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Effectiveness of Discharge Guide Module on Knowledge Regarding Nephrotic Syndrome Among Parents of Children with Nephrotic Syndrome

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Abstract

Introduction: *The majority of people with nephrotic syndrome are children. It is 15 times more common in children than adults, and it differs in many ways from adults in terms of origins, signs, and symptoms, as well as recovery, necessitating specific treatment. The objective of the current study was to assess the impact of a discharge guide module on improving knowledge about nephrotic syndrome among parents of children diagnosed with the condition.* ***Material and Methods:*** *A quantitative study was conducted on 40 parents of children with nephrotic syndrome selected by purposive sampling technique and who were admitted in pediatric medicine ward. Sociodemographic and clinical information was collected from parents using a sociodemographic proforma. Knowledge levels were evaluated before and after the intervention using a semi-structured questionnaire. The discharge guide module was explained to the parents and provided on the same day as the pretest, while the posttest was conducted two days after the intervention.* ***Results:*** *The study's results indicate a significant improvement in parents' knowledge about nephrotic syndrome following the implementation of the discharge guide module. The average pretest knowledge score was 10.21 ± 2.54, which increased to 20.57 ± 4.80 postintervention. The mean difference in scores was 10.36, with a t-value of 3.99, which was statistically significant ($p < 0.05$).* ***Conclusion:*** *The study concluded that the discharge guide module effectively enhanced the knowledge of parents with children diagnosed with nephrotic syndrome. As a result, there is a need to raise awareness and enhance information about the care of children with nephrotic syndrome.*

Keywords: Knowledge, parents, nephrotic syndrome, discharge guide module

INTRODUCTION

Nephrotic syndrome is predominately seen among children. It is 15 times more common in children than in adults, and it differs in many ways from adults in terms of origins, signs, and symptoms, as well as recovery, necessitating specific treatment. Nephrotic syndrome begins with edema around the eyes, then on the ankles and legs, which is pitting in character. Over time, the entire body becomes edematous, with fluid accumulating in the peritoneal and thoracic cavities. In up to 25% of children with nephrotic syndrome, symptoms, such as elevated blood pressure, abdominal pain, loss of appetite, and general malaise may be present. Steroid therapy is the primary treatment for primary nephrotic syndrome and can be initiated even without a kidney biopsy if the child exhibits classic symptoms of the condition. Relapses can be triggered by urinary tract infections or inadequate

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response to treatment. While steroid medications have significantly reduced mortality, they come with various side effects in children, including weight gain, growth suppression, elevated blood pressure, changes in glucose metabolism, as well as emotional distress and behavioral issues [1, 2].

Nephrotic syndrome is a global condition, with the highest incidence observed in children between the ages of 2 and 5 years. It affects males more frequently than females, with a male-to-female ratio of 2:1 [3]. The condition is 15 times more common in children than adults, impacting approximately 16 out of every 100,000 children worldwide each year. A higher incidence is also observed among siblings, indicating a familial predisposition [4]. Nephrotic syndrome is the most prevalent glomerular disorder in children, with an incidence of around 1 to 3 cases per 100,000 children under the age of 16. In addition, congenital nephrotic syndrome (CNS), known as nephrotic syndrome, is a rare glomerular disorder present in the first 3 months of life (appears 4–12 months after birth) [5]. According to the International Pediatric Nephrology Association (2020), idiopathic nephrotic syndrome affects 1–3 per 100,000 children annually. The Centers for Disease Control and Prevention reports that nephritis, nephrotic syndrome, and nephrosis together account for 51,565 deaths, with a mortality rate of 15.7 per 100,000 population. This places the condition at the 8th leading cause of death [5–7].

The International Pediatric Nephrology Association (2020) further states that around 85% of children with nephrotic syndrome achieve full remission of proteinuria following glucocorticoid therapy. However, some patients do not reach full remission within 4–6 weeks of treatment, a condition referred to as steroid-resistant nephrotic syndrome [8].

According to Dorothy Marlow R, nephrotic syndrome is the most common glomerular disorder in children, affecting approximately 1–3 per 100,000 children under 16 years of age. Additionally, CNS, a rare form of nephrotic syndrome that manifests within the first 3 months of life, typically appears between 4 and 12 months of age [9].

Nephrotic syndrome is a chronic condition characterized by periods of relapse and remission, often continuing throughout childhood. Managing a child with nephrotic syndrome requires ongoing care, patience, and long-term follow-up [10–12].

Therefore, the researcher felt that there was a high need for the education and information related to the various aspects of the child care after the discharge. Also, the education given to the parents will help to reduce the complications and improves the prognosis of the child with nephrotic syndrome. So, there was a need for creating awareness and improvement of knowledge.

Implementation of discharge guide module is beneficial for the parents and the children to cope up, by providing essential information and also the choices they have. Thus, creating and implementing a discharge guide module for parents of children with nephrotic syndrome is crucial and beneficial. It enhances the quality of care, helps reduce morbidity and mortality, and alleviates the burden on families, healthcare facilities, and the broader community [13–16].

MATERIALS AND METHODS

This study utilized a quasi-experimental one-group pretest posttest design. Ethical approval was obtained from the Institutional Ethics Committee (Reg. No. ECR/262/Inst/UP/2013/RR-19). Data collection took place from May 13, 2021, to June 15, 2021. A total of 40 participants were selected using a non-probability purposive sampling method.

Parents of children aged 1–15 years diagnosed with nephrotic syndrome, who were willing to provide consent, were included in the study. Exclusion criteria included parents of children with congenital anomalies, chronic conditions, or mental health issues. The researchers explained the purpose of the study and introduced themselves to the parents. Written informed consent was obtained, ensuring full anonymity and confidentiality.

Sociodemographic and clinical data were collected from the parents using a sociodemographic proforma. The parents' knowledge was assessed through pre- and post-tests using a semi-structured knowledge questionnaire. The pretest was conducted to evaluate the initial knowledge of parents regarding nephrotic syndrome. On the same day, the discharge guide module was explained and provided to the parents for 15 minutes. A posttest was conducted two days later to assess the impact of the discharge guide module, using the same tool. The study was carried out in the Pediatric Medicine Ward at King George's Medical University, Lucknow.

Sample Size

The sample size was estimated to be 76, as determined through power analysis.

Statistical Analysis

Descriptive statistics, including percentages and frequencies, were used to outline the sample characteristics. The mean and standard deviation were employed to measure the levels of knowledge both before and after the discharge guide module.

For inferential analysis, a paired *t*-test was conducted to assess the effectiveness of the instructional module. Additionally, the Chi-square test was used to examine the relationship between demographic variables and posttest knowledge scores.

RESULT

Out of 40 samples, most of the parents were in the age group of 26–30 years, 22 (55%) and were female 25 (62.5%). Majority of the parents were having primary education 18 (45%), monthly income between 15,001 and 30,000 rupees 18 (45%), belongs to Hindu religion 26 (65%) and residing in rural area 22 (55%). The source of information related to nephrotic syndrome for most of the parents were health professionals 16 (40%). The majority of children were aged between 5 and 8 years, accounting for 18 (45%) of the cases, with a predominance of males, 28 (70%). In terms of disease onset, most children were newly diagnosed with nephrotic syndrome, with 15 (37.5%) falling into this category (Tables 1 and 2).

The mean pretest knowledge score was 10.21 ± 2.54 in pretest which was increased to 20.57 ± 4.80 in posttest. The mean difference was 10.36. The obtained "t" value 3.99 was statistically significant at ($p < 0.05$) (Table 3).

At the appropriate degree of freedom, the analyzed data revealed that there was no significant association of pretest knowledge score with their socio demographic variables at ($p=<0.05$) level of significance (Table 4).

DISCUSSION

Nephrotic syndrome impacts the functional level of the children as well as their family. The parents or caregivers may experience a considerable amount of psychological stress and difficult caring practices. And, also there are more chances of remission and relapses of nephrotic syndrome. Therefore, this study is significant as it highlights the factors that may impact the prognosis of nephrotic syndrome. Understanding these factors can be instrumental in designing targeted interventions that assist parents in effectively caring for their children and minimizing the risk of complications associated with nephrotic syndrome [17].

In terms of knowledge, present study revealed that in pretest 11 (27.5%) of the respondents have poor knowledge, 29 (72.5%) have average knowledge, whereas no one has good or excellent knowledge regarding nephrotic syndrome. This result was similar to the study conducted by Saraswathi et al. (2013), results of the study showed that 42 (70%) mothers had inadequate knowledge, 11(18.3%) had moderate knowledge and 7 (11.7%) had adequate knowledge regarding nephrotic syndrome (Figure 1).

Table 1. Frequency and percentage distribution of the socio demographic variable of parents.

Sociodemographic Variables	**Frequency (f)**	**Percentage (%)**
Parent's personal data		
Age in years		
a. 19–25	10	25
b. 26–30	22	55
c. 31–35	6	15
d. 35 and above	2	5
Gender		
a. Male	15	37.5
b. Female	25	62.5
Educational qualification		
a. Illiterate	10	25
b. Primary education	18	45
c. Secondary education	7	17.5
d. Graduate and above	5	12.5
Monthly income (in rupees)		
a. Below 15,000	14	35
b. 15,001–30,000	18	45
c. 30,001–45,000	5	12.5
d. Above 45,000	3	7.5
Religion		
a. Hindu	26	65
b. Muslim	11	27.5
c. Christian	3	7.5
d. Others	0	0
Area of residence		
a. Urban	18	45
b. Rural	22	55
Source of information related to Nephrotic syndrome		
a. Health professional	16	40
b. Mass media	5	12.5
c. Relatives and friend	14	35
d. Others	5	12.5
Child's personal data		
Age in years		
a. 1–4	10	25
b. 5–8	18	45
c. 9–12	8	20
d. 13–15	4	10
Gender		
a. Male	28	70
b. Female	12	30
Occurrence of disease		
a. Follow- up case	13	32.5
b. Relapse case	12	30
c. Fresh case	15	37.5
d. Do not know	0	0

Note: N = 40.

Table 2. Categories wise overall pre-test and post-test comparison of knowledge regarding nephrotic syndrome based on total score.

Knowledge Level	Pre-test		Post-test	
	f	*%*	*f*	*%*
Poor	11	27.5	2	5
Average	29	72.5	5	12.5
Good	0	0	24	60
Excellent	0	0	9	22.5

Note: N = 40.

Table 3. Comparison of pre-test and post-test knowledge scores of the subjects (N = 40).

Level of Knowledge	Mean	Standard Deviation	Df	Paired T-Value
Pre-test	10.21	2.541	39	3.99
Post-test	20.57	4.808	-	P<0.05

Df = Degree of freedom.

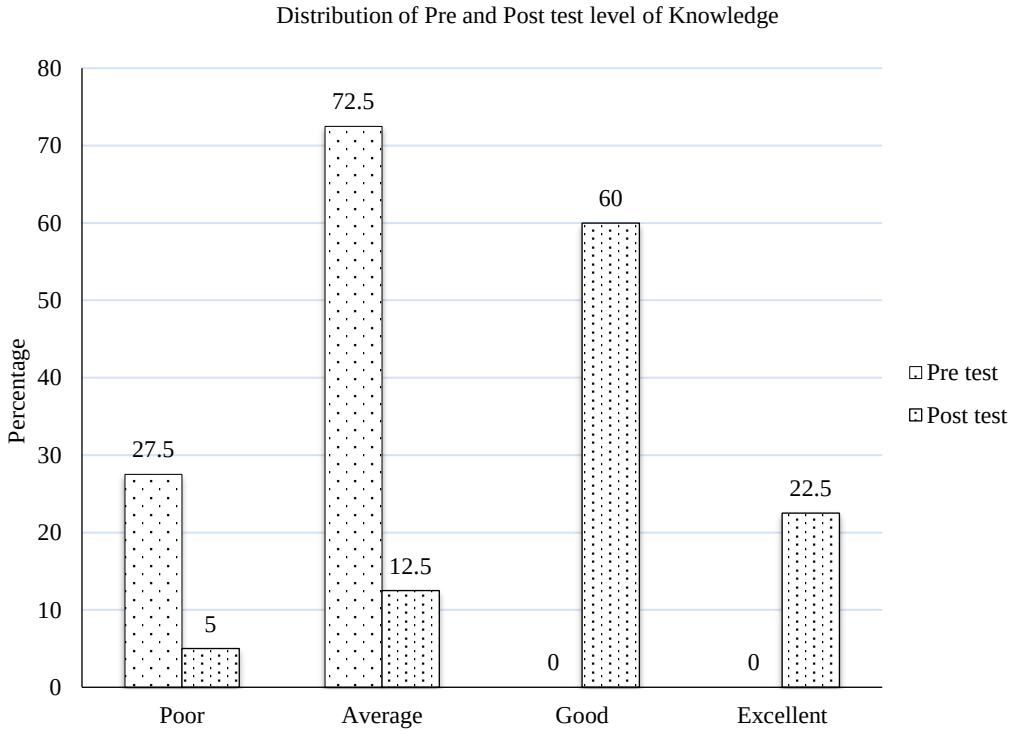

Figure 1. The comparison of pre and posttest knowledge.

The aim of this study was to improve the knowledge of parents caring for children with nephrotic syndrome. The findings of the study revealed that, out of total 40 children enrolled in study, (45%) children who belongs to the preschooler and school age group and were (70%) males.

The findings of this study align with research by Shivani Negi et al. (2020), which included 53 participants. The majority of the sample were male (66%) and in the preschool age group (41.5%), indicating that nephrotic syndrome predominantly affects young children. A significant proportion (81%) of the children lived in rural areas. Most were diagnosed with nephrotic syndrome within the past 2–6 years, and none had a family history of the condition or other related illnesses, suggesting there was no familial predisposition. Additionally, 70% of the children were in remission, and 62% had a history of recurrent hospitalizations, indicating a higher likelihood of relapses and remissions [18].

Table 4. Chi-square test showing an association between pretest level of knowledge with their sociodemographic variables.

Demographic Variables	**Level of Knowledge**				**P Value**	χ^2
	Poor	***Average***	***Good***	***Excellent***		
Parent's personal data						
1. Age in years						
a. 19–25	5	5	0	0		
b. 26–30	4	18	0	0	7.82	0.2252
c. 31–35	1	5	0	0	Df-3	
d. 35 and above	1	1	0	0		
2. Gender						
a. Male	4	11	0	0	3.84	0.0114
b. Female	7	18	0	0	Df- 1	
3. Educational qualification						
a. Illiterate	2	8	0	0		
b. Primary education	6	12	0	0	7.82	0.8650
c. Secondary education	2	5	0	0	Df- 3	
d. Graduate and above	1	4	0	0		
4. Monthly income (in rupees)						
a. Below 15,000	5	9	0	0		
b.15,001–30,000	4	14	0	0	7.82	0.8211
c. 30,001–45,000	1	4	0	0	Df- 3	
d. Above 45,000	1	2	0	0		
5. Religion						
a. Hindu	6	20	0	0		
b. Muslim	3	8	0	0	7.82	
c. Christian	2	1	0	0	Df- 3	0.2775
d. Others	0	0	0	0		
6. Area of residence						
a. Urban	7	11	0	0	3.84	0.2775
b. Rural	4	18	0	0	Df- 1	
7. Source of information related to nephrotic syndrome						
a. Health professional	6	10	0	0	7.82	
b. Mass media	1	4	0	0	Df- 3	0.7188
c. Relatives and friends	3	3	0	0		
d. Others	1	4	0	0		
Child's Personal data						
8. Age in years						
a. 1–4	3	7	0	0	7.82	
b. 5–8	6	12	0	0	Df- 3	0.7401
c. 9–12	1	7	0	0		
d. 13–15	1	3	0	0		
9. Gender						
a. Male	6	22	0	0	3.84	0.1889
b. Female	5	7	0	0	Df- 1	
10. Occurrence of disease						
a. Follow-up case	5	8	0	0	7.82	
b. Relapse case	2	10	0	0	Df- 3	
c. Fresh case	4	11	0	0		0.4735
d. Do not know	0	0	0	0		

Note: N = 40. Level of significant (p = <0.05), Df = Degree of freedom.

The study observed that the parents' knowledge of nephrotic syndrome was significantly lower in the pretest compared to the posttest. The results confirmed that the discharge guide module effectively improved parents' understanding of nephrotic syndrome. This highlights the importance of providing comprehensive education on post discharge care for children with nephrotic syndrome. It is essential for healthcare providers to actively educate parents to enhance their knowledge (Figure 1).

The study recommends that future research should replicate the study with a larger sample size to validate and generalize the findings. Additionally, a comparative study in both rural and urban settings could offer valuable insights [19].

CONCLUSIONS

The findings of the study conclude that nephrotic syndrome was more prevalent among males and preschool-aged children. Most participants had an average level of knowledge about nephrotic syndrome, and the discharge guide module proved to be an effective intervention in improving parents' understanding of the condition. Many of the children experienced relapses during their treatment. Therefore, healthcare providers should counsel caregivers on the proper home care for children with nephrotic syndrome.

Clinical Implications

The investigator has identified several key implications from the study, which are critical for clinical practice and improving the prognosis of children with nephrotic syndrome. Nurse educators can highlight the importance of preventive measures to mitigate the severity of complications associated with nephrotic syndrome. Collaboration with relevant authorities is essential to develop policies that ensure the employment of specially trained nurses in pediatric medicine wards for proper supervision and effective care. Additionally, it is crucial to provide parents with comprehensive knowledge about nephrotic syndrome. Therefore, nurse researchers should conduct related studies to fill the gaps in knowledge and practice related to prevention and management of children with nephrotic syndrome.

Limitations

The study is limited to parents of 1–15 years of children having nephrotic syndrome. And the time period for data collection is limited to 4 weeks. Due to COVID, the sample size from the hospital setting was limited.

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