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Caregivers' Knowledge Regarding Home Care of their Children with Nephrotic Syndrome

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Abstract

Background: *Nephrotic syndrome is among the most often diagnosed chronic renal disorders in pediatric populations. Aim: Assess knowledge of caregivers of children with nephrotic syndrome.*

Method: *A descriptive, cross-sectional approach was used. The study was carried out in the nephrology unit of Mansoura University Children's Hospital. Using a convenience sample approach, the study included 40 caregivers.*

Tools: *A structured interview questionnaire developed by the researcher was used for data collection.*

Results: *The caregivers' correct answers regarding treatment, cortisone side effects, nutritional sources, infection prevention, and urine characteristics were 42.5%, 15%, 5%, 52.5%, and 50%, respectively. Regarding the studied caregivers' total knowledge score about nephrotic syndrome, only 15% of participant caregivers gave correct answers.*

Conclusion and Recommendations*: In conclusion, the participating caregivers had poor knowledge related to nephrotic syndrome. In the light of the research findings, conducting educational sessions for the caregivers about nephrotic syndrome, Disseminating of posters, booklets, and leaflets for caregivers at outpatient clinic, and offering a written discharge for caregivers of children with nephrotic syndrome are recommended.*

Keywords

Assessment, Caregivers, Children, Nephrotic Syndrome.

INTRODUCTION

Proteinuria (>1 g of urine protein/m² of body-surface area/day; 3+ on a urine dipstick; and >2.0 mg protein/mg creatinine), hypoalbuminemia (<3 g of albumin/dL), edema, and hypercholesterolemia (>200 mg of total cholesterol/dL) are all characteristics of nephrotic syndrome in children [1]. About 4.7 incidences of NS occur for every 100,000 children outside of Africa (range: 1.15-16.9). Between 14.6% and 47.1% of all renal diseases reported in Africa and between 0.16% and 1.46% of pediatric hospitalizations are caused by nephrotic syndrome. African children are 7.3 years old on average when they are diagnosed with NS, which is significantly older than estimates from North America and Europe [2].

Age of disease onset, underlying renal histology, and responsiveness to steroid therapy are the three criteria used to classify nephrotic syndrome. NS can be categorized as congenital from birth to three months of age, infantile from three months to one year of age, childhood from one year of age, or adult through adult life on the basis of the age of onset **[3]**. Children with NS can be divided into two groups based on how they respond to corticosteroids: a steroid-sensitive group, representing up to 80% of the population, which has a favorable long-term prognosis but is susceptible to relapses, and a steroid-resistant group, which has a greater chance of developing chronic kidney disease (CKD) [4].

With an incidence of 85% of all cases, minimal change disease (MCD) is the most prevalent type of NS in children. It is most commonly seen in males between the ages of 2 and 7 years. In children, clinical manifestations can vary from mild to severe, exhibiting unpredictable patterns of relapse and remission. Prolonged treatment duration and the propensity for relapse in INS have substantial implications for the health-related quality of life of affected children and their families **[5]**. Children's mental health, social development, personality development, and family coping are all impacted by the physical, emotional, and social symptoms of any chronic condition [6].

Infection is a common and dangerous side effect of NS. Immunosuppressive drugs, mechanical factors such edema and ascites, and the loss of immunoglobulins and complement components in the urine are all associated with the multifactorial increased risk of infection. Two strategies for reducing severe bacterial infections (SBIs) in children with NS include vaccination and antibiotic prophylaxis [7].

Dietary salt restriction is the backbone of edema management. Fluid restriction or the use of loop diuretics may be necessary for severe edema. If these treatments fail, cautiously administer 25% albumin (0.5–1 g/kg intravenously over 2–4 hours) and then an intravenous loop diuretic to achieve diuresis. Supportive measures include monitoring daily weights, elevating swollen legs or other body parts, and recording intake and output from inpatients [8]. Parenteral albumin therapy may result in problems such as pulmonary edema, heart failure, hypertension, and volume

overload, especially when given as a rapid infusion. Children should therefore be regularly checked for these issues [9].

For children with NS who are edematous, moderate fluid and sodium restriction is recommended. Children with edema have the same energy requirements as children of the same age who are healthy. 1–2 gm/kg/d of protein is adequate for the majority of young people at this time [10]. Once the edema has decreased, the primary maintenance fluid needs can be satisfied. Children should consume a healthy, age-appropriate diet in order to meet their energy needs and the daily need of protein consumption. If catch-up growth is required, energy intake may increase to 120%–140% of the recommended dietary allowance. It is recommended to stay limited because trans and saturated fats are linked to inflammation [11].

To regulate daily caloric, sodium, calcium, and vitamin D consumption, standardized dietary recommendations are needed. Managing the side effects and associated issues of corticosteroid treatment is also crucial [12]. To prevent kidney damage from worsening, they require customized dietary choices both during the acute stage of the illness and throughout remission. A multidisciplinary strategy involving family doctors, pediatric nephrologists, dietitians, and parents is necessary for the proper management of food in children with nephrosis **[13]**.

Respecting children and their families, communicating expert medical knowledge, fostering connections between children, families, caregivers, and medical professionals, and successfully enhancing the prognosis and treatment impact of illnesses are the cornerstones of the FCNAccording to research, FCN intervention can improve children's quality of life (QoL), self-care behavior management skills, and health awareness [14]. Thus, the purpose of this study was to evaluate caregivers' knowledge regarding nephrotic syndrome.

MATERIALS AND METHODS

Research Design

Descriptive cross-sectional design was the research methodology used in this study.

The Study Setting

The study was carried out in the nephrology unit of Mansoura University Children's Hospital.

Study Participants

A purposive sample was utilized which includes (n=40 caregivers) agreed to participate and fulfilled the following criteria:

- Caregivers of children with a confirmed diagnosis of NS.
- Caregivers of School-age children aged between 7 and 12 years of both genders.
- Caregivers of Children without intellectual disabilities.

Tools and Techniques of Data Collection

Structured Interview Questionnaire Sheet

Caregivers' knowledge about Nephrotic Syndrome included MCQ questions about the definition, causes, risk factors, signs and symptoms, early signs for relapses, complications of NS, diagnosis, treatment, steroid side effects, nutritional sources and dietary instructions, preventive measures for infections, urine examination at home, edema and moon face characteristics, activities of daily living, and indications for kidney biopsy.

Scorning System

We assessed caregivers' knowledge through 27 multiple-choice questions. In accordance with Hamed et al. (2023), the overall knowledge score of the caregivers was divided into three categories: good: >75%, fair: 50 ≤ 75%, and poor: <50%

Validity of the Study Tool

A panel of five pediatric nursing professionals evaluated and corrected the content and face validity of the study instruments. The panel reviewed the scores for clarity, content, item sequence, and relevance to assess how accurately they reflected the variable for which they were designed.

Study Tool Reliability

A statistician used SPSS version 27's Cronbach's alpha coefficient test to assess the study tool's dependability. The caregivers' knowledge had a Cronbach's alpha of 0.903.

Pilot Study

Before starting a primary research, a pilot study was carried out using the data collection tools. Four caregivers, or 10% of the research sample, participated in a pilot study. They were selected at random and removed from the study. The pilot study's objectives were to ascertain the questions' viability and clarity, identify any obstacles or problems throughout the data collection process, analyze the clarity of the language, and determine how long it took to answer each question.

Ethical Considerations

The Research Ethics Committee of the Mansoura University Faculty of Nursing granted ethical approval. The study was officially approved by the relevant administrator of the hospital. After being made aware of the study's goals and design, each participant provided signed informed consent. Every participant was made aware that their involvement in the study was completely voluntary and that they might discontinue at any moment. Participants received guarantees on the privacy of the study sample and the confidentiality of the data obtained at every stage of the data collecting process.

Data Collection

The questionnaire was delivered to all available caregivers. The researcher gave instructions on how to complete the questionnaire and described the goal of the study. They completed the tool separately at once, reading the

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questions and filling out the sheets which took 25-30 minutes. Data collection was extended for three months, from the 1st of March 2024 to the end of May 2024.

Statistical Design

All statistical analyses were performed using SPSS for Windows version 20.0 (SPSS, Chicago, IL). Categorical data was represented by numbers and percentages.

RESULTS

Table 1 showed that about one-quarter of the studied caregivers (25%) was aged < 35 years. All caregivers were females (100%). Mothers form the majority of their kinship relationships (90%). The majority of them (90%) were married, and more than two-fifths (42.5%) had secondary school education. Furthermore, four-fifths of them (80%) were from rural areas.

Table 1. Distribution of the Studied Caregivers According to their Characteristics

	No.	%
Age (Years)		
< 35	10	25.0
35 – 40	15	37.5
> 40	15	37.5
Sex		
Female	40	100.0
Kinship relationship		
Mother	36	90.0
Paternal aunt	1	2.5
Maternal grandmother	1	2.5
Maternal aunt	2	5.0
Marital status		
Married	36	90.0
Widow / Widower	2	5.0
Single	2	5.0
Educational level		
Secondary school	17	42.5
Intermediate institute	12	30.0
University education	11	27.5
Residence		
Urban	8	20.0
Rural	32	80.0

Data are expressed as frequency (%)

Table 2 demonstrated that less than one-quarter of the studied caregivers (20%) had correct answers about NS definitions and causes. Moreover, only 15% of them had correct responses related to the risk factors and the commonest age group. Regarding their knowledge about symptoms and the early signs, correct answers reported by 57.5% of participants. Also, their correct responses related to complications and diagnosis was only 15% and 10%, respectively. Also showed that the caregivers' correct answers regarding treatment, cortisone side effects, nutritional sources, infection prevention, and urine characteristics were 42.5%, 15%, 5%, 52.5%, and 50% respectively. Table 2 also revealed that the correct answer of the studied caregivers regarding the importance of daily living and exercise was 60%. Regarding specialist consultation, the correct caregivers' responses was 20%. Moreover, regarding facial edema characteristics and moon face characteristics, their correct response were 10% and 5%, respectively. Lastly, only 15% of the studied caregivers had correct responses about kidney biopsy.

Table 2. Distribution of the Studied Caregivers knowledge Score about NS

	No.	%
NS definition and causes		
Incorrect	32	80.0
Correct	8	20.0
Risk factors and the common age group		
Incorrect	34	85.0
Correct	6	15.0
Symptoms & the early signs		
Incorrect	17	42.5
Correct	23	57.5
Complications		
Incorrect	34	85.0
Correct	6	15.0
Diagnosis		
Incorrect	36	90
Correct	4	10.0
Treatment		
Incorrect	23	57.5
Correct	17	42.5
Long and short side effects of cortisone		
Incorrect	34	85.0
Correct	6	15.0
Nutritional sources		
Incorrect	38	95.0
Correct	2	5.0
Infection prevention		

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	No.	%
Incorrect	19	47.5
Correct	21	52.5
Urine characteristics		
Incorrect	20	50.0
Correct	20	50.0
Activity of daily living & exercise importance		
Incorrect	16	40.0
Correct	24	60.0
Specialist consultation		
Incorrect	32	80.0
Correct	8	20.0
Characteristics of facial edema in relapse		
Incorrect	36	90.0
Correct	4	10.0
Moon face		
Incorrect	38	95.0
Correct	2	5.0
Kidney biopsy		
Incorrect	34	85.0
Correct	6	15.0

Data are expressed as frequency (%)

Regarding the studied caregivers' total knowledge score about NS, Figure 1 revealed that only 15% of participant caregivers give correct answers.

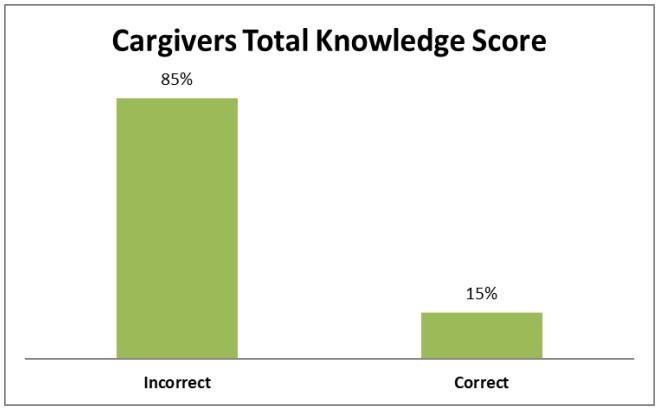

Figure 1. Caregivers' total knowledge score about NS

DISCUSSION

Nephrotic syndrome primarily affects children. Children are 15 times more likely to develop NS than adults are, and this condition differs in many ways from that of adults in terms of its origins, signs, symptoms, recovery, and the need for specific treatment [14]. This condition occurs throughout the early life stages of the children and has a substantial influence on their physical and emotional well-being.

Our findings regarding the sociodemographic characteristics of the studied caregivers revealed that approximately 25% of them were under the age of 35. All caregivers were females. Mothers form the majority of their kinship relationships. The majority of them were married, and more than two-fifths had secondary school education. Furthermore, four-fifths of them were from rural areas. This study result aligns with previous reports indicating that over half the mothers were between 20 and 30 years old, two-thirds had secondary education, more than half were unemployed, roughly three-quarters resided in rural areas, and about three-quarters of mothers had insufficient income [15]. Furthermore, our results were matched with those of [16], in which the majority of parents were mothers, fewer than half were in the 31-37 years age group, and the vast majority of them were married**.** Other similar results were reported by [17].

The complexity of NS and its treatment made decision-making difficult, as parents frequently had to assimilate information about a condition that was poorly understood, according to a qualitative study titled "Learning to Live with Nephrotic Syndrome: Experiences of Adult Patients and Parents of Children with Nephrotic Syndrome," which gathered qualitative data through semi-structured focus groups and individual interviews with 25 parents of children with NS. There were identified specific informational demands pertaining to knowing how to manage NS and comprehending the diagnosis and treatment techniques. Learning is frequently difficult when reliable knowledge is hard to come by. It was emphasized how crucial it is to learn how to keep an eye on their health, including identifying triggers that could cause a relapse, and that tailored strategies are required to guarantee that each person's particular learning needs are met [18].

Our findings matched those in their study entitled "Effectiveness of Discharge Guide Module on Knowledge Regarding Nephrotic Syndrome among Parents of Children with Nephrotic Syndrome," which indicated that parents' knowledge significantly increased after using the module. The mean knowledge score before the intervention was 10.21 ± 2.54, and after the intervention, it rose to 20.57 ± 4.80, with an increase that was statistically significant (p-value < 0.05). [19].

Furthermore, our results were consistent with a study conducted at Pediatric Minia University Hospital's urologic pediatric outpatient clinic. According to this study, prior to the health education program, moms knew very little about nephrotic syndrome, including its definition, causes, symptoms, tests, typical treatments, and complications [20]. Additionally, their pretest-posttest quasi-experimental research design, "A Pre-Experimental Study to Assess the Effectiveness of Information Booklet on Knowledge among Caregivers Regarding Care of Child with Nephrotic Syndrome in Selected Hospitals of Pune," which involved 60 caregivers of children with nephrotic syndrome, showed that

the mean posttest knowledge score of caregivers of children with nephrotic syndrome was significantly higher than the pretest knowledge score [21].

Moreover, [22] reported that over half of the study participants possessed a sufficient degree of knowledge about the home management of their children with NS. In agreement with our study findings, [22] conducted a study entitled "Effect of an Information Booklet on Nephrotic Syndrome Regarding Knowledge and Attitude of Caregivers Toward Care of Children with Nephrotic Syndrome in Tertiary Level Center of Bihar" and revealed that, out of 50 caregivers, the overall improvement in knowledge increased from 18% in the pretest to 80% in the posttest. Similarly, [18], in their study entitled "Effectiveness of Need-Based Education on Homecare of Nephrotic Syndrome on Knowledge and Practice among Caregivers of Children with Nephrotic Syndrome," reported that the mean score for posttest knowledge (19.8 ±2.47) was higher than the mean score for pretest knowledge (13.9 ±2.92).

Conversely, our results contrast with those of their quasi-experimental study, which involved 70 parents presenting to a pediatric nephrology clinic, titled "Designing and Assessing the Effectiveness of Education through Mobile Application on Knowledge, Performance, and Satisfaction of Parents of Children with Renal Disease, Tehran, Iran," which illustrated that the mean score of knowledge in both groups was equal to 6 ± 1 (moderate) [23].

CONCLUSION

In conclusion, the participated caregivers had poor knowledge related to nephrotic syndrome.

Recommendation

In the light of the research findings, the following recommendations are offered:

- Hold informational meetings regarding nephrotic syndrome for the parents and children.
- Educating caregivers about nephrotic syndrome and its treatment in the outpatient clinic through posters, booklets, and pamphlets.
- Offer a written discharge plan for caregivers of children with nephrotic syndrome.
- Nurses and other medical professionals should play a part in providing parents with psychological support.
- Special spaces for health education in nephrology units would be provided by the Ministry of Health.

Declaration of Conflicting Interests

Regarding the research, writing, and/or publishing of this paper, the author(s) have stated that there are no possible conflicts of interest that might arise.

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