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Health-related quality of life in Hispanics with chronic kidney disease

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Abstract

Health-related quality of life (HRQOL) is an important patient-reported outcome that has gained attention in research and clinical practice. In recent years, reports of chronic kidney disease (CKD) have increased. However, not much information is available for Hispanics with CKD, a group whose rates of incidents are on the rise. This review discusses the measurement of HRQOL in CKD, with a particular focus on issues pertaining to Hispanics. Future research directions also are discussed.

Health-related quality of life (HRQOL) has been recognized as an important measure of well-being in patients with both acute and chronic diseases. Not only is HRQOL an important outcome in itself, but also studies across disease states have demonstrated an association between lower HRQOL and mortality.^{1–5} Chronic kidney disease (CKD) can have a significant impact on HRQOL.^{6,7} Most studies of HRQOL in patients with CKD have focused on the end-stage renal disease (ESRD) population, but there is increasing interest in measuring HRQOL in predialysis CKD patients and in post-kidney transplantation patients. The shifting focus to patients with CKD is particularly important because there are roughly 25 times more patients with CKD compared with ESRD and the rate of CKD among Hispanics has been shown to be increasing.^{8,9}

Although the importance of HRQOL in patients with CKD is increasingly being recognized, a few studies have investigated ethnic and racial differences in these measures. Several studies have documented a lower burden of disease among African Americans who receive hemodialysis compared with their non-Hispanic white counterparts.^{10–12} However, little data are available for Hispanics. This deficiency in our knowledge is notable because the number of Hispanics with CKD is increasing at a significant rate.^{9,13} The purpose of this review is to discuss the measurement of HRQOL in patients with CKD with an emphasis on issues pertaining to Hispanics. Furthermore, this review will examine available data on HRQOL in Hispanics with CKD and will suggest future directions for research in this population.

HRQOL studies among Hispanics vary in their findings depending on the disease state of the population being studied, and the complexity of these findings are compounded by the challenges of studying HRQOL in Hispanics. Population-based studies of HRQOL among persons in the United States indicate that Hispanics are more likely to report fair or poor

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HRQOL than whites.¹⁴ However, among persons living with chronic disease, Hispanics may report better HRQOL than their Caucasian or African-American counterparts. For example, a study of heart failure patients demonstrated that Hispanic patients reported better HRQOL over time while HRQOL scores worsened for African American and white patients.¹⁵ Examination of HRQOL among Hispanics is challenging in several respects. First, translation of HRQOL instruments into Spanish for non-English speaking patients, with different versions depending on different geographic regions, complicates the measurement of HRQOL.¹⁶ Second, it must be noted that Hispanics are a culturally heterogeneous group, and this diversity can influence perceptions of chronic illness and, therefore, responses to questions regarding HRQOL.¹⁷

PSYCHOMETRIC PROPERTIES OF HRQOL INSTRUMENTS

When studying a construct such as HRQOL, it is important to remember that the data are only as good as the quality of the instrument used to measure it. Several properties determine the usefulness of a measure of HRQOL, including reliability, validity, sensitivity, and, of importance to Hispanics, cross-form and cross-cultural equivalences.

Reliability

Reliability refers to the ability of an instrument to yield consistent results. The most widely used and reported test to gauge reliability is the Cronbach alpha statistic, which measures test-retest reliability. This test has values that range from 0 to 1, and an instrument with a Cronbach alpha > 0.7 is generally considered to be reliable within the group being tested. Poor reliability can be the result of poorly worded or confusing questions and responses or a poorly designed construct. It implies that respondents are not interpreting items in the same manner or that the construct of interest is not well defined by the items.

Validity

Validity refers to an instrument's ability to measure what it purports to measure. In the case of HRQOL, because the constructs of interest being measured are often abstract, the determination of validity of an HRQOL instrument requires rigorous analysis. Evidence for the validity of an instrument must be gathered over time and across different segments of the population until we are confident with its performance. For an instrument that measures an abstract concept like HRQOL, construct validity is the most widely used method to assess the validity of an instrument. Construct validity is assessed by studying the correlation between the measure of interest and a measure of a related concept. For example, one could theorize that scores on a mental health component of an HRQOL instrument, in which lower scores indicate lower quality of life, should negatively correlate with scores on the Beck Depression Inventory (higher scores indicate higher likelihood of depression). If these instruments are administered to a group of subjects and a strong negative correlation exists between the mental health component and Beck Depression Inventory, then this lends good evidence for the validity of the measure. Several other kinds of validity include content and predictive validity, each of which can add to the evidence for the overall validity of an instrument.

Sensitivity

What if a generic instrument is used to measure changes in HRQOL in patients with CKD, but finds little difference? Although the results might be accurate, another possibility is that the generic instrument did not have adequate sensitivity to specific factors of the effects of CKD on HRQOL. In the measurement literature, sensitivity refers to the ability of an instrument to ascertain differences in the construct of interest. In the case of HRQOL, this has led to the development of disease-specific measures. Whereas generic measures of

HRQOL, such as the Short Form-36 (SF-36), have the advantage of allowing for comparisons across disease states, disease-specific measures have, in theory, the advantage of improved responsiveness to changes in HRQOL for a particular disease. There is no formal test of sensitivity, but it can be assessed by comparing the results of 2 different instruments of interest administered to the same subjects.

Cross-form and cross-cultural equivalence

Cross-form and cross-cultural equivalences are of particular importance when measuring HRQOL in different languages and ethnic groups. To say that an instrument has cross-form equivalence implies that it has undergone a relatively direct translation into another language and that the instrument exhibits similar psychometric properties as the original version, which makes it appropriate for use in comparative studies. It is important to remember that language can differ across geography and ethnicity. As an example, 1 version of a quality-of-life measure in CKD has 3 different Spanish versions: 1 developed in Spain for Spanish individuals, 1 in Argentina for Argentineans, and 1 in the U.S. for Hispanics.¹⁸

Many issues beyond language may render the meaning of an instrument significantly different in another culture. Mental health quality of life in particular may be interpreted differently by Hispanics compared with non-Hispanic whites. For example, Hispanics tend to view depression as a condition caused by interpersonal and societal factors, whereas non-Hispanic whites view depression as a disease that requires medical attention.¹⁹

Another problem that can be encountered is with idiomatic expressions. A mental health question may ask about “feeling blue” in English. Even though this expression can be translated directly into Spanish, it does not have the same meaning. Addressing these issues requires a culturally competent individual to assess the appropriateness of terminology and concepts for the target population. Formal testing might consist of comparing the distribution of scores of an instrument within different target populations. Cross-cultural equivalence is a complicated issue that can often affect a researcher’s ability to study HRQOL comparatively across different cultures. It becomes even more complicated when considering the diversity of the Hispanic population. Not only are there differences in country of origin and ethnicity within those countries, but there is also the issue of acculturation, which is the degree to which individuals have acclimated to life in the United States. These concepts are of great importance in the interpretation of HRQOL data in a multiethnic cohort, and of particular importance in the Hispanic community. For the researcher or clinician planning to use a HRQOL instrument in Hispanics, these issues must be considered when choosing the instrument, because different subgroups of Hispanics may have somewhat different interpretations of the instrument. The selection of an instrument that uses neutral terms with little variability in meaning among Hispanic subgroups is preferable.

DATA COLLECTION IN HISPANICS

Several issues in data collection can affect the results of HRQOL scores, and these issues must be considered whenever interpreting results. One important consideration is item response bias, which is bias introduced by extreme response style. In a scaled response item like those in HRQOL instruments, 1 notable phenomenon has been observed in different ethnic populations. In some cultures, responses tend to aggregate either toward the extreme choices or toward the middle. In several studies, Hispanics have been shown to choose more extreme responses.^{20,21} For example, the first item of the Short Form-36 instrument asks about the subject’s general state of health. Response options are excellent, very good, good, fair, and poor. Marin et al²¹ analyzed 4 large data sets and found that based on the literature, Hispanics are more likely to choose excellent or poor than the general population. In certain

Asian cultures, societal norms are strong and individuals may be more likely to choose the middle 3 options and avoid the extreme options.²² Such cultural differences make comparisons challenging, and an interpretation must always keep these factors in mind. If the effect is severe enough, a different scaling procedure may be required to generate composite scores that are comparable among races and ethnicities. For example, Marin et al²¹ demonstrated that Hispanics tended to be more likely to choose options at the extremes of a 5-point Likert scale compared with non-Hispanics, but these disparities between the 2 ethnic groups disappeared when a 10-point Likert scale was used. However, we are unaware of such a scaling procedure being used to transform HRQOL data among Hispanics with CKD.

In addition to item-response bias, low health literacy represents a challenge in data collection as well. A study in 1995 at 2 hospitals found that 31.5% of English-speaking patients and 61.7% of Spanish-speaking patients presenting to the emergency room had inadequate or marginal health literacy.²³ Subjects with lower health literacy may not fully understand written or verbal instructions and thus may not complete a questionnaire properly. They may also be more likely to need the assistance of an interviewer to complete a questionnaire, which can affect the results. There is little knowledge about how group differences in health literacy might bias the results obtained from HRQOL instruments, and this issue deserves further study. At the least, it may be reasonable to use health literacy screens in vulnerable populations and have an interviewer available for those with poor health literacy.

MEASURES OF HRQOL IN CKD PATIENTS

It is important to recognize that there are many facets to the quality of life. Early models of HRQOL focused on physical health and physical functioning, but eventually symptoms and mental health were also incorporated. Most HRQOL measures used today contain several domains, scored separately, to capture information related to various aspects of quality of life. A conceptual model of HRQOL in CKD includes a framework made up of global health and well-being, physical health, mental health, and CKD-specific factors.²⁴ The dimensions of importance that should be considered include demographic and cultural contexts. The latter is of particular importance to the measurement of quality of life in Hispanics with CKD. Although HRQOL instruments do not measure these dimensions directly, they can be taken into account when analyzing quality-of-life data.

HRQOL instruments in CKD

One of the first quality-of-life measures to be used in the ESRD population was the Quality of Life Index, which was created by Ferrans and Powers in 1985.²⁵ This 64-item index was developed for use in both dialysis patients and healthy subjects for comparative purposes. Psychometric analysis of this instrument in 349 ESRD patients yielded the following 4 domains of importance: health and functioning, socioeconomic, psychologic/spiritual, and family. The earliest studies of multidimensional HRQOL in ESRD were performed using this instrument.

An important development in quality-of-life research was the publication of the SF-36.²⁶ This 36-item, 8-domain, generic HRQOL measure has undergone several revisions and rewordings, but it continues to be the most widely used HRQOL instrument because of its well-documented development procedures and its track record in research, with more than 4000 publications citing it (see www.SF-36.org). Many studies of HRQOL in CKD have used the SF-36 or its scaled-down siblings, the SF-12 and SF-8. As they are generic HRQOL measures, the SF-36, SF-12, and SF-8 allow for comparison studies between subjects with and without CKD.

Although the SF-36 is a good instrument for use in most chronic disease states, some recognized the need for a disease-specific measure in CKD. Disease-specific measures provide a measurement of the impact of specific symptoms associated with an illness on HRQOL, but unlike generic HRQOL assessments, they do not allow for a comparison of the impact of an illness on HRQOL with that of other chronic diseases.²⁷ To assess HRQOL in CKD more accurately, the 134-item Kidney Disease Quality of Life (KDQOL) instrument was developed by Hays et al²⁸ in 1994. Subsequently, 2 abbreviated versions of this instrument, the KDQOL-Short Form (KDQOL-SF) and Short Form-36 (KDQOL-36), were created as more practical tools for both research and clinical practice.³⁰ The KDQOL-36 in particular has been used frequently because it incorporates items from the SF-36 with disease-specific domains. These domains address a patient's attitudes toward kidney disease with specific questions regarding disease-specific symptoms, the impact of disease-specific dietary restrictions on the patient's quality of life, and their attitude toward the illness. The following subscales are included: (1) the generic core (12 items), which includes a Physical Health Composite (8 items) and a Mental Health Composite (4 items); (2) symptoms/problems related to kidney disease (12 items); (3) burden of kidney disease (4 items); and (4) effects of kidney disease (8 items) (Table I). This contrasts with the SF-36, which contains 8 different scales (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health) along with 2 composite scores (physical health and mental health composites) that incorporate all the above scales. Thus, the KDQOL-36 has a focused core that contains fewer questions that address physical and mental quality of life generically, but it adds domains that deal directly with the social and emotional burdens of kidney disease.

As interest in the interaction of disease burden and quality of life has flourished worldwide, the KDQOL-SF and KDQOL-36 have been translated into many different languages. More than 20 translated versions are listed on The KDQOL Working Group website, including 3 Spanish versions.²⁹ The first Spanish version of this instrument was translated by J. Alonso in Spain, followed by another Spanish version that was translated by S. Giacometto in Argentina. Given the differences in level of education, vocabulary, and culture among various Spanish-speaking groups, a Spanish version of the KDQOL-36 for use in Hispanics in the United States was translated by S. Eremenco (written e-mail communication with S. Eremenco, March 2004). To date, this version has yet to be evaluated formally, which represents a serious problem in studying HRQOL in Hispanics with CKD. With regard to cross-cultural equivalency, it is important to note that the English version of the KDQOL-36 has never been validated in the English-preferring Hispanic population in the United States either. Although it is not common for validation to be studied based on ethnicity or race, this important omission in the literature may risk the accuracy of quality-of-life research.

HRQOL IN SUBJECTS WITH CKD

As awareness of the importance of HRQOL measurement in chronic disease has increased, several studies have been conducted in the CKD ESRD population. The largest study to date regarding HRQOL in patients with CKD ESRD comes from the Dialysis Outcomes and Practice Pattern Study (DOPPS).³⁰ DOPPS was a multinational, prospective, observational study of hemodialysis patients focusing on practice patterns and outcomes. HRQOL was measured using both the SF-36 and KDQOL-SF. Lopes et al¹⁰ examined HRQOL and associated outcomes among different racial and ethnic groups in the U.S. cohort within DOPPS. Hispanics had higher adjusted scores compared with non-Hispanic whites for the Physical Health Composite (PHC), but lower scores for the Mental Health Composite (MHC) and Kidney Disease Composite (KDC). The study concluded that significant differences were found in HRQOL scores among different racial and ethnic groups, even when subjects were clinically similar in other respects, including age, comorbidities, and

length of time on dialysis. The outcomes portion of this study demonstrated that lower PHC, MHC, and KDC scores were associated with increased mortality in non-Hispanic whites, blacks, and Hispanics, although the associations with MHC and KDC did not reach statistical significance for Hispanics (Table II). In general, studies of HRQOL and its relationship to mortality in dialysis patients have found stronger associations between the physical components of HRQOL measures and mortality than among mental health components.³¹⁻³³ The physical components of HRQOL are thought to act as a surrogate of overall disease burden.³³ It is interesting to note that this study found a survival advantage for non-Hispanic blacks, who had higher HRQOL than their non-Hispanic white counterparts. A study of U.S. dialysis patients using Medicare data by Frankenfield et al³⁴ also found a survival advantage for non-Hispanic blacks, as well as for Hispanics, who were initiating dialysis compared with non-Hispanic whites. Less robust but similar results were found regarding risk of hospitalization in DOPPS as well. These findings demonstrate a predictive value of HRQOL assessment in the ESRD population that may be useful in clinical practice with subsequent research.

FUTURE RESEARCH

As stated previously, the research surrounding HRQOL in Hispanic patients with CKD is limited. Comparative studies of quality of life in different racial and ethnic groups have been conducted, but the results must be interpreted with care for several reasons. First, in relation to Hispanics, the U.S. Spanish version of the widely used KDQOL-36 has not been validated, which is a major deficiency in gathering and interpreting HRQOL information in the Hispanic population. Furthermore, the psychometric properties of the English version of the KDQOL-36 should be evaluated in racial and ethnic groups to investigate the possibility of cultural differences in the interpretation of the items. Rigorous validation requires more study, and a validation procedure should be included as part of any study using the KDQOL instrument, given the paucity of current evidence. The validation of translated instruments is a time consuming, but essential process and the validation procedures should follow the general principles regarding construct, content, and predictive validity as discussed in the earlier section devoted to this topic. With these limitations in mind, comparative studies of ethnic differences in HRQOL scores have been demonstrated, but little research has been performed to determine the source of these differences or how these differences might ultimately affect clinical outcomes.

DOPPS has provided us with much information about risk factors for lower HRQOL in the ESRD population. However, little information is available for patients with CKD who have not initiated dialysis or patients who have received a kidney transplant. Research needs to determine modifiable and nonmodifiable risk factors for lower HRQOL in these patients, including HRQOL based on the stage of kidney disease. Hemoglobin level, hypertension, secondary hyperparathyroidism, and comorbidities are some other examples of risk factors for lower HRQOL that should be investigated. In the case of transplantation, immunosuppressive regimens and transplantation type (ABO incompatibility, high panel reactive antigen level, etc) may lead to important HRQOL differences and should be considered for study.

CONCLUSION

The emergence of HRQOL as an important clinical indicator for patients who suffer from chronic illness represents a positive development in patient-centered outcomes research. This type of information is increasingly being used as 1 measure of the effectiveness of various interventions for patients with CKD, including dialysis modality and hypertension management.^{35,36} Future CKD clinical trials likely will include HRQOL measurements, and

ESRD practices are beginning to incorporate these measures into routine patient care assessments. To provide guidance in this area, the National Institutes of Health has instituted an initiative called the Patient-Reported Outcomes Measurement Information System with the goal to create a core questionnaire and promote its widespread use in clinical research and clinical care.³⁷

This review discusses several important limitations and challenges in the collection and interpretation of HRQOL data, with an emphasis on special issues that affect Hispanics. As mentioned earlier, the prevalence of CKD is increasing in the Hispanic population, and we can expect that the total number of Hispanics with CKD will continue to grow in view of the increase in the U.S Hispanic population. For this reason, it is essential that we gain greater insight into HRQOL for this growing segment of the population. Although we have noted the paucity of information regarding HRQOL in minorities, and particularly in Hispanics, this review represents an opportunity to expand our knowledge of CKD and its effects on racial and ethnic populations in the United States, with the ultimate goal of improving the quality of life for patients who suffer from kidney disease.

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Abbreviations

CKD	chronic kidney disease
DOPPS	dialysis outcomes and practice pattern study
ESRD	end-stage renal disease
HRQOL	health-related quality of life
KDC	Kidney Disease Composite
KDQOL	Kidney Disease Quality of Life
KDQOL-SF	Kidney Disease Quality of Life Short Form
MHC	Mental Health Composite
PHC	Physical Health Composite
SF-36	Short Form-36

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Table IThe KDQOL-36 scoring system and its scales.²³

Scales	Items
Generic Core	
Physical Composite	1. General health rating
	2. Moderate activity
	3. Climbing several flights
	4. Accomplished less (physical cause)
	5. Limited in kind
	6. Accomplished less (emotional cause)
	7. Work as carefully
	8. Pain
Mental	9. Calm and peaceful
	10. Energy
	11. Downhearted and blue
	12. Social activities
Burden of kidney disease	13. Interference with life
	14. Time spent dealing
	15. Frustration
	16. Burden on family
Symptoms	17. Soreness
	18. Chest pain
	19. Cramps
	20. Itchy skin
	21. Dry skin
	22. Shortness of breath
	23. Faintness or dizziness
	24. Lack of appetite
	25. Washed out or drained
	26. Numbness in hands or feet
	27. Nausea or upset stomach
	28a. Access site problems [†]
	28b. Catheter site problems [†]
	Effects of kidney disease
30. Dietary restriction	
31. Ability to work at home	
32. Ability to travel	
33. Dependence on medical staff	
34. Stress or worries	
35. Sex life	
36. Personal appearance	

[†]Item completed by hemodialysis participants only.

[‡]Item completed by peritoneal dialysis participants only.

Differences between non-Hispanic whites and Hispanics in HRQOL component and subscales scores and the relationship of HRQOL scores to death and hospitalizations among American subjects enrolled in DOPPS

Table II

	Adjusted relative risk*								
	Adjusted differences in scores			Death			Hospitalization		
	White	Hispanic		White	Hispanic		White	Hispanic	
Physical component	32.0	+1.6 [§]	1.11 [†]	1.22 [†]	1.07 [†]	0.96			
Mental component	46.2	-1.4 [§]	1.08 [†]	1.09	1.03 [‡]	1.02			
Kidney disease component	62.8	-1.7 [§]	1.06 [†]	1.05	1.03 [‡]	1.00			
Symptoms/problems	72.1	-4.6 [‡]	1.04 [†]	1.08 [†]	1.04 [†]	1.00			
Effects	61.4	-3.7 [§]	1.03 [†]	1.05 [‡]	1.03 [†]	1.00			
Burden	38.9	-4.1 [§]	1.02 [†]	1.02	1.02 [†]	1.00			

Note: These data are adapted from Lopes et al¹⁰ with permission.

* Per 5 points lower score.

[†] $P < 0.001$.

[‡] $P < 0.01$.

[§] $P < 0.05$.