# **REVIEWS**

# The Prevalence of Limited Health Literacy

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**OBJECTIVE:** To systematically review U.S. studies examining the prevalence of limited health literacy and to synthesize these findings by evaluating demographic associations in pooled analyses.

**DESIGN:** We searched the literature for the period 1963 through January 2004 and identified 2,132 references related to a set of specified search terms. Of the 134 articles and published abstracts retrieved, 85 met inclusion criteria, which were 1) conducted in the United States with  $\geq$  25 adults, 2) addressed a hypothesis related to health care, 3) identified a measurement instrument, and 4) presented primary data. The authors extracted data to compare studies by population, methods, and results.

**MAIN RESULTS:** The 85 studies reviewed include data on 31,129 subjects, and report a prevalence of low health literacy between 0% and 68%. Pooled analyses of these data reveal that the weighted prevalence of low health literacy was 26% (95% confidence interval [CI], 22% to 29%) and of marginal health literacy was 20% (95% CI, 16% to 23%). Most studies used either the Rapid Estimate of Adult Literacy in Medicine (REALM) or versions of the Test of Functional Health Literacy in Adults (TOFHLA). The prevalence of low health literacy was not associated with gender (P=.38) or measurement instrument (P=.23) but was associated with level of education (P=.00), ethnicity (P=.0003), and age (P=.004).

**CONCLUSIONS:** A pooled analysis of published reports on health literacy cannot provide a nationally representative prevalence estimate. This systematic review exhibits that limited health literacy, as depicted in the medical literature, is prevalent and is consistently associated with education, ethnicity, and age. It is essential to simplify health services and improve health education. Such changes have the potential to improve the health of Americans and address the health disparities that exist today.

 $K\!E\!Y$  WORDS: prevalence; functional health literacy; health literacy; literacy.

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H ealth literacy is increasingly described as the currency for improving the quality of health and health care in America. <sup>1-3</sup> In *Health Literacy: A Prescription to End Confusion*, the Institute of Medicine (IOM) described the growing body of literature documenting the magnitude and associations of limited literacy, and made recommendations for promoting a health-literate society. <sup>4</sup> This report adopted the definition

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used in Healthy People 2010, which defined health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Multiple studies indicate that people with limited health literacy have worse health status and higher rates of hospitalization. <sup>4-6</sup> Medical and public health literature also highlight the high reading demands made on people in need of important health information. Over 300 published articles document that most health materials are beyond the comprehension skills of most Americans. <sup>6</sup>

The National Adult Literacy Survey (NALS), a nationally representative household survey conducted in 1992, profiled the functional English language literacy skills of over 26,000 American adults and found that half of U.S. adults have limited or low literacy skills. This means that American adults with average literacy skills have difficulty using complex texts to accomplish everyday tasks and lack the skills needed for full participation in our current society. The prevalence of limited health literacy in medical settings, however, has not been systematically reviewed.

In its report, the IOM committee presents a sample of published studies on the prevalence and demographic associations of low health literacy. The current article extends the background review conducted for the IOM report to a systematic review of the medical literature. This article summarizes the methods and findings of published studies on the prevalence of limited health literacy in health care contexts and synthesizes these findings by evaluating demographic associations in pooled analyses. Understanding this evidence will help practitioners, researchers, and funding institutions formulate solutions to the pressing issues that emerge from a mismatch between system demands and the average literacy skills of health care consumers.

#### **METHODS**

#### **Research Questions**

The objectives of this review are to examine 1) the prevalence of low and marginal health literacy in the medical literature; 2) the methods used in studies evaluating the prevalence of limited health literacy in medical care; and 3) the demographic factors associated with low health literacy.

#### Finding Relevant Studies

In January 2004, bibliographic database search terms were used for article retrieval. Search terms were functional health

literacy, literacy [as a title word] AND health, numeracy, TO-FHLA, Rapid Estimate of Adult Literacy in Medicine, REALM AND read, Wide Range Achievement Test, WRAT, Slosson oral reading test, SORT AND read, Peabody Individual Achievement Test, PIAT, National Adult Reading Test, NART, AMNART, Woodcock-Johnson AND test, medical terminology AND achievement, MART AND read, literacy assessment for diabetes, and adult basic education test. Databases searched were MEDLINE (1966-2004), CINAHL (1982-2003), PsycInfo (1887-2004), Linguistics and Language Behavior Abstracts (1973–2004), and Sociological Abstracts (1974-2004). After developing the search parameters, identifying databases to target, and pursuing references in consultation with the coauthors and through review of the annotated bibliographies of the National Center for Adult Learning and Literacy, 4,9 the lead author conducted the search, retrieval, and selection process.

## **Inclusion Criteria**

References were included if the study was conducted in the United States, related to health care or a health services inquiry, involved 25 or more adults, and provided evidence of direct testing of subject literacy.

# **Study Selection**

After screening 2,132 references, 134 articles and published abstracts were retrieved and 85 were included in this review. Those excluded did not present primary data, were not conducted in the United States, involved fewer than 25 adult subjects, were not part of a health services inquiry or conducted in a medical context, or did not provide literacy prevalence.

#### **Data Abstraction**

All studies were evaluated for participation rate, study design, subject selection criteria, setting and dates, literacy measure used, vision testing, cognitive testing, demographic characteristics (age, gender, ethnicity, highest level of education, and income), and prevalence of low literacy and marginal literacy. Some researchers used multiple instruments to evaluate literacy, alternative versions of these instruments, or altered instruments. For example, data extracted from studies using the full Test of Functional Health Literacy in Adults (TOFHLA), the abbreviated TOFHLA, and the shortened TOFHLA were all included.

## Statistical Analysis

Low health literacy was defined as the rate of subjects scoring at an inadequate level on versions of TOFHLA or at the sixth grade level and below on other measures. Marginal literacy was defined as the rate of subjects scoring at the marginal level on versions of TOFHLA or at the seventh to eighth grade levels on other measures. Weighted analyses of variance were used to compare the mean rates of low literacy according to quartiles of demographic characteristics: age, gender, education, and ethnicity. The percentage of subjects who had not completed high school or received a general education degree (GED) was used as the indicator of education. The percentage of female subjects was used to represent gender. Due to variation in the presentation of data on ethnicity, the percentage of black subjects was used as the indicator of ethnicity. The Wilcoxon rank-

sum test was used to compare the rate of low literacy between studies conducted with the Rapid Estimate of Adult Literacy in Medicine (REALM) versus versions of the TOFHLA, between the languages of test administration (Spanish vs English), between the total pooled estimate versus studies with greater than 300 subjects, and between the total pooled estimate versus studies not conducted with convenience samples. Prevalence data derived from different iterations of the REALM and TOFHLA were combined to make the comparison by testing instrument. Pooled analyses were conducted with weighted means, that is, each study influenced analyses in proportion to the size of the population in that study. All significance tests were two-tailed. Analyses were conducted with Stata software, version 8 (Stata Corporation, College Station, TX).

## **RESULTS**

The 85 studies included data on 31,129 subjects. Pooled analyses of these data reveal that over one quarter of subjects (26%; 95% confidence interval [CI], 22% to 29%; range, 0 to 68), had low health literacy. An additional fifth of subjects (weighted mean of 20%; 95% CI, 16% to 23%; range, 11 to 65) had marginal health literacy.

Systematic review of the published data on health literacy does not provide a nationally representative sample. Over one third of subjects did not complete high school (weighted mean of 37%; 95% CI, 32 to 41) and about half of all subjects were black (weighted mean of 55%; 95% CI, 48 to 62). Table 1 presents the studies included in this review; 10-94 an appendix (available online at http://www.blackwellpublishing.com/products/journals/suppmat/jgi/jgi40245/jgi40245.htm) includes the literacy rates and demographic characteristics for each of the studies. The first section of Table 1 presents studies conducted with the REALM, the second section presents studies conducted with versions of the TOFHLA, and the third section presents studies conducted with all other measures.

## **Analysis of Study Design and Methods**

More than three quarters of the studies (79%; 67/85) were from convenience samples of subjects. Exclusion of studies conducted with convenience samples did not significantly alter the mean rate of low health literacy (24%; 95% CI, 16% to 33%; range, 9 to 48) in comparison with the total pooled estimate (P=.90). The sample size ranged from 26 to 3,260, with an average of 366 subjects and a standard deviation of 60. Elimination of small studies (N<300) did not significantly alter the mean rate of low health literacy (25%; 95% CI, 19% to 30%; range, 9 to 48) in comparison with the total pooled estimate (P=.48). Participation rate could be calculated from published information in half the studies (54%; 46/85) and had a weighted mean of 63% (range, 48% to 100%).

Many studies specifically excluded subjects who did not speak English (18%; 15/85),  $^{12,17,19,30,70}$  read English (8%; 7/85),  $^{34,35,45,85-97,92}$  or have English as their primary (5%; 4/85) $^{48,61,69,81}$  or first language (4%; 3/85).  $^{37,52,84}$  Spanish-speaking subjects were tested in Spanish in 11% of studies (9/85).  $^{5,53,55,59,63-67}$ 

Visual function was mentioned as a specific criterion in 20% of studies (17/85).  $^{13,21,37,41,48,52,53,61-63,66,76,85-87,89,92}$  While 7 studies mention cognitive disorders as an exclusion criterion,  $^{33,34,41,53,69,84,92}$  only 2 specified details for this

Table 1. The Prevalence of Health Literacy Skills Among Various Populations

Part 1. Analyses Using the Rapid Estimate of Adult Literacy in Medicine (REALM)				
Source	Research Objectives	Primary Location	(Surveyed/Eligible) Participation Rate (787/847) 93%	
Ahluwalia et al. 2002 <sup>10</sup>	To test association of literacy and returning for randomization in a smoking cessation trial	Atlanta, GA		
Al-Tayyib et al. 2002 <sup>11</sup>	To test association of literacy and quality of responses in health survey measurements	Baltimore, MD	(992/1,224) 81%	
Arnold et al. 2001 <sup>12</sup>	To test association of literacy and tobacco knowledge, attitudes, and practices in pregnant women	LA	(599/623) 96%	
Arozullah et al. 2002 <sup>13</sup> Bass et al. 2002 <sup>14</sup>	To test association of literacy and preventable hospital admission To evaluate medical residents' ability to identify patients with low	Chicago, IL KY	(198/NS) (182/NS)	
Bass et al. 2002 <sup>15</sup>	literacy To evaluate knowledge, self-efficacy, empowerment, and literacy in	KY	(104/NS)	
Beers et al. 2003 <sup>16</sup>	patients with diabetes  To evaluate the REALM instrument according to subject ethnicity	Philadelphia, PA	(1,805/NS)	
Bennett et al. 1998 <sup>17</sup>	To test the association of literacy and stage of presentation of prostate cancer	Shreveport, LA	(212/221) 96%	
Bennett et al. 2003 <sup>18</sup>	To evaluate a screening instrument for literacy in caregivers of pediatric patients	Philadelphia, PA	(98/100) 98%	
Bryant et al. 2003 <sup>19</sup>	To test the association of literacy and adequacy of warfarin anticoagulation	Chapel Hill, NC	(58/71) 82%	
Christensen & Grace $1999^{20}$	To assess the prevalence of low literacy in an indigent psychiatric population	Gainesville, FL	(45/45) 100%	
Conlin & Schumann 2002 <sup>21</sup>	To assess the prevalence of low literacy in cardiac surgery patients	Spokane, WA	(30/34) 88%	
Coyne et al. 2003 <sup>22</sup>	To test comprehension, satisfaction, accrual, and anxiety of improved informed consent statement	44 sites	(204/226) 90%	
Davis et al. 1991 <sup>23</sup>	To validate the REALM-125	LA, AR	(207/223) 93%	
Davis et al. 1993 <sup>24</sup>	To validate the shortened REALM (66-word version)	LA, AR, TX	(203/215) 94%	
Davis et al. 1994 <sup>25</sup>	To assess the prevalence of low literacy in caregivers of pediatric patients	Shreveport, LA	(396/414) 96%	
Davis et al. 1996 <sup>26</sup>	To evaluate knowledge and attitudes regarding mammography in low-literate, low-income women	Shreveport, LA	(417/445) 94%	
Davis et al. $1998^{27}$	To test whether improved polio immunization pamphlet would improve comprehension in caregivers of pediatric patients	Shreveport, LA	(610/646) 94%	
Davis et al. 1998 <sup>28</sup>	To test whether improved informed consent statement would improve comprehension	Shreveport, LA	(183/205) 89%	
Duffy & Snyder 1999 <sup>29</sup>	To assess the prevalence of low literacy in emergency room patients and caregivers	South Carolina	(110/NS)	
Foltz & Sullivan 1996 <sup>30</sup>	To assess the prevalence of low literacy in cancer patients	New Orleans, LA	(63/73) 86%	
Fortenberry et al. 2001 <sup>31</sup>	To evaluate the association of literacy and gonorrhea-related care	CO, IN, NY, AL	(809/1,035) 78%	
Gannon & Hildebrandt 2002 <sup>32</sup>	To assess the prevalence of low literacy in patients at a women's health clinic	Midwestern	(50/61) 82%	
Galloway et al. 2003 <sup>33</sup>	To assess the prevalence of low literacy in neurology clinic patients	ОН	(99/113) 88%	
Hayes 1998 <sup>34</sup>	To compare the effect of usual emergency department discharge instructions to instructions designed for elderly patients	Midwestern	(60/NS)	
Hayes 2000 <sup>35</sup>	To assess the prevalence of low literacy among patients in a rural emergency department	KS	(195/200) 98%	
Hearth-Holmes et al. $1997^{36}$	To assess the prevalence of low literacy in patients with systemic lupus erythematosis	Shreveport, LA	(94/100) 94%	
Kaufman et al. 2001 <sup>37</sup>	To evaluate the association of literacy and breastfeeding in women at a public health clinic	Albuquerque, NM	(61/NS)	
Kim et al. 2001 <sup>38</sup>	To assess the prevalence of literacy and shared decision making in patients with prostate cancer	Chicago, IL	(30/NS)	
Li et al. 2000 <sup>39</sup>	To assess predictors of compliance in women with breast cancer	Rural South	(39/55) 71%	
Lindau et al. 2002 <sup>40</sup>	To evaluate the association of literacy with cervical cancer prevention knowledge and health behaviors	Chicago, IL	(529/584) 91%	
Mayeaux et al. $1995^{41}$	To evaluate the association of literacy and Mini-mental State Examination scores	Shreveport, LA	(105/115) 91%	
McNeill et al. 2003 <sup>42</sup>	To assess the prevalence of low literacy in patients with HIV infection	Eastern NC	(55/NS)	
Moon et al. 1998 <sup>43</sup>	To assess the prevalence of low literacy in caregivers of pediatric patients	Washington, DC	(633/662) 96%	
Murphy et al. 2001 <sup>44</sup>	To assess the prevalence of low literacy in neurology patients	Shreveport, LA	(520/531) 98%	
Raymond et al. 2002 <sup>45</sup>	To evaluate comprehension of a label for an emergency contraception	8 cities in U.S.	(395/NS)	
Rothman et al. 2003 <sup>46</sup>	pill product To evaluation literacy as a variable in a diabetes management program	Chapel Hill, NC	(218/NS)	
Sharp et al. 2002 <sup>47</sup>	To assess the prevalence of low literacy in African-American women	Chicago, IL	(130/136) 96%	
Williams et al. 1998 <sup>48</sup>	seeking colposcopy To evaluate the association between literacy and asthma knowledge	Atlanta, GA	(483/595) 81%	
Wilson & McLemore 1997 <sup>49</sup>	and inhaler technique  To assess the prevalence of low literacy in hospitalized orthopedic patients	Detroit, MI	(26/NS)	

# Table 1 (continued)

Part 1. Analyses Using the Rapid Estimate of Adult Literacy in Medicine (REALM)				
Source	Research Objectives	Primary Location	(Surveyed/Eligible) Participation Rate	
Wilson et al. 2003 <sup>50</sup>	on et al. 2003 <sup>50</sup> To assess the prevalence of low literacy among elderly African- American anticoagulation patients		(65/NS)	
Part 2. Analyses Using the Test of	of Functional Health Literacy in Adults (TOFHLA)			
Artinian et al. 2001 <sup>51</sup>	To assess the prevalence of low literacy in Veterans Administration clinic patients	Midwest	(92/NS)	
Benson & Forman 2002 <sup>52</sup>	To assess the prevalence of low literacy in retirement community residents	Albuquerque, NM	(93/123) 76%	
Gazmararian et al. 1999 <sup>53</sup>	To assess the prevalence of low literacy in new Medicare enrollees	Cleveland, OH, Houston, TX, Tampa, FL, South FL	(3,260/6,734) 48%	
Gazmararian et al. 1999 <sup>54</sup>	To assess the prevalence of low literacy in women Medicaid managed care plan enrollees	Memphis, TN	(406/825) 49%	
Golin et al. 2002 <sup>55</sup> Kalichman et al. 1999 <sup>56</sup>	To evaluate predictors of adherence to antiretroviral therapy To evaluate literacy and adherence to antiretroviral therapies in patients with HIV infection	Los Angeles, CA Atlanta, GA	(140/233) 60% (318/NS)	
Kalichman & Rompa 2000 <sup>57</sup>	To assess the prevalence of low literacy, HIV-related knowledge, and health status in patients with HIV infection	Atlanta, GA	(339/NS)	
Kalichman et al. 2000 <sup>58</sup>	To assess the prevalence of low literacy and HIV-related knowledge in patients with HIV infection	Atlanta, GA	(294/NS)	
Lasater et al. 2002 <sup>59</sup>	To assess the prevalence of low literacy and adherence in anticoagulation clinic patients	Denver, CO	(196/NS)	
Montalto & Spiegler 2001 <sup>60</sup> Nurss et al. 1997 <sup>61</sup> Paasche-Orlow et al. 2003 <sup>62</sup>	To assess the prevalence of low literacy in rural health center patients To assess the prevalence of low literacy in patient with diabetes To assess the prevalence of low literacy in patients with asthma	Charleston, WV Atlanta, GA Baltimore, MD	(70/183) 38% (131/222) 59% (80/NS)	
Schillinger et al. 2002 <sup>63</sup>	To evaluate literacy and diabetes outcomes	San Francisco, CA	(413/449) 92%	
Shea et al. 2003 <sup>64</sup> Williams et al. 1995 <sup>65</sup>	To evaluate literacy and patient satisfaction To assess the prevalence of low literacy in emergency department patients	Philadelphia, PA Atlanta, GA	(2,494/NS)	
Williams et al. $1998^{66}$	To assess the prevalence of low literacy in medical clinic patients	Los Angeles, CA Atlanta, GA	(2,659/2,856) 93%	
Win et al. 2003 <sup>67</sup>	To assess the prevalence of low literacy in anticoagulation clinic patients	Los Angeles, CA San Francisco, CA	(580/636) 91% (141/NS)	
Part 3. Analyses Using Other Tes	ts			
Coles et al. 1978 <sup>68</sup>	To assess the prevalence of low literacy in hospitalized psychiatric	NJ	(48/NS)	
Cooley et al. 1995 <sup>69</sup>	patients To assess the prevalence of low literacy in Veterans Administration oncology clinic patients	Philadelphia, PA	(63/72) 88%	
Currier et al. 2001 <sup>70</sup>	To assess the prevalence of low literacy in psychiatric clinic patients	Los Angeles, CA	(53/55) 96%	
Davis et al. 1991 <sup>23</sup> Davis et al. 1993 <sup>71</sup>	To validate the 125-word REALM test To assess the prevalence of low literacy in patient substance use	AR, LA Shreveport, LA	(207/223) 93% (114/125) 91%	
Davis et al. 1993 <sup>24</sup> Davis et al. 1994 <sup>25</sup>	treatment centers To validate the 66-word REALM To assess the prevalence of low literacy among caregivers of pediatric	AR, LA, TX Shreveport, LA	(203/215) 94% (396/414) 96%	
Fredrickson et al. 1995 <sup>72</sup>	patients To assess the prevalence of low literacy in caregivers of pediatric	KS	(646/NS) 96%	
Hanson-Divers 1997 <sup>73</sup> Hartman et al. 1997 <sup>74</sup>	patients To validate the Medical Terminology Achievement Reading Test (MART) To evaluate a nutritional education program designed for patients with	NC Twin Cities, MN	(405/NS) (204/NS)	
Jackson et al. 1991 <sup>75</sup> Jackson et al. 1994 <sup>76</sup> Johnson & Fisher 1996 <sup>77</sup> Johnson et al. 1996 <sup>78</sup>	low literacy To assess the prevalence of low literacy in primary care patients To assess the prevalence of low literacy among older patients To compare three reading tests in drug and alcohol users To assess the prevalence of low literacy among drug users in an HIV/	Northwest LA NS NS AK, OH, CO, CA,	(528/544) 97% (272/281) 97% (123/NS) (412/NS)	
Jubelirer et al. 1994 <sup>79</sup> Kicklighter & Stein 1993 <sup>80</sup> Klinge & Dorsey 1993 <sup>81</sup>	AIDS prevention study To assess the prevalence of low literacy in oncology clinic patients To assess the prevalence of low literacy in patients with diabetes To assess the prevalence of low literacy in forensic psychiatric patients	LA WV Atlanta, GA Atascadero, CA	(100/110) 91% (58/NS) (350/NS)	
Larson & Schumacher 1992 <sup>82</sup> Letz et al. 2003 <sup>83</sup>	To assess the prevalence of low literacy in Veterans Administration arthritis center patients To validate the Neuro-behavioral Evaluation System version 3-Adult Reading Test (NES3-ART)	Philadelphia, PA Atlanta, GA Boston, MA	(100/103) 97% (280/NS)	

Table 1.

Part 3. Analysis Using other tests (Continued)				
Source	Research Objectives	Primary Location	(Surveyed/Eligible) Participation Rate (136/NS)	
Manly et al. 2003 <sup>84</sup>	To assess the prevalence of literacy and memory decline in ethnically diverse elders	New York, NY		
Meade & Byrd 1989 <sup>85</sup> Meade et al. 1989 <sup>86</sup>	To assess the prevalence of low literacy in smoking cessation patients To evaluate simplification of smoking cessation literature and patient comprehension	Milwaukee, WI Milwaukee, WI	(258/NS) (129/NS)	
Meade et al. 1994 <sup>87</sup>	To evaluate the effect of printed versus videotaped colon cancer education materials	Milwaukee, MI	(1,100/NS)	
Miller et al. 1996 <sup>88</sup> Spandorfer et al. 1995 <sup>89</sup>	To validate the Deaconess Informed Consent Comprehension test To evaluate comprehension of discharge planning materials in discharged patients	St. Louis, MO Philadelphia, PA	(269/NS) (217/228) 95%	
TenHave et al. 1997 <sup>90</sup>	To assess the prevalence of low literacy in African-American patients in cardiovascular nutritional education	Washington, DC	(339/NS)	
Weiss et al. 1992 <sup>91</sup> Weiss et al. 1994 <sup>5</sup> Wydra 2001 <sup>92</sup>	To evaluate the relationship between literacy and health status To evaluate the relationship between literacy and health care costs To evaluate the effect of a self-care interactive multimedia program on fatigue in cancer patients	Tucson, AZ Tucson, AZ Los Angeles, CA Lebanon, NH Philadelphia, PA San Antonio, TX	(193/197) 98% (402/NS) (174/NS)	
Zaslow et al. 2001 <sup>93</sup>	To evaluate the relationship between literacy, depressive symptoms, and employment in families receiving welfare	Atlanta, GA	(351/427) 82%	

determination and evaluated cognitive function among included subjects as a covariate.  $^{34.53}$ 

## **Testing Instruments**

Several instruments tested multiple aspects of literacy including prose and document literacy, subdomains of reading capacity, and numeracy. Of the 14 literacy skills assessment instruments used by studies in this review, 9 were used in more than 1 study and are outlined in Table 2. 95-102 Most of these instruments are validated and have been used for the assessment of literacy skills in multiple contexts. Several instruments, developed for specific health contexts, are not yet well validated and have limited clinical data.

Several instruments, such as the Adult Basic Learning Examination (ABLE), evaluate comprehension of written text (prose literacy), capacity to use and understand tables and forms (document literacy), and arithmetic skills (numeracy). However, studies conducted with instruments that include more than 1 domain of literacy typically presented only a single summary measure. Five of the instruments are exclusively tests of word pronunciation, which is a component of prose literacy. While some of the instruments include subtests that focus on various domains of literacy, they were commonly employed in a restricted form. For example, pronunciation, but not spelling or arithmetic, was evaluated in most studies conducted with the Wide Range Achievement Test-Revised (WRAT-R). 94

The majority of tests must be completed in English. Only 3 tests, the TOFHLA, the Instrumento Para Diagnostical Lecturas/Instrument for Diagnosis of Reading (IDL), and the Test of Adult Basic Education (TABE), provide the option for Spanish language testing. No other languages are accommodated by any of the instruments in this study. Fully 68% (58/85) of the studies used either the REALM or versions of the TOFHLA. Studies conducted with the REALM had similar rates

of low literacy (22%; 95% CI, 17 to 27) as studies conducted with the TOFHLA (28%; 95% CI, 22 to 34).

## **Demographic Associations**

The most common demographic features reported to be associated with health literacy were education level, age,  $^{16,36,43,48,50-53,63,65,66,79-81}$  ethnicity,  $^{11,12,16,17,30,36,40,43,51,53,57,63,72,78,83,84}$  geographic location, and income.  $^{11,51,53,56,57,83}$  Studies reporting multivariate regression used a variety of different covariates. Most frequently, education and ethnicity remained significant in regression analyses.  $^{36,43,51,53}$ 

The rate of high school completion was significantly associated with the rate of low literacy (P=.02). For example, studies in the top quartile of high school graduation rate had the lowest prevalence of low literacy (10.7; 95% CI, 8.5 to 13.0).

The rate of black subjects was significantly associated with the rate of low literacy (P=.0003). For example, studies with the highest quartile of black subjects had the highest prevalence of low literacy (31.3; 95% CI, 26.8 to 35.7).

The average weighted age was 42.9 with a standard deviation of 1.49 years. Subject age was significantly associated with the rate of low literacy (P=.004). For example, studies in the lowest quartile of average age had the lowest prevalence of low literacy (15.9; 95% CI, 7.7 to 24.1). Studies with an average age over 50 years old (the top 2 quartiles together) had a prevalence of low literacy of 37.9 (95% CI, 31.6 to 44.2).

Overall, more women participated than men (65%; 95% CI, 59 to 70). The percentage of female subjects was not associated with the rate of low literacy (P=.38).

Data for Spanish language testing were separately reported for 5% of subjects (1,504/31,129). Subjects tested in Spanish had a higher rate of low literacy than those tested in English (44%, 95% CI, 26% to 62% vs 26%, 95% CI, 22% to 29%; P=.002). The combined weighted mean of low and marginal literacy for subjects tested in Spanish in the studies pre-

Table 2. Attributes of Literacy Assessment Instruments Used by at Least Two Studies in This Review

Test Name (Acronym)	Aspect of Literacy Tested	Scale	Correlation	Time Needed to Administer Test	Attributes	Number of Studies*
Peabody Individual Achievement Test (PIAT) <sup>94,95</sup>	Comprehension, 82 items; Pronunciation, 100 words; Spelling, 100 words; Numeracy, 100 items; Written expression	0–12th grade	Kaufman 0.84 Wechlsler 0.50	Untimed, approximately 1 hour	Training and materials needed; Long administration; Can be used with all ages	7
Rapid Estimate of Adult Literacy in Medicine, 66- word version (REALM- 66) <sup>24,96</sup>		4 categories: ≤ 3rd grade, 4th–6th grade, 7th–8th grade, ≥ 9th grade	WRAT 0.88 SORT-R 0.96 PIAT-R 0.97 TOFHLA 0.84	2–3 minutes	Quick and nonthreatening; Minimal training needed; Most frequently used	37
Slosson Oral Reading Test-Revised (SORT- R) <sup>94.97</sup>	Pronunciation, 200 words	10 categories: $<$ 1st grade, 1–8, $\ge$ 9	PIAT-R 0.83-0.94 WRMT 0.90	5–10 minutes	Can be used in all ages ( $\geq 4$ y); Minimal training	6
Test of Adult Basic Education (TABE) <sup>91,98</sup>	Reading, 50 items; Spelling, 20 items; Language, 55 items; Numeracy, 75 items	0.0–12.9th grade	GED 0.55-0.64	>1.5 hour	Long; Training and materials needed; Available in Spanish; Automated scoring available	2
Test of Functional Literacy in Adults (TOFHLA) <sup>99,100</sup>	Prose literacy, 36- cloze items; Numeracy, 17 items	Inadequate, Marginal, Adequate	WRAT 0.74 REALM 0.84	18–22 minutes	Long; Tests document, prose, and numeracy; Spanish available; 14-point font available	9
TOFHLA abbreviated <sup>53,100</sup>	Prose literacy, 36- cloze items; Numeracy, 17 items	Inadequate, Marginal, Adequate		12 minutes	Long; Tests prose and numeracy; Spanish available 14-point font available	2
Short Test of Functional Literacy in Adults (STOFHLA) <sup>99,100</sup>	Prose literacy, 36-cloze items	Inadequate, Marginal, Adequate	REALM 0.81 TOFHLA 0.91	7 minutes	Prose only; Spanish available; 14-point font available	5
Wide Range Achievement Test- Revised (WRAT-R) <sup>94,101</sup>	Pronunciation, 57 words; Spelling; Arithmetic	3rd–12th grade	Stanford achievement test reading comprehension score 0.83 PIAT 0.62–0.91	3–5 minutes for the reading subtest	Brief; Can be used in ages 5–75; Age norms available; Reports specific grade level; Can be difficult for testers; Most limited to reading subtest	19
Woodcock Reading Mastery Test-Revised (WRMT-R) <sup>94,102</sup>	Pronunciation; Passage comprehension, cloze-type; Calculation; Applied problems; Dictation; Writing samples; Science Social studies; Humanities	0.5–16.9th grade	SORT-R 0.94 WRAT-R 0.91	50–60 minutes: 15 minutes for writing subtest, 5 minutes for other 8 subtests	Short form correlates well with full test (0.98); Can be used in ages 2–95; Norms for all educational levels available; Only letter-word pronunciation and passage comprehension subtests used in studies in this review	5

 $<sup>^*</sup>$ Number of studies in Table 1 using the particular instrument. The combined total is more than 85 as studies may have used more than one instrument.

sented in this review was 62% (95% CI, 55% to 68%; range, 54 to 71).

#### Comment

One in four subjects in the studies presented in this review had low health literacy and nearly half had low or marginal health literacy. The instruments used to measure literacy, populations sampled, and study methods varied across studies. Despite these methodological differences, the level of health literacy was consistently associated with level of education, ethnicity, and age. The level of health literacy was not associated with gender, or with data collection instrument (REALM or TOFHLA).

The strengths of this study that lend weight to our conclusions are the large sample size and the use of validated literacy assessment instruments in nearly all studies. However, this systematic review has several limitations. This article presents a systematic review of the published literature on the prevalence of limited health literacy. While a systematic review of the medical literature on literacy does not provide a nationally representative prevalence estimate, the NALS provides an opportunity to compare the results of this article to a nationally representative household survey of general literacy skills. The NALS assessment exhibited that 21% to 23% of American adults scored in the lowest of 5 skill levels and an additional 25% to 28% scored 1 level better. 7 People who score at level 1 or 2 of the NALS assessment lack the skills needed for full participation in our current society.8 Direct correlation between the NALS scale and the scales used by the various instruments collected in this review is not possible. Yet, the similarities between the NALS findings and the prevalence estimates presented in this systematic review underscore the importance of basic literacy skills in health literacy and lend credence to the central findings of this article. Nevertheless, several important features of the literature on health literacy promote the possibility that the point estimates presented overestimate the true prevalence of limited health literacy. Publication bias may have limited the presentation of data on populations without high rates of limited health literacy. Similarly, it is likely that investigators interested in literacy would conduct such research in settings that have high rates of limited health literacy. In this review, it is apparent that investigators often conduct research in medical settings that cater to subjects with a low level of socioeconomic status. This may partially account for the overrepresentation of black subjects. Fully 55% of the subjects in the pooled analysis were black, 37% had not graduated high school, and the average age was  $42.9 \pm 1.49$ . These parameters have to be kept in mind in order to interpret the main findings of this article.

However, while subjects with low health literacy may be thought to be overrepresented in cited reports, it is notable that exclusion of studies conducted with subjects recruited by convenience sampling did not alter the rate of low health literacy presented. Further, while low income was associated with low literacy in some studies, income data were frequently not reported and in other studies this relationship was not exhibited. In addition, we were unable to include a summary measure of income in this analysis because of the multiple techniques used to report income data among the reviewed studies. It is also important to note that summary conclusions

for demographic associations reported in this study are unadjusted. There may be systematic confounding among the demographic characteristics summarized in this article or with other unmeasured features. However, the association between health literacy and ethnicity found in this systematic review suggests the importance of incorporating health literacy improvements in efforts related to addressing health disparities. <sup>103</sup>

There are at least 4 important reasons that this literature review may actually present a conservative assessment of the prevalence of limited health literacy. First, studies reviewed for this analysis focused almost exclusively on aspects of reading and numeracy. However, all domains of literacy—listening, speaking, writing, reading, and numeracy—are relevant to health literacy. The IOM report supports a broad concept of health literacy which includes not only the 5 skills above but cultural and conceptual knowledge of health as well.<sup>4</sup> Oral literacy skills of listening and speaking are essential to patient-provider interactions, public health communication, and understanding direct to consumer marketing.<sup>4,104,105</sup> Future research on measuring health literacy should enhance our ability to capture these other important components of health literacy.

Second, the current analysis was based on a limited pool of data for languages other than English. As people commonly maneuver through the health care system with family and friends, another important aspect of the prevalence of low health literacy relates to concepts such as linguistically isolated households and social support. 106,107 Approximately 47 million individuals in the United States (18% of the total population) speak a language other than English at home. This rate has increased between 1990 and 2000. 106 Studies excluding subjects who are not native English speakers may exclude this portion of the American population, and are likely to underestimate the prevalence of low health literacy. Furthermore, the challenge of evaluating health literacy in languages that have direct phoneme-grapheme correspondence, such as Spanish and Haitian-Creole, may be difficult to surmount as the quickest and most commonly used instruments are based on word pronunciation tests. 108

Third, most studies reviewed did not evaluate vision or cognition. Vision and cognitive capacity contribute to health literacy, and accurate assessment with the instruments used in these studies assumes normal or corrected vision and normal cognition. Vision and cognition must be tested, especially in populations such as the elderly where such deficits are known to be common and underreported. The failure to evaluate cognitive capacity likely yielded an underestimate of low health literacy in studies with older populations. Word pronunciation, used in many of the studies included in this review, is commonly retained in the face of significant dementia and has even been used as a marker for premorbid intelligence in demented cohorts. 110

Fourth, the studies may have been influenced by participation bias. People with limited literacy may participate less frequently in research. S1,111,112 Such a bias is clearly a concern as half of the studies did not disclose information to calculate the participation rate and the weighted participation rate for the remaining studies was 63% (range, 48% to 100%).

In 2003, the U.S. Department of Education initiated the National Assessment of Adult Literacy (NAAL), which contains expanded health-related components. <sup>113</sup> This second national

literacy assessment of American adults will provide data on the percentage of persons with inadequate or marginal literacy skills who can perform specific health literacy tasks related to clinical, prevention, and navigation activities. The NAAL focuses on adults' ability to use prose, documents, and numbers to accomplish specific tasks and will be used to gauge progress in meeting the Healthy People 2010 objective related to improving health literacy.

The Agency for Healthcare Research and Quality (AHRQ) recently performed an evidenced-based review of health literacy interventions and the influence of literacy on health outcomes and disparities. However, the AHRQ did not address the question of prevalence. <sup>114</sup> The current systematic review summarizing the prevalence of health literacy skills in American adults as depicted by reports in the medical literature will complement the AHRQ study. However, the focus on patients' literacy skills in these reviews reflects the state of the current literature, and should not distract attention from the overwhelming complexity of the health care system. The discourse of health literacy should address both the high literacy demands of complex systems and the skills required by individuals to navigate systems of care to self-manage chronic conditions and promote their health.

#### **Conclusions**

A pooled analysis of published reports on health literacy cannot provide a nationally representative prevalence estimate. This systematic review exhibits that limited health literacy, as depicted in the medical literature, is prevalent and is consistently associated with education, ethnicity, and age. It is essential to simplify health services and improve health education. Such changes have the potential to improve the health of Americans and address the health disparities that exist today.

The conclusions and opinions in this article are not necessarily those of the Institute of Medicine or its Committee on Health Literacy. The authors gratefully acknowledge the work of Allison M. Panzer, Institute of Medicine, National Academies, in amassing background material for this project.

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