

QUALITY OF LIFE IN HEMODIALYSIS PATIENTS

B. Nabaie, A. Shahidzade and S. Dabiran

Department of Community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran

Abstract - To determine quality of life and various factors affecting it, we conducted a cross-sectional survey among 103 hemodialysis patients in four teaching hospitals of Tehran University of Medical Sciences.

A quality of life questionnaire (QLQ), containing various items relating to physical, psychological and social aspects of life was filled by interviewing each patient and a total score ranging from 70 to 300 was assigned to denote overall life quality. We also determined the most common underlying renal diseases and comorbid conditions in these patients.

The most common underlying renal diseases were found to be primary glomeruloarteriolar disease, interstitial disease, diabetes mellitus and essential hypertension. Common comorbid conditions in this study were musculoskeletal diseases (osteoarthritis), spinal disorders, gastrointestinal, cardiovascular and endocrine problems. Moreover, restricted social life, financial difficulties, loss of independence and family/marital strain emerged as major psychosocial problems affecting the lives of our patients.

The percentage of patients who had reached a satisfactory level of adaptation with dialysis therapy (46%) was distinctly lower than that reported from the United States. Advanced age and the presence of comorbid diseases were found to have a negative impact on the patients' life quality, while a positive association was recorded between quality of life and longer duration of dialysis treatment.

Overall, these findings indicate a significant degree of psychosocial impairment in our patients and emphasize the importance of providing effective counseling and rehabilitation services to hemodialysis patients.

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in many cases quality of life and productivity are not fully restored by treatment, raising serious questions about the true benefits of the application of such technologies. Among various treatment modalities, hemodialysis has been associated with a greater negative impact on the patients' life quality.

Quality of life, as defined by Keith in 1994, is the individual's personal views indicating his degree of satisfaction with his own physical health, social activities and interactions and his ability to control various aspects of life (4). As such, a marked difference between the patients' assessment of their quality of life and the assessment made by health care professionals has been documented (5). This is largely due to the fact that in the process of obtaining "informed consent" patients often cannot understand exactly what dialysis therapy entails, causing unrealistic expectations and subsequent disappointment. This could in turn lead to inefficient allocation and, hence, loss of scarce financial resources in an already budget-starved health care system.

Therefore, quality of life in today's medicine at both individual and community level is assessed on an increasingly "subjective" basis giving an ever-greater weight and priority to the patients' view of their own life; it was with this mentality that the present survey was carried out to determine quality of life in hemodialytic patients and its relation to various physical, social and demographic factors such as age, sex, job, underlying renal disease, duration of dialysis treatment and the presence of comorbid diseases and to identify the most prevalent etiologies of end-stage renal disease and common comorbid conditions in the dialysis population.

INTRODUCTION

Despite the recent improvements in the field of transplant surgery and allograft survival, hemodialysis remains the most frequently used treatment modality for End-Stage Renal disease (ESRD). It has been estimated that 70% of ESRD patients receiving therapy worldwide are on hemodialysis (1,2). Of an estimated total of 15000 ESRD patients in Iran, approximately 8000 (>50%) are under hemodialysis (3). The development of life-sustaining technologies has prolonged life beyond previously envisioned limits, but

MATERIALS AND METHODS

In this cross-sectional study, 103 patients answered questions relating to physical, psychological and social aspects of their lives.

Our quality of life questionnaires (table 1), adapted from SF-36 (4) and EORTEC-QLQ C30 (6) questionnaires, were filled via patient interviews between August and November 2000.

Sample size was calculated on the basis of the proportion of patients who had reached a satisfactory level of overall adjustment with dialytic treatment. This proportion was reported to be around 94% in the

famous Battelle study in the United States (7); so with $P = 0.94$, $\alpha = 0.05$ and $d = 0.05$ p

The sample size was computed as:

$$n = \frac{Z^2 (1-\alpha/2) \times (1-P)}{d^2} = 98$$

In practice, a total of 103 patients undergoing hemodialysis (3 weekly sessions each of them lasting 3.5 hours) in one of the four teaching hospitals of Tehran University of Medical Sciences were randomly selected and interviewed.

Inclusion criteria were age > 18 years (adult patients), and treatment duration of at least six months (interval required for psychologic and lifestyle adjustments to occur). Of the total number of patients, 50 were receiving treatment at Emam Khomeini Hospital. Sina, Shariati and Amir A'lam hospitals contributed 22, 19, and 6 subjects respectively.

Data were analyzed by the SPSS and Stata packages.

Table 1. General Format of the Study Questionnaire

Components	Coefficient	Maximum	Minimum
	Score	Score	Score
Physical Aspects			
Physical fitness	20.3	40	5
Symptoms experienced (10 items)	1	40	10
Psychosocial Aspects			
Overall adjustment to dialysis	20	80	20
Level of independence	10	40	10
View on the future	5	20	5
Effects on religious life	5	20	5
Money problems	5	20	5
Relations with family members	5	20	5
Social life and activities	5	20	5
Total Score	-	300	70

RESULTS

The mean age of the patients was 50.37 years (SD = 15.81 years), which is slightly higher than the average reported for American patients, but the difference is not statistically significant. The sex ratio (M/F) obtained in this study was 60.40, significantly higher than the 50.50 figure for American patients (Z test, $P < 0.01$). The patients had been receiving dialysis for an average of 37.5 months (a little more than 3 years) and the average duration of the underlying disease was 53 months (= 4.5 years).

The most common causes of renal failure were: 1) primary glomeruloarteriolar diseases (35.9%); 2) Interstitial diseases (including polycystic kidneys- (23.3%); 3) Diabetes mellitus (19.4%); 4) primary hypertensive renal disease and nephrosclerosis (15.5%) (Table 2).

The prevalence of glomeruloarteriolar disease as the leading cause of ESRD is very similar to the figure cited in European and American surveys. On the other hand, interstitial renal disease and diabetic nephropathy are clearly more prevalent in Iran than in the United States (Z test, $P < 0.01$), while renal failure due to arterial hypertension is more common in the American ESRD population (Z test, $P < 0.01$).

Table 2. Frequencies of underlying renal diseases in our study

Type of renal disease	Number	Percent
Primary glomerular and arteriolar diseases	37	35.9
Interstitial renal disease*	24	23.3
Diabetes mellitus	20	19.4
Primary hypertension	16	15.5
SLE	5	4.9
Other causes	1	1
Total	103	100

* including polycystic kidney disease

Table 3. Common comorbid conditions present in hemodialysis patients

Type of comorbid disease	Number	Percent
Musculoskeletal (osteoarthritis and myalgia)	42	40.8
Backpain and spinal problems	35	34
Gastrointestinal	32	31.01
Cardiovascular (non-ischemic)	28	24.2
Ischemic heart disease	27	26.2
Endocrine (including diabetes)	19	18.4
Neurologic	12	11.4

The most frequent comorbid conditions in our patients were musculoskeletal diseases (mainly osteoarthritis and myalgia - present in 41%), backpain and spinal problems (34%) and gastrointestinal disorders (27%) - other common problems were cardiovascular (ischemic and non-ischemic), endocrine and neurologic conditions (Table 3). The symptoms most commonly reported by the subjects included fatigue and malaise (80.6%), irritability (79%), localized pain or discomfort (67%) and insomnia (56%) (Table 4).

Hemodialysis patients

Table 4. Common symptoms experienced by hemodialysis patients.

Type of symptom	Frequency	Percent
Fatigue & lack of energy	83	80.9
Irritability	79	76.7
Localized pain & discomfort	69	67.
Sleep disorders (insomnia,...)	58	56.3
Diffuse ache and discomfort	53	51.1
Sexual dysfunction & impotence	50	48.5
Problems grasping & handling	46	44.7
Nausea and vomiting	43	41.7
Problems using the eyes	41	39.8
Loss of concentration	34	33

To assess the limitation in physical performance experienced by hemodialysis patients, an objective scale consisting of six degrees of functioning was used. Table 5 shows that the majority (52%) of patients are able to sustain at least a moderate level of physical activity, 26% had trouble walking several blocks or climbing stairs and almost 10% were barely able to perform tasks like eating, dressing and self-care. Comparison with the results of the Battelle study (5.4%) shows that a greater proportion of Iranian patients are fully functional (Z test, $P < 0.001$).

Table 5. Physical impairment in hemodialysis patients

Ability	Frequency	Percent
Level 1	17	16.5
Level 2	37	35.9
Level 3	27	26.2
Level 4	12	11.7
Level 5	10	9.7
Level 6	0	0
Total	103	100

Level 1: normal, able to perform all routine and sporting activities.

Level 2: difficulty enduring heavy physical stress (eg. running and strenuous sport).

Level 3: trouble walking several blocks or climbing stairs.

Level 4: difficulty sustaining routine activities (resting most of the time).

Level 5: barely able to care for self.

Level 6: requiring institutionalization, may be moribund.

Psychosocial aspects

When asked about their overall satisfaction and how well they had adjusted to dialysis, less than 47 percent of our patients reported a satisfactory level of adjustment, 39 percent said that their lifestyle had been profoundly disturbed and 14.6% described their lives as "totally crippled" (Table 5).

When we compare these results with those of the Battelle study- in which more than 94% of the patients had attained at least a fair degree of adjustment to therapy- it becomes evident that the proportion of subjects with good adaptation is significantly lower in our patients (Z test, $P < 0.001$) (No association was found between the patients' age and their degree of adaptation).

Table 6. Frequency of different degrees of adaptation to therapy

Level of Adaptation	Frequency	Percent
Complete adaptation	6	5.8
Life slightly perturbed	42	40.8
Considerably perturbed	40	38.8
Totally crippled	15	14.6
Total	103	100

Table 7. Psychosocial problems faced by dialysis patients

Type of problem	Frequency	Percent
Restricted social life	100	97.1
Financial problems	94	90.7
Loss of independence	74	71.8
Marital/family strain	73	70.9
Anxiety & fear of the future	72	69.9
Disturbed religious life	52	50.5

The most common psychosocial problems reported by the patients were as follows (Table 6); limitation of social contacts and activities (97%), financial problems (90.7%), loss of independence (71.8%) and family/marital strain (70.8%). Interestingly, 30% of the patients indicated that their illness had brought family members closer together, while few (<3%) made the same statement. About their social relations. The prevalence of social and family problems seems to be significantly greater in Iranian patients than in Americans (Z test, $P < 0.01$).

Employment is a significant variable in assessing quality of life because it affects self-esteem, feelings of independence, and control over one's life.

We compared the employment status of hemodialysis patients before treatment followed by their current status. Results showed that 38% of the patients (men) were employed (full-time or part-time) and another 40% (women) were house-wives before dialysis, but after initiating treatment these figures dropped to 15.5% and 18.4% respectively. This is matched by a dramatic increase in the percentage of the subjects who are unable to work because of poor health (from 3% before treatment to 48% at present).

A disturbingly high percentage (74.8%) of our patients reported that they had not received any kind of

assistance (sickness benefit or rehabilitation services) from either the government or the Kidney Patients' Society. 23 percent had obtained some sort of financial support (mostly loans) and only 2% had been offered counseling services.

The outcome variable - Quality of life

The average quality - of - life score in this study was 196.37 (SD = 38.9) with 53.3 percent of the patients having scores that fell in the "moderate" category and above. 44.7 percent had life qualities that were either "poor" or "very poor" (Table 8).

Table 8. Frequencies of different quality-of-life categories

Quality of life	Frequency	Percent
Very good	3	2.9
Good	17	16.5
Moderate	37	35.9
Poor	3	35
Very poor	11	11
Total	103	100

70-109.99	Very poor
110-154.99	Poor
155-199.99	Moderate
200-244.99	Good
245-300	Very Good

In testing the association between quality of life and various independent variables the following results were obtained:

A negative correlation was found between QOL scores and patients' age ($r = -0.196$, $P = 0.048$) and there was also a negative correlation between QOL score and the number of comorbid conditions ($r = -0.323$, $P = 0.001$).

Quality of life scores were found to be positively associated with the duration of dialysis treatment ($r = 0.271$, $P = 0.006$).

Comparisons between various degrees of educational achievement revealed a significant quality-of-life difference only between the first and second categories i.e, patients with primary school education had higher QOL scores than those who were illiterate (ANOVA, $P = 0.031$).

No correlation was found between quality of life and sex, occupation, marital status, type of renal disease, duration of renal disease and length of stay at hospital.

We also examined the relation between the patients' overall subjective view of their own quality of life and the objective QOL score obtained from the questionnaire.

Results showed significant differences between the first subjective category (quality of life perceived as very

good) and the 3rd, 4th and 5th categories. (QOL considered "moderate" to "very poor") (ANOVA, $P < 0.01$). The difference in QOL score between the first category ("very good") and the second category ("Good") was not statistically significant (ANOVA, $P = 0.071$). However, the fact that higher subjective categories had invariably better mean QOL score than the lower ones indicate a good degree of concordance between the subjective perception of life quality and the objective version based on the questionnaire.

DISCUSSION

The ESRD population in Iran, whose mean age of 50.37 years is close to that of the American patients (8), is expected to follow the demographic evolution recorded in Western countries: as the number of patients receiving successful transplants increases and the number of younger patients on dialysis decreases (9,10), the average age of new enrollees in dialysis centers is expected to be 54-56.8 years (11,12).

The special health needs of this aging population and its predictably higher degree of morbidity are important factors to be considered in the planning and allocation of health services for the ESRD patients. The reasons for the gender difference between Iranian and Western ESRD populations (see above) are not well understood.

The most common cause of renal failure in our study was primary glomeruloarteriolar disease, which accounted for almost 36% of all cases, a figure very similar to those of European and American surveys (13,14).

Other frequent etiologies, i.e, interstitial renal disease and diabetic nephropathy, are significantly more prevalent than in the United States. In contrast, hypertensive renal disease shows greater prevalence among American patients (28%).

These differences could reflect:

1) poor control and inadequate follow-up of diabetes and urinary tract infections in Iranian patients, especially in lower socioeconomic groups.

2) a smaller overall prevalence of arterial hypertension in this country.

Common comorbid conditions in our study were found to be gastrointestinal and cardiovascular problems. This pattern differs from that reported from the USA, where the most common comorbid diseases (in decreasing order of frequency) are cardiac (non-ischemic), musculoskeletal, and gastrointestinal disorders.

In comparing various degrees of physical impairment, it emerges that 16.5% of our subjects (versus 5.4% of American patients) are completely

functional whereas at the bottom of the scale 9.7% were virtually bed-ridden (vs. 6.8% in the US). Therefore the proportion of fully functional patients in Iran is significantly higher than in the United States. Overall, these findings imply a slightly better level of physical health for Iranian as compared to American patients, but the reasons for this are largely unknown.

The most common symptoms that bother our patients are fatigue and lack of energy (80.6% versus 82% in US), irritability (77% in US), localized pain (67% vs. 49% in US) and sleep disorders (56.3% vs 56% in US); this pattern is largely concordant with the figures reported in the Battelle study (7).

In comparing the psychosocial aspects of life in our patients with those of other countries, it is evident that the proportion of patients in Iran who have attained a good degree of adaptation (47%) is distinctly lower than the 94% figure in American patients, a fact that is felt to be due to lower socioeconomic status, high cost of medication (erythropoietin and calcium injections, etc.) and absence of any employment assistance or job reorientation mechanisms for those who begin dialysis therapy.

The lack of a statistically significant relationship between quality of life and variables like sex, marital status and disease etiology is confirmed in an earlier survey by Niechzial (15). Our study revealed a difference in life quality between illiterate patients and those who had elementary education, whereas Niechzial did not detect any significant difference across various levels of educational achievement.

The negative associations found between 1) quality of life and age and 2) quality of life and the number of comorbid conditions are similar to the results of Moreno's work (16).

In our survey, life quality was found to improve with longer duration of treatment, while Niechzial reports a negative association between the two variables. Further, more specific research is needed to elucidate the reasons for the discrepancy.

Our survey failed to detect an association between the patients' age and their degree of overall adaptation to therapy, while Holley states that older patients (because of their conservatism and fear of surgery) have adapted better to dialytic therapy (17), and in Keogh's study the association has been of the negative type (18).

Most of our patients complained of a loss of independence, whereas the great majority of subjects in the Battelle study considered themselves very independent. Also the proportion of patients with social and family problems in our study (42% and 34% respectively) is significantly higher than in the American population (4,8).

These differences are probably due to lack of various counseling and rehabilitative services that are

supposed to help the patients cope with their new situation.

Conclusion and recommendations

1) The results of this study show a severe degree of psychosocial impairment in our dialysis patients compared to other countries.

Recent efforts by the Iranian Kidney Patients' Society (e.g. setting up patient groups to encourage social contacts, organizing outdoor activities) have made some impact, but much remains to be done.

2) Health education programs, especially those aimed at promoting greater physical activity and a healthier diet, have proved to be a major factor in achieving a better life quality (19,20,21).

Provision of face to face education courses and/or reading material urging a more active lifestyle and an appropriate diet may be effective in this regard.

3) The disturbingly high prevalence of family and social problems in our patients emphasizes the importance of offering counseling services designed to enhance the ability of the family members to cope with problems and restrictions that arise from the presence of a dialytic patients within the family circle.

4) The etiologic pattern of ESRD in Iran (i.e. high frequency of interstitial and diabetic renal diseases), illustrates the importance of proper diagnosis, treatment and follow-up of diabetes and urinary tract infections, and also of judicious use of analgesic and anti-inflammatory drugs by practising physicians across the country.

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