

# Parental Literacy Level and Understanding of Medical Information

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**ABSTRACT.** *Objective.* To ascertain the impact of literacy level on parents' understanding of medical information and ability to follow therapy prescribed for their children.

*Design/Methods.* A prospective cohort of parents accompanying their children for acute care. Parents were interviewed about demographic status, their child's health, and use of pediatric preventive services. The Rapid Estimate of Adult Literacy in Medicine (REALM) test was used to assess parental literacy. The same parent was interviewed 48 to 96 hours later and asked to recall the child's diagnosis, any medication prescribed, and instructions.

*Results.* A total of 633 patients were enrolled. Follow-up was obtained in 543 patients (85.8%). Mean parental age was 32.43 years (SD = 9.07). Mean REALM score was 57.6 (SD = 10.9), corresponding to a 7th- to 8th-grade reading level, with a mean parental educational level of 13.43 years (SD = 2.09). Low REALM score was significantly correlated with young parental age and parental education. African-American race was associated with lower REALM scores. After controlling for these variables, REALM score significantly correlated with parental perception of how sick the child was, but not with use of preventive services, comprehension of diagnosis, medication name and instructions, or ability to obtain and administer prescribed medications.

*Conclusions.* Parental literacy level did not correlate with use of preventive services or parental understanding of or ability to follow medical instructions for their children. *Pediatrics* 1998;102(2). URL: <http://www.pediatrics.org/cgi/content/full/102/2/e25>; *literacy, compliance, health status, knowledge.*

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ABBREVIATIONS. AAP, American Academy of Pediatrics; HMO, health maintenance organization; REALM, Rapid Estimate of Adult Literacy in Medicine.

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Illiteracy is a major problem in the United States. It is estimated that ~20% of American adults lack basic reading and writing skills (ranging from signing one's name to identifying basic information from a simple form), and an additional 25% are marginally literate (cannot fill out an application or interpret instructions for an appliance).<sup>1</sup> In fact, the

United States ranks 49 of the 159 members of the United Nations in average literacy level.<sup>2</sup> The problem of illiteracy in the United States may be getting worse, because the average literacy of young people in the 1993 National Adult Literacy Survey was lower than that found in a similar 1985 study.<sup>1</sup> Poor literacy skills are most prevalent among persons of low socioeconomic status but are present at all socioeconomic levels.<sup>1,3,4</sup>

Literacy levels correlate with health in adults, both in developing countries and here in the United States.<sup>5,6</sup> Maternal literacy also is associated with specific health outcomes, such as nutrition, immunization rates, and infant mortality, for children in underdeveloped countries.<sup>7-9</sup> The reason for this association is unclear, but it is theorized that better use of health care services and improved understanding of proper hygiene and child care practices are related to literacy.<sup>5</sup> In the United States, illiteracy may impede health care delivery because of the inability to access health educational materials, social services, and health care facilities and providers. In addition, literacy may impact on knowledge and understanding of health care practices. There is ample documentation that health educational materials, such as brochures, pamphlets, and guidebooks, generally are written at a level far above the average adult reading ability and thus are not appropriate for many adults.<sup>10-15</sup> Davis and associates demonstrated that reading material distributed by formula and pharmaceutical companies, the American Academy of Pediatrics (AAP), and the Centers for Disease Control and Prevention required, on average, a 10th-grade reading level, which was much higher than the average 6th-grade reading ability of the adults tested.<sup>16</sup>

Most illiterate adults are undetected, because reading ability cannot be predicted by years of education attained,<sup>10,17</sup> occupation, physical appearance, or socioeconomic status.<sup>1</sup> Because of the social stigma and shame, most illiterate people will not volunteer this information readily.<sup>18,19</sup> Indeed, often they will go to great lengths and develop various strategies to conceal and compensate for their reading difficulties. Therefore, even if a health care provider is sensitive to the issue of illiteracy, this problem may not be identified easily. An additional problem with identifying low-literate adults is that many people with limited reading skills do not realize that they have a problem with reading.<sup>1</sup> When illiteracy is unsuspected and undetected, information often is transmitted in a manner that is incomprehensible. Well-

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meaning patients thus are unable to follow medical instructions correctly.

There is not much in the literature about the effect of parental literacy on children's health in the United States. It would seem, however, that children's health would be compromised for many of the same reasons that adult literacy affects adult health. If a parent is unable to read and comprehend instructions, prescription labels, consent forms, and other reading material, it may lead to such problems as incorrect drug doses, improperly mixed infant formula, missed well-child care appointments, and delayed immunizations for the child. Because adherence to instructions is dependent on understanding what is involved and the reason for the therapy, it is incumbent on health care providers to recognize illiteracy as a widespread problem and to maximize opportunities for parent and patient understanding and education.

Understanding how parental literacy relates to children's health processes may have important implications for how medical and nursing professionals communicate with families and how the needs of those with lower reading ability can be better met. This may involve low-literacy reading materials or alternative modes not involving reading, such as improved verbal instruction, pictures or graphics, and video or audiotapes.

The purpose of this study was to determine the impact of parental literacy level on the understanding of medical information and adherence to therapy prescribed for their children. Additional study objectives were to determine the prevalence of functional illiteracy among parents/adult caretakers in the metropolitan Washington, DC, area and to assess whether parental self-assessment of reading ability can be used to predict literacy level accurately. We hypothesized that parental illiteracy has a negative impact on children's health, including but not limited to problems with understanding medical information and adherence.

## METHODS

This study was approved by the institutional review board of Children's National Medical Center, Washington, DC. Parents accompanying their children for acute care visits between January 30, 1996, and May 31, 1996, were invited to participate in the study. Parents were recruited from five sites: an urban hospital-based ambulatory care center (Children's National Medical Center, General Pediatric Ambulatory Center), an urban health maintenance organization (HMO) pediatric ambulatory care center (George Washington University Health Plan), and three suburban practices participating in the Children's Pediatric Research Network, a community-based research network in the Washington, DC, metropolitan area. The study population included all racial/ethnic and gender groups. Each family was allowed to enter the study one time. Families were excluded if 1) English was not the primary language; 2) the adult present was not the primary caretaker for the child; or 3) they would not be available for telephone follow-up. Parents were not included if the child was being seen for well-child care, because this might introduce bias in the areas of child's health status and parental knowledge regarding health maintenance procedures. Written informed consent was obtained. Parents were interviewed regarding gender and ethnic background; occupation and education of the parent accompanying the child; child's health insurance (as a proxy for family income); child's health status (including chronic medical problems and previous hospitalizations); and parental knowledge regarding

health maintenance procedures, including immunizations and well-child care visits. They were asked to rate the severity of their child's present illness. Parents also were asked to rate their reading ability and how much difficulty they had understanding the medical information provided by their child's physician.

The Rapid Estimate of Adult Literacy in Medicine (REALM) was used to assess reading skills of the parents. This instrument uses common medical terms and thus is particularly useful in assessing literacy in medical settings. It is a reading recognition test that is easy to administer and score. Patients are given a score ranging from 0 to 66, with 0 to 18 being equivalent to a 3rd-grade or below reading level; 19 to 44 equivalent to a 4th- to 6th-grade level; 45 to 60 equivalent to a 7th- to 8th-grade level; and 61 to 66 equivalent to a high school level. The REALM has been validated and scores found to correlate with other standardized tests for reading.<sup>20</sup> In addition, the REALM has been found to correlate with the Test of Functional Health Literacy in Adults, another instrument measuring literacy in the health care setting.<sup>21</sup>

Physicians were asked to include in their verbal instructions to the parents the following information: diagnosis; treatment plan (including name, purpose, and instructions for use of any medication prescribed); and follow-up instructions. Written instructions were given if deemed necessary by the physician.

The record of the medical visit was reviewed by an investigator blinded to the parental literacy level (RYM, KB). Diagnosis, medications prescribed, and instructions were recorded.

The same parent then was interviewed by telephone 48 to 96 hours after the physician encounter and asked to recall their child's diagnosis and any medication prescribed, including the name of the medicine, purpose of the medication, and the instructions for use. They were also asked about ability to obtain and administer any prescribed medication and to follow physician instructions. If they were given written instructions, they were asked questions regarding the use of the instruction sheet. Accuracy of parental report of child's diagnosis and medication instructions was scored by four independent raters who were blinded to the parental literacy level. Interrater reliability for the four reviewers was 85%.

## Sample Size

A prevalence rate of 20% for parental illiteracy was assumed. It was determined that a minimum sample size of  $n = 425$  was necessary to ensure a 99% confidence level that the estimated proportion of parental illiteracy identified with any abnormal outcome would not differ from the true mean proportion ( $P = .2$ ) by  $>5\%$ . Because of the variety in study sites and expectation of some loss to follow-up, we planned to recruit a sample of 600 parents for the study.

## Statistical Methods

Descriptive statistics (means and SD units) of demographics were tabulated by practice setting. Literacy levels were determined by REALM score. The primary outcome measure was functional understanding of medical information. Parents' understanding about health maintenance issues and discharge instructions was scored. Predictor variables included literacy level and sociodemographic variables. Demographic variables, including stated reading ability, were analyzed for correlation with literacy score, using either the Pearson correlation coefficient or the general linear model analysis of variance  $F$  test. The relationship between outcome measures and predictor variables also were analyzed, using a multiple linear regression model.

## RESULTS

### Demographic Data (Table 1)

A total of 679 families were invited to participate in the study. Seventeen (2.5%) families were excluded for the following reasons: English was not the primary language (6), no telephone was available (6), and an adult was not the primary caretaker (5). An additional 29 parents (4.3%) refused to participate in the study, resulting in enrollment of 633 families. Of the 29 parents who refused, 20 were in the hospital-based group, 5 in the HMO group, and 3 in the

**TABLE 1.** Demographic Characteristics of Parents (*N* = 633)

Variable	Results			
	Hospital ( <i>n</i> = 320)	HMO ( <i>n</i> = 127)	Practice ( <i>n</i> = 186)	Total ( <i>n</i> = 633)
Parent age (years ± SD)	29.86	33.77	35.93	32.43 (±9.07)
Parent gender	7.8% Male 92.2% Female	18% Male 82% Female	22.6% Male 77.4% Female	14.2% Male 85.8% Female
Parent race/ethnicity	0.3% Asian 95.6% African-American 2.2% Caucasian 1.3% Hispanic 0.6% African	0% Asian 76.6% African-American 32.4% Caucasian 0% Hispanic	1.6% Asian 12.9% African-American 83.9% Caucasian 1.6% Hispanic	0.6% Asian 65.7% African-American 32.2% Caucasian 1.2% Hispanic 0.3% African
Parent occupation (Hollingshead scale)	2.39	5.33	5.55	3.9 (±2.8)
Insurance type	6.6% Fee-for-service 7.2% Managed care 73.1% Medicaid 13.1% None	2.4% Fee-for-service 78% Managed care 18.1% Medicaid 1.5% None	50% Fee-for-service 40.9% Managed care 7% Medicaid 2.1% None	18.5% Fee-for-service 31.3% Managed care 42.7% Medicaid 7.6% None
Parent education (years ± SD)	12.35	14.11	14.84	13 (±2.09)
REALM score	53.95 (7th–8th Grades)	58.06 (7th–8th Grades)	63.68 (High school)	57.63 (±10.9) (7th–8th Grade)

private practices. Five of the parents in the hospital-based group refused because they “did not have their glasses” or because they “did not read out loud,” leading the research assistant to speculate that they could not read. The remaining parents refused because they were not interested (11), they were in a hurry (3), the child was too sick (2), or for unspecified reasons (8). Of the 633 families enrolled, there were 320 in the hospital-based group, 127 in the HMO group, and 186 in the private practices. Follow-up was obtained in 543 patients (85.8%). The mean patient age was 49.5 months (SD = 42.65), and the mean parental age was 32.4 years (SD = 9.1, range 13 to 78 years). Of parents in the entire sample, 85.8% were female, 65.7% were African-American, and 32.2% Caucasian. Parental occupation was scored using the Hollingshead social status scale,<sup>22</sup> with a minimum score of 1 (menial service workers, unemployed) and a maximum score of 9 (professionals, executives). The mean occupational score was 3.9, corresponding to smaller business owners and skilled manual workers (eg, mechanics, receptionists). Of the patients, 49.8% had commercial medical insurance (either fee-for-service or HMO), 42.7% were insured through Medicaid, and 7.6% were uninsured. Parents in the hospital-based group were more likely to be younger, female, African-American, and insured by Medicaid, and to have fewer years of education.

Mean parental REALM score was 57.63 (SD = 10.9, range 0 to 66), corresponding to a 7th- to 8th-grade reading level. Twelve parents (1.9%) were reading at or below a 3rd-grade level (illiterate), and an additional 48 (7.6%) were functionally illiterate (at or below the 6th-grade level). All 12 illiterate parents and approximately two thirds of the functionally illiterate parents were in the hospital sample (Table 2). Parental educational level was determined by the number of years of education completed, with a maximum score of 16 years. Educational level ranged from 7 to 16 years, with a mean of 13.43 years (SD = 2.09). Parental literacy level and educational level

**TABLE 2.** Literacy Levels by Site

	Hospital ( <i>n</i> = 320)	HMO ( <i>n</i> = 127)	Practice ( <i>n</i> = 186)	Total ( <i>n</i> = 633)
Less than 3rd grade	12 (3.7%)	0	0	12 (1.9%)
4th–6th Grade	33 (10.3%)	12 (9.4%)	3 (1.6%)	48 (7.6%)
7th–8th Grade	158 (49.4%)	44 (34.6%)	18 (9.7%)	220 (34.7%)
High school	117 (36.6%)	71 (55.9%)	165 (88.7%)	353 (55.8%)
Total low-literate*	45 (14%)	12 (9.4%)	3 (1.6%)	60 (9.5%)

\* Total number of parents with reading level at or below 6th grade.

were, on average, higher in the practice group, and these differences were statistically significant (*P* < .0001). However, in all three groups, average reading ability was several grades below educational level completed, with the gap being more pronounced in the hospital-based and HMO groups. In univariate analysis, parental literacy as measured by the REALM was significantly correlated with parental age (Pearson’s correlation *r* = 0.1569; *P* < .0001), ethnicity/race (*P* < .0001), education (*r* = 0.2994; *P* < .0001), occupational score (*r* = 0.1242; *P* < .0001), and insurance type (*P* < .0001). Parental age, African-American race, and parental educational level were found to be significant in the multiple linear regression model.

When parents were asked to rate how well they could read, 70.1% responded “really well,” 28% “fair,” and 1.9% “not great” (Table 3). When asked how often they had trouble understanding their child’s doctor, 62.4% responded “almost never,” 32.7% “sometimes,” and 4.9% “often.” Parents in the hospital sample were less likely to respond that they could read “really well” and more likely to admit that they sometimes had trouble understanding. On univariate analysis, stated reading ability (*P* < .001; Pearson’s correlation *r* = 0.391) and ability to understand (*P* < .001; Pearson’s correlation *r* = 0.272) significantly correlated with REALM score, but neither were found to be significant in multiple regression analysis.

**TABLE 3.** Parents' Stated Reading Ability

	Hospital	HMO	Practice	Total	Correlation With REALM
How well do you read?	57.8% Really well 39.4% Fair 2.8% Not great	83.5% Really well 16.5% Fair	82.3% Really well 16.1% Fair 1.6% Not great	80.1% Really well 28% Fair 1.9% Not great	$P = .0001^*$
How often do you have trouble understanding?	6.9% Often 43.1% Sometime 50% Almost never	3.9% Often 32.3% Sometime 63.8% Almost never	2.2% Often 15.1% Sometime 82.7% Almost never	4.9% Often 32.7% Sometime 62.4% Almost never	$P = .0001$

**Parental Knowledge of Health Maintenance Procedures and Child's Health Measures (Table 4)**

Parents were asked about the status of the child's well-child care and, for children older than 3 years of age, the status of dental visits. Appropriate well-child care visits were determined by the AAP Recommendations for Preventive Pediatric Health Care.<sup>23</sup> Visits were considered up to date if the last visit had occurred within 1 month of the recommended visit for children younger than 2 years of age and within 6 months of the recommended visit for those older than 2 years of age. By parental report, 79.5% of the children were up to date on well-child care visits, 15.8% were not up to date, and 4.8% of the parents could not recall their child's last visit. When asked when the next well-child care visit should occur, 56.2% were correct, 13.1% were incorrect, and 30.6% did not know. Dental visits were considered to be up to date if the child had been seen by a dentist in the past year. Of the children older than 3 years of age, 71.7% had seen a dentist in the past year, 27.1% had not seen a dentist in the past year, and 1.2% did not know. Up-to-date well-child visits, knowledge of the next well-child visit, and up-to-date dental visits were not associated with the REALM score.

Of the children, 24.2% had at least one chronic medical problem, defined as a condition that has been present for >3 months or normally has a duration of >3 months.<sup>24</sup> Of these, 131 (20.7%) had one chronic problem, 18 (2.8%) had two, and 4 (0.6%) had three or more, with an average of 0.36 chronic medical problems. In addition, 27.5% of the children had

been hospitalized at least once. Of these, 127 (20.1%) had 1 previous hospitalization, 29 (4.6%) had 2, and 18 (3%) had 3 or more, with a maximum of 20 hospitalizations. Children had an average of 0.48 hospitalizations. The number of chronic medical problems or hospitalizations did not correlate with the REALM score.

When asked to rank their child's present level of illness on a scale of 1 to 5 (5 being sickest), the mean score was 2.31 (SD = 1.17). When controlled for parental age, race, and educational level, parental perception of the child's level of illness was associated with the REALM score ( $P < .01$ ), with low-literate parents considering their children more sick.

**Parental Understanding of Medical Information (Table 5)**

When asked during the follow-up telephone call, 86.6% of parents knew the child's diagnosis. Among patients who had received prescription medication, 58.9% of the parents knew the name and instructions for the medication, 80% understood the purpose of the medication, 76.9% obtained the medication the day prescribed, and 84% had missed no doses. Parental understanding of diagnosis, medication name, instructions, purpose, and ability to obtain and administer the medication was not associated with the REALM score.

Of the parents, 50.2% had received written instructions from the physician; 91.6% of the parents receiving written instructions were seen in the hospital-based center and 8.4% were seen at the HMO. None of the patients in the private practices received writ-

**TABLE 4.** Parental Knowledge of Health Maintenance Procedures and Child's Health Measures

Variable	Results				Correlation With REALM
	Hospital	HMO	Practice	Total	
Well-child check up to date?	81% Yes 15.3% No 3.8% Don't know	89% Yes 3.1% No 7.9% Don't know	70.4% Yes 25.3% No 4.3% Don't know	79.5% Yes 15.8% No 4.8% Don't know	$P < .009^*$
When is next well-child check?	54.4% Right 19% Wrong 26.6% Don't know	41.7% Right 0.8% Wrong 57.5% Don't know	69.3% Right 11.3% Wrong 19.4% Don't know	56.2% Right 13.1% Wrong 30.6% Don't know	$P = .026^*$
Dental visits up to date?	63.3% Yes 36.1% No 0.7% Don't know	80.3% Yes 18.2% No 1.5% Don't know	78.2% Yes 19.8% No 2% Don't know	71.7% Yes 27.1% No 1.2% Don't know	$P = .05^*$
Number of chronic medical problems	0.286	0.35	0.33	0.286	$P = .41^*$ Pearson's $r = .033$
Number of hospitalizations	0.59	0.48	0.296	0.48	$P = .55^*$ Pearson's $r = -.024$
How sick is your child today?	2.425	2.17	2.22	2.31	$P = .0049$ Pearson's $r = -.086$

\* Found not to be significant in multiple regression analysis.

ten information. Of the families who received written instructions, 90% of parents reported that they had read the instructions, and 89.9% stated that the written information was helpful to them.

### DISCUSSION

The purpose of this study was to determine the impact, if any, of parental literacy on parental understanding of medical information and children's health measures. The parents in our study sample were, on average, reading at the 7th-grade level. Although the average literacy level was higher in the HMO and private practice groups, even in these groups, it was much lower than would be expected by the average educational level. It is well established that adults often read at least one or two grade levels below their highest educational level,<sup>17</sup> and Davis and associates found this gap to be as great as five grade levels in a population comparable in demographics with the population in this study.<sup>10</sup> In addition, although the majority of low-literate parents were in the hospital-based group, there were functionally illiterate parents in all of these settings. This underscores the importance of literacy awareness among pediatricians and other health care providers.

However, in this sample of patients, parental literacy did not correlate with understanding of medical information relating to the child's current medical problem. In addition, children's health measures, such as reported status of well-child care and dental care, the number of chronic medical conditions, and number of hospitalizations, did not vary significantly with parental literacy level. There are several possible explanations for these findings. It is possible that our methods for determining children's health measures and parental understanding of medical information lacked the sensitivity necessary to uncover small differences. It is acknowledged that it is difficult to measure health, but the health measures used in this study, such as reported status of well-child care, number of chronic medical conditions, and number of hospitalizations are measures frequently used. Several studies using comparable methods of measuring children's health have had similar findings.<sup>24,25</sup>

The majority of the low-literate parents were seen in the urban hospital-based ambulatory setting, where ~70% of the patients receive Medicaid. The medical and nursing staff in this setting are well aware that many parents are poorly educated and may have difficulty understanding medical information. Therefore, it is likely that more efforts are made to explain diagnoses and instructions to parents thoroughly. In addition, written information was frequently given to these parents, which may have been helpful in reinforcing the information given. Patients receiving care at the HMO and the practice sites rarely received written information.

Although low-literate parents' understanding of medical information given at the visit and of general health information was good, parental perception of the level of their child's illness correlated significantly with parental literacy level. Low-literate par-

TABLE 5. Parental Understanding of Medical Information

Variable	Results			Correlation With REALM*
	Hospital	HMO	Practice	
Understanding of diagnosis	86.8%	87.5%	85.2%	$P = .48$
	53.0% Fully understood	52.2% Fully understood	73.9% Fully understood	
Understanding of medication name/instructions	24.5% Partially understood	33.3% Partially understood	17.1% Partially understood	$P = .57$
	83.8%	73.9%	72.2%	
Understanding of medication purpose	69.3%	80.6%	92.2%	$P = .38$
	79.1%	84.7%	90.8%	
Obtained medicine the same day				$P = .57$
	Missed no doses of medication			
			Total	
			86.6%	
			58.9% Fully understood	
			24% Partially understood	
			80%	
			76.9%	
			84%	

\* Multiple regression analysis: controlling variables were parental age, African-American race, and parental education.

ents considered their children more sick for the same degree of illness. Parental perception of illness severity also may have affected adherence to medical instructions in our population. If a parent perceives that the child is severely ill, adherence is more likely.<sup>26</sup>

Recent data also suggest that low-income families (who are more likely to have low-literate parents) may be more knowledgeable about preventive health measures, particularly immunizations, than are higher-income families,<sup>27</sup> perhaps because they receive health information from additional sources, such as Women, Infants, and Children offices, other than where their children receive medical care. This reinforcement of information may be helpful for some parents. In addition, these parents may have developed strategies for compensating for any difficulties with reading or understanding.

As with any survey, the validity of these results is limited by the accuracy of the participants' answers. Questions were phrased in a manner designed to encourage truthful responses, but it is acknowledged that parental recall may not always be accurate.

Although it is reassuring to find no correlation between parental literacy and understanding of medical information in this sample of patients, it is somewhat sobering that parents' lack of knowledge about their children's health was present at all literacy levels. Even among families with high-literacy scores, approximately one third of the parents did not know when the next well-child visit was due, and fewer than two thirds of parents who were administering prescription medications as a result of the study visit knew the name of the medication and the instructions for use. This finding is worrisome and is consistent with a recent study in an HMO population in which 36% of the parents did not know when their child's next immunizations were due and 28% did not know when their child's next well-child visit was due.<sup>25</sup> Although we realize that these results may not be generalizable to the larger population, this study demonstrates the need for better communication between health care providers and families, no matter what the educational or literacy level. It is important for health care providers to assess the needs and abilities of the patients and families in their populations. Awareness of the need for improved communication and increased efforts to explain diagnoses and instructions thoroughly to parents may help to improve understanding of medical information.

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