

SPECIAL DIABETES PROGRAM FOR INDIANS: RELIABILITY AND VALIDITY OF BRIEF MEASURES OF PRINT LITERACY AND NUMERACY

Objectives: Health literacy is associated with health knowledge, behavior, and outcomes. Availability of valid measures of health literacy that require minimal time and resources to administer may provide a valuable resource for researchers and healthcare providers. We investigated the psychometric properties of brief, written tests of two components of health literacy – print literacy and numeracy – among American Indians and Alaska Natives.

Design: Secondary analysis of baseline data from the Special Diabetes Program for Indians Healthy Heart Project.

Setting: Thirty health care programs participate in the project. They span 13 states and include Indian Health Service hospitals/clinics/service units as well as tribal and urban Indian health care programs.

Participants: 3,033 American Indian and Alaska Native adults with diabetes.

Main Outcome Measures: Internal consistency was investigated for the print literacy items. Construct validity analyses examined the expected association of print literacy and numeracy with demographic characteristics and four measures of disease knowledge.

Results: The print literacy items demonstrated acceptable internal consistency. Print literacy and numeracy were more limited among older people and those with lower income and education. Both measures were strong predictors of disease knowledge.

Conclusions: Results support the value of the brief tests of print literacy and numeracy, and represent the first examination of the performance of health literacy measures in the American Indian and Alaska Native population. (*Ethn Dis.* 2012;22(2):207–214)

Key Words: Health Literacy, Psychometrics, American Indian Health

From Community and Behavioral Health, (AGB, JB, SMM) and Biostatistics and Informatics, Colorado School of Public Health (LJ) and Division of Diabetes Treatment and Prevention (KJA) and Office of the Director, Indian Health Service (YR).

Address correspondence to Angela G. Brega, PhD; Centers for American Indian and Alaska Native Health; Colorado School of Public Health; 13055 East 17th Avenue, Mail Stop F800; Aurora, CO 80045; 303.724.1470; 303.724.1474 (fax); angela.brega@ucdenver.edu

Angela G. Brega, PhD; Luohua Jiang, PhD; Janette Beals, PhD; Spero M. Manson, PhD; Kelly J. Acton, MD, MPH; Yvette Roubideaux, MD, MPH; Special Diabetes Program for Indians Healthy Heart Demonstration Project

INTRODUCTION

Health literacy (HL) represents “the capacity to obtain, process, and understand basic health information.”¹ It comprises several components, including print literacy (PL) and numeracy. Print literacy represents the ability to read and write in the context of health, whereas numeracy is the ability to understand and use health-related quantitative information.

Research suggests that HL may have significant implications for health. Numerous studies demonstrate a relationship between HL and health-related knowledge.^{2–9} Individuals with inadequate HL skills have been shown to have more restricted knowledge of a variety of health conditions and medical services, including diabetes, congestive heart failure, asthma, hypertension, cancer prevention, and family planning. Further, low-literate patients often demonstrate suboptimal health behavior^{8,10,11} and experience poor clinical outcomes.^{4,8,12–16}

These findings are concerning given that approximately half of US adults have restricted reading and numerical skills, with more than one third having HL skills considered inadequate to manage the demands of the health care system.^{17–20} Limitations are particularly common among racial/ethnic minorities, older adults, and those with lower levels of income and education.^{17–20} Although the prevalence of inadequate HL among the US Native population is not known, American Indians and Alaska Natives (AI/ANs) are likely to be at risk for poor

HL as a result of limited educational attainment and a high poverty rate (25.7%).²¹ Given the high prevalence of many serious medical conditions among AI/ANs,^{22–24} HL limitations may serve as a critical barrier to maintenance of optimal health in Native communities.

Because individuals with inadequate HL skills may struggle with written questionnaires, HL measures are generally administered through in-person interviews.^{9,16,25–29} This approach eliminates the potential for literacy skills themselves to hamper a participant’s performance. And, yet, the need for trained staff to orally administer HL items may deter investigators and health care providers from incorporating measurement of HL into their research and clinical activities. In the context of the Special Diabetes Program for Indians Healthy Heart (SDPI-HH) Project, for example, oral administration of HL measures was considered infeasible. A demonstration project designed to reduce cardiovascular risk among AI/ANs with diabetes, SDPI-HH has been ongoing in 30 AI/AN communities since 2006. Given the extensive amount of clinical and survey data collected and that HL was not a construct of primary interest, it was considered unrealistic to expect participating grantees to conduct interviews with each participant to assess HL limitations. To allow an evaluation of the impact of SDPI-HH on participants with varying levels of HL, however, seven items adapted from existing HL measures were included in the SDPI-HH participant questionnaire.

The objective of this analysis was to evaluate the psychometric properties of the Special Diabetes Program for Indians Healthy Heart health literacy items, with the goal of determining whether these brief, written tests can be used to assess print literacy and numeracy, when oral administration of items is not feasible.

The objective of this analysis was to evaluate the psychometric properties of the SDPI-HH HL items, with the goal of determining whether these brief, written tests can be used to assess PL and numeracy, when oral administration of items is not feasible. We examined internal consistency reliability as well as construct validity. To evaluate construct validity, we assessed the relationship between the SDPI-HH HL measures and other constructs with which they were expected to be associated. Based on previous research (summarized above), we hypothesized that PL and numeracy would be significantly related to specific demographic characteristics (ie, age, education, income) as well as disease knowledge.

METHODS

In recognition of the high prevalence of diabetes and cardiovascular disease (CVD) among AI/ANs,^{22,23} in 2002, the US Congress directed the Indian Health Service (IHS) to develop a competitive grant program to support demonstration projects implementing

evidence-based diabetes- and CVD-prevention activities. The SDPI-HH Project was one of two demonstrations funded. The 30 health care programs that participated in SDPI-HH served 138 tribes and were located in 13 states and each of the 12 IHS administrative areas. The programs included seven IHS hospitals, clinics, or service units as well as 23 tribal or urban IHS-contracted health care programs.

Participant Recruitment, Sample, and IRB Approval

Participant enrollment began in January 2006. Participants were identified mainly through electronic medical records or diabetes registries, and also recruited through community- and clinic-based activities (eg, health fairs, referrals).

Participants were required to be AI/ANs aged ≥ 18 and to have diabetes. Exclusion criteria included pregnancy, dialysis for end-stage renal disease, and ongoing cancer treatment or active alcohol/substance abuse deemed by provider judgment to preclude successful participation. In August 2009, an abbreviated version of the SDPI-HH participant questionnaire – which did not include all of the items needed for this analysis – was implemented. Therefore, all participants enrolled in August 2009 or later were excluded from this work.

The analysis sample included the 3,033 participants who completed the full-length participant questionnaire. This sample represents 90.0% of all participants enrolled prior to August 2009 ($N=3,370$).

The SDPI-HH protocol was approved by the Institutional Review Boards of the University of Colorado Denver and the IHS. When required, grantees obtained approval from other entities charged with overseeing research in their programs (eg, tribal review boards). All participants provided written informed consent and Health Insurance Portability and Accountability Act authorization. The grantees as well

as the Navajo Nation Human Research Review Board approved this article for publication.

Procedure

Grantees implemented an intensive case-management intervention aimed at reducing CVD risk among AI/ANs with diabetes. At baseline and then annually, participants underwent a medical examination, during which CVD risk was assessed (eg, blood pressure, glycemic control) and an individualized care plan was developed or refined. At these time points, participants also completed a questionnaire that included items assessing demographics, PL, numeracy, and disease knowledge. After completing the baseline assessment, the intervention was administered. Participants attended regular case-management meetings, at which progress toward CVD risk reduction was evaluated and education on diabetes self-management and CVD risk reduction was provided.

Measures

Participant age, education, and income were collected as part of the participant questionnaire. Age in years was coded as a continuous variable. Education represented the highest grade of school completed and was coded using a six-point scale, with larger numbers representing greater educational attainment (eg, 1= ≤ 8 th grade, 6=college/professional school graduate). Participants also reported total pre-tax income of all household members for the prior year, which was coded using a six-point scale, ranging from $< \$10,000$ (1) to $\geq \$50,000$ (6).

Table 1 presents the PL and numeracy items included in the questionnaire. The three PL items (items 1–3 in Table 1) assess self-reported confidence in reading/completing medical forms and were adapted from HL screening questions that have been previously validated using oral administration.^{30–35} Overall performance was measured as the mean of participants' responses to the

Table 1. Print literacy and numeracy items

Print Literacy Items	
1. How often do you have a hard time understanding written information about your health that you get from your clinic? (This might include information from a doctor or nurse.)	Always Often Sometimes Rarely Never
2. How confident are you in filling out medical forms by yourself? ^a	Extremely Quite a bit Somewhat A little bit Not at all
3. How often do you prefer that someone (like a family member or someone else) help you read medical materials?	Always Often Sometimes Rarely Never
Numeracy Items	
4. Which of the following numbers represents the lowest risk? (For example, which would you most like to hear from a doctor about your risk for a medical condition?)	1 in 10 people 1 in 100 1 in 1000 ^b Don't know
5. If the chance of getting a health condition is 20 out of 100 people, this would be the same as having what percent (%) chance of getting the condition?	2% 20% ^b 200% Don't Know
6. A prescription says "Take one tablet by mouth every 6 hours." If you take your first tablet at 7 a.m., when should you take your second tablet?	Later in the morning 1 p.m. ^b Sometime after 1 p.m. Whenever I need it 7 p.m.
7. Normal fasting blood sugar is 70–100. If your blood sugar today is 140, is your blood sugar normal?	Yes Close enough

Table 1. Continued

No ^b Don't know
^a Reverse scored prior to analysis. ^b Correct answer.

three items (range of 1–5, with larger values indicating better PL).

The four numeracy items (items 4–7) were adapted from two sources. Items 4 and 5 were originally developed and validated by Lipkus and colleagues, who administered the items in writing.²⁵ Items 6 and 7 were adapted from the Test of Functional Health Literacy in Adults,²⁷ which is administered orally. Overall numeracy performance was measured as the percentage of the four items answered correctly.

The questionnaire assessed four types of knowledge: general diabetes, insulin use, cholesterol, and blood pressure knowledge. Scores on each test reflected the percentage of items answered correctly. Refined items from the 23-item Diabetes Knowledge Test³⁶ were used to measure general diabetes and insulin use knowledge. These subscales showed strong internal consistency in the current sample and in previous research (Cronbach alpha=.70–.76). Cholesterol knowledge was assessed using refined items from the 11-item Cholesterol and Heart Disease IQ Test,³⁷ which showed strong internal consistency in the current sample (Cronbach alpha=.74). Blood pressure knowledge was measured using items adapted from the seven-item Hypertension Knowledge Scale.³⁸ In this sample, internal consistency among the items was moderate (Cronbach alpha=.62).

Data Analysis

Descriptive analyses were conducted to summarize the demographic characteristics of the study sample and participant HL skills. For each PL item, we computed the mean score (and standard deviation) as well as the prevalence of self-reported limitations. Consistent with earlier studies,^{32,34,35} we computed the percentage of participants

who reported that they sometimes, often, or always had a hard time understanding written health information; who were not at all confident to somewhat confident in completing medical forms; and who sometimes, often, or always preferred to have help reading medical materials. For the numeracy items, we computed the percent correct for each item.

Cronbach alpha was computed to assess internal consistency reliability of the PL items. Because the numeracy items represent a diverse array of numerical skills and use a dichotomous response format, for which Cronbach alpha is not well suited, Cronbach alpha was not computed for the numeracy items.

Two sets of analyses examined construct validity. To test the hypothesis that the HL items would be associated with demographic characteristics, we conducted two ordinary least squares (OLS) regression analyses predicting PL (or numeracy) as a function of age, education, and income. Education and income were represented by multiple dummy variables, each capturing a specific level of education or income. The lowest category on each scale was the reference group to which all other groups were compared. To avoid excluding the 19.5% of participants who did not provide information about income, an additional dummy variable was included to identify participants with missing income data.

We also tested the hypothesis that the HL measures would be significantly associated with disease knowledge. Using OLS regression, we examined the degree to which PL and numeracy (simultaneously) predicted each of the four knowledge measures. All models controlled for the age, education, and income variables described previously. Analyses related to insulin use knowledge only included individuals who used insulin.

RESULTS

Demographics

Table 2 provides descriptive information about the sample. The majority

Table 2. Characteristics of study sample (N=3,033)

	%
Age, years	
18–34	5.9
35–44	15.5
45–54	28.2
55–64	30.4
≥65	20.0
Female	66.4
Educational attainment	
≤8th grade	4.0
Some high school	8.9
High school graduate/GED	32.2
Vocational school	8.9
Some college	39.1
College/professional school graduate	6.8
Income	
<\$10,000	22.6
\$10,000–\$19,999	18.7
\$20,000–\$29,999	18.0
\$30,000–\$39,999	14.5
\$40,000–\$49,999	10.2
≥\$50,000	16.0
Employment status	
Full-time	42.2
Part-time/seasonal	9.6
Retired	18.4
Disabled	13.7
Unemployed	13.5
Student/never worked for pay	2.6
Marital status	
Married/living with partner	57.3
Separated/divorced	18.5
Widowed	9.8
Never married	14.4
Insulin user	31.6

of participants were female, with about half aged ≥55 years. More than one-quarter of participants reported being unemployed or disabled. Income levels were low and education limited for some participants. Nearly one-third of participants reported using insulin.

Psychometric Properties of the HL Measures

Descriptives and Internal Consistency Reliability

Table 3 provides information about participant performance on and internal consistency of the HL items. Partici-

Table 3. Performance of items and summary scores

	Mean (SD)	% with Limitations ^a	Item-total Correlation ^b	Cronbach Alpha ^b
Print Literacy				
1. Hard time understanding written health information	3.18 (.94)	64.9%	.45	—
2. Confidence in filling out medical forms (reverse coded)	3.63 (1.10)	41.6%	.47	—
3. Prefer that someone help read medical materials	3.45 (1.19)	47.3%	.54	—
Print Literacy Summary Score ^c	3.42 (.84)	—	—	.67
Numeracy	% correct		Item-total correlation ^a	
4. Identify lowest risk	52.2	—	.35	—
5. Convert proportion to percent	70.2	—	.34	—
6. Time to take second tablet	88.3	—	.24	—
7. Identify normal blood sugar	68.7	—	.28	—
Numeracy Summary Score ^d	69.8	—	—	—

^a Percent of respondents with self-reported limitations in PL skills.

^b Standardized value.

^c Mean scale score.

^d Mean % correct.

pants typically reported being somewhat or sometimes confident in reading or completing medical forms. Slightly less than half of participants reported limited confidence in completing medical forms by themselves and preferred to have assistance with reading medical materials. A majority reported having difficulty understanding written health information. Internal consistency among these PL items was relatively strong (Cronbach alpha=.67).

Participants answered approximately 70% of the numeracy items correctly, with the percentage of correct responses ranging widely across the four items. Although only half of participants accurately identified the ratio representing the lowest medical risk (item 4), the majority were able to identify the correct time for a second dose of medication (item 6). Item-total correlations suggested a low degree of association among the numeracy items.

Construct Validity

As shown in Table 4, demographics were associated with HL. Controlling for education and income, older participants had significantly lower PL and numeracy scores than did their younger counter-

parts. Likewise, while controlling for the other demographic variables, participants' PL and numeracy scores progressively improved as level of education or income increased. Missing income data were significantly associated with HL scores. For both HL variables, performance among those with missing income data was similar to that of individuals with household incomes between \$10,000 and \$19,999.

The HL measures were associated with disease knowledge (Table 5). Controlling for demographics, PL and numeracy scores were significantly related to general diabetes, insulin use, cholesterol, and blood pressure knowledge. In all cases, participants with higher PL and numeracy scores performed significantly better on the knowledge measures.

DISCUSSION

Results supported the value of the PL and numeracy tests used in the SDPI-HH Project. Internal consistency of the PL items (Cronbach alpha=.67) fell slightly below the commonly accepted threshold of .70 for establishing good internal consistency. However, given the same level of

Table 4. Relationship of demographics with health literacy

Parameter Estimates	Print Literacy Coefficient ^a (N=2,865)	Numeracy Coefficient ^a (N=2,845)
Age, years	-.01 ^e	-.13 ^d
Educational Attainment		
≤8th grade (reference)	—	—
Some high school	.55 ^e	10.90 ^d
High school grad/GED	.83 ^e	21.13 ^e
Vocational school	1.04 ^e	23.97 ^e
Some college	1.13 ^e	29.96 ^e
College/professional school grad	1.32 ^e	31.25 ^e
Income		
Income data missing	.10 ^b	12.38 ^e
<\$10,000 (reference)	—	—
\$10,000–\$19,999	.13 ^c	12.42 ^e
\$20,000–\$29,999	.19 ^d	14.01 ^e
\$30,000–\$39,999	.27 ^e	14.39 ^e
\$40,000–\$49,999	.31 ^e	18.08 ^e
≥\$50,000	.32 ^e	20.45 ^e
Model R ² (adjusted)	.17	.17

^a Unstandardized coefficients from OLS regression models predicting print literacy and numeracy as a function of demographics.

^b $P \leq .05$.

^c $P \leq .01$.

^d $P \leq .001$.

^e $P \leq .0001$.

correlation among items, Cronbach alpha rises substantially as the number of scale items increases.³⁹ As such, an alpha of this magnitude for a three-item scale indicates strong intercorrelations among items and suggests acceptable reliability. Further, both the PL and numeracy tests showed expected associations with demographic characteristics and disease knowledge, demonstrating strong construct validity. Overall, results suggested that these items

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provide a valid approach to assessing PL and numeracy that may prove useful when orally administered items are not practical.

Print Literacy

The findings related to the PL items were consistent with earlier work to test similar items in diverse populations. Several studies now show the screening questions developed by Chew et al³¹ to be valid indicators of HL, as measured using well-established instruments.^{31–35} Although the SDPI-HH items represent revised versions of those screening questions, our work also suggests that the

three items capture valid information about respondents' PL skills. To our knowledge, our study represents the first test of the items administered in survey format, providing the first indication that it may be possible to capture information about PL skills through written screening questions.

The SDPI-HH PL items capture a qualitatively different aspect of PL than is typically assessed. Most commonly used HL instruments are performance-based measures, which assess the ability to pronounce written words²⁹ or answer questions about health-related text.^{27,28} In contrast, the SDPI-HH items (and the items from which they were developed) measure participants' subjective perceptions that they can read and complete health-related documents. Although subjective PL is associated with performance-based measures,^{31–35} it is unclear how the relationship of PL with other health-related constructs – such as knowledge, attitudes, behaviors, and clinical outcomes – may differ depending on the type of measure used. This work suggests a strong association of subjective PL with disease knowledge, a common finding using performance-based measures as well.^{2–9} Other studies using the Chew screening questions³¹ have shown participants with limited subjective PL to be less likely to read medication information provided by a pharmacy⁴⁰ and less likely to perceive communications within their health care organizations as patient-centered.⁴¹ Although these results provide important insight into the role of subjective PL, future research should

Table 5. Association of health literacy with disease knowledge

	Print Literacy Coefficient ^a	Numeracy Coefficient ^a
Knowledge Scale		
General diabetes (n=2,832)	4.25 ^b	.25 ^b
Insulin use (n=901)	5.24 ^b	.21 ^b
Cholesterol (n=2,834)	2.75 ^b	.18 ^b
Blood pressure (n=2,833)	2.33 ^b	.17 ^b

^a Unstandardized coefficients from OLS regression models predicting knowledge as a function of print literacy and numeracy (simultaneously).

^b $P < .0001$.

address the potentially disparate impacts of subjective and objective PL.

Numeracy

Results suggested that the numeracy items included in the SDPI-HH questionnaire may provide a valid approach to assessing numerical capacity. These findings are consistent with prior studies showing the questions from which the SDPI-HH items were adapted to be valid indicators of respondents' numeracy skills.^{25,27,28} Although the SDPI-HH items do not assess all aspects of numeracy, they capture key mathematical skills, such as understanding percentages and determining medication timing. In comparison with many measures,^{9,25,26,42} the four-item SDPI-HH test provides a brief approach to assessing critical aspects of numeracy. Importantly, unlike some measures,^{9,16,26} these items can be implemented across medical conditions. Further, the present work suggests that the items can be administered in writing, whereas two of the original items from which the SDPI-HH numeracy test was developed are orally administered.²⁸

Implications

The SDPI-HH HL measures may provide an important tool for investigators wishing to capture HL in a manner that requires minimal time and staff resources. Availability of short, self-administered tests of PL and numeracy may allow researchers to examine these important constructs even when data are collected through questionnaires or when HL is not a construct of primary interest, but could play an important mediating or moderating role. Easing the burden of data collection may be particularly valuable for intervention projects, in which characterization of effectiveness by literacy level is essential.

Availability of brief, written measures of HL also may provide a valuable resource for health care providers. Although there is agreement that health-related information should be tailored to a patient's literacy

level, care providers often overestimate the literacy skills of their patients^{3,43,44} and thus may not always implement recommended strategies for enhancing patient-provider communication. The SDPI-HH HL tests can be implemented easily and unobtrusively in clinical practice (eg, as part of pre-exam paperwork), allowing providers to identify patients for whom restricted reading/writing and numerical skills may serve as a barrier. As suggested by earlier work indicating that physicians who are informed of their patients' HL status are more likely to implement management strategies recommended for low-literate patients,⁴⁵ such screening in the clinical setting could trigger providers to implement communication strategies known to enhance provider-patient communication, possibly improving self-management and disease outcomes as a result. Future research is needed, however, to establish the cut-points that would identify a patient as having limitations in HL based on these items.

To our knowledge, this work represents the first examination of HL among AI/ANs. Given the economic and educational challenges faced by many AI/ANs, HL may be an important barrier to optimal health in this population. Availability of brief, written tests of PL and numeracy that have been validated in a diverse sample of AI/ANs may enhance our ability to understand the impact of HL on the health of AI/ANs.

Limitations and Future Directions

Despite providing support for the SDPI-HH HL items, these findings are subject to limitations. Although the PL and numeracy measures were related to demographic characteristics and disease knowledge in expected ways, we were not able to examine the association between these items and previously validated HL measures, which were not collected as part of SDPI-HH. An important next step in this work is to validate these

written HL items against the gold standard, performance-based measures of HL, such as the short version of the Test of Functional Health Literacy in Adults²⁷ and the Rapid Estimate of Adult Literacy in Medicine.²⁹

Further, although there is a need for measures that capture the full breadth of health-related numerical skills,^{45,46} the SDPI-HH items assess only a small set of abilities. Although the brevity of the numeracy test can be seen as a limitation, the availability of a brief, general numeracy test may contribute to the field in a positive way by reducing the burden associated with measuring this often-overlooked construct. In future work, it will be important to establish the association of this brief test with more comprehensive measures of numeracy.

Finally, as we examined the empirical performance of these measures among a sample of AI/ANs with diabetes, these results may not be generalizable to other populations. However, given that the items were adapted from existing instruments used successfully in other racial/ethnic communities and in studies targeting other medical conditions, these measures are likely to be applicable to non-Native populations and patients without diabetes. It would be valuable to collect the SDPI-HH HL items in a diverse sample of patients to determine both validity of the measures across different groups and to allow examination of differences in PL and numeracy skills across diverse populations using these self-administered items.

CONCLUSION

In summary, results indicate that the SDPI-HH HL items may be valid measures of PL and numeracy. As these tests represent the only measures validated for use among AI/ANs, they have potential to enhance the investigation of HL as a predictor of AI/AN health and to improve clinical practice in AI/AN communities by enabling

providers to identify patients for whom poor HL skills may serve as a barrier. Given the economic and educational hardship often seen in AI/AN populations, understanding the implications of HL will be important for guiding effective intervention and clinical practice.

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AUTHOR CONTRIBUTIONS

Design and concept of study: Brega, Beals, Manson, Roubideaux

Acquisition of data: Jiang, Beals, Acton, Roubideaux

Data analysis and interpretation: Brega, Jiang, Beals, Manson

Manuscript draft: Brega, Jiang, Beals, Manson, Acton, Roubideaux

Statistical expertise: Brega, Jiang, Beals, Roubideaux

Acquisition of funding: Manson, Acton, Roubideaux

Administrative: Beals, Manson, Acton, Roubideaux

Supervision: Brega, Beals, Manson, Acton, Roubideaux