

# Psychosocial Burden among Caregivers of Children with Nephrotic Syndrome in Najaf Province

Entisar A. Fajer\*

Asst. Prof, Murtadha Ghanim Adai\*\*

\*MSc student in Nursing Science from Faculty of Nursing, University of Kufa.  
E-mail addresses:entaser@yahoo.com.

\*\*Ph.D. Community Health Nursing Department, Faculty of Nursing, University of Kufa.

## Abstract

Caregivers for children with Nephrotic syndrome reported a more negative impact and poor mental health. They seem to be at great risk of depression, tension, anxiety and distress; many caregivers have been able to overcome the constant challenge of using their patience and accepting the consequences of coping well with adversity. This study focuses on assessing Psychosocial Burden among caregiver of children with Nephrotic syndrome within a hospital in Najaf Province. **Methodology:** A descriptive cross-sectional study carried out in al-Najaf City hospitals (AL-Sadder Medical City, AL-Zahra'a teaching hospital) from (23 September 2018) to (1 September 2019), A non-probability (Purposive Sample) of (115) to determine the burden of Nephrotic syndrome on caregivers and to determine the level of psychosocial burden in relation to the effect of raising a child with Nephrotic syndrome. The instrument was presented to (21) experts from several universities to be valid, the reliability of the instrument was determined through the implicated the Cronbach's Alpha, the reliability of this instrument was ( $r = 0.81$ ). **Results:** The results of the study revealed that caregivers of children with Nephrotic syndrome experienced a moderate level of psychosocial burden. There were statistically significant differences between the psychosocial burden of caregivers and childhood syndrome, while there was a significant difference between the psychosocial burden and some social characteristics And demographic for child caregivers (age, level of education and monthly income). **Conclusions:** The study concluded that the caregivers of children with Nephrotic syndrome are affected by psychological distress more than half of them. Caregivers of children with Nephrotic syndrome are affected by psychosocial burdens at a moderate level of more than half of them. All social and demographic characteristics of caregivers do not affect caregiver's psychosocial burden except age, monthly income, level of education, and psychological distress. **Recommendations:** The study recommend that family support be provided to families with children with Nephrotic syndrome, especially psychological and educational, about the clinical behavior of early Nephrotic syndrome for early detection and family-to-community education programs for community-based services and community mental health programs.

**Key words:-** Psychosocial burden, Caregivers of children, Nephrotic syndrome.

## • Introduction

Nephrotic syndrome is an acquired disease. If left untreated, is responsible for a change in renal function. The Nephrotic syndrome can be caused by renal failure even when managed correctly. Occasionally, insufficient response occur and acute or chronic renal failure is developed (1).

One of the most common diseases during childhood is Nephrotic syndrome. In children, it is about 15% higher than in adults. Where most of Nephrotic syndrome's patient suffers from the relative kind (Steroid Sensitive Minimal Change Disease). The rating of Nephrotic syndrome relapse is around (30-40%). Such as any disease that affects the patient the Nephrotic syndrome is negatively affected the body causing biological, behavioral, and social changes. These changes negatively affect the psychological well-being, personal and social growth of patient, as well as affect the psychological and social status and family coping (2).

When parents receive the news of the diagnosis and prognosis of a chronic disease of their children, they initially experience a moment of shock. Such discovery represents an event of strong emotional impact, and consequently of sadness and anxiety due to the fear of the unknown. Families often do not feel prepared to face the situation. However, they gradually begin to accept and adapt to the new condition of their child (3).

Nephrotic syndrome predictable to affect the physical and psychosocial status of children for short- and long-term, mainly child severely affected with recurrent relapse, steroid dependency, or else steroid resistance. Steroids and other immunosuppressive are used to treat this condition, which also has special negative effects on the physical and mental health of children (4).

Childhood Nephrotic syndrome is a chronic child health disorder that, optimally, is managed by a collaborative team able to deliver continuing care. Children patient and their caregivers need teaching concerning the management of this prolonged illness, with the appropriate direction of treatments, observance to nutritional limitations, and essential for therapeutic checking. A primary twelve week (glucocorticoid therapeutic) treatment has been presented to reduction following Nephrotic syndrome relapse rates in steroid-responsive children. Taking care for a child with a chronic illness is a major challenge for any family and parents often have to give up work to do so (5).

During a chronic illness in a child, caregiver participate in activities in various areas of childcare, including assistance in the area of bio-medical, bodily rehabilitation, mental, societal and organized health. Furthermore, the caregiver is direct involved in long-period therapies, coordinating the delivery of health services, and managing the social, economic and emotion challenge associated with a chronically ill child. These responsibilities are essential to provide patients with chronic diseases by the care that the child needed and to reduce the deficiency of autonomy and independent of the children. Though, this activity must have bodily, mental and financial implications to the caregiver (4).

Nephrotic syndrome usually impacts very young children, these lead to immediate burdens on caregivers of a child with Nephrotic syndrome. The family burden has particular important effect on their life because of the effective social support systems. Earlier research point to that family anxiety can cause an undesirable effect on the child's conduct, psychological and social changes ( 8).

Nephrotic syndrome affected the child physical social and mental status, therefore, not only the medical but also the psychological and social burdens are common for children, fathers, and mothers, plus other caretakers. It is well documented that prolonged disease in children may cause(psychological suffering and social stress for the children themselves and their families), but some scientific studies have been discuss out in this part (7)

#### **Objectives of the Study:-**

1. To asses psychosocial burdens among caregivers of children with Nephrotic syndrome.
2. To find the association among caregiver's psychosocial burdens and their demographic data ( gender, age, level of education, occupation, the degree of relatives, educational level, residency area, income, and SES scale).

#### **• Methodology**

Descriptive( cross-sectional) study is a conduct through this research to determine the psychosocial burden among caregivers of patient with Nephrotic syndrome. during a period of time 23 September 2018 to1 September 2019, A purposive (non-probability) sample was selected (115) from Al-Sadder medical city and Al-Zahra'a Maternity hospital in al- Najaf province. the instrument was presented to (21) experts from several universities to be valid, the reliability of the instrument was determined through the implicated the Cronbach's Alpha, the reliability of this instrument was ( $r = 0.81$ ), The data analyzed was conducted through the application of descriptive statistics (frequencies , percentages , mean of scores , Standard deviation ) and inferential statistics (Chi-squared test) , the data was collected by utilizing the questionnaire which included four parts:-

**Part 1:** Child's Socio-Demographic Characteristics including case number, sex, age of the child, children number, order of children in the family, education of child, live father and live mother. In the social and economic situation.

**Part 2:** Child's clinical Characteristic include (4) items, number of Nephrotic syndrome children in the family, duration of illness, age of the child at diagnosis, and treatment place.

**Part 3:**Caregiver Questionnaire include a socio-demographic characteristics sheet consists of seven items, which included degree of relative , caregiver's age, Mothers age at child's birth, , number of family , marital status , Residency area , the Socioeconomic Status Scale (SES).

**Part 4:**Consist of the General Health Questionnaire (GHQ-12)and Zarit Burden Interview (ZBI).

- **Result:**

**Table (1) Distribution of the Caregivers by their Socio-Demographic Characteristics through Frequency and Percentage.**

No.	Caregiver Characteristic	Frequency	Percent	
1.	Degree Of Relative	Father	57	51.4
		Mother	54	48.6
		Total	111	100.0
2.	Age Of Caregiver/Years	19 – 24 Years	12	10.8
		25 - 31 Years	17	15.3
		32 – 38 Years	60	54.1
		34 - 45 Years	16	14.4
		46 & Above	6	5.4
		Total	111	100.0
3.	Family Members	1-3	2	1.8
		4 - 6	48	43.2
		7 - 10	47	42.3
		11+	14	12.6
		Total	111	100.0
4.	Level Of Socio-Economic Status	- Low	46	41.4
		- Moderate	45	40.5
		- High	20	18.0
		Total	111	100.0
5.	Marital Status	Married	109	98.2
		Widowed	2	1.8
		Total	111	100.0
6	Residency Area	Urban	67	60.4
		Rural	44	39.6
		Total	111	100.0
7	Caregiver Occupation	Employed	36	42.3
		Free Work	27	24.3
		Unemployed	1	.9
		Housewife	47	32.4
		Total	111	100.0

8	Caregivers' Education	Unable To Read And Write	22	19
		Able To Read And Write	15	8
		Primary School Graduated	28	13.5
		Secondary School Graduated	12	25.2
		Institute	10	10.8
		Collage	23	9.0
		Master And Doctor Degree	1	20.7
		Total	111	100.0
9	Monthly Income	Insufficient	36	32.4
		Barely Sufficient	18	16.2
		Sufficient	57	51.4
		Total	111	100.0

This table shows the caregiver demographic data that the most frequent age group is ( 32-38) years (54.1%), Regarding gender, male is more than female ( 51.4%.) Also, the study sample's majority are alive in urban residential area (60.4%), With regard to the marital status, the major of the study participant is married (98.2%),(25.2%) are primary school graduated, (51.4%) of most participants monthly income Are Sufficient , (43.2%) of them have (4-6) family number ,and Regarding occupation status the majority of male about (42.3%) are employee.

Table (2) Relationship between the Caregiver' Psychosocial Burdens and their Demographic data.

No.	Caregiver Demographic Data	Chi-Square Value	D.F.	P-Value	
1	Degree Of Relative	Father	2	.595 NS	
		Mother			
2	Age (Year)	21 - 27	16.296 <sup>a</sup>	8	.038 S
		28 - 35			
		36 - 42			
		43 - 50			
		51+			
3	Mothers Age At Child's Birth	<= 20	2.085 <sup>a</sup>	6	.912 NS
		21 - 30			
		31 - 40			
		41 - 50			
4	Level Of Socio-Economic	- Low S.E.S	5.742 <sup>a</sup>	4	.219 NS
		- Moderate			
		- High			
5	Marital Status	Single	1.334 <sup>a</sup>	4	.856 NS
		Married			
		Widowed			

6	Residency Area	Urban	4.207 <sup>a</sup>	2	.122 NS
		Rural			
7	Caregiver Occupation	Employed	4.949 <sup>a</sup>	6	0.55 NS
		Free Work			
		Unemployed			
		Housewife			
8	Caregiver Level Of Education	Illiterate	29.637 <sup>a</sup>	12	.003 S
		Literate			
		Primary School			
		Secondary School			
		Institute			
		Collage			
	Do You Enough Monthly Income For Family Needs	- Insufficient	10.767 <sup>a</sup>	4	.029 S
		Barely Sufficient			
		Sufficient			

Degree of freedom (D f) , A probability value (P-value) , Significant(S) ,Non- significant(NS)  
 , High significant (HS)

The table shows that there are important relationships among caregiver (psychosocial burden) and (caregiver's age, Socio-Economic Status p-value 0.019, caregiver Level of Education p-value 0.003). while there is no significant remaining of demographic.

• **Discussion:**

This study is conducted at two areas at al-Najaf hospital. The findings explain the age of the caregivers, more than half (54.1%) are with age ranging from (32 - 38) years old. In relation to gender, the majority of caregivers were males (51.4%). Furthermore, the study results indicated that (24.3%) of caregivers with free work and home wife (42.3%) and (60.4%) of them from urban residency. Concerning subject's level of education, (25.2%) of them are graduates from the primary school. The great majority of caregivers were of first degree in their relation with their patients. This study finds that above half of family caregivers was of the age (32-38) years and the majority of them were males, this results can be interpreted as: the male with this age was more productive and can tolerate to providing care for relatives. This is agreed by a study done in by (8) who reported that the population of the male subjects was higher compared to the female.

The result also shows the level psychological distress ranges between mild, moderate and severe. the majority of caregiver's psychological distress (72 %) was moderate. The current study explains that Nephrotic syndrome is a stress for each the child and his/her caregiver. This finding is consistent with numerous of the study result. Study finds that all caregiver for children with Nephrotic syndrome suffered from psychological depression (4) reveals that symptoms of depression are much higher in caregiver for a child with Nephrotic syndrome.

The current study finds no significant among the (degree of the relative, age of Mother at child's birth, Level of Socio-Economic Status, Marital status, residence, caregiver occupation) and the burdens. But it reported a significant association among the (age of career, caregiver Level of Education and income) with burdens, where the high burdens were noticed among males. our

justification is that males are responsible for the financial state and more expose to societal problem . The current finding is reinforced by the research conducted by( 4), which found great importance Relationship between the sex of the patient and the sex of caregiver With the level of burdens.

- **Conclusion:**

According to the discussion and interpretation of the results of the study we can conclude caregivers of children with Nephrotic syndrome are affected by psychosocial burdens at a moderate level of more than half of them. All social and demographic characteristics of caregivers do not affect caregiver's psychosocial burden except age, monthly income, level of education, and psychological distress.

- **Recommendations**

An educational program can be created for family members who provide care to careers of children with Nephrotic Syndrome to support those who face the burden by providing knowledge about Nephrotic syndrome and treatment, problem-solving education, communication assistance and provide coping skills. Special attention is to be dedicated to improving the mothers' perception and knowledge for their Nephrotic syndrome children to note the behaviors and cognition that may worse condition and improve child care and factor affect child care. Prepare a trained health professional to contract efficiently with the adverse outcomes of caregivers and recover the emotional state.

- **References**

1. Samuel, S., Scott, S., Morgan, C., Dart, A., Mammen, C., Parekh, R., ... & Wade, A. (2014). The canadian childhood nephrotic syndrome (CHILDNEPH) project: overview of design and methods. *Canadian journal of kidney health and disease*, 1(1), 17.
2. Guha P. De A., and Ghosal M.,: Behavior profile of children with Nephrotic syndrome. , 2009, *Indian journal of psychiatry*, 51(2), 122.
3. Cardoso Vaz J., Marten Milbrath V., Bärtschi Gabatz R. I., Reis Krug F., Hirschmann B., and Morais de Oliveira M.,: Care For Families Of Children With Chronic Disease, 2018. *Journal of Nursing UFPE/Revista de Enfermagem UFPE*, 12(5).
4. Mitra S., and Banerjee, S.,: The impact of pediatric Nephrotic syndrome on families. ,2011,*Pediatric Nephrology*, 26(8), 1235.
5. Gipson D. S., Massengill S. F., Yao L., Nagaraj S., Smoyer W. E., Mahan J. D., and Trachtman, H. : Management of childhood onset Nephrotic syndrome. ,2009, *Pediatrics*, 124(2), 747-757.
6. Geense, W. W., Van Gaal, B. G. I., Knoll, J. L., Cornelissen, E. A. M., & van Achterberg, T.: The support needs of parents having a child with a chronic kidney disease: a focus group study. *Child: care, health and development*, 2017, 43(6),pp. 831-838.
7. Kavanagh S.,: Nephrotic Syndrome, 2016, this article online at: [patient.info/doctor/Nephrotic-syndrome-pro](http://patient.info/doctor/Nephrotic-syndrome-pro) .
8. Zyada, F., Elbatrawy, A., Khalifa, D., Waly, S. G., Mouawad, E. M., and Ahmed, D. ,2013,: Psychosocial aspects of nephrotic syndrome among children and their caregivers. *Middle East Current Psychiatry*, 20(3), 164-171.