ESRD Patient Quality of Life: Symptoms, Spiritual Beliefs, Psychosocial Factors, and Ethnicity

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• ***Background:*** **Recent research suggests that patients' perceptions may be more important than objective clinical assessments in determining quality of life (QOL) for patients with end-stage renal disease (ESRD).** ***Methods:*** **We interviewed 165 hemodialysis patients from 3 sites using a QOL questionnaire that included the Satisfaction With Life Scale (SWLS) and the McGill QOL (MQOL) scale, which includes a single-item global measure of QOL (Single-Item QOL Scale [SIS]). The MQOL scale asks patients to report their most troublesome symptoms. We also initiated the use of a Support Network Scale and a Spiritual Beliefs Scale.** ***Results:*** **Mean patient age was 60.9 years, 52% were men, 63% were white, and 33% were African American. Patients had a mean treatment time for ESRD of 44 months, mean hemoglobin level of 11.8 g/dL (118 g/L), mean albumin level of 3.7 g/dL (37 g/L), and mean Kt/V of 1.6. Forty-five percent of patients reported symptoms. Pain was the most common symptom (21% of patients). There was an inverse relationship between reported number of symptoms and SWLS ($P < 0.01$), MQOL scale score ($P < 0.001$), and SIS ($P < 0.001$). The Spiritual Beliefs Scale correlated with the MQOL scale score, SWLS (both $P < 0.01$), and SIS ($P < 0.05$). The Support Network Scale score correlated with the MQOL Existential ($P = 0.01$) and MQOL Support ($P < 0.01$) subscales. No clinical parameter correlated with any measure of QOL, spiritual beliefs, or social support.** ***Conclusion:*** **Symptoms, especially pain, along with psychosocial and spiritual factors, are important determinants of QOL of patients with ESRD. Additional studies, particularly a longitudinal trial, are needed to determine the reproducibility and utility of these QOL measures in assessing patient long-term outcome and their association with other QOL indices in larger and more diverse patient populations.** ***Am J Kidney Dis*** **42:713-721.**

INDEX WORDS: Hemodialysis (HD); hemoglobin; albumin; gender; religious involvement; spirituality; racial disparity; quality of life (QOL); symptoms; pain.

THE MOST WIDELY used quality of life (QOL) instruments in dialysis units, the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)[1] and the Kidney Disease QOL questionnaire,[2] do not directly assess patient self-report of troublesome symptoms or patient perception of overall QOL.[3] The SF-36 also does not measure general life satisfaction, social support, and spiritual beliefs, domains found to be important to other groups of patients with chronic medical illnesses.[3-6] Recent research suggests that patient perception may be more important than objective assessments in determining the QOL of patients with end-stage renal disease (ESRD).[3-7] For example, in considering factors important for QOL at the end of life, physicians tend to focus on physical aspects of care, whereas patients with ESRD and other patients place more importance on psychosocial and spiritual factors.[8]

In the Choices for Healthy Outcomes in Caring for ESRD formal literature review of QOL research in ESRD, only 19% of instruments included a patient self-report of QOL, only 13% queried symptoms, and only 8% inquired about pain.[9] Recently, interest has focused on using QOL instruments that assess patient perceptions of QOL by using that term graded by a single Likert-like scale.[3,6,10,11] In previous work using a subset of this sample,[6] we assessed single-item QOL scores and spirituality parameters, but data were gathered in an almost exclusively African-American population.[6] The purpose of this study is to determine relationships between symptoms and other factors that patients report are most important to them in determining their QOL, including measures of religious experience and social support, in a diverse patient population.

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METHODS

Patient Population and Demographics of the Study Hemodialysis Units

Sites for data collection were BMA-Westover, Morgantown, West Virginia (WV); the Gambro–George Washington University Medical Center (GWUMC) N Street Dialysis Unit, Washington DC; and the Dialysis Center, Winthrop University Hospital, Mineola, NY (WUH). Patient populations at WV and WUH were composed primarily of white patients, and at GWUMC, of African-American patients. Planned recruitment was a minimum of 50 patients from each site.

Recruitment Techniques

All patients enrolled in long-term ESRD hemodialysis programs at the 3 units were eligible. Patients were excluded from the study if they lacked decision-making capacity, could not speak English, or were too sick to participate. Patient recruitment began May 2001 and concluded December 2001. Each patient was invited to participate in the study by a nephrologist, nurse, or trained research assistant. All participating patients gave their informed consent. The study was approved by the Institutional Review Board for the Protection of Human Subjects of West Virginia University, the GWUMC Committee on Human Research, and the Institutional Review Board of Winthrop University. After obtaining informed consent, research assistants interviewed patients during the first 2 hours of dialysis treatment. Patients were not interviewed during their first dialysis session of the week.

Data Collection

Study investigators at each site trained the research assistants to follow the identical standardized protocol for data collection. Interviews were conducted on patients' second or third dialysis treatments of the week to avoid reports of symptoms caused by the longer interval preceding the first dialysis treatment of the week. Research assistants administered all questionnaires verbally to patients by using an interview format. Laboratory measures were collected from patients' charts at the time of the interview. Demographic data were collected for all patients who entered the study.

Demographic Information and Clinical and Nutritional Parameters

Age, sex, race, cause of ESRD, and duration of therapy for ESRD were noted. Kt/V was calculated using percentage of urea reduction, as previously described.[6] Monthly Kt/V and predialytic hemoglobin and serum albumin concentrations before enrollment were collected for the 3 months before enrollment. The mean of each variable was calculated for the analyses.

Functional Status Parameter

The Karnofsky Performance Status Scale was used to determine patient level of functional ability to perform activities of daily life.[3,6] The scale ranges from 0 to 100, with 0 indicating death and 100 indicating full capacity to carry out normal activity. In general, a score less than 70 represents an individual who requires additional assistance, and a score less than 50 represents need for hospitalization, nursing home care, or institutionalization. Karnofsky score was determined by dialysis nurses familiar with the patients.

QOL Measures

The Satisfaction With Life Scale (SWLS) is a 5-item scale with a satisfaction rating of 1 to 7 (low to high) for each item.[3,4,12] Items ask about ideal life, conditions of life, and satisfaction with present and past life. Diener et al[12] reported good internal reliability, 2-month test-retest reliability, and moderate correlations of this measure with a large number of subjective well-being scales in testing with college student and geriatric subjects. The SWLS has been used previously in patients with ESRD[3,4,6,13] and is used in our study as a general global subjective measure of QOL.

We used the McGill QOL (MQOL) questionnaire[6,14] to assess perception of QOL of patients with ESRD. The MQOL questionnaire had not been used previously in patients with ESRD, but its validity and reliability have been established in patients with other chronic diseases.[14,15] The questionnaire consists of 16 items in 4 subscales (Physical, Psychological, Existential, and Support), each with scores ranging from 0 to 10. It is designed for use in chronically and terminally ill patients. Scoring on the Physical and Psychological subscales was reversed so that a higher score represents better QOL. The maximum possible total score is 160. The 4 subscale scores were calculated for each patient, as was a total scale score. The MQOL questionnaire also contains a single item that directly asks patients their overall assessment of their QOL. We termed this item the Single-Item QOL Scale (SIS).[3,6,10,11] SIS scores range from 0 for "very bad" to 10 for "excellent."

Patient Perception of Satisfaction and Support and Spiritual Beliefs

We measured patient perceptions of satisfaction with care from dialysis staff and nephrologists separately and as a total score. Two questions taken directly from the DiMatteo and Hays[16] scale of patient satisfaction with care from their doctors and 2 questions modified only by inserting "dialysis staff" rather than "doctor" inquired about patient satisfaction with the compassion and respect shown to them.[17] We previously reported the use of items from the DiMatteo and Hays Patient Satisfaction Questionnaire and such modifications in patients with ESRD treated with hemodialysis.[3,6,17]

Patients were asked to respond to 12 questions regarding the meaning and value of spiritual beliefs and level of support and comfort in talking about their illness to family or friends; other patients; a social worker or therapist; a priest, rabbi, or other religious counselor; or their physician. To assess perception of social support, we created a Support Network Scale composed of 8 items. A Spiritual Beliefs Scale contained 4 items regarding the perceived role of faith and attendance at religious services in adjusting to chronic illness. Examples of such questions regarding spiritual beliefs have been outlined previously.[6] Standard methods of data reduction were used to determine the final scale items of the Spiritual Beliefs and Support Network Scales, including

factor analyses, internal consistency, and reliability analyses. Cronbach's alpha and Spearman-Brown coefficient were used to test the internal consistency of the final scale items and reliability of the item set, respectively. The principal components analysis generated 2 factors that accounted for 64% of the variance. The Kaiser-Meyer-Olin statistic used to test sampling adequacy was 0.77, and the Bartlett test of sphericity was significant ($P < 0.0001$), suggesting an adequate factor model for the Spiritual Beliefs and Support Network Scales. Based on the principal components analysis, the Support Network Scale was reduced from 8 to 5 items. The final standardized Cronbach's alpha used for measuring the reliability of the scale was 0.84. In addition, split-half reliability analysis yielded a Spearman-Brown coefficient of 0.89, indicating strong correlation between each half of the variable set. Scores on each of the scales then were generated for each patient by using factor score coefficients. Resulting subscales were correlated with the other validated QOL measures, clinical parameters (Kt/V, hemoglobin level, and serum albumin level), and patient satisfaction scales to determine associations among scales and subscales.

Statistical Analysis

A combination of bivariate and multivariate analyses were used to assess correlations between variables of interest and determine the independent effect of demographic and other variables on QOL scores. Specifically, unpaired *t*-tests and chi-square analyses were used to calculate differences between mean values and proportions of groups. Pearson's correlation coefficients were calculated to assess correlations between variables of interest. Independent sample *t*-tests, 1-way analysis of variance with a posteriori contrast tests, and chi-square tests were used as appropriate, using 2-sided significance levels. Linear regression analysis was conducted to determine the independent effect of demographic and ethnic variables on QOL scores. In all regression analyses, predictors consisted of sex, age, race, number of months treated for ESRD, Karnofsky score, hemoglobin and serum albumin levels, and Kt/V. *P* less than 0.05 was used to determine statistical significance. Data are reported as mean ± SD.

Using data from a previous study of QOL in patients with ESRD treated with hemodialysis,[4,13] it was determined that a sample size of 146 would be needed to detect a statistically significant difference in means of 4 points on the SWLS, assuming power equal to 0.80 and an alpha equal to 0.05 with a 2-sided test of means. In a subsequent post hoc power analysis, it was determined that for the Spiritual Beliefs Scale, sample sizes of 49 in each group would have been sufficient to achieve at least 80% power to detect the 6-point difference in scores between African Americans and non–African Americans. Our study sample included 54 subjects and 110 subjects in these 2 groups, respectively.

RESULTS

Demographic and Clinical Results

One hundred sixty-five of 190 consecutive patients were interviewed, yielding a response rate of 86.8%. Nineteen patients refused, and 6 patients were too sick to participate. Approximately one third of patients were recruited from each study site. The demographics of the study sample are listed in Table 1. The distribution of sex and ethnicity in the study population is similar to that of the US hemodialysis population. Interviews took a mean of 17.6 minutes (range, 5 to 60 minutes).

There were no differences between means or distributions between African-American and non–African-American patients with respect to sex, time since starting renal replacement therapy, Karnofsky score, or hemoglobin level. African-American patients were younger (52.6 ± 12.5 versus 65.2 ± 14.9 years; $P < 0.001$), had treatments with lower Kt/V indices (1.45 ± 0.27 versus 1.63 ± 0.31; $P < 0.001$), and had greater serum albumin levels (3.78 ± 0.42 versus 3.59 ± 0.40 g/dL [37.8 ± 4.2 versus 35.9 ± 4.0 g/L]; $P < 0.007$) compared with non–African-American patients.

As expected, there was a greater proportion of African-American patients at the GWUMC site. Patients at the GWUMC site were younger than patients at other sites and more likely to have hypertensive nephrosclerosis. Patients at WUH were less likely to have diabetes mellitus and had the lowest mean serum albumin level and highest mean Kt/V. Patients at WV had the highest mean Karnofsky score. There were no differences between sites in man-woman ratios, duration of ESRD therapy, or mean hemoglobin levels (data not shown).

QOL

Results of QOL measures for the entire population and each dialysis unit are listed in Table 2. Patient mean overall assessment of QOL on the SIS was 6.8 ± 2.2. Twenty-nine percent rated their overall QOL as 5 or less (Fig 1). Mean SWLS was 23.1 ± 8.6 (range, 5 to 35), similar to that found in earlier studies.[4,13] Seventy-four patients (45%) reported 1 or more troublesome symptoms during the 2 days before the interview (Fig 2). Pain was reported by almost half the patients reporting symptoms, followed by sleep complaints in almost a third of respondents (Figs 2 and 3).

Sex Differences

There was no difference in mean age, time since starting renal replacement therapy, Kt/V, or

Table 1. Patient Demographic, Psychosocial, and Clinical Characteristics

		Dialysis Units			
	Total	WV	WUH	GW	*P*
No. of subjects	165	55	60	50	NS
Mean age (y)	60.9	67.6	60.2	54.3	<0.001
Ethnicity (%)					<0.001
African-American	33.3	10.9	11.9	82	
White	63	89.1	84.7	10	
Asian	1.2	0	0	4	
Other	2.5	0	3.4	4	
Women (%)	48	49	50	44	NS
Primary renal diagnosis (%)					<0.01
Diabetes mellitus	33.3	42.6	23.3	36	
Hypertensive nephropathy	28.5	20.4	28.3	38	
Glomerulonephritis	9.1	14.8	6.7	6	
Polycystic kidney disease	8.5	1.9	20	2	
Other and unknown	20.6	20.3	21.7	18	
Clinical characteristics					
Duration of ESRD (mo)			43.5 ± 45.3 (2-276)		
Serum albumin (g/dL)			3.7 ± 0.42 (2.2-4.6)		
Hemoglobin (g/dL)			11.8 ± 0.98 (7.7-15.3)		
Kt/V			1.57 ± 0.31 (0.85-2.7)		
Karnofsky Performance Status Scale			60.0 ± 24.5 (10-100)		

NOTE. Values expressed as number, percent, or mean ± SD (range). To convert hemoglobin or albumin in g/dL to g/L, multiply by 10.

Abbreviations: NS, not significant.

Karnofsky score between male and female patients. Thirty-four percent of men and 32 percent of women were African American (*P* = not significant). Women were older than men in the study (63.9 ± 14.0 versus 58.0 ± 16.5 years; *P* = 0.02) and had lower levels of serum albumin (3.55 ± 0.43 versus 3.76 ± 0.38 g/dL [35.5 ± 4.3 versus 37.6 ± 3.8 g/L]; *P* = 0.01) and hemoglobin (11.7 ± 0.96 versus 12.0 ± 0.98 g/dL [117 ± 9.6 versus 120 ± 9.8 g/L]; *P* <

Table 2. Mean Scores on QOL Measures by Dialysis Unit

Variable	Total (N = 165)	WV (n = 55)	WUH (n = 60)	GW (n = 50)	*P**
MQOL questionnaire					
Physical subscale	32.5 ± 7.3	31.0 ± 7.6	35.3 ± 5.2	30.8 ± 8.4	0.001
Psychological subscale	31.5 ± 9.8	35.5 ± 7.4	31.0 ± 8.6	28.7 ± 11.9	<0.01
Existential subscale	45.6 ± 12.3	43.2 ± 13.9	47.3 ± 8.7	45.6 ± 14.3	0.24
Support subscale	16.3 ± 3.8	16.7 ± 1.9	16.5 ± 3.3	15.8 ± 5.4	0.47
Total score MQOL	125.7 ± 26.4	124.0 ± 24.2	131.2 ± 19.1	120.3 ± 33.6	0.10
MQOL SIS	6.8 ± 2.2	6.7 ± 2.1	6.9 ± 2.2	6.9 ± 2.5	0.86
Spiritual Beliefs and Support Network Scales					
Spiritual Beliefs Scale	29.3 ± 12.4	26.5 ± 13.9	29.3 ± 12.0	32.1 ± 10.7	0.08
Support Network Scale	20.8 ± 12.6	17.8 ± 8.8	21.6 ± 12.7	22.8 ± 15.1	0.12
Total score	50.2 ± 21.0	44.2 ± 20.5	50.9 ± 20.8	55.1 ± 20.7	0.04
Total score SWLS	23.1 ± 8.6	24.8 ± 9.7	21.8 ± 6.7	23.0 ± 9.1	0.17
Modified DiMatteo & Hays Patient Satisfaction Score†	8.7 ± 1.8	8.3 ± 2.3	9.2 ± 1.5	8.6 ± 1.6	0.03

NOTE. Values expressed as mean ± SD.

*Two-tailed significance level.

†Total score of care and respect from doctor and dialysis staff.

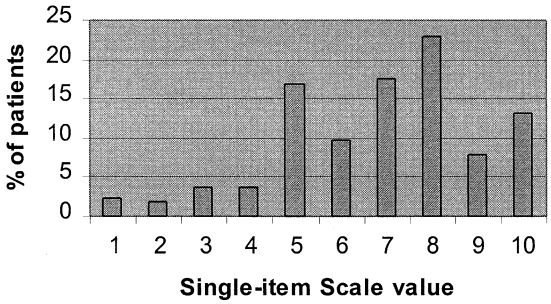

Fig 1. Patient rating of overall QOL on the SIS.

0.05). There was no difference between the proportion of men and women who reported 1 or more troubling symptoms or who reported pain as a symptom. There were no differences between mean scores of women and men on the Physical, Psychological, or Existential subscales of the MQOL Scale. Mean Support subscale score of the MQOL was 17.2 ± 2.6 in women and 15.6 ± 4.5 in men ($P = 0.01$), signifying greater perception of social support in women. Mean Spiritual Beliefs Scale score was 32.8 ± 9.8 in women and 26.1 ± 13.5 in men ($P < 0.001$). There was no difference between groups in mean MQOL score, SIS, or SWLS. There was no difference between men and women regarding perception of patient satisfaction.

Ethnic Differences

There was no difference between mean Karnofsky scores of African-American and non–African-American patients. There was no difference between the proportion of African-American and non–African-American patients reporting 1 or more symptoms (46.3% versus 45.5%) or pain as their most troubling symptom (7.4% versus 10.0%). There were no differences between mean scores of African-American and non–African-American patients on the Physical, Existential, or Support subscales of the MQOL. Mean Psychological subscale score was 28.7 ± 12.0 in African-American and 32.9 ± 8.3 in non–African-American patients ($P = 0.03$), signifying a greater perception of distressing psychological symptoms in African-American patients. There was no difference between groups in mean MQOL, SIS, or SWLS scores. There was no difference between groups regarding patient satisfaction measured by the Patient Satisfaction Questionnaire questions.

African-American patients had higher mean Support Network Scale scores (24.1 ± 14.3 versus 19.3 ± 11.3; $P = 0.04$) and Spiritual Belief Scale scores (33.6 ± 9.2 versus 27.0 ± 13.3; $P < 0.001$) than non–African-American patients.

Correlational Analyses

There was an inverse relationship between number of symptoms reported and patient assessment of QOL and satisfaction with life, such that the greater the number of symptoms reported, the lower the QOL and satisfaction with life (Fig 4). Patients with 2 or more symptoms had significantly lower MQOL, SWLS, and SIS scores than patients with fewer than 2 symptoms. There was no correlation between level of patient Spiritual Beliefs Scale and Support Network Scale scores and symptom number. Responses on the Spiritual Beliefs Scale correlated positively with MQOL scale score ($r = 0.24$; $P = 0.005$), SIS score ($r = 0.18$; $P < 0.05$), Support Network Scale ($r = 0.21$; $P = 0.007$), and SWLS ($r =$

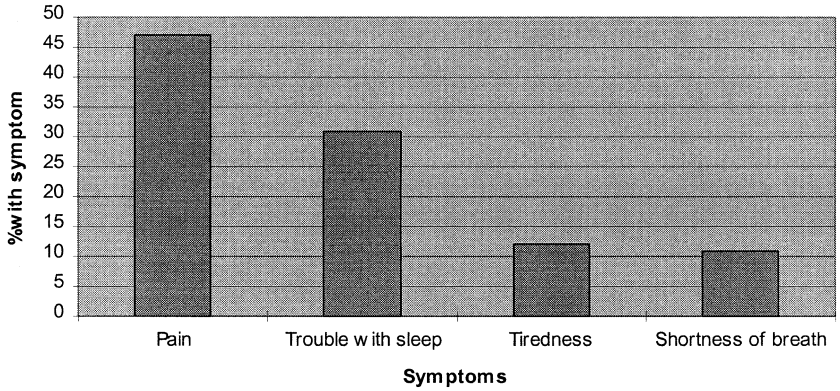

Fig 2. Most common symptoms reported by symptomatic patients.

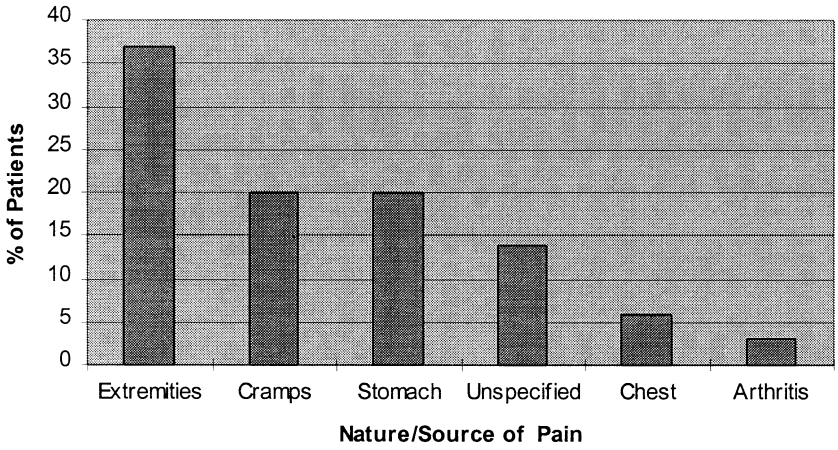

Fig 3. Source of pain in patients reporting pain.

0.20; $P = 0.01$). Responses on the Support Network Scale correlated positively with those on the MQOL Existential ($r = 0.20$; $P = 0.015$) and Support subscales ($r = 0.27$; $P = 0.001$), but not the SWLS or SIS. Demographic and clinical parameters (age, months of ESRD treatment, serum albumin level, hemoglobin level, and Kt/V) did not correlate with the MQOL, SIS, Spiritual Beliefs Scale, or Support Network Scale.

There was no correlation between the SIS and either Spiritual Beliefs Scale or Support Network Scale scores in men. Conversely, SIS score correlated highly with Spiritual Beliefs Scale score ($r = 0.31$; $P < 0.007$) in women. In non–African-American patients, there was no correlation between the SIS and either Spiritual Beliefs Scale or Support Network Scale score. Conversely, SIS scores correlated highly with Spiritual Beliefs Scale score ($r = 0.42$; $P < 0.01$) in African-American patients.

Multiple linear regression analyses showed that lower levels of distress on the McGill Psychological subscale were associated significantly with lower number of symptoms and greater serum albumin level when the effect of variation in other parameters was controlled. Higher scores on the Spiritual Beliefs Subscale were associated significantly with female sex, older age, and African-American ethnicity. There were no significant predictors of Support Network Subscale Scores in multivariate analyses.

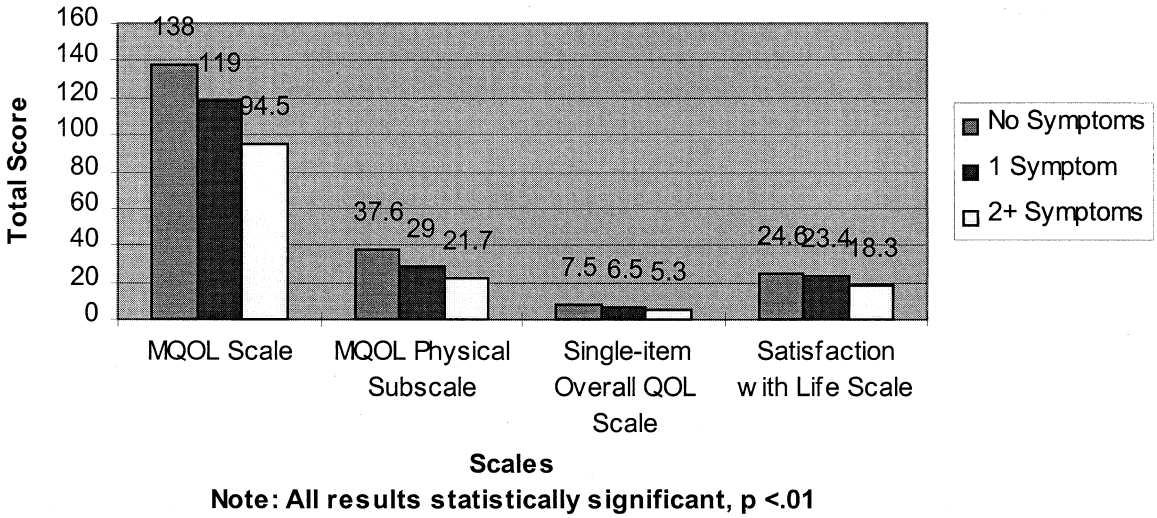

Fig 4. Association between symptoms and QOL measures.

DISCUSSION

More than a quarter of patients surveyed rated their QOL below the scale midpoint on the SIS. We know of few studies that used a similar assessment in patients with ESRD. Steele et al[18] used a 1-sentence scale (scored from 1 to 10) in patients treated with peritoneal dialysis and showed correlations with other QOL measures, as we did in the present study. Preliminary studies from the same group, using their 1-sentence scale, yielded a mean score of 6.4 in 12 hemodialysis patients, similar to the value obtained in our study.[19] Symptoms were associated strongly with scores on the various QOL scales in our study. Pain was the most commonly reported symptom. Spiritual beliefs and perception of support networks assessed by the new instruments also were associated significantly with patient assessments of their QOL in various domains. However, clinical parameters and the Karnofsky Performance Status Scale did not correlate with measures of QOL, illustrating the different nature of these domains, as seen in previous studies.[3,4,18] The implication of these findings is that if nephrologists want to provide comprehensive care and improve hemodialysis patients' QOL, they need to pay more attention to their patients' physical symptoms and psychosocial and spiritual concerns.

The role of pain in the perception of patients treated with hemodialysis appears to have been underappreciated. Binik et al[20] reported almost 20 years ago that pain was a salient experience of patients treated with dialysis. Recently, preliminary data from the Reduction of Morbidity and Mortality among Hemodialysis Patients study also highlight the importance of perception of pain in longitudinal studies of hemodialysis patients.[21] Because pain was the most frequently reported symptom in this study, better pain management for hemodialysis patients appears to be a priority to improve patient QOL. Assessment and improved management of patient symptoms, including pain, and use of well-validated QOL scales (including those introduced in this study) seem to be important in the evaluation of QOL of dialysis patients.

Sleep disturbances have been long recognized as complications of uremia.[22,23] Several studies linked sleep complaints with diminished QOL in patients with renal disease.[24-26] In this study, we confirm a relationship between complaints of sleep disturbance and diminished QOL, assessed using different measures.

QOL measures can be categorized as functional and satisfaction measures.[3,4,27] The lack of a significant association between various clinical parameters and measures of QOL used in this study underscores the relative importance from a patient perspective of pain, symptoms, and psychosocial and spiritual domains, all nonfunctional measures, to their assessment of QOL. We previously showed that satisfaction measures, in contrast to functional measures of QOL, do not correlate with Karnofsky scores,[4] emphasizing that they represent different domains. Scales used in this study have different relationships to patient parameters than the commonly used SF-36 and Kidney Disease QOL, which may be weighted more toward functional status and therefore be related to meaningful patient outcomes in different ways. Parameters related to spirituality and religiosity were related to QOL measures used in our study, including the SWLS and SIS, suggesting that these domains are meaningfully associated with patient perception of QOL. In addition, correlation between symptom number and SIS score suggest this may be a useful, practical, and comprehensible measure to quickly assess QOL in patients in research studies and clinical settings, as predicted by Gill and Feinstein[10] and Lara-Munoz and Feinstein.[11] Although more research is needed to further validate the Spiritual Beliefs and Support Network Scales, when administered in conjunction with other QOL scales, they appear to provide a more comprehensive assessment of patient psychosocial and spiritual needs.

There were few differences in perception of QOL domains between the men and women in the study. Women, as expected, had a greater perception of social support and higher Spiritual Beliefs Scale scores. We show that African-American patients perceive greater satisfaction with their care in the dialysis unit and have greater levels of perceived social support than white patients. These data confirm the previous findings of Kutner and Devins.[28] However, African-American patients scored lower on the MQOL Psychological subscale, indicating greater levels of distress. A major unsolved issue in

ESRD care is the reason for improved survival of black patients compared with white patients when many biological variables are controlled for analytically.[29] It is intriguing to speculate that the survival advantage may not be biological. Rather, a survival advantage might be a consequence of differential perception of social support, spiritual support, and/or satisfaction with care between the 2 ethnic groups.[13,30-32] Perhaps these factors may be associated with the markedly lower rates of withdrawal from dialysis therapy in blacks compared with whites.[29,32,33]

Our data also are interesting in light of the recent findings of Cooper-Patrick et al,[34] who described general patient mistrust of physicians of different ethnicity. In the present relatively small sample of hemodialysis patients, it appears that minority patients are satisfied with the care they receive from their nephrologists. This is an important issue because of the overrepresentation of minority populations in the ESRD population and the underrepresentation of minority physicians in the US workforce. Any relationship of increased importance of spiritual beliefs and satisfaction with nephrologists to enhanced survival in black patients should be explored in larger and more diverse longitudinal studies. In addition, investigators need to determine whether difference in psychological distress between ethnic groups is a generalized phenomenon, and if so, what the relationship of these differences is to clinical parameters.

This study has several limitations. The sample was relatively small and confined to 3 dialysis units in the eastern United States. Although the population reflects that reported in the US Renal Data System and was generated from an inner-city urban site, a small city, and a suburban site, results may not be generalizable to the United States. The MQOL Physical subscale inquired about troublesome symptoms only during the preceding 2 days. This time frame may have resulted in underreporting of symptoms by patients. Results, including analyses of the Support Network Scale and Spiritual Beliefs Scale, should be viewed as preliminary. Although both scales, as expected, correlated with QOL indices in this study, these scales must be validated further in studies of larger and more diverse populations of patients treated with hemodialysis and other renal replacement modalities. In addition, it is recognized that the goal of this study is to collect data that would aid in the development of new hypotheses regarding the adjustment of patients to the rigors of renal replacement therapy and new tools to evaluate patient perceptions.[3] In addition, interrater reliability was not assessed in this study. Finally, because of the demographic composition of the units in the study, it is not possible to delineate differences between ethnic groups that may be caused by site differences. Such analyses await the use of these measures in larger multicenter studies.

A longitudinal study using the multifaceted QOL questionnaire in this study is needed to determine the utility of these QOL measures in assessing patient long-term outcome. Better assessment and treatment of patients' symptoms would seem to have the potential to exert a positive effect on hemodialysis patient perception of QOL.

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REFERENCES

1. Ware JE, Sherbourne CD: The MOS 36-Item Short-Form Health Survey (SF-36). Med Care 30:473-483, 1992

2. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB: Development of the Kidney Disease Quality of Life (KDQOL) instrument. Qual Life Res 3:329-338, 1994

3. Kimmel PL: Just whose quality of life is it anyway? Controversies and consistencies in measurements of quality of life. Kidney Int Suppl 57:S113-S120, 2000

4. Kimmel PL, Peterson RA, Weihs KL, et al: Aspects quality of life in hemodialysis patients. J Am Soc Nephrol 4:1418-1426, 1995

5. Valderrabano F, Jofre R, Lopez-Gomez JM: Quality of life in end-stage renal disease patients. Am J Kidney Dis 38:443-464, 2001

6. Patel SS, Shah VS, Peterson RA, Kimmel PL: Psychosocial variables, quality of life and religious beliefs in ESRD patients treated with hemodialysis. Am J Kidney Dis 40:1013-1022, 2002

7. Cameron JI, Whiteside C, Katz J, Devins GM: Differences in quality of life across renal replacement therapies: A meta-analytic comparison. Am J Kidney Dis 35:629-637, 2000

8. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA: Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 284:2476-2482, 2000

9. Cagney KA, Wu AW, Fink NE, et al: Formal literature

review of quality of life instruments used in end-stage renal disease. Am J Kidney Dis 36:327-336, 2000

10. Gill TM, Feinstein AR: A critical appraisal of quality of life measurements. JAMA 272:619-626, 1994

11. Lara-Munoz C, Feinstein AR: How should quality of life be measured? J Invest Med 33:575-580, 1996

12. Diener E, Emmons RA, Larsen RJ, Griffin S: The Satisfaction With Life Scale. J Pers Assess 49:71-75, 1985

13. Kimmel PL, Peterson RA, Weihs KL, et al: Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. Kidney Int 54:245-254, 1998

14. Cohen SR, Mount BM, Strobel MG, Bui F: The McGill Quality of Life Questionnaire: A quality of life measure appropriate for people with advanced disease. A preliminary study of validity and acceptability. Palliat Med 9:207-219, 1995

15. Cohen SR, Mount BM, Bruera E, Provost M, Rowe J, Tong K: Validity of the McGill Quality of Life Questionnaire in the palliative care setting: A multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 11:3-20, 1997

16. DiMatteo MR, Hays R: The significance of patients' perceptions of physicians' conduct. J Community Health 6:18-34, 1980

17. Kovac J, Patel SS, Peterson RA, Kimmel PL: Patient satisfaction with care and behavioral compliance in patients with end-stage renal disease treated with hemodialysis. Am J Kidney Dis 39:1236-1244, 2002

18. Steele TE, Baltimore D, Finkelstein SH, Juergensen P, Kliger AS, Finkelstein FO: Quality of life in peritoneal dialysis patients. J Nerv Ment Dis 184:268-374, 1996

19. Reynolds JT, Harding P, Wuerth D, Finkelstein S, Simon DB, Finkelstein FO: A one-year prospective study of short daily hemodialysis: Quality of life. J Am Soc Nephrol 13:410A, 2002 (abstr)

20. Binik YM, Baker AG, Kalogeropoulos D, et al: Pain, control over treatment and compliance in dialysis and transplant patients. Kidney Int 21:840-848, 1982

21. Meyers K, Benz R, for the HEMO Study Group: Quality of life outcomes in the HEMO Study. J Am Soc Nephrol 13:421A-422A, 2002 (abstr)

22. Kimmel PL: Sleep apnea in end-stage renal disease. Semin Dial 4:52-58, 1991

23. Zoccali C, Mallamaci F, Tripepi G: Sleep apnea in renal patients. J Am Soc Nephrol 12:2854-2859, 2001

24. Iliescu EA, Coo H, McMurray MH, et al: Quality of sleep and health-related quality of life in hemodialysis patients. Nephrol Dial Transplant 18:126-132, 2003

25. Sanner BM, Tepel M, Esser M, et al: Sleep-related breathing disorders impair quality of life in hemodialysis recipients. Nephrol Dial Transplant 17:1260-1265, 2002

26. Williams SW, Tell GS, Zheng B, Shumaker S, Rocco MV, Sevick MA: Correlates of sleep behavior among hemodialysis patients. The Kidney Outcomes Prediction and Evaluation Study. Am J Nephrol 22:18-28, 2002

27. Kutner NG: Assessing end-stage renal disease patients' functioning and well-being: Measurement approaches and implications for clinical practice. Am J Kidney Dis 24:321-333, 1994

28. Kutner NG, Devins GM: A comparison of the quality of life reported by elderly whites and elderly blacks on dialysis. Geriatr Nephrol Urol 8:77-83, 1998

29. US Renal Data System: USRDS 2002 Annual Report. The National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda MD, 2002

30. House JS, Landis KR, Umberson D: Social relationships and health. Science 241:540-545, 1988

31. Uchino BN, Cacioppo JT, Kiecolt-Glaser JK: The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. Psychol Bull 119:488-531, 1996

32. Kimmel PL: Psychosocial factors in dialysis patients. Kidney Int 59:1599-1613, 2001

33. Cohen LM, Germain MJ, Poppel DM, Woods AL, Pekow PS, Kjellstrand CM: Dying well after discontinuing the life-support treatment of dialysis. Arch Intern Med 160:2513-2518, 2000

34. Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al: Race, gender and partnership in the physician-patient relationship. JAMA 282:583-589, 1999