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Social Impact of End-Stage Renal Disease & Renal Replacement Therapy on Children and Their Families

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Abstract

The term end-stage renal disease (ESRD) refers to severe, irreversible reduction in kidney function, usually requiring dialysis or kidney transplantation to sustain life [1]. The global prevalence of end-stage kidney disease (ESKD) for children (0–19 year) was estimated at 18–100/million age-related population in 2008 [2]. In Sudan, the exact prevalence of end-stage kidney disease is not known, but the etiology of chronic renal failure was found to be glomerulonephritis, congenital urological malformation, urolithiasis, hereditary nephropathy, multisystem diseases and unknown etiology in one study [3].

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 objective was to study the social impact of end-stage renal disease (ESRD) and its treatment on children and their families.

Results: The study included seventy-seven children with End Stage Renal Disease (ESRD) and their families. The children were at the age group **2** *– 16 years. Male constituted 57.1% while females were 42.9% of the total study group. Thirty-eight (49.4%) were on Hemodialysis (HD), twenty (26%) were on Peritoneal Dialysis (PD) and nineteen (24.6%) had renal transplantation. The Majority of patients had restriction of their daily activities, restriction of social visits, complete restriction of play, restriction of hobbies and dietary restriction. About thirty (39%) of patients and their families changed their residence because of the child's illness and need for follow up. Most families in the*

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study group were of low socio-economic class and spent a lot of money for the treatment of their children. Majority of patients had their schooling affected by the disease. The relationship between the patients with ESRD and their parents had strengthened in vast majority of patients and weakened in minority of patients. The relationship between the patients and siblings had strengthened in fifty-seven (74%), weakened in sixteen (20.8%) and not affected in four (5.2%). The study showed that ESRD had a negative impact on the relationship between patients and peers.

Conclusion: although the ESRD and its treatment had a limited positive effect on the inter-family relationship between affected children and their families (parents and siblings) but still it had a negative social effect on children and their families. Children on HD and PD had significant negative impact compared to transplanted children.

Keywords: social impact, children and their families, ESRD, renal replacement therapy

INTRODUCTION

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 $15ml/min/1.73m^2$ [1]. The global prevalence of end-stage kidney disease (ESKD) for children (0–19 year) was estimated at 18–100/million age-related population in 2008. The prevalence varied widely across countries differing in socioeconomic status, potentially due to inequity in access to renal replacement therapies, both within and between countries [2].

The management of children with chronic kidney disease CKD is complex and multidisciplinary. It usually requires multiple medications (some of which are delivered subcutaneously or intravenously), medically invasive procedures, hemodialysis (HD) for four to five hours (thrice-weekly) or continuous peritoneal dialysis (PD), and nutritional supplementation via enteral tubes and pump devices [4]. 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 cycler machine once at night with uninterrupted day time activities. It allows children to attend school full-time and reduce the impact of peritoneal dialysis (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 hemodialysis (HD) [5]. 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 quality of life, significant long-term problems remain unsolved, particularly in relation to severe immunosuppression related side effects [6].

The onset of chronic kidney disease ESKD and subsequent recommendation of dialysis as a treatment option involves a change in lifestyle for both patients and close persons. Patients frequently require additional support and it is often family members who provide this. Studies have shown that good family support is associated with successful adaptation to dialysis and compliance with dietary restrictions [7]. Medical and surgical advances have led to dramatic changes in physical outcomes and substantial improvement in survival rates for children with CKD. However, RRT, especially dialysis, is consuming and invasive, placing high burdens of daily management on children that restrict their physical and social activities. ESRD children must face multiples challenges, including frequent hospitalizations, painful medical procedures, irregular school attendance and restriction of activities. This can have emotional and psychosocial impacts on the children, prompting an interest in thinking about quality of life (QoL), which is increasingly recognized as a key outcome in both clinical and research settings in the pediatric ESRD population. Moreover, adolescence is an important period of transition leading to empowerment, socialization, and the development of personality. Simply surviving is not sufficient, and quality of survival has emerged as a fundamental focus of comprehensive healthcare [8].

Because parents play a core role in the care of their children with CKD, their own health and well-being are important. Parents of children with CKD face many problems, including a lower quality of life, higher levels of anxiety, and maladaptive behaviors. This can consequently have a deleterious impact on the child’s personal development and medical treatment. However, these problems can be improved by providing support for parents, which can indirectly lead to better outcomes in the children [3]. Social support is a concept recognizing patients exist to varying degrees in networks through which they can receive and give aid, and in which they engage in interactions. Social support can be obtained from family, friends, coworkers, spiritual advisors, health care personnel, or members of one's community or neighborhood. Several studies have demonstrated that social support is associated with improved outcomes and improved survival in several chronic illnesses, including cancer and end-stage renal disease (ESRD) [9].

The objective of this research paper was to study the social impact of end-stage renal disease (ESRD) and its treatment modalities on children and their families at Noora Children Center for Dialysis and Renal Transplant at Soba University Hospital and Dr. Salma Nephrology Center for Dialysis and Transplant, Khartoum, Sudan.

METHODOLOGY AND RESULTS

MATERIALS AND METHODS: This is a descriptive cross-sectional hospital-based multi-center study. The study was conducted in Nora Paediatric Center for Dialysis and Renal Transplant (Soba university hospital) and Dr. Salma Nephrology Center for Dialysis and Transplantation Khartoum, Sudan from October to December 2009. All children diagnosed as having ESRD on RRT and their age between 2-17 years.

Sample size and sampling technique: All children were diagnosed as having ESRD aged 2-17 years and coming to the centers for RRT. Inclusion criteria: All children diagnosed as having ESRD aged 2-17 years. Exclusion criteria: Children diagnosed as having ARF and on intermittent haemodialysis or intermittent peritoneal dialysis.

Consent: All children and their parents or care takers in the study were told briefly about the importance of this research and the aims of this study to evaluate the social impact in children and their families. Consent was obtained from all of them. Also, consent was obtained from head department of dialysis center.

Study Techniques: The technique used in study is based on interviewing each patient with ESRD and their parents or care-taker coming to the centers for RRT. Questionnaires: modified questionnaire includes the following aspects: Personal data which included age, sex, original home, disease circumstances, type of RRT and effect of RRT on social aspects of the children with ESRD and their families. The data obtained was coded and entered into a computer and a master sheet was constructed to arrange the raw data. Data was analyzed using the statistical package for social science (SPSS).

RESULTS: 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. While male constituted 44 patients (57.1%); females were 33 (42.9%) of the total study group. 38 (49.4%) were on Hemodialysis (HD), 20 (26%) were on Peritoneal Dialysis (PD) and 19 (24.6%) had renal transplantation figure [1]. All patients in the study have end-stage renal disease (ESRD) 77 (100%). The majority of the patients 53 (68.8%) were diagnosed as having end stage renal disease for more than 12 months, 10 (13%) were diagnosed for 7-12 months, 6 (7.8%) patients diagnosed for 3-6 months and 8 (10.4%) for less than 3 months figure [2]. Most of the patients 60 (77.9%) had never been admitted to hospital during the last three months, while 16 (20.8%) of patients admitted less than three times during the same period and only 1 (1.3%) admitted more than three times during the last three months.

Thirty-nine (39%) of patients and their families changed their residence because of the child's illness and need for follow up. 50 (64.4%) of patients and their families can afford for treatment and 27 (35.1%) cannot afford for treatment. 45 (5S.4%) of families were living in their own houses while 32 (41.6%) were not living in their own houses. Most patients in the study group were of low socio-economic class. Most of the families spent a lot of money for the treatment of their children. In this study the majority of families 40 (51.9%) spent/month between 5I - 75% of monthly income, 21 (27.3%) spent ≥ 76% of their monthly income in treatment of their children, while 10 (3%) spent /month between 26-50% of their and only 6 (7.8%) of the total families in the study spent less than 25% of monthly income Table [1].

The majority of patient's fathers in this study 32 (41.5%) were skilled-laborer, 22 (28.5%) unskilled laborer, 7 (9.1%) were official, one (1.3%) was a farmer, 7 (9.1%) other occupations, 4 (5.2%) died Table [2]. The vast majority of mothers 58 (75.3%) were house wives, 3 (3.9%) were officials, 2 (2.6%) professionals and 10 (13%) unskilled labors. 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.

The relationship between the patients with ESRD and their parents had strengthened in vast majority of patients 74 (96.1%) and weakened in minority of patients 3 (3.9%). The relationship between the patients and siblings had strengthened in 57 (74%), weakened in 16 (20.8%) and not affected in 4 (5.2%). The study showed that ESRD had a negative impact on the relationship between patients and peers. The relationship had strengthened in 36 (46.8%), weakened in 33 (42.9%) and 8 (10.4%) not affected. After RRT there is slight improvement in making friends, 46 (59.7%) found no difficulty in making friends and 31 (40%) had difficulty in making friends Table [3].

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 attendance before illness had stopped going to school after illness, 12 (20%) their school attendance become interrupted and only 7 (1 I .6%) of patients continue in their regular 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. However, school performance after treatment 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 Table [4].

Almost all patient included in this study had no medical insurance coverage. Most of the patients live in large families and got social and financial support from relatives but still they needed extra financial support. So, the need for governmental and non-governmental organizations support was essential. Many organizations were working in this field but still facing finance shortage.

Figure 1: Type of renal replacement therapy

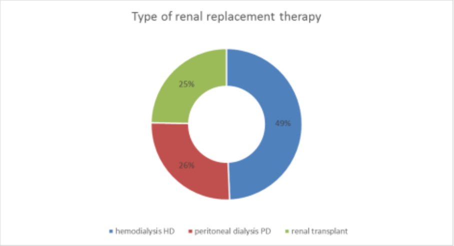

Figure 2: Duration of renal replacement therapy

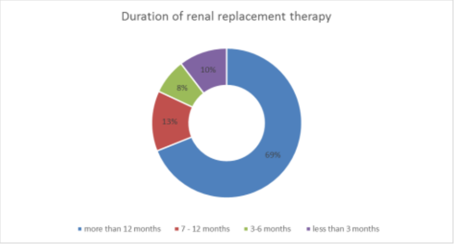

Table 1: percentage of money spent/ month on child's treatment of monthly income:

Percent of money	Frequency	Percentage
≤ 25%	6	7.8%
26 – 50%	10	13%
51 – 75 %	40	51.9%
≥ 75%	21	27.3%
Total	77	100%

Table 2: Father's occupation of the study group:

Father's occupation	Frequency	Percentage
Official	7	9.1%
Skilled labor	32	41.5%
Unskilled labor	22	28.5%
Professional	4	5.1%
Others	7	9.1%
Farmer	1	1.3%
Died	4	5.2%
Total	77	100%

Table 3: Patient's relationship with parents, siblings and peers after illness:

Relationship	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 4: School performance before and after illness

School performance	Before illness		After illness	
	N	%	N	%
Excellent	9	11.7	7	9.1
Very good	24	31.2	8	10.4
Good	20	26	11	13
Average	7	9.1	3	3.9

DISCUSSION

Childhood chronic diseases usually affect family functioning. Chronic disease greatly increases children's dependency on parents/caregivers (usually mothers) as they face new problems associated with caring for a child with chronic disease. Furthermore, family plays an important role in the child's adaptation and coping with his/her chronic disease. Therefore, children's health related quality of life (HRQoL) assessments needs to be supplemented with family functioning assessments. The assessment of family impact of chronic childhood illness is extremely useful to identify the need for family education, psychological intervention, and social support [10].

Most patients in our study were of low socio-economic class and spent a lot of money for the treatment of their children (between 26 - 75%) of monthly income. This is consistent with the results of the study from Pakistan by Ali Asghar et al where they stated that it would be impossible for most families to afford dialysis if expenses were out of pocket. A report from India suggests that of 10% of patients with end-stage kidney disease who seek care, 60% are lost to follow-up within 3 months of initiating treatment. Most developed countries have dialysis units well distributed across the country and expenses on medical care are borne by the state. However, national surveys conducted in the United States of America (USA), Canada, and United Kingdom suggest that about 40% of parents caring for children with disabilities experience financial burden. Children with disabilities are more likely to be born in families with low socio-economic status, and their parents frequently face financial difficulties as they require more time off work and cannot work overtime. Parents caring for children with chronic kidney disease in Australia reported multiple expenses and difficulties in claiming allowances from the government [2]

We found that the vast majority of mothers 58 (75.3%) were housewives. This was almost comparable to the study in Egypt by Darwish et al that showed work disruption occurred in only 8% of caregivers, as the primary caregiver is usually the mother and 94% of mothers in the study were housewives. Also, only 14% of caregivers sought an additional job, which can be attributed to unavailability of jobs, especially part-time jobs. Furthermore, most caregivers in the study were illiterate and of lower educational levels, which make their chances of finding jobs low [10].

The vast majority of parents in our study had great-full attention towards the child's illness and had stable family life. This may be contributed to the extended type of family in Sudan where the grand-parents, uncles, aunts and their small families were all live together in one big house. On the other hand, and while the relationship between the patients with end-stage renal disease and their parents and siblings had strengthened in vast majority of patients, the study showed a negative impact on the relationship between patients and peers. The relationship had weakened in 33 (42.9%). Fortunately, after RRT there is slight improvement in making friends as 60% found no difficulty in making friends.

This may be similar to the social life in Pakistan where parents depend on the support of other family members, particularly if they live in joint families in which relatives share the burden of care along with parents. Families that lack such social support are often unable to continue chronic medical management even if it is provided free of cost. On the other hand, relatives and friends may shy away from keeping contact with families with children with chronic kidney disease because they may require financial support, or from time to time, other favors such as blood donation, which may be frequently needed by children not maintained on erythropoietin due to its high cost or limited availability. Further, parents may limit socialization to avoid embarrassing their children who cannot compete with peers in sports [2].

In the other hand, care of a child with chronic illness may result in marital disharmony. While high rates of divorce are reported for parents of children with chronic disabilities, a longitudinal survey of families in Norway concluded that the divorce and separation rates are similar to those in families of healthy children. In Pakistan, conflict between spouses is frequently encountered in families taking care of children with end-stage kidney disease, possibly due to unequal sharing of responsibilities, and is particularly common where support from other family members is lacking. Conversely, the bond and understanding between spouses may be strengthened while taking care of a chronically ill child. A meta-analysis of 16 studies reported that parents of children with chronic kidney disease find it difficult to cope due to fatigue, uncertain outcome, and disruption of peer support within and outside the family. They become overprotective, leading to social isolation and fatigue. During chronic care, parents learn to recognize symptoms and their management, thus assuming the role of health-care provider. However, this added responsibility causes social withdrawal and self-neglect [2].

Furthermore, the end-stage renal disease has a negative impact on QoL of both patients and their families, changing the distribution of responsibility, house work and social activities [11]. There is a need for patients as well as their caregivers to have adequate support. Strong evidence from one systematic review demonstrated that self-accusation and blame, depression and generalized anxiety, emotional turmoil, uncertainty around diagnosis, the child's future and prognosis, and submitting the child to clinical staff were issues at pre-dialysis and dialysis for parents of children with chronic kidney disease. It has been reported that social supports (emotional, informational, instrumental, and appraisal) are useful in helping the families of children on PD to strengthen their coping mechanisms. Such support is unfortunately not available in most developing countries, such as Kingdom of Saudi Arabia (KSA). Furthermore, children stay on dialysis for long periods in KSA because of limited availability of kidneys from deceased donors [4].

Our study showed that the majority of patients who had regular school attendance before illness had stopped going to school after illness or become interrupted. School performance before illness has been excellent, very good and good performance in the vast majority of patients. However, school performance after treatment had reduced in all patients. This may be explained by the study by Lidwien A. Tjaden et al where they found several neurocognitive problems, including deficits in IQ, academic achievement, and executive functioning, have been reported in the pediatric end-stage renal disease population. Especially for children on dialysis, it is recommended to conduct age-appropriate cognitive and achievement testing on a regular basis. Dialysis units should have on-site educators to complement school-based teaching [12].

In Sudan, transplant didn't improve the schooling of the patient because of environment at school with poor hygiene of peers and friends and overcrowding which lead to infections. So, the majority of parents were afraid of sending their transplanted children to school because of infections and organ rejection. That is not the case in the study in Australia that showed children with functioning graft were attending full-time school, no learning difficulties and they were not more than 1 year behind schedule [13]. In the long term, adult survivors of pediatric end-stage renal disease have impaired physical but encouragingly good mental HRQoL. However, they do experience more difficulties integrating into the working population and building a social and family life [12].

There were many centers that provide RRT for children nationwide. This study was conducted only on 2 centers and that may not reflect the actual size of the problem. It is also noteworthy that results from this line of work can have implications for clinical- or policy-oriented segments of the nephrological community. Identifying social impact with kidney disease would enable health care providers and public health officials to develop interventions to help reduce disparities in CKD development and progression in the short term and eliminate them in the long term.

CONCLUSION

Although the renal replacement therapy is essential for survival for children with end-stage renal disease and has a positive impact on their social live and their families but there is a greater negative impact that needs for patients as well as their caregivers to have adequate social, financial, emotional and psychological support.

Compliance with ethical standards

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Disclosure of conflict of interest

Nil to disclose.

Statement of informed consent

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

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