

## A study about knowledge of parents of children with nephrotic syndrome toward recurrence of disease

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### Abstract

**Introduction:** Nephrotic syndrome is a common glomerular injury that appears in primary shape of children. Parents' knowledge quantity is important to prevent complications from the disease, so this study aimed to determination the knowledge quantity of parents about recurrence of disease.

**Material & Methods:** In this descriptive study based on a designed questionnaire that 66 parents of children with nephrotic syndrome were randomly selected. The validity of questionnaire was confirmed by teachers of the AJUMS . Cronbach's alpha showed that with  $\alpha=0.82$  the questionnaire has good validity. Collected data were analyzed using Chi-square test.

**Results:** Only 18.2 % had good knowledge about their child's recurrence of symptoms. Furthermore there is a significant relationship between of literacy of caring fathers and their education level ( $p = 0.01$ ).

**Conclusion:** It was found that most parents had n't good knowledge about the recurrence of symptoms, so recommended further studies.

**Keywords:** Nephrotic Syndrome, Knowledge, Parents, Recurrence.

### Introduction

The nephrotic syndrome is a clinical condition that is caused due to a glomerular injury (1). In fact, the nephrotic syndrome is a common kidney disease that is known with criteria such as hyper proteinuria greater than one gram per day, obvious hypoalbuminemia less than 2.5 g/dL plasma, hyperlipidemia or the increased blood cholesterol more than 250 mg/dl and a general edema that frequently is obvious. In terms of etiology, nephrotic syndrome is divided into two primary (idiopathic) and secondary (associated with systemic diseases) categories that nephrotic

syndrome in children in 95% of cases is the primary (2).

The primary nephrotic syndrome appears often in school-age children and at a distance of 1-8 year age (1). International Studies show that each year 2-7 new cases of primary nephrotic syndrome per 100,000 children under 16 years occur. Its mass incidence is 15.7 per 100,000 children (3). In childhood, this disease can be seen more in young boys (ratio of boys to girls is 2: 1), but this ratio becomes equal in two sexes at the maturity ages. A familial relationship is also known to be effective for idiopathic nephrotic syndrome (4). The incidence rate of nephrotic syndrome

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in children is 15 times higher than in adults (2). A wide range of the children are suffering from benign disease (nephrotic syndrome with minimal change) (5). Statistically, the number of patients with nephrotic syndrome with minimal change is approximately 80% of children (1).

Recurrence rate is huge so that after the first recurrence, this rate reaches to 30%-40% (5). Some children with the nephrotic syndrome suffer from recurrence 1-3 times annually. The long trend of nephrotic syndrome recurrence is causing discomfort of the child and the parents and sometimes leads to arbitrary cut off drug therapy. Intermittent blackouts and recurrence of disease stages coupled with frequent hospitalizations of the child impose a lot of stress to the family members and cause disorder in the family life program and the financial and psychological double pressure on them. In other words, this disease, due to its long-lasting nature like each other chronic diseases in addition to the physical complications resulting from illness, cause the mental, social, and economic problems for the patient and the family. In fact, the nephrotic syndrome like each other chronic disease causes worry and long-term involvement of the patient and family members (1). In addition, patients who suffer from nephrotic syndrome also need training in the field of the importance of drug therapy and therapeutic regimen and other educational needs in order to achieve proper physical, mental and social conditions (6). Since most patients with the nephrotic syndrome are young children, role of families in caring them is very important (3). Also, due to the chronic nature of the nephrotic syndrome illness, that makes the family foundation problematic and causes

serious complications, enabling an element of family affects the whole family to access health goals and empowering families leads to become useful and constructive effectiveness in their care (7).

One of the ways to empower the family to deal with the effects and side effects of their child's condition is through notifications. Hence, the knowledge of parent from different angles of the disease is essential that promoting the parental awareness along with the proper and up-to-date diagnostic and therapeutic services can be used to treat children and to enhance the quality of life and the health of the community. Undoubtedly, the effect of education in upgrading of knowledge and awareness is obvious; if the training is regular and lasting, it can have a major impact on upgrading of knowledge and awareness of the person, and consequently, it changes their wrong behavior and make a correct behavior.

In order to achieve this, the first step is to review and identify amount of and level of parental knowledge, exactly (8). Therefore, this study was designed and implemented to examine the knowledge extent of parents of children with nephrotic syndrome about the child's condition in order to make the appropriate training planning and help families and society.

### Materials and Methods

This descriptive study in 2012 was conducted on 66 parents of children with nephrotic syndrome referred to Specialized Clinic of Nephrology of Medical-Professional center of Abuzar Hospital in Ahvaz. In this survey, simple random sampling was used.

A tool for data collection was a researcher-made questionnaire that included 14 questions

concerning demographic information of patients, and 30 questions regarding the knowledge rate of parents about the symptoms of the nephritic syndrome disease recurrence. The validity of the questionnaire was confirmed by 10 teachers of the Ahvaz Jundishapur University of Medical Sciences.

Cronbach's alpha was used for attaining the questionnaire reliability. Thus in a pilot study, at first, questionnaires were distributed randomly between 15 parents of children with nephrotic syndrome who were in the studied society. Calculation of Cronbach's alpha showed that reliability of the questionnaire is  $\alpha=0.82$  that indicated proper reliability of the used questionnaire.

There was not the particular ethical problem in study mentioned above, because, the questionnaire did not require personal details of the intended parents and patients; and they gave an informed consent and completed the questionnaires. Inclusion criteria in this study included parents of children with nephrotic syndrome and satisfied by participating in the study as well as the full completion of the questionnaire; the exit criteria also included presence of other chronic disease in the child with nephrotic syndrome, and parents' unwillingness to participate in the study when doing research. The relevant information was collected by obtaining a license from the organization, and attendance of researcher at the Specialized Clinic of Nephrology at Children's Specialized Medical Center of Abuzar Hospital (while training regarding how to complete the questionnaire).

Results of the parent's knowledge quantity about symptoms and recurrence of the

nephrotic syndrome disease were ranked, if they answered 75% of questions correctly shows the knowledge level was optimum, between 50% to 75% is semi-optimal and under 50% shows the knowledge level was non-optimal. Methods of descriptive statistics and chi-square test were used, and statistical analyses were performed using SPSS version 17 (SPSS Inc., Chicago, IL, USA).

### **Ethical considerations**

This study was conducted after obtaining the confirmation of the Ahvaz Jundishapur Ethics Committee and the informed consent from all subjects participating in the study.

### **Results**

In this study, the knowledge quantity of 66 parents of children with the nephrotic syndrome was studied. 62.1% of the studied units were related to mothers. The average age of parents under investigation was  $39.16 \pm 5$  with the age range of 28-55 years. In terms of level of education of the studied units, only 7.6% were diplomas to the top (Table 1).

This study showed that only the 12 of the studied units had optimal knowledge (Table 2).

In this study, there is not a significant correlation between the average age of the studied units and their knowledge ( $p=0.4$ ) (Table 3). In addition, there is a significant correlation between the education level of caring fathers and their knowledge with  $p=0.01$  however, there is not a significant correlation between the education level of caring mothers, and their knowledge ( $p=0.6$ ) (Table 4).

**Table 1 : Frequency distribution and percentage of sex, age and education level of parents of children with nephrotic syndrome disease**

variable	Frequency	Percentage
<b>Sex</b>		
Men	25	37.9
Women	41	62.1
<b>Age</b>		
Men	(25) 30Y-55Y	37.9
Women	(41) 28Y-50Y	62.1
<b>Education</b>		
Illiterate	12	18.2
Primary	35	53
Intermediate	7	10.6
High school	7	10.6
Collegian	5	7.6

**Table 2 : Distribution level of knowledge in the caregivers**

knowledge	Frequency	Percentage
Non-optimal	5	7.6
Semi-optimal	49	74.2
Optimal	12	18.2
Totals	66	100

**Table 3 : Relationship between age and knowledge of the caregivers**

Age	Caregivers under forty years		Caregivers over forty years	
	Father N(%)	Mother N(%)	Father N(%)	Mother N(%)
Level of Knowledge				
Non-optimal	5(29.4)	5(15.6)	1(12.5)	
Semi-optimal	7(41.2)	22(68.8)	5(62.5)	8(88.9)
Optimal	5(21.4)	5(15.6)	2(25)	1(11.1)
Totals	17	32	8	9
Test results	p=0.4			

**Table 4 : Relationship between knowledge and level of education of the caregivers**

Level of Knowledge	Collegian		High school		Intermediate		Primary		Illiterate		Test results	
	Father Number	Mother Number	Father	Mother								
Non-optimal		1			1		2	3	3			
Semi-optimal		3	2	5		4	6	16	4	2	p=0.01	p=0.6
Optimal	1				1	1	3	5	2	1		
Totals		5		7		7		35		12		

### Discussion

In this study, which was conducted for investigating the knowledge of parents of children with nephrotic syndrome of recurrence of disease, it became apparent that only 18.2% of the subjects had good knowledge. In a similar study that was conducted in Kerman by Ghazanfari et al. aimed to assess the knowledge and educational needs of parents of children with thalassemia. It was found that their knowledge level was low (under 50%) and they need to a lot of educations (9). Furthermore, in another similar study conducted by Nematpur et al. aimed to assess the epilepsy knowledge amount of parents of children with epilepsy, referred to clinic and department of pediatrics of Ahvaz Golestan hospital. It was found that parental awareness about epilepsy is low and incorrect and 91.4% of them gave wrong answers to the questionnaire and this is correlated with reduction of their general health (10).

According to the results of this research and other similar studies, it was found that parental knowledge about simple issues raised about the illness of children is low and to increase the level of their knowledge through various educational programs is necessary. Paying

attention to this point is important which the first step in the process of education is reviews of needs and based on assuming individual or group needs and requirements, an appropriate program can be design and implemented.

The study concluded that between the level of knowledge of the main child caregiver (father or mother) and his or her literacy is no significant relationship. In this case, that despite the low level of education, they were with the favorable knowledge towards the disease and while in the study of Nazari et al. was determined the amount of parental knowledge in terms of genetic diseases, have had a significant relationship with their education. In other words, by increasing the level of parental education, the average of their score increases (11). In our research, there was no significant relationship between knowledge and the age of caregivers. Parents despite the high age, had no favorable knowledge towards the child's illness. But Nazari et al. showed that there was a significant relationship between age and parental knowledge and by increasing parental age, their average awareness scores increase (11).

In the care of a patient, his family needs to have a correct understanding of the disease

(12). Xue Hong et al. in 2010 conducted a study to evaluate the knowledge and understanding of parents of children with nephrotic syndrome relapsing towards factors influencing the recurrence of the disease. They measured parental knowledge in connection with disease and feeding a patient child, nursing skills at home, nursing of skin and baby monitoring in terms of the complications from the disease. It should also be emphasized that through education followed by the increased parental knowledge, the number of cases of recurrence can be reduced (13).

It was found in the case study, there is significant relationship between the education level of caring fathers and their knowledge and while there is no significant relationship between the education level of caring mothers and their knowledge. It can be understood that caring mothers with low literacy have more responsibility sense for getting knowledge in order to pursue and caring for their sick child.

It can be concluded that overall the studied units despite low literacy levels and high age are active and diligent in the learning knowledge about their child's disease.

Because the majority of patients with nephrotic syndrome are children, the function of the family in taking care of them is very important (1). Due to the chronic nature of the nephrotic syndrome disease that troubles the basis of the family and leaves serious

complications, empowering an element of family will affect the capability of whole family to achieve the effective health goals and capability of the families will lead to operative and useful effectiveness in the care affair (7). The family as the most fundamental pillar of society is responsible for providing a correct and proper health care to the patient and his or her family (6). Empowering families of the patients will notify parents through different angles of their child's illness can help raise children's quality of life (14).

### Conclusion

The quantity of parental information concerning symptoms of nephrotic syndrome disease recurrence is insufficient so upgrading parental awareness and knowledge through educational courses and providing comprehensive and necessary information concerning disease, signs and symptoms, and its complications can greatly improve the quality of the cares levels.

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