

Quality Of life of children on renal replacement therapy

Mohammed Al-Mustafa Abdelrazag Zayed ¹ and Omer Saeed Magzoub ^{2,*}

¹ Faculty of Medicine and Health Science, Kordofan University, Al-Obaid, Sudan.

² General Pediatric, Ain Al-Khaleej Hospital, Al-Ain, Abu-Dhabi, UAE.

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Abstract

This is a descriptive cross-sectional hospital-based study conducted during the period from October to December 2009 at Noora Children Center for Dialysis and Renal Transplant at Soba University Hospital, and Dr. Salma Nephrology Center for Dialysis and Transplant, Khartoum, Sudan.

The objectives were to study the health-Related Quality of Life (HRQoL) in children on Renal Replacement Therapy (RRT) and to correlate the effect of RRT in improving the Quality of Life (QoL).

The study included 77 children with End Stage Renal Disease (ESRD) and their families. The majority of children 45 (58.4%) were at the age group 13 – 16 years. 38 (49.4%) were on Hemodialysis (HD), 20 (26%) were on Peritoneal Dialysis (PD) and 19 (24.6%) had renal transplantation. Male to female ratio was 1.3:1.

Results: ESRD had negative effect on children's physical, psychological and social domains of QoL. Children on HD and PD had significant lower scores in all domains of QoL compared to transplanted children.

Keywords: Quality of Life; Children; Renal Replacement Therapy

1. Introduction

The medical field interest in the term QoL has steadily increased since 1948 when the WHO defined health as being not only the absence of disease and infirmity, but also the presence of physical, mental and social well-being (1). The term QoL refers to physical, psychological and social domain of health seen as distinct areas that are influenced by person's experience, beliefs, expectations and perception (2).

The concept of quality of life is difficult to define because of its multi- dimensional aspects and is also difficult to quantify. According to WHO the main domains of QoL are: (i) The physical domain, which includes independence in activities of daily living and symptoms of disease; (ii) the psychological domain, involving emotional, cognitive and behavioral status; and (iii) the social domain, how people perceive their role and relationship with other people (3). Because many of the components of QoL cannot be observed directly, they are typically assessed according to classical principles of item-measurement theory (4).

Psychometric tools are used to explore each domain using group of questions (items). The number of items is a crucial feature of any such tool, because it influences the sensitivity of the assessment and the questionnaire's acceptance by the subject. Answers are converted into numerical scores that are, then, combined to yield 'scale scores', which may be further combined to yield domain scores or other summary scores of statistical interest. Questionnaires may be

* Corresponding author: Omer Saeed Magzoub
General Pediatric, Ain Al-Khaleej Hospital, Al-Ain, Abu-Dhabi, UAE.

administered by means of interview or self-administered. Measuring QoL is difficult in children and adolescents and this is reflected in the few suitable tools available. Several instruments rely on the opinions of a proxy (parent or carer), but self-assessment by the child is preferable wherever possible. The need for self-reporting by the child is supported by the inconsistency observed between the assessment made by the children and proxies. Although QoL measurement is challenging, it is arousing a growing interest in the Pediatric setting, particularly in the field of transplantation where the data are very scanty (5).

There are many QoL questionnaire designed to assess different aspects of quality of life in paediatric e.g. (i) The SF-36, a Short Form Health Related Quality of Life (HRQoL) scoring system with 36 items and a self-administered questionnaire. The responses to the 36 item short form health survey questionnaire are summarized and transformed to give eight summary scales to measure HRQoL: physical functioning (PF), role limitation attributable to physical problems (RP), bodily pain (BP), general health perception (GH), vitality (VT), social functioning (SF), role limitation attributable to emotional problems (RE), and mental health (MH). The eight scales of the SF-36 have been compressed into two primary dimensions: physical component summary score (PCS) and mental component summary score (MCS). The PF, RP and BP scales are the primary members of PCS, whereas SF, RE and MB scales are the primary members of MCS. The GH and VT are considered members of both dimensions (6).

Paediatric Inventory of QoL (paedsQLTM version 4.0) Core Scales; was designed to measure HRQoL in children and adolescent, and has been validated children with variety of chronic illnesses. The 23 question survey asks respondent, both in child self-report and care giver proxy report, to score Patient functioning in 4 domains: physical (8 questions), emotional (5 questions), social questions) and school (5 questions). There are 4 versions of the test according patient's age (7).

The term end-stage renal disease (ESRD) refers to severe, irreversible reduction in kidney function, usually requiring dialysis (peritoneal dialysis PD or hemodialysis HD) or kidney transplantation to sustain life. ESRD generally denotes a glomerular filtration rate (GFR) less than 15ml/min/1.73m². (8) In children with end-stage renal disease (ESRD), health related quality of life (HRQoL) is a useful and important measure for monitoring the child's well-being and functional status. One of the commonly used generic HRQoL instruments in children is the Pediatric Quality of Life Inventory, because an ESRD-specific instrument for children is still lacking. In the limited studies of HRQoL in children with ESRD, a significant effect of ESRD is seen, with significantly lower HRQoL scores than are in healthy children. In future, a pediatric ESRD-specific instrument is needed to address differences in HRQoL between children on hemodialysis, on peritoneal dialysis and with a kidney graft. (9).

For dialyzing small children, peritoneal dialysis is the preferred mode. There is a worldwide preference of Ambulatory Peritoneal Dialysis (APD) for children with ESRD it is physically much simpler, requiring setting up a cyclor machine once at night with uninterrupted day time activities. It allows children to attend school full-time and reduce the impact of PD treatment and the way of life of the patients and their families. The freedom from dialysis during day time gives the children a sense of feeling more normal than HD (10).

The importance of measuring HRQoL in patients on HD is being increasingly recognized. But few studies especially from the Balkan region have addressed these issues. The study demonstrated that global QoL of patient on chronic HD is severely impaired. Overall, they have reduced Mental Component Summary (MCS) and Psychological Component Summary (PCS) dimensions. The lowest values were found for role-physical functioning and role emotional. Studies done in Greece are also comparable with those studies on other countries including Spain, Ireland, Holland, Japan and the USA (11).

Renal transplant offers the best renal replacement therapy for most children with end-stage renal disease (ESRD), improving their potential for growth and nutrition, neurodevelopment and quality of life. Despite of short-term improvement in QoL, significant long term problems remain unsolved, particularly in relation to severe immunosuppression related side effects. In fact, co-morbidities are the most important determinant in children QoL after transplant (12).

2. Methodology

This is a descriptive cross-sectional hospital-based study conducted during the period from October to December 2009 at Noora Children Center for Dialysis and Renal Transplant at Soba University Hospital and Dr. Salma Nephrology Center for Dialysis and Transplant, Khartoum, Sudan. The study included 77 children, 10 of them (13%) were in the age group 2 to 7 years, 22 children (28.6%) were in the group of 8 to 12 years and the majority of patients 45 (58.4%) were in the age group 13-16 years (Fig.1). While male constituted 44 patients (57.1%); females were 33 (42.9%) of the total study

group (Fig.2). The majority of patients 54 (70%) live in urban areas, whereas 21 (27.3%) reside in rural areas and only 2 (2.6%) reside in peri-urban areas (Fig.3).

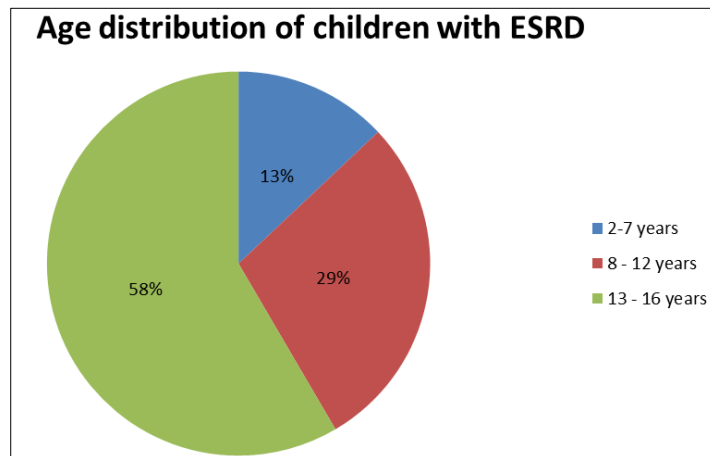


Figure 1 age distribution of children with ESRD

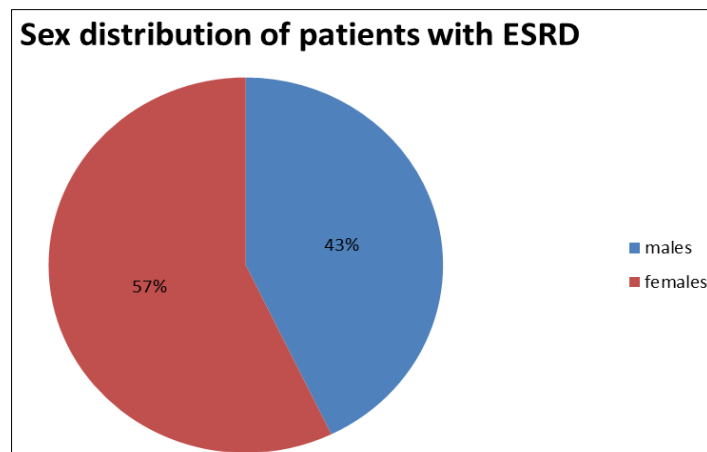


Figure 2 Sex distribution of children with ESRD

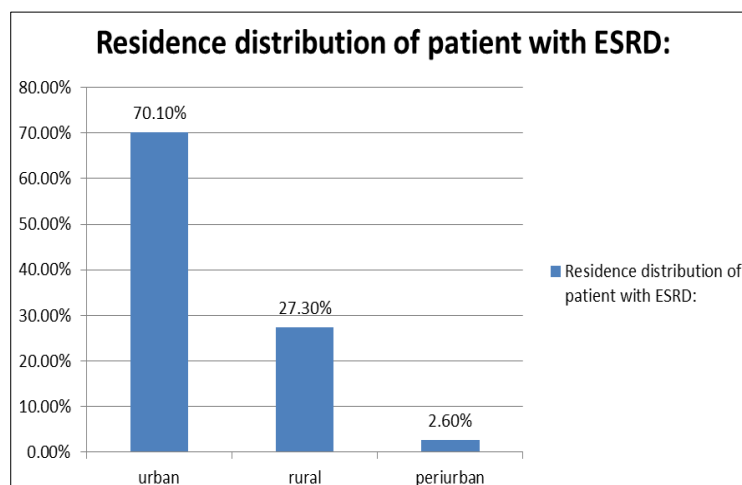


Figure 3 Residence distribution of patient with ESRD

3. Results

The effect of hemodialysis and peritoneal dialysis on daily activities of the patients: all patients on haemodialysis and peritoneal dialysis had their running and football play limited a lot. Thirty-six (62%) of hemodialysis patients and 16 (27%) of peritoneal dialysis patients had their ability to climb several flights of stairs limited a lot. 2 (3%) of HD and 4 (8%) of PD had limited little, 32 (55.1%) of HD and 16 (27.5%) of PD had limited a lot to climb one flight of stair, 6 (10%) of HD and 4 (6.8%) of PD had their climbing one flight of stairs limited little. walking several blocks were limited a lot in 23 (34%) of HD and 9 (15.5%) of PD, limited little in 15 (25.8%) HD and 8 (13.7%) PD and not limited in 3 (5%) of PD. Bathing and dressing is limited a lot in 12 (20.6%) of HD and 5 (8.6%) PD, limited little in 22 (37.9%) of HD and 11 (18.9%) of PD and not limited in 4 (6.8%) of both HD and PD (Table1).

The effect of renal transplant on daily activities: only one patient (5.3%) had his running and lifting heavy objects limited a lot, 2 (10.5%) had limited little and the remainder 16 (84.2%) had not limited at all. Playing football was not limited in 16 (84.2%) and limited little in 3 (15.8%) of transplanted patient. Climbing several flights of stairs was not limited in 15 (78.9%) and limited little in 4 (21.1%). While climbing one flight of stairs was not limited at all in 17 (89.4%) and limited little in 2 (10.6%). All transplanted patients had their ability for walking several blocks and bathing or dressing not limited.

All patients 58 (100%) on dialysis had their ability of muting and playing football limited a lot, while only one (5.2%) patient of transplanted limited a lot and 16 (84.2%) of transplanted patients not limited at all. Climbing several flights of stairs limited a lot in the vast majority of dialyzed patients 52 (89.6%), while the vast majority of transplanted patients 15 (78%) not limited. Climbing one flight of stair was limited a lot in 48 (82.7%) of dialyzed patients and not limited in 17 (89.4%) of transplanted. Walking several blocks was limited a lot in 32 (55.2%) of dialyzed patients and limited little in 23 (39.6%) of dialyzed patients while not limited at all in transplanted patients. Bathing and dressing were limited little in 33 (56.9%) of dialyzed patients while not limited in all patients of renal transplant. Patients on HD scored 281 for physical health. Those on PD scored 171 and the Transplanted scored 308.

Psychological domain: all patients of ESRD 77 (100%) had mood changes. 57 (74%) become aggressive after the period of illness and 20 (26%) have no aggressive behavior. The vast majority of ESRD patients 60 (77.6%) became depressed after diagnosis. while 17 (22.4%) had no attacks of depression. Anxiety was present in 56 (72.7%) of patients of ESRD while 21 (23.7%) had no anxiety.

The majority of patients of HD 20 (52.6%) had their mood showed no improvement after starting dialysis, 14 (36.8%) showed slight improvement in their mood, reminder 4 (10.5%) of patients showed good improvement of mood. In patients of PD only 5 (25%) showed no change in their mood, while 11 (55%) developed slight improvement of mood and 4 (20%) had good improvement of mood. Twenty-four (63.2%) of patients of HD had no changes in their aggressive behavior, while 13 (34.2%) had slight improvement and 1 (2.6%) had good improvement of his aggression. While the effect of PD did not change the aggressive behavior of 7 (35%), 9 (45%) showed slight improvement and 4 (20%) had good improvement tiller PD.

Haemodialysis did not change the feeling of being depressed in 28 (73.7%) patients, but slightly improved depression in 8 (21%) and good improvement in depression in 2 (5.3%). While 6 (30%) of patients on PD remained depressed after having dialysis and the same number reflects good improvement in depression after starting PD and 8 (40%) had slight improvement in depression. HD didn't help in changing anxiety in 27 (71.1%) of patients on HD, while slightly improved anxiety in 9 (23.7%) of patients, and 2 (5.3%) had good improvement in their anxiety. On the other hand, PD had no effect to change the anxiety in 7 (35%) patients and good improvement in 6 (30%) of patients after treatment.

Patients with ESRD developed good improvement in mood in 12 (63.2%) after renal transplant, while 4 (21.1%) patients developed slight improvement and only 3 (15.4%) had no effect of renal transplant in their mood. The majority of patients 12 (63.2%) with transplant had their aggressive behavior showed good improvement, while 3 (15.8%) showed slight improvement and the reminder 4 (21.1%) had no improvement of aggression even after transplant. Depression: (15.8%) of patients who had transplant showed no change in their depression, while there was good improvement in 12 (63.2%) the remained 4 (21.1%) patients had slight improvement. Anxiety remained unchanged in 4 (21.1%) of transplanted patients, 11 (57.9%) showed good improvement and 4 (21.1%) showed slight improvement of their anxiety (Table2&3).

There is a big difference between the dialysis and renal transplant in improving the behavioral status of patients. The majority of transplanted patient 12 (63.2%) had good improvement in their mood after transplantation and the minority of dialyzed patients 8 (13.8%) had good improvement in their mood. Dialysis had not changed the aggressive

behavior in majority of patients 31 (53.4%), while only 5 (8.6%) had slight improvement in aggression after dialysis. On the other hand, the majority of transplanted patients 12 (63.2%) had good improvement in aggression after transplantation and only 4 (21.1%) had no improvement (Table2&3).

The relationship between patients and their parents had strengthened in majority of patient on HD (89.5%) and in all patients on peritoneal dialysis (100%). (16 (80%) of patients on PD had strengthened relationship with their siblings, 3 (15%) had weekend relationship with their siblings and 1 (5%) not affected. The study showed that the relationship between the patients and peers is such more affected after treatment which show about 12 (31.5%) patients on HD had weekend relationship with their peers and about 21 (55.2%) of patients had strengthened relation with their peers, while 5 (3.1%) of patients show no change in their relationship. PD affected much of the patients' relationship with their peers; only 7 (35%) had strengthened relationship with their peers, while 8 (40%) had weekend relationship with their peers (Table 4&5).

The vast majority of patients on dialysis (93.2%) had strengthened relation-ship with their parents while (94.7%) of transplanted had strengthened relation-ship. The majority of patients on Dialysis (75.4%) had strengthened relation-ship with their siblings and to (84.2%) of transplanted patients. Forty-nine per cent of patients on dialysis had strengthened relation-ship with peers and so 66.4% of transplanted patients. Patients on HD scored 297 on social relation-ships. Those on PD scored 156 and those transplanted 157 (Table 4&5).

The study showed that 60 (77.9%) of patients with ESRD had schooling before their illness and only 17 (22.1%) of the total group of study had no schooling before illness. The study showed that the majority 41 (68.3%) of patients who had regular school 60 attendance before illness had stopped going to school after illness, 12 (20%) their school attendance become interrupted and only 7 (11.6%) of patients continue in their regular school attendance. Before starting the HD 31 (81.5%) of patients were on regular school attendance and 7 (18.4%) never went to school. The majority of patients on HD 27 (87%) out of 31 stopped schooling after HD, while just 2 (6.5%) had regular school attendance and 2 (6.5%) had interrupted schooling. Before starting the PD 15 (75%) of patients were on regular school attendance and 5 (25%) never went to school. PD was slightly better than HD in improving the school attendance, 4 (26.7%) out of 15 had regular schooling, 7 (46.7%) stopped schooling and 4 (26.7%) had interrupted school attendance. Schooling after transplant was regular in 7 (43.8%) of patients, 8 (50%) stopped schooling because the environment of school had high susceptibility for infections and only 1 (6.3%) had interrupted school attendance and 3 (15.75%) had never gone to school (Figure4).

Table 1 Effect of kidney disease on the daily life of study group

	Yes		No	
	N	%	N	%
Restriction of daily activity	72	93.5	5	6.5
Restriction of social visit	71	92.2	6	7.8
Restriction of plying 77	77	100	0	0
Restriction of hobbies	72	93.5	5	6.5
Restriction of diet	61	79/2	16	20.8
Increase stress & worries	49	63.6	28	36.4
Behavior changes	67	87	10	13
Affect schooling	57	74	20	26
Growth failure	50	64.9	27	35.1

Study showed that the majority of patients 32 (69.5%) out of 46 on dialysis stopped schooling, 8 (50%) of transplanted patients stopped their schooling. 8 (17.3%) patients on dialysis had regular school attendance. On the other hand; 7 (43.8%) transplanted patients had no problem to continue their regular schooling. 6 (13.2%) of patients on dialysis had interrupted schooling because of time of dialysis and only one (6.3%) of transplanted patients had interrupted school attendance. School performance before illness has been as follows; 9 (11.7%) of total patients of study had excellent performance, 24 (31.2%) had very good performance, 20 (26%) had good performance and 7 (9.1%) had average

performance. School performance after treatment; it had reduced in all patients, 7 (9.1%) of total patients had excellent performance, 8 (10.4%) had very good performance, 11 (14.3%) had good performance and 3 (3.9%) had average performance. Patients on HD scored 37 on school function. Those on PD scored 27 and those transplanted scored 31 (Table 6).

Table 2 Behavior status of the children with ESRD of study group before treatment

	Yes		No	
	N	%	N	%
Mood	77	100	0	0
Aggression	57	74	20	26
Depression	60	77.6	17	22.4
Anxiety	56	72.7	21	23.7

Table 3 Comparison between behavior status of the study group after treatment with dialysis & transplant

	Dialysis						Transplant					
	No change		Slight improvement		Good improvement		No change		Slight improvement		Good improvement	
	N	%	N	%	N	%	N	%	N	%	N	%
Mood	25	43.1	25	34.1	8	13.8	3	15	4	21.1	12	63.2
Aggression	31	53.4	22	37.9	5	8.6	4	21.1	3	15.8	12	63.2
Depression	34	58.6	16	27.6	8	13.8	3	15.8	4	21.1	12	63.2
Anxiety	34	58.6	16	27.6	8	13.8	4	21.1	4	21.1	11	57.9

Table 4 Patient relationship with their parents, siblings & peers after illness

	Strengthened		Weakened		Not affected	
	N	%	N	%	N	%
Parents	74	96.1	3	3.9	0	0
Siblings	57	74	16	20.8	4	5.2
Peers	36	46.8	33	42.9	8	10.4

Table 5 Comparison between patient relationship after treatment with dialysis and transplant

	Dialysis						transplant					
	Strengthened		Weakened		Not affected		Strengthened		Weakened		Not affected	
	N	%	N	%	N	%	N	%	N	%	N	%
Parents	54	93.2	2	3.4	2	3.4	18	94.7	1	5.3	0	0
Siblings	43	74.1	11	18.9	4	6.8	16	84.2	4	10.5	1	5.2
Peers	28	48.2	19	32.7	11	18.4	12	63.1	5	26.3	2	10.5

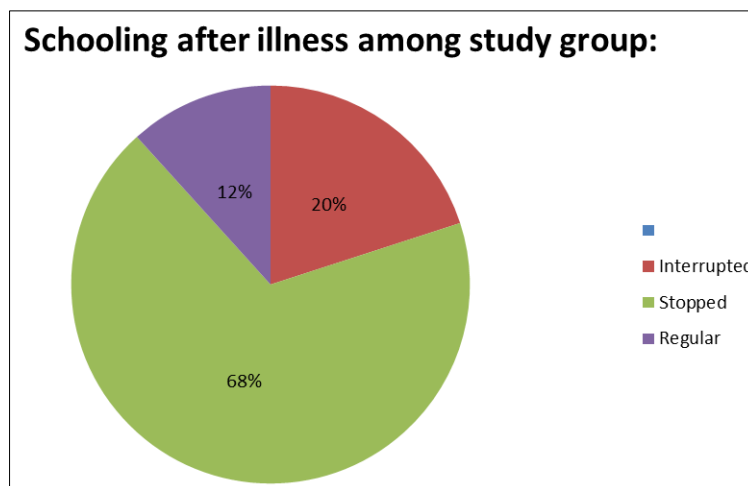


Figure 4 Schooling after illness among study group

Table 6 Comparison between schooling after dialysis and transplant in study group

	Schooling after treatment							
	Interrupted		Stopped		Regular		Total	
	N	%	N	%	N	%	N	%
Hemodialysis	2	6.5	27	87	2	6.5	31	100
Peritoneal	4	26.7	7	46.7	4	26.7	15	100
Transplant	1	6.3	8	50	7	43.8	16	100

4. Discussion

The vast majority of patients 67 (87%) were in the age group 7 years and above were only 10 (13%) were below 7 years of age which is similar to the study by Dr. Orainib in 2004. The male to female ratio is 1.3:1 indicates increase of ESRD in males more than females which is almost similar to the study by Dr. Orainib (13). The vast majority of patients (70.1%) live in urban areas. This may indicate increase incidence of ESRD among children in urban areas more than rural ones. 39% of patients and their families had changed their residence for better medical services in Khartoum. A similar finding was reported by Blumb GB in 1989 (14).

All patients in the study were on renal replacement therapy (RRT) in form of dialysis or renal transplant. One quarter of patients on RRT had successful renal transplant compared to one seventh of patient in Dr. Orainib study on 2004 (13). Both patient on hemodialysis and peritoneal dialysis had their physical activities limited a lot and their scoring system fall in the category of low score physical domain of QoL which indicated how the dialysis affect the body image.

On the other hand, the transplant had greater effect in improving physical activities of patients with ESRD and their scoring system fall in the category of high score physical domain QoL, which showed wide range between the dialysis and the transplant in improving the physical activity of patient with ESRD and their QoL. This similar to the study in Italy by Rubik J, Jakubouska which showed most transplanted children returning to the same score of physical activity as before their chronic illness (15).

Patient on hemodialysis showed behavioral problems and low scoring system of QoL because of the frequent number of dialysis / week, time spent on the scheduled dialysis that prevent the child from playing, social visits, regular schooling, the site and shape of access interfere with bathing and dressing them-selves. On the other hand, patients on peritoneal dialysis (CAPD) showed slight improvement on their behavior but still on upper limit of low degree QoL. This is because CAPD is home-based and self-administered therapy and widely available as an option to patients initiating chronic dialysis therapy, it was 4-5 times/ day at home in free time and doesn't need admission or hospital set-up and less expensive. This similar to study done in the USA by Dr. Nancy G. Kutner in 2005 that showed patients on PD reported

better QoL than patients on HD as measured by perceived ability to travel, restrictions in eating, drinking and dialysis access problem (16). The transplanted patients showed good improvement on their behavior with high score QoL. This is because transplant is associated with less distress, less hospital admission and no dialysis or access infection. Transplant was very effective in improving depression, anxiety and aggression. This similar to the study in Italy in by Hathaway DK, that showed a significant improvement in all QoL domains after successful transplant. It showed that the relationship of patient with parents, siblings and peers remained strong in most patients on RRT and they had high level QoL. Unfortunately, I was not the case in other studies where it showed negative impact on the family's relationship as it may lead to divorce or family disruption and the only improvement was in transplanted patients (17).

Most of patients in our study had regular schooling before their illness. Yet the greater effect of ESRD was interrupting school attendance where vast majority of those had regular schooling before illness had stopped going to school or interrupted school attendance. This was similar to the study by Wary J, Leng in Maria del Pralo hospital which showed that up to 40% of ESRD children and adolescents experienced problem of schooling including learning difficulties, social maladjustment with peers and school attendance (18).

In our study, patients on peritoneal dialysis had good improvement in their school attendance and their scoring system in upper limits of low QoL, while patients on hemodialysis had low degree score system. The transplant didn't improve the schooling of patients as the majority of parents were afraid to send their transplanted children to school because of poor schooling conditions. That's why transplant patients in our study showed upper limit of low score system of schooling, unlike the study in Australia by Uddin G.M. that showed children with functioning graft were attending full-time school, no learning difficulties and they were not more than 1 year behind schedule (19).

The vast majority of parents (93.5%) had great-full attention towards the child's illness, while only (6.5%) had no attention at all. The vast majority of studied patients (95 %) had stable family life while (5%) their life was not stable. This was against the study by Kutner NG, AM which revealed that ESRD has a negative impact on QoL of both patients and their families, changing the distribution of responsibility, house work and social activities (16).

Recommendations

The main conclusion and recommendations from this study are:

- To raise community awareness of renal disease for prevention and early detection.
- To raise the awareness of medical staff, families and community about the effect of ESRD in patient's QoL.
- Efforts should be directed towards solving the financial problems concerning medication, travelling, schooling and housing condition of patients with ESRD.
- Psychiatrists and social workers should work together with pediatricians to relieve the behavioral problems of children with ESRD and their families.
- More studies should be done on QoL of patients on RRT in other centers to compare the results.
- Good training of children and parents for home dialysis and its complications to reduce infection and morbidity.
- To raise the attention of the authority of public education to provide special classes for patients on RRT

5. Conclusion

The ESRD has a negative impact on quality of life of children in all domains of life, physically, psychologically and socially. In spite of renal replacement therapy in the form of dialysis (PD & HD) improves the quality of life of affected children, but renal transplant remains the best chance to improve the quality of life of these children.

Compliance with ethical standards

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Disclosure of conflict of interest

No conflict of interest to disclose.

Statement of informed consent

Informed consent was obtained from all guardians of children included in the study.

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