Department Discharge Information (7)

The articles in this grouping of citations suggest that emergency department discharge instructions are inappropriately written with the result that patients do not always comprehend their treatment instructions. Articles in this category largely focus on testing patient comprehension of such instructions, at various lengths of time after emergency department discharge. Two articles (Austin et al., 1995; Delp & Jones, 1996) suggest the use of illustrations, including cartoons, to increase patient comprehension, especially among low literacy populations.

5. Materials Assessments (33)

Articles in this category offer assessments of the reading level of specific materials and apply the SMOG, Fog, or Flesch readability formulas. Many of the authors assess cancer materials (Butow et al., 1998; Brown et al., 1993; Glazer et al., 1996; Guidry & Fagan, 1997; Meade et al., 1992; Michielutte et al., 1990); others assess contraception instructions (Ledbetter et al., 1990; Swanson et al., 1990), polio pamphlets (Davis et al., 1998), HIV/AIDS educational materials (Wells, 1994), and patient education material available on the Internet (Graber et al., 1999). Assessing patient education and other literature for readability is seen as a crucial step in the development of materials.

6. Research Tools for Assessing Health Literacy (9)

Several key articles in this category address the development and testing of health literacy assessment tools. Specific instruments used to assess health literacy include: the *Rapid Assessment of Literacy Levels in Medicine* [REALM] (Davis et al., 1991; Davis et al., 1993); the *Medical Terminology Achievement Reading Test* [MART] (Hanson-Divers, 1997); the *REALM-S for Spanish-speaking adults* (Nurss et al., 1995); the *Test of Functional Health Literacy in Adults* [TOFHLA] (Parker et al., 1995); and the short *Test of Functional Health Literacy in Adults* [S-TOFHLA] (Baker et al., 1999).

6A. Health Instruments: Readability Considered (11)

Articles in this category focus on instruments developed with literacy as a key concern. These instruments include the *Consumer Assessment of Health Plans Study* (Brown et al., 1999); the *Kidney Disease Questionnaire* (Devins et al., 1990); the *Lung Cancer Symptom Scale* (Hollen et al., 1993); the *Critical Care Family Needs Inventory* (Macey & Bowman, 1991); the *Dental Health*

Assessment Profile (McCormack-Brown et al., 1990); and the Adolescent Health Concerns Inventory (Weiler et al., 1993).

6B. Health Instruments: Validity Issues (5)

Three of the studies in this category call into question the validity of an instrument because of the education or literacy level of the participants with whom it was to be used. One focuses on an instrument to assess health behaviors among African American women (Ahijevych & Berhard, 1994), another on the American Urological Association Symptom Index (MacDiarmid et al., 1998), and the last on a screening tool used to assess brain damage (Reis et al., 1994). One study (Sullivan et al., 1995) challenges the assumption that reliable data cannot be obtained from low-income minority patients by self-administered questionnaires.

7. Program Descriptions

Some of the articles in this category focus on literacy issues, while others make note of literacy as one of several issues of interest.

7A. Literacy Noted as Key Issue (17)

The articles grouped under Program Descriptions focus on projects and programs for populations with limited literacy skills. These articles are concerned with the development of materials for low literate populations and include: an intervention to increase mammography among low-literate, low-income women (Davis et al., 1998); materials for inner-city parents (Berger et al., 1994); a stroke survivor's guide (Best, 1994); nutrition information materials (Hartman et al., 1997; Ruud et al., 1993); and a skin care manual for spinal cord injury patients (Yasenchak & Bridle, 1993). One article specifically addresses the process of developing materials with the target audience (Rudd & Comings, 1994).

Several other articles present literacy or educational level of the intended population as an important consideration for program and materials design. These include: a program for pregnant, hepatitis B-positive women (Corrarino et al., 1999); nutrition education programs for cardiovascular disease prevention (Ammerman et al., 1992; Levin, 1996); efforts to overcome medication non-compliance (Olson et al., 1996); child birth education classes (Jeffers, 1993); and a nursing school program for rural areas (Mason et al., 1995).

7B. Literacy Noted (7)

The programs and projects that mention, but do not focus on, literacy or education level include: a breast and cervical cancer screening project (Curry et

al., 1994); a hypertension control program for minority workers (Fouad et al., 1997); an HIV prevention program for runaway and homeless youth (Podschun, 1993); a program to empower laundry workers (Wands & Yassi, 1992); and a transcultural health education program with the Hmong (Shadick, 1993).

8. Guidelines for Practice

8A. Materials/Readability (16)

The articles grouped under this category offer guidelines for practitioners who wish to develop or select materials for low literate patients. Some of the articles focus on the use of readability formulas; one includes guidelines about the development and evaluation of printed health education materials (Baker, 1991), and another includes a discussion of the education process (Brez & Taylor, 1997). Two identify e-mail and the Internet as emerging sources of health information and address the need to ensure access to these technologies by low literate populations (Eng et al., 1998; Mandl et al., 1998).

8B. Patient/Health Education (15)

These articles outline strategies for patient education for populations which may have limited literacy skills and variously focus on cancer patients (Doak et al., 1998; Anscher & Gold, 1991); patients with ventricular tachycardia (Evanoski, 1990); nutrition education participants (Fain, 1994); the elderly (Hussey, 1991); and safety education for workers (Wallerstein, 1992).

AN ANNOTATED BIBLIOGRAPHY OF THE LITERACY AND HEALTH LITERATURE 1990-1998

1. Links Between Literacy and Health

Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. (1999). Health Literacy: Report of the Council on Scientific Affairs. *JAMA*, 281(6), 552-557.

A committee of health and education experts reports on the prevalence of illiteracy in the U.S., the problems presented by low literacy in health care settings, and implications for the U.S. health care system at large. Findings linking literacy and health outcomes are highlighted, and key issues for future health literacy research are identified.

Communicating with patients who have limited literacy skills (1998). Report of the National Work Group on Literacy and Health [Review]. *Journal of Family Practice*, 46(2), 168-76.

Characterizes the current status of illiteracy in the U.S., describes the relationship between poor literacy and poor health, and offers recommendations on how to deal effectively with patients who have poor reading skills.

Giorgianni, S.J. (Ed.). (1998). Perspectives on health care and biomedical research: Responding to the challenge of health literacy. *The Pfizer Journal*, 2(1). Presents dialogue from a round table discussion among health and literacy professionals. Chapters include: (1) How does literacy affect the delivery of quality health care; (2) Beyond reading: Communicating about health care; (3) Understanding literacy's link to language, class, culture and age; (4) Developing strategies to communicate about health; and (5) Establishing an agenda for the future to improve America's health literacy.

Kirsch, I., Jungeblut, A., Jenkins, L., & Kolstad. A. (1993). *Adult Literacy in America*. Washington, DC: U.S. Department of Education, Office of Educational Research and Improvement.

Describes the 1992 Adult Literacy Survey and offers key findings.

Lee, P.P. (1999). Why literacy matters: Links between reading ability and health. *Archives of Opthamology, 117*(1), 100-103.

Defines health literacy, explains methods of measurement, and illustrates the connections between literacy and health. Recommends steps for health care providers to take in addressing low literacy levels in patients.

Mayeaux, E.J. Jr., Murphy, P.W., Arnold, C., Davis, T.C., Jackson, R.H., & Sentell, T. (1996). Improving patient education for patients with low literacy skills [Review]. *American Family Physician*, 53(1), 205-211.

Suggests communication strategies for physicians wishing to offer instructions on a level understandable to the patient. These strategies are: speak in a simpler language, repeat instructions, demonstrate key points, and avoid too many directives. Also recommends combining easy-to-read written patient instructions with oral instructions and including family members in the patient education process.

National Center for Education in Maternal and Child Health. (1994). *MCH Program Interchange: Focus on Low Literacy*. Washington, DC: Maternal and Child Health Bureau, Health Resources and Service Administration, Public Health Service, U.S. Department of Health and Human Services.

Provides information about selected materials written at low reading levels. Chapters include: Prenatal and Women's Health, Infant Health, Nutrition, Breastfeeding, Oral Health, Injury, Resources and an Evaluation Form.

Parker, R.M., Williams, M.V., Baker, D.W., & Nurss, J.R. (1996). Literacy and contraception: Exploring the link. *Obstetrics & Gynecology*. 88(3 Suppl.), 72S-77S.

Reviews the literature to explore the relationship between literacy skills and contraceptive use. No single study specifically addressed this relationship; however studies by health educators have demonstrated that information for many types of contraceptives is often above patients' reading levels. The available data on the relationship of educational status and unplanned pregnancy are also discussed. The authors conclude that functional health literacy has an influence upon contraceptive knowledge, attitudes, and behaviors.

U.S. Department of Health and Human Services. Public Health Service. (1990). *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* (DHHS Publication No. (PHS) 91-50212).

Delineates national objectives for various sectors of the population and for various health issues.

U.S. Department of Health and Human Services. Public Health Service. (1991). *Literacy and Health in the United States: Selected Annotations*. Atlanta, GA: Centers for Disease Control-Center for Chronic Disease Prevention and Health Promotion.

Contains abstracts of studies, materials, and programs selected to represent the strategies used by health professionals to reach low-literate populations. Categories of citations include: The National Outlook (Literacy Issues in the U.S., Legislation, Research and Readability formulas), Health and Literacy (Health and Literacy and Health Promotion literature), Resources, and an Index.

Weiss, B.D., Hart, G., & Pust, R.E. (1991). The relationship between literacy and health [Review]. *Journal of Health Care for the Poor & Underserved, 1*(4), 351-363.

Discusses the possible factors influencing the relationship between health and literacy in the United States and in developing countries.

Additional note: Book chapter summarizing health and literacy literature.

Rudd, R.E., Moeykens, B.A., & Colton, T.C. (2000). Health and literacy: A review of medical and public health literature. In J. Comings, B. Garner, & C. Smith (Eds.), *The Annual Review of Adult Learning and Literacy: Volume 1* (pp.158-199). San Francisco: Jossey-Bass.

1A. Studies

Baker, D.W., Parker, R.M., & Clark, W.S. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine*, 13(12), 791-798.

Explores the relationship between health literacy and hospital admissions in an attempt to determine the health and economic implications inadequate literacy presents for patients and the health care system. The literacy abilities of 958 patients seeking emergency treatment for non-life threatening conditions were assessed using the TOFHLA. After adjusting for confounding sociodemographic variables, those with inadequate literacy skills were twice as likely to be hospitalized at least once over the two-year follow up period than were those with marginal or adequate literacy. The authors suggest that inadequate literacy represents a significant barrier to understanding medical diagnoses and following treatment regimens, and is thus a risk for increased hospital admission rates.

Baker, D.W., Parker, R.M., Williams, M.V., Clark, W.S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*, 87(6), 1027-1030.

Compares self-reported health of patients with various levels of functional health literacy. Patients presenting to two large, urban hospitals were administered the Test of Functional Health Literacy in Adults. Patients with inadequate functional health literacy were consistently more likely to report poor health than patients with adequate reading skills.

Bennett, C.L., Ferreira, M.R., Davis, T.C., Kaplan, J., Weinberger, M., Kuzel, T., Seday, M.A., & Sartor, O. (1998). Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology*, *16*(9), 3101-3104.

Assesses the relationship between poor literacy skills and advanced stages of prostate cancer among low-income black and white men. Of the 212 men assessed using the REALM, black men were almost twice as likely to present with stage D prostate cancer and significantly more likely to have lower than 6^{th} -grade literacy levels. However, after adjusting for literacy differences, race was not a statistically significant predictor of

advanced-stage prostate cancer. Concludes that low literacy may be a barrier to diagnosis of early-stage prostate cancer.

Creed, P.A. (1999). Predisposing factors and consequences of occupational status for long-term unemployed youth: A longitudinal examination. *Journal of Adolescence*, 22(1), 81-93.

Identifies predisposing factors and psychological consequences of occupational status through a longitudinal study of 169 unemployed young people registering for work in Brisbane, Australia. Subjects with higher literacy levels at the onset were more likely to gain employment, which in turn caused reductions in psychological distress.

Davis, T.C., Arnold, C., Berkel, H.J., Nandy, I., Jackson, R.H., & Glass J. (1996). Knowledge and attitude on screening mammography among low-literate, low income women. *Cancer*, 78(9), 1912-1920.

Assesses literacy level and screening knowledge of women who have not participated in breast cancer screening. Four hundred forty-five women age 40 and over and who had not had a mammogram in the last year were interviewed to determine knowledge of and attitudes toward mammography. Patients' reading abilities were assessed with the REALM. Concludes that limited literacy skills and lack of knowledge about breast cancer screening may contribute considerably to the underutilization of screening for breast cancer in low-income women.

Davis, T.C., Byrd, R.S., Arnold, C.L., Auinger, P., & Bocchini, J.A. (1999). Low literacy and violence among adolescents in a summer sports program. *Journal of Adolescent Health*, *24*, 403-411.

Investigates the relationship between low literacy and health behaviors in adolescents. Three hundred eighty-six adolescents participating in a summer track and field and literacy program serving low-income neighborhoods of Shreveport, Louisiana, were assessed on self-reported violence and reading grade levels. Those with below-grade-level reading abilities were 1.5 times more likely to experience violence as the perpetrator, victim, or both than were students reading at grade level.

Gazmararian, J.A., Parker, R.M., & Baker, D.W. (1999). Reading skills and family planning knowledge and practices in a low-income managed-care population. *Obstetrics & Gynecology*, *93*(2), 239-244.

Examines the relationship between health literacy and family planning knowledge and contraceptive use among low-income women in a Tennessee managed care plan. Among 406 women ages 19-45, approximately 10% of the respondents had low reading skills, as assessed by the TOFHLA and comprehension of a Medicaid form. These women were more likely to desire information about birth control and to have incorrect information about effective methods of contraception and times when pregnancy risk is highest than were women of higher reading ability. Discusses implications for health care providers.

Guralink, J.M., Land, K.C., Blazer, D., Fillenbaum, G.G., & Branch, L.G. (1993). Educational status and active life expectancy among older blacks and whites. *New England Journal of Medicine*, *329*, 110-116.

Studies the relationship between socioeconomic status and disability-free or active life expectancy among 2,219 blacks and 1,838 whites over the age of 65 in North Carolina. Results show that at the age of 65, people with 12 or more years of education had an active life expectancy 2.4 to 3.9 years longer than for people with less education for both sexes and races. Researchers conclude that education has a stronger relationship to total life expectancy and active life expectancy than does race.

Houts, P.S., Bachrach, R., Witmer, J.T., Tringali, C.A., Bucher, J.A., & Localio, R.A. (1998). Using pictographs to enhance recall of spoken medical instructions. *Patient Education and Counseling*, *35*(2), 83-88.

Tests the hypothesis that pictographs improve spoken medical instructions. Among 21 subjects, 85% correctly recalled medical information read to them accompanied by pictographs, while only 14% recalled information read without pictographs. Suggests that viewing illiteracy as a memory problem may thus be useful in designing educational materials targeting this population.

Immink, M.D.C., & Payongayong, E. (1999). Risk analysis of poor health and growth failure of children in the central highlands of Guatemala. *Social Science & Medicine*, 48(8), 997-1009.

Identifies risk factors of poor health and growth failure in under-five and school-age children in the Central Highlands region of Guatemala. Women's literacy status in particular was found to be a significant risk factor for diarrheal disease in under-five children and for growth failure in school-age children. Recommends interventions to improve women's illiteracy, along with other risk factors.

Jacobson, T.A., Thomas, D.M., Morton, F.J., Offutt, G., Shevlin, J.S., & Ray, S. (1999). Use of a low-literacy patient education tool to enhance pneumococcal vaccination rates. *JAMA*, 282(7), 646-650.

Assesses the effect of a one-page low-literacy educational tool on rates of pneumococcal immunization and patient-physician dialogue. Subjects were 433 patients at an inner-city Atlanta hospital with health illiteracy rates of over 80% among elderly patients. Patients who received the educational handout on the pneumonia vaccine were 4 times more likely to have discussed the vaccine with their physicians than were patients who received a low-literacy handout on nutrition, and were 5 times more likely to have received the pneumococcal vaccine. However, as only half of the patients who discussed the vaccine with their doctor in either group received the vaccine, the authors underscore the importance of content in doctor-patient communication.

Kalichman, S.C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*, *14*(5), 267-273.

Tests the significance of health literacy as a predictor of adherence to treatment for HIV/AIDS. Subjects, 184 HIV-positive men and women taking a triple-drug combination of antiretroviral therapies, provided self-reports on their health status, treatment adherence, reasons for non-adherence, and factors influencing adherence, such as social support. Health literacy was assessed using the TOFHLA. Results indicated that persons of low health literacy were more likely to be nonadherent and to miss

treatment due to confusion, experience of side effects, depression and wanting to cleanse their body than were persons of higher literacy.

Kim, S.P., Bennett, C.L., Chan, C., Chmiel, J., Falcone, D., Knight, S.J., Kuzel, T., Davis, T.C., Elstein, A.S., Moran, E., Robertson, C.N., & Smith, J.S. (1999). QOL and outcomes research in prostate cancer patients with low socioeconomic status. *Oncology*, *13*(6), 823-832.

Summarizes an ongoing study on factors influencing quality of life in prostate cancer patients of predominantly lower socioeconomic status, including measures of health literacy. It has been found that black men are almost twice as likely as white men to have stage D prostate cancer, and significantly more likely to have literacy levels below sixth-grade (52.3% vs. 8.7%). However, after adjusting for differences in literacy, race was no longer a significant predictor of stage D prostate cancer.

Lasater, L., & Mehler, P.S. (1998). The illiterate patient: Screening and management. *Hospital Practice*, *33*(4), 163-165, 169-170.

Suggests alternative communication methods that do not rely on patient literacy skills and discusses the importance of screening for illiteracy.

LeVine, R.A., Dexter, E., Velasco, P., LeVine, S., Joshi, A.R., Stuebing, K.W., & Tapia-Uribe, M. (1994). Maternal literacy and health care in three countries: A preliminary report. *Health Transition Review*, 4(2), 186-191.

Describes preliminary data collected from mothers in Mexico, Nepal, and Zambia, which suggests that mothers who attend school longer retain a higher level of literacy and are better able to comprehend spoken and written health information. These preliminary findings support Preston's health transition model that cites maternal literacy as an important factor in the spread of health information.

Terra de Souza, A.C., Cufino, E., Peterson, K.E., Gardner, J., Vasconcelos do Amaral, M.I., & Ascherio, A. (1999). Variations in infant mortality rates among municipalities in the state of Ceará, Northeast Brazil: An ecological analysis. *International Journal of Epidemiology*, 28(2), 267-275.

Offers findings from an ecological analysis of 140 municipalities across the state of Ceará, located within the poorest region of Brazil, conducted to identify potential predictors of infant mortality. Included among the 11 variables was female illiteracy rate, which was found to be one of the strongest determinants of infant mortality. As the average female illiteracy rate for the State of Ceará is 43.4%, the authors suggest that investing in female education could prove one of the most effective means of reducing infant deaths in Ceará.

Weiss, B.D., Hart, G., McGee, D.L., & D'Estelle, S. (1992). Health status of illiterate adults: Relation between literacy and health status among persons with low literacy skills. *J. of the American Board of Family Practice*, *5*(3), 257-264.

Compares physical health of subjects with various literacy skills. The physical health (as measured by the Sickness Impact Profile) of the 193 subjects with extremely low reading levels was poor compared with that of subjects with higher reading levels. The relation between reading level and physical health was statistically significant, as was the

relationship between reading level and psychosocial health, even after adjustment for confounding variables.

Weiss, B.D., Blanchard, J.S., McGee, D.L., Hart, G., Warren, B., Burgoon, M., & Smith, K.J. (1994). Illiteracy among Medicaid recipients and its relationship to health care costs. *Journal of Health Care for the Poor and Underserved*, *5*(2), 99-111.

Assesses the relationship between reading level of patients and health care costs. The mean reading level of the 402 randomly selected Medicaid patients in the study was grade 5.6 and the mean annual health care costs were \$4,574 per person. No significant relationship was found between literacy and health care costs.

Williams, M.V., Baker, D.W., Honig, E.G., Lee, T.M., & Nowlan, A. (1998). Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*, 114, 1008-1015.

Measures literacy levels (REALM), asthma knowledge, and metered-dose inhaler techniques of 273 patients presenting to the emergency department for asthma exacerbation and 210 patients presenting to an asthma clinic for routine care. Patient reading level was found to be the strongest indicator of asthma knowledge score and poor MDI technique was found in 89% of patients reading at or below the thrid-grade level, compared with 48% of patients reading at the high school level.

Williams, M.V., Baker, D.W., Parker, R.M., & Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine*, *158*(2), 166-172.

Uses cross-sectional survey data to examine the relationship between functional health literacy and knowledge of chronic disease and treatment in diabetes and hypertension patients. Found that inadequate functional health literacy is potentially a major barrier to educating patients with chronic diseases.

1B. Editorials and Letters

[Editorials are annotated; letters are not]

Anon. (1997). Literacy and health. AARN Newsletter, 53(5), 15.

Baker, D.W. (1999). Reading between the lines: Deciphering the connections between literacy and health [editorial]. *Journal of General Internal Medicine*, 14(5), 315-317.

Describes health effects and consequences of low literacy and ways health care settings may address this problem.

Campbell, K. (1999). Evidence based patient information: Differing standards of literacy are better catered for with computers [letter]. *British Medical Journal*, 318(7181), 462.

Elson, P.R. (1993). Literacy and health [letter]. *Canadian Medical Association Journal*, 149(10), 1379, 1382.

Estrada, C., Barnes, V., Collins, C., & Byrd, J.C. (1999). Health literacy and numeracy [letter]. *JAMA*, 282(6), 527.

Freimuth, V.S., & Mettger, W. (1990). Is there a hard-to-reach audience? *Public Health Reports*, 105(3), 232-238.

Discusses the label "hard to reach," the underlying preconceptions, and the implications for health communication campaigns. Proposes alternative constructs.

Gordon, D. (1996). MD's failure to use plain language can lead to the courtroom. *Canadian Medical Association Journal*, 155(8), 1152-1154.

Gottesman, R.L., & Kelly, M.S. (1996). Inadequate functional health literacy [letter; comment]. *JAMA*, 275(11), 840.

Grace, G.D., & Christensen, R.C. (1998). Literacy and mental health care [editorial]. *Psychiatric Services*, 49(1), 7.

Presents evidence that literacy is a critical issue in the evaluation and treatment of individuals with mental disorders. Explores reasons why clinicians may overlook literacy problems.

Johnson, M.E., Mailloux, S.L., & Fisher, D.G. (1997). The readability of HIV/AIDS educational materials targeted to drug users [letter]. *American Journal of Public Health*, 87(1), 112-113.

Compares the readability of HIV/AIDS educational materials distributed to drug users with the reading ability of the drug using population from four U.S. sites. Found the overall reading level of the subjects to be nearly concordant with the mean readability of the HIV/AIDS educational materials. Stresses the need to examine readability variability within individual sites.

Kellerman, R., & Weiss, B.D. (1999). Health literacy and the JAMA Patient Page [letter]. *JAMA*, 282(6), 525-526.

Malouff, J., Gabrilowitz, D., & Schutte, N. (1992). Readability of health warnings on alcohol and tobacco products [letter]. *American Journal of Public Health*, 82(3), 464.

Marwick, C. (1997). Patients' lack of literacy may contribute to billions of dollars in higher hospital costs [news]. *JAMA*, 278(12), 971-972.

Miles, S., & Davis, T. (1995). Patients who can't read: Implications for the health care system. *JAMA*, 274(21), 1719-1720.

Briefly describes the interaction of illiteracy and lack of access to health care in the American system and reviews key points from the Williams et al. study, found in the same volume of *JAMA*.

Morgan, P.P. (1993). Illiteracy can have a major impact on patients' understanding of health care information. *Canadian Medical Association*, *148*(7), 1196-1197.

Reports that 38% of Canadians have either limited or no ability to read and write in English or French and discusses possible implications for health care. Suggests that physicians use the "Literacy Checklist" to improve communication with patients.

Roter, D.L., Rudd, R.E., & Comings, J. (1998). Patient literacy: A barrier to quality of care. *Journal of General Internal Medicine*, *13*(12), 850-851.

Describes how health care is often inaccessible to those with low literacy skills. Recommends greater research attention to the nature of patient-physician communication barriers and how these barriers may be addressed in medical settings.

Roter, D., Rudd, R., & Koch-Weser, S. (1999). Health literacy and the JAMA Patient Page [letter]. *JAMA*, 282(6), 526-527.

Rowley, J.A. (1996). Nurse questions readability of patient-education brochures. *Oncology Nursing Forum*, 23(3), 421.

Schneider, L., & Coyne, C. (1995). Developing partnerships between literacy and health organizations. *Adults Only: A Newsletter for Colorado's Adult Educators*, 5(1).

Describes the merits of partnerships between literacy organizations and health organizations, and gives examples of such collaborations in Colorado.

Visser, A., & Antoni, M. (1994). Current perspectives on AIDS/HIV education and counseling [editorial]. *Patient Education & Counseling*, 24(3), 191-198. Offers an overview of journal contents devoted to current perspectives on HIV/AIDS education and counseling. Among the highlighted subject areas are the readability of educational materials, format of informed consent, and satisfaction with HIV counseling.

Weiss, B.D. (1993). Identifying and communicating with patients who have poor literacy skills. *Fily Medicine*, 25(6), 369-370.

Explores the relationship between literacy and health, including lack of self-empowerment. Discusses commonly recommended strategies for delivering health information to people with limited literacy including the use of non-written means of communication with patients, the development of special materials for low literacy populations, and the use of readability assessment tools, such as the REALM.

Weiss, B., & Coyne, C. (1997). Communicating with patients who cannot read. *The New England Journal of Medicine*, 337(4), 272-274.

Provides suggestions from the National Work Group on Literacy and Health and stresses the importance of effective communication with patients. Suggestions include: health care providers should not assume that they can recognize patients with poor literacy skills, nor should they assume the average patient can comprehend health education materials. If reading materials are essential, they should be prepared at the lowest reading level possible.

Weston, R. (1994). Cancer communication: The health promotion challenge. *European Journal of Cancer Care* (English Language Edition), 3(3), 111-115.

Explains some initiatives taken in the United Kingdom to communicate cancer messages to people who may seldom read or who are illiterate. The importance of training health professionals and the ethics of health promotion are also discussed.

2. Literacy Levels of Patients, Clients or Program Participants

Health literacy rated low in one third of Medicare managed care enrollees. (1999). *American Journal of Health-System Pharmacy*, 56(8), 709-710.

Reports findings of a JAMA study that 33.9% of English-speaking and 53.9% of Spanish-speaking Medicare enrollees have inadequate or marginal health literacy, with the highest rates of illiteracy found in patients over 85. Reviews literacy policy recommendations from the AMA.

Anderson, J.E. (1994). What should be next for nutrition education? [Review]. *Journal of Nutrition*, *124*(9 Suppl.), 1828S-1832S.

Describes the multiple factors that affect food choice and suggests various research ideas, including the study of the food decision-making process between different ethnic groups and literacy levels in the population. Stresses the need for innovative nutrition education techniques to reach diverse populations.

Baker, D.W., Parker, R.M., Williams, M.V., Pitkin, K., Parikh, N.S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, *5*(6), 329-334.

Delineates problems faced by patients with low literacy skills. Focus groups and interviews with low literacy and illiterate patients in two large urban hospitals revealed that patients with poor reading ability have important problems accessing the health care system, understanding treatments, and following instructions of providers. Because of shame, low literacy patients may not disclose their problem to others. Patients' coping mechanisms were explored to give insight into interventions that may improve interactions with the health care system.

Christensen, R.C., & Grace, G.D. (1999). The prevalence of low literacy in an indigent psychiatric population. *Psychiatric Services*, *50*(2), 262-263.

In a study of 45 patients seeking mental health services at a psychiatric clinic, 76% were found to read at a seventh- to eighth-grade level or below as measured by the REALM.

However, when asked to estimate their own reading ability, 76% of the sample reported reading "very well" or "well." Because the REALM tests only word recognition skills, it is suggested that actual reading comprehension skills are likely to be even lower than shown by the data. Recommends that clinicians practicing in settings with high rates of low literacy be aware of the incongruities between self-reports and actual reading ability and consider using reading materials at the lowest possible level for their patients.

Fisher, E. (1999). Low literacy levels in adults: Implications for patient education. *Journal of Continuing Education in Nursing*, 30(2), 56-61.

Reviews current literature on health and literacy. Findings indicate that low literacy is more prevalent in the U.S. than is generally assumed, and that health education materials are often written at a reading level higher than that of most patients. Discusses implications for nurses and areas for future research.

Francis, C.K. (1991). Hypertension, cardiac disease, and compliance in minority patients [Review]. *American Journal of Medicine*, 91(1A), 29S-36S.

Describes inadequate functional literacy as a barrier for inner-city Black and Hispanic patients to seek health care, and to follow a prescribed regimen of drugs, for hypertension.

Fredrickson, D.D., Washington, R.L., Pham, N., Jackson, T., Wiltshire, J., & Jecha, L.D. (1995). Reading grade levels and health behaviors of parents at child clinics. *Kansas Medical*, *96*(3), 127-129.

Measures demographics, reading ability and self-described health behaviors of 646 parents at 12 various child-related clinics. Parents tended to read at the eighth-grade level, although the mean years of school completed was 12.1. Persons with low literacy levels appeared to be at particularly high risk for adverse health behaviors (smoking, obesity, etc.).

Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M., Scott, T.L., Green, D.C., Fehrenbach, S.N., Ren, J., & Koplan, J.P. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA*, 281(6), 545-551.

Attempts to determine what proportion of Medicare enrollees within a national managed care organization have low health literacy skills. A total of 3,260 Medicare enrollees, all aged 65 or older, were interviewed on health status and behaviors and assessed on literacy using the S-TOFHLA. More than one third of the subjects were found to have inadequate or marginal health literacy, with the highest rates of functional illiteracy occurring among those 85 and older. Discusses implications for the health care delivery system.

Hartman, T.J., McCarthy, P.R., Park, R.J., Schuster, E., & Kushi, L.H. (1994). Focus group responses of potential participants in a nutrition education program for individuals with limited literacy skills. *Journal of the American Diabetic Association*, *94*(7), 744-748.

Assesses preferences of clients with low literacy skills. Forty-one clients of the Expanded Food and Nutrition Education Program (EFNEP) participated in five focus

group sessions to explore and develop a nutritional intervention program. Participants with low literacy skills wanted simple, practical, and relevant information about what foods to eat and how to prepare them and noted a preference for hands-on activities.

Jackson, R.H., Davis, T.C., Murphy, P., Bairnsfather, L.E., & George, R.B. (1994). Reading deficiencies in older patients. *American Journal of the Medical Sciences*, 308(2), 79-82.

Tests objective reading ability of 272 patients aged 30 and over from five outpatient clinics using the Peabody Individual Achievement Test-Revised. Patients 60 and older read significantly worse than did patients under 60. Older patients also completed significantly fewer years of school than did their younger counterparts.

Jackson, R.H., Davis, T.C., Bairnsfather, L.E., George, R.B., Crouch, M.A., & Gault, H. (1991). Patient reading ability: An overlooked problem in health care. *Southern Medical Journal*, 84(10), 1172-1175.

Compares educational level, reading comprehension skills, and reading level of materials. Five hundred twenty-eight outpatient clinic visitors were administered the reading sections of the Peabody Individual Achievement Test-Revised (PIAT-R) for an assessment of reading ability. The scores were compared to patients' reports of the last grade completed, as well as to the reading skills needed to comprehend 280 written materials commonly used in the clinic. Most patients were found to have reading abilities far below their last grade completed; nearly all materials tested were written on a level far above average patient reading ability.

Jubelirer, S.J., Linton, J.C., & Magnetti, S.M. (1994). Reading versus comprehension: Implications for patient education and consent in an outpatient oncology clinic. *Journal of Cancer Education*, *9*(1), 26-29.

Assesses reading comprehension among cancer patients. One hundred adult patients from an oncology clinic were found to have 12.5 grade levels of education, a reading vocabulary of 11.3 grades (as tested by the RD-VOCAB), and a reading comprehension level of 10.5 grades (as tested by the RD-COMP). After controlling for educational level, the mean grade level of CD-COMP was significantly lower than educational level. Suggests that health education materials be written at three grade levels below the educational level of the target population.

Kefalides, P.T. (1999). Illiteracy: The silent barrier to health care. *Annals of Internal Medicine*, 130(4 Pt 1), 333-336.

Reports the finding that nearly one in three Americans is functionally illiterate and outlines the resulting costs to the health care system. Recommends methods for detection of illiteracy in patients and details several intervention initiatives currently being tested, including the use of pictographs to explain clinical instructions.

Macario, E., Emmons, K.M., Sorensen, G., Hunt, M.K., & Rudd, R.E. (1998). Factors influencing nutrition education for patients with low literacy skills. *Journal of the American Dietetic Association*, *5*, 559-564.

Presents results from interviews with 35 literacy experts, physicians, nurses, and nutritionists in Boston, MA, as well as from focus groups with 50 volunteer clients from Boston adult basic education programs. Results suggested that insufficient provider time

may hinder nutrition education in patients with limited literacy skills and that such patients often turn to family members and friends for health information. The authors suggest that nutrition interventions include patients' social networks, be visually based and interactive, and be culturally appropriate.

Murphy, P.W., Davis, T.C., Jackson, R.H., Decker, B.C., & Long, S.W. (1993). Effects of literacy on health care of the aged: Implications for health professionals. *Educational Gerontology*, *19*, 311-316.

Notes the importance of older patients' understanding of oral and written instructions, prescription labels, patient education brochures, and consent forms for adequate health care maintenance. Suggests that health care professionals first assess patients' educational needs and then tailor information appropriately.

Nurss, J.R., el-Kebbi, I.M., Galliana, D.L., Zeimer, D.C., Musey, V.C., Lewis, S., Liao, Q., & Philips, L.S. (1997). Diabetes in urban African Americans: Functional health literacy of municipal hospital outpatients with diabetes. *Diabetes Educator*, 23(5), 563-568.

Assesses functional health literacy of diabetic patients. Literacy level was found to be inadequate to marginal in almost 75% of the 63 diabetes patients at various sites. 43% of these patients denied difficulty in reading. This is seen as an important barrier to healthcare delivery.

TenHave, T.R., Van Horn, B., Kumanyika, S., Askov, E., Matthews, Y., & Adams-Campbell, L.L. (1997). Literary assessment in a cardiovascular nutrition education setting. *Patient Education & Counseling*, 31(2), 139-150.

Assesses functional literacy of hypercholesterolemic or hypertensive African Americans prior to their participation in a nutrition education program. Individuals with reading scores at or below the eighth-grade level preferentially used audiotape materials as opposed to written materials.

Weiss, B.D., Reed, R.L., & Kligman, E.W. (1995). Literacy skills and communication methods of low-income older persons. *Patient Education & Counseling*, 25(2), 109-119.

Assesses literacy skills of older patients. The 177 elderly subjects' mean reading skills were at grade 5, below those of the general U.S. population. A quarter of the subjects, especially the poor readers, reported difficulty understanding written information from clinicians and nearly all of the participants reported that television was their primary source of information.

Williams, M.V., Parker, R.M., Baker, D.W., Parikh, K., Coates, W.C., & Nurss, J.R. (1995). Inadequate functional health literacy among patients at two public hospitals. *JAMA*, *2714*(21), 1677-1682.

Assesses functional health literacy of patients. A high proportion of the 2,659 patients studied was unable to read and understand basic written medical instructions. 35% of the English-speaking patients and 62% of the Spanish-speaking patients had inadequate or marginal functional health literacy. The percentage was significantly higher for elderly

patients. Inadequate health literacy is cited as a barrier to patients' understanding of medical information and to patients' receiving high-quality care.

Wilson, F.L. (1995). Measuring patients' ability to read and comprehend: A first step in patient education. *Nursing Connection*, 8(4), 17-25.

Compares level of education with reading ability. Found that self-reported grade level did not necessarily correspond with the actual reading and comprehension levels of 25 patients at an urban public clinic. Measured by the WRAT and CLOZE, patient reading level was, on average, below the eighth-grade level, despite self-report of completing twelfth grade. 52% of the subjects needed additional instructions after reading materials and 24% were not able to comprehend what they read.

Wilson, F.L., & McLemore, R. (1997). Patient literacy levels: A consideration when designing patient education programs. *Rehabilitation Nursing*, 22(6), 311-317.

Examines the relationship between patients' own reports of the highest grade completed in school and their actual reading level as well as the relationship between literacy and the level of knowledge about self-care after patients received written discharge instructions. A significant negative relationship was found between patients' own reports of highest grade completed and their actual reading level.

3. Match Between Reading Ability and Written Materials

Albright, J., de Guzman, C., Acebo, P., Paiva, D., Faulkner, M., & Swanson, J. (1996). Readability of patient education materials: Implications for clinical practice [Review]. *Applied Nursing Research*, *9*(3), 139-143.

Assesses 50 patient education materials across five units of a medical center (oncology, surgery, cardiac step-down, perinatal, and diabetes). Surgery education and oncology materials were found to have the highest readability levels. The mean readability of the five groups of materials was 9.84.

Beaver, K., & Luker, K. (1997). Readability of patient information booklets for women with breast cancer. *Patient Education & Counseling*, 31(2), 95-102.

Examines the readability of 50 information booklets available to women with breast cancer using the SMOG and Flesch reading tests (in the U.K.). Generally, the booklets were found to have a high reading level, not be suitable for the majority of the population.

Chesson, A.L., Murphy, P.W., Arnold, C.L., & Davis, T.C. (1998). Presentation and reading level of sleep brochures: Are they appropriate for sleep disorders patients? *Sleep*, *21*(4), 406-412.

Compares readability levels of written information on sleep disorders with the reading ability of 170 sleep disorders patients. Findings showed that the average patient reading level, as measured by the REALM, was seventh- to eighth-grade, with 37% of patients reading below the ninth-grade level. However, 94% of the brochures were written at a 12th-grade level or higher and most scored in the lower end of adequate range using the Suitability Assessment of Materials (SAM). The authors encourage distribution of sleep disorders education materials written at a level appropriate for most patients.

Cooley, M.E., Moriarty, H., Berger, M.S., Selm-Orr, D., Coyle, B., & Short, T. (1995). Patient literacy and the readability of written cancer education materials. *Oncology Nursing Forum*, 22(9), 1345-1351.

Compares reading skills of cancer patients reading level of materials. Used the WRAT-R2 to measure 63 cancer outpatients' reading levels and used the Flesch Index to analyze the reading levels of the booklets the patients used. Found the reading level of 27% of the sample was less than that of all 30 pamphlets. The authors recommend that written educational materials for cancer patients must be carefully matched to patient reading levels.

Davis, T.C., Crouch, M.A., Wills, G., Miller, S., & Abdehou, D.M. (1990). The gap between patient reading comprehension and the readability of patient education materials [Review]. *Journal of Family Practice*, *31*(5), 533-538.

Compares reading comprehension ability of ambulatory care patients with reading level of materials. A large discrepancy was found between the average patient reading comprehension and the skills levels needed to read patient education materials in five different ambulatory care settings. The average reading comprehension of the 151 patients was sixth grade, while the education materials required between an 11th- and a 14th-grade reading level.

Davis, T.C., Jackson, R.H., George, R.B., Long, S.W., Talley, D., Murphy, P.W., Mayeaux, E.J., & Truong, T. (1993). Reading ability in patients in substance misuse treatment centers. *International Journal of the Addictions*, 28(6), 571-582.

Tests reading ability of adult in-patients in public and private substance misuse treatment settings and compares reading ability with patient education and consent form readability levels. Between one third and one half of the patients tested below a ninth-grade reading level, whereas standard treatment materials were written on the 11th- to 18th-grade reading levels.

Davis, T.C., Mayeaux, E.J., Fredrickson, D., Bocchini, J.A. Jr., Jackson, R.H., & Murphy, P.W. (1994). Reading ability of parents compared with reading level of pediatric patient education materials. *Pediatrics*, *93*(3), 460-468.

Compares the reading ability with educational materials. Assessed the reading ability of 369 parents or caretakers accompanying pediatric outpatients with the REALM and the WRAT-R. Assessed readability of written educational materials with the computer program Grammatik IV. The mean score on the REALM placed parents at the seventh-to eighth-grade reading range, although 80% of the materials examined required at least a 10th-grade reading level. Suggests the need to screen at-risk parents for low reading levels.

Dowe, M.C., Lawrence, P.A., Carlson, J., & Keyserling, T.C. (1997). Patients' use of health-teaching materials at three readability levels. *Applied Nursing Research*, 10(2), 86-93.

Examines the extent to which patients used and learned from drug literature written at three readability levels. Concludes that people with little formal education would benefit the most from materials written at lower readability levels than are to be found in the many health-teaching materials available today.

Estey, A., Musseau, A., & Kehn, L. (1994). Patient's understanding of health information: A multi-hospital comparison. *Patient Education & Counseling*, 24(1), 73-78.

Applies the Cloze technique to test 189 patients' ability to understand health information prepared at grade levels 5 and 9. Recommends that patient materials be written at the fifth-grade level.

Foltz, A., & Sullivan, J. (1996). Reading level, learning presentation preference, and desire for information among cancer patients. *Journal of Cancer Education*, 11(1), 32-38.

Assesses preferences of cancer patients. 90% of the 63 cancer patients studied indicated a desire for all available cancer information, 68% wanted to be involved in care decisions, and 77% preferred personal interactive learning. The REALM was administered and the mean score was a seventh- to eighth-grade reading level. Over half of the patients read below their stated educational levels and would be unable to read many patient education materials.

Guidry, J.J., Fagan, P., & Walker, V. (1998). Cultural sensitivity and readability of breast and prostate printed cancer education materials targeting African Americans. *Journal of the National Medical Association*, 90(3), 165-169.

Assesses cancer education materials developed for African Americans. Results from the Cancer Prevention Materials and African Americans Project indicate that only 54% of the breast cancer and 40% of the prostate cancer materials were culturally sensitive. In addition, many of the materials were written at inappropriate reading levels.

Hearth-Holmes, M., Murphy, P.W., Davis, T.C., Nandy, I., Elder, C.G., Broadwell, L.H., & Wolf, R.E. (1997). Literacy in patients with a chronic disease: Systemic lupus erythematosus and the reading level of patient education materials. *Journal of Rheumatology*, 24(12), 2335-2339.

Compares literacy in patients with systematic lupus erythematosus (SLE) to the reading level of patient education materials specific to SLE. Found that current SLE patient education materials were written on too high a level for many patients and that low-literacy patients must be provided with appropriate materials.

Hill, J. (1997). A practical guide to patient education and information giving [Review]. *Baillieres Clinical Rheumatology*, 11(1), 109-127.

Provides an overview of patient education for practicing rheumatoid arthritis clinicians. Alternative methods of delivering patient education are compared and practical guidance is given on methods of ensuring that written information is readily understandable by patients.

Hosey, G.M., Freeman, W.L., Stracqualursi, F., & Gohdes, D. (1990). Designing and evaluating diabetes education material for American Indians. *The Diabetes Educator*, 16(5), 407-414.

Compares reading skills of American Indian diabetic patients using the WRAT (66% read at fifth-grade or higher) and with the readability of a sample of diabetic education materials (mean readability was 10th-grade level). Education booklets were then developed to target a fifth- to seventh-grade reading level.

Larson, I., & Schumacher, H.R. (1992). Comparison of literacy level of patients in a VA arthritis center with the reading level required by educational materials. *Arthritis Care & Research*, *5*(1), 13-16.

Tests reading levels of 100 patients at an urban VA Arthritis and Immunology Center using the WRAT-R2 and used the SMOG formula to determine reading level of Arthritis Foundation education materials. Nearly 50% of patients read below the 10^{th} -grade level and 31% below the seventh-grade level. However, education materials required an 8^{th} - to 13^{th} -grade level of reading comprehension.

Meade, C.D., McKinney, W.P., & Barnas, G.P. (1994). Educating patients with limited literacy skills: The effectiveness of printed and videotaped materials about colon cancer. *American Journal of Public Health*, 84(1), 119-121.

Compares educational approaches. A total of 1,100 patients receiving colon cancer screening were randomly selected and assigned to one of three groups: receiving a colon cancer education booklet, view a videotape, or receive no intervention. Subjects

receiving the interventions showed increased knowledge compared to control subjects, suggesting the usefulness of personalized educational materials to improve colon cancer knowledge.

Michielutte, R., Bahnson, J., Dignan, M.B., & Schroeder, E.M. (1992). The use of illustrations and narrative text style to improve readability of a health education brochure. *Journal of Cancer Education*, 7(3), 251-260.

Compares two versions of a cervical cancer brochure—one containing text in a bullet format, and the other containing text in narrative style together with drawings to complement the text. Women gave significantly higher overall ratings to the brochure with illustrations and narrative text than the one with bullet-type and no illustrations. Among poor readers, comprehension was significantly greater for women who read the narrative text with illustrations, with no differences in comprehension of the two brochures for better readers.

Murphy, P.W., & Davis, T.C. (1997). When low literacy blocks compliance. RN, 60(10), 58-63; quiz 64.

Overland, J.E., Hoskins, P.L., McGill, M.J., & Yue, D.K. (1993). Low literacy: A problem in diabetes education. *Diabetic Medicine*, *10*(9), 847-850.

Compares comprehension of materials prepared at different reading levels. Eighty-five diabetic patients were randomly assigned to read diabetes foot care material at grade 6 and 11 or at grade 6 and 9 (as assessed by the SMOG formula). The mean Cloze score (measure of comprehension) was better for patients who read the grade 6 materials than for both the grade 9 and 11 information. Concludes that reducing literacy demands of health literature improves patients' comprehension.

Siminerio, L.M., & Frith, M. (1993). Need to assess readability of written materials for diabetes education curricula [Review]. *Diabetes Care*, 16(1), 391-193.

Discusses why attention to readability in diabetes programs and their publications is important and emphasizes the importance of self-care of management routines to achieve good metabolic control.

Sumner, W. (1991). An evaluation of readable preventive health messages. *Family Medicine*, 23(6), 463-466.

Studies the comparative effect of tailored materials. A computer program was written to produce appropriate health information brochures based on the patients' education level and answers to a health history questionnaire. After 3 months, there was no increase in specific health-seeking behavior among the 81 patients receiving the booklets when compared with 213 controls who did not receive the computer-generated booklets.

Watkins, G.R. (1995). Patient comprehension of gastroenterology (GI) educational materials. *Gastroenterology Nursing*, 18(4), 123-127.

Studies the comprehension of patient information among 30 discharged GI patients with an average of post-high school education and mean word recognition score at the high school level. Found a moderate correlation between years of schooling and word recognition score and a strong correlation between word recognition and reading

comprehension scores. Attention to word recognition ability and educational level may be insufficient to ensure comprehension.

4. Functional Literacy and Institutional Settings

Baker, D.W., Parker, R.M., Williams, M.V., Ptikin, K., Parikh, N.S., Coates, W., & Mwalimu, I. (1996). The health experience of patients with low literacy. *Archives of Family Medicine*, *5*, 329-334.

Applies the REALM (Rapid Estimate of Literacy in Medicine), focus groups, and individual interviews to understand the health care experiences of 60 illiterate or low literate patients in two large urban public hospitals. The five main areas of literacy demands faced by the participants were: navigating the health institution, completing forms, following medication instructions, interacting with health care providers, and understanding appointment slips.

Brez, S.M., & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040-1047.

Examines the experience of adults tested for literacy. This qualitative study focused on eight self-identified low-literate adults screened for literacy in a hospital setting. Three general themes emerged: stigma, non-disclosure during hospitalization, and trust (participants indicated that the hospital would be a "special" place where staff can be trusted and would use literacy information to help patients)

Dexter, E.R., LeVine, S.E., & Velasco, P.M. (1998). Maternal schooling and health-related language and literacy skills in rural Mexico. *Journal of Comparative Education Review*, 42(2), 139-162.

Investigates the relationship between schooling and the health-related oral language and reading skills in 78 Mexican mothers. Correlations were found between reading skills and oral language skills, as well as between scores on decontextualized language tasks and skills on health-related listening, reading, and speaking tasks. Length of schooling was a predictor of the women's understanding of spoken and written health messages. Authors note the importance of including oral language abilities in discussions of literacy.

Estey, A., Musseau, A., & Keehn, L. (1994). Patient's understanding of health information: A multi-hospital comparison. *Patient Education & Counseling*, 24, 73-78.

Studies comprehension. The Cloze technique was used to test 189 patients' ability to understand health information prepared at grade levels 5 and 9. Recommended that written patient materials be written at the fifth-grade level.

Moon, R.Y., Cheng, T.L., Patel, K.M., Baumhaft, K., & Scheidt, P.C. (1998). Parental literacy level and understanding of medical information. *Pediatrics*, 102(2), e25.

Examines the impact of parental literacy level on the understanding of medical information and ability to follow therapy prescribed for their children. Five hundred

forty-three parents accompanying their children for acute care visits to hospitals and other health care facilities were interviewed before and after appointments regarding their child's health status and parental knowledge of health maintenance procedures, and assessed on literacy levels using the REALM. Results showed that low-literate parents tended to view their child's illness as more serious, but literacy level was not predictive of use of preventive services, comprehension of diagnosis and medication, or ability to administer medication.

Olmstead, W.T. (1995). Sign of the times. *Health Facilities Management*, 8, 35-39.

Parikh, N.S., Parker, R.M., Nurss, J.R., Baker, D.W., & Williams, M.D. (1996). Shame and health literacy: The unspoken connection. *Patient Education & Counseling*, 27, 33-39.

Studies relationship between low functional health literacy and shame. Assessed functional health literacy of 202 patients from emergency departments and a walk-in using the TOFHLA. Participants were asked questions about literacy and shame. 40% of patients with low functional literacy admitted shame, which may play an important role in the interaction between low literate patients and health care providers.

Weiss, B.D., Hart, G., McGee, D.L., & D'Estelle, S. (1992). Health status of illiterate adults: Relation between literacy and health status among persons with low literacy skills. *Journal of the American Board of Family Practice*, 5, 257-264.

Studies health status of adult students. Study used the Tests of Adult Basic Education and the Mott to assess literacy skills in 193 adult students and measured health status using the Sickness Impact Profile (SIP). SIP score, and especially the SIP Physical score, was found to be related to reading levels of participants.

Williams, M.V., Parker, R.M., Baker, D.W., Parikh, N.S., Ptikin, K., Coates, W., & Nurss, J.R. (1995). Inadequate functional health literacy among patients at two public hospitals. *JAMA*, 274(21), 1677-1682.

Studies the ability of 2,659 patients to complete basic reading and numeracy tasks required to function adequately in the health care system. The test (TOFHLA) found that a high proportion of patients, especially Spanish-speaking patients, were unable to read and understand basic medical instructions, prescription instructions, appointment schedules, and informed consent documents. Authors discuss issues related to literacy demands in the health care setting.

4A. Consent Forms

Agre, P., McKee, K., Gargon, N., & Kurtz, C. (1997). Patient satisfaction with an informed consent process. *Cancer Practice*, *5*(3), 162-167.

Evaluates patients' and family members' levels of satisfaction with informed consent procedures before colonoscopy or upper GI endoscopy. Found highest patient and family

member satisfaction with the use of videotape followed by a discussion with a physician. The authors suggest that using videotape as part of the informed consent process may eliminate the problems associated with the readability of written consent forms.

Davis, T.C., Holcombe, R.F., Berkel, H.J., Pramanik, S., & Divers, S.G. (1998). Informed consent for clinical trials: A comparative study of standard versus simplified forms. *Journal of the National Cancer Institute*, 90(9), 669-674.

Assesses patient preferences for consent forms. Of the 183 adults participating in the study, 62% preferred the simplified Louisiana State University Medical Center (LSU) consent form, written at the seventh-grade level, to the standard Southwestern Oncology Group (SWOG) consent form, written at the 16th-grade level. Nearly all participants found the LSU form easier to read than the SWOG form, although levels of patient understanding were nearly the same for both forms.

Goldstein, A.O., Frasier, P., Curtis, P., Reid, A., & Kreher, N.E. (1996). Consent form readability in university-sponsored research. *Journal of Family Practice*, 42(6), 606-611.

Analyzes 284 consent forms submitted to and approved by five Institutional Review Boards (IRBs) with Right Writer software. The mean reading level of all consent forms was at a 12th-grade level. Recommends that IRBs require readability checks for research consent forms.

Hammerschmidt, D.E., & Keane, M.A. (1992). Institutional Review Board (IRB) lacks impact on the readability of consent forms for research. *The American Journal of the Medical Sciences*, 304(6), 348-351.

Analyzes 65 new applications to the IRB and their consent documents through computer applied Flesch/Fry scoring to determine readability levels. The mean grade of readability of the forms was 15, implying that they could be comprehended by only 1% of the U.S. population. Authors suggest that the IRB review process incorporate the readability of forms.

Hopper, K.D., TenHave, T.R., & Hartzel, J. (1995). Informed consent forms for clinical and research imaging procedures: How much do patients understand? *American Journal of Roentgenology*, *164*(2), 493-496.

Assesses 265 clinical consent forms used by Radiologists. Assessments applied a variety of readability formulas and resulted in a mean readability level of 15. Similarly, 284 research forms were calculated to have a readability level of 12. Results indicate that most consent forms used in radiology practice are too complex for the average patient to understand.

Hopper, K.D., TenHave, T.R., Tully, D.A., & Hall, T.E.L. (1998). The readability of currently used surgical/procedure consent forms in the United States. *Surgery*, *123*, 496-503.

The mean grade level required to understand 616 surgical/procedural consent forms was 12.6 (using RightWriter software). The authors conclude that a majority of such informed consent documents currently in use in the United States are complex and may

be difficult to understand for the average patient. They also note that many of the forms do not explain specific benefits and risks involved with the surgery/procedure.

Jubelirer, S.J. (1991). Level of reading difficulty in educational pamphlets and informed consent documents for cancer patients. *West Virginia Medical Journal*, 87(12), 554-557.

Assesses educational materials and consent forms. Materials were found to be written at the 11th- to 14th-grade level, with some group consent forms requiring a college-level reading comprehension. In comparison, 127 patients reported a mean educational level of 10th-grade, although many could not be expected to read at this level. The authors suggest that outpatient populations should be surveyed and the reading level of written materials adjusted accordingly.

Mader, T.J., & Playe, S.J. (1997). Emergency medicine research consent form readability assessment. *Annals of Emergency Medicine*, 29(4), 534-539.

Assesses the readability of 88 emergency medicine research consent forms and the relationship between readability and degree of protocol risk. Found the consent documents too complex for the average patient to understand. Also found a positive correlation between procedure risk and consent form complexity.

Meade, C.D., & Howser, D.M. (1992). Consent forms: How to determine and improve their readability. *Oncology Nursing Forum*, 19(10), 1523-1528.

Analyzes 44 consent forms from active studies at the National Cancer Institute with the SMOG formula and determined readability levels to be from grade 12 to 17.5. Concludes that many consent forms are written above most subjects' reading levels and suggests a number of strategies nurses could use to enhance comprehension of informed consent documents.

Montgomery, J.E., & Sneyd, J.R. (1998). Consent to clinical trials in anesthesia. *Anesthesia*, *53*, 227-230.

Evaluates patient satisfaction with and recollection of the consent process for six clinical trials, three conducted by a drug company and three "in-hospital" trials. The commercial patient information sheets were found to be slightly longer and more difficult to read than the "in-house" information sheets as assessed by the Flesch reading ease and Flesch-Kincaid grade level assessments. However, patterns of patient satisfaction responses were the same for both types of trials, and 99% of patients thought the forms were easy to read. The authors conclude that increased amount and complexity of information in the patient information sheets does not benefit patient satisfaction with the consent process.

Olver, I.N., Tureell, S.J., Olszewski, N.A., & Willson, K.J. (1995). Impact of an information and consent form on patients having chemotherapy. *The Medical Journal of Australia*, 162, 82-83.

Assesses informed consent. One hundred patients having chemotherapy were given written information and consent forms. Thirty-four understood the purpose of the form, 75 patients could not name any of their drugs, 26 did not know the goal of therapy and only 15 remembered all of the four general side effects. Implies that informed consent requirements for patients receiving chemotherapy may not be satisfied.

Philipson, S.J., Doyle, M.A., Gabram, S.G., Nightingale, C., & Philipson, E.H. (1995). Informed consent for research: A study to evaluate readability and processability to effect change. *Journal of Investigative Medicine*, *43*(5), 459-467.

Assesses informed consent. Seventy-six informed consent forms approved by Hartford Hospital in 1993 were evaluated for readability, and neither the Fry score nor the Readability and Processability Form (RPF) score was in the target eighty-grade range. Suggestions were made to improve readability on specific areas where the forms need to be studies and revised.

Taylor, H.A. (1999). Barriers to informed consent. *Seminars in Oncology Nursing*, 15(2), 89-95.

Reviews current research in order to highlight patient- and process-centered barriers to informed consent. Patient-centered barriers include level of education and patient-physician relationship. Process-centered barriers include readability and content of consent form.

Tarnowski, K.J., Allen, D.M., Mayhall, C., & Kelly, P.A. (1990). Readability of pediatric biomedical research informed consent forms. *Pediatrics*, 85(1), 58-62.

Assesses informed consent. Fry and Flesch Readability analyses were conducted on 238 pediatric biomedical informed consent forms from large mid-western children's hospital. Consent forms were written on the college graduate level. Suggestions for solving this critical problem are discussed.

4B. Emergency Department Discharge Information

Austin, P.E., Matlack, R. 2nd, Dunn, K.A., Kesler, C., & Brown, C.K. (1995). Discharge instructions: Do illustrations help our patients understand them? *Annals of Emergency Medicine*, 25(3), 317-320.

Studies use of illustrations. A total of 101 discharged emergency room patients, with the diagnosis of laceration, were randomly assigned to receive discharge instructions with or without illustrations. Found that the addition of illustrations improved patient comprehension, especially among patients who were non-white, female, or who had no more that a high school education.

Delp, C., & Jones, J. (1996). Communicating information to patients: The use of cartoon illustrations to improve comprehension of instructions. *Academic Emergency Medicine*, *3*(3), 264-270.

Studies wound care instructions. Two hundred thirty-four outpatients at an emergency department were randomly assigned to receive wound care instructions with or without cartoon illustrations and were followed-up three days later. Patients given cartoon instructions were more likely to have read the instructions, answered wound care questions correctly, and were more compliant with daily wound care.

Jolly, B.T., Scott, J.L., Fried, C.F., & Sanford, S.M. (1993). Functional illiteracy among emergency department patients: A preliminary study. *Annals of Emergency Medicine*, 22(3), 573-578.

Studies Emergency Department information. Part 1 of the study required that 400 urban Emergency Department patients read a set of standard discharge instructions and answer 5 questions related to the material. In Part 2, 47 sets of standard discharge instructions were computer analyzed for readability level. A significant proportion of patients failed to answer correctly 4 out of the 5 questions and the average grade level required to read the materials ranged from 6 to 13.4.

Jolly, B.T., Scott, J.L., & Sanford, S.M. (1995). Simplification of emergency department discharge instructions improves patient comprehension. *Annals of Emergency Medicine*, 26(4), 443-446.

Studies simplified Standard Emergency Department (ED) discharge instructions. The simplified material was tested on 423 ED patients, followed by 5 comprehension questions. The mean score for the simplified instruction group was significantly improved over that of the original group.

Logan, P.D., Schwab, R.A., Salomone, J.A., & Watson, W.A. (1996). Patient understanding of emergency department discharge instructions. *Southern Medical Journal*, 89(8), 770-774.

Studies patient recall of discharge information. 72% of patients, interviewed immediately after discharge outside the emergency department could read the discharge instructions. When asked to recall their diagnosis and treatment plan, 79% provided the correct diagnosis and 49% the correct treatment information. 37% of patients answered all questions correctly. Illiteracy is cited as one of many factors accounting for low rates of recall in this population.

Spandorfer, J.M., Karras, D.J., Hughes, L.A., & Caputo, C. (1995). Comprehension of discharge instructions by patients in an urban emergency department. *Annals of Emergency Medicine*, 25(1), 71-74.

Assesses emergency department patients' comprehension of discharge instructions. Comprehension was assessed to be good; however, 23% of patients did not understand at least one component of the instructions. The mean reading ability of patients was at the sixth-grade level, although the printed discharge instructions were written at an 11th-grade level. Suggests that verbal instructions from the discharging physician may have a significant effect on patient comprehension.

Williams, D.M., Counselman, F.L., & Caggiano, C.D. (1996). Emergency department discharge instructions and patient literacy: A problem of disparity. *American Journal of Emergency Medicine*, *14*(1), 19-22.

Analyzes 10 preprinted Emergency Department discharge instructions with the Flesch Reading Ease Score. The mean grade level necessary for comprehension was found to be 9.8. The Stanford Diagnostic Reading Test was administered to 82 Emergency Department patients and the mean reading level was 9.8. Therefore, about 45% of the patients would be able to understand the preprinted discharge instructions.

5. Materials Assessments

Alexander, R.E. (1999). Patient understanding of postsurgical instruction forms. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology & Endontics*, 87(2), 153-158.

Examines issues surrounding patient comprehension of dental instruction materials, including literacy statistics, methods of assessment, and means of effective doctor-patient communication. Offers guidelines for improving written materials. Notes the lack of attention given to issues of patient comprehension within dentistry and encourages a reversal of this trend.

Basara, L.R., & Juergens, J.P. (1994). Patient package insert readability and design. *American Pharmacy*, *NS34*(8), 48-53.

Analyzes 63 Patient package inserts (PPIs), from three types of sources. Materials were found to have, on average, a 10th-grade reading level. Design characteristics, such as type size, were poorest in PPIs produced by pharmaceutical companies. The authors recommend designing and testing of new PPI formats and a reassessment of readability.

Beckman, H.T., & Lueger, R.J. (1997). Readability of self-report clinical outcome measures. *Journal of Clinical Psychology*, *53*(8), 785-789.

Assesses readability for five frequently employed measures: Beck Depression Inventory, Integrated Outpatient Tracking Assessment, MOS 36-Item Short-Form Health Survey, Social Adjustment Scale-Self Report, and Symptoms Checklist-90-Revised. Measures were generally shown to be useful for patients with an eighth or ninth grade education.

Butow, P., Brindle, E., McConnell, D., Boakes, R., & Tattersall, M. (1998). Information booklets about cancer: Factors influencing patient satisfaction and utilization. *Patient Education and Counseling*, *33*(2), 129-141.

Investigates factors influencing patient satisfaction with and use of informational booklets. Thirty-six cancer patients undergoing chemotherapy evaluated five commonly used cancer information booklets. Results showed that subjects overwhelmingly preferred a booklet with a grade 8 readability level, in contrast to the other booklets written at grade levels 11-12.

Brown, P., Ames, N., Mettger, W., Smith, T.J., Gramarossa, G.L., Friedell, G.H., & McDonald, S.S. (1993). Closing the comprehension gap: Low literacy and the Cancer Information Service. *Journal of the National Cancer Institute*. Monographs (14), 157-163.

Reviews the link between cancer and illiteracy; the magnitude of the problem; and the association between cancer, certain health-related behaviors, and educational attainment. Also examines National Cancer Institute (NCI) and Cancer Information Service programs and materials designed to reach this high-risk population.

Cardinal, B.J. (1995). Readability analysis of health, physical education, recreation, and dance journal articles. *Perceptual & Motor Skills*, 80(1), 255-258.

Assesses 40 articles from the Journal of Health Education, Journal of Physical Education, Recreation and Dance, Research Quarterly for Exercise and Sport, and Strategies: A Journal for Physical and Sport Educators. Articles were estimated at college junior level.

Daiker, B.L. (1992). Evaluating health and safety lectures: How to measure lucidity. *AAOHN Journal*, 40(9), 438-445.

Applies readability formulas to transcripts of health and safety lectures and found differences within the lectures of one instructor and between the CPR instructors.

Davis, T.C., Fredrickson, D.D., Arnold, C., Murphy, P.W., Herbst, M., & Bocchini, J.A. (1998). A polio immunization pamphlet with increased appeal and simplified language does not improve comprehension to an acceptable level. *Patient Education and Counseling*, *33*, 25-37.

Compares readability, comprehension and patient preference for two polio vaccine pamphlets, one developed by the CDC and one developed by the authors at LSU, among 610 subjects with a mean reading level of seventh-eighth grade (as measured by the REALM). Though both pamphlets were written on a sixth-grade level, results showed that more patients preferred the LSU pamphlet, which was written in primarily question-answer format, used colors and instructional graphics, and contained 49% as many words as the CDC pamphlet. However, comprehension was not significantly improved for either packet except for those items presented with instructional graphics.

Dollahite, J., Thompson, C., & McNew, R. (1996). Readability of printed sources of diet and health information. *Patient Education & Counseling*, 27(2), 123-134.

Surveys the readability of 209 nutrition education pamphlets using three different tests. Materials from the educational institutions had lower reading levels than materials from professional organizations and government agencies. 68% of the publications were written at the ninth-grade level or higher.

Ebrahimzadeh, H., Davalos, R., & Lee, P.P. (1997). Literacy levels of ophthalmic patient education materials [Review]. *Survey of Ophthalmology*, 42(2), 152-156.

Reviews literature on the relationship between patients' literacy skills and the literacy levels required to read educational health care materials. Applied a similar analysis to commonly used ophthalmic patient-educational materials.

Glanz, K., & Rudd, J. (1990). Readability and content analysis of print cholesterol education materials. *Patient Education & Counseling*, 16(2), 109-118.

Assesses the readability of 38 cholesterol education materials available from government, health agency, professional associations, university and industry sources using SMOG and Fog Grading formulas. The average readability level was grade 11, which is too difficult for many adults.

Glazer, H.R., Kirk, L.M., & Bosler, F.E. (1996). Patient education pamphlets about prevention, detection, and treatment of breast cancer for low literacy women. *Patient Education & Counseling*, 27(2), 185-189.

Analyzes 19 breast cancer education pamphlets using Right Writer. Materials were found to have an average readability of ninth grade. The authors suggest that literature should be analyzed for readability before assuming it is an aid to patient education.

Graber, M.A., Roller, C.M., & Kaeble, B. (1999). Readability levels of patient education material on the World Wide Web. *Journal of Family Practice*, 48(1), 58-61.

Assesses readability of patient education materials on the Internet. Fifty samples of patient information were downloaded from a variety of web sites and analyzed using the Flesch reading score and the Flesch-Kincaid reading level. On average, materials were found to be written at a 10th-grade, 2nd-month reading level, whereas the reading ability of many patients is well below this level. It was thus concluded that much of the information available on the Internet is likely incomprehensible to most patients.

Guidry, J.J., & Fagan, P (1997). The readability levels of cancer-prevention materials targeting African Americans. *Journal of Cancer Education*, 12(2), 108-113.

Assesses readability levels and cultural sensitivity of 100 cancer-prevention materials targeting African Americans. The overall SMOG grade was 9.32. Although the reading level may be appropriate for some materials, it may not be appropriate for African Americans at high risk for cancer.

Husted, G.L., Miller, M.C., & Brown, B. (1999). Test of an educational brochure on advance directives designed for well-elderly people. *Journal of Gerontological Nursing*, 25(1), 34-40.

Evaluates readability and comprehension of a brochure on advance directives designed for well-elderly people and developed using information from literature on educational materials and well-elderly focus groups. The brochure was first assessed by a group of nurses, clinicians and educators using the Bernier Instructional Design Scale 2, receiving 244 points out of a possible 280. Subjects, 20 well-elderly people (17 of which had a minimum of a high school education), responded favorably to the appearance and user friendliness of the brochure and answered 90.5% of the comprehension questions correctly. Thus, the use of this brochure and the techniques used to develop it are recommended.

Klingbeil, C., Speece, M.W., & Schubiner, H. (1995). Readability of pediatric patient education materials. Current perspectives on an old problem. *Clinical Pediatrics*, *34*(2), 96-102.

Evaluates the readability of 33 pediatric education materials using three formulas: the Fog, Fry and SMOG. The majority of the pamphlets were written at grade 9 levels or above. Stresses the need to use multiple readability formulas (all of which were found to be significantly different from one another). Also suggests a need to focus on the readability of multiple sections within a pamphlet, not only on the overall readability.

Ledbetter, C., Hall, S., Swanson, J.M., & Forrest, K. (1990). Readability of commercial versus generic health instructions for condoms. *Health Care for Women International*, 11(3), 295-304.

Analyzes 15 sets of condom patient package inserts (PPIs) prepared commercially and 30 sets of generic instructions (GIs) prepared by health care providers with six standard readability formulas (Fry, Fog, Dale-Chall, Flesch, Flesch-Kincaid, SMOG). Readability levels ranged from 6.3 to 13.7 and the PPIs were found to require a significantly higher grade level for comprehension than were the GIs (10.32 vs. 8.69).

Meade, C.D., Diekmann, J., & Thornhill, D.G. (1992). Readability of American Cancer Society patient education literature. *Oncology Nursing Forum*, 19(1), 51-55.

Analyzes 51 patient education booklets for readability using the SMOG formula. Materials were assessed at a mean level of 11.9. Although 55% of the booklets were too difficult for many Americans to read and understand, booklets produced after 1985 were written at significantly lower reading levels than those published in earlier years.

Merritt, S.L., Gates, M.A., & Skiba, K. (1993). Readability levels of selected hypercholesterolemia patient education literature. *Heart & Lung*, 22(5), 415-420. Assesses reading grade levels of four hypercholesterolemia patient education pamphlets. Materials were at levels 14.4, 15.8, 14 and 14.4 with the FOG, Fry and SMOG formulas. The authors suggest the pamphlets may not be appropriate for use with most of the adults in the United States who may be candidates for this specific patient education.

Michielutte, R., Bahnson, J., & Beal, P. (1990). Readability of the public education literature on cancer prevention and detection. *Journal of Cancer Education*, 5(1), 55-61.

Examines 183 cancer education brochures and computes reading level (SMOG) scores for 159 of them. The average reading level of the materials was found to be between 10th- and 11th-grade, and therefore may be of limited value in providing information to the low-education population.

Mumford, M.E. (1997). A descriptive study of the readability of patient information leaflets designed by nurses. *Journal of Advanced Nursing*, 26(5), 985-991.

Examines the readability of 24 nurse-designed written information leaflets using FOG and SMOG formulae. Results showed readability levels with a mean grade of 11.3, a level too high for many patients. Guidelines available for developing information leaflets are explored and recommendations for further research are offered.

Newton, J.T. (1995). The readability and utility of general dental practice patient information leaflets: An evaluation. *British Dental Journal*, 178(9), 329-332.

Assesses 179 dental practice leaflets for readability and the amount of information contained. Most leaflets were written at too high of a reading level and provided only a minimum of information. Recommendations are made to dental practitioners who want to improve their patient education materials.

Ormrod, J., & Robinson, M. (1994). How readable are health education leaflets? *Health Visitor*, 67(12), 424-425.

Assesses widely-produced samples of health education leaflets for readability and message delivery.

Ott, B.B., & Hardie, T.L. (1995). Readability of written materials: Implications for critical care nurses [Review]. *Dimensions of Critical Care Nursing*, 14(6), 328-334.

Stresses the importance of patients and families having understandable materials to help them make the difficult decisions often faced in critical care units. Reviews the definitions and measurement of readability and a selection of studies that measured the reading levels of patients. Provides research and practice recommendations for critical care nurses.

Petterson, T., Dornan, T.L., Albert, T., & Lee, P. (1994). Are information leaflets given to elderly people with diabetes easy to read? *Diabetic Medicine*, 11(1), 111-113.

Examines 15 different leaflets given to elderly patients in the diabetes unit of a British teaching hospital. The Fog was used to determine readability and the size and style of the print were also examined. 10% of the leaflets were as difficult to read as the British Medical Journal and 73% failed to meet the print guidelines suggested by the Royal National Institute for the Blind.

Primas, P., Lefor, N., Johnson, J., Helms, S.M., Coats, L., & Coe, M.K. (1992). Prenatal literature testing: A pilot project. *Journal of Community Health*, 17(1), 61-67.

Examines 65 prenatal education pamphlets with the SMOG Readability Formula and found materials to be at the 10th- to 12th-grade level, higher than the skill level of many women in the high risk prenatal population. A modified literature testing was also used on eight of the pamphlets to assess the literature for accuracy, usability, believability, appeal and cultural relevance. Four pamphlets were identified that may be the most appropriate for the target population.

Sarma, M., Alpers, J.H., Prideaux, D.J., & Kroemer, D.J. (1995). The comprehensibility of Australian educational literature for patients with asthma. *Medical Journal of Australia*, *162*(7), 360-363.

Applies the Australian Rix readability formula to assess the readability of 50 Australian pamphlets on asthma. The mean grade of reading difficulty was 8, with one third of the materials being written at or above grade 9. The authors suggest that a substantial number of pamphlets on asthma are beyond the reading and comprehension abilities of many of the target population.

Slaten, D., Parrott, R., & Steiner, C. (1999). Readability of skin cancer prevention brochures targeting parents of young children. *Journal of the American Academy of Dermatology*, 40(6 Pt 1), 997-999.

Assesses reading levels of eight skin cancer brochures aimed at educating parents of young children using SMOG and FOG readability formulas. Readability levels ranged

from eighth- to twelfth-grade levels. Recommends all brochures be written at the eighth-grade level in order to ensure comprehension by the widest audience possible.

Swanson, J.M., Forrest, K., Ledbetter, C., Hall, S., Holstine, E.J., & Shafer, M.R. (1990). Readability of commercial and generic contraceptive instructions. *Image—The Journal of Nursing Scholarship*, 22(2), 96-100.

Offers findings from an analysis of patient package inserts (PPIs), from commercial diaphragm, pill, and condom manufacturers and generic contraceptive instructions (GIs), written by health agency staff members, using six readability formulas (Dale-Chall, Fry, Fog, Flesh, Flesch-Kincaid and SMOG). Readability levels ranged from grade 5.5 to 13.6 and the PPIs tended to require higher levels of reading comprehension than the GIs.

Thomas, L.G., & Corwin, E.J. (1998). The readability of printed education materials regarding hormone replacement therapy. *Journal of the American Academy of Nurse Practitioners*, 10(10), 447-452.

Identifies patient education materials (PEMs) as an important source of information on hormone replacement therapy, but suggests that many PEMs are failing to reach their target audiences because their level of reading difficulty is beyond that of their intended audience.

Valaitis, R.K., & Shea, E. (1993). An evaluation of breastfeeding promotion literature: Does it really promote breastfeeding? *Canadian Journal of Public Health*, 84(1), 24-27.

Discusses the evaluation of breastfeeding pamphlets for accuracy, degree of positive approach to breastfeeding, readability and compliance with the WHO/UNICEF Code on the Marketing of Breast Milk Substitutes. Only two of the 22 pamphlets tested were written at the recommended fifth- to eighth-grade level. The authors conclude that none of the materials met all of the criteria for good breastfeeding literature.

Wells, J.A. (1994). Readability of HIV/AIDS educational materials: The role of the medium of communication, target audience, and producer characteristics. *Patient Education & Counseling*, 24(3), 249-259.

Describes the readability assessment of 136 HIV/AIDS educational items using the SMOG Index. Comic books and brochures were found to be more readable than were books and pamphlets. The author suggests that an understanding of the literacy of target audiences is needed to produce materials with appropriate reading levels and that more readable materials must be created.

Wong, I.C.K. (1999). Readability of patient information leaflets on antiepileptic drugs in the UK. *Seizure*, *8*, 35-37.

Assesses the readability levels of UK patient information leaflets (PILs) on antiepileptic drugs. Twelve PILs, six antiepileptic drug articles from medical journals, and six headline articles from British newspapers were analyzed using the Gunning Fog test and the Flesch Reading Ease index. Results showed that PILs had a mean readability index of 69 (an index of 60-70 is recommended to ensure comprehension by most adults) and reading age of 8.8, both significantly lower than the medical articles and newspapers. Concludes that PILs for antiepileptic drugs in the UK are suitable for reading by the general adult population.

6. Research Tools for Assessing Health Literacy

Baker, D.W., Williams, M.V., Parker, R.M., Gazmararian, J.A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling*, *38*, 33-42.

Describes the short Test of Functional Health Literacy in Adults (S-TOFHLA), an abbreviated version of the TOFHLA. Tests showed that the S-TOFHLA has similar reliability and validity to the TOFHLA but may be more practical in health care settings as it reduces administration time from 22 to 12 minutes. Findings also suggest that the S-TOFHLA, though longer, is a more valid test of health literacy than the REALM, which appears to both over- and underestimate patient reading ability.

Davis, T.C., Crouch, M.A., Long, S.W., Jackson, R.H., Bates, P., George, R.B., & Bairnsfather, L.E. (1991). Rapid assessment of literacy levels of adult primary care patients. *Family Medicine*, 23(6), 433-435.

The Rapid Estimate of Adult Literacy in Medicine (REALM) and the reading sections of the Peabody Individual Achievement Test-Revised and the Slosson Oral Reading Test were used to test reading ability in 207 adults in six clinics. REALM scores correlated highly with those of the standardized reading tests, which indicate that it may be a practical instrument to estimate patient literacy.

Davis, T.C., Long, S.W., Jackson, R.H., Mayeaux, E.J., George, R.B., Murphy, P.W., & Crouch, M.A. (1993). Rapid estimate of adult literacy in medicine: A shorthand screening instrument. *Family Medicine*, 25(6), 391-395.

Describes the testing of the REALM. 203 patients in four hospital clinics and 100 inmates were given the REALM and three other standardized reading tests (PIAT-R, WRAT-R, and SORT-R) to test for correlations and test-retest reliability. The REALM correlated well with the three other tests and the test-retest reliability was significant. The REALM is suggested as a practical instrument for busy primary care settings.

Davis, T.C., Michielutte, R., Askov, E.N., Williams, M.V., & Weiss, B.D. (1998). Practical assessment of adult literacy in health care. *Health Education and Behavior*, 25(5), 613-624.

Reviews the use of various literacy assessments, discusses the use of such instruments in the health care setting, and suggests issues for clinicians to consider before testing their patients. Among the instruments reviewed are the REALM, WRAT-3, the Cloze procedure, the TOFHLA and others in both English and Spanish. Includes an Appendix with information on how to order the above literacy tests.

Foltz, A., & Sullivan, J. (1996). Get real: Clinical testing of patients' reading abilities. *Cancer Nursing*, 21(3), 162-166.

Notes that in medical settings, health care providers often supply written material about a disease that requires a reading level higher than that of most patients. Reviews seven tests of reading ability commonly used in clinical settings to determine appropriateness of educational material. Provides a detailed description of the REALM and recommends this test as an effective and easy tool for use in medical settings.

Hanson-Divers, E.C. (1997). Developing a medical achievement reading test to evaluate patient literacy skills: A preliminary study. *Journal of Health Care for the Poor & Underserved*, 8(1), 56-69.

Describes the development and testing of the medical terminology achievement reading test (MART). MART was administered to 405 participants from five populations, along with the Wide Range Achievement Test (WRAT), to determine the likelihood that the MART score is a good estimate of the true score (WRAT) and, therefore, of reading ability. Analysis showed that the MART was in fact a good estimate of reading ability. Recommendations were made to test the MART design in low-literate populations.

Mosenthal, P.B., & Kirsch, I.S. (1998). A new measure for assessing document complexity: The PMOSE/IKIRSCH document readability formula. *Journal of Adolescent and Adult Literacy*, 41(8), 638-657.

Describes a document readability formula, the PMOSE/IKIRSCH, used to measure document complexity primarily through measures of structure and density (or the number of labels and items). The formula allows for comparison of the structural complexity of documents that are unrelated to one another, for example, matrix, graphic, locative, time line, and entry documents.

Nurss, J.R., Baker, D.W., Davis, T.C., Parker, R.M., & Williams, M.V. (1995). Difficulties in functional health literacy screening in Spanish-speaking adults. *Journal of Reading*, *38*(8), 632-637.

Describes the inadequacy of using common literacy screening instruments, such as the REALM, with Spanish-speaking populations. A Spanish screening instrument (the REALM-S) was developed and tested on 52 Spanish-speaking adults. However, this list of medically related words, used to test functional health literacy, was not successful due to the close phoneme-grapheme correspondence of Spanish.

Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, *10*(10), 537-541.

Describes the development of the Test of Functional Health Literacy in Adults (TOFHLA). TOFHLA uses actual hospital materials and consists of a 50-item reading comprehension and 17-item numerical ability test. It takes 22 minutes to administer. The TOFHLA, the WRAT-R, and the REALM were administered to 500 patients, and the TOFHLA was shown to be a valid and reliable indicator of patient ability to read health-related materials.

6A. Health Instruments: Readability Considered

Brown, J.A., Nederend, S.E., Hays, R.D., Short, P.F., & Farley, D.O. (1999). Special issues in assessing care of Medicaid recipients. *Medical Care*, *37*(3 Supp.), MS79-88.

Describes the process of developing user-friendly survey items targeted towards Medicaid recipients for the Consumer Assessment of Health Plans Study (CAHPS). Emphasizes the importance of including a formal literacy review in order to ensure accessibility to a wide range of consumers.

Crittenden, K.S., Manfredi, C., Lacey, L., Warnecke, R., & Parsons, J. (1994). Measuring readiness and motivation to quit smoking among women in public health clinics. *Addictive Behaviors*, 19(5), 497-507.

Presents findings of pilot tests of an instrument developed to assess stage of readiness and level of motivation to change smoking behavior. The instrument accommodates low literacy requirements for use in clinic setting, as well as for use in either a self-administered questionnaire or interview format.

Devins, G.M., Binik, Y.M., Mandin, H., Letourneau, P.K., Hollomby, D.J., Barre, P.E., & Prichard, S. (1990). The Kidney Disease Questionnaire: A test for measuring patient knowledge about end-stage renal disease. *Journal of Clinical Epidemiology*, 43(3), 297-307.

Presents data and issues related to the administration, readability, and demographic correlates of the KDQ test, which is used to measure patient knowledge about end-stage renal disease and its treatment.

Hollen, P.J., Gralla, R.J., Kris, M.G., & Potanovich, L.M. (1993). Quality of life assessment in individuals with lung cancer: Testing the Lung Cancer Symptom Scale (LCSS). *European Journal of Cancer*, 29A(Suppl. 1), S51-58.

Presents the development and pilot testing of the LCSS, which measures the physical and functional dimensions of quality of life in lung cancer patients. The readability of the patient scale index was reported to be at the second-grade level and at the eighth-grade level for the observer scale. The authors conclude that the instrument demonstrated good feasibility, reliability, and content validity.

Johnson, R.K., Soultanakis, R.P., & Matthews, D.E. (1998). Literacy and body fatness are associated with underreporting of energy intake in US low-income women using the multiple-pass 24 hour recall: A doubly labeled water study. *Journal of the American Dietetic Association*, 98(10), 1136-1140.

In a study of 35 low-income women, those with low literacy and increased body fat were more likely to underreport daily food intake. Discusses implications for dietetics professionals in evaluating diet and health and measuring the impact of food assistance programs.

Knight, S.J., Chmiel, J.S., Kuzel, T., Sharp, L., Albers, M., Fine, R., Moran, E.M., Nadler, R.B., Sharifi, R., & Bennett, C.L. (1998). Quality of life in metastatic prostate cancer among men of lower socioeconomic status: Feasibility and criterion related validity of 3 measures. *The Journal of Urology*, *160*, 1765-1769.

Assesses the feasibility of interviewer administration of quality of life questionnaires in a clinical setting with patients of low socioeconomic status, many with limited literacy skills. Three quality of life instruments previously validated with self-administration methodology were administered via interview to 110 men with metastatic prostate cancer. Results indicated that interviewer administered tests are a valid method of quality of life assessment in low literacy, low socioeconomic populations.

Macey, B.A., & Bouman, C.C. (1991). An evaluation of validity, reliability, and readability of the Critical Care Family Needs Inventory. *Heart & Lung*, 20(4), 398-403.

The readability of the CCFNI was assessed with the Gunning Fog Index, and found to be at the ninth-grade reading level, which may be too high for some family members of critical care patients.

McCormack-Brown, K.R., Vitello, E.M., McDermott, R.J., & Richardson, C.E. (1990). Development of the Dental Health Assessment Profile. *Journal of School of Health*, 60(9), 455-458.

Describes the 30-item Dental Health Assessment Profile as having adequate validity, reliability, and readability when it was tested on junior high students. The instrument can be used to facilitate direct assessment of dental health knowledge, beliefs, and practices.

Ott, B.B., & Hardie, T.L. (1997). Readability of advance directive documents. *Image—The Journal of Nursing Scholarship*, 29(1), 53-57.

Assessed the readability of advance directive documents used to inform patient choice in end-of-life decisions. All documents examined were above the reading levels usually recommended for patients. Refinement of such documents was recommended to support patient understanding and autonomy in end-of-life care.

Weidmer, B., Brown, J., & Garcia, L. (1999). Translating the CAHPS 1.0 Survey Instruments into Spanish. *Medical Care*, *37*(3 Suppl), MS89-96.

Tests the validity of a translation-backtranslation method of translating the Consumer Assessment of Health Plans Study (CAHPS) survey instruments into Spanish. Results showed that the Spanish-language versions of the survey instruments were adequate for those with higher levels of education, but inadequate for respondents with fewer than 6 years of education. Recommends that future Spanish-language instruments be subject to rigorous testing and evaluation by a literacy expert.

Weiler, R.M., Sliepcevich, E.M., & Sarvela, P.D. (1993). Development of the Adolescent Health Concerns Inventory. *Health Education Quarterly*, 20(4), 569-583.

Describes the three forms of the AHCI, which assessed the health concerns of adolescents and teachers' and parents' beliefs about adolescent health concerns. Readability of the Inventory was estimated at the eighth-grade level with the SMOG readability formula.

6B. Health Instruments: Validity Issues

Ahijevych, K., & Berhard, L. (1994). Health-promoting behaviors of African American women. *Nursing Research*, 43(2), 86-89.

A comparison of the health-promoting lifestyle behaviors of 187 African American women with scores on the Health-Promoting Lifestyle profile (HPLP). The scores of the women in the study were lower than HPLP reports for other groups, indicating the

readability and applicability of the HPLP may affect reliability and validity in a diverse sample.

Ferraz, M.B., Quaresma, M.R., Aquino, L.R.L., Atra, E., Tugwell, P., & Goldsmith, C.H. (1990). Reliability of pain scales in the assessment of literate and illiterate patients with rheumatoid arthritis. *Journal of Rheumatology*, *17*, 1022-1024.

Studies the reliability of three pain scales, visual analogue scale (VAS), numerical rating scale (NRS), and verbal rating scale (VRS), in 66 literate and 25 illiterate rheumatoid arthritis patients. Concludes that NRS has the highest reliability as a measure of chronic pain in both groups of patients.

MacDiarmid, S.A., Goodson, T.C., Holmes, T.M., Martin, P.R., & Doyle, R.B. (1998). An assessment of the comprehension of the American Urological Association Symptom Index. *Journal of Urology*, *159*(3), 873-874.

Assessment of the reading level of the American Urological Association (AUA) symptom index. The index requires a minimum grade 6 reading level. A significant percentage of patients could not read the index and required assistance from others.

Reis, A., Guerreiro, M., & Castro-Caldas, A. (1994). Influence of educational level of non brain-damaged subjects on visual naming capacities. *Journal of Clinical & Experimental Neuropsychology*, 16(6), 939-942.

Study of the visual naming capability of patients with different education levels. Poor visual naming skills were correlated with illiteracy and there was a clear influence of educational level on the ability to name photographs and line drawings. The authors suggest that these results be taken into consideration when selecting tests for poorly educated or illiterate populations.

Sullivan, L.M., Dukes, K.A., Harris, L., Dittus, R.S., Greenfield, S., & Kaplan, S.H. (1995). A comparison of various methods of collecting self-reported health outcomes data among low-income and minority patients. *Medical Care*, *33*(4 Suppl.), AS183-194.

Study compared response rates, item completion rates, and internal reliabilities and consistencies of self-reported health status measures between patients with and without literacy limitations. Three methods of data collection (mail-out/mail-back, hand-out/assisted, or in-home interview) were used. Those patients with limited literacy skills provided high quality, reliable data across all methods of collection, challenging the assumption that reliable data cannot be obtained from low-income minority patients by self-administered questionnaires.

7. Program Descriptions

7A. Literacy Noted as Key Issue

Ammerman, A.S., DeVellis, B.M., Haines, P.S., Keyserling, T.C., Carey, T.S., DeVellis, R.F., & Simpson, R.J. Jr. (1992). Nutrition education for cardiovascular disease prevention among low income populations—Description and pilot evaluation of a physician-based model. *Patient Education & Counseling*, 19(1), 5-18.

Describes components of the Food for Heart Program, developed to facilitate primary care physicians' dietary counseling of patients with low literacy skills. Materials used in the program were assessed at the fifth- to sixth-grade level. Behavior change theory was used to guide the intervention and evaluations show that the program had a positive impact on physicians' counseling styles.

Berger, D., Inkelas, M., Myhre, S., & Mishler, A. (1994). Developing health education materials for inner-city low literacy parents. *Public Health Reports*, 109(2), 168-172.

Describes "A Parent's Guide: When Your Child Is Sick," an easy-to-use reference booklet directed at low-income, low-literacy parents.

Best, D.G. (1994). The development of a guide for stroke survivors and their families. *Canadian Journal of Cardiovascular Nursing*, *5*(3), 35-38.

Describes the development of an educational guide for stroke survivors and their families in Canada. The content of the guide is discussed, as well as the process used in its development. A literacy expert assisted in the preparation of the final product.

Corrarino, J.E., Walsh, P.J., & Anselmo, D. (1999). A program to educate women who test positive for the hepatitis B virus during the perinatal period. *American Journal of Maternal Child Nursing*, 24(3), 151-155.

Describes a computerized program designed to educate women who test positive for the hepatitis B virus during the perinatal period about the disease and the risk of transmission to infants. The program, an 18-page color slide presentation intended to be jointly viewed by a nurse and a patient during a home visit, was developed using techniques for low-literacy populations, including the use of short sentences, illustrations, and adequate spacing between information.

Davis, T.C., Berkel, H.J., Arnold, C.L., Nandy, I., Jackson, R.H., & Murphy, P.W. (1998). Intervention to increase mammography utilization in a public hospital. *Journal of General Internal Medicine*, *13*, 230-233.

Describes a randomized intervention study, which sought to increase utilization of screening mammography in 445 low-income, low-literate women over age 40. At six months follow-up, there was a 30 percent increase in the mammography utilization rate in the group that received a recommendation by a physician, and easy-to-read National Cancer Institute brochure, and a 12-minute interactive educational program developed in collaboration with the women from the target population. Results indicate that simply

providing women with low-literacy educational materials is not sufficient and that the only significant predictor of increased utilization of mammography was the custom-made intervention program.

Harlander, C., & Ruccione, K. (1993). Fotoplacia: An innovative teaching method for families with low-literacy and high stress. *Journal of Pediatric Oncology Nursing*, 10(3), 112-114.

Hartman, T.J., McCarthy, P.R., Park, R.J., Schuster, E., & Kushi, L.H. (1997). Results of a community-based low-literacy nutrition education program. *Journal of Community Health*, 22(5), 325-341.

Offers evaluation findings of the Twin Cities Metropolitan area Expanded Food and Nutrition Education Program (EFNEP), which focused on low-fat eating pattern changes in low-literacy participants. Principal effects seen for the program are related to changes in eating pattern scales.

Jeffers, D.F. (1993). Outreach childbirth education classes for low-income families: A strategy for program development. *AWHONNS Clinical Issues in Perinatal & Women's Health Nursing*, 4(1), 95-101.

Describes the Florida Outreach Childbirth Education Project as an example of a program specifically designed to serve a low-income, low-literacy population. The goal of the program is to give parents the knowledge, desire, and confidence they need to change damaging health behaviors.

Levin, S. (1996). Pilot study of a cafeteria program relying primarily on symbols to promote healthy choices. *Journal of Nutrition Education*, 28(5), 282-285.

Describes a program using symbols (such as a heart to imply "heart smart") at the point-of-purchase in two urban worksite cafeterias to promote healthy food choices that would be understood by employees with a range of literacy skills. Sales of targeted entrees increased significantly after being labeled with heart smart symbols and the increase persisted for at least 7 months.

Mahloch, J., Jackson, J.C., Chitnarong, K., Sam, R., Ngo, L.S., & Taylor, V.M. (1999). Bridging cultures through the development of a cervical cancer screening video for Cambodian women in the United States. *Journal of Cancer Education*, *14*(2), 109-114.

Describes the development of an educational and motivational video on Pap-testing within a low-literacy Cambodian refugee community in Seattle. Extensive qualitative collection helped inform the 18-minute Khmer language video, which aimed to provide information about cervical cancer and Pap-testing in a manner consistent with traditional Cambodian beliefs about disease and health practices. Offers suggestions as to how health educators may develop and use videos to bridge literacy and cultural gaps with immigrant communities.

Mason, T., Duffy, M.A., Faulk, D., & Lazenby, R. (1995). A collaborative effort for rural health. *Nursingconnections*, 8(1), 45-49.

Describes the collaboration between the W.K. Kellogg Foundation and a school of nursing to meet environmental and health care needs in two rural counties, both with high rates of poverty and illiteracy.

Olson, R.M., Blank, D., Cardinal, E., Hopf, G., & Chalmers, R.K. (1996). Understanding medication-related needs of low-literacy patients. *Journal of the American Pharmaceutical Association*, *NS36*(7), 424-429.

Describes an evolving project to increase pharmacy students' understanding of the medication-related needs and perspectives of low-literacy patients through a three-step oral interview process. A caring relationship between pharmacists and patients was found to be essential for patients to be open and receive advice about medication use.

Paskett, E.D., Tatum, C., Wilson, A., Dignan, M., & Velez, R. (1996). Use of a photoessay to teach low-income African American women about mammography. *Journal of Cancer Education*, 11(4), 216-220.

Describes and offers findings of a breast cancer screening education program for African American women living in low-income housing communities. The use of a photoessay, depicting the process of getting a mammogram, was used to address issues of limited knowledge and low literacy. Evaluations of the program showed women liked the photoessay, felt it provided knowledge about mammography, and indicated that it reduced fears about the procedure.

Plimpton, S., & Root, J. (1994). Materials and strategies that work in low literacy health communication. *Public Health Reports*, *109*(1), 86-92.

Describes the Maine Area Health Education Center's program focusing on low literacy health communication. Professionals were trained to produce easy-to-read health materials. The discussion provides a model for teaching oral communication skills to health care providers who deal with low-literacy adults.

Rudd, R.E., & Comings, J.P. (1994). Learner developed materials: An empowering approach. *Health Education Quarterly*, *21*(3), 313-327.

Describes four case examples based on a Freirian educational method to include participant involvement in the development of learning materials. Discusses the production process as empowering for participants and the final product as reflecting the people and language of the larger community. The authors suggest that participatory materials development be incorporated into community-based programs.

Ruud, J., Betts, N.M., & Dirkx, J. (1993). Developing written nutrition information for adults with low literacy skills. *Journal of Nutrition Education*, 25, 11-16.

"The Dietary Guidelines and Your Diet" was developed for use by adults with low literacy skills and was written at the fifth-grade reading level. The booklet was tested by approximately 150 men and women with limited literacy, and then revised as needed. Participants were especially interested in "how to" and "did you know" sections, indicating the need for nutrition information among low literate adults.

Yasenchak, P.A., & Bridle, M.J. (1993). A low-literacy skin care manual for spinal cord injury patients. *Patient Education & Counseling*, 22(1), 1-5.

Describes the development of a patient education manual for people with low literacy skills. The pamphlet included information about ulcer prevention for patients with spinal cord injuries. It was written at the fifth-grade level.

7B. Literacy Noted

Branche, G.C. Jr., Batts, J.M., Dowdy, V.M., Field, L.S., & Francis, C.K. (1991). Improving compliance in an inner-city hypertensive patient population. *American Journal of Medicine*, 91(1A), 37S-41S.

Describes measures taken to increase patient compliance among inner-city hypertensive patients, many of whom lived in poverty, were illiterate, or used drugs. A strong correlation was noted between patient compliance and the administration of agents with longer dosing intervals and improved side effect profiles.

Curry, R.H., Moen, J.B., Morris, S.J., & Scheivelhud, L. (1994). Community-directed cancer screening program. *Cancer Practice*, 2(4), 256-263.

Describes the Atlanta Project, an American Cancer Society demonstration project with a focus on breast and cervical cancer prevention, which encourages African American women to accept responsibility for their own health. Discusses the Project's goals, objectives, intervention strategies, and key personnel, as well as lessons learned.

Fouad, M.N., Kiefe, C.I., Bartolucci, A.A., Burst, N.M., Ulene, V., & Harvey, M.R. (1997). A hypertension control program tailored to unskilled and minority workers. *Ethnicity & Disease*, 7(3), 191-199.

Describes and offers evaluation findings of a comprehensive worksite health promotion program designed to reduce risk factors for cardiovascular disease among blue-collar, city of Birmingham employees. Low literacy is noted as one of the barriers to hypertension control. Results showed the educational intervention, tailored to the specific needs of low literacy populations, had a significant effect on hypertension control.

Podschun, G.D. (1993). Teen Peer Outreach-Street Work Project: HIV prevention education for runaway and homeless youth. *Public Health Reports*, 108(2), 150-155.

Describes a project that trains teen peer educators to work in three San Diego youth service programs with street outreach staff members to provide HIV prevention education and referral services to San Diego's homeless youth. The author suggests the need for education materials specifically targeted to homeless youth with low literacy levels.

Shadick, K.M. (1993). Development of a transcultural health education program for the Hmong. *Clinical Nurse Specialist*, 7(2), 48-53.

Describes a pluralistic model of education and its application in the development and implementation of a health education program for the Hmong. The author also analyzes the appropriateness and effectiveness of such a transcultural education process.

Shea, S., Basch, C.E., Weschler, H., & Lantigua, R. (1996). The Washington Heights-Inwood Healthy Heart Program: A 6-year report from a disadvantaged urban setting. *American Journal of Public Health*, 86(2), 166-171.

Summarizes a large community-based cardiovascular disease prevention program in an urban setting. The population served included many Latino immigrants with low SES and education levels. All of the materials were written for low literacy levels in both English and Spanish. The authors offer suggestions for those developing similar complex programs in other socially disadvantaged communities.

Wands, S.E., & Yassi, A. (1992). "Let's Talk Back": A program to empower laundry workers. *American Journal of Industrial Medicine*, 22(5), 703-709.

Describes a program that provided formal educational assistance, physical demand analyses, and a forum for communicating concerns and suggestions for improvements in laundry worker safety. Low literacy levels were discussed as a barrier, requiring innovative educational approaches.

8. Guidelines for Practice

8A. Materials/Readability

Anscher, M.S., & Gold, D.T. (1991). Literacy and laryngectomy: How should one treat head and neck cancer in patients who cannot read or write? *Southern Medical Journal*, 84(2), 209-213.

Surveyed 192 physicians who treat patients with head and neck cancer in North Carolina and found that illiteracy is perceived as a problem that may impact patients. Notes that doctors lack the data needed to enable them to quantify the effect of illiteracy on treatment outcome.

Baker, G.C. (1991). Writing easily read patient education handouts: A computerized approach [Review]. *Seminars in Dermatology*, 10(2), 102-106.

Describes the use of computerized readability formulas and offers suggestions for writing handouts.

Bernier, M.J. (1993). Developing and evaluating printed education materials: A prescriptive model for quality. *Orthopaedic Nursing*, *12*(6), 39-46.

Describes the use of the Evaluating Printed Education Materials (EPEM) model as a guide for developing printed education materials. The five phases of the model and design principles are discussed in terms of increasing the relevance, readability and comprehensibility of materials. Presents an example of how this patient-centered model can be used with orthopedic patients.

Buck, M.L. (1998). Providing patients with written medication information. *The Annals of Pharmacotherapy*, 32, 962-969.

Reviews literature on written medication information and provides recommendations on developing and using these tools for patient education. Notes that many materials are often written at reading levels higher than that of the average patient, and advocates the use of resources written at the sixth-grade level.

Brez, S.M., & Taylor, M. (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25(5), 1040-1047.

Highlights the importance of assessing understanding among patients with low-literacy skills to facilitate the planning of patient teaching in a hospital setting. A conceptual model of the screening responses was developed and compared to the Health Belief Model and Knox's Proficiency Theory of adult learning. Implications for the health professions were discussed.

Eisert, D.C., Sturner, R.A., & Mabe, P.A. (1991). Questionnaires in behavioral pediatrics: Guidelines for selection and use [Review]. *Journal of Developmental & Behavioral Pediatrics*, 12(1), 42-50.

Eng, T.R., Maxfield, A., Patrick, K., Deering, M.J., Ratzan, S.C., Gustafson, D.H. (1998). Access to health information and support: A public highway or private road? *JAMA*, 280(5), 1371-1375.

Though emerging information technology has the potential to reduce health disparities, universal access to health information via this medium is hampered by several barriers including illiteracy. Recommends that public and private sector agencies work together to ensure greater access to health information by diverse populations.

Evanoski, C.A. (1990). Health education for patients with ventricular tachycardia: Assessment of readability. *Journal of Cardiovascular Nursing*, 4(2), 1-6.

Giordano, B.P. (1996). Ensuring the readability of patient education materials is one way to demonstrate perioperative nurses' value. *AORN Journal*, 63(4), 699-700.

Kenny, T., Wilson, R.G., Purves, I.N., Clark, J., Newton, L.D., Newton, D.P., Moseley, D.V. (1998). A PIL for every ill? Patient information leaflets (PILs): A review of past, present and future use. *Family Practice*, *15*(5), 471-479. Reviews patients' and doctors' perspectives on written medical information and advocates the distribution of well-written PILs, emphasizing the importance of testing materials for comprehension and readability.

Kohlmeier, L., Mendez, M., McDffie, J., & Miller, M. (1997). Computer-assisted self-interviewing: A multimedia approach to dietary assessment [Review]. *American Journal of Clinical Nutrition*, 65(4 Suppl.), 1275S-1281S.

Review of computer-assisted self-interviewing (CSAI) programs for dietary assessments. The diet-history approach was taken in development of a CSAI prototype, which was then tested in focus groups with encouraging results. Suggests the development of a multimedia-based dietary assessment tool as a logical next step.

Mandl, K.D., Kohane, I.S., Brandt, A.M. (1998). Electronic patient-physician communication: Problems and promise. *Annals of Internal Medicine*, *129*(6), 495-500.

Identifies potential promises and pitfalls of electronic patient-physician communication, and proposes a research agenda to evaluate this emerging form of communication. Addresses the need for new medical communication systems to be accessible to populations with varying degrees of literacy.

Morra, M.E. (1991). Future trends in patient education. *Seminars in Oncology Nursing*, 7(2), 143-145.

Notes increasing illiteracy rates as one factor that will create challenges and opportunities in the field of patient education.

Root, J., & Stableford, S. (1999). Easy-to-read consumer communications: A missing link in Medicaid managed care. *Journal of Health Politics, Policy and Law*, 24(1), 1-26.

Describes three national training workshops entitled "How to Write for the Medicaid Market," sponsored by the Center for Health Care Strategies. Training was provided for organizations designing and implementing Medicaid managed care programs in developing easy-to-read materials for individuals moving into these programs. Based on post-workshop evaluations, offers conclusions on communication failures in the Medicaid system and proposes a national agenda to address the problem.

Stephens, S.T. (1992). Patient education materials: Are they readable? *Oncology Nursing Forum*, 19(1), 83-85.

Describes the discrepancy between the reading level of the average adult (between fifth- and eighth-grade) and the level required to read cancer education materials (between eighth- and twelth-grade). Also gives an example of how to calculate a readability formula.

Szczepanik, M.E. (1995). Assessment and selection considerations: ESRD patient and family education materials and media [Review]. *Advances in Renal Replacement Therapy*, 2(3), 207-216.

Discusses four specific types of materials and media for patients with end-stage renal disease; highlights considerations for developing in-house materials.

8B. Patient/Health Education

Barnes, L.P. (1992). The illiterate client: Strategies in patient teaching. *MCN: American Journal of Maternal Child Nursing*, 17(3), 127.

Beitz, J.M. (1998). Education for health promotions and disease prevention:

Convince them, don't confuse them. *Ostomy Wound Management*, 44(3A Suppl.), 71S-76S.

Provides guidelines for successful health education programs, including ensuring that health education materials match learners' literacy levels.

Brunt, M.J., Milbauer, M.J., Ebner, S.A., Levenson, S.M., Millen, B.E., Quatromoni, P., & Chipkin, S.R. Health status and practices of urban Carribbean Latinos with diabetes mellitus. *Ethnicity & Disease*, *8*, 158-166.

Identifies health characteristics of 70 urban Caribbean Latinos with diabetes through interviews and reviews of medical records in an attempt to determine effective treatment strategies for this high-risk group. Based on findings, the authors recommend more culturally sensitive treatment programs in order to reduce the risk factors among this population, including the provision of low literacy materials to better communicate weight goals and dietary guidelines.

Crawford, S. (1995). Promoting dietary change [Review]. *Canadian Journal of Cardiology, 11*(Suppl. A), 14A-15A.

Examines ways in which nutrition counseling can be enhanced to ensure that patients can develop a heart-healthy diet. Emphasizes active problem solving and development of self-efficacy.

Davis, T.C., Meldrum, H., Tippy, P.K., Weiss, B., & Williams, M.V. (1996). How poor literacy leads to poor health care. *Patient Care* (October 1996), 94-127.

Offers suggestions to health care providers for improved communication: address poor literacy, recognize the problem, simplify written and oral communications, and verify that patients have received and understood important health-related messages.

Doak, C.C., Doak, L.G., Friedell, G.H., & Meade, C.D. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. *CA—A Cancer Journal for Clinicians*, 48(3), 151-162.

Provides clinicians with strategies to improve their communication with cancer patients, especially those who have limited literacy skills. Topics discussed in the article include how literacy problems affect the course of cancer treatment and practical strategies to help patients understand medical advice. Methods for developing low-level reading materials and techniques to help patients remember information are also described.

Dudley, T.E., Falvo, D.R., Podell, R.N., & Renner, J. (1996). The informed patient poses a different challenge. *Patient Care* (October 1996), 128-138. Suggests how health care practitioners can enhance relationships with patients who want to learn as much as they can about their health, but are sometimes misled.

Evans, J.H.C., Collier, J., Crook, I., Garrud, P., Harris, P., Mackinlay, D.R.E., & Redsall, S.A. (1998). Using multimedia for patient information—A program about nocturnal enuresis. *British Journal of Urology*, 81(Suppl. 3), 120-122. Describes the development of an interactive program about bedwetting, which runs on a personal

computer and uses sound, voice, cartoon drawings, and animation. Results show that knowledge increased in clinic patients and schoolchildren after using the program. The authors suggest this method of communication is useful for children with low literacy skills.

Fain, J.A. (1994). Assessing nutrition education in clients with weak literacy skills. *Nurse Practitioner Forum*, *5*(1), 52-55.

Presents various strategies for Nurse Practitioners wishing to provide nutrition education and counseling to clients with low literacy skills.

Gollop, C.J. (1997). Health information-seeking behavior and older African American women. *Bulletin of the Medical Library Association*, 85(2), 141-146. Explores the ways in which urban, older, African American women obtain health information and those factors influencing their action. Determinants of health-seeking behavior included: self-perceived literacy, access, and mobility. Findings indicate health information is received from physicians, the media, and social networks. Recommends the provision of health information at public libraries.

Hussey, L.C. (1991). Overcoming the clinical barriers of low literacy and medication noncompliance among the elderly. *Journal of Gerontological Nursing*, 17(3), 27-29.

Suggests the use of tailoring and cueing to improve elderly patients' compliance with medication. Highlights the importance of not altering the patients' everyday lives and supporting patients' control of the medication schedule.

Lynch, M.E. (1992). When the patient is illiterate: How nurses can help. *Journal of Practical Nursing*, 42(1), 41-42.

Describes the importance of "teachable moments," when nurses can contribute to the care of illiterate patients. The author recommends that discharge teaching should not be a time to begin teaching but should instead offer a review of all of the instructions given during the patient's hospital stay.

Ventres, W., & Gordon, P. (1990). Communication strategies in caring for the underserved. *Journal of Health Care for the Poor and Underserved*, 1(3), 305-314.

Describes specific strategies that practitioners and educators can use to empower and improve communication with poor patients. These strategies include employing attentive patient care, being aware of the use of jargon, and using language that is self-empowering.

Wallerstein, N. (1992). Health and safety education for workers with low-literacy or limited-English skills. *American Journal of Industrial Medicine*, 22(5), 751-765.

Describes the various dilemmas facing health and safety professionals in incorporating knowledge about language and literacy skill levels. Explores creative strategies and innovative programs that lead to worker empowerment.

Wallerstein, N., & Weinger, M. (1992). Health and safety education for worker empowerment. *American Journal of Industrial Medicine*, 22, 619-635. Introduces the special issue of the *American Journal of Industrial Medicine*, which describes many approaches to worker education and health safety. Empowerment education is described and contrasted with other training methods and suggestions are made on translating theory into practice. Evaluation issues are discussed and other articles in the journal are briefly reviewed.