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Research Paper

Economic Impact on Families With Childhood Idiopathic Nephrotic Syndrome: A Cross-sectional Observational Study

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ABSTRACT

Background and Aim: Childhood idiopathic nephrotic syndrome (INS) needs long-term treatment as well as frequent hospitalization. This study aimed to assess the economic impact on families with childhood INS.

Methods: This cross-sectional study was conducted on children aged 1–17 years with INS in the Department of Pediatric Nephrology from January 2021 to December 2021. Baseline demographic characteristics including age, gender, type of nephrotic syndrome, duration of disease and treatment, number of hospitalizations, treatment costs, educational status of parents, and socio-economic status using modified Kuppuswamy's socio-economic status scale 2021 were recorded. The economic impact of nephrotic syndrome on families was assessed during parental interviews. Data were analyzed using SPSS software, version 19.

Results: Among the 63 families, most were in the upper-lower economic class (55.6%), 91.8% had to disrupt work, 61.9% had to bear expenses from more than one source, 65.6% in which one family member needed to take on an additional job, 87.3% had to travel to another district, 76.2% needed to spend money on accommodation for the accompanying person, 41% of families had to face moderate financial hardship and 14.8% had to face great financial hardship, 28.15% had to take out a loan. There was no significant difference in the economic impact on families among various INS subtypes.

Conclusion: Most families disrupted work, spent money from more than one source, had family members take on additional jobs, faced moderate to great financial hardship, and needed to take out loans.

Keywords: Childhood idiopathic syndrome, Economic impact, Family

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Introduction

Childhood idiopathic nephrotic syndrome (INS) is a common chronic disease affecting children worldwide [1]. The estimated incidence of childhood INS is 7 to 16 per 100,000 children under 16 years, with a significantly higher rate in the South Asian region [2, 3]. Around 80% of children with INS respond to treatment with corticosteroids [4]. About 40–60% of steroid-sensitive NS (SSNS) follow a course of frequent relapse or steroid dependency requiring a prolonged course of steroids or other immunosuppressive drugs [5, 6]. About 10%-20% of children with NS developed steroid-resistant nephrotic syndrome (SRNS) with high-dose corticosteroids [7].

According to ISKDC, 3.3% of subjects ultimately develop steroid resistance after an initial remission (late steroid resistance) [4]. A significant percentage of SRNS patients have a pattern of glomerular injury, focal segmental glomerulosclerosis, associated with a high risk of developing chronic kidney disease in the long run [8]. Thus, the course of childhood nephrotic syndrome is usually prolonged with relapses requiring frequent visits and hospitalizations, and multiple immunosuppressive drugs [9].

Childhood INS causes significant economic stress on families in spite of having an excellent long-term outcome. Expenditure for disease is significantly higher in families with INS patients, varying between 30% and 60% of monthly income depending on disease severity, compared with 6.9% in normal healthy controls. In a certain percentage of cases, it is more than the total family income, forcing families to deplete savings or incur debt [10]. As childhood INS patients require frequent hospitalization, mean total hospital charges increased from 11,338 to 16,760, and aggregate hospital charges increased from 21 to 31 million dollars from 2000 to 2006 [9]. Infections are a common cause of hospitalization of INS and also lengthen the length of hospital stay and increase total hospital costs compared with those without infections [11]. There are limited studies on the economic burden and the economic impact on families. Therefore, the aim of this study was to assess the economic impact on families with childhood INS.

Materials and Methods

This cross-sectional study was conducted at the Department of Pediatric Nephrology, Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh, from January 2021 to December 2021. Sixty-three families with cases of childhood INS aged 1-17 years were included.

Baseline demographic characteristics including age, gender, type of nephrotic syndrome, duration of disease, duration of treatment, number of hospitalizations, treatment costs, educational status of the parents, and socioeconomic status by using the modified Kuppuswamy's socio-economic status scale 2021 were collected and recorded (Table 1) [12]. The scale included occupation of the head family (scored 1–10), education of the head of the family (scored 1–7), total monthly income of the family (scored 1–12). Rupees were converted to Bangladeshi taka (BDT) during classification of total monthly income. Then each family's score was summed and classified: Total scores of 26–29 were upper class, 16–25 upper-middle class, 11–15 lower-middle class, 5–10 upper-lower class, and less than 5 lower class. Expenditure for the illness was calculated during parental interviews. The economic impact of nephrotic syndrome on families of affected children was assessed by asking questions including the type of payment for the treatment, work disruption, need for an additional job by a family member, need to travel to another district, need for accommodation expenses, degree of financial hardship, and coping strategies. Childhood INS was further subdivided into nephrotic syndrome 1st attack (NS 1st attack), infrequent relapse nephrotic syndrome (IFRNS), frequent relapse nephrotic syndrome (FRNS), steroid-dependent nephrotic syndrome (SDNS), and SRNS.

Data were analyzed by SPSS software, version 19. The differences between groups were analyzed by analysis of variance (ANOVA), and $P<0.05$ was considered statistically significant.

Results

This study was conducted on 63 families with INS patients. The mean age of the patients was 7.4 years; 60% were male. NS first attack accounted for 9.5%, and the rest were relapse and resistant cases. The mean duration from disease onset to diagnosis and the mean duration of therapy were 3.1 and 2.2 years, respectively. More than fifty percent (55.6%) of families were upper-lower class according to the Kuppuswamy's socioeconomic status scale. The mean number of hospitalizations was 3.3, and the mean financial expense was 2036 USD (exchange rate BDT to USD, 85:1 in 2021) (Table 2).

Table 1. The modified Kuppuswamy's socioeconomic scale updated for the year 2021 [12]

Occupation of the Head of the Family		
No.	**Occupation of the Head**	**Score**
1	Legislators, senior officials, and managers	10
2	Professionals	9
3	Technicians and associate professionals	8
4	Clerks	7
5	Skilled workers and shop and market sales workers	6
6	Skilled agricultural and fishery workers	5
7	Craft and related trade workers	4
8	Plant and machine operators and assemblers	3
9	Elementary occupation	2
10	Unemployed	1

Education of the Head of the Family		
No.	**Education of the Head**	**Score**
1	Profession or honors	7
2	Graduate degree	6
3	Intermediate degree or diploma	5
4	High school certificate	4
5	Middle school certificate	3
6	Primary school certificate	2
7	Illiterate	1

Total Monthly Income of the Family					
No.	**Updated Monthly Family Income in Rupees (y)**				**Score**
	2012	**2018**	**2020**	**2021**	
1	30,375	126,360	199,862	123,322	12
2	15,188–30,374	63,182–126,359	99,931–199,861	61,663-123,321	10
3	11,362–15,187	47,266–63,181	74,755 –99,930	46129-61,662	6
4	7594–11,361	31,591–47,265	49,962–74,755	30,831-46,128	4
5	4556–7593	18,953–31,590	29,973– 49,961	18,497-30,830	3
6	1521–4555	6327–18,952	10,002–29,972	6,175-18,496	2
7	1520	6326	10,001	6174	1

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The Kuppuswamy Socioeconomic Status Scale Score (2021)		
No.	**Score**	**Socioeconomic Class**
1	26–29	Upper (I)
2	16–25	Upper-Middle (II)
3	11–15	Lower-middle (III)
4	5–10	Upper-lower (IV)
5	<5	Lower (V)

Table 2. Baseline characteristics of children with INS (n=63)

Characteristics	Category	Mean±SD/No. (%)
Age (y)		7.44±3.6
Sex	Male Female	38(60) 25(40)
Diagnosis	NS 1st attack IFRNS FRNS SDNS SRNS	6(9.5) 16(25.4) 19(30.2) 17(27) 5(7.9)
Time since diagnosis (y)		3.1±2.5
Duration of therapy (y)		2.29±1.9
Kuppuswamy's socioeconomic status	Upper class Upper-middle class Lower-middle class Upper-lower class Lower class	1(1.6) 3(4.8) 19(30.2) 35(55.6) 5(7.9)
Number of hospitalization		3.34±2.3
Financial expense (USD)		2036±1954

Abbreviations: NS: Nephrotic syndrome; IFRNS: Infrequent relapse nephrotic syndrome; FRNS: Frequent relapse nephrotic syndrome; SDNS: Steroid-dependent nephrotic syndrome; SRNS: Steroid-resistant nephrotic syndrome.

Table 3 shows that 36.5% of families bore the treatment cost from their own finances and 61.9% from more than one source; 91.8% of families had to disrupt work; one family member needed to take on an additional job in 65.6% of cases; 87.3% of cases had to travel from another district; 76.2% of cases needed to spend money on accommodation for the accompanying person during hospitalization; 41% of families had to face moderate financial hardship and 14.8% had to face great financial hardship; 28.15% of families had to take out a loan.

Table 4 shows the comparison of the economic impact on families in different subtypes of nephrotic syndrome, where 66.7% of NS 1st attack, 43.4% of IFRNS, 57.9% of FRNS, 82.4% SDNS, and 60% of SRNS families had to manage financial expenses from more than one source, but all values were statistically non-significant. The highest number of work disruptions was seen in IFRNS and SRNS patients, and the highest number (76.5%) of family members needed to take on additional jobs, observed in SDNS patients. The highest number (94.1%) of patients needed to travel to another district and also incur accommodation expenses in SDNS cases.

Discussion

Childhood INS is one of the common chronic illnesses in children, with a relapse–remission course. Like other chronic illnesses, it causes a substantial economic and psychological impact on families. This study included 63 families of INS children. Most of the children were frequent relapser. The majority of the families were in the upper-lower class according to Kuppuswamy's socioeconomic status scale. Almost all families experienced economic impact and faced moderate to great financial hardship.

Table 3. Economic impact of INS on families of affected children (n=63)

Characteristics	Category	No. (%)
Type of payment for treatment	Own finance	23(36.5)
	Out-of–pocket	1(1.6)
	Government expense	0(0)
	Partial	-
	Total	-
	More than one source	39(61.9)
Work disruption	Yes	56(91.8)
	No	5(8.2)
Need for additional job by a family member	Yes	40(65.6)
	No	21(34.4)
Need to travel to another district	Yes	55(87.3)
	No	8(12.7)
Accommodation expense	Yes	48(76.2)
	No	15(23.8)
Degree of financial hardship	No	3(4.9)
	Low	24(39.3)
	Moderate	25(41)
	High	9(14.8)
Coping strategies	None	18(31.6)
	Selling property	1(1.8)
	Taking out a loan	16(28.1)
	Skipping big purchases	1(1.8)
	Fundraising	8(14)
	More than one factor	13(22.8)

Table 4. Comparison of economic impact on families with children with various types of INS (n=63)

Characteristics	Category	No. (%)					P
		NS 1st Attack (n=6)	IFRNS (n=16)	FRNS (n=19)	SDNS (n=17)	SRNS (n=5)	
Type of payment for treatment	Own finance	2(33.3)	9(56.3)	7(36.8)	3(17.6)	2(40)	0.31
	Out-of–pocket	0(0)	0(0)	1(5.3)	0(0)	0(0)	
	Government expense	0(0)	0(0)	0(0)	0(0)	0(0)	
	More than one source	4(66.7)	7(43.8)	11(57.9)	14(82.4)	3(60)	
Work disruption	Yes	5(83.3)	16(100)	16(84.2)	16(94.1)	5(100)	0.42
	No	1(16.7)	0(0)	3(15.8)	1(5.9)	0(00)	
Need for additional job by a family member	Yes	3(50)	11(68.8)	13(68.4)	13(76.5)	2(40)	0.54
	No	3(50)	5(31.2)	6(31.6)	4(23.5)	3(60)	
Need to travel to another districts	Yes	5(83.3)	14(87.5)	16(84.2)	16(94.1)	4(80)	0.75
	No	1(16.7)	2(12.5)	3(15.8)	1(5.9)	1(20)	
Accommodation expense	Yes	4(66.7)	10(62.5)	15(78.9)	16(94.1)	3(60)	0.16
	No	2(33.3)	6(37.5)	4(21.1)	1(5.9)	2(40)	
Degree of financial hardship	No	1(16.7)	0(0)	1(5.3)	1(5.9)	0(0)	0.52
	Low	2(33.3)	7(43.8)	7(36.8)	5(29.4)	3(60)	
	Moderate	3(50)	8(50)	8(42.1)	8(47.1)	0(0)	
	High	0(0)	1(6.3)	3(15.8)	3(17.6)	2(40)	
Coping strategies	None	3(50)	5(35.7)	4(22.2)	3(21.4)	3(60)	0.31
	Selling property	0(0)	0(0)	1(5.6)	0(0)	0(0)	
	Taking out a loan	1(16.7)	3(21.4)	7(38.9)	3(21.4)	2(40)	
	Skipping big purchases	0(0)	0(0)	0(0)	1(7.1)	0(0)	
	Fundraising	1(16.7)	4(28.6)	3(16.7)	0(0)	0(0)	
	More than one factor	1(16.7)	2(14.3)	3(16.7)	7(50)	0(0)	

Abbreviations: NS: Nephrotic syndrome; IFRNS: Infrequent relapse nephrotic syndrome; FRNS: Frequent relapse nephrotic syndrome; SDNS: Steroid-dependent nephrotic syndrome; SRNS: Steroid-resistant nephrotic syndrome.

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Since our country is a lower-middle-income country (LMIC) and this study was conducted in a public university hospital where the government allowed some subsidy, patients from low-economic class families, like our cases, are more likely to seek treatment at this hospital. The mean duration of treatment, together with frequent hospitalizations due to complications, contributed to a mean treatment cost of USD 2,036 per patient, representing 63% of the annual per-capita income in Bangladesh (USD 3, 216) [13, 14]. Other studies have shown an association between treatment costs and a family's monthly income, with costs exceeding two-thirds of the monthly family income [10, 11].

In this study, most of the families were financially self-supporting [15] and had to spend money from more than one source in terms of medical expenses [10], travel cost [10], and accommodation cost. The majority of families had to travel long distances, especially from another district, due to a lack of local pediatric nephrological care and had to bear extra expenses for accommodation costs. Miedema et al. showed that caregivers of children with cancer had to incur extra expenses for travel, lodging, and meals away from home. This statement strongly supports our study [16].

Work disruption among family members was the most alarming family impact, because almost all families experienced work disruption. It increased over time, ultimately creating a substantial impact on family income, and this is supported by other studies [10]. Like other chronic diseases, e.g. chronic kidney disease (CKD) [17], work disruption and unemployment were major family impacts in this study.

Most of the families faced moderate to great financial hardship and had to adopt more than one coping strategy, such as selling property, taking out a loan, forgoing large purchases, and raising funds. For coping, most family members needed to take on extra jobs. These difficulties may be due to little or no government support, lack of medical insurance support, and the historically low per-capita income of our country. Like other developing countries, families in this study faced a similar type of economic impact [10].

Comparing the economic impact of different nephrotic syndrome groups on the family, no significant difference was observed between the groups. This study found that NS 1st attack incurred costs from multiple sources compared to other types. This may be due to the small number of patients in this group, which did not reflect the actual nature. However, other impacts were more significant in NS with relapse and the family of SRNS patients. This study was conducted during the COVID-19 pandemic, when most people around the world lost their jobs and their family income suddenly plummeted. Almost all families reported facing an economic crisis. Therefore, there was no significant difference between the groups.

Conclusion

This study concludes that most of the study cases came from the 55.6% upper-lower-class families. Most families had to spend money from more than one source, had to disrupt work, and needed additional jobs among family members; a significant number of cases faced moderate to severe financial hardship and had to take out loans.

Ethical Considerations

Compliance with ethical guidelines

There were no ethical considerations to be considered in this research.

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Authors' contributions

All authors contributed equally to the conception and design of the study, data collection and analysis, interpretation of the results, and drafting of the manuscript. Each author approved the final version of the manuscript for submission.

Conflict of interest

The authors declared no conflict of interest.

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