HEALTH LITERACY IN A RURAL CLINIC

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ABSTRACT

Purpose: Health literacy is a critical prerequisite to effective self-management of any health problem. Nearly half of all adult U.S. citizens have difficulty with reading skills. For those living in rural areas who also experience health literacy deficits, self-management of health needs is doubly problematic. Rural dwellers are more likely to delay treatment for health problems and more likely to experience chronic health problems than their urban counterparts. The purpose of this research was to assess the health literacy of those seeking care in a rural health clinic.

Design: The design of this descriptive study was a one-time survey using a convenience sample of 57 patients (89% Caucasian, 65% female) from a rural clinic in the southeastern United States. Data were collected in Fall 2003.

Methods: The REALM (Rapid Estimate of Adult Literacy in Medicine) test and a demographic questionnaire were administered by trained nursing students to consenting patients as they arrived for clinic appointments. Data were analyzed descriptively and with non-parametric one-way ANOVA.

Findings: The mean REALM score was 55.9 on a scale of 0 to 66. Half of the participants (n = 29; 50.8%) read at the high school level, and 6 (11%) read at grade six or lower. Females scored significantly higher than males. The more difficult words included "impetigo," "colitis," "osteoporosis," and "diagnosis."

Conclusions: Health literacy is a significant barrier to effective health care for many rural dwellers, particularly males. Health care providers can minimize the negative consequences of limited health literacy by assessing the literacy of their population and adjusting written and verbal communications accordingly.

INTRODUCTION

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (United States Department of Health and Human Services [USDHHS], 2000) or even more simply, as "the ability to read, understand, and act on health information" (Andrus & Roth, 2002, p. 283). Health literacy is crucial if patients are to benefit from health care. People who cannot read or understand the words used to describe health problems, diagnostic tests, medications, and directions for care experience yet another source of confusion in negotiating the health care system and are significantly handicapped in the tasks of self-care or caring for family members.

The problems of low health literacy may be especially acute for those who live in rural areas. Rural areas are characterized by residents with lower levels of education, higher rates of unemployment, lower salaries, and lack of health insurance (Ricketts,

1999; Gamm, Hutchison, Dabney, & Dorsey, 2003). Rural dwellers are culturally likely to delay seeking health care until a condition has become advanced or urgent or until multiple chronic conditions exist. They then experience a relative shortage of health care sites and choices, a need to travel greater distances to reach health care, problems of transportation, and, very probably, an explanation of a complicated treatment regimen to act upon (Eberhardt, Ingram, Makuc et al. 2001; Doak, Doak, & Root, 1996).

Recognition of the importance of health literacy is a relatively recent phenomenon. Ten years ago the concept was rarely studied or remarked upon. Today, more than 400 articles and books have been published on the topic. As effective self-care can occur only in those who understand what they must do and why, the purpose of this research was to assess the health literacy of those seeking care in a rural health clinic.

BACKGROUND

Health Literacy

The state of general functional literacy in the United States is not high. According to the National Adult Literacy Survey (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993), nearly half of all adult U.S. citizens have difficulty with reading skills. The state of health literacy can be even lower than general functional literacy because the medical vocabulary people encounter in health care settings or in the news is more complex than that of other areas of life, and because changes in the nature of illness from episodic to chronic conditions and in health care delivery now require patients to be active participants in their care. For example, the patient is the primary caregiver in diabetes. The health care provider assists the patient, since nearly all diabetes care occurs outside the formal health care environment.

In addition to self-care for illness, patients must now make critical life choices on entrance into the health care system. Consent to treatment, Health Insurance Portability and Accountability Act (HIPAA) acknowledgements, advanced directives, health history forms, and assignment of responsibility all must be completed before entering the patient treatment area. The actual instructions for care, directions to other facilities for diagnostic procedures known by either mystifying initials or "hard" names like "computerized tomography," and prescriptions and product inserts that appear to be written in a foreign language are difficult enough for educated people but can be overwhelming to those with limitations in health literacy.

People of low health literacy are neither unintelligent nor unmotivated (Cheatham, 1993; Doak, Doak, & Root, 1996). Although reticent to ask for assistance because of shame and embarrassment (Cheatham, 1993; Nurss et al. 1997; Parikh et al. 1996), those who struggle with literacy do have the ability to learn, if appropriate explanations are given or if patient education materials are presented at their level. Until quite recently the difficulty of educational materials for patients was not considered and the reading level of many materials was high. Health care instructions are frequently written at a ninth grade level (Davidhizar & Brownson, 1999). A minimum 7th grade reading level was calculated for all but one over-the-counter drug label in a study of 21 common medications (Holt, Hollon, Hughes et al. 1990). For those invited to participate in research, the informed consent is a formidable challenge when written at the 13th-31st

grade level (Andrus & Roth, 2002), leading one to question whether the consent can truly be informed.

Although the production of print and web-based patient education materials is growing and is likely to increase, there is still a need for practitioners to be aware of the importance of health literacy and to assess their populations. Nath, Sylvester, Yasek, and Gunel (2001) reported that helping with low health literacy is challenging, but the actual difficulty is identification of those in need. The elderly seem to be at high risk. More than a third of Medicare managed care enrollees had poor health literacy in research reported by Gazmararian et al. (1999).

The only health literacy research focused on a rural population (Montalto & Spiegler, 2001) was conducted to assess the literacy level of a clinic population and the resultant adjustments in care made by the health care providers. That research used the Test of Functional Health Literacy in Adults (TOFHLA) and reported that 15% of the 70 participants had a literacy/numeracy deficit.

Health care providers who are aware of the very real ill effects of low health literacy may be more willing to consider it in their care. Williams, Baker, Parker, and Nurss (1998) compared the health literacy of people with hypertension and diabetes to knowledge about the disease and found that only around half of those with inadequate health literacy knew important clinical signs required for disease self-management. Glycemic control was worse for people with diabetes and health literacy problems according to Schillinger et al. (2002). The combination of inadequate health literacy and chronic illness, such as diabetes, reduces the likelihood that people will participate in their care to the extent needed for effective disease management (Chwedyk, 2003). The complexity of adherence to HIV therapies is made more difficult for those with low health literacy. Interventions directed at those with low health literacy were recommended after health literacy was identified as an independent predictor of missed drug doses for HIV-seropositive men and women (Kalichman, Ramachandran, & Catz, 1999).

Problems with health literacy also increase the costs of care. Compared with persons with adequate health literacy, persons of low health literacy experienced greater difficulty in navigating the health care system (Weiss, 1999), 50% more hospital admissions (Baker, Williams, Parker, & Clark, 1998), and more errors in personal health management (Williams, Baker, Honig, Lee, & Nowlan, 1998). Estimates of 2001 expenditures for health care as a result of low literacy ranged from $32-58 billion (Center for Health Care Strategies, 2003).

METHODS

Population

The accessible population for this research consisted of patients in a rural health clinic managed by a college of nursing and university located in the southeastern United States. The nearest acute care facility is 30 miles away. Care is provided by nurse practitioners. The clinic serves as a site for baccalaureate nursing student experiences for the college of nursing, and all students enrolled in the medical-surgical course provide care in the clinic each semester.

The clinic serves approximately 2,500 people of all ages who live in the area. More than half of all visits (57.7%) are made by patients with Medicare (35.7%) and Medicaid (22%) while the uninsured population accounts for 29.7% of all visits to the clinic. A significant proportion of the patients have chronic health problems such as hypertension, diabetes, cardiovascular disease, and lung disease (J. Dunkin, personal communication, December 23, 2003). Low literacy is likely, considering the nature of the population. All patients age 18 or older were invited to participate in the research during their clinic visit.

Instruments

Rapid Estimate of Adult Literacy in Medicine (REALM) Test is a word recognition test appropriate for adults that has been used with patients in clinical settings. The 66-item test consists of three columns of 22 words frequently used in health care that progressively increase in difficulty. The test takes less than 5 minutes to administer and score. Grade-range equivalents and probable patient abilities to manage health information are provided as well. For example, scores of 61-66 indicate that the person reads at the high school level and will be able to read most patient education materials. Scores of 45-60 reflect a 7th-8th grade reading level and patients will experience difficulty with most patient education materials. Those scoring between 19 and 44 will need low literacy materials, and those scoring below 19 will need information presented using a format other than written. Reported correlations with other standardized health literacy assessments ranged from 0.88-0.97 and test-retest reliability was reported at 0.99 (Davis et al. 1993).

The REALM was selected for its brevity, ease of administration and scoring, and relevance to the clinic population in that health-related words are used. Although word recognition tests do not measure comprehension recognition is a precursor to the more complex skill of comprehension. An individual experiencing difficulty with word recognition will likely have problems with comprehension, as well. Comprehension tests also take much longer to administer (Nath et al. 2001). The REALM provides grade-range data; not specific grade-level assessment of literacy, but for use in most health care situations, the lack of grade-specific data is irrelevant (Doak, Doak, & Root, 1996).

Procedure

The research was approved by The University of Alabama Institutional Review Board and the rural health clinic in which data were collected. Data were collected between September and November 2003. All fall semester students were trained as data collectors by the investigator. The importance of confidentiality in data collection and management was stressed. Student ability to read each word correctly was verified. Students were instructed in the scoring procedure and their scoring was validated by the investigator.

Patients were approached in the waiting room of the clinic and informed about the research. Oral consent to participate in the research was read to prospective participants by the student data collectors. The oral consent was organized in a question and answer format to facilitate understanding by potential participants. Those agreeing to participate

completed the data collection instruments in a private area to avoid possible embarrassment. The only notation of patient participation was "HL" (health literacy) in the chart to indicate that the patient had been asked to participate in the research. This strategy was designed to prevent repeated requests to patients who may have sought care at the clinic several times during the data collection period. REALM scores of participants were not recorded in the patient record to prevent any adverse consequences for the patients, as recommended by Giorgianni (1998) and Davis et al. (1998).

FINDINGS

Students provided care to 133 eligible clinic patients during the data collection period. Sixty patients agreed to participate, of whom three withdrew before finishing. The final sample of 57 represented a participation rate of 43%.

Sample characteristics are displayed in Table 1. Racially, the sample mirrored the county population with 89% (n=51) Caucasian and 11% (n=6) African American. Most participants (n=52; 91%) resided in the county in which the clinic is located; the remainder lived in adjacent counties. Approximately two-thirds were female (n=37; 65%), and one-third male (n=20; 35%). The mean age of these clinic patients was 46.7 (S.D.=5.3) with a range of 23 to 70. Only 18 (32%) of the participants had education beyond the high school diploma; 30% (n=17) had earned the high school diploma and 35% (n=20) had not completed high school.

Table 1
Demographic data of participants in health literacy assessment

	Male		Female	
Variable	n	%	n	%
Age				
20-29	0	0%	3	8%
30-39	8	40%	6	16%
40-49	3	15%	14	38%
50-59	5	25%	8	22%
60-69	4	20%	5	14%
70-	0	0%	1	3%
Ethnicity				
Caucasian	0	0%	34	92%
African American	8	40%	3	8%
County of Residence				
Same as clinic	20	100%	32	68%
Adjacent county	0	0%	5	14%
Years education completed [1]				
Less than 6	2	10%	1	3%
6-9	1	5%	2	5%
10-13	4	20%	10	27%
High school diploma	6	30%	11	30%
Some college	6	30%	8	22%
College degree	0	0%	4	11%

[1] Missing data n=2; 4%

REALM scores, displayed in Table 2, ranged from 0 to 66. The mean REALM score was 55.9 (S.D. = 16.3). Nine participants (16%) correctly pronounced all 66 words and 2 (4%) were unable to pronounce any of the words on the assessment.

Table 2
REALM scores (Possible Range 0-66; Actual Range 0-66)

	Male		Female	
REALM score	n	%	n	%
0-18	3	15%	1	3%
19-44	0	0%	2	5%
45-60	10	50%	12	32%
61-66	7	35%	22	59%

Non-parametric one-way analysis of variance was used to test for a difference in REALM scores. This test was selected because the distribution of REALM scores was not normally distributed. Statistical analysis of the relationships between age and REALM score, gender and REALM score, and ethnicity and REALM score yielded only one significant finding. Females scored significantly higher than males on the REALM in this sample (p=0.036) using the Kruskal-Wallis test.

More than half (n=35; 61%) were unable to pronounce the word "impetigo"; "colitis" was problematic for 30 (53%) of the participants (Table 3). Other words that were difficult for these clinic patients included "osteoporosis" (n=23; 40%), "anemia" (n=18; 32%), "inflammatory" (n=14; 25%), "allergic" (n=13; 23%), and "diagnosis" (n=12; 21%).

Table 3
Frequently missed words

	Male		Female	
Word	n	%	n	%
Impetigo	19	95%	17	46%
Colitis	16	80%	14	38%
Osteoporosis	13	65%	10	27%
Anemia	12	60%	6	16%
Diagnosis	6	30%	6	16%
Rectal	5	25%	6	16%
Appendix	7	35%	5	14%
Allergic	7	35%	6	16%
Inflammatory	6	30%	8	22%
Gonorrhea	7	35%	6	16%

DISCUSSION

This research demonstrated that health literacy is a very basic problem in the rural clinic population. Nearly half (n=28; 49%) of the clinic patients who consented to participate in this research would be unable to read most patient education materials, based on their REALM score, and would benefit from low literacy and audiovisual education strategies. The grade equivalent range provided with the REALM test indicated that four of the participants (7%) functioned at lower than a fourth grade level in which even low literacy materials would be problematic; another 2 (4%) scored between the fourth and sixth grade levels indicating that these patients would most likely struggle with reading prescription labels and would benefit from low literacy materials. Twenty-two (38.6%) were able to read at the seventh or eighth grade level and probably would struggle with reading most patient education materials. Twenty-nine participants (50.8%) read at the high school level on this health literacy assessment, a level which should signify ability to read most patient education materials. Compared with the research by Montalto and Spiegler (2001) in which only 15% of the rural population studied experienced health literacy deficits, this research identified nearly half of the sample (49%) with health literacy difficulties.

In the county where this research was conducted, only 67.2% of the population had attained high school diplomas in contrast to 75.3% statewide; only 9.1% had earned baccalaureate degrees in the county compared to 19% in the state where data were collected (U.S. Census Bureau, 2003). Even though 62% of the participants had completed high school, nearly half were unable to read health care terminology at a high school level, supporting Davidhizar and Brownson's assertion that "reading is a skill that atrophies with disuse" (p. 42, 1999). The number of clinic patients who declined to participate in the research is probably an indicator of literacy difficulties as well (Nurss et al. 1997). The research also demonstrated that a quick, easy-to-use assessment of health literacy can be administered and scored as part of the admission assessment in a health care facility.

For this sample, females scored significantly higher on the REALM than male participants. Based on these data, nurses should be particularly attentive to data provided by male patients during the subjective assessment and should use strategies in addition to the printed word to meet the health teaching needs of male patients.

Nearly one of every five (19-21%) of the participants was unable to read words commonly used in health care. Words such as allergic, diagnosis, and inflammatory are extremely common and are critical to effective self-management of many health problems. Inability to understand these common words can lead to detrimental health outcomes. Patients are frequently given forms to complete asking if they have any allergies. Misreading this word could be life-threatening to the person who has a drug or treatment allergy but fails to share that information as a result of inability to recognize the printed word. Likewise, the word inflammatory is a common term used with many health care problems. Anti-inflammatory medications are prescribed for treatment of many conditions, and a lack of understanding of the word may lead to drug misuse.

Adherence to treatment prescriptions is likely affected by low health literacy in the 49% of this sample who had difficulty recognizing the words on the REALM test. Further research should explore the relationships among medication adherence, self-

management of health problems, and health literacy to assess the extent to which health literacy contributes to health outcomes such as disease management and cost of care.

Limitations

Several limitations may have affected the outcomes of this research. First, selection bias may have excluded those who were unable to read who did not want to reveal their literacy problems. If this did occur, the results would have yielded an even greater literacy problem within the rural clinic clientele. Shame and embarrassment are common among those with literacy difficulties, and making the choice not to participate in a study in which the patient would perform poorly is a self-protective mechanism. Those who attempt to conceal their literacy difficulties are at increased risk for treatment failure if they are unable to follow written prescriptions.

Second, the proportion of ethnic minorities in the sample was not large enough to represent rural African Americans. Further research should strive to achieve diversity in the sample to assess if a difference exists in the health literacy of rural dwellers based on ethnicity.

Finally, vision of the participants was not assessed and may have affected the performance of some of the participants, although none indicated difficulty during data collection. One of the most common reasons given for inability to complete forms is vision difficulty. "I forgot my glasses" may actually mean "I cannot read these words." Assessment of visual acuity by the researchers will ensure that the word recognition is not limited by inability to see the printed words.

CONCLUSIONS

Identification of those with limited health literacy is useful if the data are integrated into practice. Reducing the literacy level of all patient education materials will improve understanding for the majority of patients. Yet some will need even more assistance. Nurses have an obligation to ensure that teaching is not only provided, but understood. Validation of learning can only be assured if the patient is able to apply the knowledge shared between provider and patient. Many useful web-based and print resources are available including the references provided in this paper and the following:

- http://www.pfizerhealthliteracy.org
- http://www.askme3.org
- http://execsec.od.nih.gov/plainlang/guidelines/index.html
- http://cancer.gov/cancerinformation/clearandsimple
- http://www.hsph.harvard.edu/healthliteracy/index.html

These references provide assistance with assessing literacy and creating user-friendly education materials.

Although most patients in a rural clinic are well known to the health care providers, staff turnover will occur. Patient-centered policies need to be developed that allow staff to know which patients need assistance while promoting patient dignity. Nath et al. (2001) recommended research to evaluate the effect on patient outcomes and patient

relationships with health care providers for those who are identified to have literacy deficits and with whom interventions are conducted. Nurses and other health professionals can recognize the scope of functional health literacy problems and work to identify and assist those who struggle to meet the challenges of health care.

ACKNOWLEGMENTS

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