

## Original article

# Awareness About Disease among Parents of Children with Nephrotic Syndrome

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## Abstract

**Introduction :** Nephrotic syndrome, a Chronic kidney disease has a higher incidence in underdeveloped and developing nations compared to western countries with an incidence of 2 to 7 cases per 100,000 children per year(1) and a prevalence of 12 to 16 cases per 100,000 children(2).

**Materials and methods:** This is a cross sectional study, carried out over a period of 18 months in a tertiary care teaching hospital in Mumbai. Parents of Children diagnosed with Nephrotic syndrome aged up to 12 years of age group were included in the study. Our study consisted of 50 parents, 82% were less than 40 years of age and 18% more than 40 years of age.

**Results:** The overall knowledge about various aspects of Nephrotic syndrome among parents in our study was poor. Optimal knowledge about the disease was shown by only 38% (19) of them. The overall Attitude about various aspects of Nephrotic syndrome among parents in our study was Optimal/Good. Illiterates had less knowledge than the literates significantly. (P <0.01). Illiterate ones had poor Attitude compared to the literates which was significant (P <0.01).

**Conclusions:** It is essential to improve the knowledge and attitude of the parents of children with nephrotic syndrome.

**Keywords:** Awareness, Nephrotic syndrome, children, questionnaire

## Introduction

There is an epidemiological evidence of a higher incidence of nephrotic syndrome in children from south Asia. The condition is primary (Idiopathic) in 95 percent of cases (2). An underlying disorder that might be identified in less than 5 per cent cases [Includes Systemic lupus erythematosus, Henoch Schonlein purpura, amyloidosis and infection with HIV, parvovirus B19, hepatitis B and C viruses(2)]. A 4-year retrospective review of paediatric renal admissions conducted in a tertiary hospital in Sub-Saharan Africa showed 8.9% of paediatric admissions were due to kidney diseases with prevalence of 22.3 per 1000 child admissions per year (3). Most Caucasian series report Nephrotic syndrome as a disease of preschool aged children with peak age of incidence of 2 to 3 years. In a country like ours, many children between the age groups of 3 to 10 years are affected by Nephrotic Syndrome. This disease is characterised by a long treatment course with steroids and marked by intermittent exacerbations. Awareness among parents will help them to understand about the presentation of the disease, requirement of a prolonged course of treatment with strict adherence to drugs, identification of symptoms of relapse and the importance of home monitoring to prevent further complications of the disease.

## Material and Methods:

This is a cross sectional study, carried out over a period of 18 months from January 2015 to October 2016 of parents of children who were admitted to the pediatric inpatient department or attending the outpatient clinics of the Seth G.S. Medical College and KEM Hospital, a tertiary care teaching general hospital in Mumbai. Parents of Children diagnosed with Nephrotic syndrome aged up to 12 years of age group were included in the study. Newly diagnosed patients with the first episode were excluded.

**Study procedure**

A written informed consent was obtained from the parent or guardian, after explaining the nature and mode of study. All enrolled cases were assigned a case number. Demographic details of the child and the parent was taken. Parents were interviewed using awareness and attitude questionnaire during their routine visits. The questionnaire contained two domains; 1) Knowledge about the disease; 2) Attitude towards the disease. The questionnaire was formed after expert’s review by Paediatricians practicing in our tertiary care hospital. The questionnaire was pre-validated and pretested.

**Sample size calculation:**

For our sample size, considering the expected frequency of parents having good knowledge of the condition is 18.2% and with a 5% variation allowed, the sample size at 95% confidence level for infinite population size is calculated as follows.

$$N_0 = \frac{Z^2 * [p * (1-p)]}{d^2}$$

Here N<sub>0</sub> is sample size for infinite population, Here Z is 1.96 for a 95% Confidence limit, p: 0.18, 1-p: 0.82, and d: 0.05.

$$N_0 = \frac{1.96 * 1.96 * [0.18 * 0.82]}{0.05 * 0.05}$$

$$N_0 = 227$$

However, in the last 2 years a total of 60 patients of nephrotic syndrome visited our institute. So for the limited sample size the following correction needs to be applied:

$$n = \frac{N_0}{1 + (N_0 - 1) / N}$$

Where, n: sample size for our study and N is the population sample size

$$n = \frac{227}{1 + (227 - 1) / 60}$$

$$n = 49.$$

Hence sample size for our study was 50 patients with nephrotic syndrome.

**Statistical analysis:**

Data was analysed using Chi-square test or Fisher exact test for testing the significance of categorical variables, while student’s t- test was used for the quantitative and parametric data. One point was given for a correct answer to each question. A maximum possible score of 17 with a minimum score of 0 in Knowledge based questions and maximum possible score of 4 with minimum score of 0 in Attitude based questions was given. Parents were categorized as having optimal, semi optimal and non-optimal knowledge if they answered more than 75%, 50 to 75% and less than 50% of the correct answers respectively. Independent sample t-test, chi-square test and multiple logistic regression analysis (p-value<0.05) were performed to examine the differences and associations.

**Results:**

There were 50 parents, 82% were less than 40 years of age. Mean age of parents was 32.02. Females were 36 (72%) comprising of 35 (70%) mothers, and 14 males (28%) comprising of 13 (26%) fathers and 2 guardians. There were 43(86%) Hindus and 7 (14%) Muslims. There was only one graduate whereas 22 (44 %) had education level less than Secondary school certificate (SSC), 18 (36%) had completed their Higher secondary education (HSC). and the remaining 9 (18%) were illiterate. Most mothers were homemakers 36 (72%). Lower middle class comprised 35(70%), followed by upper lower class 11 (22%) and the least number belonged to upper

middle class consisting of 4 (8%) parents. In knowledge based questions, the name of their child's disease was known by 22 (44%) parents, the organ of involvement was the kidney was known by 44 (88%). Parents who knew that facial puffiness is present during relapse was 48 (96%), 1 (2%) disagreed about facial puffiness during relapse and 1 (2%) had no knowledge of the same. That urine output could decrease during relapse was known by 40 (80%), while 6 (12%) thought that urine output would not decrease during relapse and 4 (8%) had no knowledge about it. Most parents 38 (76%) knew that infection was responsible for relapse while 6 (12%) didn't feel that infection was responsible for relapse and 6 (12%) didn't know whether infection played any role in causing relapse. A majority of 38 (76%) felt that completion of duration of treatment was essential whereas 8 (16%) felt that it was not required to complete the duration of treatment and the remaining 4 (8%) were not aware about completing the duration of treatment. The cause of the relapse being salty diet and outside food was the opinion of 23 (46%) parents, while 15 (30%) were against the idea and 12 (24%) didn't know whether diet had any role to play in relapse. That increase of protein intake was required was felt by 40 (80%) parents, while 2 (4%) declined to increase protein intake and 8 (16%) parents had no awareness about it. Regarding salt restriction in the diet 46 (92%) were for salt restriction, while 2 (4%) were against the idea whereas 2 (4%) were not aware of the need for salt restriction. Restricting the intake of water during relapse was felt by 20 (40%), while 22 (44%) felt that the restriction of water intake was not necessary and 8 (16%) didn't know anything about water intake restriction.

Regarding testing for urine albumin, 45 (90%) knew how to do it, 1 (2%) did not feel that it was important to do urine albumin test and 4 (8%) did not know how to do it and that they were supposed to do it. Majority of the respondents 37 (74%) were not aware about the role of special vaccines in the management of nephrotic syndrome, 12 (24%) were aware about giving special vaccines while 1 (2%) did not agree with giving special vaccines. The knowledge regarding follow up regular eye check-up while on long term steroids was seen in only 9 (18%), 2 (4%) felt that eye check-up was not required and a majority of 39 (78%) did not know about regular eye check-up.

*Questions regarding monitoring the parameters of weight, urine albumin, blood pressure and edema were checked and our study revealed the following findings:*

**Weight monitoring can be done at home** was the opinion of 32 (64%), while 10 (20%) felt that monitoring weight was not required and 8 (16%) did not know anything about it.

**Urine test:** The need for daily urine albumin testing at home was agreed upon by 44 (88%) parents, while 4 (4%) said that there was no need for daily testing and 04 parents (8%) didn't know anything about home monitoring of urine albumin.

**Edema:** To look for edema at home was agreed upon by 45 (90%) parents, while one (2%) said that there was no need to look for edema and 4 (8%) didn't know about the same.

**BP:** Necessity of regular BP monitoring at home was affirmed by 27 (54%) 50 parents, 8 (16%) said that there was no need for monitoring BP and 15 (30%) did not knowing anything about BP monitoring.

Illiterates had less knowledge than the literates significantly. ( $P < 0.01$ ). Among the literates there was no significant difference in the knowledge irrespective of the level of education. There was no significant difference in the knowledge between higher education ( $n=12$  %) and secondary school certificate education ( $n=22$ , 44%) ( $P > 0.05$ ). Illiterate ones had poor Attitude compared to the literates which was significant ( $P < 0.01$ ).

## Discussion

The total knowledge of the study population of 50 was calculated based on percentage of correct answers given. Total knowledge based questions were 10. Mean knowledge was 66.7 %, minimum was 11.8% and maximum was 94 %.

The study population was also divided into three groups based on the percentage of correct responses given(4).

Optimal- If percentage is between 75 to 100.

Semi optimal- If percentage is between 50 to 75.

Non optimal- If percentage is between 0 to 50.

In our study population ,19 (38%) had Optimal knowledge, 22 (44%) had Semi optimal knowledge and 9 (18%) had Non optimal knowledge. In a study by Hakim et al (4), only 18.2% of the subjects had good knowledge. In a study by Ghazanfari et al regarding the knowledge and educational needs of parents of children with Thalessemia, their knowledge level was less than 50 %( 5).

### Attitude based questionnaire:

In psychology Attitude is an expression of favour or disfavour towards a person, place, thing or event.

Response to these questions were marked on Likert scale (6) as

1-Strongly disagree

2-Disagree

3-Somewhat disagree

4-Agree

5-Strongly agree

Total Attitude based questions were 4. Among attitude based questionnaire, 37(74%) of the study population gave an optimal response, 15(30%) gave semi optimal response and 1(2%) gave non optimal response. Out of the total 50 study population mean percentage was 91%, minimum was 25% and maximum was 100%. It means mean population gave 91% correct responses. Kuppuswamy class doesn't have any significant correlation with Knowledge and attitude of the study population ( $p=0.975$ ,  $p=0.581$ ). Kuppuswamy class has positive correlation with Number of relapses and Number of hospitalizations ( $p-.004$ ,  $p-.005$ ), paradoxically the better the socioeconomic status, more was the relapse rate, which requires further studies for evaluation. Number of relapses has correlation with Kuppuswamy class but not with the Knowledge ( $p-0.612$ ) and Attitude ( $p-0.563$ ) in the study population. Number of hospitalizations has correlation with Kuppuswamy class and Number of relapses, but not with the Knowledge ( $p-0.083$ ) and Attitude ( $p-0.835$ ) in the study population.

In the study conducted by **Xue-hong** et al(7)and **Chen Yimin**(8) et al ,poor knowledge was seen in lower socioeconomic class but in our study there was no significant association between the Kuppuswamy class and level of knowledge and attitude. **Xue-hong C** et al. (7) (2010) conducted survey on cognition of parents of children with recurrent nephrotic syndrome and analysis of the related influencing factors. It was revealed that the parents' knowledge about the disease was related to the frequency of recurrence of this disease, but not with sex and age(6). In a study conducted by **Hakim A** et al (4), **Chen yimin** et al (8) and **Xue-hong** et al (7) revealed that parent's knowledge about the disease was related to the educational background. But in our study illiterates had poor knowledge and attitude, but there was no significant difference between the Secondary School Certificate (SSC), Higher Secondary Certificate (HSC) and Graduates.

Mean Knowledge and Attitude is more in HSC and above compared to SSC education and least in illiterates. As literacy level is increasing the percentage of mean knowledge among the caretaker is increasing. There is no significant difference in the knowledge irrespective of the level of education, HSC versus SSC ( $P >0.05$ ). Illiterate ones have less knowledge than the other groups (HSC and SSC) significantly ( $P <0.01$ ). Illiterate ones have poor Attitude than the other groups (HSC and SSC) significantly ( $P <0.01$ ). The

other two groups (HSC and SSC) do not differ significantly ( $P > 0.05$ ). [Student-Newman test was used for comparison within the education level]

Despite 74% parents having optimal attitude, it did not translate into the appropriate implementation of practices and appropriate response to patients' symptoms. Due to our small sample size, it is less accurate to extrapolate our findings to the entire population. 38% (19) parents showed optimal knowledge. Age of the parent was not found to have correlation with Knowledge; even older parents had the same knowledge. There was no significant difference between mothers and fathers' knowledge. Illiterates have poor knowledge but there was no significant difference in knowledge between SSC, HSC and Graduates. Higher education did not contribute significantly to their knowledge. Kuppuswamy class did not have correlation with Knowledge; even lower socio-economic parents have favourable knowledge. Kuppuswamy class has significant correlation with Number of relapses and Number of hospitalizations. Knowledge level did not make any difference in the number of relapses or number of hospitalizations.

37 (74%) parents have Optimal attitude, 11 (22%) have Semi optimal attitude and 2 (04%) have Non optimal attitude about the disease. In our study population Age has no correlation with Attitude, even older parents have similar attitude, and there was no significant difference between the attitudes of the mother or father. Kuppuswamy class has no correlation with the Attitude of parents; even lower socio-economic class parents have optimal Attitude. Illiterate ones have poor Attitude than the other groups significantly ( $P < 0.01$ ). The other two groups of HSC, SSC and graduates did not differ significantly ( $P > 0.05$ ).

**Conclusion:**

Favourable Attitude did not play a role in the number of relapses and number of hospitalizations. Knowledge and Attitude have significant correlation, the more the knowledge; more was the optimal/favourable Attitude.

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**Table 1: Attitude based questionnaire (original)**

	<b>1-Strongly disagree</b>	<b>2-disagree</b>	<b>3-Somewhat disagree</b>	<b>4-Agree</b>	<b>5-Strongly agreed</b>
1. If your child gets symptoms of relapse do you yourself restart the same medication used earlier?	48 (96%)	1 (2%)	0 (0%)	0 (0%)	1 (2%)
2. Is it okay to stop medication as soon as edema decreases??	47 (94%)	0 (0%)	0 (0%)	0 (0%)	3 (6%)
3. Do you allow your child go to school when he is better?*	4 (8%)	0 (0%)	1 (2%)	0 (0%)	43 (86%)
4. Is it necessary to test urine albumin daily?	2 (4%)	2 (4%)	1 (2%)	1(2%)	44 (88%)

\*remaining two children were too small to go to school.

**Table 2: Knowledge based questionnaire(original)**

	Yes (%)	No (%)	Don't know (%)
Do you know the name of the disease your child is suffering from?			
	44	56	0
Do you know which part of the body is primarily affected in the disease your child is suffering from?			
	88	0	12
3. What are the common presenting features during repeated attacks of the disease your child is suffering from?			
Facial Puffiness	96	2	2
Decreased urine output	80	12	8
Urine albumin positive test	90	2	8
Is any particular diet responsible for elapse of disease?			
	46	30	24
Has recurrent infections any role in the subsequent episodes of disease			
	76	12	12
Is there any role of special vaccines in the treatment of your child			
	24	2	74
Will complete treatment of previous attack prevent the recurrence of the disease?			
	76	16	8
While your child is on steroids do you need to have his/her regular eye checkup			
	18	4	78
What do you know about dietary modification to be followed during relapse?			
Decreased salt intake			
	92	4	4
Increased protein intake			
	80	4	16
Restriction of water intake			
	40	44	16
What should you watch for after discharge?			
Weight			
	64	20	16
Urine output			
	88	4	8

**Table 3: Correlation with Kuppuswamy class(original)**

Variable	Kuppuswamy classification	Relapse(coefficient p)	hospitalisation	Knowledge	Attitude
Kuppuswamy classification (Pearson correlation)  (sig.(2-tailed))	-	0.404  0.004	0.393  0.005	-0.005  0.975	-0.080  0.581
Relapse (coefficient p) (Pearson correlation)  (sig.(2-tailed))	0.404  0.004	-	0.622  0.000	-0.074  0.612	-0.084  0.563
Hospitalisation (Pearson correlation)  (sig.(2-tailed))	0.393  0.005	0.622  0.000	-	0.247  0.083	-0.030  0.835
knowledge (Pearson correlation)  (sig.(2-tailed))	-0.005  0.975	-0.074  0.612	0.247  0.083	-	-

Attitude				-	-
(Pearson correlation)	-0.080	-0.084	-0.030		
(sig.(2-tailed))	0.581	0.563	0.835		

**Table 4. Comparison within the level of education of knowledge and attitude(original)**

		N	Mean	Std. Deviation	95% Confidence Interval for Mean		p value
					Lower Bound	Upper Bound	
Knowledge	Illiterate	9	<b>47.059</b>	22.011	30.14	63.978	
	<SSC	22	69.252	17.7809	61.369	77.136	
	HSC and above	19	73.066	13.3444	66.634	79.498	
	Total	50	66.707	19.2226	61.244	72.17	
Attitude	Illiterate	9	<b>80.556</b>	27.3227	59.553	101.558	
	<SSC	22	92.614	11.3515	87.581	97.647	
	HSC and above	19	95.395	9.5111	90.811	99.979	
	Total	50	91.5	15.4524	87.108	95.892	

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