

Health-Related Quality of Life (HRQoL) in Haemodialysis Patients in Khartoum, Sudan

Samira Khatir Ali Fadlalla

Correspondence:

Dr. Samira Khatir Ali Fadlalla
Alwaab Health Center
Qatar

Email: Samiraali71@hotmail.com

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Abstract

Much research has been conducted in many countries on the Health-Related Quality of Life (HRQoL) of haemodialysis patients, but few have been conducted in Khartoum, Sudan. All studies have shown that patients' Quality of Life regarding the dimensions of physical, psychological, social, and environmental was affected by the disease. Previous research ignored the impact of religious beliefs on haemodialysis patients. We used the WHOQOL-BREF questionnaire (the English standard version) to collect data from 181 participating patients. Religious beliefs had a significant impact on the overall outcome of the study, and strong social relationships among the Sudanese population (which distinguishes the Sudanese population from other nations) increased the patients' satisfaction rate with their social relationships. The lack of transport facilities from the patients' homes to the dialysis center (and vice versa) forced the patients to reduce the number of prescribed sessions.

Background: In recent decades, Health-Related Quality of Life (HRQoL) endpoints have proven to be valuable research tools for evaluating the outcomes of therapeutic interventions in chronic diseases. End-stage renal disease (ESRD) is one such chronic disease that leads to a high degree of disability in various aspects of the patient's life and impairs their quality of life.

Objectives: The main objectives of this study were to assess the QoL in haemodialysis patients concerning their physical, psychological, social, and environmental health dimensions, and to assess the effects of age, sex, income, and level of education, in addition, to identify modifiable factors in Khartoum Sudan, associated with Health-Related Quality of Life (HRQoL) among chronic haemodialysis patients.

Instrument and Material: A sample of 181 patients was recruited for this study. To collect the data we used the WHOQOL-BREF (the English standard version), a generic health-related questionnaire developed by the

WHOQOL group and available in 19 different languages. The English standard version was recommended by Mrs Sibel Volcan (WHOQOL representative) because it is best suited to Sudan.

Scoring and Validation of WHOQOL-BREF

Questionnaire: A detailed step-by-step guide to using the WHOQOL-BREF questionnaire was clearly explained to me in a separate document by the WHOQOL representative.

Results: Religious beliefs have a significant impact on the overall outcome of the study. No correlation was found between patients' age, gender, and quality of life. Physical pain prevented 63.5% of the participating patients from doing what they needed to do, 49.2% of the haemodialysis patients had the energy to carry out their daily activities, 71.8 were satisfied with their sleep, 34.3% often had a negative feeling, 83% were satisfied with their sex life, 2.8% do not have a physically healthy environment, 43.3% were dissatisfied with the condition of their living spaces, the transportation was a nightmare for the majority of patients, 84.5% were satisfied with their social relationships and the support they receive from people around them, and .6% of patients have no way at all to meet their daily needs.

Discussion: Physical pain prevented 63.5% of patients from doing what they needed to do to some extent, 40.9% were dependent on medical treatments to perform their daily activities, more than half of haemodialysis patients can get around, the lack of important information harms patients and transportation is a nightmare for the majority of participating haemodialysis patients.

Conclusion: Inadequate distribution of dialysis centers in Sudan, lack of stable transportation from patients' homes to dialysis centers (and vice versa), and insufficient information on how to deal with the disease were significantly associated with lower scores for all general and several kidney disease-related HRQoL scores.

Key words: HRQoL, Haemodialysis, Sudan

Background

In recent decades, quality of life (QoL) endpoints have proven to be valuable research tools for evaluating the outcomes of therapeutic interventions in chronic diseases. End-stage renal disease (ESRD) is one such chronic disease that leads to a high degree of disability in various aspects of the patient's life, which in turn affects quality of life.

Due to these reasons, loss of financial income, the physical, psychological, socioeconomic, and environmental aspects of life are negatively affected, leading to compromised QoL.

The availability of haemodialysis centers in Khartoum has reduced the severity of symptoms and led to longer patient survival. Haemodialysis therapy is time-consuming and requires restrictions on fluid intake and diet. Long-term dialysis therapy often leads to a loss of freedom, dependence on carers, disruption to marital, family, and social life, and a reduction or loss of financial income. For these reasons, the physical, psychological, socioeconomic, and environmental aspects of life are negatively affected, resulting in a reduced quality of life.

In Sudan, haemodialysis remains the main modality of Renal Replacement Therapy (RRT) for most of the treated ESRD patients. Because of financial constraints, the prescribed haemodialysis sessions are often below the recommended number of sessions per week, with most patients being provided with haemodialysis twice weekly. For practical purposes, the Urea Reduction Ratio (URR) has been used as an approximate method for assessing urea clearance rather than the formal urea kinetic modeling; it has remained the most commonly used parameter used to assess the dialysis dose in all haemodialysis units. As per the National Kidney Disease Outcome Quality Initiative (KDOQI) recommendations, adequate clearance is determined by a URR of not less than 65%.

The total number of patients requiring RRT by far exceeds the available treatment facilities. Despite that, all patients were prescribed four hours of haemodialysis sessions, practically, not all of our patients normally complete the four-hour sessions. The reasons for interrupted haemodialysis sessions among our patients included late arrival, delayed initiation of dialysis, intra-dialytic complications, and patients' non-adherence, which often causes the delivered dialysis doses to be less than the prescribed doses. Short dialysis sessions often cause impaired control of fluid volume and reduced clearance of middle-size molecules, which are known as independent predictors of patient outcomes. On the other hand, longer dialysis sessions provide better tolerance of ultrafiltration, less frequent intra-dialytic hypotensive episodes, and better control of blood pressure, and were independently associated with lower mortality. Increasing the duration of haemodialysis sessions to more than four hours might be a useful method for improving urea clearance and patients' mortality, but it is often hindered by patients' intolerance and the cost of the session.

To compensate for the reduced number of weekly dialysis hours, most haemodialysis units try to achieve maximum urea clearance during individual haemodialysis sessions, although limitations are often seen.

Review of Literature

A study conducted by the Official Journal of the International Society of Nephrology in the USA, European countries, and Japan, comparing the HRQoL of dialysis patients in three continents (Asia, America, and Europe), found that ESRD and haemodialysis significantly affected HRQoL in all three continents. In the USA, the impact on mental health is lower than in other countries; Japanese haemodialysis patients perceived their kidney disease as a greater burden, but their physical performance was significantly higher.

The different distribution of socioeconomic factors and comorbid diseases could explain only a small part of these differences in physical performance. Other possible factors, such as the quality of dialysis and related health care, deserve careful investigation.

The level of aerobic physical activity was higher in patients treated in dialysis units that offered an exercise program than in those that did not. This suggests the possibility of improving the level of physical activity of patients by offering more such programs to haemodialysis patients.

Two other studies in the journal found that depression in dialysis patients increases the risk of hospitalization and that older adults with kidney dysfunction have an increased risk of mental impairment, depression, fatigue, falls, and mobility problems.

Depression is thought to be the most common psychiatric disorder in haemodialysis (HD) patients. There is a paucity of data using psychiatric diagnostic criteria and a lack of large, well-designed epidemiological research studies on ESRD patients that can provide definitive results on this topic. The prevalence of major depression or a defined psychiatric disorder in ESRD patients is not known but is probably between 5 and 10%. The prevalence of increased levels of depressive affect is higher. Estimates of prevalence vary depending on the screening techniques used. Depression may affect medical outcomes in ESRD patients through multiple mechanisms. Correction analysis suggests that stressors and protective factors play a role in mediating the level of depressed mood and associated outcomes. Although many studies have found a negative impact of depression on survival in ESRD patients, more recent studies have not confirmed these results. The use of longitudinal analyses and larger samples has confirmed an association between depressive mood and morbidity and mortality in more modern ESRD populations. The importance of depressed affect versus the presence of a defined psychiatric syndrome in mediating clinically important outcomes in patients with chronic kidney disease has not been established. Studies of interventions aimed at reducing the level of depression in ESRD patients are urgently needed.

Religious and spiritual aspects of quality of life (QOL) have not been extensively studied in patients with end-stage renal disease (ESRD) treated with haemodialysis (HD), but psychosocial factors are associated with patient survival. To investigate the relationships between religious beliefs and psychosocial and medical factors, a study on 53 (HD) patients was conducted. Psychosocial and medical variables included perception of the importance of faith (spirituality), attendance at religious services (religious commitment), the Bech Depression Inventory, the Illness Effects Questionnaire, the Multidimensional Scale of Perceived Support, McGill QoL Questionnaire scores, Karnofsky scores, dialysis dose, and pre-dialysis haemoglobin and albumin levels

Result

In the study mentioned above, Eighty-seven percent of the participants were African-American. Men had higher depression scores, felt less social support, and had higher religious commitment scores than women. No other parameters differed between the genders. Perceptions of spirituality and religiosity did not correlate with age, Karnofsky score, dialysis dose, or haemoglobin or albumin levels. A stronger perception of spirituality and religiosity correlated with a stronger perception of social support and quality of life as well as with a less negative perception of the effects of disease and depression. Single-question global QOL measures correlated with depression, life satisfaction, perception of disease burden, social support, and satisfaction with nephrologist, but not with age or Karnofsky score. Religious beliefs are related to perceptions of depression, disease burden, social support, and quality of life independent of medical aspects of the disease. Religious beliefs may serve as coping mechanisms for patients with ESRD. The relationship between religious beliefs and clinical outcomes should be further investigated in patients with ESRD.

Objectives

The main objectives of this study were to evaluate the Quality of Life of haemodialysis patients in Khartoum, Sudan, in terms of their physical, psychological, social, and environmental health dimensions and to assess the impact of age, gender, income, and educational level, as well as to identify modifiable factors associated with Health-Related Quality Of Life (HRQOL) in chronic haemodialysis patients.

The quality of life (QoL) of haemodialysis patients in some haemodialysis centers in Khartoum State was investigated in a cross-sectional study. The WHOQOL-BREF questionnaire was used to assess the QoL of patients in the last two weeks. It was found that the quality of life of haemodialysis patients was significantly lower in all four WHOQOL-BREF domains. No difference was found between male and female haemodialysis patients in terms of their Quality of Life, patient transportation from homes to dialysis centers (or vice versa) and lack of patient awareness of diet and exercises (which could have been provided

during dialysis sessions) is causing some negative impacts on patient health. A positive association was seen between higher education and the psychological functioning and the environmental dimensions of WHOQOL-BREF

Method and Material Used

Patients were recruited from dialysis centers of Alwaddain Health Center, Ahmed Gasim Teaching Hospital, and Alsafia Dialysis Center. The only criterion for inclusion was age; participating patients were between 18 and 65 years of both genders; with no regard to the frequencies of haemodialysis sessions. It was explained to enrolled patients that the questionnaire questions were about the last two weeks of their lives, and the patient needed to be able to speak so he/she could answer the questionnaire.

Instrument for Assessment of QOL

WHOQOL-BREF is a generic health-related questionnaire developed by the WHOQOL group. It is available in 19 different languages, however, Arabic is not included, and according to the correspondence that took place before choosing the right version of the WHOQOL questionnaire for this research, the standard English version was recommended as the one that best fits Sudan. The WHOQOL-BREF consists of 26 facets and provides a profile of scores on four dimensions of Quality of Life; physical health, psychological, social relationships, and the environment, as shown in Table 1. WHOQOL-BREF is available in both self-administered and interview-administered forms.

Scoring The WHOQOL-BREF

The WHOQOL-BREF produces four domain scores (as mentioned in the table above). Two items are examined separately: question 1 asks about an individual's overall perception of quality of life and question 2 asks about an individual's overall perception of his/her health. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 (first transaction) to domain comparable with the scores used in the WHOQOL-100 and subsequently transformed to a 0 – 100 scale (second transformation) using a given formula (COMPUTER PHYS = (PHYS-4)*(100/16)).

Validation Of WHOQOL-BREF Questionnaire

The American WHO-BREF questionnaire version has been validated and has demonstrated good content validity, discriminate validity, test-retest reliability, and internal consistency.

Data was collected from patients and documented in a suitably designed data collection form. The WHOQOL-BREF was administered to the Haemodialysis patients to assess their QoL and to analyze the correlation between different variables.

Table 1 WHOQOL-BREF 4 Domains

Domain	Facets Incorporated with Domains
Physical Health	Physical Pain (Q3) Dependence on Medications (Q4) Energy for Everyday Life (Q10) Mobility (Q15) Sleep Satisfaction (Q16) Daily Living Activities Performed (Q17) Work Capacity (Q18)
Psychological	Positive Feeling (Q5) Meaning of Life (Q6) Concentration (Q7) Bodily Appearance (Q11) Self-satisfaction (Q19) Negative Feelings and Depression (Q26)
Social Relationship	Personal Relationship (Q20) Sex Life (Q21) Support From Friends (Q22)
Environment	Daily Life Safety (Q8) Physical Environment (Q9) Sufficient Money (Q12) Information Availability (Q13) Leisure Activities (Q14) Condition Of Living Place (Q23) Access To Health Services (Q24) Transportation (Q25)

Results

Statistical Analysis

Statistical Analysis was done using IBM SPSS statistics version 19. Bivariate Pearson correlations, cross-correlations and One-Way ANOVA test, and WHOQOL-BREF SCORES were analyzed with one-way ANOVA and t-test. When performing ANOVA A, if the omnibus F-test was found to be statistically significant, multiple comparisons between QoL scores of each domain of WOHQOL-BREF. We conducted a linear regression analysis to determine the stronger predictions of QoL. $P < 0.05$ was regarded as being statistically significant.

Analysis Of QoL Scores

QoL of haemodialysis patients was found to be significantly ($P < 0.05$) impaired particularly concerning the physical, psychological, social relationships, and the environmental domain. It was interesting to note that the environmental domain has the lowest score despite the fact this domain contains the transportation question; 63% of responders were dissatisfied with the transportation means they use to and from the haemodialysis centers, 35.9% were satisfied and 1.1% were very satisfied (as shown in Table 2). In haemodialysis patients, the highest QoL score was observed in the psychological health domain (75.00) followed by the physical domain (60.71) and social relationships (58.33)

Table 2: QoL Scores

Physical	Psychological	Social Relationships	Environment
60.71	75.00	58.33	53.13

The research was conducted on a sample of 181 haemodialysis patients, male patients (123), and female patients (58), which are presented in Table 3.

Table 3: Gender

Gender	Frequency	Percent	Valid Percent	Cumulative Percent
Male	123	68	68	68
Female	58	32	32	100
Total	181	100	100	

Association Between Gender and QoL

The correlation Bivariate Pearson statistical technique was used to determine whether there is a bond between haemodialysis patients' gender and their Quality of Life and analyze the correlation if it exists.

Table 4 reveals there is no significant correlation between gender (male or female) and Quality of Life, however, religious beliefs have a great impact on this correlation because patients' responses were heavily influenced by the patient's belief that what happens to them is a matter of act of God, which is why their responses were immeasurable by neither statistical nor scientific mean.

Table 4: Correlation Between Gender and QOL

		Gender	Rate of QOL
Gender	Pearson Correlation	1	-.034
	Sig. (2-tailed)		.653
	N	181	181
Rate of QOL	Pearson Correlation	-.034	1
	Sig. (2-tailed)	.653	
	N	181	181

Association between Education and QoL

A test was done by Pearson correlation to see whether there is any association between the education level haemodialysis patients received and QoL.

According to Table 5, the significance was 0.139 and the Pearson correlation was .081 which means there is no statistical correlation between patients' level of education and their QoL. The results of our study are not consistent with the findings of previous studies that reported a positive relationship between the level of school education and the QoL. Higher school education is known to play an essential role in raising awareness of chronic diseases and in a better coping ability with chronic disease, however, other factors affect high school education patients' QoL such as poor financial situations, and some psychological factors. The association depended on religious and cultural reasons rather than on satisfaction reasons.

Table 5: Correlations between Education and QOL

		The Higher Education Received	Rate of QOL
The higher education received	Pearson Correlation	1	-.081
	Sig. (2-tailed)		.139
	N	181	181
Rate of QOL	Pearson Correlation	-.081	1
	Sig. (2-tailed)	.139	
	N	181	181

Detailed Analysis of the 4 Domains

Physical Domain

Q3: To what extent do you feel that physical pain prevents you from doing what you need to do?

Table 6 below shows that .6% of respondents were not affected by physical pain, 63.5% were a little bit affected by the pain the disease causes them, 20.4% were moderately affected by the pain, and 11.00% the physical pain was very much affecting them and 4.4% of them were extremely affected by the physical pain.

Table 6: To what extent do you feel that the physical pain prevents you from doing what you need to do?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not At All	1	.6	.6	.6
A little	115	63.5	64.1	64.1
A moderate amount	37	20.4	20.4	84.5
Very much	20	11.0	11.0	95.6
An extreme amount	8	4.4	4.4	100
Total	181	100	100	

Q 10: Do you have enough energy for everyday life?

49.2% of haemodialysis patients have the energy to perform their daily life activities, 40.3% of them moderately had enough energy, 9.9% were not able to do their daily activities due to the lack of enough energy, and 5.1% of haemodialysis patients completely don't have enough energy for their daily activities.

Table 7: Do you have enough energy for everyday life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	9	4.9	5.1	5.1
Moderately	115	63.5	64.1	63.5
Mostly	37	20.4	20.4	84.5
Completely	20	11.05	11.0	95.6
Total	181	100	100	

Q 16: How satisfied are you with your sleep?

Table 8 explains the result of haemodialysis patients' satisfaction with sleep. 71.8% were satisfied, 27.1% were dissatisfied and 1.1% were very satisfied with their sleep.

Table 8: How satisfied are you with your sleep?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	49	27.1	.6	.6
Satisfied	130	71.8	64.1	64.1
Very satisfied	2	1.1	20.4	84.5
Total	181	100	100	

Q 4: How much do you need medical treatment to function in your daily life?

40.9% and 39.8% depended on medications as well as 19.3% of haemodialysis patients needed medical treatment to function in their life.

Table 9: How much do you need medical treatment to function in your daily life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	35	19.3	19.3	19.3
A moderate amount	74	40.9	40.9	60.2
Very much	72	39.8	39.8	100
Total	181	100	100	

Q 15: How well are you able to get around?

According to the following table, 51.4% of respondents could move around, 40.9% could only move around poorly, 7.2% could sometimes move around, sometimes relied on the help of others to do what they needed to do, and 0.6% were strong enough to move around .

Table 10: How well are you able to get around?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Poor	74	40.9	40.9	40.9
Neither poor nor good	13	7.2	7.2	48.1
Good	93	51.4	51.4	99.4
Very good	1	.6	.6	100
Total	181	100	100	

Q 17: How satisfied are you with your ability to perform your daily living activities?

Table 11 shows that 68% of haemodialysis patients were satisfied with the way they performed their activities of daily living, 28.7% were not satisfied, 1.7% were neither satisfied nor dissatisfied and the same percentage of haemodialysis patients were very satisfied with the way they performed their activities of daily living.

Table 11: How satisfied are you with your ability to perform your daily living activities?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	52	28.7	28.7	28.7
Neither satisfied nor dissatisfied	3	1.7	1.7	30.4
Satisfied	68	68	68	98.3
Very satisfied	123	1.7	1.7	100
Total	181	100	100	

Q18: How satisfied are you with your work capacity?

48.1% of haemodialysis patients were satisfied because they were able to go about their work. Slightly fewer haemodialysis patients (47.5%) were dissatisfied and 3.9% of them were between satisfied and dissatisfied with their ability to work.

Table 12: How satisfied are you with your work capacity?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	86	47.5	47.5	47.5
Neither satisfied nor dissatisfied	7	3.9	3.9	51.4
Satisfied	87	48.1	48.1	99.4
Very satisfied	1	.6	.6	100
Total	181	100	100	

Psychological Domain:**Q 5:** How much do you enjoy your life?

51.4% of patients were very much enjoying their lives, 37% moderately enjoying it, and 11.6% were a little bit enjoying their lives.

Table 13: How much do you enjoy your life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	21	11.6	11.6	11.6
A moderate amount	67	37.0	37.0	48.6
Very much	93	51.4	51.4	100
Total	181	100	100	

Q 6: To what extent do you feel your life to be meaningful?

74.6% of them think their life is meaningful, 21% to some extent their life is meaningful, 3.9% their life was a little bit meaningful, and only one participant's life was extremely meaningful.

Table 14: To what extent do you feel your life is meaningful?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	7	3.9	3.9	3.9
A moderate amount	38	21.0	21.0	24.9
Very much	135	74.6	74.6	99.4
An extreme amount	1	.6	.6	100
Total	181	100	100	

Q 7: How well are you able to concentrate?

64.6 of patients were very much able to concentrate, 34.3% of their concentration was moderate and 1.1% of their concentration was low.

Table 15: How well are you able to concentrate?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	2	1.1	1.1	1.1
A moderate amount	62	34.3	34.3	35.4
Very much	117	64.6	64.4	100
Total	181	100	100	

Q 11: Are you able to accept your bodily appearance?

Table 16 indicates that the majority of patients accepted their physical appearance (64.1), half of them accepted their appearance moderately, only 13 (7.2%) accepted their appearance only slightly, one patient liked his appearance completely and only one disliked his appearance.

Table 16: Are you able to accept your bodily appearance?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not at all	1	.6	.6	.6
A little	13	7.2	7.2	7.7
Moderately	50	27.6	27.6	35.4
Mostly	116	64.1	64.1	99.4
Completely	1	.6	.6	100
Total	181	100	100	

Q 19: How satisfied are you with yourself?

Regarding self-satisfaction, 87.8% were very satisfied with themselves, 6.6% were dissatisfied, 3.3% were very satisfied and only one haemodialysis patient was very dissatisfied with themselves.

Table 17: How satisfied are you with yourself?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Very Dissatisfied	1	.6	.6	.6
Dissatisfied	12	6.6	6.6	7.2
Neither satisfied nor dissatisfied	3	1.7	1.7	8.8
Satisfied	159	87.8	87.8	96.7
Very satisfied	6	3.3	3.3	100
Total	181	100	100	

q 26: How often do you have negative feelings such as blue mood, despair, anxiety, or depression?

Only 3 (1.7%) patients were full of hope, 12.2% often had negative feelings, 45 (4.9%) always had negative feelings, 49 (27.1%) seldomly had hope, and 62 (34.3%) quite often had negative feelings.

Table 18: How often do you have negative feelings such as blue mood, despair, anxiety, or depression?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Never	3	1.7	1.7	1.7
Seldom	49	27.1	27.1	28.7
Quite often	62	34.3	34.3	63
Very often	22	12.2	12.2	75.1
Always	45	24.9	24.9	100
Total	181	100	100	

Social Relationship Domain

Q 20: How satisfied are you with your relationships?

3.9% of haemodialysis patients were very satisfied with their relationships, 11.6% were dissatisfied and 153 (84.5%) were satisfied.

Table 19: How satisfied are you with your relationships?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	21	11.6	11.6	11.6
Satisfied	153	84.5	84.5	96.1
Very satisfied	7	3.9	3.9	100
Total	181	100	100	

Q 21: How satisfied are you with your sexual life?

152 (84%) were satisfied with their sexual lives, 13.8% were dissatisfied and very few patients were very satisfied.

Table 20: How satisfied are you with your sexual life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	2	1.1	1.1	1.1
A moderate amount	62	34.3	34.3	35.4
Very much	117	64.6	64.4	100
Total	181	100	100	

Q 22: How satisfied are you with the support you get from your friends?

82.9% were satisfied with the support they get from their friends, 12.7% were dissatisfied and 3.3 % were very satisfied.

Table 21: How satisfied are you with the support you get from your friends?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Very Dissatisfied	1	.6	.6	.6
Dissatisfied	23	12.7	12.7	13.3
Neither satisfied nor dissatisfied	1	.6	.6	13.8
Satisfied	150	82.9	82.9	96.7
Very satisfied	6	3.3	3.3	100
Total	181	100	100	

Environmental Domain

Q 8: How safe do you feel in your daily life?

126 patients were feeling safe in their normal lives, 46 of them to some extent felt safe, and a small number of haemodialysis patients were not feeling safe in their daily lives.

Table 22: How safe do you feel in your daily life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
A little	8	4.4	4.4	4.4
A moderate amount	46	25.4	25.4	29.8
Very much	126	69.6	69.6	99.4
Extremely	1	.6	.6	100
Total	181	100	100	

Q 9: How healthy is your physical environment?

2 patients were living in an extremely healthy environment, 51.4% were living in a healthy one, 29.3% said their physical environment was not healthy enough and 2.8% lived in an unhealthy environment.

Table 23: How healthy is your physical environment?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not At All	5	2.8	2.8	2.8
A little	28	15.5	15.5	18.2
A moderate amount	53	29.3	29.3	47.5
Very much	93	51.4	51.4	98.9
Extremely	2	1.1	1.1	100
Total	181	100	100	

Q 12: Do you have enough money to meet your needs?

39.2% moderately had enough money, 30.9% mostly had money, 28.2% did not have enough money to meet their needs and few patients did not have enough money at all.

Table 24: Do you have enough money to meet your needs?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not At All	1	.6	.6	.6
A little	51	28.2	28.2	28.7
Moderately	71	39.2	39.2	68
Mostly	56	30.9	30.9	98.9
Completely	2	1.1	1.1	100
Total	181	100	100	

Q 13: How available to you is the information that you need in your day-to-day life?

Information concerning haemodialysis patients is mostly available to the majority of them; very few of them don't have proper information about their day-to-day lives as sick people.

Table 25: How available to you is the information that you need in your day-to-day life?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not At All	1	.6	.6	.6
A little	13	7.2	7.2	7.7
Moderate	34	18.8	18.8	26.5
Mostly	126	69.6	69.6	96.1
Completely	7	3.9	3.9	100
Total	181	100	100	

Q 14: To what extent do you have the opportunity for leisure activities?

More than three-quarters of participant patients were enjoying their lives and having leisure activities.

Table 26: To what extent do you have the opportunity for leisure activities?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Not At All	2	1.1	1.1	1.1
A little	43	23.8	23.8	24.9
Moderately	92	50.8	50.8	75.7
Mostly	42	23.2	23.2	98.9
Completely	2	1.1	1.1	100
Total	181	100	100	

Q 23: How satisfied are you with the conditions of your living place?

106 out of 180 participating patients were satisfied with their living places, 62 were dissatisfied, 9 of them were in the middle between satisfied and dissatisfied, and 4 patients were very satisfied with the places they lived.

Table 27: How satisfied are you with the conditions of your living place?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	62	34.3	34.3	34.3
Neither satisfied nor dissatisfied	9	5	5	39.2
Satisfied	106	58.6	58.6	97.8
Very satisfied	4	2.2	2.2	100
Total	181	100	100	

Q 24: How satisfied are you with your access to health services?

121 (66.9%) were satisfied with their access to health services, 29.3% were dissatisfied, 2.2% were very satisfied, and only 3 patients were in the middle between satisfied and dissatisfied.

Table 28: How satisfied are you with your access to health services?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Dissatisfied	53	29.3	29.3	29.3
Neither satisfied nor dissatisfied	3	1.7	1.7	30.9
Satisfied	121	66.9	66.9	97.8
Very satisfied	4	2.2	2.2	100
Total	181	100	100	

Q25: How satisfied are you with your transportation?

63% were dissatisfied with their transportation, 35.9% were satisfied and only 2 of the patients were facing real transportation problems.

Table 29: How satisfied are you with your transportation?

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Very dissatisfied	2	1.1	1.1	1.1
Dissatisfied	114	63	63	64.1
Very satisfied	65	35.9	35.9	100
Total	181	100	100	

Discussion

Quality of life is becoming an important measure of outcomes following the initiation of haemodialysis therapy. The main therapeutic goal is to improve the functional capacity of these patients so that they can enjoy their lives as much as possible. The results of this study illustrate how physical, psychological, and social functioning as well as the environment and general health of haemodialysis patients were affected when patients responded to whether physical pain prevented them from doing what they needed to do. The analysis showed that physical pain did not prevent the majority (63.5%) of patients from doing what they needed to do, regardless of their age. 20.4% of the patients were able to do what they had to do despite the physical pain, 11% were severely impaired by the physical pain, and 4.4% of the patients' physical pain extremely impaired their ability to do what they had to do, and only one patient was not affected by the physical pain at all. Regarding the loss of energy caused by the disease, the study found that less than half (49.2%) of the participating patients had enough energy for their daily activities, 40.3% were moderately able to do their daily activities, 9.9% did not have enough energy and 0.6% of the haemodialysis patients were completely dependent on the help of others for their daily tasks; some of them even had no daily activities at all and this is due to the disease they have.

It was interesting to find that despite the physical pain and loss of energy often caused by the disease, the patient's responses indicated that the disease was not seen as an obstacle that restricted patients' movement or took away their ability to do anything, therefore physical pain and loss of energy were not associated with the WHOQOL-BREF. The study showed (as in Table 8) that 71.8% of haemodialysis patients recruited for this study had enough hours of sleep so that they were satisfied with their sleep, 27.1% were not satisfied with their sleep, for some reasons related to the disease, they did not have enough sleep, and only 2 patients (1.1%) were very satisfied, i.e. they had enough hours of sleep.

As shown in Table 9, all haemodialysis patients are dependent on medical treatment to cope with everyday life. 40.9% are moderately dependent on medication, 39.8% are unable to lead a normal life without medical treatment, and 19.3%, which is still considered a large number of haemodialysis patients, are somewhat dependent on medical treatment, but none of the recruited patients lead their normal lives without medication to facilitate their lives.

Table 10 clearly shows that despite the disease, 51.4% of haemodialysis patients were able to move around and do what they needed to do. On the other hand, 40.9% of them were barely able to move around and take care of themselves, which is considered a strong indication that the disease harms their ability to move around and makes them rely on others. However, 7.2% sometimes relied on others and sometimes on themselves to get around, and only 0.6% relied on themselves to get around.

The majority of haemodialysis patients were completely satisfied with the way they carried out their activities of daily living, meaning that the disease did not prevent them from carrying out their normal activities. 28.7% were unable to perform their activities of daily living due to disease-related reasons, 1.7% of patients were sometimes able to perform their activities of daily living, sometimes not, but only 1.7% were dissatisfied, meaning they did not have enough ability to perform their activities of daily living without the assistance of others.

As shown in Table 12, the disease prevented a large number of haemodialysis patients from earning a living to their satisfaction, which affected their financial situation. 48.1% responded with their satisfaction with their ability to work, influenced to some extent by their religious beliefs, some of them were neither satisfied nor dissatisfied with the way they did their work, and only a small number of haemodialysis patients relied entirely on themselves to do their work.

When summarising the physical domain, it became very clear that the physical pain caused by the disease did not prevent the majority of patients from doing what they needed to do. However, they had a great loss of energy (due to the disease) that prevented them from leading a normal life. In other words, even though most patients got enough hours of sleep, they were not able to do what they needed in their daily lives because they did not have enough energy, not because of the physical pain caused by the disease. The number of patients who were satisfied with their ability to work was almost equal to the number of those who were dissatisfied, which indicates that the disease harms patients' ability to work.

Religious belief plays an important role in the patient's answers to psychological questions. Although all the participants were ill and most of them did not have the energy to live normally and go about their normal work, their lives were meaningful as 51.4% of them enjoyed their lives very much, 37% enjoyed them moderately and only 11.6% enjoyed their lives less.

Table 15 clearly shows that most of the patients were able to concentrate very well. Some of them were able to concentrate moderately and very few of them showed a decline in concentration. Although most patients were significantly affected by the disease and it was so obvious that the disease had affected their appearance, most responses to the question about acceptance of their appearance did not match their appearance. 116 (64.1%) were mostly accepting of their appearance and 87.8% were satisfied with themselves, with religion still playing a role.

Table 18 shows that only 3 out of 180 patients who participated in the study had no negative feelings caused by the disease, which is a good thing, but this number is small compared to the number of patients in whom the disease caused various types of negative feelings, such as low mood, despair, anxiety, and depression. 12.2 % of patients have negative feelings very often, 24.9 % always have some kind of negative feelings, 27.1 % have negative feelings frequently and 34.3 % have this bad feeling

quite often, which has affected their lives. Nevertheless, a large number of haemodialysis patients still had good relationships with the people around them. The Sudanese are shy by nature and do not reveal the truth when it comes to questions about their private lives. Therefore, when asked how satisfied they are with their sex life, the majority of respondents were satisfied. Research in other countries shows that the majority of respondents, especially men, are dissatisfied with their sex life and admit that their interest in sex has declined or that they are not interested in it. Similar results were reported for both sexes after starting dialysis treatment.

Strong social relationships distinguish Sudanese patients from patients of other nations. Supporting each other is common among people in Sudan; the support that sick people receive from those around them is very strong, and this was reflected in patients' satisfaction with the support they receive from their friends.

My results in the area of social relationships generally indicated that patients have very good relationships and receive sufficient support from friends and people around them. However, their answers about their sex life did not reflect their true answers for cultural reasons. However, the good treatment that haemodialysis patients receive from the people around them has a good impact on their quality of life.

Our study has shown that there is a lack of information that haemodialysis patients need. Information on diet, exercise, etc. is not available in the dialysis centers, around their homes, or in the general media. The study found that some patients eat foods that are harmful to their health and should be avoided, others do not eat the right foods even though they are available in their neighborhood, and some others do not know that they should eat healthily as sick people because they lacked the information they should have received.

69.6% is the percentage of haemodialysis patients who feel safe because they live in a safe environment; on the other hand, some of them do not feel safe for unclear reasons.

The study found that for most patients living in rural areas, their physical environment was not healthy, which harmed their quality of life. In contrast, for those living in urban areas, their physical health environment was healthy, meaning they had a better quality of life. The results of the study are consistent with the results of other studies that have found a positive correlation between family income and quality of life. A high income improves the patient's ability to afford the necessary treatment and ensures a better quality of life. A secure income reassures patients and contributes to their psychological well-being. Financial difficulties due to early retirement or loss of employment due to the disease can lead to a deterioration in the quality of life.

All (66.9%) of patients who were able to regularly attend their dialysis sessions because they live close to the dialysis centers or have stable transportation from their

places of living to centers, make them satisfied with their access to health services. On the contrary, those who were living far from the dialysis centers or didn't have stable transportation means to regularly attend their sessions on time. Some of those patients had to use the vehicles that transport vegetables early in the morning hours, and they often reached the centers hours before their scheduled time and had to spend the waiting time in inconvenient places until the scheduled time came. Those patients lose their commitment to stick to the scheduled sessions and become dissatisfied with their access to the health services, as a result of this conflict. Arguments between patients and the staff of dialysis centers occur because center staff would prefer to use the machines for available patients rather than wait for late patients and keep the machines unused.

Conclusion

The small number and inadequate distribution of dialysis centers in Sudan force haemodialysis patients to move to the big cities where dialysis centers are located. They leave their homes, jobs, and families behind to receive treatment, and this migration has a significant impact not only on the quality of life of haemodialysis patients but also on their families.

The physical pain affected the mobility of more than half of the participants; some of them could hardly move to carry out their daily activities. The majority of patients believed that their lives had meaning and that the disease prevented them from concentrating and leading a good life. However, many haemodialysis patients experienced negative feelings, depression, and anxiety, which affected their quality of life.

Strong social relationships between people in Sudan have overwhelmed haemodialysis patients with the different types of support they need.

Religious beliefs had a major influence on the patient's responses regarding their satisfaction with their quality of life, appearance, and sex life.

Lack of a stable means of transport from patients' homes to the dialysis center (and vice versa) and insufficient information on diet and physical activities were significantly associated with lower scores for all generic and multiple kidney diseases, particularly for haemodialysis patients in the Sudan-focused HRQOL measures.

Recommendations

We strongly recommend the following:

- Lack of nutrition information. We recommend educating patients and raising their awareness of proper nutrition. This could be done during the dialysis sessions by showing the lessons in the form of films on screens in front of the patients during dialysis sessions or by putting pictures and flyers on wall charts or giving them to the patients explaining to the haemodialysis patients which foods they should eat and which are harmful and should be avoided.
- No exercise programs. We recommend raising awareness among haemodialysis patients that exercise programs have a major positive impact on their health. Some centers can offer this in the form of films during dialysis sessions, but in unqualified centers, it may be offered in the form of pictures showing patients what movements should be performed during exercise and how often. Patients take advantage of the long hours they spend in dialysis and watch or read whatever they can find around them.
- The provision of government-funded, consistent transport for haemodialysis patients helps them to avoid missing their sessions and waiting for hours in inconvenient places before the start or after the end of their sessions.
- We encountered many patients with comorbid conditions such as DM, hypertension, HBV, and HCV. Most of these patients are not followed up with other diseases, especially HBV and HCV patients, and this was due to the lack of availability of hepatologists. I recommend establishing communication between the different disciplines.
- Haemodialysis patients are very depressed. I recommend using psychologists in dialysis centers.

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