Physical Burden among Caregiver of Child with Nephrotic Syndrome in Najaf City in Iraq

Entesar Abdulameer Fajr

Research Scholar, Department of nursing , Altoosi University College, Najaf, Iraq

Abstract

Caregiver of children with Nephrotic syndrome report negative impact on their physical and psychological health. The descriptive (cross-sectional) research is an investigation done to determine the physical burden among caregivers of children with Nephrotic syndrome. During the time from September 23, 2018 to September 1, 2019, an intended (non-random) samples (115) are select from Al-Sadr Medical City in Najaf city. The tool is present to (21) professionals from different academies to be effective, and the reliable of the tool is determine complete by coefficient alpha implicit, and the consistency of this tool is (r = 0.81). Nephrotic syndrome is the greatest cause of burden for patients and caregiver. This may be related to patients, needs that include physical, psychological, and emotional support. This requires much knowledge and more skills from caregivers and developed responsibilities for them. These responsibilities may lead to much burden that includes social and economic burdens. It can be concluded that more than half of the caregiver of child with Nephrotic Syndrome were affect by physical burden at moderate to severe degree.

Keywords: *Physical burden, Nephrotic syndrome, Caregiver of children.*

Introduction

One of the common glomerular disease influence childhood stages is Nephrotic syndrome . Additionally, Nephrotic syndrome was commonly happened in general pediatrics. In some of the case, Nephrotic syndrome can be congenital and acquired disease. Primary hereditary syndrome might be cause by a hereditary alteration or secondary might be cause by congenital infection. The more common is acquired disease and is commonly idiopathic. Idiopathic arranged in connection toward the reaction to corticosteroid management as either steroid-resistant or steroid sensitive disease. Infections, pharmacological agents or neoplasia can be also due to acquired Nephrotic syndrome [(1)] .

Infantile Nephrotic syndrome is a long-lasting health disorder at childhood that manage by a cooperative teams capable of providing ongoing caring . Caregiver and their Child needs instruction in the managing of this syndrome, with adequate guidance for treatment, monitoring of dietary restrictions, and essential for curative. Twelve weeks of initial treatment (glucocorticoid) was introduced to reduce relapse rates of Nephrotic syndrome in children who respond to steroids. Caring for children having long-lasting disease are great trial for any personal, and parent frequently must leave their work to fulfill these responsibilities [(2)] .

Chronic disease in child was recognized that due to excessive mental and financial stress among children and their caregivers. Research of family with child that have chronic renal disease, hemodialysis or renal transplantation, have shown disturbance of daily life, with lower quality of life scores in both child and caregiver and a high level of hopelessness in caregiver. Psychological and societal studies in child with Nephrotic syndrome\ expose significant elevate in conduct abnormality in affected child, which associate with occurrence of deterioration, increasing steroid dose, and cytotoxic therapy [(3)] .

Corresponding author:
Entesar Abdulameer Fajr
E-mail : intisar.abdulameer@altoosi.edu.iq

Nephrotic syndrome, a primarily chronic child health disorder, was related to a high relapse rate. Studies were stated difficulties in behavior and psychological status of a patient with Nephrotic syndrome, their caregivers in addition to a family member, a reason specifically expected toward impact general consequence of illness in an adversative way [1] .

Nephrotic syndrome incidence at child life fifteen times more than an adult patient, it is a pediatric illness. A majority of the child with Nephrotic syndrome be burdened with relative develop steroid sensitive minimal change disease. However the deterioration rate, remains to be in elevation, and the risks of deterioration after a primary incidence is remaining higher about thirty to forty percent [4] .

Common incidence of Nephrotic syndrome is (two-sixteen-nine) per (two per one hundred thousand) of universal children. Minimal change Nephrotic syndrome prevalence is greater in childhood with a reported occurrence of (two per one hundred thousand) yearly among Caucasian children and greater than before rates for kids of Arabian and Asian countries [5] .

Family care provider has psychological and social needs that must be address so that the caregiver can sustain his/her wellbeing and deliver the best care possible to the child . Nephrotic syndrome is recognized due to short- and long-period physically and psychosocially difficulties, mainly in children severer impacted with recurrent relapses of disease, steroid dependence, or steroid resistance [6] .

The capability of face a long-lasting illness in childhood generate demand for caring to the family, also change in daily routine. families start to living below sever stress for being responsible for the sick child who now depend on continuous attention, care of their food, drug treatment, besides the constant concern with their clinical state, which imposes on families overload and suffering until they adapt to the new situation, family caregivers feel completely helpless to do anything. On the other hand, Caring for children who live with a chronic disease necessarily implies considering them from the perspective of their connection with the figure of the mother, father and/or caregivers, in that the well-being of one directly affects the condition of the other, because the care advances according to the orientation and involvement of the family in this process . There are few studies that indicate people who may develop symptoms to become future patients or commonly became a part of the renal career group In Iraq and other Arab countries. So, current study began to study the psychological and social and daily life of caregivers interested in helping them and allowing them to live with Nephrotic Syndrome [7] . The present study aimed to assess physical burden among caregiver of child with Nephrotic syndrome. The other aim is to to find out relationship between caregiver's physical burden and their biological data (age ,sex , education ,occupation , the degree of relative, residency, income ,and SES scale).

Methods

The descriptive (cross-sectional) research is an investigation done to determine the physical burden among caregivers of children with Nephrotic syndrome. During the time from September 23, 2018 to September 1, 2019, an intended (non-random) samples (115) are select from Al-Sadr Medical City in Najaf city. The tool is present to (21) professionals from different academies to be effective, and the reliable of the tool is determine complete by coefficient alpha implicit, and the consistency of this tool is (r = 0.81), descriptive statistics was used to analyzed the data by application of frequency, percentage, mean scores, standard deviation and inferential statistics (Chi-square test), the data was collected by use a survey that include four parts :

Part one: The children biological data , include the cases number, gender , child's age , children number in the family, arrangement of children , the child's education, Is father or mother live?.

Part two : the clinical characteristics of the child include (4) elements, the number of children with Nephrotic syndrome in the families, the period of the diseases, the child's age at the time of diagnosis, and the location of treatment.

Part three: The caregiver's questionnaire includes a socio-demographic profile sheet consisting of seven components age of the caregiver, age of the mother at the birth of the child, family number, marital status, region of residence, socio-economic level ,socioeconomic status scale (SES).

Part four : Contain of the General Health Questionnaire (GHQ-12).

Results

Table (1) Dissemination of the Caregiver by the Biological Characteristic by Frequencies and Percentages.

Caregiver Characteristic		Frequency	Percent
The relative degree	Father	56	51.4
	Mother	55	48.6
	Total	111	100.0
Age of Caregivers/ Year	19 – 25	12	10.8
	26- 32	17	15.3
	33 – 39	60	54.1
	35 - 46	16	14.4
	≥ 47	6	5.4
	Total	111	100.0
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
Level Of Socio-Economic Status	Low	46	41.4
	Moderate	45	40.5
	High	20	18.0
	Total	111	100.0
Marital Status	Married	109	98.2
	Widowed	2	1.8
	Total	111	100.0

The tables show the biological characteristic of caregiver that the maximum ages groups are (33-39) year. In terms of gender about (54.1%) are men more than women (51.4%). Likewise, majority of the research samples lived in an urban residential area. In terms of married status, the majority of the research participants are marital (98.2%), (25.2%) elementary schools graduates, (51.4%) most of the participants have sufficient monthly income, (43.2% of them have (4-6) families. In terms of work status, majority of men (42.3%) are employed.

Table (2) Overall Psychologically Wellbeing among caregiver of Children with Nephrotic Disorder.

No.	Psychological Well-Being G.H.Q	N=111		Overall Assessment
		Freq.	%	
1.	Non/Mild Psychological Distress	4	3.6	2.28 Moderate
2.	Moderate Psychological Distress	72	64.9	
3.	Sever Psychological Distress	35	31.5	

Tables above indicates majority of psychological distress (72 %) was moderate psychological distress and minority of them(3.6 %) were sever psychological distress**.**

Table (3) Association among the Caregiver' Physical Burden and the Demographic data.

Demographic Data		Chi-Square	D.F	P Values
Degree Of Relative	Father	1.040	2	0.595 NS
	Mother			
Age (Year)	21 - 27	16.296a	8	0.038 S
	28 - 35			
	36 - 42			
	43 - 50			
	51+			
Mothers Age At Child's Birth	<= 20	2.085a	6	0.912 NS
	21 - 30			
	31 - 40			
	41 - 50			
Level Of Socio-Economic	Low	5.742a	4	0.219 NS
	Moderate			
	High			
Marital Status	Single	1.334a	4	0.856 NS
	Married			
	Widowed			
Residency Area	Urban	4.207a	2	0.122 NS
	Rural			

Cont... Table (3) Association among the Caregiver' Physical Burden and the Demographic data.

Occupation	Employed	4.949a	6	0.55 NS
	Free Work			
	Unemployed			
	Housewife			
Level Of Education	Illiterate	29.637a	12	0.003 S
	Literate			
	Primary School			
	Secondary School			
	Institute			
	Collage			
	Postgraduate			
Income	Insufficient	10.767a	5	0.029 S
	Barely Sufficient			
	Sufficient			

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

The table above shows that there is an significant relationship amongst caregivers (physical burdens) and (age of caregiver, Sociological-Financial Status (p-value 0.019), Level of Education of caregiver (p-value 0.003). whereas there is no significant among remain of biological data.

Discussion

In relation to the occupation and level of education, our study finds that (24.4%) of family caregiver were with wage earner, also most of them (25.2%) were primary school graduates. This result may be because they have more time and freedom. Therefore most of the family caregivers are from them. This result agrees with the results of the study conducted by Mishra, et al. who found that one-third of family caregivers were self-employee. More than half for family caregivers are from urban residency (68.5%). These result can be interpreted via the place of the oncology center that is located in the city. People living in the city are more urbanized, therefore, more conscious in seeking medical care. This results are in contrast to reported that (74%) from the rural areas [(8)] .

This also agrees with Mitra and Banerjee who reported Nephrotic syndrome caused great mental and financial stress in caregiver. All anxiety factor should be examined and family system should be design to provide genuine complete care [(9)] .

According to researcher, this is normal because Nephrotic syndrome is the greatest cause of burden for patients and caregiver. This may be related to patients, needs that include physical, psychological, and emotional support. This requires much knowledge and more skills from caregivers and developed responsibilities for them. These responsibilities may lead to much burden that includes social and economic burdens. Therefore, the caregiver is constant expose to the greatest burden and do not pay care to themselves.

The result above also agree with Tsai, et al. who reported Caregiver plays numerous role for their child, include maintain of their health, a professional counseling , in addition to the typical demand for raising a patient. Therefore, it's not surprise that the caregiver experience significant low life's quality than the parents of health children . Caregiver experience significant low life's quality than the parents of health children. In end, the results of study showed (high important) association among caregiver burden and the level of education and concluded that caregivers with a high educational degree have a low burden [10].

This result may be related to the fact that learners people are more tolerant and more understand of the instruction from doctors. The present result are reinforce the study finding conducted by Alnazly who recorded that caregivers with higher levels of education were associated with lower levels of burden [11] .

Conclusion

Regarding to the discus and interpret of the study result, we can determine that more than half of the caregiver of child with Nephrotic Syndrome were affect by physical burden, since the caregiver of child with Nephrotic Syndrome was affect by physical burden at moderate to severe degree. Not all socio-demographic characteristic of caregiver affect the caregiver's physical burden, excepting of age, the monthly income, education level, and psychological distress.

Ethical Clearance : Taken from University of Kufa ethical committee

Source of Funding : Self

Conflict of Interest : Nil

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