Predictors of Functional Health Status of End Stage Renal Disease Patients

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Potential predictors of the functional health status of 125 end stage renal disease (ESRD) patients were studied cross-sectionally. When health status was assessed by the physician with the Karnofsky Index, younger patient age, lower ESRD severity of illness, lower comorbidity severity, and higher albumin levels were predictors of better health \( R^2 = 0.48 \). When patients self-reported their health status with the Duke Health Profile, African-American race, higher family support, lower family stress, and lower ESRD severity were positive predictors \( R^2 = 0.23 \). The importance of measuring functional status, severity of illness, and social support and stress of ESRD patients is supported by these findings.

INTRODUCTION

Should nephrologists measure and monitor the functional health status (i.e., health-related quality of life) of their ESRD patients? This issue was broached by the Institute of Medicine (IOM) in a national conference held in 1993, which concluded that both clinical and health status outcomes are important for monitoring quality of care (Schrier et al., 1994; Rettig, 1995). The practical issues of how to measure health status and which measurement instruments are available were addressed in an IOM workshop in 1994 (Rettig et al., 1997). In the workshop, four measures were considered as potentially suitable for ESRD patients: the Dartmouth COOP Charts (Nelson et al., 1990 and 1996), the Duke Health Profile (DUKE) (Parkerson, Broadhead, and Tse, 1990; Parkerson, 1997), the SF-36 Health Survey (SF-36) (Ware and Sherbourne, 1992; Ware, 1993), and the RAND Kidney Disease Quality of Life instrument (KDQOL) (Hays et al., 1994). As a result of these IOM initiatives, the ESRD Health Status Outcomes Group (HSO Group), was organized in 1995, specifically to clarify issues relating to health status measurement and to encourage widespread use of this methodology in clinical settings for ESRD patients.

As a result of the HSO Group's efforts to encourage nephrologists to look more closely at the practical application of health status measures, the authors (RG, a nephrologist and GP, one of the developers of the DUKE), performed the study reported here to take an in-depth snapshot of the health status of ESRD patients and some of the multiple sociodemographic and clinical factors that are possible determinants of their health status.

The purposes of the study were: (a) to measure the functional health status of ESRD patients using the DUKE in the renal dialysis unit, (b) to compare health status self-reported by ESRD patients on the DUKE with that reported by the nephrolo-
gist on the Karnofsky Performance Index (Karnofsky and Burchenal, 1949), (c) to compare health status of ESRD patients with primary care patients and with persons who are not in a clinical population, and (d) to measure patient-reported social support and stress, and physician-reported severity of illness as possible determinants of health status. An initial report from the study focused on anxiety and depression symptoms and disablement (Parkerson and Gutman, 1997), while the present report includes much broader analyses of multiple factors.

METHODS

Study Design and Study Population

This was an observational study that analyzed cross-sectional data for ESRD patients requiring hemodialysis three times a week. All patients in the Durham Dialysis Center, Durham, NC, and the Neuse River Dialysis Center, Creedmoor, NC, were asked to enroll in the study unless they were mentally incompetent, in the hospital, or too sick on the day of enrollment. Although the dialysis units are located only 15 miles apart, the Durham unit serves primarily an urban population, and the Creedmoor unit, primarily a rural population.

Data were collected by interview while the patients were receiving hemodialysis. After informed consent was obtained, three questionnaires (the Duke Health Profile [DUKE]) (Parkerson, Broadhead, and Tse., 1990; Parkerson, 1997), the Duke Social Support and Stress Scale (DUSOCS) (Parkerson, Broadhead, and Tse, 1991), and a sociodemographic form were administered to all patients. All data were collected by the authors, one of whom (RG) is one of the attending physicians for patients in the two dialysis units, and the second of whom (GP) is a physician epidemiologist who helped develop the health and severity measures used in the study, and who was unknown to patients in the dialysis units. The questionnaires were administered by the physician epidemiologist, who read each of the 58 questionnaire items verbatim to each of the patients and recorded their responses while they were receiving hemodialysis. There was sufficient background music and/or noise to ensure confidentiality. Within 48 hours of questionnaire administration, the nephrologist completed the Karnofsky Performance Index (Karnofsky and Burchenal, 1949) and the Duke Severity of Illness Checklist (DUSO) (Parkerson, Broadhead, and Tse, 1993 and 1995) on each patient, and the physician epidemiologist obtained data from the medical records regarding demographic factors, laboratory values, hospitalizations, cause of renal failure, and length of time since beginning dialysis.

Instruments

The DUKE is a 17-item patient-report questionnaire that measures functional health status (i.e., health-related quality of life) using five mutually exclusive scales (physical health, mental health, social health, perceived health, and disability, i.e., confinement because of health problems) and four overlapping scales (general health, self-esteem, anxiety-depression, and pain). The physical health scale has five items (walking up a flight of stairs, running the length of a football field, hurting or aching, getting tired easily, and trouble sleeping); the mental health scale has five items (like who I am, give up too easily, difficulty concentrating, feeling depressed or sad, and nervousness); the social health scale has five items (not an easy person to get along with, happy with family relationships, comfortable being around people,
socialize with other people, and take part in social activities); perceived health has one item (I am basically a healthy person); and disability has one item (confinement because of health problems). General health has the 15 items of physical, mental, and social health combined; self-esteem has five items (the first two listed above for mental health and the first three for social health); anxiety-depression has seven items (nervousness, feeling depressed or sad, trouble concentrating, getting tired easily, trouble sleeping, give up too easily, and comfortable being around people); and pain has one item (hurting or aching). Each DUKE item has three response options for the respondent, such as “none”, “some”, or “a lot” (Parkerson, Broadhead, and Tse, 1990; Parkerson, 1997).

The Karnofsky Performance Index is a one-item physician-report questionnaire with 11 response options indicating functional status from 0 for “dead” to 100 for “normal, no complaints”. Scores greater than 70 indicate that the patient is able to “carry on normal activity” (Karnofsky and Burchenal, 1949).

DUSOCS is a 24-item patient-report questionnaire that determines how much support is given (12 items) and/or stress is caused (12 items) by certain types of family members or persons outside of the family. For example, the patient responds “none,” “some,” or “a lot,” to one question about how much support is received from “your wife, husband, or significant other person” in the family component, and to a similar question on support from “your neighbors” in the non-family component (Parkerson, Broadhead, and Tse, 1991). DUSOI is a physician-report questionnaire on which all current diagnoses are listed and the severity of each is rated along four severity parameters (symptom status, complication status, prognosis during the next 6 months without treatment, and treatability, i.e., the expected response to treatment if indicated). DUSOI scores are generated for each diagnosis (diagnosis DUSOI), for all diagnoses combined (overall DUSOI), and for all diagnoses except for any one designated diagnosis of interest, which was ESRD in the present study (comorbidity DUSOI) (Parkerson, Broadhead, and Tse, 1993 and 1995).

The sociodemographic questionnaire included 17 items on personal identification, number of persons in the household, and marital, educational, and work status. Some of the items, such as name, age, and address, are included not so much for data gathering but rather for estimating the patient’s orientation to person, time, and place. The Green Scale (Green, 1970), which was used to indicate socioeconomic status, is based on education and occupation, with possible scores ranging from a low of 28 to a high 84.3. For example, a farm laborer with no schooling would have the lowest score, and a physician or dentist, the highest. A bank teller with a high school diploma would score 58.7.

Statistical Methods

The chi-square statistic was used for associations between categorical variables. Student’s t-test was used to test for differences in mean scores when two groups were compared. Analysis of variance was used for comparisons among the group scores of ESRD patients, primary care patients, and insurance policyholders. The Bonferroni method (Miller, 1981) was used to control for the overall significance level of these latter comparisons. Stepwise regression analyses were used to demonstrate the cross-sectional relationships between functional health status and independent variables that are potential predictors of health status. Those variables were entered first that accounted for the
most variance in the dependent variable, controlling for variables already entered in the model. This means that it would be possible for a given independent variable not to be included in the stepwise model and yet be a statistically significant correlate of the dependent variable in other types of analysis. Cronbach’s alpha (Cronbach, 1951) (scale = 0 - 1.0) was used to estimate reliability in terms of internal consistency for the measurement scales that include multiple items. To indicate acceptable reliability the Cronbach coefficients should exceed .50 according to Helmstadter (Helmstadter, 1964), and .70 according to Nunnally (Nunnally, 1978).

RESULTS

Data were collected during the 5-month period ending in January 1996. Administration of the 58-item packet of three questionnaires required an average of 8.6 minutes, with a minimum of 5 and a maximum of 14 minutes. The DUKE itself required an average of 3 minutes, and recording severity of illness with the DUSOI by the nephrologist required approximately 1 to 3 minutes for most patients.

Of the 142 patients receiving hemodialysis (93 in Durham and 49 in Creedmoor), five were considered to be demented, two were in the hospital, one was too sick, and one did not show up for dialysis, leaving 133 eligible for the study. Of these, 125 (94.0 percent) consented to participate and were included in the analyses. The 125 study patients ranged in age from 24 to 92 years, with a mean of 59.6 ± 15.0 SD years. Fifty-six percent were women, and 79.2 percent were African American. Of all patients, 42.4 percent were married; 13.6 percent, divorced; 24.8 percent, widowed; 7.2 percent, separated; and 12.0 percent, never married. Most patients (74.4 percent) lived with their own family; 92.0 percent were disabled and/or retired, and 4.8 percent were working part- or full-time, or attending school. With regard to formal education, 61.6 percent had never graduated from high school, 18.4 percent had only high school diplomas, and 20.0 percent had more advanced education. The socioeconomic class ratings by Green scores ranged from 32.9 to 77.5, with a mean of 53.1 ± 9.7 SD. There was no statistically significant difference in SES score between African-American [52.9 ± 10.0 SD] and white patients [53.8 ± 8.7 SD].

Study patients had been on dialysis from a minimum of <1 month to a maximum of 197 months, with a mean duration of 37.8 ± 38.2 SD months. At the time of entry to the study, their mean Kt/V was 1.47 ± .22 SD, ranging from .85 to 2.00. During the 18 months before data intake, hospitalization was required by 68.8 percent of the patients, with a maximum of 8 and a mean of 1.4 ± 1.4 SD hospitalizations.

Renal failure was caused primarily by hypertension (40.0 percent) and diabetes mellitus (36.0 percent). In addition to their diagnosis of ESRD, the 125 patients had an average of 3.3 comorbid diagnoses, the most prevalent of which were: hypertension (51.2 percent), diabetes mellitus (34.4 percent), ischemic heart disease (12.0 percent), obesity (12.0 percent), and depression (9.6 percent). The clinical severity of each diagnosis was determined by the nephrologist, using the DUSOI scoring system [scale = 0 - 100, from lowest to highest severity]. In Table 1, the diagnoses with a prevalence of >2 percent are rank ordered by decreasing severity of illness. For example, the mean DUSOI score for ESRD was 54.3 ± 9.8 SD, ranging from 37.5 to 81.3 for different patients. For the comorbid diagnoses shown in the table, the mean scores ranged from a low of 17.2 ± 9.4 SD for hypothyroidism, to a high of 69.1 ± 14.5 SD for insulin-dependent diabetes mellitus.
Table 1
Current Most Prevalent Diagnoses and Their Severity of Illness in Renal Hemodialysis Patients (n=125)

| Diagnosis                              | ICD-9  | n   | Maximum | Mean (SD) | Minimum |
|----------------------------------------|--------|-----|---------|-----------|---------|
| Diabetes (Insulin-Dependent)           | 250.41 | 33  | 37.5    | 93.8      | 69.1 (14.5) |
| Arteriosclerotic Cardiovascular Disease| 429.2  | 9   | 37.5    | 87.5      | 68.8 (16.2) |
| Multiple Myeloma                       | 203    | 3   | 37.5    | 87.5      | 60.4 (25.3) |
| Personality Disorder                   | 301.7  | 3   | 50      | 75        | 60.4 (13.0) |
| Depression                             | 311    | 12  | 31.3    | 81.3      | 58.9 (15.8) |
| Cachexia                               | 799.4  | 5   | 43.8    | 75        | 58.8 (13.0) |
| Obesity                                | 278    | 15  | 31.3    | 81.3      | 55.8 (14.1) |
| Ischemic Heart Disease                 | 414.9  | 15  | 31.3    | 93.8      | 55.4 (18.7) |
| Peripheral Neuropathy                  | 356.9  | 4   | 37.5    | 81.3      | 54.7 (21.3) |
| ESRD (Chronic Renal Failure)           | 585    | 125 | 37.5    | 81.3      | 54.3 (9.8)  |
| Peripheral Vascular Disease            | 443.9  | 5   | 31.3    | 62.5      | 52.5 (13.0) |
| Osteoarthritis                         | 715    | 5   | 31.3    | 68.8      | 51.3 (13.5) |
| Anxiety                                | 300    | 3   | 31.3    | 62.5      | 50.0 (16.5) |
| Diabetes (Non-insulin-Dependent)       | 250.4  | 10  | 25      | 56.3      | 39.4 (11.4) |
| Hypertension                           | 401    | 64  | 6.3     | 56.3      | 31.3 (12.7) |
| Congestive Heart Failure               | 426    | 5   | 18.8    | 56.3      | 30.0 (15.5) |
| Reflux Esophagitis                     | 530.1  | 6   | 18.8    | 37.5      | 24.0 (7.3)  |
| Gout                                   | 274    | 6   | 0       | 56.3      | 22.9 (18.8) |
| Hypothyroidism                         | 244.9  | 4   | 6.3     | 25        | 17.2 (9.4)  |

1 Only those diagnoses with a prevalence of >2 percent in the study group are listed. Diagnoses are arranged in descending rank-order by their severity scores.
2 International Classification of Diseases, 9th Revision.
3 Scores from the nephrologist-reported Duke Severity of Illness Checklist (DUSOI). Scale= 0-100, from lowest to highest severity.

SOURCE: Parkerson, G. R., Jr. and Gutman, R.A., 1995.

Health status, social support and stress, and severity of illness scores of the ESRD patients are shown in Table 2. Their self-reported health status scores are compared with those of 413 primary care patients (mean age = 40.4 ± 13.1 SD years, 58.6 percent women) from a community health center located about 50 miles from the dialysis units, and with 3,525 policyholders (mean age = 52.2 ± 12.0 SD years, 59.2 percent women) from a health insurance company in Oklahoma.

As shown in Table 2, ESRD patient-reported physical health (48.9 on a scale of 0-100) and perceived health (39.2) were lower than reported by primary care patients (59.4 and 70.4, respectively), which were in turn lower than by non-patient insurance policyholders (67.5 and 84.8, respectively). For the two patient groups, physician-reported severity of illness was much higher for the ESRD patients than for the primary care group. Confinement during the past week was about the same for the two patient groups but much higher than for the policyholders. General health was lower for both patient groups than for policyholders. Mental health, social health, and pain were similar for ESRD patients and non-patient policyholders. Mental and social health were higher, and pain was lower than for primary care patients. For example, the mental health score for ESRD patients was 81.1 and for policyholders was 81.4, compared with 72.5 for primary care patients. In addition, the self-esteem of ESRD patients was higher than that of the policyholders, which in turn was higher.
### Table 2
Health Status Scores for Renal Hemodialysis Patients Compared With Primary Care Patients and Health Insurance Policyholders

| Health Status Scale               | Hemodialysis Patients (n=125) | Primary Care Patients (n=13) | Insurance Policyholders (n=3,521) |
|-----------------------------------|-------------------------------|-----------------------------|---------------------------------|
| **Patient Report**                | Mean (Standard Deviation)     |                             |                                 |
| Functional Health                 |                               |                             |                                 |
| Physical Health                   | 48.9 (23.4)                   | 59.4 (23.8)                 | 67.5 (21.0)                     |
| Mental Health                     | 81.1 (20.5)                   | 72.5 (20.4)                 | 81.4 (17.5)                     |
| Social Health                     | 75.8 (17.0)                   | 65.6 (19.3)                 | 77.6 (17.8)                     |
| General Health                    | 68.6 (14.8)                   | 65.8 (16.2)                 | 75.5 (14.0)                     |
| Perceived Health                  | 39.2 (40.9)                   | 70.4 (32.8)                 | 64.8 (25.8)                     |
| Self-Esteem                       | 50.2 (13.5)                   | 75.1 (19.0)                 | 82.2 (18.6)                     |
| Anxiety-Depression                | 25.7 (19.6)                   | 31.8 (19.9)                 | 21.7 (16.7)                     |
| Pain                              | 39.8 (39.1)                   | 42.3 (33.0)                 | 38.0 (31.0)                     |
| Confinement Past Week             | 22.0 (37.2)                   | 19.4 (30.6)                 | 3.5 (14.2)                      |
| **Social Support and Stress**     |                               |                             |                                 |
| Family Support                    | 46.9 (23.6)                   | 52.5 (25.0)                 |                                |
| Non-Family Support                | 38.0 (20.2)                   | 48.0 (24.8)                 |                                |
| Family Stress                     | 8.7 (12.8)                    | 20.1 (18.9)                 |                                |
| Non-Family Stress                 | 2.3 (6.6)                     | 13.0 (16.6)                 |                                |
| **Physician Report**              |                               |                             |                                 |
| Functional Health                 | 71.6 (15.0)                   | 43.4 (18.6)                 |                                |
| Severity of Illness               |                               | 54.3 (9.8)                  |                                |
| Overall Severity                  | 74.7 (13.9)                   | 43.4 (18.6)                 |                                |
| ESRD Severity                     | 54.3 (9.8)                    | 54.3 (9.8)                  |                                |
| Comorbidity Severity              | 62.1 (25.6)                   | 54.3 (9.8)                  |                                |

1 Primary care patients of a community health center located approximately 50 miles from the dialysis units. Mean age = 40.4 (13.1 SD) years, 56.6 percent women.

2 Policyholders of a health insurance company in Oklahoma. Mean age = 52.2 (12.0 SD) years, 59.2 percent women.

3 Scores from the Duke Health Profits (DUKE). High scores = good for physical health, mental health, social health, general health, perceived health, and self-esteem. Low scores = good for anxiety-depression, pain, and confinement.

4 Scores from the Duke Social Support and Stress Scale (DUSOC). High scores = good for support. Low scores = good for stress.

5 Scores from the Karnofsky Performance Index. High scores = good (>70.0 = self-care).

6 Scores from the Duke Severity of Illness Checklist (DUSOC). Low scores = good.

7 p < 0.05 for the difference between hemodialysis, primary care, and policyholder group scores.

8 p < 0.05 for the difference between hemodialysis and primary care group scores.

9 p < 0.05 for the difference between hemodialysis and policyholder group scores.

10 p < 0.05 for the difference between primary care and policyholder group scores.

11 Data not available.

SOURCES: Parkerson, G. R., Jr., and Gutman, R.A., 1995; Mold, J. W., University of Oklahoma. 1994; Parkerson, G. R., Jr., Broadhead, W.E., and Tse, C-KJ, 1991.
than that of the primary care patients. Anxiety-depression for ESRD patients was lower than for primary care patients, but higher than for policyholders. Social support and stress scores (available only for the patient groups) indicated that the ESRD patients had both lower support and lower stress than the primary care patients.

The results of stepwise regression analyses for potential cross-sectional predictors of functional health status are shown in Table 3. The greatest amount of variance in functional health explained was 48.1 percent of the Karnofsky score by the combination of age, severity of ESRD, severity of comorbid health problems, and serum albumin. Younger age, lower severity of illness, and higher albumin levels predicted better health. Comorbidity severity was the strongest single predictor at 24.1 percent. Neither the social factors, nor the \( \text{Kt/V} \) had a statistically significant effect on the Karnofsky score. In this particular analysis, the perceptions of both functional health status and severity of illness were those of the nephrologist.

When the patients’ perceptions of functional health were measured with the DUKE, less of the total variance could be explained. Neither the albumin nor the \( \text{Kt/V} \) were significant predictors, but the social factors were significantly predictive of health status. For example, the greatest percentage of variance explained (22.5 percent) was in the analysis with general health as the outcome, where African Americans and patients with higher family support, lower family stress, and lower ESRD severity had better health. The DUKE general health scale combines physical, mental, and social health. When these component scales were analyzed separately, there was considerable difference in the amount of variance explained. For example, while the predictors for higher physical health were younger age, female sex, and lower comorbid severity, the predictors of mental health and social health were the social support and stress factors. Comorbidity severity of illness, which was the strongest predictor of physician-reported Karnofsky scores (24.1 percent), predicted only 5.1 percent of patient-reported physical health and 3.8 percent of perceived health.

In the stepwise regression analyses where social factors were predictive, all except one indicated that higher social support was associated with better functional health, and higher social stress with worse functional health. As shown in Table 3, this exception was the association of higher non-family stress with higher perceived health reported by the patients (variance explained = 6.1 percent), whereas in the same predictive model, higher family stress and higher comorbid severity predicted lower perceived health. Only 16 patients (12.8 percent) reported non-family stress above zero, compared with 45.6 percent who reported at least some degree of family stress. Comparison of the 16 patients who had stress from persons outside of their families with the other patients revealed that the stressed patients were younger (mean age = 52.1 versus 60.7 years, \( p=.03 \)) and had higher socioeconomic status (mean SES = 58.1 versus 52.3 units, \( p=.02 \)). Although their perceived health scores were higher than the patients without non-family stress, the difference was not statistically significant (mean perceived health score = 56.3 versus 36.7, \( p=.07 \)).

Reliability estimates were made for the functional health, social support, and social stress scales that have multiple items that can be tested for internal consistency. Cronbach’s alphas were as follows: physical health = .60, mental health = .65, social health = .50, general health = .71, self-esteem = .35, anxiety-depression = .64, family...
| Predictive Factors | Physician-Reported Kamofsky Performance | Physical Health | Mental Health | Social Health | General Health | Perceived Health | Self-Esteem | Anxiety/Depression | Pain | Confinement |
|--------------------|----------------------------------------|----------------|--------------|--------------|---------------|-----------------|-------------|-------------------|------|-------------|
| Demographic        |                                        |                |              |              |               |                 |             |                   |      |             |
| Older Age          | **3.8 (-)**                            |                |              |              |               |                 |             |                   |      |             |
| Female             |                                        |                |              |              |               |                 |             |                   |      |             |
| African-American   |                                        |                |              |              |               |                 |             |                   |      |             |
| Social             |                                        |                |              |              |               |                 |             |                   |      |             |
| Higher SES*        |                                        |                |              |              |               |                 |             |                   |      |             |
| Family Support*    |                                        |                |              |              |               |                 |             |                   |      |             |
| Non-Family Support*|                                        |                |              |              |               |                 |             |                   |      |             |
| Family Stress*     |                                        |                |              |              |               |                 |             |                   |      |             |
| Non-Family Stress* |                                        |                |              |              |               |                 |             |                   |      |             |
| Severity of Illness|                                        |                |              |              |               |                 |             |                   |      |             |
| ESRD*              | ***6.2 (-)**                           |                |              |              |               |                 |             |                   |      |             |
| Comorbidity*       | ****24.1 (-)                           | **5.1 (+)      |              |              |               |                 |             |                   |      |             |
| Laboratory         |                                        |                |              |              |               |                 |             |                   |      |             |
| Albumin            | .2.5 (+)                               |                |              |              |               |                 |             |                   |      |             |
| Kt/V               |                                        |                |              |              |               |                 |             |                   |      |             |
| Variance by Model  | ****48.1                               | ****18.8       | ***10.3      | **10.2       | ****22.5       | **10.5          | ***11.2     | ***13.5           | **13.1 | 4.6         |

*p ≤ .05.
**p ≤ .01.
***p ≤ .001.
****p ≤ .0001.

High scores = good health.
Low scores = good health.
1 Percent variance (100 x partial R square) in the functional health outcome variable that is explained by each independent variable, after controlling for the effects of the other variables remaining in the stepwise regression model. Dashes indicate variables that did not enter the model or did not remain in the model because P > .05. Direction of association is shown in parentheses.
2 Socioeconomic status indicated by the Green score.
3 Measured by the Duke Social Support and Stress Scale (DUSOCS).
4 Measured by the Duke Severity of Illness Checklist (DUSOIC).

SOURCE: Parkerson, G.R., and Gutman, R.A., 1995.
support = .60, non-family support = .38, and family stress = .61. The alpha could not be calculated for non-family stress because of insufficient variability among the scores (i.e., 87.2 percent of patients had a score of zero for non-family stress). These estimates are very similar to those reported for the primary care patient group (Parkerson, 1997), except for self-esteem, which was .50, and non-family support, which was .70 for the comparison group. Non-family stress reliability reported for the primary care patients was .53.

DISCUSSION

This study showed that functional health status and three of its potential predictors (i.e., severity of illness, social support, and social stress) can be measured in the hemodialysis unit with minimal difficulty using brief scientifically validated survey instruments. The scientific measurement of outcomes in terms of the patient’s own perspective of health status provides a dimension that is essential for comprehensive quality assessment of clinical care, and that has not been widely available in the past. The scientific measurement of severity of illness by the nephrologist according to specific severity parameters and criteria provides an indicator of how sick patients are that is much more informative than assessments that are based entirely upon diagnostic labeling. The scientific measurement of social support and stress provides a tool for detecting social problems that may be hindering optimal patient care, and that may not have been recognized and addressed in traditional medical care.

Early studies described the health status of ESRD patients (Johnson, McCauley, and Copley, 1982; Evans et al., 1985; Simmons and Abress, 1990). This study confirmed the previous finding that health status is not necessarily dismal for ESRD patients requiring hemodialysis. From the nephrologist’s perspective of the health status of his patients, the mean Karnofsky performance score was 71.5 (median=70.0), indicating the ability for about half of these patients to care for themselves, and for some to carry on normal activities. From the patients’ perspective, although the physical and perceived health scores were low, their mental health, social health, and self-esteem scores were high, resulting in relatively low anxiety-depression scores. These indicators of psychosocial health were similar to those of a comparison group of non-patient insurance policyholders and better than those of a group of primary care patients in the same geographic area. Hemodialysis, in spite of its difficulties and expense, certainly is enabling many of these patients to enjoy a reasonably high health-related quality of life.

How is it possible for the ESRD patients to report such high mental and social health status? Apparently, many of the dialysis patients have adjusted somehow to their handicap in a very positive way. Losing their kidneys has ended up no worse to them than losing some other important part of their body that can be replaced functionally. In essence, because of the technology of dialysis, these patients seem to be no worse off mentally and socially than an amputee with a good prosthesis.

While the principal rehabilitation of ESRD patients for maintenance of physical health is dependent upon the excellence of dialysis, further rehabilitation for psychosocial health may depend upon improvement of the social environmental factors that were implicated in this study as partial determinants of their health. Interventions may be indicated in many patients to improve their social supports and decrease their social stresses. Although ESRD patients reported much less family and non-family stress than primary care patients,
their reported support also was less. Certainly, ESRD patients have a need for social support that is equal to or greater than that of primary care patients.

Why do the ESRD patients report less difficulty with social stress than primary care patients? This may be related somehow to the more stable and chronic nature of their illnesses compared with those of the primary care group. Also, the social environment of ESRD patients is enhanced by the group ambience of the dialysis unit and is less volatile than that of most people who are working in a public job, and who are not restricted by thrice-weekly, 2- to 4-hour hemodialysis treatments. Although the social stress of ESRD patients in this study was relatively low, it still was a very important negative factor for both their mental and social health, and warrants special attention by their health care providers. The unexpected paradoxical finding that patients with higher non-family stress had better perceived health may be related to their degree of social isolation, in that those patients who have better health perceptions may also be more socially active and more likely to encounter stress from persons outside of their family. This finding needs further study for adequate explanation.

When the physician-reported Karnofsky and the patient-reported DUKE were compared as health status outcome measures, both measures seemed to reflect the impact of ESRD and comorbid illness on the patient. However, severity of illness and age appeared to affect the functional assessment by the physician more than they affected the assessment by the patient. On the other hand, social factors influenced the health status reports by the patients more than those by the physician. These findings indicate the importance of quantitative measurement of all three major constructs: health status, severity of illness, and social factors. Severity ratings using the DUSOI showed wide ranges of severity for ESRD and each of the comorbid illnesses among different patients, confirming that diagnostic labeling in itself is not adequate for indicating severity. As more and more nephrologists begin to measure and monitor patient-reported health status as an outcome of their medical care, it should be helpful to them also to measure and monitor severity of illness and social factors, and to include social interventions in their therapeutic armamentarium.

The importance or lack of importance of laboratory values in relationship to functional health outcomes is an interesting issue that is only touched on in the present study. The fact that serum albumin level had a statistically significant positive relationship with functional status as assessed by the nephrologist makes sense clinically because of the usual association of higher albumins with better nutritional status. On the other hand, Kt/V, which has become such an important clinical indicator of the efficiency of hemodialysis, had no statistically significant relationship to any of the functional outcomes that were measured in this study.

The methodology of administration of questionnaire instruments to ESRD patients is an important issue. We chose to read the questions to each patient instead of having them try to check off the answers themselves. This approach was necessary for many of the patients in our population because of the high prevalence of poor vision and limited education. Also, self-administration at the time of dialysis is difficult for most patients because of the reclining body position and the vascular access connections which often are located in the arms. We found that it was quite feasible to administer health questionnaires to
patients while they are receiving hemodialysis. Most patients were receptive to the questions, had little or no difficulty understanding what was being asked, and gave straightforward answers. The DUKE questionnaire required an average of only 3 minutes for all of the 17 questions to be read verbatim by the administrator and answered by the patient. This speed of administration was partly due to the simplicity of the questions and partly due to the fact that each item has only three response options from which the respondent has to choose. We also found that the attending nephrologist, with minimum training in the DUSOI methodology, could assess the severity of each diagnosis for each patient with relative ease. Longer and more complex instruments may be suitable in other populations with fewer impaired patients.

The present study has the limitations of including patients from only two dialysis units, with one investigator making all the provider assessments and one investigator administering all of the patient-report measures. Also, only one functional health status instrument (i.e., the DUKE) was used, when there are other generic measures available, such as the SF-36 and the COOP Charts. In addition, the DUKE was not supplemented by one of the disease-specific instruments, such as the KDQOL. However, the findings of this small study are potentially important enough to nephrologists and third-party payers to stimulate larger, more generalizable studies comparing different instruments in larger and more diverse patient populations.

While the study did not test whether or not health status, severity of illness, and social factor measurement will facilitate the medical care of ESRD patients, it certainly presented some compelling support for such a thesis. More extensive studies are needed to confirm these results and test the hypothesis that quantifiable patient-reported and physician-reported health status data will actually improve the quality of care for ESRD patients. Also, studies are needed to see if baseline patient-reported health status and physician-reported severity of illness, along with age and gender of ESRD patients, can be used as predictive indicators of future morbidity, mortality, and health services utilization, such as has been done with the APACHE (Knaus et al., 1981) system in intensive care units and with the combined DUKE and DUSOI in the primary care setting (Parkerson, Broadhead, and Tse, 1995).

This study confirmed the clinical reality that no one parameter of clinical status of patients can be considered in isolation, and that for patients as complicated as those with ESRD, multiple factors are important clinically. We believe that the data we have presented give strong support for including not only functional health status, but also severity of illness and social support and stress, among the factors that warrant measurement by nephrologists. All of these parameters are being assessed implicitly by nephrologists every day as they manage their patients, but the assessments usually are not made systematically and scientifically, and often are not recorded in the medical record. The time has come when it is possible to measure these parameters in a systematic and reproducible way, similar to, albeit not as refined and precise as the measurement of laboratory tests. We advocate a concentrated effort by nephrologists and functional health status instrument developers to refine the measures and make them available in user-friendly formats so they can be utilized widely in the day-to-day management of ESRD patients.
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