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Original Article

PEOPLES' PERCEPTION ABOUT CHILDHOOD NEPHROTIC SYNDROME

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Abstract:

Background: *The perception of the people in the community about nephrotic syndrome is varied. This was not previously studied in Bangladesh.*

Objective: *To know the Peoples' perception about childhood nephrotic syndrome.* ***Methods:*** *A cross-sectional study was conducted in the inpatient department of pediatrics, Sir Salimullah Medical College & Mitford hospital for 06 months (From November 2013 to April 2014). Purposively 50 children with diagnosed case of nephrotic syndrome were included for the study. Four groups of people were interviewed, e.g. father, mother, one relative and one neighbor/attendant of adjacent bed patient. Total 200 persons were interviewed (father-50, mother-50, relatives-50 (Uncle, Aunt, Brother, Sister, Grandfather, Grandmother), neighbor-18, attendants of adjacent bed patient-32). A semi-structured questionnaire was developed for this purpose. The investigator collected data through face-to face interview in the hospital and telephonic interview from neighbors. Data were analyzed with the help of software SPSS version 16.0.*

Results: *Among the patients, 2-6 years age group were 60.0% and 7-11 years age group were 40.0%. Seventy two percent patients were male. Among all patients 20(40%) were first attack and 30(60%) were relapse case. Among the respondents, 45.5% were within 28-37 years age, 30.5% were 18-27 years age. More than 50% respondents had idea that the disease was caused by infectious agent and other 45.5% had no idea about the cause of the disease. Perception about passing 'white element' (albumin) in urine was significantly different between first attack and relapse cases (p=0.02). Perception about management of the disease between first attack and relapse was statistically significant (p=0.00). Perception about side effects of the drug (prednisolone) among attendants of first attack (16.7%) and relapse (83.3%) were highly significant statistically (p=0.00). Perception about complications of the disease among first attack and relapse was not statistically significant (p=0.106). Perceptions about special diet for the disease and follow-up plan of the disease among attendants of first attack and relapse were highly significant (p=0.00).*

Conclusion: *There is lack of knowledge as to the nature of disease nephrotic syndrome, its etiology, course & prognosis of the disease. Respondents of relapse cases of nephrotic syndrome had better perception in some aspects of the disease than those of first attack. There are still information gap among the respondents which reflect that our counseling is not up to the mark.*

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Introduction:

The perception of the people in the community about nephrotic syndrome is varied. Many questions are raised by the parents and people staying around a case of childhood nephrotic syndrome. The following are the examples of such queries-1. What is Nephrosis?

Nephrosis is a catch-all word which can mean different things to different people. Many physicians prefer to use the term nephrotic syndrome. This refers to a kidney disorder manifested by the following;

- A massive leak of protein (albumin) into the urine (proteinuria)
- A low blood level of albumin due to the large amount lost in the urine
- An increased level of cholesterol in the blood
- Retention of fluid in the body (edema) causing swelling

Nephrotic syndrome refers to all four of the above findings occurring together. Several different kidney diseases can cause nephrotic syndrome. A renal biopsy is sometimes necessary to help distinguish among the possibilities.

2. How does the kidney with nephrosis differ from a healthy kidney?

   The main function of the kidneys is to filter the blood, removing or clearing waste products of metabolism, which are then excreted in the urine. The filtering membrane of a healthy kidney does not leak more than a minimal amount of blood protein (mainly albumin) into the urine and the test of urine for the presence of albumin, using a dipstick test indicator. The leak of large amounts of albumin into the urine causes depletion of blood albumin to low levels, which can be confirmed by a blood test.

3. Does it run in families?
   Not usually.[1]

4. Does it affect both kidneys?
   Yes.[1]

5. What is the common type of nephrotic syndrome?
   Among the three idiopathic nephrotic syndrome, minimal change nephrotic syndrome (85%) is the commonest.

6. Is there a treatment for nephrotic syndrome?
   Yes. One medication is called prednisone. This medication resembles hormones (steroids) produced by the adrenal glands, such as cortisone. Up to 90% of children with minimal change nephrotic syndrome treated with this medication will have complete disappearance of protein from the urine and of the swelling of the body. However, a small number of children with nephrosis, perhaps up to 10 to 15%, will not respond to prednisone and may never achieve a remission. This is referred to as steroid-resistant nephrotic syndrome.

7. Does nephrotic syndrome ever come back?
   A small number of children may either have only one illness or merely an occasional relapse, perhaps two or three, during the first three years after onset. However, more than one-half of the children with nephrosis will have one or more relapses per year during the first 3 to 5 years of illness.

8. Are there side effects of prednisone treatment?
   Yes.[1]

9. How long my child will suffer?
   After 5 years, the majority of children, up to 75%, will not have more relapses and are considered healthy. However, the remaining 25% of children with nephrosis may have relapses for as long as 10 to 15 years after onset of the illness.

10. Does my child need a special diet?
    Yes. During the period of illness when the kidney is leaking protein and has a tendency to retain salt and fluid in the body, it is necessary to restrict salt (sodium) in the diet.[1] There is also required adequate protein diet.

11. Can my child go to school?
    Yes. There is no medical reason to avoid going to school. The only instance in which caution is advised is if certain epidemic, contagious diseases are spreading through the school population, such as chickenpox (varicella) or measles (rubella).[1]

12. Will my child's later life be normal? Will my daughter be able to have children?
    The answer to both questions is yes. Nephrosis or treatment with prednisone does not prevent a woman from having children. There is no evidence that pregnancy triggers a relapse.

13. Does nephrotic syndrome cause permanent damage to the function of the kidneys?

    Although the kidneys of children with nephrosis leak large amounts of protein, the protein spillage is usually a short-term problem and does not damage the kidney.[1]

Peoples' perception about many other diseases like childhood asthma, pulmonary tuberculosis, thalassaemia, malaria, different cancers, mental health issues, etc. is known by different studies in different countries.[2-7] I would like to do such type of study to know the peoples' perception of childhood nephrotic syndrome. This will help the parents and the community people to gather information on the level of disease awareness; it will also solve the answer of certain questions raised by parents of children with nephrotic syndrome. Problem in the kidneys (blood purifying and urine producing organ) resulting in leakage of fluid from blood vessels into surrounding tissues giving rise to puffy face, swelling of limbs and ascites. Kidney functions usually preserved/disease is characterized by relapse and remission/ prognosis usually good/ there is high chance of cure at the end of first decade.[8]

Methods and materials:

This prospective cross sectional study was done from November 2013 to April 2014 at Department of Pediatrics, Sir Salimullah Medical College Mitford Hospital (SSMCMH), Dhaka. Here, frequently encounter the parents of a child of nephrotic syndrome admitted in the hospital with the query whether the kidneys of the child are damaged or not. This idea is generated within the family of the child or neighbors around who make comments about the bad prognosis of the disease. To know the peoples' perception about childhood nephrotic syndrome is the main objective of this study. Inclusion criteria included, parents of the diagnosed case of nephrotic syndrome, close relatives who visited the child in the hospital, attendant of adjacent bed patient concomitantly admitted who were not suffering from nephrotic syndrome at that time. Here, sample size was calculated purposively according to the inclusion and exclusion criteria which was 200. Purposively 50 children with nephrotic syndrome were considered for the study. 200 persons were interviewed (father-50, mother-50, relatives-50, neighbor-18, attendants of adjacent bed patient-32). A semi-structured questionnaire was developed for this purpose. The data were analyzed with the help of software SPSS for windows programmed version 16.0 after frequency run, data were cleaned and frequencies were checked.

Result:

Table 1a

Distribution of age group among patients

Age group		Frequency (n)	Percent (%)
Age group	2-6 years	30	60.0%
	7-11 years	20	40.0%

Among the patients, 2-6 years age group were 60.0% and 7-11 years age group were 40.0%.

Table 1b

Distribution of age group among the respondents

Age group distribution (Yr)	Frequency (n)	Percent (%)
18-27 years	61	30.5
28-37 years	89	44.5
38-47 years	27	13.5
48-57 years	12	6.0
58 years and above	11	5.5
Total	200	100.0

Meant SD (33.52 ± 10.73) Min : 18, Max : 70 Range: 52

Majority were within 28-37 years age followed by 18-27 years.

Table II

Distribution of sex group among the respondents and their perception about the disease (first attack and relapse of nephrotic syndrome)

Sex group	Knew about the disease (NS)		Did not Know about the disease (NS)		Total	X^2	df value	P
	First attack n(%)	Relapse n(%)	First attack n(%)	Relapse n(%)		89.38	18	0.000 s
Male	47 (44.3%)	52(49.0%)	4(3.7%)	3(2.8%)	106 (100.0%)			
Female	33 (35.1%)	46(48.9%)	10(10.6%)	5(5.3%)	94 (100.0%)			

Table III

Association of level of education with perception about the disease (first attack and relapse of NS) among the respondents

Level of education	Knew about the disease(NS)		Did not Know about the disease (NS)		Total	X^2	df	P value
	First attack n(%)	Relapse n(%)	First attack n(%)	Relapse n(%)				
Illiterate	00(0.0%)	10 (7.3%)	50 (36.7%)	04 (2.9%)	64(100.0%)	70.38	15	0.004 s
Literate	40 (29.0%)	80(58.8%)	10 (7.3%)	6(4.4%)	136 (100.0%)			

Note: Literacy means: Completed Primary education + SSC+HSC+ Graduation and above Illiteracy means: No education.

Association of level of education with perception about the disease (first attack and relapse of nephrotic syndrome) among the respondents were significant.

Table IV

Perception about 1st attack & relapse among

Relation of Patient	Knew about first attack Frequency (%)	Did not know about relapse Frequency (%)	Knew about Relapse Frequency (%)	Total Frequency (%)	X^2	df	P value
Father(n=50)							
Father	20 (40.0)	0(0)	30 (60.0)	50 (100.0)			
Mother (n=50)							
Mother	20 (40.0)	0(0)	30 (60.0)	50 (100.0)			
Relatives (n=50)					89.38	18	.000 s
Uncle	3 (37.5)	0(0)	5 (62.5)	8 (100.0)			
Aunt	5(62.5)	0(0)	3 (37.5)	8(100.0)			
Brother	7 (58.3)	0(0)	5(41.7)	12(100.0)			
Sister	2(28.6)	0(0)	5(71.4)	7(100.0)			
Grand Father	1 (16.7)	0(0)	5 (83.3)	6(100.0)			
Grand Mother	2 (22.2)	0(0)	7 (77.8)	9(100.0)			
Neighbor and attendants of adjacent bed patient n=50)							
Neighbor	8 (44.4)	9 (50.0)	1 (5.6)	18 (100.0)			
Attendants of adjacent bed patient	12(15.0)	13(59.1)	7(21.9)	32(100.0)			
Knew about disease occurs only once (first attack -							

Father 20(40.0%), Mother 20(40.0%), Uncle 3 (37.5%), Aunt 5(62.5%), Brother 7 (58.3%), Sister 2(28.6%), Grand Father 1 (16.7%), Grand Mother 2 (22.2%), Neighbor 8 (44.4%) and attendants of adjacent bed patient 12(15.0%). Knew about relapse -Father 30(60.0%) , Mother 30 (60.0%), Uncle 5 (62.5%), Aunt 3 (37.5%), Brother 5 (41.7%), Sister 5 (71.4%), Grand Father 5 (83.3%), Grand Mother 7 (77.8%), Neighbor 1 (5.6%) and attendants of adjacent bed patient 7(21.9%). Did not know about relapse—Neighbor 9(50.0%), attendants of adjacent bed patient 13(59.1%).

Table V

Perception about the cause of the disease

Perception about the cause of the disease	Frequency (n)	Percent (%)
Familial	5	2.5
Infectious agent	104	52.0
Does not Know	91	45.5
Total	200	100.0

Most of the respondents had idea that the disease was caused by infectious agent and 45.5% had no idea about the cause of the disease.

Table VI

Perception about passing 'white element' (albumin) in urine between first attack and relapse.

Perception about passing 'white element' (albumin) in urine	Relapse n(%)	1st attack n(%)	Total	X^2	df	P
Yes	86 (67.2)	42 (32.8)	128	7.6	2	0.02
No	34 (47.1)	38 (52.9)	72			

Perception was significantly different between first attack and relapse

Table VII

Perception about Complications of the disease

Perception about Complications of the disease	Complications of the disease	n (%)	Frequency (n)	Percent (%)
Yes	Abdominal pain and distension	09 (9.09%)	99	49.5
	Fever with respiratory distress	40 (40.4%)		
	Burning micturition	25 (25.2%)		
	Loose motion (diarrhoea)	25 (25.2%)		
No	No idea about complication	101	50.5	
Total		200	100.0	

About half of the respondents had idea about the complications of the disease.

Table VIII

Perception about different aspects of management of the disease between first attack and relapse

jPerception about treatment of the disease	Relapse n (%)	1st attack n (%)	Total	X^2	df	P
Yes	39 (92.9%)	3(7.1%)	42 (100.0)	23.915^3	1	.000
No	81 (51.3%)	77 (48.7%)	158 (100.0)			

The result was statistically highly significant

Table IX

Perception about side effects of prednisolone

Perception about side effects of prednisolone	Type of side effects	Number (%)	Frequency (n)	Percent (%)
Yes	Swelling of the body and increased appetite	75 (96.1%)	78	39.0
	Not getting tall	03 (3.8%)		
No	No idea about the side effects of drugs	122	61.0	
Total	200	100.0		

Most of the respondents had no idea about side effects of the drug.

Table-X

Perception about special diet used for the disease

Perception about special jdiet for the disease	Special diet used in nephrotic syndrome	n (%)	Frequency (n)	Percent (%)
Yes	Salt restricted diet & adequate protein diet	80 (73.3%)	109	54.5
	Only salt restricted diet	15(13.7%)		
	Only adequate protein diet	14(12.8%)		
No	No idea about special diet	91	45.5	
Total	200	100.0		

Nearly half of the respondents had no idea about special diet.

Discussion

Two hundred persons whose near kindred hospitalized for nephrotic syndrome were interviewed about the perception of nephrotic syndrome. Type of respondents were father, mother, relatives (uncle, aunt, brother, sister, grandfather, grandmother), neighbor and attendants of adjacent bed patients. The association of level of education with perception about the disease (first attack and relapse of NS) were significant. Seventy two percent patients were male. The association between male and female with their perception about the disease were highly significant. 45.5% does not know about the disease. Their knowledge about treatment options, complications, and side effects of prednisolone was not satisfactory.

In this study, among the respondents, 44.5% were within 28-37 year age, 30.5% were 18-27 years age. In a similar type of study done by Ashrafalsadat Hakim, Simin Madhooshi, Ehsan Valavi found that 37.9% respondents were between 32-55 years and 62.1 % respondents were within 28-50 years.[9]

In this study, peoples' perception about symptoms of nephrotic syndrome is so obvious that they could tell the features of nephrotic syndrome.

In present study, 128 (64.0%) respondents who had idea about passing 'white elements' (albumin), among them most of the attendants 86 (67.2%) were relapse case, only 42 (32.8%) were first attack. Perception about passing 'white elements' was significantly different between first attack and relapse (p=0.02). 71.5% believed that the disease is cured with medication. This is due to their faith on the doctor and on modern medical treatment.

The present study, out of 200 respondents, small number 49.5% had idea about complications of NS, such as abdominal pain and distention 9.09%, fever with respiratory distress 40.4%, burning micturition 25.2% and loose motion 25.2% and most of the respondents (50.5%) did not know about the complications of the disease. This is due to their poor knowledge about the disease and illiteracy.

In this study, only 39.0% respondents had idea about the side effects of the drug, like swelling of the body and increased appetite, not getting tall. The people who knew about side effects of the drug, 83.3% were attendants of relapse patient. This is a gap in our health education. In other study, done by Feryal A. Zyarah and Eqbal G Mau'ala found that 91.2% parents had no idea about urine test among nephrotic syndrome patient.[10]

In present study, 109 (54.5%) had knowledge about special diet for NS. Among them 73.3% knew about salt restricted & adequate protein diet. Other study revealed that more than half (56.3%) of mothers sometimes avoid adding salt to the child's food. It has been emphasized that salt should be restricted and any food containing high sodium should be avoided during appearance of edema that associated NS.[10]

Conclusion

It can be concluded from this study that most of the people in the community does not know the name of the disease. A small group have the apprehension that the kidneys are damaged in this disease, they do not know the actual etiology at all.

They are not well aware about the complications of NS and so also about the follow up plan. We need to counsel the parent and this counseling will help in communication development for the better management of nephrotic syndrome in children.

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