

The Role of Culture in Health Literacy and Chronic Disease Screening and Management

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Kathryn Orzech's name was spelled incorrectly as submitted and published online, but is now correct as displayed above. Susan Shaw regrets the error.

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Abstract Cultural and language differences and socioeconomic status interact with and contribute to low health literacy, defined as the inability to understand or act on medical/therapeutic instructions. Health literacy is increasingly recognized as an important factor in patient compliance, cancer screening utilization, and chronic disease outcomes. Commendable efforts have been initiated by the American Medical Association and other organizations to address low health literacy among patients. Less work has been done, however, to place health literacy in the broader context of socioeconomic and cultural differences among patients and providers that hinder communication and compliance. This review examines cultural influences on health literacy, cancer screening and chronic disease outcomes. We argue that cultural beliefs around health and illness contribute to an individual's ability to understand and act on a health care provider's instructions. This paper proposes key aspects of the intersection between health literacy and culturally varying beliefs about health which merit further exploration.

Keywords Culture · Health literacy · Cancer screening · Diabetes · Hypertension

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Introduction

Researchers and practitioners are becoming increasingly aware of the pivotal role health literacy can play in both cancer screening behaviors and the management of chronic disease. Health literacy, the ability to understand and act on a physician's instructions, is related to morbidity and mortality from a variety of conditions [1, 2]. Too often, people with the greatest chronic disease burdens have limited access to health information and limited ability to process that information. Health care providers are often unable to recognize, however, when cultural differences between patient and provider contribute to misunderstandings around chronic disease management, health status, disease severity, and treatment regimens. While much research has been done on patient literacy and readability of forms such as informed consent and patient education materials, fewer studies have explored the relationship between cultural differences and health literacy. This paper examines cultural influences on health literacy, cancer screening and chronic disease outcomes. We argue that cultural beliefs around health and illness, including but not limited to those shared by ethnic minorities or immigrants, contribute to an individual's ability to understand and act on a doctor's instructions in ways that are intimately connected with literacy levels. An understanding of health literacy that neglects the role of cultural beliefs about health and illness is limited in the range of populations it can describe. This paper proposes key aspects of the intersection between health literacy and culturally varying health beliefs that merit further exploration.

One of the major limitations to the research on health literacy is confusion or lack of clarity between the various meanings of health literacy. In its broadest usage, health literacy may refer to education level, which is in turn

treated as a proxy for socioeconomic status [3]. However, education level or socioeconomic status may shape patients' morbidity and mortality in ways quite unrelated to their disease knowledge or adherence to disease management protocols [4]. Literacy assessments can also be used to measure a patient's ability to understand instructions from a health care provider. This more specific understanding of literacy is known as *health literacy* which may include disease knowledge. Operational definitions of health literacy are often limited to patient reading skills and material readability (e.g., [5, 6]). But health literacy should be understood as distinct from socioeconomic status or education level. For example, even elderly patients in an affluent retirement center reported low health literacy on the Test of Functional Health Literacy (TOFHL) [7]. Kalichman et al. [8] report that education and health literacy were significant independent predictors of medication adherence among a community sample of 182 HIV-seropositive participants. A patient's ability to comprehend her physician's instructions is shaped by cultural factors that extend beyond literacy or education. Important work remains to link research on culture, low health literacy and language barriers, especially as they affect low-income minorities and immigrants to the U.S. This paper seeks to outline the contributions cultural differences can make to a patient's ability to understand and act on his or her physician's instructions.

Cultural Influences on Health and Illness

Health care professionals in primary care settings are often challenged by the cultural differences between themselves and their patients that may inhibit effective and satisfactory health care [9]. Expanded access and refugee health programs have brought increasing numbers of cultural and ethnic minorities into the U.S. health care system, especially the public health system. The concept of cultural difference is becoming more salient in primary health care and the management of chronic illness, yet remains problematic for health care providers and patients alike. Lifestyle, diet and stress are areas of human behavior clearly shaped by cultural differences. All play an important role in the management of chronic diseases such as diabetes and high blood pressure. Primary health care providers are daily confronted by the effects of cultural and language differences on disease outcomes and patient compliance.

Cultural variation can be seen in beliefs about disease etiology, appropriate treatments, proper self-care and preventive treatment, human physiology, and appropriate doctor and patient conduct. Cultural differences even influence perceptions of symptoms and emotional states.

For example, Uppaluri et al. [10] found that recent Asian immigrants were less likely than whites to report stress over a 2-week period, while Asian immigrants who had been in the United States for at least 15 years reported higher levels of stress. This suggests cultural influences on the perception of "stress" that change as immigrants become acculturated to American lifestyles. Interviewing rural, southern African-Americans, Schoenberg and Drew [11] discovered a list of high blood pressure symptoms that exceeded most doctors' descriptions of hypertension as "the silent disease." The authors suggest that African-Americans make daily decisions about chronic disease management based on culturally-informed experiences of disease that include symptoms such as headaches, nose-bleeds, and hallucinations.

A range of medical domains have begun to address cultural diversity in health care, including nursing [12], genetic counseling [13], health education [14], pediatrics [12], even dentistry [15]. Primary care providers often find themselves trying to (re)shape culturally-determined lifestyles, behaviors and practices (e.g., [16]) as they strive to help patients manage their chronic diseases. Health care that fails to accommodate cultural differences is associated with more severe disease outcomes [17]. Building on existing scholarship, a fuller understanding of health literacy must incorporate such cultural differences into research, interventions and recommendations.

Culturally Appropriate Health Care

These and other unique challenges presented by cross-cultural medicine prompt many in the field of primary health care to call for tailoring care to the specific needs and beliefs of diverse cultural groups. Culturally appropriate health care, or culturally competent care, has been proposed as a means to reduce health disparities among ethnic groups [18]. The literature on cultural competency includes programs to recruit bilingual and bicultural health care providers, development of interpreter services and language-appropriate patient education materials, the use of lay health advisors, and cultural competency training for health care providers [19].

Language access through interpreters or bilingual providers is the most basic and frequently cited aspect of culturally-appropriate health care (e.g., [20]). However, the simple and direct translation from English to another language is usually not enough to make care culturally appropriate to non-English-speaking populations [21] especially in the case of ad hoc or family interpreters [22]. Indeed, while medical interpreters are critical to enhancing the health care access of patients who speak little or no English, interpreters play other gatekeeping roles as well,

such as limiting the information that reaches the physician from the patient and limiting the amount of time a physician spends with a patient [21].

Few studies have assessed the effect of medical interpreters on patients with low health literacy. Baker et al. found that professional medical interpreters were used with only 12% of a sample of 467 Latino patients at a public hospital emergency department, while an additional 22% of patients wanted but did not receive an interpreter [23]. Nearly half of interpreters were RNs or MDs [23], while another study found that 50% of medical visits in which nurses served as translators instead of professional medical interpreters resulted in some kind of miscommunication “that affected either the physician’s understanding of the symptoms or the credibility of the patient’s concerns” [24, p. 1343]. In the study by Baker et al. [23, p. 783], “a high proportion of Latino patients had poor knowledge of their diagnosis and recommended treatment.” An Australian study by Bonacruz-Kazzi and Cooper [25] found that 17% of 131 non-English speaking patients who required an interpreter at a hospital ED received a trained interpreter, while 20% used “ad hoc” interpreters and 8% received no interpreting assistance.

Some research has found higher patient satisfaction among minority group members who share a language and/or ethnic background with their health care provider [26]. On the other hand, some primary health care providers note that ethnic resemblance in and of itself is not sufficient to providing culturally appropriate care [27].

Health Literacy and Doctor–Patient Communication

Effective communication between patients and providers is key to successful health care encounters and outcomes [28]. For example, if patients are unable to comprehend the language used in consent forms, can they actually be said to consent to medical procedures [29]? Cultural differences between providers and patients also contribute to communication problems [30], while patient-provider resemblance has been reported to enhance communication effectiveness [22]. Schillinger et al. [31] found that patients with inadequate health literacy were more likely to report worse communication with their health care providers in the domains of general clarity, explanation of condition, and explanation of processes of care. Poor health literacy may be a marker for clinician-patient communication problems, particularly in the technical, explanatory domains of dialogue [32], or a factor in communication barriers [33].

In addition to poor communication, ethnic minority and low-income patients may have more difficulty accessing quality health information. For example, Benjamin-Garner et al. [34] found that minority and low-income respondents

to a random telephone survey of 1200 Americans reported less exposure to chronic disease prevention information. Types of messages received were determined in part by the sources of health information that were most popular among demographic subgroups. When members of affected groups have direct input into the development of materials, tools and interventions, those products are seen as more culturally appropriate and more successful for low health literate patients [35]. In a sample of Pakistani immigrants to the UK, one-on-one health education using pictorial flashcards improved the diabetes knowledge and glycemic control of women participants overall [14]. However, low literate women still scored lower on knowledge parameters and did not show an improvement in glycemic control [14], raising the possibility that unaddressed cultural issues may be involved in achieving or maintaining diabetes control in this population.

Culturally appropriate public health education campaigns have yielded successes that offer opportunities for further research in the clinical realm. Using a participatory action research approach, Watson and colleagues [35] developed a visual educational tool for aboriginal populations, who have the highest rate of complications from diabetes in Australia. Griffin et al. [36] took a similar approach to designing a diabetes education program for the Native American Diabetes Project that showed high rates of participant retention and satisfaction, though no behavior or outcome change was evaluated. The National Heart, Lung, and Blood Institute (NHLBI) developed a multimedia bilingual community intervention for cardiovascular disease that included lay health advisors, radio programs and public service announcements, videos, and recipe booklets for U.S. Latino populations. An evaluation with 300 participants by Alcalay and colleagues [16] found that the intervention increased knowledge and awareness of cardiovascular disease risk factors and prevention techniques. Due in part to limited outcomes research, culturally-appropriate health education interventions seem to show more success than do culturally-appropriate treatment efforts [36, 37].

Cultural Barriers to Cancer Screening and Treatment

The kinds of cultural differences outlined here can create barriers to both cancer screening and treatment. Cultural barriers to care include language, religious beliefs, family ties, interactional styles, gender norms, and misconceptions about Western medicine [38]. Beliefs about cancer and its treatment may affect patients’ willingness to seek screening tests and professional care [39]. Disparities have been identified in cancer screening tests [40] related to access to health care [41] and other factors [42]. Cancer mortality

rates are a significant contributor to the disproportionate mortality rates experienced by African-Americans compared to whites [43]. Some minority groups may be more reluctant to use cancer screening services than others [44]. For example, one qualitative study identified a “lack of a health promotion/disease prevention perspective” among low-income Latina women interviewed regarding cervical cancer screenings. As one participant in this study explained, “You go if you have something hurting. If not, you don’t go. All our body works like that” [45, p. 242]. Further, increasing health literacy may mitigate these cultural barriers to care [46]. Women in a Louisiana public hospital, for example, were more likely to have had a mammogram if they accurately understood the purpose of the procedure [42].

Perceived cancer risk is culturally variable and may shape patients’ willingness to utilize preventive screenings. For example, Latina immigrants in one study emphasized the role of physical stress, trauma to the body, and behavior in determining their risk for breast and cervical cancer [47]. A follow-up study found that stigma associated with “non-normative” sexual behavior may keep unmarried Latinas from seeking out Pap smears [48]. More recently, Somali, Chinese, Russian and Latino immigrants in Canada all identified common risk factors for cancer including genetics, tobacco use, and other environmental variables [49]. Beyond these commonly recognized risks, however, the groups diverged, with Chinese immigrants raising concerns about genetically modified foods as a cancer risk while Russians focused on radiation as a primary risk factor. Chinese participants spoke of specific medicinal foods, while Somali and Latino participants cited the importance of emotional and spiritual well-being as a protective factor against cancer [49]. Age, acculturation, and English proficiency are all strongly associated with immigrants’ use of screening services [48, 50].

Immigration and Health

Immigrants have always brought health care beliefs, practices and traditions with them from their homelands. Immigrants to the U.S. often use traditional homeland remedies in addition to biomedical treatments [51]. These remedies may come into conflict with prescribed care, or may interact in a negative way if the prescribing doctor is unaware of such ancillary treatments [52]. For example, one study found that Mexican-Americans in the U.S. frequently combine *botanicas* with remedies from conventional health care providers [53]. Ries and colleagues [54] found that Vietnamese families may use traditional practices including coining, cupping, pinching, oil or steam inhalation, bleeding, herbal ingestion and

acupuncture to treat asthma at home. Similarly, Puerto Rican families use an array of interventions to care for their children’s asthma, including breathing exercises and rubbing the child’s chest with herbal remedies [55], and African American mothers in another ethnographic study relied on steam inhalation, herbal teas, and homemade syrups. Prayer was used by both Hispanic and African American mothers [56]. The notion of “health culture” has been advanced to address the complex interactions among cultural beliefs, practices and illness that can shape health outcomes. “The notion of health culture usefully emphasizes the existence of complex patterns of ethnomedical knowledge and illness management, which influence therapeutic decision making in pluralistic medical systems and compliance with prescribed regimens” [57, p. 338]. Immigrants to the U.S. provide particularly vivid examples of contrasting health cultures around chronic disease management. It is imperative that health care providers have the capacity to understand and address diverse health cultures as we seek to tackle low health literacy among multiple groups.

Immigrants experience dramatic changes in both culture and environment that can influence the onset and severity of chronic disease [58]. While it is commonly believed that assimilation to American culture involves the shedding of traditional beliefs and the adoption of modern, Western beliefs and behaviors, ethnographic research has shown that acculturation is not necessarily as unidirectional as originally thought [59]. Further, many ‘traditional’ practices are now thought to be protective to some extent, as researchers are beginning to identify a process of “negative assimilation” among Latinos [60]. One study found that asthma rates for Mexican-Americans increased among the second and third generations compared to first-generation immigrants [61]. Similarly, Zambrana et al. [62] found more low birthweight babies and higher rates of preterm delivery and prenatal risk behaviors among Mexican-American compared to Mexican-immigrant women. Findings such as these raise questions about the degree and kinds of changes encouraged by acculturation to American culture.

Explanatory Models of Illness and Chronic Disease Management

Sociocultural factors influence the explanatory models that patients use to understand and respond to illness. An explanatory model (EM) is a culturally-specific understanding of a particular disease or health condition and includes beliefs about the etiology, prevention and treatment of illness [63]. Explanatory models may refer to a biomedically-recognized disease such as asthma, or they

may describe folk illnesses such as *empacho*, a highland Mexican folk illness characterized by diarrhea and caused, according to this model, by an obstruction in the digestive system [64]. Traditional cultural and biomedical health beliefs may also be combined in an explanatory model, especially among immigrant groups [65]. For example, in cultures with humoral (hot/cold) theories of disease, asthma often is seen as a “cold” type of illness [66] with treatments involving the application of “hot” elements to counteract the “cold” and restore balance. Ethnographic and other studies with immigrant groups have shown that these health beliefs and practices evolve over time as populations encounter new information, experiences, and changes in the social context [59].

Many societies have explanatory models for acute illness conditions that include an array of specific responses and treatments, yet lack an understanding of the idea of chronic disease [67]. As a consequence of this lack, the Hmong, for example, “in general are not as willing to treat asymptomatic chronic diseases such as hypertension, diabetes, or hyperlipidemia as they are to treat acute, symptomatic illness” [30, p. 181]. Some argue that the concept of chronic disease is a product of ongoing contact with biomedical systems of health care [68]. Even in the U.S., according to Becker et al. [67, p. 173], “remission of symptoms may be considered to be a cure by people in some ethnic groups.” In Becker et al.’s [67, p. 176] mixed method (qualitative and quantitative) study, Latinos with chronic illnesses in California perceived “each exacerbation of symptoms as a separate illness that was unrelated to previous episodes. Diagnosis and treatment was seen as a discrete entity with each illness event, ... particularly for illnesses that had a variety of symptoms.” The authors attribute this to a lack of information about the nature and meaning of chronic disease. In such cases, physicians seeking to educate their patients about hypertension, for example, must be sure that the patient first understands the ideas of chronicity and asymptomatic illness.

Health Literacy and Racial and Ethnic Health Disparities

Minority ethnic groups are at higher risk for several diseases and suffer from more severe illnesses than their majority-culture counterparts [16, 17]. It is important to bear in mind that research on culture and health must take care to specify salient differences among populations, while avoiding the construction of ethnic groups as “monolithic entities” [69, p. 145]. Cross-cultural research can be inappropriately reductive, identifying “traditions, beliefs and behaviors that are supported by one population yet criticized by another” [70]. This problem is particularly

apparent in generalizations about “Latinos,” who may come from many different countries, and/or several different cultural/ethnic traditions within a single country. Indeed, the demographic category “Hispanic” may conceal widely varying disease prevalence rates according to country of origin [71] or other differences [56]. Further, reductionistic biological understandings of race are increasingly criticized for neglecting the complex social history of racial categories [72]. Research on health disparities must balance a genetic understanding of disease risk with a critical examination of the social and economic factors that combine to create racial and ethnic health disparities [73].

Health Literacy and Patient Adherence

With several notable exceptions (e.g., [30, 46, 68, 74]), most literature on health literacy and patient adherence does not seek to investigate culture or ethnicity as variables related to health literacy, though it is commonly observed that low health literacy is more prevalent in ethnic minority, low-income and elderly populations. In general, low health literacy is associated with worse health status [74] and poor chronic disease management. In a sample of 408 English- and Spanish-speaking patients with diabetes, Schillinger et al. [75] found that patients with inadequate health literacy were less likely than patients with adequate health literacy to achieve tight glycemic control and were more likely to have poor glycemic control. Inadequate health literacy was independently associated with worse glycemic control and higher rates of retinopathy. Similarly, poor medication knowledge was positively associated with lower adherence and lower literacy among 128 HIV-seropositive patients [76]. Lack of adherence with chronic disease management plans, especially among low-income, urban and minority patients, is widespread, leading to costly ED visits for patients with asthma and other chronic diseases.

The successful management of chronic disease is often achieved by combining lifestyle modifications such as diet and exercise with a physician-supervised medication regimen. The doctor-patient relationship and patients’ capacity for self-management are both critical to this process. In their study with three California ethnic groups, Becker et al. [67, p. 176] report that Latinos had the highest burden of chronic illness yet the least knowledge of the U.S. biomedical system. This lack of familiarity contributed to “vague[ness] about illness management... and they did not understand that they had a role in managing their illness beyond taking medication.” In addition to lack of exposure to biomedical care, culturally varying health beliefs may also influence patients’ health-seeking behaviors and

willingness to comply with treatment regimens [22, 77]. For example, in a study of prophylactic TB treatment among Vietnamese immigrants, researchers found recent immigrants were more reluctant to complete the medication regimen because its side effects were deemed too “hot”, “while Asian herbal medicines were [seen as] more benign and cooling” [57, p. 352]. Situations like this call for, first, the recognition of different explanatory models, and second, a cultural broker who understands both the EM and the biomedical aims of the recommended treatment to develop an explanation that is both comprehensible and acceptable to recent arrivals.

Diet and nutrition are commonly recognized as culturally-influenced domains of behavior [37] that are particularly relevant to diabetes management and education [78]. However, patients with diabetes may be especially reluctant to modify their eating habits when they feel that the recommended changes ask them to give up culturally meaningful habits and practices. Research suggests cultural differences coupled with low health literacy may be a factor in patient noncompliance with dietary, medication and screening regimens. Mull et al. [79] report that low patient adherence with diabetes medications was common in a convenience sample of 38 Vietnamese diabetics in California. Two-thirds of participants reported using traditional remedies for their diabetes and some discontinued their oral medications while doing so. According to Rosal et al. [80], diabetes prevalence among Hispanics is inversely related to educational status. As we might expect, low health literacy is related to knowledge about disease. Gazmararian and colleagues [81] report that of 653 Medicare recipients, 266 of whom had diabetes, 36% had marginal or inadequate health literacy. Health literacy in this population was independently related to knowledge about diabetes. Lutfey and Wishner [82] give a thorough review of the many individual, psychological, social and socioeconomic studies that have been done on noncompliance among diabetics and others with chronic diseases, reporting that a range of factors from the psychological to the cultural account for lack of adherence to treatment regimens.

Other factors also influence patients’ ability to maintain adherence with dietary, physical activity and medication regimens. Samuel-Hodge and colleagues [83] conducted focus group interviews with African-American women with type 2 diabetes, and learned that their multiple caregiving responsibilities often interfered with managing their own illnesses. Participants in this qualitative study reported that faith and spirituality were important and under-recognized coping mechanisms for people living with chronic disease. In exploratory research with 30 Puerto Rican adults with type 2 diabetes, von Goeler et al. [84] found that most participants regularly self-monitored their blood

glucose but did not use the results to improve their diabetes control. Many frequently missed doses of their medications. Barriers to adequate self-management included financial and social obstacles, and competing health and family concerns. In a community study of 625 African-American adults with diabetes, lack of health insurance was the most consistent correlate of inadequate preventive care for their diabetes [4]. Similarly, a qualitative study with members of three ethnic groups in California found that “uninsured respondents were much less effective at managing their [chronic] illnesses” compared with insured respondents. “The uninsured had poorly controlled illnesses, frequent health crises, difficulty procuring medication...and displayed little knowledge of self-care measures or risk awareness” [85, p. 19]. In another multimethod study, African-American participants described barriers to healthy eating and physical activity that included lack of places to exercise and lack of grocery stores [86].

Conclusion

The social science and medical literature reviewed here explores the impact of cultural differences and low health literacy on chronic disease outcomes and screening utilization. Since cultural beliefs around health and illness are an integral part of a patient’s ability to understand and act on his or her doctor’s instructions, efforts to improve health literacy that fail to consider these beliefs are unlikely to fully address the needs of those populations suffering from the highest levels of low health literacy. Rather than attempting to “control” for or hold constant the effects of ethnic, language or cultural differences among groups, we argue that these are the very dynamics that require exploration in our efforts to understand and address health literacy. Well-rounded programs are needed that address language barriers, cultural barriers and low health literacy simultaneously in primary care and prevention settings.

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