Original Article

Parental knowledge of nephrotic syndrome: A questionnaire based study

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ABSTRACT

Introduction: When parents lack adequate knowledge about nephrotic syndrome, it can delay them from seeking timely medical attention. Unfortunately, many parents demonstrate insufficient understanding of effectively managing their children's nephrotic syndrome at home. **Aim:** The purpose of the present study was to examine the parental knowledge of relapsing nephrotic syndrome and the effects of the gaps in this knowledge on the outcome of the nephrotic syndrome. **Materials and methods**: The present study was a prospective, questionnaire-based descriptive study that examined the parental knowledge of a paediatric patient with nephrotic syndrome. A second questionnaire study was conducted after parents received a pamphlet and an educational film in the vernacular language with information about nephrotic syndrome. **Results:** None of the parents had heard the diagnosis of nephrotic syndrome before it disturbed their child. The risk of one relapse was known to 85% of parents, but only 17.2 % of parents were informed that the child might have more than one relapse. The home monitoring for the urine albumin was not informed to 75% of parents. Accordingly, the majority did not perform home monitoring. The scholastic status of the mother emerged as the only significant risk factor ($p = 0.035$) that could influence the parental knowledge of relapsing nephrotic syndrome. **Conclusion:** Following this study, the department began disseminating educational materials (film on social media, booklet, fact sheet) in the local vernacular language for parents of children with nephrotic syndrome to improve accessibility.

Key words: Knowledge; Parents; Nephrotic Syndrome; Surveys and Questionnaires; Pamphlets

Over the past half century, sufficient and prolonged proteinuria has been recognised as the precursor to a series of consequences known as Nephrotic syndrome [1]. Nephrotic syndrome is a clinicopathological entity characterised on the one hand by massive proteinuria, hypoalbuminaemia, hyperlipidaemia, and oedema, and on the other by histological abnormalities in children, including minimal changes, focal and segmental glomerular sclerosis, and diffuse mesangial proliferation. All of these features are associated with the fusion of the foot processes of epithelial cells on electron microscopy and insignificant deposition of immunoglobulins or complement.

Prednisone remains the reference drug to date in the treatment of nephrotic syndrome. Patients who respond to steroid therapy may relapse, but the majority continue to respond throughout the subsequent course of the disease [2].

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Only 1 to 3 % of initially steroid-sensitive patients subsequently become steroid-resistant. The proportion of patients who had only one attack varies greatly from one series to another, from 6 to 40 % [2-5].

Persistent remission for 18 to 24 months after stopping adequate steroid treatment is likely to reflect definitive cure, and the risk of later relapses is low, although possible. Such cases almost always remain steroid-sensitive. [2, 6-7] In 10 to 20 % of cases, relapses occur several months after stopping treatment, and a cure may take place after two or three episodes that respond quickly to a standard course of steroids. The remaining 40 to 50 % of patients who responded initially to steroids experience frequent relapses [8]. Relapse occurs in 60 to 70 per cent of unselected patients with steroid-sensitive idiopathic nephrotic syndrome [9, 10], and the majority of these (85%) had multiple relapses.

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Parents of the paediatric patients with a disease that could relapse might harbour feelings of trepidation of relapse, exasperation of failure to prevent such a relapse and self-flagellation for not acting at the appropriate time. The parental knowledge of the disease with which the child is suffering would enhance the sensitivity of the response of parents to the child's needs. When parents trained appropriately in the nephrotic syndrome-specific knowledge would enable them to seek medical attention early.

A literature survey showed that the majority of the parents had below average knowledge regarding home management of children with nephrotic syndrome and only 18.2% of 66 parents of children with nephrotic syndrome had good knowledge about their child's recurrence of symptoms [11]. The purpose of our study was to examine the parental knowledge in nephrotic syndrome and the effects of the gaps in this knowledge on the outcome of the nephrotic syndrome.

MATERIALS AND METHODS

The present study was a descriptive, questionnaire-based study that examined the parental knowledge of a paediatric patient with nephrotic syndrome. It was conducted at a state government-run tertiary care nephrology department in a super-speciality institute. The study spanned a duration of 2 years (January 2022 to December 2024).

Parents with infrequently relapsing, frequently relapsing, steroid-dependent and steroid-resistant nephrotic syndrome patients from the age of 11 to 18 years were included in the study. Patients with other kidney diseases were excluded.

The questionnaire was developed based on the following steps

1. Two nephrologists of our department drafted a first version of the questionnaire.
2. A group of three nephrologists, along with the first set of two nephrologists and a faculty member of the community medicine department, had read through the first draft of the questionnaire. The group had evaluated whether the questions effectively captured the management and treatment practices of nephrotic syndrome. We had six iterations of the questionnaire before the final version was set.
3. External validity and pilot testing: The questionnaire was sent to three eminent nephrologists to determine the validity of applying the questions and the study conclusions outside to the setting of the study. Based on their opinions of, the words used in the questionnaire were changed, and a few questions were shortened.

The present study was conducted after obtaining ethical clearance from the institutional ethical committee with approval number 1036. The questionnaire consisted of two sections. The first section comprised demographic data of parents, date of birth, ethnicity, highest education level, occupation and total monthly family income. The second section was on parental knowledge of nephrotic syndrome and disease relapse; it was further divided into three components: (i) questions on parental general knowledge of nephrotic syndrome; (ii) questions on parental knowledge of management of nephrotic syndrome; and (iii) questions on home monitoring and disease relapse. The correct answers to the questions were taken as a positive response.

A written consent was taken from those who agreed to participate. Only one of the parents was recruited to participate in the study if both were present. Authors ST and PO had helped the parents who had difficulty answering questions. The process of answering the questionnaire by a parent took 20 minutes. After the first questionnaire study on parental knowledge of nephrotic syndrome, a second survey was conducted using a different questionnaire. We presented the second questionnaire to parents after they had received a pamphlet and an instructional film about nephrotic syndrome in the vernacular language. A similar pattern of administration for the second questionnaire to that of the first questionnaire was followed

Statistical analysis

Data was entered in Microsoft Excel (Microsoft Corporation. (2019). Categorical variables such as socio-demographic variables, disease status and knowledge regarding nephrotic syndrome were presented as frequencies and percentages. Continuous variables such as age and income were presented as mean and standard deviation or median and interquartile range as appropriate. Chi-Square test/Fisher's exact test was used to test the significance of the association between knowledge level and categorical variables. The Mann-Whitney U test was used to test levels of significance. The Kruskal-Wallis Test was used when there were more than two categorical variables. IBM SPSS 26th version was used to do statistical analysis. A p-value less than 0.05 was considered statistically significant.

RESULTS

In the current study, we included 100 nephrotic syndrome patients and their parents. All parents had consented and completed the questionnaire.

Mothers accompanied the majority of the patients (70%). The mean age of the parents (mother 35.0 ± 5.8 years and father 43.2 ± 6.4 years), Table 1. The majority of the mothers and fathers lacked any scholastic achievement, with mothers (40%) and fathers (30%). However, overall, fathers had slightly better education than mothers. Most of the mothers are homemakers (40 %) and daily wage labourers (20 %). The mean monthly income of the family was 16947.4 ± 233.8 rupees.

Socio-demographic variable		Frequency (n=100)	Percentage (%)
Relationship with the child	Mother	70	70
	Father	30	30

Mother age	< 40 years	80	80
	> 40 years	20	20
Occupation	Home makers	40	40
	Govt. employee	10	10
	Teacher	5	5
	Business	10	10
	Farming/Tractor driver	15	15
	Maid/Labour/Daily wages	20	20
Mean age of child (Mean ± SD) (years)		12.6 ± 6.2	
Mean age of mother (Mean ± SD) (years)		35.0 ± 5.8	
Mean age of father (Mean ± SD) (years)		43.2 ± 6.4	
Mean monthly income (Mean ± SD) (rupees)		16947.4 ± 23327.8	
Sex	Boys	51	51
	Girls	49	49
Education of mother	No education	40	40
	Primary	25	25
	Secondary	10	10
	Matriculation	15	15
	Graduates	10	10
Education of father	No education	30	30
	Primary	20	20
	Secondary	10	10
	Matriculation	25	25
	Intermediate	5	5
	Graduates	5	5
	Post graduates	5	5
No. of siblings	0	5	5
	1	65	65
	2	25	25
	3	5	5
Sibling affected	No	90	90
	Yes	10	10

The median age of patients at first presentation was 5.85 years (Table 2) (interquartile range (IQR): 2-9), and the mean age at the time of interviews was 12.6 years. The median duration of disease from first diagnosis to patient recruitment was 6.8 years (IQR: 4 to 12). The median number of relapses since diagnosis was 7.5 (IQR: 3 to 25, range: minimum 1-maximum 40).

Disease status		**Frequency (n=100)**	**Percentage**
Current status	Remission	5	5
	Relapse	95	95
Mean age at first episode		5.85 ± 4.16	
Follow proper course of medication	No	5	5
	Yes	95	95
Follow-up frequency	Monthly once	55	55
	Once in 3 months	30	30
	Once in 6 months	5	5
	Once in 6-12 months	5	5
	Yearly once	5	5
Need admission for nephrotic syndrome	No	40	40
	Yes	60	60
Use alternate medicine	No	75	75
	Herbal	15	15
	Ayurvedic	5	5
	Homeopathic	5	5

None of the parents had heard the diagnosis of nephrotic syndrome before it afflicted their child. However, all parents of the patients were informed of nephrotic syndrome as a diagnosis. The parents received information from the nephrologists and nephrology residents. The risk of one relapse was known to 85 % of parents, but only 17.2 % of parents were informed that the child might have more than one relapse (Table 3).

Knowledge	**No Number (%)**	**Yes Number (%)**
Did you know that the child can get more than one episode of Nephrotic syndrome despite complete treatment?	15 (15)	85 (85)
Do you know what percentage of children get more than one episode of nephrotic syndrome? (n=85)	70 (82.3)	15 (17.6)
Did you know you can test your child's urine at home using a dipstick?	95 (95)	5 (5)
Do you find testing the urine at home difficult or easy?	5 (5)	95 (95)
What do you do if your child has 1+ or 2+ protein?	15 (15)	85 (85)
What do you do if your child has 3+ or 4+ protein?	10 (10)	90 (90)
What is relapse	40 (40)	60 (60)
Did you know that if your child has cold it can precipitate a relapse?	50 (50)	50 (50)
Do you monitor fluid intake in your child?	15 (15)	85 (85)
Do you know of any complications of nephrotic syndrome? Can you name the complications you know of?	90 (90)	10 (10)
Do you know the side effects of the drugs that your child is currently taking?	70 (70)	30 (30)
Do you know the side effects of the drugs that your child was previously treated with?	85 (85)	15 (15)
Does your child require regular blood tests? If yes, what are the tests done?	0 (0)	100 (100)
Do you yourself medicate your child during relapse without consulting a doctor?	90 (90)	10 (10)
Are you confident in your management of a relapse?	40 (40)	60 (60)
Have you looked up online regarding nephrotic syndrome?	85 (85)	15 (15)
Have you looked up online about the drugs used in nephrotic syndrome?	80 (80)	20 (20)
Did looking up information online scared you or it reassured you? (n = 20)	9 (45)	11 (55)

Would you like more information about nephrotic syndrome? If yes by what way?	15 (15)	85 (85)
Do you think you having more information about your child's disease helps in better management of your child?	10 (10)	90 (90)
Do you know the main side effects of the prednisolone? If yes, mention them	85 (85)	15 (15)
What would you do if the child develops in fever and abdominal pain?	10 (10)	90 (90)

The home monitoring for the urine albumin was not informed to 75% of parents. Accordingly, majority did not perform home monitoring. However, two parents had learnt the procedure from health care personnel of a different facility. These two were in addition to five, who were informed at our institute. All the seven parents expressed that the procedure was "very easy". These parents were aware that if the urine for albumin was 3+ or more, that they should approach the institute immediately.

The concept of that the "cold' in the child might precipitate a relapse was known to 50% of parents. But 75% were not aware that the urine to be checked with the dipstick more frequently when there was an upper respiratory tract infection in the child.

Parents were educated about the monitoring of the fluid intake and output. The majority of the patients (90/90%) could not mention even one complication of the nephrotic syndrome. Additionally, the majority of parents were not aware of the side effects of the current or past medications. "Mooning" of the face was the only side effect that at least 75% of parents could associate with the prednisolone therapy. No parent knew that cold hands and feet might herald hypovolaemia in a child with relapsed nephrotic syndrome, for which immediate medical attention is needed.

The department's policy was to encourage parents to learn the steps of prednisolone dose tapering. Only 20 (20%) parents were confident in reducing the dose. At least eight mothers (out of 20/40%) hiked the dose of prednisolone to preclude admission of the child when their urine dipstick revealed protein. Some of the parents did read about the nephrotic syndrome and the drugs used for it on the web, and 55% were scared by the information received online. The majority desired to have more information from the doctor (85%) treating the child and believed that would help them to understand the disease (Table 3).

We considered the following factors (Table 4) that could influence the parental knowledge on nephrotic syndrome – ages and the scholastic achievements of the mothers and fathers, number of siblings, an affected sibling in family, the current status of the patient, the need of admission for nephrotic syndrome, number of relapses, parents who acquired knowledge from other sources. Of these, the scholastic status of the mother emerged as the only significant risk factor (p = 0.035).

Variable		Poor knowledge Number (%)	Good knowledge Number (%)	Total Number (%)	Mean rank	P value
Relationship with the child	Mother	50 (71.4)	20 (28.6)	70	9.86	0.357
	Father	15 (50)	15 (50)	30	11.00	
	Uncle					
Mother age	<40 years	50 (62.5)	30 (37.5)	80	10.72	0.750
	>40 years	15 (75)	5 (25)	20	9.63	
Occupation	Housewife	25 (62.5)	15 (37.5)	40	10.75	0.278
	Govt. employee	5 (50)	5 (50)	10	12.00	
	Teacher	0 (0)	5 (100)	5	17.00	
	Business	10 (100)	0 (0)	10	7.00	
	Farming/Tractor driver	5 (33.3)	10 (66.7)	15	13.67	
	Maid/Labour/Daily waged	20 (100)	0 (0)	20	7.00	
Education of mother	No education	35 (87.5)	5 (12.5)	40	8.25	0.035
	Primary	15 (60)	10 (40)	25	11.00	
	Secondary	0 (0)	10 (100)	10	17.00	
	Matriculation	15 (100)	0 (0)	15	7.00	
	Graduates	0 (0)	10 (100)	10	17.00	
Education of father	No education	20 (66.7)	10 (33.3)	30	10.33	0.121
	Primary	20 (100)	0 (0)	20	7.00	
	Secondary	0 (0)	10 (100)	10	17.00	
	Matriculation	20 (80)	5 (20)	25	9.00	
	Intermediate	5 (100)	0 (0)	5	7.00	
	Graduates	0 (0)	5 (100)	5	17.00	
	Post graduates	0 (0)	5 (100)	5	17.00	
No. of siblings	0	5 (100)	0 (0)	5	7.00	0.767
	1	40 (61.5)	25 (38.5)	65	10.85	
	2	15 (60)	10 (40)	25	11.00	
	3	5 (100)	0 (0)	5	7.00	
Sibling affected	No	55 (61.1)	35 (38.9)	90	10.89	0.442
	Yes	10 (100)	0 (0)	10	7.00	
Current status-remission/relapse	Remission	0 (0)	5 (100)	5	17.00	0.400
	Relapse	65 (68.4)	30 (31.6)	95	10.86	

Need of admission for nephrotic syndrome	Yes	43 (38.3)	17 (61.6)	60	10.00	1.000
	No	28 (70)	12 (40)	40	7.65	
Number of relapses	> 1	27 (67.5)	13 (32.5)	40	7.90	0.832
	> 3	39 (35)	21 (65)	60	11.23	
Parents who acquired knowledge from other sources	Yes	17 (68)	8 (32)	25	9.31	0.067
	No	65 (86.6)	10 (13.4)	7	6.00	

The second questionnaire was administered to 40 of the 100 parents who answered the first questionnaire. These parents watched a film and read a pamphlet that contained information on nephrotic syndrome. The results of the second questionnaire survey are given in the supplementary Table 1. The results were positive after 40 parents; thus, the second questionnaire was no longer administered. The second survey had favourable results with almost all parents understanding in most of the aspects of nephrotic syndrome in the child. Parents understood that the children might experience a relapse, a cold could precipitate relapse and the relapse could be recognised by performing a urine dipstick test at home. Parents also understood the diet to be given to the children and the side effects of prednisolone.

DISCUSSION

We studied the parental knowledge on nephrotic syndrome with the help of a questionnaire. We understood that this study was indeed an eye-opener. The leadership in the department did not change in the last decade and the leadership failed to provide an exact guideline to the residents that education of the patients and their parents about the nephrotic syndrome was also a part of the treatment of the condition. Even though we informed parents the diagnosis of the nephrotic syndrome, it's frequently relapsing course was not explicitly communicated to the parents – only 15% parents were informed that the child might have more than relapse. Many other information was also not made known to the patients. We did not enlighten the patients on the jeopardizing role of upper respiratory tract infection, home monitoring for the urine albumin, complications of the nephrotic syndrome, recognition of spontaneous bacterial peritonitis and side effects of the medications.

In our study, poor scholastic achievements of the parents could not be cited as the reason for the benightedness of parents. The failure by the department to invest time in informing the parents could be the primary reason. A confutation that might be put forth that whether the expanding the knowledge and awareness of the parents would indeed better the home management given to their children.

Sarika in 2017 [12] conducted a study with the aim to find out the relationship between knowledge and practices of parents regarding home management of children with nephrotic syndrome. The study concluded that the majority of the parents had below average knowledge and poor practices regarding home management of children with nephrotic syndrome. However, significant positive co-relation was found between knowledge scores and practices scores of parents regarding home management of children with nephrotic syndrome.

Diong et al. [13] reported that the parents of patients with frequent relapse had higher parental knowledge from both univariate analysis and multiple linear regression test. Chao et al., [14] also reported that parental knowledge of disease was related to educational background, and the frequency of recurrence (p=0.05). It is understandable that the parents of patients with frequent relapses would have had more visits or hospital admissions which provided an opportunity to learn more information. However, in our study that was not the case which suggested that the opaqueness of our system and reticence of our nephrology department.

The educational film and pamphlet did, in fact, improve parental knowledge, as shown in supplementary table 1. A self-assured parent would actively participate in the child's care. The dissemination of the information in a proper channel was indeed found to be effective amongst the parents of the paediatric patients with nephrotic syndrome. In a study by Mamatha et al. [15] found that an information booklet on knowledge regarding nephrotic syndrome lowered the parents with inadequate knowledge of the nephrotic syndrome from 75% to 6.6%.

CONCLUSION

In conclusion, the nephrology department realised that it was incorrect to presume that parents of children with nephrotic syndrome would be knowledgeable enough to comprehend the subtleties of the condition. Following this study, the department has started the distribution of an educational film on social media, a booklet and a fact sheet to the parents of the children of the nephrotic syndrome. These are in vernacular language that is intended for local patients.

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