RESEARCH ARTICLE

Evaluation of Quality of Life of Egyptian Adolescents with End Stage Renal Disease before and after Start Regular Maintenance Hemodialysis

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Abstract

Background: Chronic diseases can influence the quality of life significantly. Thus, the present study is designed to compare the quality of life of adolescents with End Stage Renal Disease (ESRD) before and after Start regular maintenance Hemodialysis (HD).

Methods: The present study was a longitudinal study on 34 of adolescents who had referred to Pediatric Nephrology and Hemodialysis Unit at Tanta University Hospital (TUH). The subjects were selected through convenience sampling method and 68 of adolescents continued the research until the end. The results were analyzed using descriptive and analytic statistics (frequency, mean ± standard deviation, repeated measure test, and post hoc test) in SPSS 20.

Results: Results showed that the average of quality of life total score was sequential and not the same in the 4 times slots under study. The total quality of life score upon admission was significantly different from 1, 4, and 8 months after maintenance HD. However, quality of life at 1-month was not significantly different to that at 4 and 8 months after the treatment; quality of life at 4 months after the treatment was not significantly different to that at 8 months after.

Conclusions: According to the present study, it can be concluded that the quality of life of adolescents referring to HD centers increases 1-month after the treatment; nevertheless, it is worth to note that the degree of quality of life increase in 4 and 8 months after the treatment is not as much as that in 1-month after the treatment.

Keywords: Hemodialysis; Adolescents; Quality of life

Introduction

Adolescents with chronic diseases are prone to the greater risk of psychosocial problems and thus, adolescence years are of greater significance with regard to risky behaviors [1]. Great effective, social, cognitive, and biological changes occur during the early years of adolescence; these changes can affect adolescents' behavior and selection. They also increase their tendency toward depression and social maladjustment [2].

The available information shows that ESRD has increased dramatically among adolescents and young adults. One way to decrease ESRD in adolescence is controlling it during infancy and childhood years [3]. Children with end-stage renal disease (ESRD) under regular hemodialysis suffer from various health problems that result either from the sequelae of the disease itself or its various lines of therapy [3].

ESRD is a permanent obstacle to a normal child's daily physical, emotional, and social activates. ESRD also causes a financial burden on the patient's family that adversely affects their own daily needs [2].

Health-Related Quality of Life (HRQOL) scores in children with ESRD under HD or peritoneal dialysis are significantly lower than in healthy controls and in transplant recipients [3]. Moreover, the parents of children on maintenance dialysis also exhibited the lower quality of life and more depression symptoms than the parents of healthy children [4]. Nevertheless, only a limited number of studies have thus far been conducted on the effect of HD on quality of life [4].

World Health Organization defines the quality of life as an individual's perception of his or her own position in life with regard to cultural and value systems and in relation to goals, expectations, standards, and concerns [5]. On the other hand, quality of life is considered as a reliable measure for assessing the outcome of therapeutic methods employed for treatment of patients [5].

As individual treatment plans such as conservative measures, hemodialysis, peritoneal dialysis and renal transplantation aim to reduce complications of ESRD, rehabilitate them to the social, individual, family, educational, and vocational life circle, and improve their health-related quality of life. Presence of certain personality traits, the low quality of life and demographic characteristics render all therapeutic efforts fruitless as "building a house on a flowing river" [6].

As shown by Roccella M [7], The quality of life, it is expected that the quality of life of in developing age subjects with chronic renal diseases .through the 4th or 8th months of their dialytic treatment should be greater than that of patients in the first stage of dialysis treatment [7].

If the opposite is witnessed, then adequate assessments should be conducted to specify the area not showing any development in QOL so that appropriate solutions can be offered to increase the quality of life and decrease the possibility of psychosocial impacts [7].

Therefore, a non-improvement of the quality of life can indicate inadequate HD treatment. It is then necessary to increase teenagers' quality of life to decrease the possibility of emotional, behavioral and psychosocial complications [7].

Objectives

The present study aims to compare the quality of life of adolescents who have diagnosed as ESRD under regular HD treatment at different time periods before HD and 1, 4, and 8 months after maintenance HD treatment.

The study posed the question whether there is a difference in adolescents' quality of life before the start of HD and 1, 4, and 8 months after maintenance HD treatment.

We aim that the results of this study can be beneficial to respective authorities with regard to appropriate planning for increasing adolescents' quality of life and decreasing the possibility of psychiatric complications of children with ESRD.

Subjects and Methods

The study population and sample

The present longitudinal study was conducted on 34 patients after approval from the research ethical committee center of Tanta University Hospital and obtaining informed written or oral consents from parents of the included children at the pediatric nephrology and hemodialysis Unit of the Pediatric Department of Tanta University Hospital where the included 34 patients were referred from different hospitals and clinics at Gharbia Governate for receiving maintenance HD as treatment of ESRD. The study was carried out from November 2015 to November 2017 on 34 children on regular hemodialysis with ESRD. The patients' ages ranged from 12 to 18 years. All patients were undergoing hemodialysis three times per week, with each dialysis session lasting three to four hours. Dialysis was started when GFR is equal or less than 15 ml/min/1.73 m2. Patients were dialyzed on a Fresenius 4008 B dialysis machine (Germany) at a blood flow rate=2.5 weight (kg) +100 ml/min, using polysulfane hollow fiber dialysers suitable for the surface area of the patients (Fresenius F3 = 0.4 m2, F4 = 0.7 m2, F5 = 1.0 m2, and F6 = 1.2 m2). Bicarbonate dialysis solutions were used. All patients were receiving supportive therapy in the form of subcutaneous (SC). Erythropoietin in a dose of 50 IU/kg/session, IV iron dextran 100 mg/kg/week, oral folic acid 1 mg/day, oral calcium 1000 mg/day, oral vitamin D (one alpha) in a dose of 0.01-0.05 mg/kg/day, and oral antihypertensive medications for hypertensive patients.

Inclusion criteria

All adolescents with ESRD and treated for the 1st time by regular maintenance hemodialysis. All adolescents had referred to the HD centers voluntarily and were in the 1st few weeks of their diagnosis as ESRD.

Methods

All patients were subjected to the following:

(1) Thorough history taking: including biodemographic data of adolescents, age, sex, birth order, level of education, residence and living conditions, and common complaints before and after regular HD sessions using the General Information Sheet [8].

(2) The objectives of the study were explained to the adolescents. They have then ensured that their data captured on questionnaires would be kept confidential.

What questionnaire was used?

An Arabic-translated and validated version of short form-36 (SF36) quality of life questionnaire form (a questionnaire measure format) which was one of the World Health Organization (WHO) questionnaires that were used for measuring one's health and assessing one's quality of life. This questionnaire includes 36 questions and 8 scales, each comprised of 2-10 questions assessing one's health in eight areas of physical functioning, physical health problem, pain, general health, energy and emotions, social activities, emotional health problem, and mental health. The total score of the eight scales may range between 0 and 100; 0 represents the worst and 100 represents the best state in the scale in question [9].

How was it validated?

Construction of validity for non-clinical samples, clinical samples, and diverse samples: criterion validity includes predictive validity and postdictive validity. The sensitivity rate was 0.92, and the specificity rate was 0.82 [9].

Validity analysis of the Arabic version of the SF36 questionnaire has been performed by measuring the internal consistency between the dimensions of the scale. Convergent validity test was employed to determine the validity of this questionnaire. The resultant correlation coefficients stood higher than the recommended value (0.4) (coefficients stood between 0.58 and 0.95) [10].

The questionnaire was completed by the parent or caretaker who spent most of the time with the child. The scientific reliability of the questionnaire has also been examined in various studies through internal consistency Reliability for which the Cronbach's alpha of 0.77-0.90 was obtained [10].

It is worth to note that the demographic characteristics were filled out upon admission before the start of HD, but the quality of life questionnaire was filled out upon admission before the start of HD, 1, 4, and 8 months after the HD treatment. In addition, the questionnaires were filled out by me with the assistance of nurses. The parents of involved patients were completely clarified about the research objectives.

Exclusion criteria

Children with other medical diseases such as Type 1 diabetes, heart diseases, chronic liver diseases, or mental retardation were excluded.

Statistical analysis

The collected data were tabulated and analyzed through descriptive and inferential statistics of SPSS version 20 (SPSS Inc, Chicago, ILL Company), and Microstat-W (India, CNET Download.com). Categorical data were presented as number and percentages, while quantitative data were expressed as the mean ± standard deviation [11].

Results

According to the obtained results, the number of ESRD who were referred to the Pediatric Nephrology and Dialysis Unit of Tanta University Hospital was as follow: Tanta University Hospital outpatient clinic 18(52.9%) El-Menshawi General Hospital 10(29.4%), El-Mahalla General Hospital 4(11.8%), El-Mabara health insurance hospital 2(5.9%). The patients were 24 males (70.6%) and 11 females (29.4 %).

Furthermore, the results showed that the majority of the population 28(82.4%) were of the secondary educational level. The average of quality of life total score and the eight aspects in the 4 times slots after the maintenance HD treatment are shown in table 1. The average of

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Table 1: Mean ± SD of Quality of life in the studied patients before and after start of regular HD.

Time of QOL assessment	Total QOL score	General Health	Physical Function	Physical Health Problems	Pain	Emotional Health Problems	Social Activity	Energy and Emotions	Mental Health
Before HD	44.4 ± 19.1	28.2 ± 13.3	57.4 ± 26.9	68.1 ± 32.4	50.1 ± 29.1	66.7 ± 36.1	24.8 ± 16.4	44.4 ± 23.6	44.4 ± 19.1
1 month from start of HD	53.7 ± 21.3	55.5 ± 13.8	73.9 ± 26.7	53.5 ± 35.1	40.3 ± 22.8	61.7 ± 33.9	44.3 ± 15.8	56.7 ± 21.1	53.7 ± 21.3
4 month from start of HD	54.4 ± 24.8	55.3 ± 11.9	66.6 ± 37.8	52.1 ± 36.5	37 ± 23.5	52.5 ± 37.5	43.4 ± 12.6	59.9 ± 21.6	52.4 ± 24.8
8 month from start of HD	55.4 ± 17.9	51.7 ± 12.2	69.1 ± 26.3	57.9 ± 34.2	37.7 ± 25.7	53.1 ± 38	48.5 ± 16.8	57.1 ± 25.1	59.6 ± 22.2

- P 1 = 0.001* (comparison between total QOL score before HD,1 months , 4 months and 8 months after HD.
- P 2 > 0.05 (comparison between each of the 8 individual scales of QOL score before HD,1 months ,4 months and 8 months after HD.

quality of life score before the start of HD maintenance treatment in adolescents with ESRD who were referred to the Pediatric Nephrology Unit of TUH Stood at 44.4 ± 19.1. The average for 1, 4, and 8 months after the maintenance HD treatment were 53.7 ± 12.3, 54.4 ± 24.8, and 55.4 ± 17.9, respectively. A comparison of above averages with upon admission value had a significant difference (P=0.001).

The variance analysis through iterative observations showed that the average of quality of life total score in the eight scales (physical functioning, physical health problem, pain, general health, energy and emotions, social activities, emotional health problem, and mental health) were not equal at the 4 times slots and quality of life total score had a significant increase in 1, 4, and 8 months after maintenance treatment in comparison with the upon admission's time slot. However, no significant difference was witnessed in the quality of life score in 1, 4, and 8 months after the maintenance HD treatment.

Discussion

As shown by the results, the average of quality of life score in the beginning of adolescent's maintenance treatment was lower than the average. In general, due to the negative effect of disease and dialysis on all aspects of quality of life, adolescents' quality of life was usually of a lower quality [12]. As per Goldstein SL study, patients' quality of life was also lower in all aspects before the beginning of dialytic treatment which was consistent with the results of the current study [12].

Goldstein SL [12] maintained that the quality of life was a proper criterion for assessing the effect of disease and treatment in these patients [12]. In addition, adolescents who were of a low quality of life had a greater tendency to physical and psychosocial disturbances [12]. It is also worth to note that the adolescents' low quality of life was an important factor causing their inability to overcome their complications [12]. The comparison results of quality of life average upon admission before and 1, 4 and 8 months after maintenance HD treatment in adolescents were not significant. It seems that more time was required for assessing this scale and appropriate plans should be made for improving this scale of quality of life [13].The social activities scale is one of the most important aspects of patients' quality of life [13].

In the present study, the average of quality of life score in social activities scale was not the same in the 4 times slots (P=0.2). However, some previous studies showed that the quality of life in social activities scale shows no significant difference between before and 1, 4 and 8 months after dialytic treatment [13]. As shown by Brown J [14], the patients with good religious and spiritual backgrounds were of good social relations [14]. As per Brown J [14] study, there was a significant increase in the social activities scale 12 months after the start of maintenance HD treatment [14]. However, none of such increases was observed in the current study. Due to the significance of this scale, it is thus worth to explore, in another study, the reasons of lack of increase

in social activities scale, especially in this age group. However, the lower degree of the social aspect of patients' quality of life probably indicates their greater vulnerability through the course of time [14].

Riano-Galen [15] concluded that considering the role of social relations, group sessions and appropriate communications with family members and therapists can be employed during the treatment process [15]. Considering the previous studies conducted in this area, the researcher believes that a combination of HD and psychosocial support were necessary for treating the adolescents with ESRD [12-15].

The average of quality of life score in energy and emotions scale was not the same in the 4 times slots (P=0.003). However, a paired comparison of time slots showed that quality of life in energy and emotions scale shows a significant difference between before and 1, 4 and 8 months after HD treatment. In addition, there was no significant difference between 1, 4 and 8 months after HD treatment. An increase in energy and emotions after maintenance treatment is expected as a fine result of maintenance HD treatment. However, this trend needs to continue in the next months and be considered as a preventive factor for the occurrence of the complications of uremia. The average of quality of life score in mental health scale was not the same in the 4 times slots after the maintenance treatment (P=0.001). However, a paired comparison of time slots showed that the quality of life in mental health scale shows a significant increase after maintenance HD treatment in comparison to that before dialysis The results of the current study confirmed those obtained by Roccella M [7] who showed that quality of life of their subjects was higher 4 months after their treatment in their late stages than that in the early stages of chronic renal disease [7]. As per Riano-Galen [15], an increase in quality of life was observed 12 months after HD treatment [15]. Goldstein SL [12] studied the quality of life of patients who were under dialytic treatment serially after HD treatment; the obtained results showed a considerable improvement in their quality of life; however, it was still much lower than ordinary people's level of quality of life [12].

With regard to the eight scales of quality of life, the results showed that the average of quality of life score in general health dimension was not the same in the 4 times slots and the highest score belonged to 1 month after maintenance treatment (P = 0.004).

In addition, a paired comparison of quality of life assessment time slots showed that the quality of life in general health dimension showed a significant difference between before and 1, 4, and 8 months after the HD treatment. However, no significant difference was observed in general health in 1, 4, and 8 months after treatment. As per the results obtained by similar studies and what was expected, general health in 1, 4, and 8 months after treatment had increased [12-15]. The results of this study showed that although the quality of life has increased in general health dimension, this scale has taken a descending trend in the 8 months after maintenance HD treatment. It may be concluded that

patients' public health was not taken into serious considerations after they could overcome uremic manifestations as a result, this scale of quality of life decreases. The average of quality of life score in physical functioning scale was not the same in the 4 times slots (P=0.002) and the highest score belonged to 1 month after maintenance HD treatment. In addition, a paired comparison of time slots showed that the quality of life in physical functioning scale shows a significant difference in the 4 times slots. Nevertheless, no significant difference was observed in 1, 4, and 8 months after treatment. In Goldstein's study as well, their patients who were under treatment showed a significant increase in their physical functioning after the maintenance HD treatment [12].

This indicates that the quality of life improves right after therapeutic dialytic interventions, but it slows down with the same intensity. This could probably be attributed to greater attention which was paid to the patients in the preliminary stages of HD treatment. As per our obtained results, the average of quality of life score in physical health problem scale was not the same in the 4 times slots (P>0.05). It was also determined that quality of life in physical health problem scale is of significant difference between before, 1 and 4 months after the treatment. However, no significant difference was observed between before and 8 months after treatment. Furthermore, no significant difference was observed between 1, 4, and 8 months after HD treatment in physical health problem scale. It thus seems necessary to explore the reasons for a lack of increase in this scale despite 8 months of maintenance treatment. As per the obtained results, there was a significant difference between before, 1 and 4 months after the maintenance treatment. However, the difference was not significant 8 months after the HD treatment for which some non therapeutic measures might be needed to be taken. The average of quality of life score in pain scale was not the same in the 4 times slots (P=0.018). The sequential test showed that there was a significant difference in pain aspect of quality of life between 1, 4, and 8 months after treatment. However, no significant difference was observed between before and 8 months after treatment. A decrease in pain is expected after receiving HD maintenance treatment due to the reassurance of patients and their parents. As mentioned before, complementary conservative treatments could be used for alleviating patients' physical and psychic pains and improving their quality of life. It is thus recommended to employ conservative treatments alongside maintenance HD treatment. Our obtained results showed that the average of quality of life score in emotional health problem scale was not the same in the 4 times slots (P=0.086). It was also determined that quality of life in emotional health problem scale is of significant difference between before, 4 and 8 months after the treatment. However, no significant difference was observed between 4 and 8 months after HD treatment. It can be concluded based on the results that the emotional health problem scale, in comparison with other scales, required greater time to improve. As witnessed, there was no significant difference between before and 1month after the HD. Despite the increase in this scale, the intensity of increase was between before, 1, 4, and 8 months after HD treatment. However, there was no significant difference between 1, 4, and months after treatment. Thus, it is possible that this dimension of patients' quality of life suffers in this study.

In another study, the results showed that mental health improves 6 and 12 months after maintenance treatment [15].

Limitation of the study

One of limitations of this study was the inability to determine whether changes in QOL in these dialysis adolescents were attributed to improvement in Hb levels, BUN, CTR, blood pressure, and/or any symptoms as our patients as Arab adolescents had a behavior of non compliance for different follow up recommendations regarding routine laboratory investigations and conservative treatment.

Conclusion

According to the results obtained by the present study, it could be concluded that the quality of life of adolescents with ESRD could improve through various stages of HD treatment.

However, it is noteworthy that this trend of quality of life improvement was of considerable pace 1 month after maintenance HD treatment (short-term) while the progress proves inconsiderable and insignificant 4 months after maintenance significance. It is thus necessary to take into consideration appropriate plans for long-term improvement of the quality of life. The quality of life scale that suffered most was the social activities of adolescents. No noticeable improvement was observed on this scale even after maintenance HD treatment. As per the obtained results, and in addition to maintenance HD treatment, different scales and dimensions of quality of life, particularly the social scale, social network, and support should be taken into consideration as significant factors for treatment of children and adolescents with ESRD and decreasing the chance of psychosocial complications. It was recommended that the effect of social support be studied and assessed in future studies on a larger scale.

Recommendations

It will be recommended in further studies for QOL in adolescents with ESRD on a wider scale to determine correlations between total and individual scales of QOL with different laboratory findings like Hb levels, BUN, CTR, as well as different demographic and clinical findings like blood pressure, and other uremic symptoms.

Conflict of interest

No conflict of interest.

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