

END-STAGE RENAL DISEASE AND RENAL REPLACEMENT THERAPY: PSYCHOLOGICAL IMPACT ON CHILDREN

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ABSTRACT

End-stage renal disease (ESRD) is when kidney function has deteriorated to such a poor level that without renal replacement therapy (RRT), dialysis or transplantation, death is probable within weeks or months. While dialysis and renal transplantation are life-saving treatments, they are also demanding and impact appreciably on the everyday lives of ESRD patients, often negatively affecting emotional and psychological wellbeing.

This is a descriptive cross-sectional multi-center 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 psychological impact of end-stage renal disease (ESRD) and renal replacement therapy on children.

Results: The study included 77 children diagnosed with End Stage Renal Disease (ESRD) on renal replacement therapy. Children were at the age group 2-16 years. Male constituted 57.1% while females were 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. 49 (63.6%) of patients had increasing stress and worries, 67 (87%) had behavioral changes, 57 (74%) of patients had their schooling affected by the disease, 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 while 21 (27.3%) had no anxiety. There was no much improvement in mood, aggression, depression or anxiety after starting dialysis unlike patient with renal transplant

who showed good improvement in all aspects.

Conclusion: ESRD and renal replacement therapy has a negative psychological impact on children. There was a big difference between the dialysis and renal transplant in improving the behavioral status of patients. The majority of transplanted patient had good improvement in their behavioral status and psychological domain after transplantation and the minority of dialyzed patients had good improvement in their behavioral status and psychological domain.

Keywords: psychological impact, children, ESRD, renal replacement therapy.

Introduction

End-stage renal disease (ESRD) is when kidney function has deteriorated to such a poor level that without renal replacement therapy (RRT), dialysis or transplantation, death is probable within weeks or months. While dialysis and renal transplantation are life-saving treatments, they are also demanding and impact appreciably on the everyday lives of ESRD patients, often negatively affecting emotional and psychological wellbeing. Many patients find the transition to dialysis frightening and traumatic [1]. Social scientists have noted that living in economically and socially challenging environments can be psychologically harmful. Constant exposure to distressing environments can reinforce constraints on one's existence and lead to higher levels of anger, anxiety, depression, and/or stress. The number of studies examining the relationship between psychosocial factors and kidney disease has grown in recent years, as a larger segment of the nephrologic community has become interested in identifying and addressing modifiable risk factors. However, the study of the psychosocial aspect of nephrology is still relatively new and requires scientists to devote considerable attention to nontraditional risk factors such as anxiety, stress, and social support [2]. The diagnosis of chronic illness not only has implications for the child, but also for the whole family. A child with chronic kidney disease (CKD) can be offered treatment, but not cure, even with transplantation [3]. Chronic kidney disease (CKD) is an established independent risk factor for

cognitive decline. Psychiatric disorders are also very common in patients with CKD. Hospitalizations due to psychiatric disorders (particularly depression, anxiety, and substance abuse) are 1.5 to 3 times more common among patients with CKD than individuals with other chronic diseases. In addition, cognitive impairment and psychiatric disorders can be leading factors of poor quality of life in CKD patients [4]. Several studies support the association between decreased renal function and cognitive impairment. For a decrease of 15 ml/min/1.73 m² in glomerular filtration rate (GFR), there is an estimated decline in cognitive function similar to that of a 3-year aging. The mechanisms underlying this cognitive impairment are not completely elucidated. Direct effects of uremic toxins can cause cognitive decline. However, the cognitive impairment persists despite adequate dialysis prescription, thus concluding that other factors may contribute to brain dysfunction [4]. In 2000, we found intelligence quotient (IQ) scores among the Long-term Effects of RRT in Children (LERIC) patients to be on average 10 points lower than in the age-matched Dutch population, in line with studies on IQ performed in chronic kidney disease (CKD) children. The most important determinant of impaired schooling and cognition was a relatively long period of dialysis during youth [5]. With modern medical advances, such as dialysis and kidney transplantation, the survival of children and young people with CKD have noticeably increased. While long-term survival improves among children with CKD, their overall quality of life remains hampered and often continues in adulthood. The prolonged need to take medica-

tions, frequent contact with medical professionals, and interruptions in schooling and everyday activities may be mechanisms through which the illness increases affected children's psychological problems. Caregivers often experience emotional, marital, social, and financial burdens, which may leave families feeling unable to deliver the complex care that children with CKD require [6]. Although there are potential benefits in terms of schooling, socialisation and travel costs for children on home dialysis (peritoneal and haemodialysis) compared with hospital haemodialysis, it was naive of us to expect parents, particularly mothers, to cope with the burden of running a "high dependency unit" at home for their child on home dialysis. Transplantation is the stated goal for all children requiring RRT, but with young infants it may be some time before they reach the size appropriate for transplantation, and support from tertiary nephrology, local paediatric units and primary care may be essential through networks of care [3]. The parents of children with CKD undergoing hemodialysis (HD) report a worse academic performance of their children in comparison to those undergoing conservative treatment and in the control group. It is also noteworthy the low school performance of siblings of children and adolescents with CKD [7]. Children can be easily upset by invasive procedures, despite the use of local anesthetic creams and sprays. Many have varying degrees of needle and procedural phobia, which makes aspects of their care very stressful to patient, family and staff. The work of play therapists or child life specialists, often in conjunction with the psychologists, in preparing children for procedures throughout their RRT cannot be over-emphasized. Experience would also suggest that the presence of a psychologist in close proximity to the renal team, particularly participating in a joint clinic, allows early referral for assessment and advice, especially when families are attending from some distance [3]. Routine psychological evaluations should be integrated to ensure better understanding of the illness and the child's overall quality of life. During an evaluation, if problems such as anxiety, withdrawn behavior, low self-esteem, school refusal, attention deficit, poor scholastic performance, or poor treatment adherence are perceived or reported, the primary physician can refer the child to a mental health professional or a medical social worker for further evaluation. Warady and Chadha reported that therapeutic camps organized for children with kidney failure were successful, indicating reduced depression, improved self-esteem and self-confidence, and overall promotion of emotional maturity [6]. The patients with ESRD and RRT reported high levels of stress, depression, anxiety, mood changes, aggression, anger and feelings of hopelessness related to worries concerning their own health and the perception of their limitations. Thus, an important point to be discussed is that the understanding and re-channeling of stress in children with ESRD and RRT constitute an effective form of relief of their emotional suffering and improvement in their quality of life. In this paper we would like to high-light this problem and help officials understanding and improving health services provided for better quality of life of these patients and their families.

Methodology

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.

Sample: All children were diagnosed as having ESRD, their age was between 2 and 17 years whom were treated in the centers with 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. 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 psychological impact in children and their families. Consent was obtained from all of them. Also, consent was obtained from head department of dialysis center and hospital administration.

The technique used in this study was based on interviewing each patient with ESRD and their parents or caretaker coming to the centers for RRT. A modified questionnaire includes the following aspects: Personal data which included age, sex, original home, disease circumstances, type of RRT and effect of RRT on psychological aspects of the children with ESRD. 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 with End Stage Renal Disease (ESRD) on renal replacement therapy. The children were at the age group 2 – 16 years. Male constituted 57.1% while females were 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. Patients on hemodialysis received their sessions 3 times/ week regularly and those on peritoneal dialysis are on continuous ambulatory peritoneal dialysis (CAPD) received their sessions about 4 times/ day. 15 (78%) of the transplanted children had been transplanted for more than 1 year and 4 (22%) for less than 1 year. 2 (11%) of the transplanted children had problem of rejection. 10 (26%) of patients on hemodialysis had access infection whereas 4 (20%) patients on peritoneal dialysis had catheter site infection and peritonitis. The vast majority of patients 63 (81.8%) take their medications regularly, and 14 (18.2%) don't take their medications regularly. 10 (26%) of patients on hemodialysis had access infection whereas 4 (20%) pa-

tients on peritoneal dialysis had catheter site infection and peritonitis.

Behavior status after illness: 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 [Table 1].

Table 1: Behavior status of children with ESRD:

	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

Behavior status after hemodialysis and peritoneal dialysis:

Mood: 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.

Aggression: 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. 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 after PD.

Depression: 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.

Anxiety: 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 start of treatment [Table 2].

Table 2: Behavior status of children with ESRD after treatment with dialysis (HD & PD):

	HEMODIALYSIS						PERITONEAL DIALYSIS					
	No change		Slight improvement		Good improvement		No change		Slight improvement		Good improvement	
	N	%	N	%	N	%	N	%	N	%	N	%
Mood	20	52.6	14	36.8	4	10.5	5	25	11	55	4	20
Aggression	24	63.2	13	34.2	1	2.6	7	35	9	45	4	20
Depression	28	73.7	8	21.1	2	5.3	6	30	8	40	6	30
Anxiety	27	71.1	9	23.7	2	5.3	7	35	7	35	6	30

Behavioral status after transplant:

Mood: 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.

Aggression: 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: 3 (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: anxiety remained unchanged in 4 (21.1%) of transplanted patients, 11 (57.9%) showed good improve-

ment and 4 (21.1%) showed slight improvement of their anxiety [Table 3].

Table 3: behavior of children with ESRD after renal transplant:

	No change		Slight improvement		Good improvement	
	N	%	N	%	N	%
Mood	3	15.8	4	21.1	12	63.2
Aggression	4	21.1	3	15.8	12	63.2
Depression	3	15.8	4	21.1	12	63.2
Anxiety	4	21.1	4	21.1	11	57.9

The comparison between behavioral status after Dialysis and Transplantation:

Mood: There was 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.

Aggression: 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.

Depression: The depression remained unchanged in 34 (58.6%) patients even after dialysis. only slight im-

provement in 16 (27.6%) and showed good improvement in 8 ((3.8%) patients of dialysis. While the majority of transplanted patients 12 (63.2%) showed good improvement of depression, 3 (15.8%) of patients had no change in their depression.

Anxiety: The anxiety remained unchanged in the majority of patients on dialysis 34 (58.6%), 16 (27.6%) showed slight improvement and the remained 8 (13.8%) had good improvement after dialysis. A good effect had been noticed in patients with renal transplant and showed good improvement in anxiety in majority of patients 11 (57.9%), 4 (21.1%) had slight improvement after transplant and only 4 (21.1%) remained anxious [Table 4].

Table 4: Comparison between behavior status after treatment with dialysis & renal transplant:

	DIALYSIS						TRANSPLANT					
	No change		Slight improvement		Good improvement		No change		Slight improvement		Good improvement	
	N	%	N	%	N	%	N	%	N	%	N	%
Mood	25	34.1	25	43.1	8	13.8	3	15.8	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

Effect of kidney disease on Schooling:

Schooling before illness: 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 (11.6%) of patients continue in their regular school attendance.

Schooling after treatment HD and PD: 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 table [5].

Table 5: Comparison between schooling behavior after treatment with dialysis:

	schooling after treatment							
	Inter-rupted		Stopped		Regu-lar		Total	
	N	%	N	%	N	%	N	%
He-mo-dialy-sis	2	6.5	27	87.0	2	6.5	31	100
Per-iton-eal	4	26.7	7	46.7	4	26.7	15	100

Schooling after transplant: The effect of renal transplant on school attendance: It 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 NB. 3 (15.75%) had never gone to school table [6]. The 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 [Table 6].

Table 6: Comparison between schooling behavior after treatment with dialysis & renal transplant:

	schooling after treatment							
	Inter-rupted		Stopped		Regular		Total	
	N	%	N	%	N	%	N	%
Dialy-sis	6	14.6	29	70.9	6	14.6	41	100
Trans-plant	1	6.3	8	50.0	7	43.8	16	100

DISCUSSION

In this study we aim to provide insight into the preva-

lence of psychological distress in this chronic pediatric condition that have received little research attention. We found that males were more than female as 57.1% were males while females were 42.9% of the total study group which similar to the result from Sudan reported by Eltigani et al 2006 [8] and unlike the study from Egypt by Mohamed A. El-Gamasy et al where they found that 56.7% of the studied children were females. Their finding was in agreement with the studies by Ramzy et al. and Sabry et al. who reported that there was a high prevalence of kidney disease among females [9]. We found that the vast majority 60 (77.6%) of ESRD patients became depressed after diagnosis. This was almost similar to the report by Ana Cristina where depression is the most frequently reported psychiatric condition in CKD patients, especially in those at end-stage renal disease (ESRD). The prevalence of depression among patients with CKD can be as high as 100%, depending on the diagnosis criteria and the studied population. The prevalence of depression and the risk of hospitalization due to psychiatric disturbances are higher in patients on dialysis in comparison with pre-dialysis and post-transplant patients [4]. On the other hand, the reported prevalence rate of depression in patients with CKD ranges from 20% to 30%. Notably, the assessment method used to identify depression can affect the prevalence estimates. This was illustrated in a meta-analysis of 249 studies conducted within patients undergoing dialysis, the prevalence rates of depression were found to be 22.8% using clinical interviews. However, when self- or clinician-rated questionnaires were used the prevalence rates were found to be 39.3%, which was statistically higher than the previous one figure [10]. A systematic review and meta-analysis that analyzed 216 studies involving 55,982 patients with CKD or ESRD showed a prevalence of 26.5% of depressive symptoms in CKD patients when evaluated by screening questionnaires, and of 21.4% of clinically significant depression when evaluated by clinical interview [11].

The prevalence of mental disorders was high in our study compared to other international studies for example Renata Cristiane et al reported that the prevalence of mental disorders was 52.6%, divided as follows: behavior 18.4%; depression 22.4%; neuro cognition disorders 7.7%; anxiety 5.1%, and elimination disorders, 2.6%. When comparing the incidence of psychiatric disorders in patients undergoing dialysis and conservative treatment, the prevalence was 68.4% and 36.8%, respectively [7]. It's obvious that ESRD and RRT has negative effect of kidney disease on Schooling as shown in our study. Similarly, Mohamed A. El-Gamasy et al reported that all children undergoing dialysis showed irregular school attendance, and 20% failed to pass school exams, while 36.7% earned low marks. These results may be attributed to regular visits to dialysis centers for dialysis sessions three days a week, leading to irregular school attendance and low achievement [9]. Caring for children with ESRD on CPD has substantial adverse psychosocial effects on the caregivers. Health care for these children and their families, therefore, should not be limited solely to managing catheters and dialysis solutions. In particular, attention must be paid to the physical, psychological health, and social welfares of the patients and their caregivers [12].

Conclusion

ESRD and renal replacement therapy has a negative psychological impact on children and their families. It is clear that there was a big difference between the dialysis and renal transplant in improving the behavioral status of patients. The majority of transplanted patient had good improvement in their behavioral status and psychological domain after transplantation unlike the dialyzed children who showed minimal or no improvement in their behavioral status and psychological domain. Identifying psychological impact with kidney disease would enable medical professionals and public health planners to develop interventions to help reduce negative impact in

CKD development and progression in the short and long terms.

Recommendations

1. It's recommended that a multi-professional team of play therapist, social worker, psychologist and family/systemic psychotherapist in conjunction with medical/nursing colleagues needs to constantly address the potential and actual trauma to ESRD children.
2. Early referral is advocated with regular team meetings to facilitate knowledge transfer. It is essential that each family is assessed by a social and psychological worker so that the burden of the disease and its treatment is understood.
3. Transplantation is the preferred modality of treatment for children needing RRT.

Compliance with ethical standards:

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Disclosure of conflict of interest

Nil to disclose.

Consent: Informed consent was obtained from head of emergency department and hospital administration.

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