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Chronic Disease Self-Management and Health Literacy in Four Ethnic Groups

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Abstract

Research from several fields has explored health literacy as a multidimensional construct. The authors' multimethod study, "The Impact of Cultural Differences on Health Literacy and Chronic Disease Outcomes," assessed health literacy and chronic disease self-management among 296 patients from four ethnic groups (Vietnamese, African American, White, Latino) at a Massachusetts community health center between 2006 and 2010. Health literacy was assessed using the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), and the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA) measures. Qualitative research methods, including in-depth interviews ($n = 34$), home visits ($n = 12$), chronic disease diaries ($n = 15$), and focus groups ($n = 47$), were completed with a subset of participants. Qualitative interviews indicated a wide range of interpretations of S-TOFHLA questions in which participants substituted their own illness or health care experiences for the abstract examples offered in the instrument, at times leading to incorrect responses. Situating these responses in a broader social and cultural context, this article describes examples of the wide range of chronic disease self-management abilities among participants with limited education and/or low health literacy. It also discusses the culturally variable health beliefs identified among participants interviewed that may play important roles in their chronic disease self-management practices.

Our aim in this article is to situate the understanding of health literacy in the broader context of cultural beliefs and practices around health. While most health literacy measures and interventions still focus on reading skills (Andrulis & Brach, 2007; Hironaka & Paasche-Orlow, 2008; Nutbeam, 2008),[1] Zarcadoolas, Pleasant and Greer propose an expanded model of health literacy that encompasses four domains: "fundamental literacy (reading,

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[1] An exception is the Newest Vital Sign (Weiss et al., 2005), which measures comprehension using a sample nutrition label. For diabetes, Huizinga and colleagues developed the Diabetes Numeracy Test on the basis of concern that existing literacy scales may not adequately assess the numeracy skills needed for self-management (Huizinga et al., 2008).

writing, speaking and numeracy), science literacy, civic literacy, and cultural literacy" (2005, p. 195). This framework acknowledges the effects of health status, demographic, psychosocial, and cultural factors on health literacy (see also Lupton, 1994), and defines health literacy as "the wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life" (Zarcadoolas et al., 2005, pp. 196–197). We seek to contribute to such an expanded model of health literacy by bringing into focus the diverse cultural resources we found among low-income patients from four ethnic groups at a federally funded community health center. Patients with varying levels of health literacy described chronic disease self-management practices that drew on individual, social, and cultural factors.

Many instruments and analyses focus on health literacy as an individual rather than a social or community-level characteristic (Berkman, Davis, & McCormack, 2010; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; S. Y. Lee, Arozullah, & Cho, 2004). In a call for an empowerment-based understanding of health literacy, Kickbusch (2001) compares several definitions of the concept (see also Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011, for a more recent systematic review). Kickbusch recommends that health literacy researchers should strive to "separate clearly education, general literacy, and health literacy; look particularly closely at how these three factors interrelate; and distinguish what reinforcing mechanisms might be at work" (2001, p. 293). Baker's model of health literacy incorporates individuals' reading fluency, prior health knowledge, and ability to understand written health information, as well as the communication environment (the "complexity and difficulty" of spoken and printed messages) and "other factors" that could include "culture and norms" and barriers to change (2006, p. 879).[2] Similarly, Nutbeam's "health outcome model" of health literacy integrates functional, interactive and critical health literacy to empower patients (Nutbeam, 2000).

Several measures of health literacy exist for speakers of English and Spanish. These include the Test of Functional Health Literacy in Adults (TOFHLA) and S-TOFHLA (Short Test of Functional Health Literacy in Adults; Baker, Williams, Parker, Gazmararian, & Nurss, 1999), the Rapid Estimate of Adult Literacy in Medicine (REALM; Davis et al., 1993), the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA; S. Y. Lee, Bender, Ruiz, & Cho, 2006), and the Health Activities Literacy Scale (HALS; Rudd, 2007). In response to Nurss and colleagues' reflections on the challenges of developing a Spanish health literacy-screening instrument that works like the REALM (Nurss, Baker, Davis, Parker, & Williams, 1995), Lee and colleagues along with a panel of Spanish-speaking experts developed the SAHLSA, which measures readers' comprehension of common medical terms (Lee et al., 2006). While efforts to develop similar tests for Asian populations are underway (e.g., Pan, Su, & Chen, 2010; Wong et al., 2012), to our knowledge no such instruments exist for Vietnamese speakers. Further, concerns remain regarding the nature of the underlying constructs measured by the most widely used health literacy instruments (Jordan, Osborne, & Buchbinder, 2011) and the extent to which actual self-care abilities or appropriate use of health services can be assessed by them (Sarkar, Fisher, & Schillinger, 2006; Schillinger & Chen, 2004).

As part of this ongoing assessment of health literacy instruments in diverse populations, it is vital to gain a better understanding of the role of culture in health literacy (Shaw, Vivian, Huebner, Orzech, & Armin, 2009; Thomas, Fine, & Ibrahim, 2004). Andrulis and Brach argue for the need to integrate health literacy interventions with efforts to improve the cultural competence of health care, emphasizing the importance of culture as the lens

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[2] See also the Workshop Summary of the Institute of Medicine Roundtable on Health Literacy (2009).

through which “people define health and illness and perceive and respond to health messages” (2007, p. S123). They point out that “individuals from diverse cultures … may not comprehend easy-to-read materials if Western constructs of health and health care are assumed” (p. S124).

Medical anthropologists understand cultures as multiple, contradictory, and overlapping, with permeable boundaries that can change over time (Melhuus, 1999). The most useful way to grasp the meaning of culture is to think about it as practice: exploring cultural differences by looking at everyday behavior (Borovoy & Hine, 2008).[3] Cultural health beliefs, sometimes called *explanatory models*, may be an important factor in health management decisions (Greenhalgh, Helman, & Chowdhury, 1998). Explanatory models (EMs) are culturally variable concepts that people use to define and explain the causes, treatment, and effects of illnesses to themselves (Gesler, 1999; Sensky, 1996). EMs can compete with, overlap, extend, or contradict one another, and multiple EMs may exist for one condition (Hewlett & Amola, 2003; Horowitz, Tuzzio, Rojas, Monteith, & Sisk, 2004). Cultural health beliefs are part of internally consistent ethnomedical systems (for example, humoral or hot/cold theories of illness) that may or may not incorporate biomedical information (Ito, 1999). EMs can travel with immigrants (Borovoy & Hine, 2008; Connett & Lee, 1994; Ito, 1999; H. Lee & Vang, 2010) and may influence patients’ compliance with recommended treatments (Heurtin-Roberts & Reisin, 1992). For example, EMs of cancer may shape the ways U.S. women understand risk and make decisions about cancer treatments (Charles, Whelan, Gafni, Reyno, & Redko, 1998; H. Lee & Vang, 2010). In this article, we draw on contributions from medical anthropology as well as social science studies of health literacy and report health literacy data in order to frame qualitative discussions of patients’ interpretations of health literacy scales. We suggest that contemporary understandings of health literacy as measured by three popular instruments may be culturally specific and may not capture important self-care abilities that can be found even among patients with low health literacy scores.

Method

This community-based research study used a multimethod, prospective research design. The research site was Caring Health Center, a Section 330 federally qualified community health center located in a medically underserved, refugee resettlement area. The clinic provides primary care services to predominantly low income and minority patients, over half of whom require translation services.

We completed longitudinal surveys with 297 patients from four ethnic groups (African American, Latino, Vietnamese, and White) at baseline (213 patients at follow-up 12 months later).[4] These quantitative data were triangulated with data collected through four qualitative methods (focus groups, interviews, chronic disease diaries, and home visits). All incoming patients during specified time frames were screened for eligibility, and those diagnosed with diabetes and/or hypertension were invited to participate in the survey. Bilingual/bicultural interviewers administered surveys in participants’ preferred language (English, Spanish, or Vietnamese) at the clinic or another location of participants’ choosing. We adapted existing health literacy scales by translating the S-TOFHLA into Vietnamese and pretesting the instrument with members of the target population (monolingual Vietnamese immigrants with limited education).[5] To get the best measures possible, but sacrificing comparability

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[3] While our analysis is also shaped by a political economic perspective that considers the role of socioeconomic and structural factors in the distribution of health and illness in populations, this discussion builds on an understanding of culture as a framework in which meaning is expressed and understood (Taylor, 2003).

[4] See Orzech and colleagues (in press) for further detail on methods.

[5] Note that the S-TOFHLA has not been normed or validated for Vietnamese speakers.

across ethnic/language groups, we matched health literacy scales to participants' language of choice. All participants completed the S-TOFHLA numeracy scale at baseline. In addition, Latinos completed the SAHLSA, and Black and White English-speakers completed the REALM. At follow-up 12 months later, we added the S-TOFHLA reading comprehension scale, translating it into Vietnamese and administering English, Spanish, and Vietnamese versions of the entire TOFHLA short form. (We did not repeat the SAHLSA and REALM.)

A subsample of 71 participants participated in qualitative data collection, allowing the research team to gain insight into day-to-day chronic disease self-management practices. Participants were invited to complete more than one qualitative activity. Focus groups aided instrument development, explored people's understandings of selected TOFHLA items, and invited participants to discuss their chronic disease experiences in an open-ended format. In-depth interviews ($n = 35$) were completed in the language of the participants' choice and explored participants' illness histories and indigenous understandings of chronic disease. Other qualitative methods included chronic disease diaries ($n = 15$) and home visits ($n = 12$). The University of Arizona Institutional Review Board approved this study.

Data Analysis

With participants' permission, focus groups and in-depth interviews—including chronic disease diary discussions and home visits—were audiorecorded, transcribed verbatim, and translated into English if conducted in another language. English transcripts were coded following an open coding method (Strauss & Corbin, 1990) in the qualitative data management program Atlas. ti (Muhr, 1997). Coders developed a preliminary list of themes (codes) on the basis of a review of the literature. These codes were then discussed by the coding team, using examples to explore the conceptual framework behind a code and to ensure that all coders had the same understanding of it (MacQueen, 1998). During regular meetings, we discussed coding approaches in detail by comparing transcripts that had been coded by up to three individual coders. In doing so, we ensured intercoder agreement and refined our code list as necessary.

To analyze our quantitative survey results, we relied on SPSS-X v.18. Analyses presented here included analysis of variance for comparisons of mean health literacy scores across ethnic groups.

Results

Sample Overview

The median age of participants was 56 years, with roughly equal numbers of women and men distributed across the four ethnic groups represented in the study. Over half (59%) reported that they were disabled, and more than two thirds (67%) rated their health as fair or poor. Three quarters (75%) of respondents estimate their household income to be less than $1,200/month, and more than one third (34%) of participants had an eighth grade education or less. The Vietnamese participants were, on average, older and less educated than the sample as a whole. Vietnamese refugees have settled in Springfield since the mid-1990s. Among people we interviewed, the average length of their residence in the United States was 15 years, and many still have low English proficiency. All (100%) of the Vietnamese participants speak Vietnamese or other Southeast Asian languages at home, and 83% of Latino participants, who are predominantly Puerto Rican, speak Spanish at home.

Measuring Health Literacy Among Diverse Groups

Table 1 presents mean scores for each instrument. White and African American participants had similar overall S-TOFHLA scores, and these scores were significantly higher than those of Vietnamese and Latino participants. Vietnamese participants appeared to have particular difficulty relative to other groups on the reading comprehension subtest of the S-TOFHLA. The effect of ethnicity was largest on the reading comprehension test (η^2 = .338.). The Latinos appeared to have more difficulty, relative to the others, on the numeracy subtest of the S-TOFHLA. Mean scores on the REALM were similar across the groups of participants who completed the test.

To better understand participants' interpretations of the S-TOFHLA instrument, we presented Latino and African American focus group participants with sample items taken from the numeracy scale, asked them to select the correct answer, and then asked them to explain their responses. We found that participants tended to substitute their own personal experience in place of the abstract examples presented in S-TOFHLA. For example, we recorded the following exchange in a Latino focus group:

> Interviewer (in Spanish): So, this is a card that says, "The normal blood glucose level is between 60 and 150."
>
> Participant 3 (in English): That's incorrect.
>
> Interviewer (in Spanish): And below it says, "Today your level is 160."
>
> P3: That's incorrect.
>
> Interviewer: If this was your result, would it be within the normal range?
>
> P1: No … incorrect.
>
> Interviewer: And why?
>
> P1: Because as I understand, it is from 80 to 120.
>
> P3 (interrupting P1): It's up to 132.
>
> P1: And here it says 160, which is too much. If someone has 160 they need to inject a little bit of insulin. At least 1 mg or 2.
>
> P3: Or take a pill.

This helps to explain why participants are not able to answer the apparently straightforward numerical reasoning question of whether 160 is between 60 and 150. They may not take the abstract example as the condition for the question and instead interpret the question's context as referring to *their own* health status or what they've been told by their health care providers. We observed a similar exchange among participants in an African American focus group:

> Q: So this first one … you see the card there, card 1? It says, "if your blood sugar today is 160 would your blood sugar be normal today?"
>
> P1: I'd say, No! My, my blood sugar usually don't be 150 and you know … It be under that, 120, or something, uh, 138 … So it can go up and down.
>
> Q: It's usually about what, you said?
>
> P1: One …, one … no higher than 138.
>
> Q: Okay.
>
> P2: Me, I probably would be normal and I got high blood sugar, so I … have a problem with that.
>
> Q: So what would your answer be to this one, you were saying?
>
> P2: I'd put say um … It would be normal.

> Q: It would be normal. And your reasoning behind that you said, was because your …
>
> P2: Yeah, I uh, I have high blood sugar and when I first went to Caring Health [Center], I started going there in ’95, and the doctor there told me, well actually mine was around 80, 90 to 170 … .That’s always been kinda normal for me, ever since I had it’s been, high and, high and low, like this morning I woke up and took my blood sugar, ooh, it’s 220. That was at 9:00 this morning!

These African American participants are responding to S-TOFHLA numeracy items by drawing on their own personal understandings of what their “correct” blood glucose levels should be. We suggest that researchers interested in functional health literacy, that is, a person’s ability to adequately self-manage their illness, should seek to capture this type of information, which may even be more important to patients’ health outcomes than an individual’s abstract reasoning or numeracy skills.

Vietnamese patients in particular had difficulty with the cloze (fill-in-the-blank) procedure used in the reading comprehension portion of the S-TOFHLA, as reflected in their significantly lower scores shown in Table 1. Our Vietnamese interviewer explained that many Vietnamese immigrants who were schooled in Vietnam would be unfamiliar with the cloze format since it is seldom used in Vietnamese educational materials. This lack of familiarity may lead Vietnamese participants to be uncomfortable with the instrument, and we even observed participants who were hostile to completing it despite their ability to eventually arrive at correct answers. For example, the Vietnamese interviewer reported that one survey participant kept saying “I’m too old” and “I don’t know” during the test. Initially, the participant seemed willing to try the test but appeared upset when she was unable to understand the questions. Another survey participant, confronted with the S-TOFHLA reading-comprehension scale, reported that she didn’t want to read, and then said she needed her eyeglasses but was reluctant to go get them when asked. These responses suggest that even if high-quality translation of the S-TOFHLA in Vietnamese were available, existing measures of health literacy may use embedded structures that may not “travel” well across cultures.

Even those patients who are unable to perform well on health literacy scales such as the S-TOFHLA may succeed in accurately self-managing their medication for chronic illness. For example, a White female participant who described herself as someone who is “actually really, really, slow and who has problems with reading, writing and math and stuff” scored less than 50% on the REALM but got 94% right on the S-TOFHLA numeracy scale. In an in-depth interview, she described her medication management practices this way:

> … when I very first got the insulin, I had asked the pharmacy about what the sliding scale was for it, and he actually explained it to me. So, now that I’m gonna be taking insulin again I know what the sliding scale is for the insulin. Say like, if it goes over 250 to 300 you only take um … 2 units, which is only a very small amount, but if it goes over 300 to 400, or even higher than that, you have to take anywhere between 4 and 8 units.

This diabetic participant was apparently able to retain numerical instructions, allowing her to correctly manage her insulin dose.

Many low-literacy participants we spoke with confused aspects of their chronic conditions such as high blood pressure with high blood sugar or high cholesterol. A middle-aged, homeless White gentleman displayed this kind of confusion, yet in an in-depth interview he described taking very concrete steps in managing his diet and exercise:

> A: Then they take your regular blood for the high blood–high tension once a year. You take your blood test for high blood pressure. I've got cholesterol.
>
> Q: Okay, you also have high cholesterol.
>
> A: (Talking over Q) High ch … high … it turns out I have high blood pressure.
>
> Q: Did they put you on drugs right away?
>
> A: Yeah. They were putting me on 20 mg … I used to take 20 then at one point, they jumped it up to 40, then they jumped it back down to 20.
>
> Q: —back to 20. Do you know why that change happened?
>
> A: (Pause) Yes I do! Uh, 6 months before I was released [from prison], I said, "well, something's wrong here." I said, "well, I gotta do somethin', my cholesterol's gettin' high. I don't want to take 40 mg. I want to go back to where I was." So I started jogging.

Although he was similarly confused about the reasons it was good to do so, this individual also noted the importance of avoiding canned soups because of their high levels of "salturated fat." While this gentleman clearly lacked the literacy skills to perform adequately on the REALM or S-TOFHLA, he does seem to have grasped some of the key behaviors, such as exercise and making dietary changes, to stay healthy. Rather than literacy levels, the primary barriers he identified to weight loss were lacking a kitchen while he was homeless and staying at a local shelter.

Chronic Disease Self-Management

Other participants we spoke with incorporated significant amounts of biomedical information into their understandings of disease when we asked them to explain to us how their diseases work. Some, like this Latino male giving an in-depth interview, discussed explanatory models that include biomedical-style explanations of the effects of cholesterol on veins and meanings of pressure:

> In my understanding, hypertension is that the heart is pumping the blood very fast. The flow of the blood is very fast. Faster than normal. And that, well, since it's not normal in the system of the human body, it can bring on complications … and heart problems because the heart is going to be very agitated, um, if it has, like in my case, where I already have high cholesterol, that means the veins are obstructed, they're … since they have too much fat, the blood is passing through there but like very pressurized. When you have high blood pressure and pumping faster it can get blocked.

Also noticeable are the emotional meanings embedded in this explanation are ("my heart is very agitated"; see also Schoenberg & Drew, 2002). The partial incorporation of biomedical information into EMs may provide physicians and researchers an opportunity to explore how patients use the health information they have. In contrast, a middle-aged Vietnamese male we interviewed could not say much about biomedical explanations for diabetes, but he believed that his diabetes could be related to his imprisonment during the Vietnam War and to the bad food and forced labor he endured there. In an in-depth interview, Mr. Nguyen[6] explained, "I don't know much about diabetes or what it does, I just follow my doctor's recommendations. But I think the years I spent in prison in Vietnam, and overwork, and bad food can cause diabetes." Many Vietnamese participants, like Mr. Nguyen, have very low health literacy scores, perhaps due to their lack of familiarity with the cloze format, but

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[6] This is a pseudonym, as are all names of individuals reported herein.

understand disease within a cultural context that includes positive self-care behaviors and health outcomes.

Another Vietnamese male described diabetes as a disease of aging, related to a humoral understanding of health as a balance between forces in the body, here described in almost biomechanical terms of input and output:

> The cause is the high intake of sugar versus how much your body can use. So in old age my body works less and needs less of the sugar. But if I eat a lot of sugar, like the sweetcake and different kind of foods that have a high level of sugar—that's not to say—our body does need sugar, it just doesn't need as much any more at this age. So I use the sugar in the food and the vegetables instead of the other kind of sugar.

This quote from an in-depth interview offers another example of an EM that incorporates enough information that is similar to biomedical models to provide a point of departure for further chronic disease self-management education.

Efforts to reconceptualize health literacy as a socially influenced capacity are a response to patients' explanations for their health behaviors, which are situated in a social context. For example, Mr. Gonzalez, a Latino male, emphasized the significance of social support in describing changes he made in his eating habits after learning he had high cholesterol. Significantly, it's not only his doctor's instructions but peer support that were central to this change:

> A: In my house we got used to eating a lot of salad, because since the doctor and some other people as well have told me that salad is really healthy for when you have cholesterol since it doesn't have any fat. So, in between meals, if I get hungry, I eat a salad.
>
> Q: Who else said that to you besides your doctor?
>
> A: People who are also waiting to get called up in the clinic. I have talked to them about my situation … so they have told me, "look the same thing happened to me and my cholesterol went down because I had a diet that was this way," so, I have done it because of that.

In addition to sharing health-related information, many participants, particularly Vietnamese participants, described concrete forms of social support that allowed them to carry out dietary changes. For example, when Mr. Dang, a disabled Vietnamese gentleman who lived in a rooming house, shared news of his recent diabetes diagnosis with his landlord and his landlord's wife, he reported that his landlord "felt compassion, so he told his wife, when she goes to do the shopping, he always told her to get more vegetables. To always have vegetables in the refrigerator for [him]." Mr. Dang did understand the dietary recommendations made by the nutritionist he visited, but it was only through the assistance of those he lived with that he was able to follow those recommendations: since he used a wheelchair to get around and did not own a car, he was seldom able to shop for himself.

Similarly, Mr. Vo, who is significantly better off than the previous participant, credits his wife with his ability to adhere to his recommended exercise regimen: in an in-depth interview, he commented, "my wife is the person that, behind the scenes, helps me a lot. I'm old and weak, so there's times that I'll be on the couch resting and don't want to do much. She's the one that pushes me to get up and go downstairs [to his exercise bike] to exercise." In fact, Mr. Vo appears to be a youthful and fit middle-aged man in his late 50s. In addition to the social support provided by his wife, Mr. Vo's exercise regimen benefits from the exercise bike in the basement and from his family's collective walks around their peaceful, green suburban neighborhood.

These examples reveal just a few factors, including indigenous explanatory models, socioeconomic resources, and social support, that may play equally important roles as health literacy levels in chronic disease self-management in diverse low-income populations.

Discussion

A large body of literature explores patient decision-making and the ways patients act on biomedical information (e.g., Armstrong & Murphy, 2008; Kiser et al., 2012; Sudore, Schillinger, Knight, & Fried, 2010). In an article in the *British Medical Journal*, Trisha Greenhalgh and colleagues recommend that health care providers build their health education efforts drawing on their patients' already-existing explanatory models of disease. We have presented several ethnographic examples of explanatory models that indicate congruence with biomedical explanations, providing a potential starting place for biomedical health education efforts. Rather than presenting barriers to effective health education, explanatory models may facilitate patients' abilities to understand and incorporate biomedical information, especially for those patients with limited health literacy. Because it is difficult to uncover cultural beliefs that frequently "go without saying"—people literally have a hard time putting their implicit cultural beliefs into words—both our ethnographic and survey data collection focus on the everyday practices of diverse groups. However, just as there is not one monolithic "scientific culture" but rather overarching characteristics that most scientists share and a diversity of disciplinary subcultures within that, "cultural health beliefs" should not be understood as reducible to a single ethnic group, nor as necessarily shared by all members of that group. "Cultural health beliefs" may also exceed group boundaries, so others who are not members of a cultural group may also share such beliefs because of shared experiences with biomedicine, cross-cultural families, social networks, or other reasons.

With these caveats in mind, the analysis of cultural health beliefs by Horowitz and colleagues (2004) reflects our findings regarding cultural and other socioeconomic facilitators of and barriers to chronic disease self-management. Horowitz and colleagues report that, for the low-income African-American and Latino patients with hypertension they interviewed, "clinician-recommended diets [were] difficult to follow in the context of their family lives, social situations, and cultures. These diets were often considered expensive, an unwelcome departure from traditional and preferred diets, socially isolating, and not effective enough to obviate the need for medications." Horowitz and colleagues argue for "culturally sensitive approaches to dietary improvements," a call we echo here and elsewhere (Orzech et al., in press).

Our discussion of culturally specific health literacy instruments and culturally variable encounters with them is necessarily subject to some limitations. We recognize the contradiction posed by using the S-TOFHLA, which we translated into Vietnamese but that has been neither normed nor validated for use in that language, as an example of the cultural specificity of health literacy instruments. Yet it seemed necessary to include this data on at least an impressionistic basis to indicate the wide range of health literacy scores among the ethnic groups discussed here. On the basis of our experience attempting to translate the S-TOFHLA into Vietnamese, we suggest that simple translation of health literacy instruments may not be adequate for diverse groups. Instead, instrument development efforts should draw on focus groups and other qualitative formative research techniques. Should translation be unavoidable, back-translation of instruments can improve accuracy (Berkanovic, 1980).

New instruments should be pretested using qualitative methods to explore diverse patients' understandings of items.

As we have shown here, qualitative methods, while they have their own strengths and weaknesses, can provide vital information that is difficult to capture with closed-ended questions. Our qualitative data analysis strategies were designed to enhance generalizability by highlighting consistencies within and among groups, while preserving the uniqueness of individual cases. In focus group discussions we conducted, both African American and Latino participants seemed to call to mind their own physicians' advice regarding optimal blood glucose levels when they explained what the "correct" response to S-TOFHLA numeracy items would be. While this may lead to incorrect S-TOFHLA responses, the enthusiasm with which these participants kept hold of this information does much to recommend their ability to adequately self-manage their diabetes. Related to this, Mancuso and Rincon and others call for patient education efforts that promote chronic disease self-management skills for patients at all health literacy levels (Mancuso & Rincon, 2006; Sarkar et al., 2008), and Martin and colleagues (2011) argue in favor of promoting patient activation (specifically, help on speaking and listening skills for better doctor-patient communication).

Conclusions

In addition to incorporating self-management and patient activation efforts, health literacy researchers may need to further broaden our understanding of health literacy to include the culturally variable explanatory models of disease that inform patients' self-care abilities. While the purpose of the present analysis was not to evaluate the psychometric integrity or practical utility of formal measures of health literacy such as the TOFHLA, many sources verify that they are reliable and at least somewhat valid across cultural groups. Nevertheless, the foregoing discussion makes plain that members of different cultural groups bring diverse experiences and beliefs to the testing procedure that might influence overall performance on these tests.

Existing instruments such as the S-TOFHLA, REALM, and SAHLSA may be reasonably good measures of individual capacity to understand written health-related information in particular, but they may not prove to be highly reliable predictors of one's ability to maintain health. With culturally diverse patients, providers will have to go well beyond scores on health literacy tests to accurately anticipate patient understanding, adherence, and health maintenance. Health care providers should further consider capitalizing on patients' understandings of health in their health education efforts, given that indigenous explanatory models may have unexpected congruence with biomedical frameworks. Recognizing that health literacy scores may be affected by culturally shaped models of health and illness, it is important to expand our understanding of literacy to include the strengths that patients bring to chronic disease self-management.

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Table 1

Health literacy across ethnic groups

Measure	White (n = 24)	African American (n = 41)	Vietnamese (n = 74)	Latino (n = 67)	F(3, 202)	η^2
S-TOFHLA						
Overall score	75.83_a	80.34_a	47.55_b	59.38_b	14.54^*	.178
Numeracy	40.50_a	39.49_a	32.20_{ab}	27.85_b	6.72^*	.091
Readingv comprehension	37.42_{ab}	40.73_a	15.34_c	31.51_b	34.39^*	.338
	White (n = 40)	African American (n = 64)		Latino (n = 67)		
REALM	52.00	53.79	N/A	52.71	0.15	*ns*
SAHLSA	N/A	N/A	N/A	35.34		

Note. S-TOFHLA = Short Test of Functional Health Literacy in Adults; REALM = Rapid Estimate of Adult Literacy in Medicine; SAHLSA = Short Assessment of Health Literacy in Spanish-speaking Adults. Means with totally unlike subscripts differ at $p < .05$ (Tukey's HSD).

[*] $p < .0001$.