

AN ASSESSMENT OF QUALITY OF LIFE IN LIBYAN PATIENTS UNDERGOING
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ABSTRACT

Background: In patients with end-stage renal disease, the need for renal replacement therapy to prolong life represents the final stage of living. Quality of life is one of the concepts that was accepted as a criterion for evaluating the outcome of medical efforts and the situation of patients with mental and somatic disorders. The aim of this cross-sectional study was to assess the quality of life of Libyan patients undergoing hemodialysis. **Method:** A cross sectional questionnaire-based survey. **Results:** 266 surveys were distributed, of which 227 were returned, giving a response rate of 85.3%. More than half of HD patients included in the study were females (119; 52.4%), married (124; 54.6%), and belonged to the age group of 31 to 50 years (106; 46.7%). Duration of dialysis has a clear impact on patients overall health included in the study. 50% of the patients undergoing dialysis for more than 10 years reported their health was worse than last year compared to 21.8% of patient undergoing dialysis for less than 5 years. When patients were asked about the effect of haemodialysis and kidney problems on their sexual life, the majority of patients (84.4%) reported "Yes". Furthermore, more than half (57.1%) of respondents reported that their health prevented them from working continuously. **Conclusion:** Libyan Kidney Diseases Centers should put the dialysis patients under the spot and try to improve their quality of life by understanding their needs and educating them about the disease.

KEYWORDS: Quality of Life; End-stage renal disease; Dialysis; Libya; Kidney diseases centers.

INTRODUCTION

Chronic renal failure is a progressive destruction of the kidney function in which the body metabolism, water and electrolyte balance are disturbed. In patients with end-stage renal disease (ESRD), the need for renal replacement therapy to prolong life represents the final stage of living. Globally, it was reported that almost 60000 persons die annually due to renal failure but with various incidence.^[1] The annual incidence of ESRD in North Africa, including Libya, ranges between 34 and 200 persons per million.^[2,3] This incidence is much higher than that in the West, which may indicate poor renal health care standards. The principal causes of ESRD are interstitial nephritis (14-32%) attributed to environmental pollution and inadvertent use of medications, glomerulonephritis (11-24%), diabetes (5-20%) and nephrosclerosis (5-21%).^[4,5]

Treatment of ESRD is hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation. HD is usually conducted at in-hospital dialysis unit where attendance few times a week and few hours per visit is required. Patients on PD can self-dialyze at home with regular infusions of dialysis solution into the peritoneal cavity,

which offers flexibility and privacy for patients. Dialysis treatments are now viable even for elderly patients and those with co-morbid diseases.^[6,7] Patients who receive HD encounter many pathological states as hypertension, lack of appetite, anemia, genital disorders, skin disorders and others.^[8] Mortality rate among dialysis patients remains high at 10-20%^[9], the annual growth in number of ESRD patients receiving treatment is 7-8%.^[10] There was an estimated 1.9 million ESRD patients receiving some form of renal replacement therapy where 80% of the patients receive dialysis and 20% receive transplantation.^[10] The transplant activity in North Africa is impressive, most donors are living, since the law either does not permit or has just permitted cadaver donor transplantation. The outcome of renal transplantation in terms of patient and graft survival conforms to the international standards. However, the major cause of patient morbidity and mortality is infection.^[11]

Quality of life (QoL) is one of the concepts that was accepted as a criterion for evaluating the outcome of medical efforts and the situation of patients with mental and somatic disorders.^[12] Although improving survival of the patients on dialysis is the highest, clinicians now

also recognize the importance of assessing the quality of this survival. Dialysis treatment is time consuming, intrusive and can be burdensome for patients^[13] and patients encounter many physical, psychological and social stressful factors that are not controllable.^[14] Therefore, patients' perceptions of the impact of dialysis on the quality of their remaining life is an important consideration when providing care. Dialysis patients consistently perceive themselves as having a poor health-related quality of life (HRQoL).^[14,15] Patients treated with HD have many stressful factors in their life as family problems, changes in sexual function, becoming dependent on others, social isolation, changes in body image, mental stresses and suicide.^[16] Reduced physical functioning can compromise employment opportunities and participation in social and leisure activities resulting in poorer HRQoL and higher risk of mortality.^[17,18] Poorer HRQoL could increase the mortality risk through inferior adherence to the strict dietary and medical regiments of dialysis.^[19] The focus is to optimize parameters of clinical variables to achieve a better HRQoL in dialysis patients. Previous studies suggest that management of anemia with recombinant human erythropoietin^[20,21] and improving nutritional status by increasing the serum albumin levels of dialysis patients^[22] were associated with improved HRQoL. Different factors can be effective in increasing QoL in HD patients. One is self-care ability, which is a learnable behavior that would solve patient's general, developmental and health deviation needs, and its continuous efforts that people do themselves to continue their life and to provide health and welfare. Several studies were conducted for the same purpose and had highlighted the high and positive relationship between QoL and the outcome of medical efforts and the situation of patients with mental and somatic disorders.^[12,23] However, there is still inadequate research on the subject in Libya. The aim of this cross-sectional study was to assess the QoL of Libyan patients undergoing hemodialysis.

METHOD

A total of 266 patients undergoing hemodialysis were approached, either directly or via telephone, in order to arrange a 15-minute interview with the researcher at a time convenient to them. Two hundred twenty seven (85.3%) agreed to participate in the study and completed the questionnaire during the interview. Lack of time, illness, or not willing to participate were the main reasons for the 39 patients who refused to take part in the study. The study was carried out over a period of six months (May to October 2015).

All patients who were 15 years old or more and were on haemodialysis for more than one month were included. All peritoneal dialysis patients, patients with CNS diseases, or those with acute illness were excluded from the study.

Kidney Disease and Quality of Life™ Short Form (KDQOL-SF™) Arabic Version 1.3 Copyright© 1993-1995 by RAND and University of Arizona was used with permission from Dr Samar Abdulhafid (Personal Communication; 9/03/2014).

KDQOL-SF™ is available in English and was translated into Arabic by KDQOL-SF™ group and RAND. KDQOL-SF1.3 is a disease targeted items focus on particular health related concerns of individuals with kidney disease and on dialysis. The questionnaires consist of eight sections including symptoms and problems (4 items), effect of kidney disease on daily life (8 items), burden of kidney disease (4 items), work status (2 items), cognitive function (3 items), quality of social interaction (3 items), sexual function (2 items) and sleep disorders (4 items). The survey also include three additional QoL scales: social support (2 items), dialysis staff encouragement (2 items, not included in the Arabic version) and patient's stratification (1 item).^[24,25]

Data collection

The purpose of the study was described to each patient who were reassured about the confidentiality of their data and informed that their material would not be disseminated for any other purpose. Their answers on the survey were considered as a consent from their side to take part in the study. Participants who had problems in reading or understanding the questionnaire or could not read and write were assisted by the researcher.

Data analysis

The participants' responses were encoded and the data were analyzed using Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, version 20.0, (IBM Corp., Armonk, NY., USA). Descriptive analysis was used to calculate the proportion of each group of respondents with each statement in the questionnaire. Chi-Square was used to ascertain any significant difference among the participants' responses. The level $p < 0.05$ was considered as the cutoff value for significance.

Ethics Statement

Ethical review and approval was sought from the Ethical Committee of University of Tripoli (UOT 21015) Tripoli, Libya. Informed consent was obtained from all the patients before data collection and appropriate measures were taken to minimize risks and maintain confidentiality.

Informed consent

"Informed consent was obtained from all individual participants included in the study."

RESULTS

A total of 266 surveys were distributed, of which 227 were returned, giving a response rate of 85.3%. More than half of HD patients included in the study were females (119; 52.4%), married (124; 54.6%), and

belonged to the age group of 31 to 50 years (106; 46.7%). Eighty-nine (39.2%) of the respondents reported that they had a university degree, and 141 (62.1%) reported that they have had hypertension, diabetes, or both at the time of the study. Duration of being under dialysis and respondents characteristics are summarized in Table 1.

Despite the fact that 61.3% of female patients and 34.2% of male patients under investigation reported that their health is better compared to the same time of the last year, more than one quarter (26.9%) of male and female patients still believe that their health is worse compared to their health one year ago. Interestingly, patients have not agreed that haemodialysis is affecting their social activities or increasing their feeling of pain. However, severe muscle cramps were reported by 28.6% of female and 12% of male respondents. Furthermore, 20.4% of male and 31.1% of female patients reported their health was limiting a lot in lifting the groceries. Disturbance of sleep patterns was reported by more than half of male (54.3%) and almost half (49.0%) of female patients.

Patients undergoing haemodialysis were very concerned about the time they spent dealing with their kidney disease and dialysis. Almost three quarters of males (78; 72.2%) and females (89; 74.8%) reported either definitely true or mostly true on the questionnaire statement "too much time is spent dealing with my kidney disease".

When the patients under investigation were asked if they had any difficulty concentrating or thinking, more than three quarters 82 (76.0%) of females and more than half 67 (56.3%) of males reported "Either none of the time or a little of the time". Duration of dialysis has a clear impact on the overall health of patients included in the study. About 50% of the patients undergoing dialysis for more than 10 years reported that their health was worse than last year compared to 21.8% of patient undergoing dialysis for less than 5 years. When patients were asked about the effect of haemodialysis and kidney problems on their sexual life, the majority of patients (84.4%)

reported "Yes". Furthermore, more than half (57.1%) of respondents reported that their health prevented them from working continuously.

Relationship between sociodemographic characteristics (educational level) and the survey questions/ statements "Kidney disease interferes too much with my life, React slowly to things that were said or done, Act irritable toward those around you" is summarized in Table 2.

Table 1: Characteristics of 227 participants

Parameters	n (%) (n = 227)
Age	
< 30 years	43 (18.9)
31-50 years	106 (46.7)
51-70 years	63 (27.8)
> 70 years	15 (6.6)
Gender	
Male	108 (47.6)
Female	119 (52.4)
Marital status	
Married	124 (54.6)
Single	79 (34.8)
Widowed	24 (10.6)
Educational levels	
No education	26 (11.5)
Primary/Middle school	70 (30.8)
High secondary school	42 (18.5)
High Institute/University	89 (39.2)
Co-morbidities	
None	65 (28.6)
Diabetes mellitus	16 (7.0)
Hypertension	86 (37.9)
Diabetes/hypertension	39 (17.2)
Other diseases	21 (9.3)
Duration of dialysis	
< 5 years	160 (70.5)
6 - 10 years	53 (23.3)
> 10 years	14 (6.2)

Table 2 Responses of haemodialysis patients for cognitive function and the burden of kidney disease.

Statement/Question	School level n (%) 112	High level n (%) 90	Illiterate n (%) 25	Chi Square
Kidney disease interferes too much with my life				
• Either definitely true or mostly true	81 (73.3)	59 (65.5)	13 (52.0)	0.01
• Don't know	2 (1.8)	6 (6.7)	0 (0.0)	
• Either mostly false or always false	29 (25.9)	25 (27.8)	12 (48.0)	
React slowly to things that were said or done				
• Either none of the time or a little of the time	77 (68.8)	69 (76.6)	20 (80.0)	0.05
• Either some of the time or a good bit of the time	20 (17.8)	15 (16.7)	3 (12.0)	
• Either Most of the Time or All of the Time	15 (13.4)	6 (6.7)	2 (8.0)	
Act irritable toward those around you				
• Either none of the time or a little of the time	64 (57.1)	63 (70.0)	17 (68.0)	0.01
• Either some of the time or a good bit of the Time	26 (23.2)	24 (26.7)	4 (16.0)	
• Either most of the time or all of the time	22 (19.6)	3 (3.3)	4 (16.0)	

DISCUSSION

Several studies have previously been reported on variability in mortality in various centers (26-29) but with no data on differences in HRQoL between dialysis centers. Center characteristics that improve survival rate are: pre-dialysis care, center access to transplantation, non-profit vs. for-profit and length of ownership.^[26-29] In Libya kidney centers are governmental non-profit and have access to renal transplantation. Differences in pre-dialysis care among centers were observed throughout this study which may explain some of different findings. The most studied determinants are age, gender, marital status, educational level, employment status and family support.^[30-33] The influence of gender on QoL was assessed in patients on dialysis with contradictory findings between male and female scores on QoL measures. Two studies by Acaray and Pinar^[34] on Turkish HD patients and by Kalantar-Zadeh *et al.*^[35] on American HD patients found that gender is not significantly different in determining QoL using SF-36 health survey. In contrast, a study by Mingardi and others^[22] on Italian dialysis patients reported that QoL varied according to gender with the physical dimension of QoL was higher in males. The present study indicates that women have lower QoL in all domains of physical and mental health as compared to men except in estimation of their general health as previously reported.^[36,37] This may be explained by women's multiple domestic tasks and responsibilities that, unlike men, they cannot circumvent.^[38] The reasons for the differences between genders remained speculative and include biological factors, cultural conditioning or biases in the provision of care according to gender.

Ross and van Willigen^[39] investigated the relationship between education and a variety of indicators of subjective QoL in USA. Thus, using two representative national samples collected in 1990 and 1995, the well-educated have lower levels of emotional and physical distresses but have lower levels of dissatisfaction. Education reduces distress by way of paid work and economic resources, which are associated with high personal control. The extent to which it reduces distress by way of marriage and social support is much more modest. Several studies found a relationship between educational levels and QoL. Each one used a different QoL tool. Pakpour *et al.*^[40] studied Iranian HD patients using Persian version of SF-36 and found that patients with lower level of education have poor QoL scores. Acaray and Pinar^[34] found differences in educational levels of four groups of dialysis patients. They reported that the overall total scores of SF-36 increased as educational status increased. Another study by Mozes *et al.*^[41] investigated patients receiving dialysis therapy by using QoL index while the study by Suet-Ching^[42] reported that QoL in Hong Kong dialysis patients using Chinese Dialysis QoL scale. Both studies linked high QoL scores with higher educational level. Similar findings were observed in a sample of stable Spanish dialysis patients using KSSIP tools.^[43] In contrast, a

study by Kao and others^[44] reported that educational level is not associated with HRQoL. Nevertheless, higher levels of education appear to positively affect and promote health. Educated dialysis patients could take some responsibility of their own health and thus would learn and employ strategies to cope with the disease and its symptoms leading to enhanced QoL.^[22,45] The present findings of a significant difference among educational levels as have previously been reported where educational level increase and so the QoL.^[44,46] Patients with high education level were found to have better QoL in all domains of physical health, while in mental health, patients with high educational level seem to have better QoL in vitality, emotional well-being and role emotional domains. Patients with no education and those with school level seem to have better social functioning compared to patients with high education level. This might be due to patients with lower levels have less concerns about life matters and not getting busy with any work or duties.

Dialysis patients not only face treatment-related stressors but also have to deal with changes in their life, self-confidence and family roles.^[47] Bohlke *et al.*^[33] used a cross-sectional design to study predictors of QoL in patients undergoing dialysis (94 on HD and 46 on PD) in three southern Brazilian dialysis facilities using SF-36 survey. They found that patients who had been on dialysis for short lengths of time had higher QoL scores compared to patients who are on dialysis for longer periods of time. Co-morbidity and length of time on dialysis are the main predictors of physical QoL whereas socioeconomic issues determine mental QoL. Pakpour *et al.*^[40] and Mittal, *et al.*^[48] evaluated QoL of American HD patients using SF-36 three-monthly over two years. Thus, an inverse relationship of physical function, body pain and general health vitality with duration of dialysis was observed. HD normally removes small molecular weight of waste products as urea and creatinine and makes patients feel better and improve QoL.^[49] Morsch *et al.*^[49] reported that patients who had been receiving HD for more than one year had better QoL scores than patients who had been on a less time. Patients with long duration of dialysis had no problem with their physical abilities or their emotional role. This might be due to habituation and adaptation of the patients with their life extending condition while mental health was better in patients with relatively short duration dialysis. Patients with short dialysis might experience less depression and better mental health comparing to patients with longer years under dialysis. Middle molecules such as β_2 -microglobulin and phosphorus are poorly removed by HD and causes calcium-phosphorus imbalance and skin itching.^[50] This leads to dialysis amyloidosis and the associated pathology tends to increase in severity with time on dialysis.^[51]

CONCLUSION

In conclusion, this study shows a negative impact caused by ESRD and HD in patients with low educational

levels, longer periods of dialysis and on females. Thus, Libyan Kidney Diseases Centers should put the dialysis patients under the spot and try to improve their QoL by understanding their needs and educating them about the disease.

Conflict of interest: The authors report no conflict of interest

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