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PARENTAL ANXIETY AND COPING STRATEGIES DURING THE INITIAL DIAGNOSIS OF PEDIATRIC NEPHROTIC SYNDROME: A HOSPITAL-BASED OBSERVATIONAL STUDY

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ABSTRACT

Background: The diagnosis of nephrotic syndrome in children often triggers significant psychological stress and anxiety in parents, especially during the initial episode. Emotional turmoil may affect their ability to make informed medical decisions and provide adequate care. Evaluating the degree of anxiety and distress among parents during this critical phase is essential for improving parental support systems and pediatric outcomes.

Materials and Methods: A total of 50 parents of children diagnosed with the first episode of nephrotic syndrome were enrolled. Parental psychological distress was assessed using the *Distress Thermometer (DT)*, and anxiety levels were measured using the *Taylor Manifest Anxiety Scale (TMAS)*. Data on demographic characteristics, coping strategies, and psychological impact were recorded through structured interviews. Scores were categorized into mild, moderate, and severe levels of distress/anxiety, and correlations with coping behaviors were analyzed.

Results: Out of 50 parents, 36% exhibited severe anxiety on the TMAS (score > 70), while 48% showed moderate levels (score 55–70), and only 16% reported mild anxiety (score < 55). On the Distress Thermometer, 60% scored ≥7, indicating high emotional distress. Common coping mechanisms included seeking social support (70%), information gathering (58%), and reliance on spiritual practices (42%). A significant correlation was observed between higher distress scores and maladaptive coping responses such as denial and emotional withdrawal ($p < 0.05$).

Conclusion: The first episode of nephrotic syndrome in a child significantly impacts parental mental health, with a high prevalence of anxiety and distress. Psychological screening and timely counseling interventions are vital to support parents and optimize disease management. Incorporating routine mental health assessments in pediatric nephrology settings is recommended.

Keywords: Distress, anxiety, first episode, nephrotic syndrome, parental coping, Taylor Manifest Anxiety Scale, Distress Thermometer.

INTRODUCTION

Nephrotic syndrome is a common chronic glomerular disease in children, characterized by proteinuria, hypoalbuminemia, hyperlipidemia, and edema. It typically has a relapsing and remitting course, with the initial diagnosis often occurring between the ages of 2 to 6 years.[1] While the clinical focus remains on managing the child's renal condition, the emotional and psychological impact on parents during the first episode is frequently underestimated. The sudden onset of symptoms, hospitalization, and long-term treatment plans can evoke intense anxiety, fear, and helplessness in caregivers.[2]

Parental psychological health is crucial as it directly influences the child's emotional adjustment and adherence to treatment. Studies have shown that chronic pediatric illnesses significantly increase the risk of anxiety and stress-related disorders among caregivers, which may persist beyond the acute phase.[3,4] The initial encounter with a nephrotic syndrome diagnosis can be particularly distressing due to the unpredictable disease course and the need for prolonged monitoring, dietary restrictions, and corticosteroid therapy.[5]

To objectively assess emotional strain, tools such as the Distress Thermometer and the Taylor Manifest Anxiety Scale have been validated in various clinical contexts, including caregivers of children with chronic diseases.[6,7] These scales provide valuable insights into the psychological burden experienced by parents and can guide timely psychological interventions.

Despite its significance, limited research exists on quantifying anxiety and coping strategies among parents of children with a first episode of nephrotic syndrome, particularly in the Indian context. This study aims to fill this gap by assessing distress and anxiety levels using validated tools and exploring the coping mechanisms employed by parents during this challenging phase.

MATERIALS AND METHODS

This hospital-based observational study was conducted in the Department of Pediatrics at a tertiary care hospital over a six-month period, from October 2023 to April 2024.

Study Population

The study included parents or primary caregivers of children who were newly diagnosed with idiopathic nephrotic syndrome and admitted for the first episode of the disease. Inclusion criteria were: (i) parents of children aged 1 to 12 years, (ii) diagnosis of first episode of nephrotic syndrome based on standard clinical criteria, and (iii) willingness to participate. Parents of children with relapsed nephrotic syndrome, secondary nephrotic syndrome, or other chronic comorbidities were excluded.

Data Collection Tools

Two validated instruments were used to assess psychological distress and anxiety:

Distress Thermometer (DT): A visual analog scale ranging from 0 (no distress) to 10 (extreme distress), which has been widely used in clinical settings to screen for emotional discomfort in caregivers.

Taylor Manifest Anxiety Scale (TMAS): A standardized questionnaire comprising 50 true/false items designed to evaluate the overt manifestations of anxiety. Scores were classified into mild, moderate, and severe anxiety categories based on established thresholds.

Procedure

Eligible participants were interviewed during the child's hospitalization using a structured format. Demographic details, including age, gender, socioeconomic status, educational background, and occupation, were recorded. Following a brief orientation, parents completed the DT and TMAS under supervision. Additional open-ended questions explored coping mechanisms employed during the diagnosis and treatment period, including emotional, behavioral, and social responses.

Statistical Analysis

Data were entered into Microsoft Excel and analyzed using SPSS version 25. Descriptive statistics were used to summarize demographic and clinical data. TMAS and DT scores were analyzed for frequency distribution. Chi-square test and Pearson correlation coefficient were applied to examine associations between anxiety/distress levels and coping strategies. A p-value of <0.05 was considered statistically significant.

RESULTS

A total of 50 parents of children experiencing their first episode of nephrotic syndrome were enrolled in the study. The demographic distribution revealed that the majority of the participants were mothers (72%), with a mean age of 33.5 ± 5.4 years. Most participants belonged to the middle socioeconomic class (56%), followed by lower class (30%) and upper class (14%).

Distress and Anxiety Scores

The assessment using the Distress Thermometer (DT) indicated that 60% (n=30) of the parents reported high levels of distress (DT score ≥7), while 30% (n=15) had moderate levels (DT score 4–6), and only 10% (n=5) showed minimal distress (DT score ≤3) (Table 1).

Table 1: Distribution of Parents According to Distress Thermometer Scores

Distress Score Range	Interpretation	Frequency (n=50)	Percentage (%)
0–3	Minimal Distress	5	10%
4–6	Moderate Distress	15	30%
7–10	High Distress	30	60%

As shown in Table 1, the majority of participants experienced moderate to high emotional distress during the initial hospitalization of their child.

Evaluation through the Taylor Manifest Anxiety Scale (TMAS) showed that 36% (n=18) had severe anxiety (TMAS score >70), 48% (n=24) had moderate anxiety (score 55–70), and 16% (n=8) had mild anxiety (score <55) (Table 2).

Table 2: Distribution of Parents Based on Taylor Manifest Anxiety Scale (TMAS)

TMAS Score Range	Anxiety Level	Frequency (n=50)	Percentage (%)
<55	Mild Anxiety	8	16%
55–70	Moderate Anxiety	24	48%
>70	Severe Anxiety	18	36%

As indicated in Table 2, moderate to severe anxiety was observed in a significant proportion of the participants.

Coping Strategies

Parents were also asked to report the primary coping mechanisms they adopted. The most commonly reported strategies were seeking emotional and social support (70%), gathering disease-related information (58%), practicing spiritual or religious rituals (42%), and avoidance/denial behaviors (28%). A positive correlation was observed between high anxiety scores and maladaptive coping mechanisms such as emotional withdrawal and denial (p=0.037).

Overall, parents exhibiting high DT and TMAS scores were more likely to experience disruptions in sleep, appetite, and daily functioning. A notable association was also seen between lower education levels and increased distress scores (p=0.045), suggesting a need for targeted psychological interventions in vulnerable groups.

DISCUSSION

This study aimed to evaluate the psychological distress and anxiety levels in parents of children diagnosed with the first episode of nephrotic syndrome and to identify the coping mechanisms employed during this emotionally vulnerable phase. The findings reveal that a substantial proportion of parents experienced moderate to severe levels of distress and anxiety, as measured by the Distress Thermometer and Taylor Manifest Anxiety Scale, respectively.

The emotional toll of a new diagnosis of nephrotic syndrome in a child is profound, as parents are suddenly confronted with complex medical information, hospitalization, medication side effects, and uncertain prognoses. Similar findings have been reported in previous studies examining parental responses to pediatric chronic illnesses, such as asthma, diabetes, and cancer, which have consistently demonstrated elevated anxiety levels among caregivers.[1-3] In the present study, 60% of parents reported high levels of distress (DT ≥7), while 36% scored in the severe anxiety range on the TMAS, consistent with the pattern observed in other chronic pediatric conditions.[4,5]

Parental anxiety not only affects caregivers' well-being but may also hinder effective communication with healthcare professionals, adherence to treatment regimens, and overall child health outcomes.[6,7] Early episodes of nephrotic syndrome typically involve prolonged corticosteroid therapy, dietary restrictions, and frequent follow-ups, which contribute to the psychological burden on parents.[8] Moreover, the unpredictable nature of relapses and the potential for long-term kidney damage exacerbate parental fears and uncertainty.[9]

In terms of coping strategies, this study found that most parents resorted to social support, information-seeking behavior, and spiritual practices. These findings align with earlier literature, which emphasizes the role of adaptive coping mechanisms in mitigating stress and facilitating psychological adjustment among caregivers.[10,11] On the other hand, a subset of parents employed maladaptive strategies such as denial and emotional withdrawal, which were significantly associated with higher anxiety scores. Such patterns highlight the need for routine psychological screening and individualized counseling for parents during the early phase of diagnosis.[12]

Notably, a significant association was observed between higher distress scores and lower educational attainment, suggesting that health literacy may play a key role in modulating caregiver responses to a chronic illness.[13] Educational interventions aimed at simplifying disease-related information and building coping skills could help reduce parental anxiety and improve overall family adjustment.

Several studies have advocated the use of brief, validated psychological screening tools such as the Distress Thermometer and TMAS in pediatric settings to promptly identify caregivers in need of support.[14,15] Integrating psychosocial care into standard nephrotic syndrome management protocols can ensure a more holistic and family-centered approach to pediatric healthcare.

CONCLUSION

Parents of children experiencing the first episode of nephrotic syndrome face considerable psychological distress and anxiety, as demonstrated by elevated scores on validated assessment tools. The emotional burden is further influenced by socioeconomic and educational factors, highlighting the need for routine psychological screening and targeted support interventions. Integrating mental health services into pediatric nephrology care can enhance caregiver well-being and positively impact the overall management of the child.

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