

Assessment of Quality of Life in End-Stage Renal Disease

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Ten different multi-item indexes and nine single-item measures were used to assess the quality of life of patients undergoing one of four major modalities of treatment for end-stage renal disease (ESRD). Assessments were made on a population-based sample of Michigan patients with onset of ESRD after November 1, 1981, during the period May 1984 to September 1986. The nature of these measures is described and correlations among them are reported. The correlations suggest that these indexes tend to represent either function or feeling, with moderate relationships within the two clusters but little between them. Findings are also reported in terms of age, race, and sex. Depending on the measure chosen to assess quality of life, different conclusions about the relationship of quality of life to these demographic characteristics will be reached. These conclusions may help readers think more critically about the nature of quality of life in arriving at judgments on the relative validity of these different measures.

When the techniques of dialysis and kidney transplantation became available to patients with end-stage renal disease (ESRD), attention

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focused on the degree to which they extended life. More recently, concern about the quality of the lives that were being preserved was expressed by physicians, medical sociologists, psychologists, and others (Naish 1975; Levy and Wynbrandt 1975; Levine 1987; Poznanski et al. 1978; Atcherson 1978). The issue came to the fore dramatically when some dialysis patients decided to stop treatment with full understanding of the consequences (Port et al. 1989). As concern grew, attempts were made to assess the quality of life of patients in an objective, quantitative way using a wide variety of measures (Kaplan, DeNour, and Shanahan 1980; Johnson, McCauley, and Copley 1982; Simmons, Anderson, and Kamstra 1984; Evans et al. 1985; Chubon 1986).

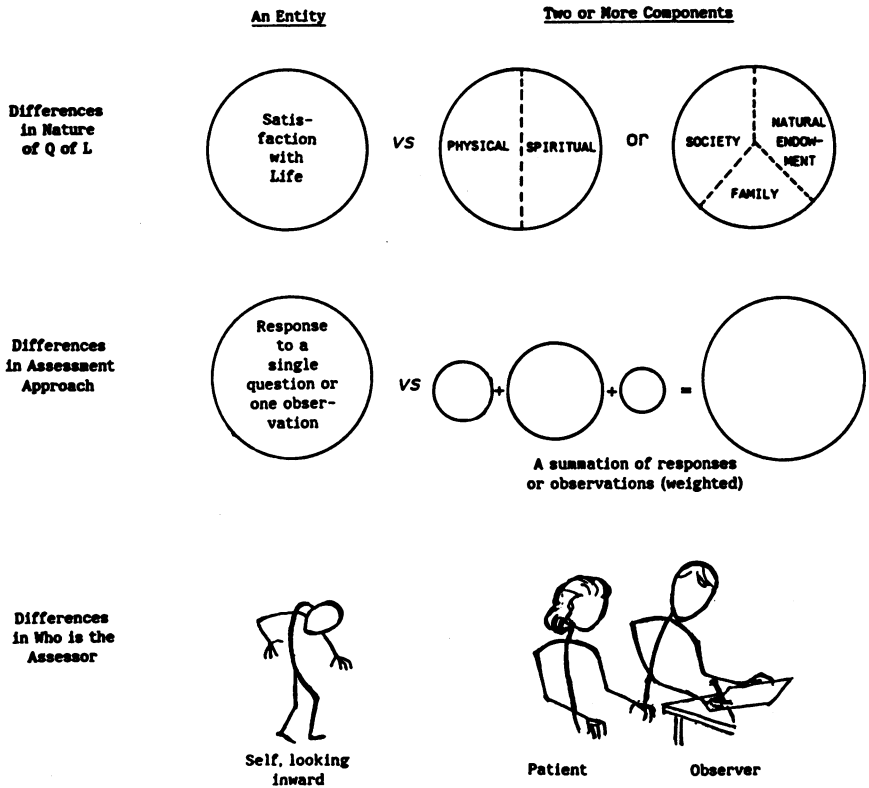
In 1976, Campbell et al. described quality of life as a "vague and ethereal entity, something that many people talk about, but which nobody very clearly knows what to do about" (p. 471). More recent literature suggests that we are far from agreement on how to measure the concept (Edlund and Tancredi 1985; Feinstein 1987; DeHaes and Van Knippenberg 1985).

A 1985 review (DeHaes and Van Knippenberg) proposes that definitions given by authors in quality of life reports differ mainly along two dimensions: (1) the nature of quality of life and (2) ways in which it is assessed. Some researchers conceptualize quality of life as an entity and propose to measure it as an overall evaluation—a global measure. Others see quality of life as made up of two or more different domains, each of which must be assessed and then summed with or without weighting.

A second area of differences has to do with the one who conducts the assessment, generally dichotomized as self or other. Frequently the health literature distinguishes the assessments as subjective if the patient does them and objective if they are done by a health professional. Others use the word *objective* to refer to easily documented circumstances (for example, gets out of bed without help), whereas *subjective* would refer to the degree of difficulty in getting out of bed and would not necessarily require self-observation. Some graphic examples of ways in which quality of life has been assessed in prior studies are presented in Figure 1.

These observations only partially illustrate the wide variety of ideas that lie behind current research on quality of life. All combinations of the elements with the examples shown are possible and are utilized. If one takes only a single combination of these concepts and procedures—for example, an interpretation of quality of life, not easily measured or documented, with two components assessed by an observer—there can

Figure 1: Graphic Examples of Research Differences Found in Quality of Life Studies



remain great heterogeneity in the components selected, the way questions are phrased, the weight given to each component, the type of observer selected, and the way the response is quantified.

In addition to the many and varied components used in those investigations that approach quality of life as an entity composed of a number of elements is the variability that exists in the mode of assessment. Data may be collected on a self-administered questionnaire or by personal interview in a medical service facility or at the respondent's home. A further complication arises from lack of agreement on distinguishing essential elements of quality of life from correlated entities

that may be either causes or consequences. For example, some see the performance of activities of daily living as a partial determinant and others view it as a component of quality of life.

PURPOSE

This article is based on the Health Care Financing Administration-supported study of the relative effectiveness and cost of transplantation and dialysis in end-stage renal disease; it describes and compares a variety of measures being used to assess quality of life of ESRD patients in Michigan. The quality of life study is part of a larger project currently underway to investigate the relationship of choice of treatment modality to costs of care and to survival, using four major treatment modalities: in-center hemodialysis (CH), continuous ambulatory peritoneal dialysis (CAPD), kidney transplantation from a living relative (RT), and transplantation from a cadaveric donor (CT).

Because this is an empirical study of the relationship between treatment modality and quality of life, we make use of a large variety of items and scales that have been used by others investigating this concept. Long after this study began, Feinstein (1987) offered very appropriate advice in his discussion of the 1987 Portugal Conference, which had focused on measuring quality of life and functional status in clinical and epidemiological research:

We may not be able to evoke universal agreement on what it [quality of life] is. We are probably better off letting people propose indexes, which we can then use or not use, rather than try to get a multi-individual consensus on what ought to be there. (p. 639)

Selection of quality of life measures for this study was influenced by the need for comparability of our findings with the findings of the National Kidney Dialysis and Kidney Transplantation Study conducted in the early 1980s by the Battelle Human Affairs Research Centers. That study had surveyed 859 ESRD patients from 11 selected dialysis and transplantation centers throughout the United States (Health Care Financing Administration 1987). However, the initial report on quality of life from that study (Evans et al. 1985) was criticized in an accompanying editorial for drawing the study sample from selected centers and thus not presenting data representative of the overall ESRD population (Freeman 1985). The present study, to some degree, is a replication of the Battelle study, but based on a state's ESRD population. The current investigation employs most of the quality of life measures of the prior study supplemented by a single-item measure that asks patients

how many good days they experienced in the past week—a measure that appeared promising in another earlier study, of arthritis patients (Deniston and Jette 1980).

A measure of physical functioning is used to enhance comparisons with the Battelle study. The Karnofsky Index, employed by that study, is not used, since it requires assessment by the caregiving staff and we had access only to patients. In addition, our format of responses on Bradburn's Affect Balance Scale (Bradburn 1969) is more detailed than that used by Battelle (yes/no) in that we used three points (often, sometimes, never), a format used in other earlier studies (Berkman 1971; McDowell and Praught 1982).

The extent to which the various quality of life measures relate to each other for this group of patients and their quality of life scores in terms of demographic characteristics is reported here. Future reports will include quality of life analyses by treatment modality when additional data are available.

MEASURES AND METHODS

Figure 2 presents the quality of life indexes and items used, and describes the general nature of their content. Ranges for scores are also given. (Detailed methods of scoring are available from the authors.)

Table 1 lists some of the prior studies that have employed these measures. The Affect Balance Scale and the Index of General Well-Being have been used in six or more other studies while the Activities of Daily Living (ADL) Index is unique to this study.

The ten-item Activities of Daily Living (ADL) Index combines items that assess function from the Index of ADL (Katz et al. 1970) with some suggested by Duke University's OARS protocol (Pfeiffer 1975). The format of the questions allows for measures of both actual performance and the ability to perform on a selection of self-care, mobility, and instrumental activities. The scale is designed for use as a screening instrument for the general population and to assess functional limitation in the chronically ill. Validation of this index is reported elsewhere (Julius et al. 1989).

From 1984 through summer 1986, data were collected from 742 patients. The sample included all patients age 18 or over, residing in Michigan, with onset of ESRD between 1981 and 1985 who, at six months after onset, were receiving CAPD, had received a living related-donor transplant, or had received or were awaiting a cadaver transplant, along with a random sample of those receiving in-center

Figure 2: Quality of Life Indexes, Items, and Range of Scores

General Well-Being (GWB) 1-6

(During the past month):

Feeling in general? Bothered by nerves? In control of self? So sad, etc., wondered if anything worthwhile? Under stress? Satisfied with personal life? Wonder if losing control? Anxious, upset? Downhearted, blue? Emotionally stable?

Index of General Affect (IGA) 1-7

(Feel about present life):

Boring—Interesting? Enjoyable—Miserable? Useless—Worthwhile? Friendly—Lonely? Full—Empty? Discouraging—Hopeful? Disappointing—Rewarding? Brings out the best in me—Doesn't give me much chance?

Good Days Last Week 0-7

(# GOOD DAYS)

Hard—Easy 1-7

(HARD/EASY)

Tied Down—Free 1-7

(TIED/FREE)

Satisfaction with 1-7

(Dissatisfied—Satisfied)

Marriage (SAT MAR)

Sex (SAT SEX)

Family Life (SAT FAM)

Standard of Living (SAT LIV)

Friends (SAT FRDS)

Overall Life Satisfaction (OLS) 1-7

Index of Well-Being (IWB) 2.1-14.7

1.0 IGA + 1.1 OLS = IWB

Continued

Figure 2: Continued

<i>Affect Balance Scale (ABS)</i>	1-9
<i>Positive Affect Scale (PAS)</i>	0-5
Excited	
Proud	
Pleased	
Top of world	
Going my way	
<i>Negative Affect Scale (NAS)</i>	0-5
Restless	
Lonely	
Bored	
Depressed	
Upset	
<i>Sickness Impact Profile (SIP)</i>	
(Percent dysfunction)	
<i>Physical Dimension (PHY SIP)</i>	0-100
Based on 45 items	
<i>Psychosocial Dimension (PSY SIP)</i>	0-100
Based on 48 items	
<i>Total SIP</i>	0-100
Based on 136 items	
<i>Activities of Daily Living Index (ADL)</i>	0-30
Uses phone	
Walks/Wheels	
Gets places	
Feeds self	
Does chores	
Uses toilet	
Climbs stairs	
Dresses self	
Transfers (bed)	
Bathes self	

Table 1: Previous Research that Used Quality of Life Measures Employed in Current Study

<i>Activities of Daily Living</i>	<i>Reference</i>						
	<i>HCFA (1987)</i>	<i>Johnson et al. (1982)</i>	<i>Campbell et al. (1976)</i>	<i>Bremer et al. (1986)</i>	<i>Bradburn (1969)</i>	<i>Berkman (1971)</i>	<i>McDowell et al. (1982)</i>
Sickness Impact Profile	■						
General Well-Being Index	■						
Index of General Affect	■	■	■	■			
Index of Well-Being	■	■	■	■			
Overall Life Satisfaction	■	■	■	■			
Affect Balance Scale	■	■		■	■	■	■
Satisfaction with marriage	■	■	■				
Satisfaction with sex life	■						
Satisfaction with family life	■		■				
Satisfaction with standard of living	■		■	■			
Satisfaction with friendships	■		■	■			
Feelings about present life (hard/easy)	■	■	■	■			
Feelings about present life (tied down/free)	■	■	■	■			
Number of good days in past week							

hemodialysis at that time. The sample design, which attempted to generate approximately equal numbers for the four modalities, distributed over the period of treatment up to five years, has been described in more detail elsewhere (Michigan ESRD Study 1988) and is available on request.

Data were collected by personal interview at sites of the respondents' choice, usually their home. (Nearly half of all in-center hemodialysis patients chose to be interviewed during the dialysis procedure.) Trained interviewers read to the patients most of the questions from the printed questionnaire and recorded their responses. For those patients who could read with ease (75 percent), the Index of General Affect and the Sickness Impact Profile (SIP) were completed as self-administered forms in the interviewer's presence; they were read and recorded by the interviewer for the remaining 25 percent. For reference purposes, a booklet with response alternatives for most of the quality of life measures was provided to the patient.

Table 1: Continued

U.S. Dept. of Comm. (1980)	USDHHS (1977)	Reference							
		Simmons et al. (1984)	Schmale et al. (1983)	McSweeney et al. (1982)	Bergner et al. (1976)	Bergner et al. (1984)	Deyo et al. (1983)	Costa et al. (1987)	Deniston et al. (1980)
■	■	■	■	■	■	■	■	■	■
■									■
■									
■									
■									
■									
									■

RESULTS

CHARACTERISTICS OF PATIENTS AT ASSESSMENT

Patients in the sample ranged in age from 20 to 89 years as shown in Table 2. Patients were equally distributed in the age ranges 20-40 and 41-60 with somewhat fewer in the range of 61-89. Their race and sex ratios corresponded to those of the total Michigan ESRD population. About 60 percent were married. Patients were fairly evenly divided in the educational categories—less than high school, completed high school, and more than high school. The primary cause of ESRD was glomerulonephritis for nearly a third, diabetes for a quarter, and hypertension for a fifth of the sample, similar to the proportions found in the statewide ESRD population.

About one-third of the sample were being treated by in-center hemodialysis at time of assessment, and a quarter were assigned to CAPD. About one in five had a functioning related-donor kidney, and another fifth had a functioning kidney from a cadaver source. This distribution was achieved by the sampling design.

Table 2: Characteristics of Michigan ESRD Patients in the Quality of Life Sample at Time of Assessment ($N = 742$)

<i>Variable</i>	<i>Percent</i>	
<i>Age</i>		
20-40	36	
41-60	37	
61-89	27	
<i>Race</i>		
White	70	
Black	27	
Other	3	
<i>Sex</i>		
Male	54	
Female	46	
<i>Marital Status</i>		
Never married	15	
Married	61	
Divorced/Separated	16	
Widowed	7	
<i>Education, Years Completed</i>		
Less than high school	33	
High school	34	
More than high school	33	
<i>Primary Cause of ESRD</i>		
Glomerulonephritis	29	
Diabetes	26	
Hypertension	20	
Other	25	
<i>Treatment Modality at Assessment</i>		
In-center hemodialysis	35	
CAPD	25	
Cadaver transplant	18	
Related transplant	19	
Other	3	
	<i>Mean</i>	<i>SD</i>
Duration of ESRD, months	25	12
Number of different modalities of treatment	2	0.8
Number of changes in modality of treatment	1.2	1.2
Reported income, per capita	\$8,230	\$6,065

The average duration of ESRD at time of assessment was 25 months (range 7 months to 62 months). Patients had had an average of one treatment other than the current modality. The details of the variety and stability of treatment experiences for this sample are reported elsewhere (Deniston et al. 1989). Average per capita income, calculated by dividing the middle value of a family income range by the number of people being supported by the reported income, was about \$8,200 but was quite variable.

RELATIONSHIPS AMONG THE VARIOUS QUALITY OF LIFE MEASURES

The first set of Pearson correlation coefficients for the quality of life measures is presented in Table 3. Some indexes (Index of General Affect, Index of Well-Being, Affect Balance Scale, and Positive Affect Scale) are scored so that higher scores indicate higher quality of life; thus, correlations between these indexes are positive. The Negative Affect Scale; the Activities of Daily Living Index; and the Sickness Impact Profile scale with its two scoring dimensions, the physical dysfunction and psychosocial dysfunction dimensions, are scored so that low scores indicate higher quality of life. Since in all cases the signs were as would be expected (e.g., Negative Affect Scale correlated negatively with all scores except the three SIP scores and the ADL score), signs have been omitted from this and subsequent tables.

The indexes in the upper left-hand corner of Table 3 attempt to measure general well-being and affect, while those in the lower right-hand corner are related to the health component of quality of life. The strongest relationship observed was between the physical dysfunction dimension of the SIP and the ADL Index. Obviously, these two scales are measuring substantially the same area of well-being, that is, physical functioning and their strong association, .80, gives some evidence of their validity as measures of that domain.

Moderate to strong relationships are also found among the indexes in the upper-left portion of Table 3 (which also gives evidence of the validity of each as a measure of affect). The generally weaker relationships in the lower left-hand corner suggest that health may be a determinant or a component of a generalized or affective notion of quality of life—but that it certainly is not the sole one. It is interesting, but not surprising, to note that the SIP psychosocial dysfunction dimension scores are more strongly related to the well-being and affect indexes than are those of the physical and total SIP measures and the ADL scale. Due to its relatively strong relationship to several of the

Table 3: Pearson Correlation Coefficients for Multi-Item Quality of Life Indexes

	General Well-Being Index	Index of General Affect	Index of Well-Being	Positive Affect Scale	Negative Affect Scale	Affect Balance Scale	Psychosocial Dimension	Physical Dimension	Total SIP
Index of General Affect	.61								
Index of Well-Being	.63	(.84)*							
Positive Affect Scale	.37	.48	.45						
Negative Affect Scale	.48	.43	.44	.12					
Affect Balance Scale	.55	.58	.57	(.67)	(.79)	.43			
Psychosocial dimension	.53	.51	.48	.37	.31	.28	.71		
Physical dimension	.32	.32	.33	.28	.15	.28	(.90)	(.92)	
Total SIP	.46	.44	.46	.35	.23	.38	(.90)	.80	.72
Activities of Daily Living Index	.26	.21	.25	.27	.13	.25	.50	.80	
Mean r	.47	.45	.45	.34	.29	.36	.48	.40	.43

*Parentheses indicate "part-whole" cases; for example, the Index of General Affect score is a component of the Index of Well-Being score. Such scores are omitted from calculation of the mean.

“feeling” measures, and to the physical function measures, the psychosocial dysfunction dimension of the SIP has the highest average correlation with the other eight independent multi-item measures. The General Well-Being Index is nearly as strongly related to the other eight multi-item measures. If each of these multi-item scales was judged to have some, but inadequate, face validity, this analysis of concurrent validity would suggest the psychosocial dysfunction subscale as the most valid, with several others nearly as valid. The Affect Balance Scale and its two subscales would appear less valid as measures of quality of life under this assumption.

Table 4 gives the correlation coefficients for the single-item quality of life measures. It can be noted that these relationships are generally weaker than those among the multi-item indexes. If one looks at the degree to which each is related to all of the others by computing average correlations, Overall Life Satisfaction is strongest with a mean of .38, while satisfaction with sex life has the lowest mean correlation (.19).

In Table 5 the relationships for single-item and multi-item quality of life measures are reported. Again looking at average correlations, the single-item measures Overall Life Satisfaction (.39) and “number of good days in the past week” (.38) were the most strongly related to multi-item scales. The overall correlation between single-item and multi-item indexes (.29) was very modest. Average correlations for satisfaction with marriage (.18) and with sex life (.19) showed the weakest relationships with the multi-item indexes.

The well-being and affect multi-item scales are found to be more strongly related to the single items than are the health-related scales, with average correlations for the Index of General Affect and the Index of Well-Being (both at .44) showing the strongest relationships with the single items. The ADL (.12) and the physical dysfunction SIP scores (.16) have the weakest mean associations with the various single-item measures.

The relationships reported in Tables 3 through 5 are very similar to those reported earlier for the Battelle study of ESRD patients (Evans et al. 1982). For the 15 correlations reported in the top five rows of Table 3, the multi-item affect-based indexes, the mean difference between the two sets of coefficients is .032 with a range of 0 to .14. Eight of the 15 comparisons differ by 0 (two comparisons) or .01 (six comparisons). The greatest difference is for the correlation of the General Well-Being Index with the ABS Negative Affect Scale; this study found .48 contrasted with the earlier study's .62. However, scoring of the ABS and its subscales by the earlier study was not equivalent to the method used for this study

Table 4: Pearson Correlation Coefficients for Single-Item Quality of Life Measures

	<i>Satisfaction with</i>								
	<i>Overall Life Satisfaction</i>	<i>Marriage</i>	<i>Sex</i>	<i>Family Life</i>	<i>Standard of Living</i>	<i>Friends</i>	<i>Hard/Easy</i>	<i>Tied Down/Free</i>	<i>Good Days Last Week</i>
<i>Satisfaction with</i>									
Marriage	.32								
Sex	.27	.15							
Family life	.41	.47	.19						
Standard of living	.52	.33	.22	.34					
Friends	.37	.28	.18	.29	.32				
Hard/easy	.36	.16	.11	.27	.29	.27			
Tied down/free	.38	.08	.20	.26	.26	.19	.34		
Good days last week	.40	.20	.18	.29	.27	.33	.33	.39	
Mean r	.38	.25	.19	.32	.32	.28	.26	.26	.30

Table 5: Pearson Correlation Coefficients for Single-Item and Multi-Item Quality of Life Measures

	<i>Satisfaction with</i>							<i>Mean</i> <i>r</i>	
	<i>Overall Life Satisfaction</i>	<i>Marriage</i>	<i>Sex</i>	<i>Family Life</i>	<i>Standard of Living</i>	<i>Hard/ Easy</i>	<i>Tied Down/ Free</i>		<i>Good Days Last Week</i>
General Well-Being	.51	.28	.23	.47	.35	.40	.40	.51	.39
Index of General Affect	.60	.27	.29	.43	.41	.42	.55	.54	.44
Index of Well-Being	(.93)*	.33	.31	.48	.53	.43	.51	.52	.44
Positive Affect Scale	.35	.16	.15	.23	.27	.28	.27	.30	.25
Negative Affect Scale	.36	.21	.14	.29	.22	.25	.30	.34	.27
Affect Balance Scale	.46	.26	.18	.34	.31	.33	.38	.41	.34
Physical dimension	.27	.00	.13	.16	.12	.11	.12	.24	.16
Psychosocial dimension	.38	.16	.25	.31	.23	.27	.21	.29	.27
Total SIP	.37	.09	.21	.24	.20	.20	.18	.29	.24
Activities of Daily Living	.20	.01	.08	.13	.10	.06	.09	.25	.12
Mean <i>r</i>	.39	.18	.19	.31	.27	.28	.28	.35	.38

*The part-whole correlation (.93) was omitted from means.

Table 6: Quality of Life of Michigan ESRD Patients as Assessed by a Variety of Measures (in order from lowest to highest quality of life)($N = 742$)

	N	Mean	Standard		Range	
			Deviation	Skewness	Minimum	Maximum
Negative Affect Scale	729	33	30	+ 0.7	0	100
Satisfaction with sex	716	54	37	-0.2	0	100
Affect Balance Scale	706	55	21	0.0	0	100
Hard/Easy	730	55	31	-0.1	0	100
Tied down/Free	731	59	34	-0.4	0	100
Overall Life Satisfaction	734	66	30	-0.6	0	100
Index of Well-Being	704	67	24	-0.6	0	100
Good days last week	731	69	31	-0.7	0	100
Index of General Affect	709	70	23	-0.6	0	100
Satisfaction with standard of living	738	70	30	-0.8	0	100
Satisfaction with friends	737	73	29	-0.9	0	100
General Well-Being	729	75	18	-0.7	20	100
Satisfaction with family life	738	75	27	-1.1	0	100
Satisfaction with marriage	485	84	28	-1.9	0	100
Total SIP	719	85	14	-1.4	21	100
Psychosocial dimension	722	87	15	-1.8	13	100
Physical dimension	730	87	16	-1.7	23	100
Positive Affect Scale	713	89	20	-2.2	0	100
Activities of Daily Living	614	91	13	-1.8	33	100

and, therefore, the correlations are not strictly comparable. Still comparing across studies, for 48 correlations between the six multi-item affect indexes and eight single-item measures, the mean difference was .03 with a range of 0 to .09 (modal difference = 0, $N = 8$). When the two sets are combined, in only 1 of 63 cases did the correlation among measures differ as much as .10 for those two groups of ESRD patients. (Data are not presented in tabular form.)

To allow comparisons of the variances of quality of life for this sample, depending upon the measure used, the scores have been standardized to a 0-100 scale. Thus, possible scores for "number of good days," which range from 0 to 7, were converted to 0, 14, 29, 43 . . . 100. (Scores in original units are available from the authors.) Each quality of life measure was assumed to have interval properties. Mean scores and measures of variation are reported in Table 6. The standardized scores have been transformed, if necessary, so that higher scores indicate higher quality of life.

The highest mean score (91 units) is found for the ADL measure, due in part to the large number of patients who reported no limitation

in activities of daily living (41.6 percent). The next highest and the lowest estimates of quality of life for this group of ESRD patients are found for the components of the Affect Balance Scale. Patients report much (89 units) positive affect, but also report a good deal (67 units) of negative affect, which translates to an absence of negative affect of only 33 units. The ABS as a whole is the third lowest index of quality of life, with a mean value of 55. Indexes indicating higher quality of life are the SIP (85 units) and its two dimensions (physical dysfunction and psychosocial dysfunction, at 87 units). Again, this is largely due to the number who reported no dysfunction at all related to their health (18.1 percent). Scores for satisfaction with marriage, the three SIP scales, the Positive Affect Scale, and the ADL had the most skewed distributions.

Scores for the two single-item, yet rather broad, measures of quality of life, hard/easy and tied down/free, have somewhat low values (55 and 59 units, respectively), and higher quality of life is represented by scores on both number of good days (69 units) and Overall Life Satisfaction (66 units). The remaining affect-based indexes, the Index of Well-Being, the Index of General Affect, and the General Well-Being Index, also have mean scores in the midrange (67 to 75 units).

The five domain-based satisfaction items, each of which specifies a narrow aspect of life, are shown to have produced a wide range of mean scores, from quite high (84 units) for satisfaction with marriage, to quite low (54 units) for satisfaction with sex life. Satisfaction with family, friends, and standard of living are in the midrange (70 to 75 units).

Table 7 reports the extent to which patients differ in terms of the demographic measures of sex, race, and age across the quality of life measures. Analysis of variance was employed to test for significance. Scores again have been standardized (and transformed if necessary). Differences between male and female patients tend to be small, with 4 of 19 comparisons producing differences statistically significant at the .05 level. However, a difference greater than five units is observed for only two items, the first being "satisfaction with sex life," where women report greater satisfaction by 21 units on the standardized scale. The second is the Negative Affect Scale of the ABS, where men report less negative affect than women.

Somewhat greater differences are found by race. Nine of the 19 comparisons provide differences that are statistically significant at the .05 level, and five differences are greater than five units. The largest difference is for satisfaction with standard of living; whites report more satisfaction by 14 units than blacks. Whites report "health" scores (SIP and ADL) higher than those of blacks but report life as being more "tied down" and "harder" than do blacks.

Table 7: Differences between Patients by Sex, Race, and Age on a Variety of Quality of Life Measures

	Sex		Race			Age	
	Male	Female	Black	White	20-40	41-60	61-89
General Well-Being	74	75	74	75	72	77	76*
Index of General Affect	68	72*	71	69	67	72	70
Index of Well-Being	66	69	67	68	64	68	70*
Overall Life Satisfaction	66	67	65	67	62	66	73*
Positive Affect Scale	88	89	86	90*	90	89	86*
Negative Affect Scale	36	30*	33	33	26	37	39*
Affect Balance Scale	55	54	53	55	52	57	55*
Satisfaction with marriage	86	82	76	87*	75	86	91*
Satisfaction with sex	45	66*	56	53	58	49	56*
Satisfaction with family life	75	76	74	76	69	77	83*
Satisfaction with standard of living	69	72	60	74*	63	73	77*
Satisfaction with friends	73	74	71	74	69	75	78*
Hard/Easy	54	57	60	54*	48	58	61*
Tied down/Free	57	61	64	57*	57	62	59
Good days last week	68	71	69	69	65	74	70*
Physical dimension	88	87	84	88*	92	86	82*
Psychosocial dimension	86	85	82	88*	88	87	84*
Total SIP	85	87	81	86*	88	85	80*
Activities of Daily Living	93	89*	89	92*	96	91	87*
	N = 404	N = 338	N = 200	N = 518	N = 267	N = 272	N = 203

*Differences between groups at statistical significance level of $p < .05$.

The analysis by age groups (20-40, 41-60, and 61-89) finds considerably more difference than the previous two analyses; analysis of variance indicates statistically significant differences among age groups for 17 of the 19 measures. Three patterns are noted, the most frequent being an increase in quality of life with increased age for 8 of the 19 measures. The first example of this pattern is found in scores for the Index of Well-Being together with its component, the Overall Life Satisfaction item. Scores for four of the satisfaction items—with marriage, with family, with friends, and with standard of living—also fit this pattern, as do the mean scores for the Negative Affect Scale (subscale of the ABS) and the “life is ‘easy’” item.

An opposite pattern—of decreasing quality of life with increased age—is seen for five measures: the three SIP indexes, the ADL Index, and the Positive Affect Scale (subscale of the ABS). Scores for four measures have a pattern of highest scores for the 41-60 age group: the Index of General Affect, the ABS Index, and the “life is ‘free’” and “good days” items. The remaining two measures result in the following: the middle-age group reports less satisfaction with sex life than either the younger or the older group, and General Well-Being Index scores are lower for the youngest group and approximately equal for those in the older groups.

As noted earlier, quality of life data were collected by interviews, usually in the patient’s home except for patients on hemodialysis. Almost half of the latter patients were interviewed while undergoing hemodialysis in their treatment center; questions may be raised about the comparability of those data. Preliminary analyses show no statistically significant differences in any of the quality of life measures, nor in age or sex distributions between patients interviewed at home or in the treatment center. There is a slight tendency for patients who had dialysis earlier in the day of interview to report higher “feeling” scores but lower “function” scores than patients whose last dialysis was the day before or longer ago, or those on dialysis at the time of interview. These differences will be explored in future reports but do not appear to bias the findings of this report on relationships among the various quality of life measures.

DISCUSSION

A wide array of measures is being used in examining a group of ESRD patients in Michigan to identify the relationship between modality of treatment and quality of life. All but one of the measures have been

used in prior studies of quality of life—in ESRD, other chronic diseases, or both.

However, some patient groups when examined by sex, race, or age will show higher quality of life in one subgroup by one measure, but higher quality of life in a different subgroup by another measure (see Table 7). One explanation could be that these measures are simply unreliable—that an occasional finding of statistical significance is a random occurrence, a statistical artifact. This could also explain rather low correlations among measures that seem at first to indicate low validity. This would be due to the attenuation of correlations that occurs when scores are unreliable, that is, when they contain random errors.

On the other hand, one might argue that the relationships reported here appear stronger than they are in reality, since they may contain systematic or correlated errors. Since all measures represent patients' self-reports and share similarities in format, such systematic errors would be common to all, thus increasing the correlation coefficients.

Andrews (1984) has addressed these issues of measurement and suggests procedures for estimating the true degree of association between measures, taking both unreliability and correlated error into account. We have applied Andrews' procedures to a sample result, the correlation of Overall Life Satisfaction with number of good days in the past week. This correlation, .40 as shown in Table 4, is estimated to be at least .40 but not greater than .55 when attenuation due to unreliability and enhancement due to correlated error are taken into account. The procedures would result in similar estimates for most of the other results reported here due to the similarities of the assessment format for the various indexes of quality of life. Thus, we believe the relationships reported here to be conservative as measures of concurrent validity.

A main issue is the validity of these various indexes as measures of quality of life. How might one judge the validity of these indexes? The first, and most frequently used standard is face validity (sometimes labeled content or definitional validity). In judging face validity, one examines the nature of the measure and compares it to one's conception of the phenomenon of interest; then one reaches a decision on whether or not the index is adequate. Since the conception of quality of life varies from person to person, some of the indexes reported here may be immediately rejected by some readers as not representing quality of life. It is also possible that an index can be accepted, on its face, as valid.

However, many readers may be unable to accept a quality of life

measure on face validity alone. Results of concurrent validation, the degree of association between two or more potential measures, each containing a degree of face validity but none completely adequate, may be helpful.

In examining the relationships among these measures of quality of life, based on 742 assessments, some are found to relate quite strongly, but others hardly at all. Thus, if any one measure is validly assessing quality of life, the others are capturing that concept to a greater or lesser degree. The problem is to identify which of the measures is the most valid.

The multi-item indexes we have used can be roughly classified as measures of how people feel about their lives and of how people are functioning within their lives. Measures within these groups of indexes correlate quite highly with each other, but show weak correlations across groups. An exception is the psychosocial dysfunction dimension of the SIP, which correlates highly with the feeling indexes. This suggests that psychosocial function is a component or correlate of quality of life as expressed in affect, or how people feel about their lives.

The single-item indexes can be broken into two groups. One contains five "satisfaction with" items, each referring to a rather narrow portion or domain of an individual's whole life; the other group contains four more-general items, Overall Life Satisfaction, good days, tied/free, and hard/easy. The strongest of the 36 relationships among these items is Overall Life Satisfaction with satisfaction with standard of living. Overall Life Satisfaction was also most strongly related to the other eight single-items on average, followed by satisfaction with standard of living and satisfaction with family.

To the extent that each of these is seen to be conceptually related to quality of life, the Overall Life Satisfaction item is highest on this analysis of concurrent validity. Exclusion of indexes judged not to have face validity would allow new calculations of concurrent validity, defined as the index that correlates most strongly with other indexes possessing some, but inadequate, face validity.

If one wants to select a single-item measure, and thinks that one or more of the multi-item indexes might be more valid but too extensive for use, the data in Table 5 should be helpful. If one assumes the ten multi-item scales to be equally valid, we note again that Overall Life Satisfaction has the highest concurrent validity with the multi-item measures, followed closely by number of good days.

Data on quality of life by sex, race, and age may be of interest in their own right, and may also help judge the validity of the various measures through the third general approach to validity assessment,

construct validity. Construct validity is defined here as the degree of relationship between a potential measure of a phenomenon of interest and a measure of some different phenomenon, but where the two phenomena are taken as strongly related. This relationship may be one based on undocumented theory, or on prior empirical work using measures accepted as valid but now unavailable for use. Anyone who believes that male ESRD patients experience better quality of life will give more credence to the Negative Affect Scale (subscale of the ABS) and the ADL Index while anyone believing female patients experience higher quality of life might put more trust in the Index of General Affect and the measure of satisfaction with sex life. Similar judgments can be made from these data on similarities and differences between blacks and whites and among the three age groups.

This article has reported the relationships among 19 measures of quality of life, with a particular focus on patients with ESRD. If each measure should suggest the same result as the others when used to assess the relative effectiveness of different forms of treatment, there should be little doubt about the findings. However, if one—or some—should suggest that one treatment is more effective, while others favor a different treatment, prior judgment will be needed to determine the more valid index in order to decide which treatment leads to the greatest quality of life. If at least one of the measures reported is determined to have sufficient validity, readers of future reports on relationships of modality of treatment to quality of life will be able to reach a judgment regarding the relative effectiveness of treatment modalities.

REFERENCES

- Andrews, F. M. "Construct Validity and Error Components of Survey Measures: A Structural Modeling Approach." *Public Opinion Quarterly* 48, no. 2 (Summer 1984):409-42.
- Atcherson, E. "The Quality of Life: A Study of Hemodialysis Patients." *Health and Social Work* 3, no. 4 (November 1978):55-69.
- Bergner, L., et al. "Health Status of Survivors of Out-of-Hospital Cardiac Arrest Six Months Later." *American Journal of Public Health* 74, no. 5 (May 1984):508-10.
- Bergner, M., et al. "The Sickness Impact Profile: Validation of a Health Status Measure." *Medical Care* 14 (January 1976):57-67.
- Berkman, P. L. "Measurement of Mental Health in a General Population Survey." *American Journal of Epidemiology* 94, no. 2 (August 1971): 105-11.
- Bradburn, N. *The Structure of Psychological Well-Being*. Chicago: Aldine Publishing Company, 1969.

- Bremer, B. A., and C. R. McCauley. "Quality-of-Life Measures: Hospital Interview versus Home Questionnaire." *Health Psychology* 5, no. 2 (1986):171-77.
- Campbell, A., P. E. Converse, and W. L. Rodgers. *The Quality of American Life*. New York: Russell Sage Foundation, 1976.
- Chubon, R. A. "Quality of Life and Persons with End-Stage Renal Disease." *Dialysis and Transplantation* 15, no. 8 (1986):450-52.
- Costa, P. T., Jr., et al. "Longitudinal Analyses of Psychological Well-Being in a National Sample: Stability of Mean Levels." *Journal of Gerontology* 42, no. 1 (1987):50-55.
- DeHaes, J. C. J. M., and F. C. E. Van Knippenberg. "The Quality of Life of Cancer Patients: A Review of the Literature." *Social Science and Medicine* 20, no. 8 (1985):809-17.
- Deniston, O. L., and A. M. Jette. "A Functional Status Instrument: Validation in an Elderly Population." *Health Services Research* 15, no. 1 (Spring 1980):21-34.
- Deniston, O. L., et al. "Change of Treatment in Studies of End-Stage Renal Disease Patients." Paper, in progress, Dept. of Public Health Policy and Administration, The University of Michigan, Ann Arbor, 1989.
- Deyo, R. A., and A. K. Diehl. "Measuring Physical and Psychosocial Function in Patients with Low-Back Pain." *Spine* 8, no. 6 (September 1983):635-42.
- Edlund, M., and L. R. Tancredi. "Quality of Life: An Ideological Critique." *Perspectives in Biology and Medicine* 28, no. 4 (1985):591-607.
- Evans, R. W., et al. *A Comparative Assessment of the Quality of Life of Patients Undergoing Treatment for Chronic Renal Failure: Results from the National Kidney Dialysis and Kidney Transplantation Study*. Update 15. Battelle Update Series. Battelle Human Affairs Research Centers, Seattle, WA, 1982, 1-94.
- Evans, R. W., et al. "The Quality of Life of Patients with End-Stage Renal Disease." *New England Journal of Medicine* 312, no. 9 (1985):553-59.
- Feinstein, A. R. "Clinimetric Perspectives." *Journal of Chronic Diseases* 40, no. 6 (1987):635-40.
- Freeman, R. B. "Treatment of Chronic Renal Failure: An Update." *New England Journal of Medicine* 312, no. 9 (1985):577-78.
- Health Care Financing Administration. *Special Report: Findings from the National Kidney Dialysis and Kidney Transplantation Study*. Washington, DC: Government Printing Office, 1987.
- Johnson, J. P., C. R. McCauley, and J. B. Copley. "The Quality of Life of Hemodialysis and Transplant Patients." *Kidney International* 22, no. 3 (September 1982):286-91.
- Julius, M., et al. "Independence in Activities of Daily Living for End-Stage Renal Disease Patients: Biomedical and Demographic Correlates." *American Journal of Kidney Diseases* 13, no. 1 (January 1989):61-69.
- Kaplan DeNour, A., and J. Shanan. "Quality of Life of Dialysis and Transplanted Patients." *Nephron* 25, no. 3 (1980):117-20.
- Katz, S., et al. "Progress in Development of the Index of ADL." *The Gerontologist* 7, Part 1 (Spring 1970):20-30.
- Levine, S. "The Changing Terrains in Medical Sociology: Emergent Concern

- with Quality of Life." *Journal of Health and Social Behavior* 28 (March 1987):1-6.
- Levy, N. B., and G. D. Wynbrandt. "The Quality of Life on Maintenance Hemodialysis." *Lancet* 1 (14 June 1975):1328-30.
- McDowell, I., and E. Praught. "On the Measurement of Happiness: An Examination of the Bradburn Scale in the Canada Health Survey." *American Journal of Epidemiology* 116, no. 6 (1982):949-58.
- McSweeney, A. J., et al. "Life Quality of Patients with Chronic Obstructive Pulmonary Disease." *Archives of Internal Medicine* 142 (March 1982): 473-78.
- Michigan ESRD Study. *Final Report to the Health Care Financing Administration, 1988*. Report prepared by V. H. Hawthorne et al., School of Public Health, The University of Michigan, Ann Arbor, 1989.
- Naish, P. "Dialysis and Transplantation and the Quality of Life." *British Medical Journal* 1 (13 January 1975):122-23.
- Pfeiffer, E. *OARS Multidimensional Functional Assessment Questionnaire*. Durham, NC: Duke University, Center for the Study of Aging and Human Development, 1975.
- Port, F. K., et al. "Discontinuation of Dialysis Therapy as a Cause of Death." *American Journal of Nephrology* 9 (March-April 1989):145-49.
- Poznanski, E. O., et al. "Quality of Life for Long-Term Survivors of End-Stage Renal Disease." *Journal of the American Medical Association* 239, no. 22 (2 June 1978):2343-47.
- Schmale, A. M., et al. "Well-Being of Cancer Survivors." *Psychosomatic Medicine* 45, no. 2 (May 1983):163-69.
- Simmons, R. G., C. Anderson, and L. Kamstra. "Comparison of Quality of Life of Patients on Continuous Ambulatory Peritoneal Dialysis, Hemodialysis, and after Transplantation." *American Journal of Kidney Diseases* 4, no. 3 (1984):253-55.
- U.S. Dept. of Commerce. *Social Indicators III. Selected Data on Social Conditions and Trends in the United States*. Washington, DC: Government Printing Office, 1980.
- U.S. Dept. of Health and Human Services. National Center for Health Statistics. "A Concurrent Validation Study of the NCHS General Well-Being Schedule." *Vital and Health Statistics*. Report prepared by A. F. Fazio. Series 2, Number 73, Publication No. (HRA) 78-1347. Washington, DC: Government Printing Office, 1977.