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Effect of an information booklet on nephrotic syndrome regarding knowledge and attitude of caregivers towards care of children with nephrotic syndrome in tertiary level centre of Bihar

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ABSTRACT

Background: Nephrotic syndrome, the most common renal disease in pediatric age group, is responsible for frequent hospitalization of children. As parents are the most responsible person for care of their children, it is necessary for them to be aware and have knowledge regarding strict adherence to therapeutic regimen, about the disease recurrence and measures for adequate care of their child's health. An information booklet on nephrotic syndrome can help the caregivers in understanding the disease process and in maintaining their child's health.

Aim: Effect of an information booklet on nephrotic syndrome regarding knowledge and attitude of caregivers towards care of children with nephrotic syndrome in tertiary level centre of Bihar

Materials and Methods: This cross sectional study was carried out on admitted patients in Indira Gandhi Institute of Medical Science, Bihar from January 2021 to December 2021. An information booklet on nephrotic syndrome was given to caregivers of children diagnosed with nephrotic syndrome. About 50 parents/caregivers were interviewed with a preformed structured questionnaire before and after reading the information booklet.

Results: Of 50 respondents, an overall improvement in knowledge increased from 18% in pretest to 80% in post test. This result proves that the information booklet helped in improving the knowledge of caregivers towards care of their children.

Conclusions: The present study concluded that there was significant improvement in knowledge of caregivers after administering information booklet.

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1. Introduction

One of the fatal problems affecting children's health are the renal diseases.^{1,2} Nephrotic syndrome, being the most common renal diseases among children, damages glomeruli.^{3,4} It is also one of the most common reason for recurrent hospitalization of children. As nephrotic syndrome is a curable disease information regarding the same among parents and caregivers can not only reduce the hospitalization rate of children but also improve the

overall health and prognosis among children suffering from nephrotic syndrome. Nephrotic syndrome, as we know it, is a combination of proteinuria, hypoalbuminemia, hyperlipidemia, and edema.⁵

Nephrotic syndrome is characterised by nephrotic range proteinuria (proteinuria >3.5 g/24 hour or a urine protein:creatinine ratio > 2), edema, hypoalbuminemia (serum albumin <2.5 g/dL) and hypercholesterolemia (cholesterol >200mg/dL).^{6,7}

More than 80% cases of childhood nephrotic syndrome is Minimal Change Nephrotic Syndrome. Minimal change

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nephrotic syndrome is the most common cause of steroid sensitive nephrotic syndrome which has a satisfactory long term outcome.³ More than 95% of children with minimal change disease respond to corticosteroid therapy.⁷

Corticosteroids remain the mainstay for treatment of nephrotic syndrome. Those children responding to corticosteroid therapy are steroid-sensitive group that has a favourable and good long term prognosis whereas those dependent or resistant to corticosteroid therapy are steroid resistant group that has poor outcomes despite immunosuppression therapy.⁸ 85-90% are steroid sensitive, approx 50% show frequent relapses or steroid dependence, and 3-10% are the late steroid resistance.⁹⁻¹¹ Long term corticosteroid therapy itself has many deleterious effect on health of children. So, parents should have the knowledge about the strict adherence to the corticosteroid therapy.

In India, the incidence of minimal change nephrotic syndrome among children is high. An Indian journal of nephrology article shows that its prevalence varies within India. It is approximately 33% in Haryana and <12% in Vellore.¹² It is known to affect 1-3 / 1 lakh children under 16 years of age.⁷

As minimal change nephrotic syndrome is the most common acute and curable renal disease. Educating the parents and the caregivers regarding the disease process, its symptoms, management, and care at home is of utmost importance for the treatment and better prognosis of the disease among children with nephrotic syndrome.

2. Objectives

1. To spread awareness about nephrotic syndrome.
2. To assess the knowledge and attitude of caregivers on nephrotic syndrome.

3. Materials and Methods

This cross-sectional study was carried out on admitted patients in Indira Gandhi Institute of Medical Science and hospital, Bihar. The caregivers of children with new onset nephrotic syndrome were identified and addressed about the study, its process and its purpose by the investigators. A total of 50 caregivers of admitted patients diagnosed with new onset nephrotic syndrome were included in the study. The investigator conducted the pretest after briefing about the procedure by providing a preformed structured questionnaire. An information booklet on nephrotic syndrome published in Hindi and English was given to the caregivers. 2 days duration was given to read the information booklet. After reading and clarification of the information booklet the investigator conducted post test. The validated preformed structured questionnaire published in Hindi and English, included demographic profile of the patient, function of kidney, meaning of nephrotic syndrome, signs and symptoms giving clue to the disease,

urine tests done at home, medical management, supportive management, need of treatment adherence, prevention of complications due to disease and due to treatment and regular follow up.

3.1. Inclusion criteria

1. Children 1-12 years diagnosed with new onset nephrotic syndrome admitted in pediatric ward.
2. Parents/Caregivers willing to participate.

3.2. Exclusion criteria

1. Children who were shifted to PICU.
2. Caregivers not understanding Hindi or English language.

4. Results and Discussion

The present study consists of 50 parents/caregivers of children of nephrotic syndrome admitted to our pediatric ward, IGIMS, Bihar over a period of 1 year. Among the 50 caregivers who were included in the study, 56% of them had male child. 52% of them were of 5-10 years age group. 56% of them had edema of duration < 1 week. Demographic profile of the patient is shown in Table 1.

Table 1: Demographic profile of patients with nephrotic syndrome

Variables	Number	Percentage
Age in years		
1-5	18	36
5-10	26	52
>10	6	12
Sex		
Male	28	56
Female	22	44
Religion		
Hindu	41	82
Muslim	9	18
Duration of edema in weeks		
<1	28	56
1-2	14	28
>2	8	16

Table 2: Knowledge score of sample

Test	Frequency	Percentage
Pre-test	9	18%
Post-test	40	80%

Knowledge of caregivers of children with new onset nephrotic syndrome with respect to various aspects of nephrotic syndrome in pretest was 18% which increased to 80% in post test after reading the information booklet as shown in Table 2. Result of our study was found to be concordant with the study by Chhameshwari Verma.¹³

Overall, the information booklet improved the better understanding of the caregivers regarding the disease process, its management and in improving the health care of children. There was no association of demographic variables with the gain in knowledge of the caregivers. As this study was conducted in small group of population, furthermore awareness programme are required for betterment of children with nephrotic syndrome.

5. Conclusion

As nephrotic syndrome is the most common pediatric renal disease associated with frequent hospitalization. Information about the care of children with nephrotic syndrome is of utmost important for remission of the disease and to prevent relapses and serious complications leading to fatality. During our study, it was observed that the caregivers were keen to know about the disease, edema, diet, urine testing, medication, warning signs and recurrence of the disease and the complications associated with it. Our study concluded that there was marked increase in awareness and knowledge of caregivers regarding nephrotic syndrome after reading the information booklet. Caregivers also shared their experience about the benefit of providing such type of information booklet on the disease and care for the same. This study highlighted the need of spread of awareness about care of children with nephrotic syndrome in IPD as well as OPD patients.

6. Conflicts of Interest

All contributing authors declare no conflicts of interest

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None

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