

Patients' Shame and Attitudes Toward Discussing the Results of Literacy Screening

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We investigated patients' willingness to have their reading ability documented in their medical records and the degree of shame and embarrassment associated with such disclosure. Structured interviews were conducted among a consecutive sample of 283 primary care patients at an urban public hospital. Patients' literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM). Self-report of degree of shame and embarrassment related to literacy skills was measured using an orally administered questionnaire. Fifty-one percent of patients had low literacy skills (\leq sixth grade) and 27.9% were assessed as having marginal literacy (seventh–eighth grade). Half (47.6%) of patients reading at or below the third-grade level admitted feeling ashamed or embarrassed about their difficulties reading, compared with 19.2% of those reading at the fourth–sixth-grade level and 6.5% of those reading at the seventh–eighth-grade level ($p < 0.001$). More than 90% of patients with low or marginal literacy reported it would be helpful for the doctor

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or nurse to know they did not understand some medical words. Patients with limited literacy were more likely to report feelings of shame as a result of disclosure ($p < 0.05$). Health care providers must recognize the potential shame patients might experience as a result of literacy screening.

Patients' literacy skills have been found to significantly impact various domains of health, including the timely use of preventive services (Scott, Gazmararian, Williams, & Baker, 2002), understanding of disease and treatment (Gazmararian, Williams, Peel, & Baker, 2003; Wolf, Davis, et al., 2005), adherence to medical instructions (Kalichman, Ramachandran, & Catz, 1999), self-management skills (Schillinger et al., 2002), and health outcomes (Baker, Parker, Williams, Clark, & Nurss, 1997; Schillinger et al., 2002; Wolf, Gazmararian, & Baker, 2005). The National Assessment of Adult Literacy (NAAL) survey conducted in 2003 revealed that 43% of adults in the United States are at the lowest levels of reading proficiency (Kutner, Greenberg, & Baer, 2005). According to the Institute of Medicine, these individuals are likely to have a substantial amount of difficulty obtaining, processing, and understanding basic information and services needed to make appropriate health decisions (Institute of Medicine, 2004).

Several instruments have been developed to efficiently measure patient literacy specifically in the health care setting, with the primary intent being a research tool to aid in the study of the literacy–health relationship (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Davis, Kennen, Gazmararian, & Williams, 2004; Davis, Michielutte, Askov, Williams, & Weiss, 1998; Hanson-Divers, 1997; Parker, Baker, Williams, & Nurss, 1995; Weiss et al., 2005). The overwhelming evidence now available that depicts limited literacy as a formidable risk factor for poor health outcomes however, has led to a debate over whether these literacy tests should be used by clinicians to screen patients for potential problems. The benefits of literacy screening are apparent, as it could lead to a proper allocation of health education and care management resources (DeWalt et al., 2004). The risks are less clear however, identifying patients as having limited literacy may result in adverse consequences, such as concerns for social stigma and the avoidance of health services out of shame.

While many patients simply are unaware of their limited literacy skills, others clearly are ashamed and make attempts to conceal this knowledge from others (Baker et al., 1996; Elson, 1993; Parikh, Parker, Nurss, Baker, & Williams, 1996). Thus, not all patients may be receptive to routine measurement of their literacy and want this documented in their medical chart. In a previous study conducted by this research team, nearly 40% of patients with poor literacy skills admitted shame (Baker et al., 1996; Elson, 1993; Parikh et al., 1996). Remarkably, two thirds of these patients divulged they had never told their spouses, half had never told their children, and 19% had never disclosed their difficulty reading to anyone. Thus, the seemingly facile solution of screening patients' literacy skills may create significant problems, even alienating patients who already face a significant barrier to accessing health care.

Before pursuing the potential benefits of measuring patients' reading skills, health care providers and educators need to fully understand the risk of uncovering such a potentially shameful personal handicap. For the current study, we sought to determine patients' attitudes toward literacy screening as they were to be assessed within an effort to improve their health care. We interviewed patients presenting for scheduled medical appointments to assess difficulties they had experienced

performing health-related reading tasks. For example, we sought to determine if they had made mistakes taking medications or missed appointments due to difficulties reading and understanding pill bottles or appointment slips. After inquiring about such problems, we assessed their reading skills and discussed the level of their reading deficiency with them. Given the finding of limited literacy, we assessed patients' willingness to have their reading ability documented in their medical records and the degree of shame and embarrassment associated with this disclosure.

Methods

During the summers of 1995 and 1996, patients were recruited from the General Medical Clinic at Grady Memorial Hospital in Atlanta, Georgia. Grady Memorial Hospital is a large, urban public hospital; the General Medical Clinic is the site of approximately 58,000 outpatient primary care visits each year. The vast majority of patients seen are indigent and African American. The Human Investigation Committee of Emory University approved the study design and survey instruments.

Patients were recruited and interviewed while they waited to see a primary care physician. To diminish selection bias, patients were enrolled in the order in which they arrived at the clinic. Exclusion criteria included the following: (1) age less than 18 years, (2) unintelligible speech, (3) overt psychiatric illness, (4) English as a second language, (5) too ill to participate, or (6) visual acuity worse than 20/100. Patients who agreed to be interviewed were taken to a private room, where they were read the informed consent statement. Patients were told that their participation was voluntary and confidential. After obtaining informed consent, the investigators orally administered the survey.

The survey began with a demographic inventory, followed by questions regarding difficulty reading materials typically encountered in the health care setting, and problems encountered because of difficulties reading such materials. Visual acuity then was performed using a pocket vision screener (Rosenbaum, Graham-Field Surgical Co, Inc., New Hyde Park, NY). Patients with 20/100 or better visual acuity had their reading ability assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is a reading recognition test composed of 66 health-related words, and it is the most commonly used assessment of patient literacy in medical settings (Davis, Michielutte, Askov, Williams, & Weiss, 1998; Davis, Kennen, Gazmararian, & Williams, 2004). Administering the REALM involves having patients read aloud from the list of medical terms, which are arranged in increasing order of difficulty. It can be administered in less than 3 minutes, and raw scores are calculated by a simple sum of the correctly pronounced words that can be converted into one of four reading grade levels: Level I, third grade or less (0–18); Level II, fourth to sixth grade (19–44); Level III, seventh to eighth grade (45–60); and Level IV, ninth grade and above (61–66). The REALM is highly correlated with standardized reading tests and the Test of Functional Health Literacy in Adults (TOFHLA) (Davis et al., 2004; Parker et al., 1995).

After the REALM assessment, Patients scoring 61 or higher (adequate literacy) were thanked and asked no further questions. The remaining participants then were told the following:

It appears you have trouble reading “most” Level IV, “some” Level III, or “a few” Level II words on the word list we just used [i.e., the

REALM]. I would like to talk to you about this a little further. We are trying to help patients in the hospital with difficulties reading things here in the hospital.

Patients then were asked if they would want a note placed in their medical chart that documented they didn't "understand some medical words." Those responding "yes" were asked how "ashamed or embarrassed" they would feel if this information was in their chart. Subsequent questions asked patients how helpful it would be to the doctors, nurses, and clerks to know that the patients experienced difficulty reading, and how ashamed or embarrassed they would feel if these individuals knew this information. Patients initially responding "no" to placing a note in their medical chart were told that "half" of the patients coming to the hospital "have trouble reading and understanding medical information," and were asked again if they would want a note placed in their medical chart that documented they did not "understand some medical words." Next, patients were asked whether they would want to have information about their difficulty reading marked on their hospital card and in an open-ended question asked how they would feel if such information was on their card. Finally, patients were asked, "Is there anything else you want to tell me?"

Categorical variables were analyzed using unadjusted χ^2 tests. Continuous variables (e.g., age) were analyzed using Student's *t* test. A nonparametric test for trend was used across ordered groups. A *p* value of 0.05 was considered statistically significant. All data analyses were performed using the statistical software program STATA 8.0 (College Station, TX).

Results

Of the 313 patients invited to participate in the study, 306 (97.8%) agreed to be interviewed; of these, 23 (7.5%) were excluded because of poor visual acuity. Thus, 283 patients completed the initial interview and had their reading skills assessed with the REALM. Patients ranged in age from 22 to 85, with a mean age of 57.5 ± 14.0 ; almost half (46.6%) were age 60 or older. The majority were African American (90.1%) and female (70.0%), and 58.6% had less than a high school education. Almost one fourth (23.3%) of patients were reading at or below the third-grade level, 27.6% at the fourth–sixth-grade level, and 27.9% at the seventh–eighth-grade level. Only 21.2% were reading at a high school level or above. These patients were not asked to complete the last portion of the survey, which dealt with whether they would want a note placed in their medical chart that documented that they did not "understand some medical words." Participants with lower literacy skills were more likely to be older, male, African American, and less educated (Table 1).

Limited literacy was associated with self-report of problems with taking medications, need for help with health-related reading tasks (i.e., health literacy), and difficulty understanding and following instructions on appointment slips (Table 2). Differences were most notable when comparing patients with the poorest literacy skills (\leq third grade level) with patients with adequate literacy (ninth grade and above). For example, 19.7% of patients reading at or below the third-grade level (Level I) reported becoming confused about their medications because of trouble reading or understanding the directions on a medicine bottle compared with 6.6% of those with adequate literacy skills ($p = 0.005$). More than half of patients reading at Level I (57.6%) reported requesting help to read medicine bottles compared with

Table 1. Patient characteristics, stratified by literacy level

Variable	REALM Score				P value
	Level I ≤3rd grade (n = 66)	Level II 4th–6th grade (n = 78)	Level III 7th–8th grade (n = 79)	Level IV ≥9th grade (n = 60)	
Age, Mean (SD)	58.6 (12.6)	62.0 (11.8)	56.9 (16.8)	51.3 (11.9)	<0.001
Female, %	56.1	76.9	74.7	70.0	0.03
Race					0.03
Black	97.0	93.6	88.6	80.0	
White	3.0	6.4	8.9	18.3	
Other	0.0	0.0	2.5	1.7	
Years of schooling					<0.001
≤6th grade	42.4	12.8	5.1	0.0	
7th–11th grade	47.0	60.3	45.6	16.7	
12th grade	10.6	23.1	34.2	43.3	
Some college	0.0	2.6	11.4	18.3	
College graduate	0.0	1.2	3.7	21.7	

16.7% of literate patients ($p \leq 0.001$). Fifteen percent of poor readers reported missing a medical appointment because of being unable to understand an appointment slip compared with 3.3% of patients with adequate literacy ($p = 0.01$).

Overall, nearly half (47.8%) of patients reading at or below the third-grade level acknowledged having felt shame or embarrassment about their difficulties reading, compared with 19.2% of respondents reading at the fourth–sixth-grade level, and 6.5% of those with marginal literacy skills (seventh–eighth-grade level, $p < 0.001$). Yet the majority of patients reported that it would be a little, somewhat, or very helpful to the doctor (95.0%), nurse (93.1%), or clerk (86.1%) to know that they did not understand some medical words. There was increasing reports of a little, some, or a very strong feeling of shame or embarrassment associated with this based on the patient's literacy level (Table 3). Among patients with marginal literacy skills (seventh–eighth-grade level), shame estimates ranged between 13% and 17% (depending on physician, nurse, or clerk) regarding whether they would feel a little, somewhat, or very ashamed if medical staff would know about their difficulties reading. These estimates of perceived shame increased twofold among patients reading at or below the third-grade level (34%–36%).

The majority (83.7%) of patients with marginal or low literacy skills ($n = 221$; 2 declined to respond) were willing to have a note placed in their medical chart documenting that they did not understand some medical words. There was no difference in the proportion of affirmative responses by reading level ($p = 0.89$). Half of those patients initially responding negatively to this idea ($n = 18$) responded affirmatively after they were informed that “half of the patients” coming to this hospital have trouble reading and understanding medical information.

Despite the majority of patients expressing a willingness to have their reading deficiencies documented in their medical chart, many confirmed that this

Table 2. Self-reported difficulties and requests for assistance due to trouble reading

Health Task	REALM Score				<i>P</i> value
	Level I ≤3rd grade (<i>n</i> = 66)	Level II 4th–6th grade (<i>n</i> = 78)	Level III 7th–8th grade (<i>n</i> = 79)	Level IV ≥9th grade (<i>n</i> = 60)	
Confused about medications.	19.7	5.1	5.1	6.6	0.01
Took medicines wrong.	7.6	7.6	0.0	1.7	0.04
Took a medicine by mistake.	12.1	6.5	1.3	5.0	0.05
Has someone help them read medicine bottles.	57.6	28.2	22.8	16.7	<0.001
Asks someone to help read name of medication and directions.	56.1	25.6	12.7	1.7	<0.001
Missed an appointment.	15.2	6.4	1.3	3.3	0.01
Had trouble finding a clinic.	22.7	19.2	5.1	10.0	0.01
Has someone help them read appointment slips.	48.5	18.0	8.9	5.0	<0.001
Asks for help with hard-to-read written instructions or forms.	86.4	60.3	44.3	40.0	<0.001

Table 3. Patient perceptions of shame associated with disclosure of literacy ability

Disclosure	REALM Score			P Value
	Level I ≤3rd grade (n = 66)	Level II 4th–6th grade (n = 78)	Level III 7th–8th grade (n = 79)	
Doctor				
Helpful if doctor knows	93.9	96.0	94.8	0.78
Feel ashamed if doctor knows	36.4	24.4	16.7	0.03
Nurse				
Helpful if nurse knows	95.5	92.1	92.1	0.26
Feel ashamed if nurse knows	33.8	21.9	15.5	0.05
Clerk				
Helpful if clerk knows	93.7	91.9	84.2	0.28
Feel ashamed if clerk knows	34.4	20.5	13.0	0.08
Ashamed if documented in chart	35.7	19.7	14.1	0.03
Ashamed if documented on card	36.9	22.1	20.6	0.39
Refuses to have a card	9.2	13.0	16.7	0.42

documentation would be shameful or embarrassing (Table 3). Overall, 22.6% of patients reported they would feel a little, somewhat, or very ashamed or embarrassed about having this information in their medical chart. This was more common among patients reading at or below the third-grade level (35.7%), followed by 19.7% of patients reading at the fourth–sixth-grade level, and 14.0% of participants reading at the seventh–eighth-grade level ($p = 0.03$). Similar proportions of patients by reading level reported shame and embarrassment at having their reading difficulty coded on their card (Table 3). Many patients selected the response option of not wanting any such documentation on their card (refusal) instead of acknowledging any degree of shame or embarrassment. While not statistically significant, this was more common among patients with marginal literacy skills (16.7% [seventh–eighth grade] vs. 13.0% [fourth–sixth grade] vs. 9.2% [\leq third grade], $p = 0.42$).

When patients were asked how they would feel about having their literacy level documented on their hospital card, categorization of patients' responses ranged from being strongly opposed to strongly desiring. For example, representative comments categorized as strongly desiring accounted for 11% of all responses and included, "would appreciate that," "make me feel a lot better," or "would like that very much." Forty-seven percent of responses were categorized as moderately desiring such documentation and included comments such as "wouldn't bother me," "that'd be fine," or "it'd be alright." Many patients, however, were opposed or ambivalent about this. Almost one third of patients (31.0%) were moderately or strongly opposed to having their difficulty reading documented on their hospital card when

asked in an open-ended manner. Comments such as, “don’t think that should be public,” “wouldn’t like that,” or “very ashamed” reflected the strong reaction by some patients to this idea.

Discussion and Conclusion

In our study, many patients with lower literacy skills reported problems due to difficulties with “health literacy” tasks (reading and understanding prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient [Institute of Medicine, 2004]. In particular, patients with low literacy more frequently reported confusion about their medications and missing medical appointments than more literate patients. Recognizing these difficulties, patients overwhelmingly reported that it would be helpful to doctors, nurses, and clinic staff clerks to know about their reading difficulty. Although most patients were willing to allow documentation in their charts concerning their literacy level, a substantial number of patients were not agreeable to this disclosure.

This study sheds light on a controversial issue, and the findings are consistent with our previous work; limited literacy skills was associated with older age, less education, and significant shame and embarrassment (Baker et al., 1996; Parikh et al., 1996). The common report by patients of shame associated with documentation explains the lack of universal acceptance. Almost half (48%) of patients reading at \leq third-grade level admitted having felt some shame and embarrassment about their difficulties reading, and more than a third reported they would feel ashamed if medical staff knew this information. Such provocation of shame should be avoided. A powerful negative emotion, shame creates significant internal conflict that also can generate difficulties with interpersonal interactions necessary to function in the health care environment (Martin, 1993). If the requirement of reading skills to navigate the medical environment elicits shame in patients, such negative feelings may be externalized to the health care provider, prompting counterproductive actions such as noncompliance or malpractice suits. Shame also appears to be associated with submissive behavior that can hinder patients’ ability to obtain needed health care when they lack understanding of issues or simply cannot read their prescription instructions or appointment slips (Gilbert, Pehl, & Allan, 1994). Compounding the barrier of limited literacy, shame may have an adverse impact on patients accessing health care.

Patients with limited literacy face a daunting effort to seek health care, especially when handicapped by the shame associated with potential disclosure. Shame may inhibit individuals with low literacy from admitting their communication difficulties and revealing such inadequacies in literacy ability. The intensity of the shame is evident in some of the study participants’ comments when they were asked how they would feel if their reading difficulties were documented in their medical record. Statements such as “would not want everyone to know,” “don’t think that should be public,” and “very ashamed” were common among participants and reflect the fear and intensity of the emotion. Because of this, the self-report rates of shame in this study may be an underestimate as shame, like illiteracy, often is hidden during the medical encounter (Kaufmann, 1996). Although more than 90% of patients reported it would be helpful for doctors and nurses to know about their reading difficulties, health care providers must recognize the difficulty patients face in allowing this information to be ascertained.

This is one of the first studies to our knowledge to assess in detail patients' willingness to have their difficulties reading and understanding medical materials documented in their medical chart or on their medical card. Seligman and colleagues (2005) previously implemented an intervention that included literacy screening and documentation in patient charts; most patients in the study found screening to be helpful. For our study, some limitations restrict generalizing the findings. This study was conducted at an urban public hospital serving an indigent, predominantly African American population. The responses may be quite different among people of different ethnicity or in a rural setting. Also, we were unable to account for individual differences in the training and experience of health care providers at the clinic. This, along with patients' own varied experience with different providers may have affected perceptions of shame with regard to literacy screening. Additional research using more sophisticated methodologies to measure shame may provide further insight into how best to address the shame associated with patients' inadequate literacy (Tangney, 1996). This also should include a more in-depth investigation of the various possible screening tool options, as some of these tests may be less acceptable than others.

Conclusion

Identifying patients with limited literacy through screening tools and documenting this information in their medical record to support enhanced health education activities has been a proposed response to the health literacy problem. Our study findings suggest a significant proportion of patients will experience shame and embarrassment as a result of such actions. Yet, given the magnitude of the problem, we feel that the notion of screening cannot be ignored. For instance, it has become increasingly evident that reading ability is a very powerful independent predictor of health outcomes, and it may be a marker for many cognitive abilities involved with carrying out the necessary tasks for self-care (Barnes, Tager, Satariano, & Yaffe, 2004; Manly, Schupf, Tang, & Stern, 2005; Schillinger et al., 2002; Sudore et al., 2006; Sudore, Schillinger, Wolf et al., 2005). Knowing a patient's literacy level, therefore, may be justified, as those determined to have limited literacy ultimately may require a different approach and manner of instruction. This also may affect how resources (i.e., provider time, follow-up activities) are allocated, especially in difficult settings such as safety-net clinics. It should be stated, however, that it is currently not known whether patients differ by literacy level with regard to how they wish to learn health information and receive medical instruction.

In the event that literacy screening may be perceived as a useful endeavor, we found that most patients are willing to have documentation of their limited literacy placed in their medical record. But informed consent should be obtained first, even if refusal is not in the "best interest" of the patient. Better approaches to literacy screening that standardize the way the assessment is presented to patients, the time required to complete it, and how the results are discussed afterward should be developed and evaluated.

Additional future efforts should aim to foster a friendly and open health care environment that provides equitable access to health information regardless of patients' literacy skills (Institute of Medicine, 2004). In many ways, health systems first may want to institute "universal precautions" and not always assume patients understand health information provided to them. As part of this approach, health

care providers should continuously strive to optimize the manner in which they, and their health care system at large, effectively communicate with all patients. Guidance through existing resources and health communication training programs are available, specializing in low literacy populations (Doak, Doak, & Root, 1996; Ferreira et al., 2005; Institute of Medicine, 2004). The emphasis of these programs may benefit every patient, as plain language, clarification of medical jargon, and simplification of steps for medical instruction often is highlighted.

Literacy eventually may become the next “vital sign”, if future studies support a divergent approach to education and disease management. Yet before screening becomes commonplace, it is important to first understand the problem and then prepare a viable response. This likely will require the use of multimedia sources to serve as alternatives to the written word, and novel approaches to health education such as using pictographs and health “navigators” in certain situations (Diefenbach & Butz, 2004; Freeman, Muth, & Kerner, 1995; Gerber et al., 2005; Houts et al., 1998; Houts, Witmer, Egeth, Loscalzo, & Zabora, 2001).

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