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Racial differences in health-related quality of life among hemodialysis patients

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Background. Despite technical progress in therapy, hemodialysis patients continue to report health-related quality of life (HRQOL) substantially lower than that of the general population. While African Americans with end-stage renal disease (ESRD) survive longer than members of other races, few studies have compared the HRQOL of African Americans with that of non-African Americans.

Methods. We examined differences in sociodemographic, clinical, and HRQOL variables by race. A multiple regression model assessed the extent to which race was associated with differences in HRQOL scores after adjustment for sociodemographic and clinical variables. Racial differences in the relationship between comorbid disease severity and HRQOL were explored.

Results. In adjusted models, African Americans had higher scores in the Index of Well-Being and burden of kidney disease, but lower scores in cognitive function (all $P < 0.05$). For scales reflecting symptoms and effects of kidney disease, sleep quality, and the Physical Component Summary, the fall in HRQOL with increasing comorbidity was significantly greater in non-African Americans (all $P < 0.05$). After adjustment, there were no racial differences in scores on the Mental Component Summary, social support, dialysis staff encouragement, or patient satisfaction.

Conclusion. To our knowledge, ESRD is the only chronic illness for which African Americans report significantly better psychologic well being and a lower burden of disease than non-African Americans. Further research is needed to understand whether these experiences affect health care utilization, medical decision making, and patient survival. Clarification of the reasons for race differences may suggest measures to improve HRQOL for all patients with ESRD.

Key words: quality of life, race, hemodialysis.

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African Americans bear a disproportionate burden of end-stage renal disease (ESRD). They constitute almost one third of treated ESRD patients, but only 13% of the United States population [2]. After adjusting for age, gender, and the primary cause of kidney disease, African Americans treated by hemodialysis survive longer than whites [3]. In addition, African Americans with ESRD are less likely to be treated by peritoneal dialysis [4], and less likely to be listed for kidney transplantation [5]. Whites withdraw from dialysis treatment more often than African Americans [6]; some have suggested that this implies that African Americans' quality of life in ESRD is better than whites' [7].

Previous studies of racial differences in health-related quality of life (HRQOL) in ESRD have had methodologic limitations and conflicting findings. A study of older dialysis patients conducted in the late 1980s showed that whites were more likely to report physical symptoms and dissatisfaction with their health than were African Americans [8]. These findings are difficult to interpret because standards of dialysis care have evolved substantially since the data were collected; patients did not receive erythropoietin therapy, the standard dialysis dose was lower than current practice, and high-flux membranes were not used. Erythropoietin use has subsequently been associated with significant improvements in health status, particularly in physical functioning and energy [9]. Furthermore, the study assessed individual symptoms rather than measuring HRQOL with accepted instruments. A small study of 79 incident dialysis patients showed the mental well being of African Americans to be similar to that previously reported for whites [10]. However, the study population was entirely African American, and one third had experienced dialysis for less than one month. In a large observational study of 5167 patients, investigators have found African American report higher QOL scores in Physical Component Summary, Mental Component Summary, and kidney disease

summary [11]. However, this study used race and ethnicity classified by the coordinator rather than race reported by the patient, and it lacked a validated comorbidity assessment. Indeed, other studies have also included only African Americans [10, 12]. Yet others may have failed to adjust adequately for case-mix differences [8, 13, 14]. In all of these studies, apparent HRQOL differences may have been at least partly attributable to the lesser burden of comorbid disease in African Americans with ESRD [15].

The present study assesses the relationship between baseline HRQOL scores and race among participants in the Hemodialysis (HEMO) Study, a large multicenter population that measured HRQOL using validated instruments and assessed comorbidity and case-mix variables. We hypothesized that African American race would be associated with a higher HRQOL after adjusting for demographic, socioeconomic, center, patient case-mix, and other treatment-related factors.

METHODS

Study design

The HEMO Study is a 15-center randomized clinical trial of the effects of hemodialysis dose and membrane flux on mortality and morbidity in patients treated with chronic hemodialysis [16]. The primary end point is all-cause mortality. Patient eligibility criteria and other study design issues have been previously described [1, 17]. The Institutional Review Board at all the institutions approved the study protocol, and written consent was obtained from all study participants. At randomization, 1813 of 1846 study participants completed the survey. Enrollment in the HEMO Study began in March, 1995, and ended in December, 2001. We report a cross-sectional analysis of responses to the Index of Well-Being (IWB) and to the Kidney Disease Quality of Life-Long Form (KDQOL-LF) at the time of randomization.

Data collection

Demographic information and clinical history were collected through review of medical records and self-reported questionnaires. The race of the respondent was assessed by self-report and all those that were self-described as white, Asian, American Indian/Alaskan Native, or other were collectively classified as non-African American for this report. Clinical data including laboratory measurements were obtained using standardized protocols [16]. Comorbidity was assessed at baseline using the Index of Coexistent Disease (ICED) [4, 18, 19]. The ICED aggregates the presence and severity of 19 medical conditions and 11 physical impairments into 2 summary indices: the Index of Disease Severity (IDS) and the Index of Physical Impairment (IPI) [18]. An algorithm combining peak scores for the IDS and IPI determined the final ICED score. ICED scores range from 0 to 3, with a higher score reflecting increasing disease severity.

HRQOL instruments

The IWB consists of 10 bipolar items on which the patient indicates how one feels about life, and one bipolar item asking how satisfied a patient currently feels about one's life. The range for the IWB is 2.1 (low well-being) to 14.7 (high well-being). The IWB has been shown to be reliable and valid in both ESRD and non-ESRD populations [20].

The KDQOL-LF assesses generic and kidney-disease targeted HRQOL domains. The SF-36 is the generic core of the KDQOL-LF. The SF-36 has been extensively evaluated both in the general population and the ESRD population [21–29]. The SF-36 questions are grouped into eight scales: physical functioning (10 items), role-physical (4 items), bodily pain (2 items), general health (5 items), vitality (4 items), social functioning (2 items), role-emotional (3 items), mental health (5 items) [26]. Two component summary scores are derived from these eight scales. The Physical Component Summary scale (PCS) aggregates items from physical functioning, role-physical, bodily pain, general health, vitality, and social functioning. The Mental Component Summary scale (MCS) aggregates items from role-emotional, mental health, and also includes elements of general health, vitality, and social functioning. In the general population, the mean for each summary scale is 50 points, with a standard deviation of 10 points [30].

The KDQOL family of survey instruments has been widely used in dialysis studies [31–35]. KDQOL-LF includes a Symptoms/Problems scale (34 items) that assesses the extent to which symptoms bother the subject, such as dry itchy skin, thirst and hunger, pain in the joints or back, muscle cramps or soreness, and clotting or other problems with the access site [6]. The Effects of kidney disease scale (20 items) measures the impact of kidney failure on daily life with questions about restrictions on fluid and dietary intake, work, travel, lifting, and personal appearance. Burden of kidney disease (4 items) considers the impact of kidney failure on the sense of accomplishment and achievement. Social support (4 items) assesses satisfaction with family and social life. Sleep (10 items) assesses subjective sleep initiation and maintenance, as well as daytime somnolence. Dialysis staff encouragement (6 items) measures the extent to which the dialysis staff encourages patients to be independent and to lead as normal a life as possible. Patient satisfaction (2 items) gauges how well dialysis care meets expectations. Cognitive function (6 items) considers difficulty with memory and concentration. Because it had less than adequate internal

consistency reliability, we excluded the KDQOL-LF social interaction scale from this analysis. The range of scores for the dialysis-targeted scales was 0 to 100, with a higher score reflecting better health.

Statistical analysis

Differences between African Americans and non-African Americans were assessed in demographic variables (including race), socioeconomic, clinical and laboratory variables, and HRQOL scores. Two sample *t* tests were used for continuous variables (e.g., age), and chi-square test was used for categorical variables (e.g., ICED). Descriptive statistics (mean, standard deviation, response rate, and percentage of patients at the floor or ceiling) were calculated for each HRQOL scale, and internal consistency reliability was estimated (data not shown) [36]. Scale scores were estimated using the average of an individual's non-missing items when at least half of the items in a scale were completed (non-missing).

The associations with HRQOL scales of demographic variables (including race), socioeconomic, clinical and laboratory variables were evaluated using linear regression. A separate regression model was created for each scale of the HRQOL instrument. To explore the extent to which racial differences in HRQOL are accounted for by other case-mix factors, we constructed three multivariable models for each scale, sequentially adding additional factors to adjust for potential confounders on the relationships of race with HRQOL domains. Because study center was highly correlated with race, we considered center a possible confounder and included it in each of the multiple regression analyses [37]. Therefore, the first model contained race, sex, age, and duration of dialysis. In the second model, we included additional socioeconomic variables (employment, education level, self-administration of survey, number of those in household, marital status, tobacco use, disability, and insurance status). The third model included additional comorbid disease and laboratory parameters [ICED comorbidity index, more than one hospitalization in the past year, diabetes as a cause of ESRD, equilibrated normalized protein catabolic rate (enPCR), serum albumin, hematocrit, creatinine, phosphorus, and equilibrated Kt/V (eKt/V)]. The models accounted for factors significant at the $P < 0.05$ level and included a few variables that were non-significant but thought to be clinically important (age, years on dialysis, the number of individuals in the patient's household, whether the patient was listed for transplantation, and baseline eKt/V). We found that it was unnecessary to adjust for flux when including center as a variable, because membrane flux at baseline was strongly correlated with center. The signs of the estimated coefficients and the R^2 were examined for each model.

We examined interaction terms for two reasons. First, because 56.3% of HEMO Study participants were female, we tested for differential gender effects on scale scores. Second, we hypothesized that the relationship between race and HRQOL might vary with severity of illness. Therefore, we examined interactions between the race covariate and duration of dialysis, diabetes, ICED score, whether the patient was working, and the number of hospitalizations in the past year. All interaction terms were tested in the full model for each scale. Because 12 quality-of-life indices were investigated, a total of 72 interaction tests were performed, thereby inflating the risk of a type I error. In this context we present both the preplanned overall analysis of the "main effect" of race, and then the interactions and associated subgroup analyses that should be interpreted with caution because of the risk of a type I error with multiple hypotheses [38–40]. All significance tests were two-tailed and a *P* value of less than or equal to 0.05 was considered statistically significant. All analyses were performed with Unix SAS 6.12 (Cary, NC, USA).

RESULTS

HEMO Study patient characteristics

Of 1846 patients randomized in the HEMO Study, 1813 patients completed the HRQOL questionnaire at baseline. The 33 patients who did not respond did not speak either English or Spanish. Of the remaining 1813, 1156 were African Americans (65.76%), 598 were white (33%), 32 were Asian (1.8%), 16 were unknown (0.88%), and 11 were American Indian/Alaskan Native. Among those classified as African American, eight were self-designated as Hispanic (0.7%), and of the 657 classified as non-African American (white, Asian, other, and American Indian/Alaskan Native), 99 were Hispanic (15.1%). Among all of the participants in this study, the mean age was 58 years, and 56% was female. The mean duration of dialysis was 3.74 years, and mean eKt/V was 1.35. A majority had either diabetes (38%) or hypertension (33%) as the cause of ESRD, and one third (33%) had severe comorbidity as represented by an ICED score of 3.

Differences in baseline characteristics

Table 1 shows that African American patients were more likely to be female, to have less than a high school education, and to have a history of tobacco and alcohol use. African American participants were less likely to be married, less likely to have had more than one hospitalization in the past year, and their comorbid illness severity was significantly less. The mean enPCR, hematocrit, and serum phosphate of African Americans were lower, while the mean serum creatinine was higher. African Americans were more likely to have been treated

Table 1. Sociodemographic and clinical characteristics of African American and non-African American HEMO Study participants

	Variable	African American (N= 1156)	Non-African American (N = 657)	P value
Demographic	Age *years*	57.8 (13.1)	57.3 (15.5)	0.52
	Female %	61.6	47.2	0.001
	Duration of dialysis *years*	3.76 (4.2)	3.72 (4.7)	0.85
Socioeconomic and health behaviors	Working %	9.5	15.4	0.001
	At least high school education %	56.9	70.7	0.001
	Self-administer the survey %	58.7	63.5	0.044
	Number in household	2.6 (1.6)	2.6 (1.6)	0.87
	Listed for transplant %	19.7	19.7	0.99
	Married/common law marriage %	30.3	53.4	0.001
	Divorced/separated/widowed %	50.1	27.6	
	Single/never married	19.5	19.2	
	Tobacco (current) %	20.4	12.2	0.001
	Alcohol (abuse) %	20	9.6	0.001
	Receives disability %	53	40.6	0.001
	Private insurance %	42.7	60.8	0.001
Severity of illness and clinical factors	Diabetes %	46.9	41.9	0.07
	ICED (0–1) %	37.9	30.8	0.007
	ICED 2 %	31.5	30.0	
	ICED 3 %	30.6	39.1	
	Hospitalized >1 in past year	38.2	46.3	0.001
	enPCR	.98 (.25)	1.05 (0.24)	0.0001
	Albumin *g/dL*	3.61 (0.39)	3.64 (0.41)	0.14
	Hematocrit %	33.3 (4.5)	34.0 (4.4)	0.0017
	Creatinine *mg/dL*	10.7 (2.9)	9.4 (2.6)	0.0001
	Phosphorus *g/dL*	5.65 (1.8)	6.0 (1.9)	0.0003
	eKT/V	1.34 (0.22)	1.36 (2.2)	0.21

Table 2. Mean HRQOL scores of African American and non-African American HEMO Study participants

	HRQOL Scale	African Americans	Non-African Americans	P value
Generic domains	Index of Well-Being	10.34 (3.1)	9.44 (2.6)	0.0001
	Physical Component Summary Score	36.3 (9.8)	34.78 (10.5)	0.0037
	Mental Component Summary Score	50.1 (11.0)	49.4 (10.8)	0.14
Dialysis targeted	Symptoms	75.9 (14.1)	74.1 (13.9)	0.009
	Effects of kidney disease	67.9 (21.0)	63.0 (20.5)	0.0001
	Burden of kidney disease	53.0 (29.6)	46.3 (28.3)	0.0001
	Cognitive function	74.6 (21.0)	76.8 (19.9)	0.03
	Social support	66.8 (23.2)	67.0 (22.9)	0.82
	Sleep	58.9 (22.12)	56.2 (21.9)	0.02
	Dialysis staff encouragement	68.9 (17.0)	67.4 (17.3)	0.03
	Patient satisfaction	67.2 (19.6)	72.8 (20.0)	0.0001

by high-flux dialysis before study entry (65% vs. 53%, $\chi^2 = 23.9$, $P < 0.0001$).

Unadjusted differences in HRQOL by race

Table 2 shows that African American hemodialysis patients reported a substantially higher average quality of life on the IWB, had significantly higher SF-36 Physical Component Summary scores (indicating better physical health), and better scores on the scales symptoms of kidney disease, effects of kidney disease, burden of kidney disease, and sleep. African American patients reported slightly lower cognitive function. They were significantly less satisfied with their care than non-African American patients, but reported more dialysis staff encouragement.

Adjusted differences in HRQOL for African Americans

Table 3 shows that higher scores (better health) in the domains of the IWB and burden of disease persist in the African American group after adjustment for center, demographic, socioeconomic, clinical factors, and severity of comorbid illness. On the IWB, the difference between the two groups was reduced, but remained statistically significant after adjustment ($P = 0.013$). After adjustment for covariates, the differences in scores measuring Physical Component Summary and symptoms and effects of kidney disease were reduced in magnitude. Despite adjustment for observed differences between groups, burden of kidney disease scores remained significantly higher (lower burden) in the African American group ($P = 0.012$), and cognitive function

Table 3. Adjusted mean differences between HRQOL scores of African American and non-African Americans[a]

HRQOL Scale	Unadjusted difference[b]	Adjusted difference
Index of Well-Being	0.9°	0.46 (0.18)[c]
Physical Component Summary score	1.49°	0.02 (0.97)
Mental Component Summary score	0.81	0.24 (0.72)
Symptoms	1.8[d]	1.2 (0.87)
Effects of kidney disease	4.9[e]	2.0 (1.3)
Burden of kidney disease	6.67[e]	4.6 (1.8)[c]
Cognitive function	−2.2[c]	−3.04 (1.29)[c]
Social support	−0.24	0.51 (1.4)
Sleep	2.5[c]	0.9 (1.38)
Dialysis staff encouragement	1.9[c]	2.04 (1.1)
Patient satisfaction	−5.65[e]	−1.31 (1.22)

[a] All adjusted models account for clinical center, age, sex, duration of dialysis, employment, education level, self-administration of survey, number of those in household, marital status, listed for transplantation, tobacco use, alcohol abuse, disability and insurance status, ICED comorbidity index, more than one hospitalization in the past year, diabetes, enPCR, serum albumin, hematocrit, serum creatinine, serum phosphate, eKT/V, and positive scores mean better quality of life in all domains.

[b] African American minus non-African American scale score.

[c] $P < 0.05$.

[d] $P < 0.01$.

° $P < 0.001$.

scores remained lower (more cognitive symptoms) in the African American group ($P = 0.019$). Finally, significant unadjusted differences in sleep, dialysis staff encouragement, and patient satisfaction by race were reduced in magnitude after adjustment for covariates. As discussed in the subsequent section, interactions were found between the ICED score and race, although these are not included in the Table 3 results. The Table 3 results, therefore, should be interpreted as the effects of race averaged across comorbidity level for the HEMO Study population.

Differences in adjusted HRQOL scores by race for level of comorbidity

In several domains, the relationship between race and quality of life was influenced by comorbidity. Figures 1 to 4 stratify the relationships between race and HRQOL scores by comorbidity level in the fully adjusted model. Figure 1 shows the racial differences in SF-36 Physical Component Summary score for level of comorbidity (the *P* value for race by comorbidity interaction was 0.003). For those with mild and moderate comorbidity (ICED 0 to 2), there were no clinically meaningful differences in PCS scores between African Americans and non-African Americans. However, among those with severe comorbid illnesses, African Americans perceived less physical disability as compared with non-African American. There were also differential effects of race across ICED levels for the symptoms score, effects score, and sleep scores. As shown in Figures 2 to 4, for individuals with mild-moderate comorbidity, there were no clinically meaningful differences by race in the respective health status domains. However, the different perception of disability across racial groups becomes manifest among individuals with severe comorbid disease. At ICED level 3, African Americans perceived less disability in Physical Composite Score, symptoms, effects of kidney disease, and sleep domains, as compared to non-African Americans.

As a sensitivity analysis, we examined the individual scales that are components of the PCS and MCS. After adjustment for demographic, socioeconomic, center, patient case-mix, and other treatment-related factors, the interaction of race and level of comorbidity was significant in scales measuring physical functioning ($P = 0.02$), role-physical ($P = 0.02$), general health ($P = 0.002$), and social functioning ($P = 0.047$). Second, no consistent interactions across HRQOL domains were found between race and gender, duration of dialysis, diabetes, work status, or number of hospitalizations. Third, because of the ethnic heterogeneity of the non-African American group, we repeated our analyses using only non-Hispanic African Americans and non-Hispanic whites. The results from these analyses did not materially differ from our original findings. Some small differences were presumably related to a loss of power resulting from exclusion of a number of subjects from the non-African American group. However, our interpretation of the data was unchanged, and we have chosen to present the more inclusive racial groupings because of our limited sample size.

DISCUSSION

It is well known that African Americans who have suffered chronic kidney failure survive longer than non-African Americans [41]. Unfortunately, there has been little exploration of possible racial differences in patient experience, either in chronic kidney disease or in other common disease states. The data reported here add two important details to our understanding of race and kidney failure. First, African Americans' general psychologic well being appears to be more preserved on chronic hemodialysis treatment than non-African Americans', and African Americans appear to experience kidney failure as relatively less of a burden than do non-African Americans. However, African Americans reported slightly more cognitive problems. Second, African Americans seem to be less vulnerable to deterioration in the quality of life as comorbidity worsens.

The finding that African Americans have significantly better psychologic well being and that they experience kidney disease as a smaller burden extends findings from previous studies of race and HRQOL. These findings are supported by a study using a two-item measure of overall life satisfaction, adjusted for social support, which found that African Americans with kidney failure reported greater overall life satisfaction than non-African Americans. That study, however, did not adjust

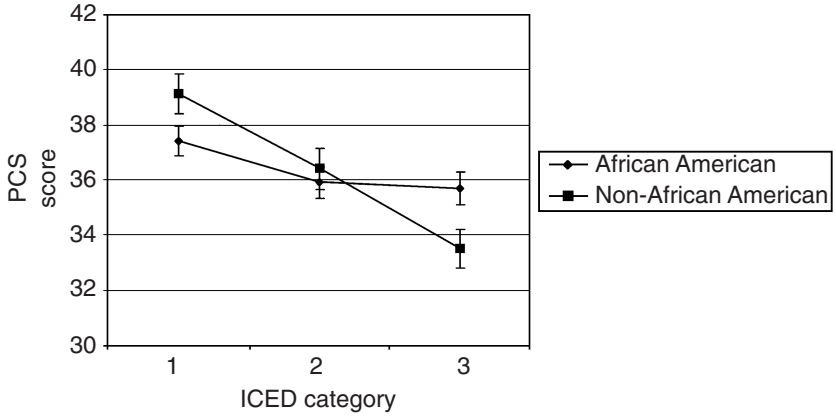

Fig. 1. Physical Composite Score (PCS) among African American and non-African Americans by level of comorbidity. Adjusted PCS mean scores for African Americans and non-African Americans by level of comorbidity. African Americans' PCS scores declined less than non-African Americans' scores, with increasing levels of comorbidity ($P = 0.003$). There were no substantial differences in PCS scores in the mild to moderate levels of comorbidity. At the highest comorbidity level, the African American mean adjusted PCS score is 2.2 points higher than non-African American.

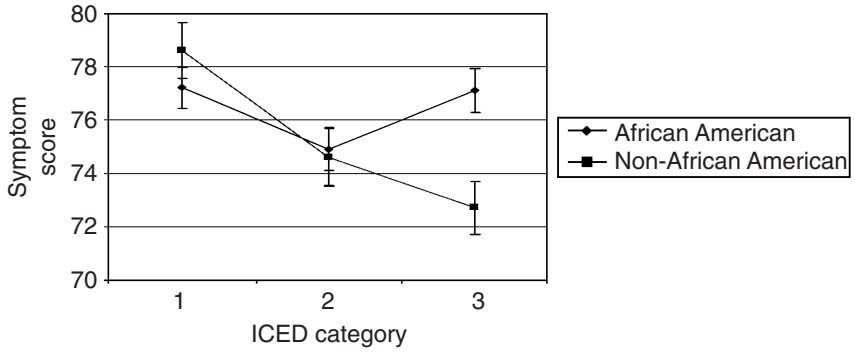

Fig. 2. Symptoms of kidney disease among African American and non-African Americans by level of comorbidity. Adjusted symptoms scores were significantly different for African Americans and non-African Americans by level of comorbidity ($P = 0.0015$). There were no substantial differences in Symptom scores in the mild to moderate levels of comorbidity. However, African Americans in the third ICED group were 4.4 points higher.

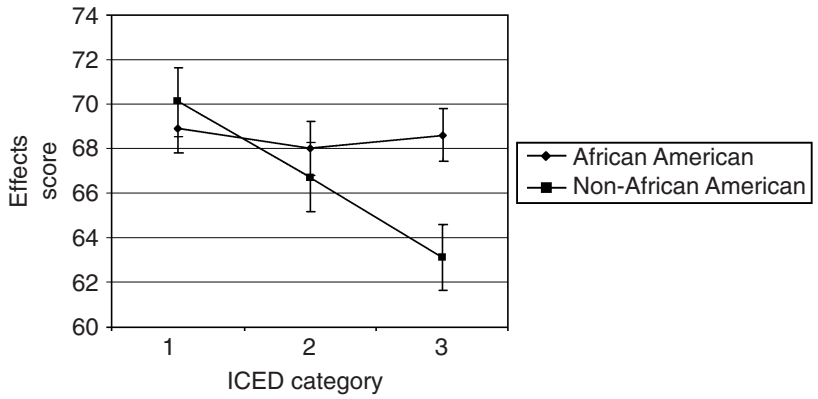

Fig. 3. Effects of kidney disease among African American and non-African Americans by level of comorbidity. Adjusted mean Effects scores for African Americans and non-African Americans by level of comorbidity. As comorbidity level increases, non-African Americans' kidney disease effect scores worsen significantly ($P = 0.02$) compared to African Americans. There were no substantial differences in Effects scores in the mild to moderate levels of comorbidity. At the highest level of comorbidity, African Americans' Effects scores were 5.5 points higher than non-African Americans.

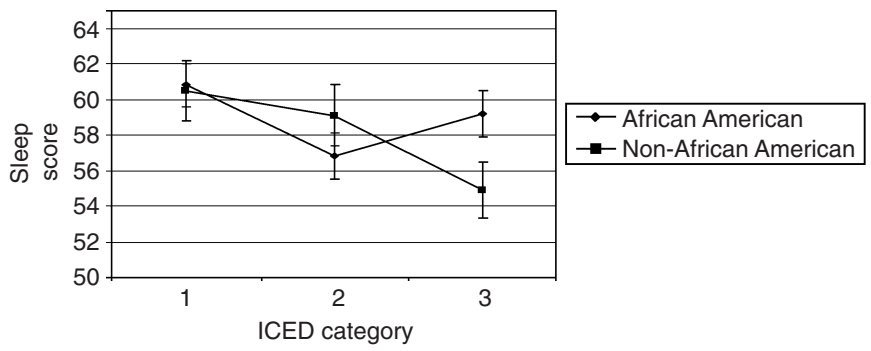

Fig. 4. Sleep quality among African American and non-African Americans by level of comorbidity. Adjusted mean Sleep scores for African Americans and non-African Americans by level of comorbidity. For individuals with no to mild comorbidity, there are no differences in sleep quality between African Americans and non-African Americans. For those with intermediate severity of comorbidity, African Americans report lower sleep quality (2.3 points lower than non-African Americans), but this relationship reverses itself in those with the highest grade of comorbidity, where sleep is less disturbed in African Americans as compared with non-African Americans (4.3 points higher in African Americans vs. non-African Americans).

extensively for socioeconomic variables or comorbidity [14]. The Dialysis Outcomes and Practice Patterns (DOPPS) Study has reported black participants to have a 1.3-point higher PCS and 1.1-point higher MCS than whites [11], which were larger differences than we found among our study population in the fully adjusted model. Although the DOPPS analyses adjust for the presence of a wide range of comorbidities, data characterizing severity of disease were limited in this study [42]. Because disease severity varied across racial groups, inadequate adjustment for comorbidity could affect the estimate of the association between race and HRQOL, and explain the differences between DOPPS and our fully adjusted estimates for PCS and MCS. Our findings that mean MCS scores did not vary significantly by race may be partly explained by the circumstance that our population of hemodialysis patients' MCS scores was nearly the same as those of the general population. Our finding that African Americans reported a slightly lower cognitive function score was not observed in the DOPPS results; we have no explanation for this discrepancy except that the HEMO Study used the KDQOL-LF and surveyed a different patient population. The KDQOL-LF has more items assessing cognitive problems, and therefore may be slightly more sensitive to differences than the KDQOL-SF cognitive scale. Of the items measuring cognition measured by the HEMO Study in the KDQOL-LF but not found in the KDQOL-SF used by DOPPS, African Americans reported significantly more problems with forgetting things ($\chi^2 = 30.2, P < 0.0001$) compared to non-African Americans. We speculate that this lower score in cognitive function may represent unobserved differences in education, and the social and cultural influences on perception of cognitive abilities.

Other authors who have observed racial differences in HRQOL have speculated that differences in nutrition might play a role [43, 44]. However, in adjusting for serum albumin, creatinine, and enPCR, our analysis accounted for much of the impact of nutrition [45]. Some authors have suggested that racial differences in HRQOL may reflect differences in social support [46]. In the present cohort, however, no significant racial differences were reported in social support. One can speculate that increased knowledge of the impact of dialysis on daily life may play a role in observed HRQOL differences of African Americans compared to non-African Americans. The strong familial clustering of ESRD found in African Americans with non-insulin dependent diabetes mellitus [47] may mean that some of these patients have family with ESRD, and are thus familiar with dialysis treatment. Experiences within family or community may influence African American patients' expectations. Some models of quality of life [48] suggest that attenuated expectations may cause participants to report relatively better well being and fewer symptoms.

At higher levels of comorbidity, African Americans reported better physical well being and fewer kidney disease symptoms and effects than did non-African Americans. These findings may be related to the improved survival of African Americans on hemodialysis, and to the lower likelihood of African Americans' withdrawal from dialysis therapy. This finding was previously suggested by an apparently paradoxical relationship observed in an African American hemodialysis cohort: as severity of illness increased and objective function decreased, global satisfaction with life increased [12]. It is possible that some of these perceived differences in HRQOL for the sickest patients may be caused by racial differences in religiosity [49]. Greater religiosity may lead very ill patients to report fewer physical symptoms [50, 51]. A study in a largely African American hemodialysis population showed that increased spirituality was significantly associated with better quality of life [52]. In addition, an assessment bias may account for these differences, because an ethnic minority may be more skeptical of a research study and health care and may withhold more when reporting symptoms. However, in at least one study, lack of trust could not be shown to predict terminally ill African Americans' reluctance to forgo life-sustaining treatments [53]. Furthermore, the participants in the HEMO Study trusted their health care providers enough to enroll in a randomized trial, perhaps limiting the sample of those inclined to change their self-report because of mistrust.

The finding that those African Americans who are at the highest level of comorbidity report better HRQOL contrasts with studies of racial differences in HRQOL in the general population and in other chronic disease states, but is consistent with previous work on racial differences in patient utilities [54]. For example, in the general population, the National Center for Health Statistics reported that non-Hispanic African Americans are less likely to rate their health status as very good or excellent, when compared with non-Hispanic whites (58.2% for African American non-Hispanic persons, and 70.3% for white non-Hispanic persons). Previous studies in other chronic illnesses have found that whites report better HRQOL than African Americans [55, 56]. In a comparison of African American and white older male patients with arthritis, African American ethnicity was negatively associated with overall quality of life rating, after adjustment for demographics, comorbidity, and psychologic parameters [56]. Patients' utilities, which measure preferences regarding states of health, are distinct from individuals' reports of their experience, as measured by questionnaires assessing HRQOL. African Americans have been found to assign higher levels of utility to relatively low levels of functioning than whites [54]. Common underlying attitudes, perhaps related to expectations, may influence both these utilities and the report of relatively

preserved quality of life in the face of severe comorbid disease.

These results have important implications for health care utilization and medical decision making. In previous studies, higher HRQOL has been associated with longer survival [41]. Although no cause-and-effect relationship has been established, it is possible that the better HRQOL of African Americans contributes to their improved survival. It is also possible that racial differences in quality of life are related to racial differences in the rates of voluntary dialysis discontinuation. It may also be that better HRQOL on hemodialysis affects the choice of renal replacement therapy and leads African Americans to delay listing for transplantation. Few studies have examined the relationship of quality of life to health care utilization, although data from studies in the general population have shown a strong relationship between HRQOL and clinic visits and hospitalization [57]. Furthermore, the finding that HRQOL consistently decreased with increasing comorbidity emphasizes the importance of targeting interventions to patients with the highest comorbidity burden. Our results identify those with the highest comorbidity as those with the most need for interventions to improve HRQOL. Efforts to target these high-risk individuals, through delivery of more intensive health care services, may improve the physical functioning and well being of these patients, in addition to prolonging survival. However, the amount of variability in HRQOL explained by demographic and laboratory variables remains rather small, even when including the level of comorbidity. This means that health care providers need to make an effort to assess HRQOL by self-report rather than by inference from laboratory data and severity of comorbid illness.

The HEMO Study design overcame many of the limitations of earlier reports regarding race and quality of life: the study population was a large, multicenter hemodialysis cohort, and the HRQOL instrument captured a multidimensional concept of health. The analysis incorporated extensive adjustment for demographic and socioeconomic factors, as well as a validated index of comorbidity. In addition, the HEMO Study employed the standard technique for classification of race by using patient self-identification of race and ethnicity. The study recapitulated the findings of other reports on HRQOL in the hemodialysis population: patients reported very impaired physical well being, but mental aspects of health were less affected [23, 24, 28].

Several limitations of this study should be considered when interpreting our findings. First, this is a cross-sectional analysis and suffers from the general limitation of these analyses, such as a selection or survivorship bias. However, the use of a comorbidity index and adjustment for observed differences in covariates should limit the impact of these biases. Second, our understanding of differences in HRQOL by race is limited by the lack of variables related to patients' culture, life experience, and attitudes about health, functioning, and expectations about functioning. Further prospective data collection is needed to understand the relationship of these factors to our findings, and may lead to further understanding of racial differences in HRQOL. Future studies of racial differences in HRQOL should consider using instruments such as the McGill Quality of Life questionnaire [58], or the Missoula-Vitas instruments [59], both of which include spiritual/existential aspects in their assessment of quality of life. Indeed, spirituality may play an additional role beyond the dimensions measured by these instruments, requiring new instrument development.

CONCLUSION

Improving the health-related quality of life of hemodialysis patients is an important goal of hemodialysis treatment. To our knowledge, chronic kidney failure is the only chronic illness in which African Americans report significantly better HRQOL than non-African Americans. The persistent association of African American race with better physical functioning and fewer dialysis-related symptoms and effects suggests either that there are unmeasured differences between patients, or that the race of the respondent influences perceived functioning and well being at the highest level of comorbidity. Future investigation should examine social, cultural, and spiritual influences on the HRQOL of persons undergoing hemodialysis. Clarification of the reasons for racial differences may suggest measures to improve the quality of life for all patients receiving dialysis treatment for chronic kidney failure.

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