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Progression of CKD in Hispanics: Potential Roles of Health Literacy, Acculturation, and Social Support

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Abstract

Hispanics are the fastest growing minority group in the United States and, compared with non-Hispanic whites, have a higher incidence of end-stage renal disease (ESRD). Examining novel factors that may explain this disparity in progression of chronic kidney disease (CKD) in Hispanics is urgently needed. Interpersonal and patient-centered characteristics, including health literacy, acculturation, and social support have been shown to affect health outcomes in other chronic diseases. However, these characteristics have not been well studied in the context of CKD, particularly in relation to disease knowledge, attitudes, and behaviors. In this paper, we examine the potential roles of these factors upon CKD progression in Hispanics and propose targeted therapeutic interventions.

Keywords

Chronic kidney disease; Hispanics; health disparities; health literacy; acculturation; social support

Hispanics are the fastest growing ethnic minority group in the United States. While Hispanics currently compose 15% of the population, they are projected to compose a quarter of the US population by 2050.¹ Hispanics with CKD are at increased risk of disease progression compared with non-Hispanic whites.^{2–4} Accordingly, a better understanding of the factors contributing to the progression of mild to moderate CKD in Hispanics is critical for reducing health disparities and developing therapeutic interventions. While different names have been used to refer to Hispanics, Latinos, and Mexican Americans, for the purpose of this review, the term “Hispanic” refers to the ethnic background of persons of Latin American origin living in the United States.

A number of previous studies have found an increased prevalence of microalbuminuria in Hispanics compared with non-Hispanic whites.^{5,6} However, an analysis of the National

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Health and Nutrition Examination Survey (NHANES) found a lower prevalence of moderate kidney disease (eGFR <60 mL/min/1.73 m²) in Mexican Americans compared with non-Hispanic whites (1.0% vs 4.8%, respectively).⁷ Despite these inconsistent findings, the prevalence of ESRD is almost 2-fold higher in Hispanics than in non-Hispanic whites, and increased by 44% between 1996 and 2006.² One potential explanation for the discrepancy between the lower prevalence of earlier stages of CKD compared with the higher ESRD prevalence is that Hispanics have a more rapid progression of kidney disease after its onset. Data from Kaiser Permanente of Northern California demonstrated that in patients with stage 3–4 CKD, Hispanic ethnicity was associated with a 1.3-fold increased risk for progression to ESRD when compared with non-Hispanic whites, suggesting that Hispanics may have a more rapid progression of CKD.³ The reasons for the increased prevalence of and risk for ESRD in Hispanics remain unclear and understudied.

Drawing upon the literature on Hispanic health in other clinical contexts, we suggest several possible interpersonal and patient-centered factors that may influence the progression of CKD among Hispanics: health literacy, acculturation, and social support. In this paper, we present a conceptual model for the role of these patient-centered factors in the progression of CKD in Hispanics (Fig 1). We propose that the relationship of health literacy and acculturation with CKD progression in Hispanics is mediated by other patient-level factors, including knowledge, attitudes, and behaviors (Box 1). More specifically, we hypothesize that lower levels of health literacy and acculturation are associated with poorer understanding of CKD, decreased adherence to prescribed medication therapy, and poorer health behaviors, including diet, physical activity, and tobacco use. These factors have been found to result in worse control of chronic diseases such as diabetes and hypertension, which in turn lead to the progression of CKD.^{8–10} Furthermore, we propose that social support may buffer the negative effects of low health literacy and low level of acculturation on progression of kidney disease.

We recognize that Hispanics are a culturally, socioeconomically, and genetically heterogeneous group and therefore these relationships may have subtle differences across Hispanic subgroups. Additionally, undocumented immigrants represent a growing and understudied segment of the Hispanic population.⁴ We speculate that the barriers outlined in our model are amplified for this vulnerable population. Also, since the relationships between these patient-centered factors are likely complex and may be interrelated, we acknowledge that our model may require iterative elaboration pending future research. Lastly, according to the socio-ecological perspective, health outcomes and behaviors result from the interplay between various health determinants including individual and interpersonal factors, the social community and the environment (Fig 2).³¹ From this perspective, health literacy and acculturation are important issues in Hispanics and need to be addressed in a systematic manner at the level of the individual, health care provider, and health care system.

Health Literacy

Health literacy is the ability “to obtain, process and understand the basic health information and services needed to make appropriate health decisions.”³² A recent study by the US Department of Education estimated that 93 million US residents (43% of American adults) have limited health literacy skills,³³ which may make it difficult for them to understand and act on patient education materials. Patients with low health literacy have decreased use of preventive services,³⁴ knowledge of chronic diseases,¹¹ and medication adherence.¹⁶ Additionally, individuals with low health literacy have poorer self-reported health,³⁵ increased hospitalizations,³⁶ and increased mortality.³⁷ Moreover, low health literacy is associated with up to four times higher health care costs.³⁸ The potential for health literacy

to affect patients' chronic disease management has been recognized by the Institute of Medicine, which in 2004, issued a call to action for research in health literacy.³⁹

Examining health literacy in Hispanics is important because minorities and non-English speakers are more likely to have low functional health literacy than non-Hispanic whites.⁴⁰ Additionally, according to the 2005 American Community Survey, 73% of foreign-born Hispanics speak English "less than very well" as did up to 13% of US born Hispanics.⁴¹ Spanish-speaking Hispanics have a nearly two-fold greater likelihood of weak or insufficient health literacy compared with English-speaking Hispanics.⁴⁰ These lower levels of health literacy may contribute to adverse lifestyles and poorer chronic disease understanding and self-management, as has been demonstrated for conditions such as diabetes and hypertension.^{11,42}

The potential importance of health literacy in CKD has recently received recognition,⁴³ but has not been extensively investigated.⁴⁴ Educational level, a construct that is correlated with health literacy, has been well studied and found to correlate with poor CKD health outcomes.⁴⁵⁻⁴⁷ However, only a few studies have evaluated health literacy and CKD outcomes.^{44,48,49} These studies have focused on characterizing literacy levels of dialysis or kidney transplant recipients^{44,48} or on assessing how literacy explains patients' access to transplantation.⁵⁰ More recently, a prospective study of incident dialysis patients demonstrated an association between health literacy and increased mortality.⁴⁹ Virtually no research has investigated the relationship between literacy and CKD outcomes, albeit, others have conceptualized and called for investigation into such relationships.⁴³

Low health literacy may likely contribute to poor health outcomes in CKD through various mechanisms involving knowledge, attitudes, and behavior (Fig 1). Low health literacy can be problematic because of the need to understand forms, signs, and instructions encountered in navigating the health care system. Understanding of disease and adherence to treatment represent additional challenges for those with limited health literacy.^{11,16} Low literate individuals with CKD may have difficulty communicating with health care providers, which is essential to process disease information and carry out instructions regarding diet, physical activity, and medication use. For example, a patient with advanced CKD often must adhere to complex medication and dietary regimens, which may include multiple medications for hypertension and diabetes, a phosphate binder, an erythropoiesis stimulating agent, and a low potassium diet. To effectively adhere to such complex regimens, patients must have a clear understanding of the instructions provided, a basic understanding of the importance of these regimens for CKD, and the severity of CKD complications if regimens are not followed. Hyperphosphatemia, for instance, a common complication of advanced CKD, requires adherence to binders which, to be efficacious, must be taken with meals. A patient who has been instructed to take phosphate binders three times a day may believe that they are adherent, but without adequate understanding of when to take the binder and/or of how the binder works, will not receive the therapeutic benefit of the medication.

Patients with limited health literacy may encounter difficulty learning about their CKD from various sources of health information. Although health care providers often rely on written materials for patient education, these materials are frequently created at higher education levels and may not be appropriate for those with low health literacy.⁵¹ In 2003, the National Assessment of Adult Literacy (NAAL) found that 44% of Hispanics had below basic prose literacy levels.⁵² Feelings of shame may prevent patients from informing health care providers about their limited ability to read. Also, providers rarely screen their patients for health literacy level, and frequently overestimate their ability to accurately make this assessment.⁵³ With the increased reliance on technology to deliver health information and services, those with low health literacy are at increased risk of being inadequately educated

about their CKD. The internet has increasingly become a source of health information and health empowerment for patients. However, compared with non-Hispanic whites, Hispanics are less likely to search for health information online and are less likely than non-Hispanic whites to use electronic health services.⁵⁴ Information-seeking opportunities though growth in internet-based technologies may magnify the difference in information access between those with lower and higher health literacy.

Several types of health communication interventions have been successfully utilized in patients with low health literacy and medical conditions including diabetes,⁵⁵ asthma,⁵⁶ and cancer.⁵⁷ Interventions have included pictorial aids, group informational sessions, pharmacists, automated phone calls and the use of media (eg, other nontextual formats, including audiovisual aids and the internet).^{58–60} These types of interventions have been most successful in improving knowledge and self-efficacy in disease self-management. More recent interventions aimed at individuals with limited health literacy have also been shown to improve pneumococcal vaccination rates and accuracy of self-reported medication adherence. These findings suggest that the effect of health literacy on health outcomes may be modifiable. By understanding the relationship between health literacy and CKD, we may identify a therapeutic target in CKD progression. A health literacy intervention for Hispanics with CKD would need to address not only literacy, but also language and cultural needs. One available educational tool (RenalTouch™; www.renaltouch.com) provides education on CKD-related topics to predialysis patients through the use of interactive, computer-based modules which do not require computer skills.⁶¹ Another potential educational tools for Hispanics with CKD is the fotonovela. A fotonovela is an informational tool that incorporates photographs with simple text bubbles to deliver a message within a captivating, dramatic story.⁶² Fotonovelas have been used to provide education regarding tuberculosis, depression, and nutrition to Hispanics.^{62–64} The National Kidney Foundation has developed a fotonovela to educate dialysis patients.⁶⁵ The effects of RenalTouch and fotonovelas on CKD outcomes in Hispanics need to be evaluated.

Acculturation

Acculturation refers to the manner by which people take on the attitudes, mores, traditions, convictions, and behaviors of another culture.⁶⁶ A common misunderstanding about acculturation is that individuals select between their own or the mainstream cultural tradition.⁶⁷ Yet, many choose to adopt multiple cultural traditions to different degrees. Determining where an individual falls along this continuum of acculturation is difficult to ascertain.⁶⁷ Frequently proxy variables are used to measure acculturation,¹⁸ including: primary language, length of residency in the new culture, place of birth, preferred ethnic identity, ethnicity of friends and associates, among others.⁶⁷ However, these measurements fail to capture values and beliefs, which are fundamental expressions of an individual's cultural orientation and inform perceptions of health and illness. Logistically, culturally-based values and beliefs are difficult to enumerate and to measure. For this reason, current measurements of acculturation tend to separate culture from the social structure and processes that generate beliefs and behaviors.⁶⁷ Therefore, some scholars advocate that current measurements of acculturation are incomplete because they are unidimensional and that better measures need to be explored.⁶⁷ Nonetheless, there is value in the available data regarding acculturation and the health of Hispanics as it may provide clues regarding health disparities in this ethnic group.⁶⁸

Although it is well documented that level of acculturation is associated with health outcomes, studies report conflicting findings regarding the direction of the relationship between Hispanics' acculturation and chronic diseases.^{69,70} For instance, Hispanics with less acculturation have a decreased prevalence of hypertension and diabetes,^{69,70} however,

they have worse control of blood pressure, and an increased prevalence of cardiovascular risk factors.⁷¹ Similarly, acculturation has been found to have an impact on health-related behavior (eg, physical activity, diet, and other lifestyle habits) in both positive and negative ways.^{27,72} Higher levels of acculturation have been associated with unhealthy behaviors such as increased alcohol consumption, increased tobacco use, increased fast food consumption, and lower intake of fruits and vegetables.²⁶ On the other hand, higher acculturation has also been associated with factors that may have a positive impact on health, including increased use of preventive health service, higher rates of health insurance, and higher health literacy.^{40,73,74}

The relationship between acculturation and CKD in Hispanics has not been well studied. A recent analysis of Hispanics enrolled in MESA (the Multi-Ethnic Study of Atherosclerosis) found that more acculturated individuals had lower eGFR compared with less acculturated individuals. This association was not attenuated by traditional risk factors for CKD, but was attenuated by behaviors.⁷⁵ The relationship between acculturation and CKD progression has never been evaluated. Differences in acculturation level among Hispanic individuals may explain health disparities in CKD progression and understanding this association may help to identify individuals who are at risk of progression. In considering this association, it is important to recognize the close interactions between acculturation, health literacy, and socioeconomic status. Compared with US-born individuals, foreign-born Hispanics tend to have lower educational attainment (a proxy for lower health literacy) and lower median income.⁶³ Lower socioeconomic status is an important predictor of CKD prevalence and progression and may mediate the potential relationship of acculturation with progression of CKD.^{28,29} However, acculturation may influence progression of CKD in Hispanics through a variety of patient level factors (Fig1).

English language proficiency is a prominent marker of acculturation.⁷⁶ Non-English-speaking individuals may face significant barriers to health care access and effective patient-provider interaction.⁷⁷ Language barriers have been associated with poorer quality of care⁷⁷ and dissatisfaction with care.⁷⁸ However, the concept of acculturation also encompasses beliefs and values which may affect how a person experiences and responds to illness and the type of health care that they seek. For example, some Hispanics may believe in folk illnesses or may classify illness as natural (the will of God) or unnatural (arising from an evil force acting on the individual).⁷⁹ People holding these beliefs may feel they cannot control their illness,⁷⁹ and may not seek medical help or not follow medical advice. Cultural differences between the health care provider and the patient can inform their communication, which can potentially affect medical care. For instance, patients with CKD are often asked to follow low phosphorus and potassium diets. Less acculturated Hispanics whose diet includes beans, fruits, and tuberous vegetables, which are high in potassium and phosphorus, may not receive culturally-relevant information regarding these foods if their providers are not aware of the typical Hispanic diet. Health care providers whose clinical practices include Hispanic patients should try to be familiar with Hispanic cultural dietary habits to better educate their patients about the effects of such foods on CKD and to help suggest culturally appropriate alternatives.

Although no interventions have been implemented to slow progression of CKD among Hispanic patients with low acculturation, interventions have been used successfully in diabetes. Health promoters (*promotoras*) have been utilized to improve patients' knowledge, self-care, and glycemic control in Hispanics with diabetes.^{80,81} *Promotoras* are health community workers, who are usually a member of the community, and serve as a liaison between the community and health care providers. As a member of the community, the *promotora* inspires trust and is aware of underlying cultural beliefs that affect patients' access to health care, disease understanding, adherence to therapy, and other health

behaviors. Accordingly, *promotoras* are in an ideal position to address patients' health beliefs in a culturally sensitive manner. Patients who interact with *promotoras* are more likely to ask questions regarding disease and therapy, which may lead to improved disease understanding and adherence. Furthermore, *promotoras* can help patients navigate the health system, and translate and simplify provider instructions. Interventions utilizing health promoters for Hispanics with CKD may help overcome barriers related to lower acculturation and health literacy.

Social Support

Social support refers to resources provided by others that "lead the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations."⁸² Members of one's social network who provide support include: peers, family members, religious groups members, professionals, etc. While social networks overlap with social support, not all members of one's social network provide support.⁸³ Perceived social support is the extent to which an individual believes that their social support needs are being met by this social network.⁸⁴ Perceived social support has long been recognized to have an impact on health.⁸⁵ Higher levels of social support have been shown to associate with enhanced use of preventive services⁸⁶ and decreased morbidity and mortality.⁸⁷ Among dialysis patients, greater perceived social support is associated with improved mortality, greater adherence,⁸⁸ decreased symptoms of depression, improved perception of illness, and increased quality of life.⁸⁹ The mechanisms by which perceived social support affects chronic disease outcomes such as those relevant to CKD are not well understood.

These mechanisms may include decreased stress through motivational, emotional, or neuroendocrine effects⁸⁵; as well as alterations in the cardiovascular, endocrine, and immune system.⁹⁰ According to posited theories, members of social networks provide emotional (intimacy or confiding about emotions), tangible (providing financial assistance, goods, services, or assistance with tasks), informational (providing useful information, guidance), and companionship support (social companionship).⁹¹ These types of supports can be instrumental to self-care management of diabetes, hypertension, and other risk factors for progression of CKD. Similarly, greater perceived social support may help buffer the adverse effects of lower levels of health literacy and acculturation on CKD progression (Fig 1). For example, a patient with CKD may not understand their physician's instructions regarding home blood pressure monitoring, but they may have a partner who does and can help the patient implement the recommendations. Similarly, a partner may help by reading medication labels or, for Spanish speakers, by translating instructions. Many Hispanics have a strong sense of *familismo*, or strong attachment to nuclear and extended families.⁹² As such, they have a strong reliance on relatives to provide support and help, and they feel a duty to support their relatives with both material and emotional assistance.⁹² An analysis of the effect of acculturation on *familismo*, found that *familismo* is similar across Hispanic subgroups but changes with increasing acculturation.⁹³ With higher levels of acculturation, the perceived cultural obligation to provide support for family members was found to diminish, however the perception of family support remained the same. Social support represents a modifiable factor and may serve as a therapeutic target for Hispanics with CKD. As discussed earlier, the use of *promotoras* could be a potential social support intervention.

Conclusions

As the number of Hispanics with CKD continues to grow and disparities among this group remain prominent, it is imperative to examine factors contributing to the problem of CKD progression in Hispanics. We have outlined potential mechanisms by which health literacy, acculturation, and social support may influence the progression of kidney disease in

Hispanics. Lower levels of health literacy and acculturation are associated with differences in knowledge, attitudes, and behaviors which may contribute to CKD progression. Higher levels of social support may ameliorate the effects of low health literacy and acculturation on CKD progression. However, these patient-centered factors have not yet been studied in Hispanics with CKD and their effects on CKD progression remain unknown. Future research is needed to elucidate the relationship between these factors and the progression of CKD in Hispanics and could form the basis for targeted interventional trials focused on retarding the progression of CKD in this growing population.

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Box 1

Association of health literacy, social support, and acculturation with knowledge, behaviors and attitudes

Health literacy*Knowledge*

- Disease knowledge^{11,12}
- Information comprehension¹³

Behavior

- Diet¹⁴
- Treatment adherence^{15,16}

Attitudes

- Perception of disease¹⁷
- Perception of provider communication¹⁸
- Health beliefs¹⁹

Social Support*Behavior*

- Diet²⁰
- Physical activity²⁰
- Treatment adherence^{21,22}

Attitudes

- Perception of aisease²³

Acculturation*Knowledge*

- Disease knowledge^{24,25}

Behavior

- Diet²⁶
- Physical activity²⁷
- Treatment adherence²⁸

Attitudes

- Perception of disease²⁸
- Perception of provider communication²⁹
- Health beliefs³⁰

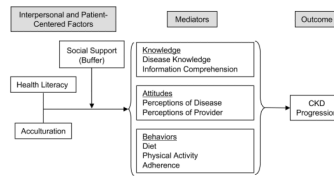


Figure 1. Role of Health Literacy, Acculturation, and Social Support in the Progression of Chronic Kidney Disease in Hispanics.

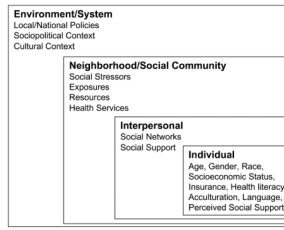


Figure 2. Socio-ecological model of factors influencing chronic kidney disease.