

Health-Related Quality of Life, Financial and Psychosocial Impact on Parents Having Children with Nephrotic Syndrome

Raihana Tahshin¹, Shafiun Nahin Shimul², Fahmida Akter³, Shitil Ibna Islam⁴

ABSTRACT

Background & objective: Childhood nephrotic syndrome (NS) follows a chronic course in most children. However, little has been studied about the burden of NS on the caregivers despite evidence that caregiver burden or impairment in their well-being may alter the outcome of chronic childhood illnesses. We aimed to study the multi-dimensional impact on the quality of life (QOL) of families of children with the NS to determine the significant predictors of caregiver burden and psychological distress among caregivers of children with NS in terms of Parents HRQOL (health related quality of life), Pediatrics Health-related quality of life Family Impact Module (PedsQLTM FIM) and Family Functioning Summary Score (FaF-SS).

Methods: This cross-sectional analytical study was conducted over a period 6 months from October 2019 to March 2020. Parents of children with diagnosed nephrotic syndrome (frequent relapsers, steroid dependent and steroid resistant), on treatment for at least one year, attending at the Outpatient and In-patient Units of Pediatric Nephrology, Dhaka Medical College & Hospital (DMCH) and Dhaka Shishu Hospital were taken as cases. A total of 40 cases and 64 controls were consecutively included in the study. The control group consisted of parents of healthy age-sex matched children attending at the immunization clinic to have their children immunized. Data were collected by face-to-face interview of the parents using questionnaire of Pediatric Quality of Life Inventory 4 (PedsQLTM), Family Impact Module (FIM). PedsQL FIM is a multi-item scale comprising of 36 questions grouped under eight domains related to physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities and family relationships.

Results: Parents HRQOL-SS was compromised with certain aspect of their demographic characteristics. Parents with debt and widows had compromised HRQOL than the parents without debt and both of the spouses are living together ($p = 0.174$ and $p=0.027$ respectively). Parents whose children responding well to treatment had a better HRQOL than those whose children were not responding to treatment ($p = 0.102$). As PedsQLFIM-SS was compared between the demographic characteristics of the parents, again widows and parents with debt had significantly worse PedsQLFIM-SS ($p = 0.007$ and $p = 0.038$ respectively). Parents with debt also had impact on family functioning as evidenced by commendably reduced FaF-SS (family functioning summary score) in parents with debt than those in parents without debt ($p = 0.029$). There was no difference between case and control groups in terms of Parents HRQOL-SS and FaF-SS (956.8 ± 195.9 vs. 970.9 ± 287.7 , $p = 0.786$ and 404.5 ± 87.8 vs. 391.4 ± 119.1 , $p = 0.549$ respectively) and each of the six individual domains, except emotional functioning which was significantly poor in the case group than that in the control group ($p = 0.005$) Physical functioning was also considerably worse in the case group than that in the control group, although the difference was not statistically significant ($p = 0.130$).

Conclusion: The study concluded that parents of the children with NS suffer from immense financial, physical and psychological burden. Burden is significantly greater for widows or when the families are in debt due to continued effort to cope with the stresses resulting from caregiving of their compromised children. Early diagnosis and treatment of parents' burden is of utmost need to help improve parents' health-related quality of life.

Key words: Health, quality of life, financial, psychosocial, impact on parents, children, nephrotic syndrome etc.

Author's information:

¹ **Dr. Raihana Tahshin**, Medical officer, Department of Epidemiology, National Institute of Preventive and Social Medicine (NIPSOM), Dhaka, Bangladesh.

² **Shafiun Nahin Shimul**, Associate professor, Institute of Health Economics, University of Dhaka, Dhaka, Bangladesh.

³ **Dr. Fahmida Akter**, Associate professor, Department of Epidemiology, National Institute of Preventive and Social Medicine (NIPSOM), Dhaka, Bangladesh.

⁴ **Shitil Ibna Islam**, Research Officer, Ibrahim Cardiac Hospital & Research Institute, Shahbag, Dhaka, Bangladesh.

Correspondence: Dr. Raihana Tahshin, Cell Phone: +8801716593391 Email: drraihanatahshin@yahoo.com

INTRODUCTION:

Nephrotic syndrome is the most common chronic disease affecting children worldwide with a prevalence of approximately 16 cases per 100,000 children and an incidence of 2 to 7 per 100,000 children.^{1,2} Although a substantial proportion of these children respond to treatment with corticosteroids,³ about half of them have a frequently relapsing or a steroid-dependent chronic course⁴ requiring prolonged follow-up at health-care facilities and constant alterations of drug dosage. Such a disease pattern and its complications, beyond doubt, would demand a rather high level of social, emotional and physical adjustment, not only from the affected child but also from the parents and family members⁵ child but also from the family members.

For parents, learning that their child has a chronic and potentially life-threatening disease is a very stressful and potentially traumatic event. Nephrotic syndrome causes significant lifestyle changes to the parents. Long term illness, even in most stable and supportive families, brings changes in family relationship. Illness produce disequilibrium in the family structure until adjustments can occur. Information on the quality of life of the families will allow the identification of families with special needs for support or psychological intervention. Paediatric health-related quality of life (HRQOL) is an important health outcome measure in clinical trials and health services research and evaluation.^{6,7} On the other hand, Pediatric Quality of Life Inventory 4 (Peds QLTM) Family Impact Module (FIM)⁸ is another tool to measure the parents' burden and adapted family functioning resulting from adjustment with their compromised child. This is a salient concern for the health care management given the essential role of the family in child adaptation to disease.^{6,9,10} We aimed to study all aspects of health-related quality of life (HRQOL) of families of children with chronic NS and to determine the predictors of poor QOL among Bangladeshi families having children with nephrotic syndrome.

METHODS:

This descriptive cross-sectional study was designed to assess the health-related quality of life of parents and families having children with NS. Parents of children with diagnosed nephrotic syndrome (frequent relapsers, steroid dependent and steroid resistant), on

treatment for at least one year, attending at the Outpatient and In-patient Unit of Pediatric Nephrology, Dhaka Medical College & Hospital (DMCH) and Dhaka Shishu Hospital were taken as cases, while parents of healthy age-sex matched children attending at the immunization clinic to have their children immunized were included as control. A total of 40 cases and 64 controls were consecutively included in the study. Details of all the cases, including their age, gender, socioeconomic status, type of NS, duration of treatment and complications during the course, were obtained from the records.

The PedsQL™ Measurement Module was designed to measure HRQOL in children. The PedsQL™ 4.0 Generic Core Scales were developed to be integrated with the PedsQL™ Disease-Specific Modules. The newly developed PedsQL™ Family impact Module was designed to measure the impact of pediatric chronic health conditions on parents (family). The PedsQL™ Family Impact Module, among others, collect information on parents' self-reported 36 questions grouped under eight domains related to physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities and family relationships. Recall time was one month and a five-point response scale was used from zero (never a problem) to four (almost always a problem). The scores of each item were then reversed and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0), with higher PedsQL scores indicating better QOL. The PedsQL FIM Total Scale Score was calculated as the sum of all 36 items divided by the number of items answered. The Parents HRQOL Summary Score (SS) (20 items) was derived from the sum of the items divided by the number of items answered in the physical, emotional, social and cognitive functioning scales. The Family Functioning Summary Score (eight items) was derived from the sum of the items divided by the number of items answered in the Daily Activities and Family Relationships Scales.

The data were processed and analyzed using SPSS (Statistical Package for Social Sciences) version 16.0. Descriptive statistics including means, medians, standard deviations, ranges for continuous data and frequencies with its corresponding percentages for categorical data were calculated. For inferential

statistics, mainly, one way ANOVA, t-Test and Chi-square (χ^2) test were used. Statistical significance was assessed at 5% level and p-value < 0.05 was considered significant.

RESULT:

The questionnaire intended to explore the general status of the respondents (Parents having child with nephrotic syndrome). These characteristics are displayed in Table I. Among respondents, majority (83.7%) was literate (17.3% primary level, 32.7% secondary and higher secondary level educated, 33.7% were graduate or higher level educated). Most (77.9%) of the respondents were trying to manage themselves with their own income but 22.1% became indebted to treat their children. For taking care of the children with nephrotic syndrome, 42.3% wives and 17.3% of the husbands sacrificed their job. In 10.6% cases both the spouses sacrificed job. Among the patients 85% were in improvement phase (Table II).

Table III shows the PedsQLFIM-SS compared between their demographic characteristics and financial outcome as a result of treatment of their children with NS. Widows had a significantly worse score than the women with husbands present ($p = 0.007$). Parents without debt had a better PedsQLFIM-SS than the parents with debt ($p = 0.038$). Family type and place of residence did not have any influence on PedsQLFIM-SS ($p = 0.825$ and $p = 0.831$ respectively). Children's response to treatment also did not have any impact on PedsQLFIM-SS ($p = 0.406$). Table IV shows the Parents HRQOL-SS compared between their demographic characteristics and financial outcome as a result of treatment of their children with NS. Widows had a worse HRQOL than the women living with their husbands had ($p = 0.174$). Parents without debt had a better HRQOL than the parents with debt ($p = 0.027$). Family type and place of residence did not have any influence on ParentsHRQOL ($p = 0.880$ and $p = 0.786$ respectively). Parents whose children were responding to treatment had a better HRQOL than those whose children were not responding to treatment ($p = 0.102$).

Table V shows that FaF-SS (family functioning summary score) was significantly greater in families of NS children with debt than their counterparts without debt ($p = 0.129$). No other characteristics had any impact on FF-SS. There was no difference between case and

control groups in terms of Parents HRQOL-SS and FF-SS (956.8 ± 195.9 vs. 970.9 ± 287.7 , $p = 0.786$ and 404.5 ± 87.8 vs. 391.4 ± 119.1 , $p = 0.549$ respectively) and each of the six individual domains, except emotional functioning which was significantly poor in the case group than that in the control group ($p = 0.005$). Physical functioning was also considerably worse in the case group than that in the control group, although the difference was not statistically significant ($p = 0.130$) (Table VI).

Table I. Distribution of responded by their demographic characteristics (n=104)

Demographic Characteristics	Frequency	Percentage
Age (years)		
≤ 30	64	61.5
30 – 40	38	36.5
>40	2	1.9
Education		
Illiterate	17	16.3
Primary	18	17.3
Class 8	21	20.2
SSC	7	6.7
HSC	6	5.8
Graduate or above	35	33.7
Wife occupation		
Home maker	87	83.7
Service holder	12	11.5
Day labor	5	4.8
Husband Occupation		
Service holder	44	43.6
Businessman	15	14.9
Day labor	22	21.8
Farmer	6	5.9
Others	14	13.9
Income (Taka)		
≤ 10000	19	18.3
10000 – 20000	33	31.7
20000 – 30000	14	13.5
30000 – 40000	8	7.7
40000 – 50000	7	6.7
>50000	23	22.1
Expenditure		
Without debt	81	77.9
With debt	23	22.1
Marital Status		
Married	98	94.2
Divorced	6	5.8
Place of residence		
Rural	32	30.8
Urban	72	69.2
Family type		
Nuclear	56	53.8
Joint	48	46.2
Job Sacrifice		
Husband	18	17.3
Wife	44	42.3
No job sacrifice	31	29.8
Both sacrifice	11	10.6

*Mean Age 29.1 ± 6.3 ; range (18-50) years

Table II. Treatment progress of child

Treatment progress of child	Frequency	Percentage
Not improved	6	15
Improving	34	85

Table III. Influence of demographic and financial characteristics on PedsQLFIM-SS

Characteristics	N	PedsQLFIM-SS	Test Statistics	*p-value
Marital Status				
Widow	3	672.9 ± 144.7	t = -2.836	0.007
Both spouses present	37	979.9 ± 182.0	df=38	
Place of residence				
Village	25	2069.9 ± 290.7	t = -0.223	0.825
City	15	2090.3 ± 274.5	df=37	
Family type				
Nuclear	22	2087.5 ± 296.4	t = 0.239	0.813
Joint	18	2065.6 ± 2685	df=37	
Debt				
Without debt	17	2188.9 ± 219.9	t = 2.151	0.038
With debt	23	2000.8 ± 297.3	df= 37	
Rx Progress				
Not improved	6	1988 ± 275.6	t = -0.841	0.406
Improved	33	2094.2 ± 283.3	df= 37	

*Data were analysed using **Unpaired t-Test** and were presented as **mean ± SD**.

Table IV. Influence of demographic characteristics and financial position on ParentsHRQOL-SS

Characteristics	N	PedsQLFIM-SS	Test Statistics	*p-value
Marital Status				
Widow	3	1864.4 ± 114.8	t = -1.386	0.174
Both spouses present	37	2095.8 ± 284.3	df=37	
Place of residence				
Village	25	690.6 ± 209.5	t = 0.153	0.880
City	15	950.7 ± 177.7	df=38	
Family type				
Nuclear	22	964.6 ± 197.3	t = 0.274	0.786
Joint	18	947.4 ± 199.4	df=38	
Debt				
Without debt	17	1035.4 ± 156.9	t = 2.296	0.027
With debt	23	898.8 ± 204.4	df=38	
Rx Progress				
Not improved	6	836.0 ± 240.4	t = -1.676	0.102
Improved	34	978.2 ± 182.9	df=38	

*Data were analysed using **Unpaired t-Test** and were presented as **mean ± SD**.

Table V. Influence of demographic characteristics family's financial position on FF-SS

Characteristics	N	FF-SS	Test Statistics	*p-value
Marital Status				
Widow	3	427.1 ± 98.1	t = 0.459	0.649
Both spouses present	37	402.6 ± 88.1	df=38	
Place of residence				
Village	25	394.4 ± 90.8	t = -0.936	0.355
City	15	421.3 ± 82.7	df=38	
Family type				
Nuclear	22	409.8 ± 87.4	t = 0.421	0.676
Joint	18	397.9 ± 90.4	df=38	
Debt				
Without debt	17	439.3 ± 82.4	t = 2.273	0.029
With debt	23	378.7 ± 84.2	df=38	
Rx Progress				
Not improved	6	400.0 ± 62.1	t = -0.133	0.895
Improved	34	405.2 ± 92.3	df=38	

*Data were analysed using **Unpaired t-Test** and were presented as **mean ± SD**

Table VI: Comparison parents' burden between case and control groups

Parents burden	Group		*p-value
	Case (n = 40)	Control (n = 64)	
Parents HRQOL-SS	956.8 ± 195.9	970.9 ± 287.7	0.786
FaF-SS	404.5 ± 87.8	391.4 ± 119.1	0.549
Physical functioning	387.1 ± 150.9	427.5 ± 90.5	0.130
Emotional functioning	241.3 ± 84.5	304.3 ± 123.1	0.005
Social functioning	272.5 ± 91.6	264.8 ± 91.2	0.678
Cognitive functioning	292.9 ± 77.9	311.9 ± 87.5	0.254
Family relationships	364.5 ± 114.9	379.4 ± 85.8	0.481
Daily activities	200.6 ± 62.1	215.2 ± 77.6	0.317

*Data were analysed using **Unpaired t-Test** and were presented as **mean ± SD**.

DISCUSSION:

After online search, the impact of the frequent relapsing and remitting course of NS on the family of the affected child has been rarely found in the literatures. Of the limited literatures found, most performed assessing the QOL and behavioral pattern of children with NS and how a stressful family environment has a detrimental effect on the children.¹¹⁻¹⁴ Not much information is found regarding the effect of the children's disease has on parents' health related quality of life (HRQOL). That purpose the present study was done to assess the impact of NS on parents' HRQOL and family function

(FaF). The present study evaluated the multi-dimensional impact on the life of parents of children with the NS.

Management of a child with NS demands immense input from medically unoriented family members, usually for a long period of time. As parents HRQOL-SS were compared between their different demographic characteristics, it is evident that ParentsHRQOL-SS was compromised with certain aspect of their demographic characteristics. Parents with debt had poor HRQOL than the parents without debt. Widows with NS children had compromised life, although NS children did not tell on families where both the spouses are living together. Parents whose children responding well to treatment had a better HRQOL than those whose children were not responding to treatment. As PedsQLFIM-SS was compared between the demographic characteristics of the parents, again widows and parents with debt had significantly worse PedsQLFIM-SS indicating that these two demographic factors negatively influence the life of the parents of children with NS. When emotional functioning and physical functioning domains of PedsQLFIM-SS of the case group parents were compared with those of control parents, the scores of these two domains were also found to be much reduced in the former group than those in the latter group. Parents with debt also had impact on family functioning as evidenced by much reduced FaF-SS in parents with debt than those in parents without debt.

The findings of the present study support the viewpoint that caregivers of children with NS, like other chronic childhood illness, carry significant burden of care and suffer from psychological distress as a result of their caregiving role.¹⁵⁻¹⁶ In a similar study from Canada, Esezobor et al¹⁷ reported that 1 in 3 and 1 in 6 caregivers of children with NS suffer psychological distress and significant caregiver burden respectively. Only few studies that looked at the impact of childhood NS on the parents burden consistently reported that caregivers of children with NS are negatively affected to a varying degree as a result of their children's chronic illness. For example, Mitra and Banerjee¹⁸ reported evidence of moderate

and severe depression in 48% of parents of children with NS using the Beck Depression inventory.

Similarly, Mishra et al⁵ and Dhooria et al¹⁵ observed that parents of children with NS in India reported lower quality of life than controls using the PedsQL Family Impact Module. Thus, the findings of the present study and consistent negative association of caregiver burden and quality of life with chronic illnesses (like NS) of their children in other studies support the viewpoint that caregivers of children of NS, similar to those of children with chronic kidney disease, require supports and interventions aimed at improving their caregiving experience. This is particularly important, for evidence indicates that the health of the caregiver have immense impacts on the outcome of chronic illnesses of their children.^{19,20}

Unlike our results, the family impact of children with the NS, which was assessed by Vance et al, based on 10 questions, showed that cases and controls were almost similar, with "limitations on travel" being the only problem much more frequently seen among cases. The authors explained that their essentially negative findings were because of using closely matched controls, taking into account most of the confounding variables.²¹ Similar findings were also reported by Soliday et al in families of children with kidney diseases who concluded that majority of the families with children suffering from chronic kidney diseases adapt to their children's illness within one year and become accustomed to managing their compromised children.²²

When Parents HRQOL-SS was compared between case and control groups in terms of FaF-SS and each of the six individual domains of family functioning, emotional functioning and physical functioning were observed to be much poor in the case group than those in the control group. Not much has been studied regarding predictors of poor QOL among caregivers of children with kidney diseases. While one study reported that depression was inversely proportional to the socioeconomic status²³ another study concluded that it was most affected by the recent health status of the caregivers.²⁴ Tsai and associates observed that greater happiness perception and

higher income were associated with higher scores in the domains of environmental quality, social relationships and psychological condition of the life of care givers of children on chronic peritoneal dialysis.²⁴ The onset of a chronic illness in a child imposes an unexpected additional stressor on the caregiving role of parents, it disturbs the balance between the usual demands of parenting, which is stressful in itself, and the intrinsic and extrinsic resources of the family. When the family's coping mechanisms are overwhelmed, a state of distress occurs.²⁵ Childhood NS requires many additional caregiving activities that include home testing and recording of urine for protein, administration of immunosuppressants, liaising with the medical team, and hospital visits during relapse, major illness, or scheduled clinic appointments. These additional demands on the family may be overwhelming, disruptive, and distressful.¹³

CONCLUSION:

Summarizing the overall findings of the study, it is evident that parents of the children with NS suffer from immense financial, physical and psychological burden. Burden is significantly greater for widows or when the families are indebted as a result of continued treatment of their ill child. Early diagnosis and treatment of parents' burden is of utmost need to help parents cope with the stresses resulting from the management of their compromised child and to improve their quality of life. Social and family support can improve the quality of life of parents having children with nephrotic syndrome. As similar studies are limited, there is a need of further study to create adequate evidence base.

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