Psychological and Social Status of Children Treated with Renal Dialysis and their Mothers at Tanta City

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Abstract

Background and Aim: Renal dialysis treatment of children with end-stage kidney disease (ESKD) poses various challenges including financial difficulties, social challenges and psychological problems. Parents frequently face financial difficulties as they require more time off work and cannot work overtime. Sickness of a child causes a decline in the financial and socioeconomic status of the family and also hampers its functionality. Moreover, care for those children involves considerable psychological and social stress. This study aimed to assess psychological and social condition of children treated with renal dialysis and their mothers.

Materials and Method: The research was conducted on children with End-stage renal disease (ESRD) treated with renal dialysis and their mothers. The total studied population in this study was 40 child and their mothers (N= 40). One tool was used to collect data about the children illness and socio-demographic characteristics. Children psychological and social status is assessed using the Paediatric Quality of Life Inventory (PedsQL)and their parents the PedsQL-proxy version. Mothers health, social, and psychological data were collected using General Health Questionnaire (GHQ-12), and Berlin Social Support Scales(BSSS).

Result: Children psychological and social status were significantly low as reported by the children or the mothers who provide primary care for APD children**.** The mothers perceived available and actually received support is low. Overall score of General Health Questionnaire of the mothers was very high by median and quartile 17 (15–18).

Conclusions: Children psychological and social status were low according to PedsQL test. The family of children with renal dialysis need financial support. Mothers who provide primary care to children on renal dialysis require emotional support and assistance in self fulfillment. The mothers have high GHQ-12 scoring which means that they are have greater chance for increase of non-psychotic mental disorders. There is a strong need to provide continuous psychological care for caregivers.

Keywords: *Psychological, Social, Children Treated with Renal Dialysis, Mothers.*

Introduction

End-stage renal disease in children is a life-threatening disorder. It is considered to be a major public health problem because of increasing in its incidence and prevalence. It is still a health problem in children with increasing morbidity and affecting children's quality of life (QoL). The prevalence of children with chronic kidney disease worldwide is approximately 82 cases/year/1 million children (2019)(1,2). Children with chronic kidney disease (CKD) need lifelong medical treatment, which put significant uncertainty and inconvenience on their lifestyle and on that of their families. Renal dialysis treatment of children with end-stage kidney disease (ESKD) poses various challenges including financial difficulties, social challenges and psychological problems. Parents frequently face financial difficulties as they require more time off work and cannot work overtime. Sickness of a child causes a decline in the financial and socioeconomic status of the family and also hampers its functionality(3,4). The challenges of kidney failure for children involve physical effects from the loss of kidney function and emotional effects due to their illness. Physical effects of kidney failure can encompass extreme fatigue, weak bones, nerve damage, sleep problems, and growth failure. Emotional effects of kidney failure can include depression and feelings of isolation, which is especially a problem for children, who put great importance on making friends and fitting in. Individualized plans may be needed for children with kidney failure to help them to become active, productive, well-adjusted adults(5, 6).

From the moment of diagnosis and beginning of living with the disease, chronic kidney failure (CKF) causes changes in habits and excite emotional changes in children and adolescents. These changes may be appeared through feelings of insecurity and fear, limitations on quality of life (QOL), resulting in a higher incidence of psychological changes than in the general population(7,8). Families caring for a child with kidney failure face certain challenges including understanding treatment options, scheduling and performing dialysis, and learning how to keep the child as healthy as possible. Constant stress on caretakers is reported to alter neural, neuroendocrine, and immune responses, which impact physiologic and psychological outcomes. The prevalence of anxiety and depression is expected to be high in parents of children with ESKD and treated with renal dialysis.(9, 10).

Families that lack 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 CKD 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.(11). Parents assume various important roles, including those of nurses, pharmacists, and physicians. Parents deliver home-based interventions, including dialysis and nutritional supplementation, which are technically demanding and are basically provided by highly trained nurses in hospitals(12). Because of the core role which were played by parents in the care of their children with CKD, their own health and well-being are important and at risk. Parents of children with CKD face many social and psychological problems, including a lower quality of life, higher levels of anxiety, and maladaptive behaviors. This problems by turn have a deleterious impact on the child's personal development and medical treatment. However, these problems can be decreased and eliminated by providing support for parents, which can indirectly lead to better outcomes in the children(13).

Nevertheless, impaired health-related quality of life among children on dialysis remains a challenge(14). Children's QoL is closely related to the family, especially when the child is on renal dialysis. In addition to the usual parental responsibilities and activities of providing support, parents must also be involved in the therapeutic process(15,16). In many cases, family members becoming the main caregivers burdened with many responsibilities and thus affects the life of the children's family. On the other hand, each parent's perception of their psychosocial situation, as well as their reaction to it, may affect the relationship between parents and their children and the child's functioning(17,18). Before the decision concerning renal replacement treatment is made, it is necessary to assess the family's social, psychological, and economic background and recognize the needs of parents/caregivers(19). Disregarding those factors creates the risk of complicating the method**.** Children with CKD usually have a poor quality of life because of the disease itself and dialysis are invariably quite stressful. As a result, it considered a predisposing factor for the development of psychiatric disorders in these patients and their family members, particularly in their main caregivers (14).Psychological and social aspects of children with chronic kidney disease (CKD) treated with renal dialysis have rarely been analyzed, and never in Tanta, Egypt. Therefore, we conducted national study with the aim of analyzing the psychosocial situation in families of children treated with renal dialysis and their mothers.

Material and Method

Research Design: A descriptive research design was used in the current study.

Research Setting: This study was conducted at pediatric dialysis unit of pediatric medical department of Tanta university Hospital. It has a capacity of 10 beds. It also provide health care services to three Governments, namely El Gharbeya, El Menofeya, and Kafr El Sheikh. **Subjects:** The research was conducted on children with End-stage renal disease (ESRD) treated with renal dialysis and their mothers. It include all available children and their parent whom admitted to dialysis unit from July to September 2019 for a period of 3months. The total studied population in this study was 40 child and their mothers (N= 40), they are selected by convenience method of sampling if they have the inclusion criteria. Inclusion criteria for children were as follows: CKD diagnosed at least 12 months prior to the study, renal dialysis beginning at least 3 months prior to the study, age ≥2 years, and informed consent. Exclusion criteria for children comprised: a history of severe to profound mental retardation, renal, other solid-organ, bone marrow, or stem cell transplantation, cancer/leukemia diagnosis, hospitalization within 14 days (excluding hospitalization due to peritoneal dialysis control visit), and a significant life event unrelated to their kidney disease in the past 30 days, such as losing a family member.

Tools of the Study: Four tools were used by the researchers to obtain the necessary data.

Tool I: Structured interview questionnaire sheet. A structured interview questionnaire sheet which was designed by the researchers based on thorough review of literature. This tool comprises the following parts:

Part 1: *Child' Socio-demographic* and clinical data: age, sex, level of education, primary diagnosis of kidney disease, patient's age at time of CKD diagnosis, illness duration, Family renal history, dialysis duration, renal care duration, additional non-renal comorbidities, and number of hospitalizations.

Part 2: *Parents' demographic* information and certain changes as a result of child illness include: age, working status, place of residence educational level, health problems, having another children, who care of child, participation of other people in child care, change in economic status, and change in residence after starting dialysis, changes in attitude toward the ill child, changes in social contacts.

Tool (II): Assessment of children psychological and social status by *Pediatric Quality of Life Inventory (PedsQL) and their parents the PedsQL-proxy version.* It developed by ***Varni JW(2003)***(20,21). The PedsQL assesses physical, emotional, social, and school functioning in children and adolescents. The measure comprises a report from children 5–18 years of age and a parent report for children between 2 and 18 years of age regarding the child's HRQoL. The PedsQL 4.0 Generic Core Scales were specifically designed to measure the core health dimensions outlined by the World Health Organization. The PedsQL is composed of 21 items comprising 4 dimensions (physical Functioning 8, psychological 5, social Functioning 5, and school functioning 3). The Scoring of The PedsQL include 5-point Likert scale from 0 (Never) to 4 (Almost always). Scores are transformed on a scale from 0 to 100. Higher scores indicate better psychological, and social Functioning.

Tool (III): Assessment of mothers psychological *status by General Health Questionnaire (GHQ-12).* It developed by ***Goldberg D***(22). The GHQ-12 measures psychological distress and is used to detect nonpsychotic psychiatric disorders such as depression or anxiety in adults. The scale asks whether the respondent has experienced a particular symptom or behavior recently. Each item is rated on a four-point scale (less than usual, no more than usual, rather more than usual, or much more than usual). The GHQ-12 is brief, easy to complete, and its application in research settings as a screening tool is well documented. We used the original scoring method in our study (response categories score: 0, 0, 1, and 1, respectively). This produces scores ranging from 0 to 12; the higher values indicate more psychological symptoms.

Tool (IV): Assessment of mothers Social status *by Berlin Social Support Scales (BSSS):* It developed by ***Schwarzer R (2003)***(23). The original BSSS includes six independent subscales (perceived available support, need for support, support seeking, actual received support, provided support, and protective buffering) and measures both the cognitive and behavioral aspects of social support of the mother. Four subscales were used for this study: perceived available support (8 items), need for support (4 items), support seeking (5 items), and actual received support (15 items). The perceived support subscale comprises items of emotional and instrumental support; the overall received support includes items of emotional, instrumental, and informational support. The response format is the same for all subscales. Individuals rate their agreement with the statements on a four-point scale [strongly disagree (1), somewhat disagree (2), somewhat agree (3), and strongly agree (4)]. An average mean within the range of 1–4 was calculated for each subscale. A higher score indicated greater burden (24).

Method: Before conducting the study, a written permission letter was obtained from the Faculty of Nursing Tanta University to the manager of pediatric medical department of Tanta university Hospital in order to obtain an approval to carry out the study. The manager was informed about the goal of the study, the date and time of data collection. **Ethical consideration:** Approval of the study was taken from the Faculty of Nursing to the manager of the previous settings in order to attain an approval to carry out the study. Informed written and oral consent was obtained from children and their parents to participate into the study. Also Confidentiality was assured. **The procedure of data gathering;**Structured interview schedule related to socio-demographic data (tool I) was developed by the researcher. Either tools(III, IV, & V) were translated into Arabic language by the researcher. A pilot study was done before embarking in the field of work on 10% from total subjects to ascertain the clarity and applicability of the study tools. The pilot subjects were excluded from study sample. This study was performed in 3 steps: The first; after obtaining a written permission from the previous settings, the researchers presented it to the pediatric renal dialysis unit. The study protocol was thoroughly explained to children and their parents and written informed **consent** was obtained from parents and children >16 years of age before enrollment in the study. Verbal consent was obtained from children <16 years where possible. The second; Medical files were analyzed to obtain child' clinical data. Third; All tools questionnaires related to child were collected by researcher through an individual interview. While each parent filled out the questionnaire separately. Each session of data collection with each study subject last from 20-40 minutes.

Statistical Analysis: The data were coded, entered and analyzed using SPSS (version 20). Descriptive statistics (frequency numbers and Percentages) identified demographic characteristics and parents‟ responses to the questionnaire. The median and quartiles were calculated for children and parents quality of life. Paired t tests were used to analyze the relationships; statistical significant was set at P value < 0.05% results of tests of significance.

Results

Characteristics of the examined children are showed in Table 1. As regard children sex, slightly more than half of children (55%) were males. The mean of the children age was (Mean ±SD: 11.85 ± 3.62). Majority of children (75%) hadn't family renal history. Less than half (45%) of children had anomaly of urinary tract and chronic pyelonephritis. More than three quadrant of children (80%) lived in rural areas. Most children (90%) were hospitalized from 1-4 times. Median of children's age at CKD diagnosis was 1.5 year. Whiles median number of years of dialysis therapy among children was 2.98.

The characteristics of APD children's families, their mothers in particular as all examined children was accompanied by their mothers at time of dialysis, are presented in Table 2. Most children were growing up in complete families; only two of them lived with one parent (mother). The age of the mothers of examined children was ranged from 30-50 years old. 60% of children' mothers were having moderate level of education. Most of children' mothers) 85%) were employees. Half of the mothers hadn›t any health problems.

Parents' perceived change in their families ‹situation after the child's diagnosis with CKD is summarized in Table 3. It appeared a harsh deteriorated change in economic situation for the family, where all families (100%) had changes in their financial status. While there wasn›t changes in location of residence of all families after CKD diagnosis in their children. More than half (60%)of mothers stated that the father give care more for their ill children. Thirty percent (30%) of mothers report that grandparents participate with parents in child care. About three quadrant of mothers (70%) report that there isn›t change in their attitude toward their children. The majority of mother (85%)stated that there were change in relations among their children, 70% of them stated that the relations among their children and the ill child was improved. Also there are improvement changes in social contact of other with ill child represented by 60%.

Table 4 illustrates Pediatric Quality of Life Inventory of the studied children. The PedsQL test results of the studied children as reported by the children or the mothers who provide primary care for APD children were significantly lower in relation to results among parents of healthy children as median and quartile of overall PedsQL test was (250(195–275) and 280(225–315)). In explaining different aspects of PedsQL test results among APD patients, it was found that the studied children have problems in physical functioning as they cannot walking more than one block, running, participating in sports activity or exercise, lifting something heavy with median and quartile 252 (182–316) as reported by children and 235 (192–260) by the mothers compared to normal child. Also the emotional functioning of the studied children was lower than the healthy children as reported by both the children and the mothers (150 (112–165) and 190(125–210) respectively. The test results also revealed that the children have low social function in relation to normal PedsQL score with median and quartile 120 (93–130.75) as reported by the children and 150 (112–165)by the mother. Also the school functioning was low as reported by the studied children with median and quartile 190(125–210) and mothers 120 (93–130.75). There were no significant differences between children and mothers reporting in the PedsQL test results as P > 0.05.

Berlin Social Support Scale (BSSS) test results among mothers of children on renal dialysis was showed through table (5). It is clear that the mothers perceived available support and actually received support is low. Regarding to perceived social support, median and quartile of perceived emotional and instrumental social support was 5 (4–7) and 6 (5–7.75) respectively. While median and quartiles of studied mothers whom need for support and support seeking were 9 7 (6–8.5) and 5 (4–6.75) respectively. On the other hand of the other subscale BSSS test « actually received support», the studied mother report that they actually received low emotional, informational and instrumental support as revealed by median and quartiles 5 (4–6.75),6 (5–7.7), and 5 (4–7.8) respectively.

Table 1: Characteristics of the studied children

Characteristics of the studied children	**Studied children (n=40)**	
	No	**%**
Sex:		
Males	22	55
Females	18	45
Age in Years:		
6-10	16	40.0
11-15	16	40.0
>15	8	20.0
Range	6-17	
Mean±SD	11.85±3.65	
Family renal history:		
Yes	10	25.0
No	30	75.0
Causes of CKD:		
- Chronic glomerulonephritis	6	15.0
- Anomaly of urinary tract and chronic pyelonephritis	18	45.0
- Hereditary kidney disease	8	20.0
- Others	6	15.0
- Unknown cause	2	5.0
Place of residence		
- Urban	8	20.0
- Rural	32	80.0
Number of hospitalization		
- 1-4	36	90.0
- 5-10	4	10.0
Age at CKD diagnosis (years)	Median (quartiles), 1.5 (0.02–6.0)	
CKD duration (years)	Median (quartiles) 2.17 (1.21–2.75)	
Dialysis therapy (years)	Median (quartiles) 2.98 (1.0–2.20)	
Distance from Dialysis therapy center (km)	Median (quartiles) 55.0 (15.5–75.5)	

Table 2: Characteristics of mothers of children on Dialysis therapy

Characteristics of the studied children	**Studied children (n=40)**	
	No	**%**
Age in Years:		
30-35	20	50.0
36-40	10	25.0
>40	10	25.0
Range	30-50	
Mean±SD	63.7±8.65	
Educational level:		
- Illiterate	8	20.0
- Moderate	24	60.0
- High	8	20.0
Employment:		
-Yes	34	85.0
- No	6	15.0
Presence of healthproblems		
- Yes	20	50.0
- No	20	50.0
Presence of Sibling		
- Yes	38	95.0
- No	2	5.0
Type of family		
- Full	38	95.0
- Single parent	2	5.0

Table 3: Family Changes after chronic kidney disease (CKD) diagnosis in the child

Family Changes	**Mothers' evaluation**			
	Yes		**No**	
	No	**%**	**No**	**%**
Change in location of residence	0	0.0	40	100.0
Change in financial status	40	100.0	0	0.0
Caring for the child				
- Mother	10	25.0		
- Father	24	60.0		
- Both parents	6	15.0		
Participation of others in child care				
- Grandparents	12	30.0	2	6.6
- Sisters	10	25.0		
- Relatives	18	45.0		
Changes in attitude toward the ill child	12	30.0	28	70.0
- Improved	12	30.0		
- Deteriorated	0	30.0		
Changes in relations among children	34	85.0	6	15.0
- Improved	28	70.0		
- Deteriorated	6	15.0		
Changes in social contact	26	66.6	14	33.4
- Improved	24	60.0		
- Deteriorated	2	6.6		

Table 4: Children Psychological and Social Status and Overall PedsQL

Pediatric Quality of Life Inventory (PedsQL)	Studied children	Mothers
	Median and quartiles (first–third quartile)	Median and quartiles (first–third quartile)
Physical functioning	252 (182–316)	235 (192–260)
Emotional functioning	150 (112–165)	190(125–210)
Social functioning	120 (93–130.75)	150 (112–165)
School functioning	190(125–210)	120 (93–130.75)
Overall PedsQL	250(195–275)	280(225–315)

Table 5: Berlin Social Support Scales (BSSS), General Health Questionnaire test results among Mothers of children on renal dialysis.

Berlin Social Support Scales (BSSS)	Mothers
	Median and quartiles (first–third quartile)
Perceived available support:	
Emotional	5 (4–7)
Instrumental	6 (5–7.75)
Need for support	7 (6–8.5)
Support seeking	5 (4–6.75)
Actually received support:	
Emotional	5 (4–6.75)
Informational	6 (5–7.7)
Instrumental	5 (4–7.8)
General Health Questionnaire	
Total	**17 (15–18)**

Discussion

Care for children with chronic renal dialysis encompass considerable social and psychological stress. These children are dependent on their parents for dialysis-related home care procedures(26). The results of the current study showed that there is deterioration change in economic situation for the family of children with renal dialysis, as all mothers 100% claimed the deterioration of financial situation followed the diagnosis of their child's illness. There is a positive correlation between change in financial status and children dialysis duration. Also there is positive correlation between change in financial status and place of residence as the majority of families from rural area which increase the economic burden during transportation to the place of dialysis. This result is in agreement with Katarzyna et al. (2013)(27), who found a harsh deterioration change in economic situation for the family of children with renal dialysis.

Psychological and social status among the studied children was low according to PedsQL test, which is in consistent with the findings of ***Anouck Splinter, eta.l**, **(2018)***(28) who stated that both dialysis and renal transplantation have a severe impact on the health related quality of life of children with end stage renal disease. The decrease in children psychological and social status may be related to the deterioration in their school and physical functioning as mentioned by the studied Children and mothers. There significant correlation between children physical, school, social and psychological status. It is worth of glory that the overall quality of life was rated as low by parents than by their children. The same findings were obtained by other researches which applied on children with chronic disorders(28,29). This condition may lead to over protectiveness and thus inhibit the child's development of self-reliance and sufficiency and, as a result, increase the perceived burden experienced by the mothers. The mothers in this study evaluated their total burden as median and low, this could be related to assistance from the father of the diseased child and other members in her family. There is appositive correlation between the perceived burden and the Perceived available support. It can be also proposed that participating as a caregiver also carries positive effects that decrease the perceived burden. Among such positive effects, mothers become stronger with different interactions with others while accompanying the child to the haemodialysis sessions, like; the mother's communication with the health team, with the other mothers at the Center, with the family and the child himself. This result is consistent with the claimed enhancement of relationships with the sick child by the parents (or lack of changes in attitude toward the child) and the evaluation of the relationship with the patient as very good in most cases.

Child's illness make changes in the family that usually include living location rearrangement, involving of additional individuals in caring for the sick child, and the deterioration of existing social relationships. Parents often establish only new friendships with other sick children's parents which supposed to be beneficial in exchanging experiences; however,it also indicates the affected families' isolation(30). Any information provided by the parents about changes in the family connected with the child's disease should be taken into consideration during interaction with medical personnel(31). Schwarzer and Schulz definedsocial support as resources and help provided by other people(23). Researchers and theorists distinguish different types of social support: instrumental support (sharing certain goods), informational support (advice on how to solve a problem), and emotional (comforting and showing compassion(22,23,27). Findings of Our research suggest that children's mothers are in the need for social supportas most of the mothers are employees and in greet need for social support to coordinate between her work and child care. There is appositive correlation between mothers' social support and their work. This result is in agreement with Katarzyna et al(27) whom found in their research that parents of children under renal dialysis have the need for social support. Also, the finding of the current research revealed that there is a positive correlation between the mother general strain and the amount of given support, their feelings towards their children, and social isolation.

In the current study the researchers used GHQ-12 screening instrument to assess mothers' psychological status(24). The result of our study indicated that the mothers have high GHQ-12 scoring which means that they are have greater chance for increase of non-psychotic mental disorders. However, the results may indicate anxiety, the loss of confidence, and depression as a reaction to difficulties and the inability to fulfill their own objectives(32). Our study found that there is a positive correlation between the mother support request and their health status which suggests that external environmental factors may be an important determinant of an individual's mental state. Moreover, significantly higher general strain and poorer overall mental health as a consequence of greater burdens. The results underline the strong need to provide continuous psychological care for mothers.

Mothers from urban area are at a disadvantage in terms of the sense of social isolation, overall burden, and perceived available instrumental support. This may stem from anonymity and loosening of social ties, more intensified need. There is a significant positive correlation between mothers' psychological and social status and that of their children which means that if the mothers' psychological and social status are high, the children psychological and social status on turn will be high and vise viscera.

Conclusion

Health-related quality of life among the studied children was low according to PedsQL test. The family of children with renal dialysis need financial support. Mothers who provide primary care to children on renal dialysis require emotional support and assistance in self fulfillment. The mothers have high GHQ-12 scoring which means that they are have greater chance for increase of non-psychotic mental disorders. There is a strong need to provide continuous psychological care for caregivers.

Ethical Clearance: Approval for study conducting was taken from the Faculty of Nursing to the manager of pediatric dialysis unit of pediatric medical department of Tanta university Hospital in order to attain an approval to carry out the study. Informed written and oral consent was obtained from children and their parents to participate into the study. Also Confidentiality of children and mothers data was assured**.**

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