

“PARENTAL BURDEN AND PSYCHOLOGICAL DISTRESS AMONG PARENTS OF CHILDREN WITH NEPHROTIC SYNDROME, A CROSS-SECTIONAL STUDY”

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Abstract

Background:- Childhood nephrotic syndrome (NS) is a chronic disorder among most children that is frequently observed throughout the world. Parent can experience a variety of physical, emotional, economic, and social harms, which are often collectively referred to as parent's distress. As parental burden directly impacts physical and mental health and well-being.

Objectives:-

- To assess the level of Parental Burden and Psychological Distress.
- To determine the association between parental burden and psychological distress among parents of children having Nephrotic Syndrome.

Design:- A cross sectional study

Setting:- Tertiary care Hospital, Bhubaneswar, Odisha, India

Method: A cross sectional study was performed in the Paediatric Units of selected tertiary care hospitals in Bhubaneswar, Odisha, India. The Institutional Review Board granted ethical approval. The investigator used consecutive sampling technique to select a sample of 62 parents of children with NS. Data were collected by using structured questionnaire and the tools consist of socio demographic performa, Zarit Burden interview and General Health questionnaire. Data was calculated using descriptive and inferential statistics.

Results: In this study included 62 parents of children with NS were mainly in the age between (31-35) where as age of father 26(41.9%) and age of mother 32 (51.6%) .Most 38 (61.3%) of the children has FRSD ,Including SRNS 13(21%) and SSNS 11(17.7%).A total number of 42 (67.7)parent reported psychological distress where GHQ-12 Score is between (12-20). on the other side the Zarit Burden interview score range(0-88) so,49 (79.05%) reported significance of burden .result showed Parental burden and psychological distress had a strong and positive Co-rrrelation.(r value is 0.6, $p < .000$).

Limitations:-As some parents is not fully opened up so it may restrict the amount of information that can be obtained from the respondents.

Future research should be brief and involve a large group of children with SRNS and FRSD.

Conclusion:-The main conclusion drawn from this study is that, As a caregiver Parents have significant psychological disturbances and burden in their daily live activities at moderate level. Parents of Children with Nephrotic Syndrome , is associated with severe parental burden and psychological stress. Number of children have a significant association ($p < 0.05$) with level of burden and psychological distress both.

Key words:- Nephrotic syndrome, psychological distress, parental burden, General Health Questionnaire, Zarit Burden Interview

Introduction:-

Nephrotic syndrome (NS) is among the most common chronic illness in children throughout the world, with a higher incidence in South Asian children. In nephrotic syndrome, protein leaks from the blood through the glomeruli into the urine, causing hypoproteinemia and generalized edema. Most children with minimal change disease (MCD) obtain remission through two weeks of steroid therapy. In approximately 95% of children with MCNS, steroid medication results in a decrease in proteinuria after 8 weeks of prolonged steroid therapy, and in approximately 98% of cases, proteinuria goes away after a year^[1]

Most children with NS respond to steroid therapy. However, approximately 40% to 60% of children with steroid-sensitive nephrotic syndrome (NSS) follow a course of frequent relapse or steroid dependence, making NS a chronic kidney condition. Recent data indicate that steroid-sensitive nephrotic syndrome (SSNS) can no longer be considered benign because up to 50% of patients are frequently affected. These changes have a negative impact on the patient's psychological well-being, personal and social growth, as well as their psychological and social status and family coping. The disease occurs in over 75% of patients.²

The disease occurs in over 75% of patients. The development of steroid dependence is one of the difficult problems in taking care of children with idiopathic nephrotic syndrome, resulting in increased morbidity, complications and treatment costs. Therefore, an early prediction of the course of the disease is helpful for the counseling of the parents and can improve the treatment strategy. The Nephrotic syndrome, like any other disease that affects the patient, has a negative impact on the body, causing biological, behavioural, and social changes. These changes have a negative impact on the patient's psychological well-being, personal and social growth, as well as their psychological and social status and family coping. Therefore, an early prediction of the course of the disease is helpful for the counseling of the parents and can improve the treatment strategy.^{1,2}

Nephrotic Syndrome has a consistently good initial response to corticosteroid therapy and a favorable prognosis. Despite the fact that there is evidence that parental burden or a disability of well-being, little is known about the psychological impact of NS on parents. While caring for a child with nephrotic syndrome has a profound impact on the lives of caregivers, according to a recent survey, moms made up the majority of carers (77.1%) while boys made up the majority of children ($n = 172$) (65.1%). 53 (30.8%) and 30 (17.4%) of the 172 carers felt mental distress and a heavy burden, respectively. caregivers for children involved. [3]

Caregivers can experience a variety of physical, emotional, economic, and social harms, which are often collectively referred to as caregiver distress. The degree of stress experienced is related to caregiver characteristics, such as gender, type of NS such as stage of nephrotic syndrome. The impact of caregiving, though sometimes positive, but generally find as negative, with high rates of distress and psych morbidity, accompanied by social isolation, physical illness, and economic hardship. Parental burden represents a vital area for nephrologists to advocate for patients and their families; along with that nephrologists must also recognize the realities caregivers face today. [4]

Caregiver burden is a key matter for nephrologists to fight for patients and caregivers; however, nephrologists must also realise the difficulties caregivers suffer today. [5]

Parents of children with chronic kidney disease (NS) play a crucial role in their child's illness management. The burden on parents is high: they are frequently exhausted, depressed, subjected to high levels of stress and low quality of life negatively impacting the health of their child. NS decreases the functional capacities of children and parents are affected by physically and psychologically too. Having NS in a child imposes additional roles and burdens on other family members, particularly the mother. Parents frequently denied the occurrence of stressful experiences, but the siblings' personality profiles revealed lower levels of self-acceptance and social confidence. [6]

Most children are unable to continue their schooling or careers or maintain a normal family life without tremendous effort from their loved ones. The integration of a patient with chronic renal disease into a chronic stress caused by hemodialysis schedule results in long-term adaptation changes, both physiological and pathological, as well as modifications unique to dialysis. [7]

Usually, the physical, psychosocial, and economic well-being of caregivers suffers, although to varying degrees depending on a variety of factors including such coping resources. [8-9]

Importantly, the "stress process model" considers that caregiving is difficult (stressful) and may herald a decline in mental health. [10]

Caregivers play a critical role in the management and care of people who have chronic medical illnesses. This is so they can help their wards on an emotional, physical, economical, and spiritual level. Caregiving is, however, frequently accompanied by a sense of load and psychological discomfort [11]

Methods:-

A cross sectional study was conducted in the Paediatric Units of selected tertiary care hospitals in Bhubaneswar, Odisha, India. The Institutional Ethical Review Board granted ethical approval.

We included parents of children who are under 18 years with NS. If the child had received NS treatment for at least six months, the parents were also considered as the participant. We excluded parents of children who have Secondary NS with other long-term conditions including epilepsy and asthma. Additionally, we disqualified parent who had a history of mental illnesses such schizophrenia, mania, or depression. Before participating in the trial, each parent gave written informed consent.

Data collection:-

Using a data collection form, we gathered information about the parent's sociodemographic traits as well as the clinical course of NS in the child. Information of interested parent included parent's education (father & mother), Residence, occupation, socio economic class, number of the children in the family, number of children with NS. We also went over the children's clinical notes to gather information about Severity of Nephritic Syndrome, Duration of Illness, Hospitalization in the prior 6 months. The 12-item General Health Questionnaire was then used to interview each caregiver (GHQ-12). The GHQ-12 is a well-validated short screening questionnaire for psychological distress or minor mental health morbidity that focuses primarily on depression and anxiety symptoms. Each item received a score of (0,1,2,3). Finally, we used the 22-item Zarit Burden Interview (ZBI) questionnaire to interview each parent to determine whether they were experiencing considerable caregiver burden. The ZBI questionnaire measures carers' perceptions of their psychological, social, physical, and financial status as a result of their caregiving duty. It is a frequently used and dependable tool. It has a Likert scale of 0 to 4, with "0" indicating "never" and "4" indicating "nearly always". The GHQ-12 is a brief screening test for psychological distress or minor mental health illness that focuses mostly on depressive symptoms and worry.

Statistics Interpretation:

As percentages, categorical data were summed up. We have done an analysis by calculating chi square value of each demographic characteristics to find out the factors associate with the level of burden and psychological distress. .Lastly, interconnection of psychological distress and parental burden, we used pearson correlation to test for a linear association between GHQ-12 and ZBI-22scores,where the p value was ($<.05$) determined as statistically significant.

Results:

In this study the included 62 parents of children with NS were mainly in the age between(31-35) where as age of father 26(41.9%) and age of mother 32 (51.6%) .Most 38 (61.3%) of the children has FRSD ,Including SRNS 13(21%) and SSNS 11(17.7%).In the 6 months before to the study the children of 48 (77.4%) were admitted in hospital at least for 1 time.(Table 1).

Parental Burden & Psychological Distress:

The result shows that 49 (79.0 %) parent's had moderate to severe burden. parent's who had severe burden were 9 (14.5 %). Mild to moderate burden were seen among 4 (6.5 %) of the parent's.Majority of the participants , 7(27.4%)had severe distress. participants who had moderate distress were 42(67.7 %). Mild / No distress were seen among 3(4.8 %) of the study participants.Parental burden and psychological distress had a strong and positive co-rrelation .(r value is 0.6, $p < .000$) (Table 2).

Sl.No	Demographic variables		Frequency	Percentage
1	Age years	0– 5years	36	58.1
		6– 8years	14	22.6
		9– 11years	12	19.4
2	Sex	Male	42	67.7
		Female	20	32.3
3	Age of Father	25 - 30	19	30.6
		31 - 35	26	41.9
		36 - 40	17	27.4
4	Age of Mother	25 - 30	24	38.7
		31 - 35	32	51.6
		36 - 40	6	9.7
5	Residence	Urban	30	48.4
		Rural	32	51.6
		Secondary	10	16.1

6	Education of Father	Higher Secondary	30	48.4
		Diploma Degree	22	35.5
7	Education of Mother	No formal education	2	3.2
		Primary	29	46.8
		Secondary	23	37.1
		Higher Secondary	8	12.9
8	Occupation of Father	Unemployed	5	8.1
		Govt employed	4	6.5
		Private employed	44	71.0
		Others	9	14.5
9	Occupation of Mother	Govt employee	4	6.5
		Private employee	11	17.7
		Home Maker	43	69.4
		Others	4	6.5
10	Socio-Economic Class	Upper class (7770 & above)	3	4.8
		Upper middle class (3809-7769)	26	41.9
		Middle class (2254-3808)	21	33.9
		Lower middle class (1166-2253)	12	19.4
11	Number of Children	One	36	58.1
		Two	22	35.5
		More than 2	4	6.5
12	Children with NS	One	60	96.8
		Two	2	3.2
13	Severity of Nephritic Syndrome	Steroid resistance	13	21.0
		Frequent relapse or steroid dependence	38	61.3
		SSNS	11	17.7
		6 Months	29	46.8

14	Duration of Illness	More than 6 Months	33	53.2
15	Hospitalization in the prior 6 months	1 time	48	77.4
		2 time	11	17.7
		More than 2 time	3	4.8
16	Previous Knowledge	Yes	7	11.3
		No	55	88.7

Note:- **FRSD** = frequent relapses or steroid dependence; **SSNS** = steroid-sensitive nephrotic syndrome (infrequent relapser); **SRNS** = steroid-resistant nephrotic syndrome.

Table – 2: Frequency and Percentage Distribution of Subjects According to Level of Burden & Level of Psychological Distress (n=62)

Sl.NO	Level of Burden	Frequency	Percentage
1	Mild to Moderate Burden	4	6.5
2	Moderate to Severe Burden	49	79.0
3	Severe Burden	9	14.5
	Level of Psychological Distress		
1	No / Mild Distress	3	4.8
2	Moderate Distress	42	67.7
3	Severe Distress	7	27.4

Table- 3. correlation between level of parental burden with psychological distress

(n=62)

Variables	Mean	Standard Deviation	'r' value	Level of Correlation	'p' value
Burden	51.66	10.10	0.6	Strong positive correlation	.000*
Distress	18.91	6.2			

Discussion:

The development of a chronic disease in a baby adds an unexpected stressor to the caregiving role of parents; it disrupts the balance between the regular duties of parenting, which is stressful in and of itself, and the family's intrinsic and extrinsic resources. A state of anguish happens when the family's coping mechanisms are

overburdened. Our findings suggest that psychological distress and the presence of considerable parental burden are correlated. This linear association implies that high parental burden may cause psychological distress in the parent and vice versa. This link also shows that measures that improve the parent's experience may indirectly increase the parent's overall well-being. However, we have not found any association between the severity of Nephrotic Syndrome with parental burden and psychological distress, which may be due to the short period of research study.

Limitations of the study:

As some parents are not fully opened up, so it may restrict the amount of information that can be obtained from the respondents.

Future research should be brief and involve a large group of children with SRNS and FRSD.

Conclusion:

The main conclusion drawn from this study is that because NS is a chronic childhood condition, as a caregiver, parents have significant psychological disturbances and burden in their daily live activities at moderate level. Parents of Children with Nephrotic Syndrome, is associated with severe parental burden and psychological stress. Number of children have a significant association ($p < 0.05$) with level of burden and psychological distress both.

Ethics Approval and Consent to Participate:

The research project received ethical approval from the Kins School Level Research committee, KIMS Hospital and other tertiary care Hospitals (KALINGA INSTITUTE OF NURSING SCIENCES) NO:KINS/R&D/03/22

Consent for Publication:

The final version of the manuscript for publication was reviewed and approved by all experts.

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Author Contributions:

All investigators (Ms. Piyali Sen [PI] and Dr. Niyati Das) conceptualized the study; Primary Investigator gathered the data; analysed the data and wrote the manuscript; Ms Piyali Sen & Mrs. Purnima Sahoo interpreted the results and authorized the final manuscript for submission.

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