Anxiety level among parents of children with Chronic Kidney Disease Undergoing Hemodialysis Therapy

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□ ABSTRACT □

Parents of children with a chronic kidney disease (CKD) have a crucial role in the management of their child's disease. The burden on parents is high, they are often exhausted, and experience high levels of anxiety and a low quality of life, which could have a negative impact on health of their children. This study aimed to measure level of anxiety. A sample consisting of 20 parents of children with chronic kidney disease undergoing hemodialysis therapy at hemodialysis unit following to Eben Al- Rushed Hospital in Aleppo city. Data was collected by using the Arabic Version of Perceived Stress Scale 10-Items (pss10) to measure perceived level of anxiety in participants during the period from August 2020 to March 2021. Results of the current study showed that most of parents (60%) reported high level of anxiety and (40%) had an average anxiety level. A statistically significant difference was found in parental anxiety related to place of living, and number of children in family. This study recommended that renal nurses should have the ability to provide a supportive environment for parents, in order to reduce their level of anxiety, in addition to conducting more researches on a larger number of parents to identify stressors perceived by parents of children undergoing hemodialysis and causing factors.

Keywords: level of anxiety, Parents, Chronic Kidney Disease, Hemodialysis.

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مستوى القلق لدى أهل الأطفال المصابين بمرض كلوي مزمن وخاضعين للغسيل الكلوي

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□ ملخّص □

يلعب آباء الأطفال المصابين بمرض الكلى المزمن (CKD) دورًا مهمًا في تدبير مرض أطفالهم، ويتحملون عبئاً كبيراً، يجعلهم عرضة للإرهاق والتعب والقلق وتدني صحة أطفالهم، مما قد يؤثر سلبياً على النتائج الصحية لأطفالهم. لذا هدفت الدراسة الوصفية الحالية إلى تحديد مستوى القلق لدى عينة ملائمة من 20 فرد من أهل الأطفال المصابين بمرض كلوي مزمن وخاضعين للغسيل الكلوي في وحدة غسيل الكلى التابعة لمستشفى ابن رشد في مدينة حلب. وجمعت البيانات باستخدام النسخة العربية من مقياس القلق المدرك (PSS10) لقياس مستويات القلق المدركة لدى المشاركين، خلال الفترة من آب 2020 إلى آذار 2021. وبينت نتائج الدراسة أن معظم آباء الأطفال المرضى الخاضعين للغسيل الكلوي 60% كان لديهم مستوى عالٍ من القلق و40٪ منهم كان لديهم مستوى قلق متوسط. وبينت وجود فروق ذات دلالة إحصائية مهمة في درجة قلق الأهل تعزى لمكان معيشتهم وعدد الأطفال في الأسرة. وأوصت الدراسة بضرورة امتلاك ممرضات الكلية المقدرة على تأمين بيئة داعمة للأهل، لتخفف من مستوى اجهادهم، بالإضافة الى إجراء المزيد من الأبحاث على عدد أكبر من الأهل لتحديد الضغوط المدركة من قبل أهل الأطفال الخاضعين لغسيل الكلى والعوامل المسببة لها.

الكلمات المفتاحية: مستوى القلق، الأهل، المرض الكلوي المزمن، الغسيل الكلوي.

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Introduction:

Being a parent of a child who suffers from a chronic illness is a major challenge both psychologically and practically. When a child is diagnosed with a chronic illness or disability, a significant stressor have an impact on both the child and his parent emotional and social function. Parents are not only responsible for taking physical care of their child, but must also deal with the disease in terms of medical, school-related and other social aspects. [1]

Chronic Renal Failure (CRF) incidence and etiology vary with age. Congenital malformations and obstructive uropathy are the most frequent causes in children before age 5; while hereditary and acquired kidney diseases prevail in the age group of 5 to 15 years. Approximately, 18 out of every 1 million children under age 19 suffer chronic renal failure with End Stage Renal Disease (ESRD). [2, 3] In Syria, there is not enough data in the medical literature regarding the true incidence of chronic renal disease (CRD) in children. WHO and Ministry of health website did not publish any data or statistics about chronic kidney disease [4]

Caring of children with CRF is complex and multidisciplinary and often requires multiple medications (some delivered subcutaneously or intravenously), invasive procedures, thrice-weekly hemodialysis for 4 to 5 hours or continuous peritoneal dialysis, and nutritional supplementation via enteral tubes and pump devices. Hemodialysis (HD) is the most common selection for patients with ESRD. Hemodialysis is usually long term and does not ultimately cure but rather help body functions to perform normally for longer periods of time. [5]

Hemodialysis is a process of filtering and cleaning the blood from undesirable substances such as creatinine and urea that need to be eliminated from the human blood stream due to deficiency in the filtration mechanism in patients with CRF. In hemodialysis, the transfer of solutes occurs between the blood and the dialysis solution through a semipermeable membrane within the dialyzer. Hemodialysis procedure and its consequences are stressful for the children and their families. [6]

Children often suffer from growth and development retardation, delayed development of secondary sexual appearances. Children undergoing HD may face some physical complications such as headache, vomiting, muscle cramps, and fatigue. [7] Additionally, children have to restrict their diet and fluid intake, and have to use numerous medications accompanied with recurrent visits to hospital to do dialysis.[8,9] Moreover, those children are more vulnerable to psychological problems such as anxiety, stress, depression, sadness, and reduced quality of life than patients diagnosed with many other chronic diseases. [10,11]

Children undergoing hemodialysis are considered individuals with special health care needs, creating greater demands for care in terms of patience, monitoring and intensity. [12] Parent of children on HD take on the role of primary caregivers, they have to change life style to adapt with this situation and to deal with their child's emotion. Those parents have been found to be frightened about their child's future. [13] Parents whose children have chronic renal failure are reported to have a low quality of life, difficulty taking care of their children, high levels of anxiety, and maladaptive behaviour. Poor life quality of the children leads to mental health issues for the family.[14]

Previous studies on children diagnosed with chronic diseases and their parents have frequently found that some children and their parents face considerable risk for stress. Later, this group of population developed symptoms of post-traumatic stress disorder.

[15,16] It is acknowledged in the literature that parenting an ill child is stressful and is accompanied with new parental roles and responsibilities. [17] Parents of children on HD need to adapt to stress to be able to support their children. In particular, increased social support can decrease the level of anxiety, increase perception of quality of life, and increase patient's compliance with prescribed therapy. [18]

Paediatric nurses are the healthcare team members who most frequently interact with families of children undergoing hemodialysis, so they are playing an important role in providing the information and emotional support needed by families. Nurses are also among the frontline professionals who can provide services designed to assess the physical, psychological, and economic requirements of these families.[19]

Importance and aim of the study:

Importance of the study

The fact that HD is still considered as one of the best solution for the survival of children suffering from chronic kidney disease is reflected by the number of syrian children, who visit hospitals frequently for this purpose. Therefore, many families experience stressors and develop some psychological problems related to having a child who is on dialysis and requires special attention including physical, psychological, and financial support. There was no previous studies in Syria related to anxiety level in parents of children on HD. Therefore, the present study is designed to measure stress levels in parents of children undergoing HD in Syria.

Aim of the study:

- To measure level of anxiety of parents of who their children have chronic kidney disease undergoing hemodialysis therapy.

Materials and method:

Study design:

A descriptive design was used in this study.

Setting and Period of research: The study was conducted at hemodialysis unit followed to Eben Al- Rushed Hospital in Aleppo city during the period from August 2020 to March 2021.

Subjects: A sample of 20 parents of children on HD was used in this study.

- **Inclusion criteria:** participants older than 18 years, and they have a child treated on hemodialysis for one-month minimum.
- **Exclusion criteria:** participants excluded from the study if they have diagnosis of mental illness, or a serious disease such as cancer, or parenting another child with any other serious diseases

Tools of the study:

Tool one: Socio-Demographic Data. The list included information about participating parents, the ill child and the family such as; parents age, gender, financial status, employment and level of education. Additionally, age of the ill child, gender of the ill child, duration of dialysis session, frequency of dialysis per week, type of vascular access. Moreover, number of family members and health status of all family members.

Tool two: The Arabic Version of Perceived stress Scale 10-Items (PSS10). [20]

The Perceived Stress Scale (PSS10) is a rating scale ranged from never (0) to very often (4) on a Likert-type scale. The scores can range from 0 to 40 with higher scores representing higher level of anxiety. Parental stress was categorized to three levels: low level of anxiety: the total degrees from 0-13.32, Average level of anxiety from 13.33-

26.66, and high level of anxiety from 26.67-40. The (PSS10) was adapted from (Cohen, 1988). [20] It showed very good internal consistency reliability (α = 0.78).

Method of the study

1. An official letters was taken from faculty of nursing in tishreen university and hemodialysis unit followed to Eben Al- Rushed Hospital in Aleppo city to facilitate the research implementation.
2. Tool of the study (PSS10) was adapted from Cohen 1988. It was valid and the internal consistency reliability was (a= 0.78).
3. A pilot study was carried out on 10% of parents in a previously mentioned setting to test the applicability and visibility of the tool and no modification was done.
4. Oral consent of parents for their participation in the study was obtained after explaining the aim of the study; with confirm the confidentiality of the data taken.
5. An interview with each participant lasted from 15-30 minute.
6. Data were analyzed using Personal computer with Statistical Package for Social Sciences (SPSS) version 20. Using Descriptive statistical tests (frequency (N) and percentage (%)) were used. A T-test for independent samples and One Way Anova to study the significant of statistically deference's in stress degree according to demographic variables, and the differences at the significance threshold (p value ≤0.05) were considered statistically significant

Results and Discussion

Results:

Table 1: Percent distribution of parents according to their demographic Variables

Personal Demographic Variables		N = 20	
		N	%
Parents	Mothers	8	40
	Fathers	5	25
	Relative of parent	7	35
Age in yeas	< 25	5	25
	25- 40	7	35
	> 40	8	40
Employment	Employed	5	25
	Unemployed	15	75
Education	Elementary school	7	35
	High school	9	45
	College	3	15
	postgraduate	1	5
Financial status	Poor	3	15
	Medium	12	60
	good	5	25
Effect of haemodialysis on parental finance	No effect	2	10
	Minor effect	8	40
	Major effect	10	50
Residence	Rural	8	40
	Urban	12	60

Table (1) showed the percent distribution of parents according to their demographic Variables. Three quarters of parents were unemployed (75%). Two third (60%) of them

reported that financial status was medium, and hemodialysis had effected on 50% of parental finance. 60% of sample were lived in city.

Table 2: Percent distribution of sick children according to their Personal variables data

Personal Variables		N = 20	
		N	%
sex	male	9	45
	female	11	55
Age of the ill child in years	< 6	3	15
	6- 10	8	40
	> 10	9	45
Vascular access method	Central line	3	15
	Fistula/graft	17	85
Frequency of dialysis per week	One time	9	45
	Two or three	11	55
Duration of dialysis in hours	Less than 4 hours	8	40
	4 hours	12	60
Number of children in the family	1-3 children	13	65
	> 3 children	7	35
Paying for treatment	Self-funded	4	20
	Treatment fees are covered	16	80

Table 2 presented percent distribution of ill children according to their Personal variables data. It was noticed that 45% of ill children was more than 10 years. Moreover the highest percent of ill children having fistula (85%), and 55% were dialyzed more than one time. The duration of dialysis lasted 4 hours at 60% of ill children. According to paying for treatment 80% of them their treatment fees are covered.

Table 3: Distribution of parents according to their Level of anxiety

Level of PSS	Low		Average		High	
	N	%	N	%	N	%
	0	0	8	40	12	60

Table 3 showed that 60% of parents in this study had high anxiety level and 40% had an average anxiety level.

Table 4: Relationship between parental anxiety level and their variables data

variables		N	M	SD	F/t	P Value
parental finance	Low	3	27.33	2.309	f. 0.655	0.532
	Average	12	28.00	2.296		
	High	5	26.60	2.408		
residence	Rural	8	26.25	1.035	t. 2.304	0.033*
	urban	12	28.42	2.503		

T: t. test. **F**: One Way Anova test, *****: p value ≤0.05

Table 4 presented statistically significant difference between residual and parental anxiety level (P= 0.033) < 0.05. However; there was no statistical difference between parental anxiety level and their financial status (P = 0.532) > 0.05.

Table 5: Relationship between parental anxiety level and children variables data

variables		N	M	SD	t. test	P Value
Vascular access method	Central line	3	27.33	2.517	0.174	0.864
	Fistula/graft	17	27.59	2.320		
Duration of dialysis in hours	Less than 4 hours	8	27.13	2.417	0.670	0.511
	4 h	12	27.82	2.250		
Paying for treatment	Self-funded	4	27.50	1.915	0.048	0.962
	Treatment fees are covered	16	27.56	2.421		
Child sex	male	9	27.11	2.472	0.940	0.452
	female	11	27.91	2.166		
Number of children in the family	1-3 children	13	28.31	2.136	2.224	0.039*
	> 3 children	7	26.14	1.952		

T: t. test. *****: p value ≤0.05

Table 5 presented statistically significant difference between numbers of children in family and anxiety level of parents (P= 0.039) < 0.05. However, there was no statistical significant difference between vascular access methods, duration of dialysis in hours, paying for treatment, child sex and parental anxiety level. P= 0.864, 0.511, 0.962, 0.452) > 0.05.

Discussion

Chronic renal failure in children who require hemodialysis therapy results in various physical, psychological, and behavioural changes. These changes, apart from their illness. The changes occurring in children undergoing hemodialysis therapy initiate anxiety for the caregiving family. Anxiety responses arise when the family is dominated by emotional responses such as sadness, fear, irritation, and even approval. [21] Results of this study showed that hemodialysis treatment affected on half percent of parents, this due to the most of parents were unemployed and their financial status was medium as reported in table (1). This is consistent with many previous studies illustrated the bad effect of chronic illness on ill children and the psychological status of their parents. [22]

A literature review of more than 100 studies of parents of children with various chronic diseases reported that parents of children with chronic illness reported significantly higher parental anxiety. The review revealed that higher parental anxiety was associated with greater parental responsibility for treatment management. [17, 21] This is congruent with the current study, which stated that the majority of parents reported higher level of anxiety, caused by disbelief, facing the risk of mortality, having fundamental feelings of security disappear and falling into a state of the unknown, as mentioned in table (3).

In the current study, there was a positive significant between residence and parental level of anxiety as shown in table (4) this is due to the distance of their home from hospital, most of participants talked about their suffering in reaching to hospital. The results of this research is congruous with studies that highlighted on the relationship

between parental stress level and their living, these results showed a positive significant correlation. According to Raghda M. et al., (2018). [23]

The economic effect of children on HD on their parents was reported in the literature. A qualitative study aimed to investigate the impact of having children undergoing dialysis of parents was conducted by (Medway M. 2015) five major themes emerged in this study related to financial impact of the disease on the parents. [24] This is disagreed with the current study that mentioned to negative correlation between parental finance and their stress levels of anxiety, this is may contributed to the small sample size, and most of parents in this study said their finance status was medium.

Results emerged from this study showed a positive significant between the number of children in family and the parental anxiety level. Parents with less than 3 children experienced higher level of stress. This results were agreed with the results of previous study conducted by (Šegota N et al., 2018) who mentioned that the highest level of parental anxiety is reported by parents who had less than 3 children. [1]

Results of the current study presented a negative significant relation between level of parental anxiety and vascular access methods, duration of dialysis in hours, paying for treatment, and child sex as shown in table 5. This is my contributed to the number of participants and their children, this number may not enough to presenting relationship between these variables and level of parental anxiety. Another reason is the method of vascular access the majority of ill children have fistula. Fistula was found to have better longevity and had lowest association with morbidity and mortality compared to central lines. This may explain a negative relationship between the type of venous access device and parental anxiety. [25]

Results of this study was disagreed with (Šegota N et al., 2018) who stated in his study that parents of children having central line had significantly higher levels of anxiety than parents of children with fistula. Central line has higher risk of thrombosis, infection and higher hospitalization rates and cardiovascular complications than fistula. [1]

The results of this study highlighted the importance of giving more attention to parents of children on HD. Renal nurses should be aware that those parents are the main caregivers of their children. Renal nurses should be able to contribute to this anxiety by talking to the families, explaining the signs and symptoms of disorders, and educating them about ways to deal with their patient behaviours and giving medications. [23]

Conclusion and Recommendations:

Conclusion

Based on the results of this study it can be concluded that being a parent of a child on HD is very stressful. The level of anxiety in this study may depend on parents' residence and number of children in family.

Recommendations:

1. Nurses of renal unite should understand the burden that parents of children on dialysis face and should have the abilities to provide them with a supporting environment in order to decrease their levels of anxiety, which in turn will positively affect the physical and psychological health of the children and improve their quality of life.
2. Further researches needed for investigating stressors perceived by parents of children undergoing hemodialysis therapy and causing factors.
3. Replicate the study anxiety level in parents of children undergoing hemodialysis on large number of subjects.

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