Health Related Quality of Life of Parents Having Nephrotic Syndrome Children

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Abstract

Background: Nephrotic syndrome of children have deleterious effect on parents. But a very little attention had been paid to address the riddle. This study was conducted to assess health related quality of life (HRQoL) of the parents having children with nephrotic syndrome with clinical attributes of nephrotic syndrome and sociodemographic characteristics.

Methods: This cross-sectional study was conducted among 128 parents of nephrotic syndrome children selected consecutively following the purposive sampling method from three different health facilities of Dhaka city. The 36 items PedsQL Family Impact Questionnaire Module was used to measure parents' HRQoL. Data were analyzed using SPSS software.

Results: This study revealed that 76% of the respondents were mothers and 24% were fathers. Among all respondents, 63.3% were housewives, 87.5% were Muslim and belonged to nuclear family (68%). Mean age of respondents was 24.19±4.67 years and more than one-third of them passed SSC (35.9%). Most of them (40%) lived in semi-pucca houses. Source of fund for health care expenditure was 37.5% from monthly income and remaining 62.5% from self-management. More than half of the children (56.2%) suffered from complications of nephrotic syndrome. Mean of frequency of relapse was 6.55±7.02 times and mean duration of treatment 4.27±5.04 years. We have found 6.3% parents had poor, 53.1% had below average, 34.3% had average and 6.3% had good health related quality of life. Among the parents, fathers showed good health related quality of life ($p< 0.050$) than mothers. Parents who completed post graduate study, had good HRQoL than illiterate parents. There was significant relationship with monthly family income and HRQoL ($p<0.001$). The study showed that parents living in semi-pucca and kacha houses were unlikely to develop HRQoL. Presence of complications of nephrotic syndrome found significant ($p=.010$) with HRQoL of parents. There was statistically significant relationship ($p=0.02$) between age of nephrotic children and HRQoL of parents. In terms of funding sources, parents who used their monthly income had good HRQoL ($p<.001$) than those who used their savings.

Conclusion: Nephrotic syndrome can affect the quality of life of parents in multiple domains od functioning. Findings of this study can support to improve the health-related quality of life of parents having nephrotic syndrome children.

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Introduction

Nephrotic syndrome is a collection of symptoms due to kidney damage. This includes protein in the urine (usually>3.5g/24hrs), low blood albumin levels (<30g/L), oedema and generalized fluid retention, intravascular volume depletion with hypotension, or expansion.[1]Annual incidence rate of Nephrotic syndrome in children aged below 16 years is 2 to 7 new cases per 100000, with a prevalence rate of 16 cases per 100000 all over the world. Incidence peaks between 2-5 years old. Male are more affected than female the ratio is 2:1. The incidence rate of Nephrotic syndrome in children is 15 times higher than in adults.[2] Ninety percent childhood nephrotic syndrome is due to the primary idiopathic cause of which eighty percent has minimal change disease.[3] In developed countries, the incidence is reported to be 20 to 40 per million population while in the Indian subcontinent it is estimated at 90 to 100 per million population.[4] Nephrotic syndrome usually affects very young children, So the immediate burden of the disease is largely borne by the parents. This family effect is of particular importance in Asia, where the majority of families pay directly for all expenses during an illness and effective social support systems for chronic illnesses are yet to be developed. Previous studies indicate that parental stress can have a negative impact on the child's behavior and psychosocial adjustments.[5] Data regarding pediatric kidney diseases in Bangladesh are scanty due to absence of a national registry. A study by Dhaka Shishu Hospital in Bangladesh reveals that commonest (68%) renal disease in pediatric population is nephrotic syndrome and is characterized by a relapsing and remitting disease course treated with steroids at disease onset and at each relapse.[6] This disease pattern requires the child and family members to make a relatively high level of adjustment in the social, emotional and physical aspect. Furthermore, multiple courses of corticosteroids have potential side effects such as stunted growth, obesity, high blood pressure and osteoporosis. However, the frequency of relapses reduces with increasing age of the child in which 58% to 90% no longer have relapse after the age of 18 years.[3] Health-related quality of life (HRQoL) characterizes a person's perception of how health influences an individual's life quality and overall well-being.[7]HRQoL of parents of children with nephrotic syndrome is not well established since only a few studies have comprised in this regard. Little data are available on HRQoL of the parents of nephrotic syndrome children as compared to other chronic disorders.[8] Previous studies have uniformly found elevated levels of parenting stress among parents of children with disabilities.[9] HRQoL of parents of children with nephrotic syndrome is not well established in Bangladesh. On the basis of the scenario, this study was designed to unveil the HRQoL of parents raising children with nephrotic syndrome in the context of Bangladesh.

Objective

To find out health-related quality of life of parents having nephrotic syndrome children.

Methods

A cross sectional study was carried out among parents of children with diagnosed nephrotic syndrome of Bangabandhu Sheikh Mujib Medical University (BSMMU), Dhaka Shishu Hospital and National Institute of Kidney Diseases & Urology (NIKDU) hospital.The hospitals were selected purposively. This study was conducted during the period of July 2019 to June 2020. It included total duration of protocol development to final report submission. Pretest was done at January 2020. Data was collected from February to April 2020. The sample size was calculated by using the formula: $n=z^2pq/ d^2$. Here, n=desired sample size, z=standard normal deviate usually set at1.96 which correspondents to 95% confidence level, p=prevalence (0.50%) and d= Degree of accuracy usually set at 0.05%.

Considering those parameters, the calculated sample size was 384. Due to resource constrain and COVID-19 pandemic, calculated participants could not be interviewed. Finally, 128 participants were enrolled by purposive sampling technique within the study period.An interview schedule with semi-structured pre-tested questionnaire and checklist were used for data collection. For this study, Face to face interview and review of medical records were done. Pediatric Quality of Life (PedsQL) Family Impact Module (FIM) was used. The Bangla translated version of the questionnaire was obtained with permission from the MAPI Research Trust, France, after signing the User Agreement Form. It was pre-tested in Kidney Foundation Hospital and Research Institute, Mirpur, Dhaka. Necessary modifications were done and the questionnaire was finalized before final data collection. The data were thoroughly edited through checking and rechecking for quality control. Coding, editing, cleaning and categorization were done as required.The data were coded, entered and analyzed by using SPSS (Statistical Package for Social Science) version 23 statistical software. Chi square test were carried out to assess relationships between variables and total score of quality of life. To conduct the study, formal ethical approval was obtained from the review committee of National Institute of Preventive and Social Medicine (NIPSOM), Dhaka. Informed written consent was obtained from all the participants prior to the interview.

Results

Table I of Section -A, describes the sociodemographic characteristics of parents having nephrotic children. Among the 128parents, 97 were mother,28 parents have higher education,51 parents hail from semipucca house.

Table I: Distribution of sociodemographic characteristics (n=128)

Characteristics	Frequency(f)	Percentage (%)	Remarks
Age of the parents (in years)			
18-29	35	27.3	Mean±SD: 24.19±4.67; Range: 18-52
30-39	63	49	
40-52	30	23.7	
Sex of the parents			
Female	97	76.0	
Male	31	24.0	
Religion			
Islam	112	87.5	
Hinduism	12	9.4	
Christianity	4	3.1	
Marital status			
Married	119	93.0	
Divorced	3	2.4	
Widow/Widower	6	4.7	
Educational qualification			
Illiterate	12	9.4	
Primary	42	32.8	
SSC	46	35.9	
HSC and above	28	21.8	
Occupational status			
Housewife	81	63.3	
Service holder	19	14.8	
Business	16	12.5	
Day labour	7	6.3	
Student	4	3.1	
Type of family			
Nuclear family	87	68.0	
Joint family	41	32.0	
Age of the affected child (in completed years)			
1-5 years	86	65.4	Mean±SD: 5.09±3.082
6-10 years	34	28.2	
11-15 years	7	5.6	
>16 years	1	0.8	
Housing condition			
Pucca house	41	32.0	
Semi pucca house	51	40.0	
Kacha house	36	28.0	

Table II: Distribution of nephrotic syndrome characteristics(n=128)

Characteristics	Frequency(f)	Percentage (%)
Complications of nephrotic syndrome		
Yes	72	56.3
No	56	43.7
Frequency of relapses; Mean 6.55±7.02		
<6	89	69.6
6-10	18	14.0
11-15	9	7.0
>15	12	9.4
Duration of treatment (in completed year); Mean±SD: 4.27±5.04		
1-5	107	83.7
5-8	17	13.4
9-12	3	2.3
13-18	1	0.6
Source of fund for expensed money		
Monthly income	48	37.5
Self-management (borrowing, donation/help, selling of property and saved money)	80	62.5
Type of complication during illness (n=72)		
Hematological	11	8.6
Steroid induced	26	19.7
Systemic infection	35	27.9

Table II of Section -B, describes the clinical attributes of nephrotic syndrome. Among the 128 children, 72 developed different types of complications related to nephrotic syndrome.

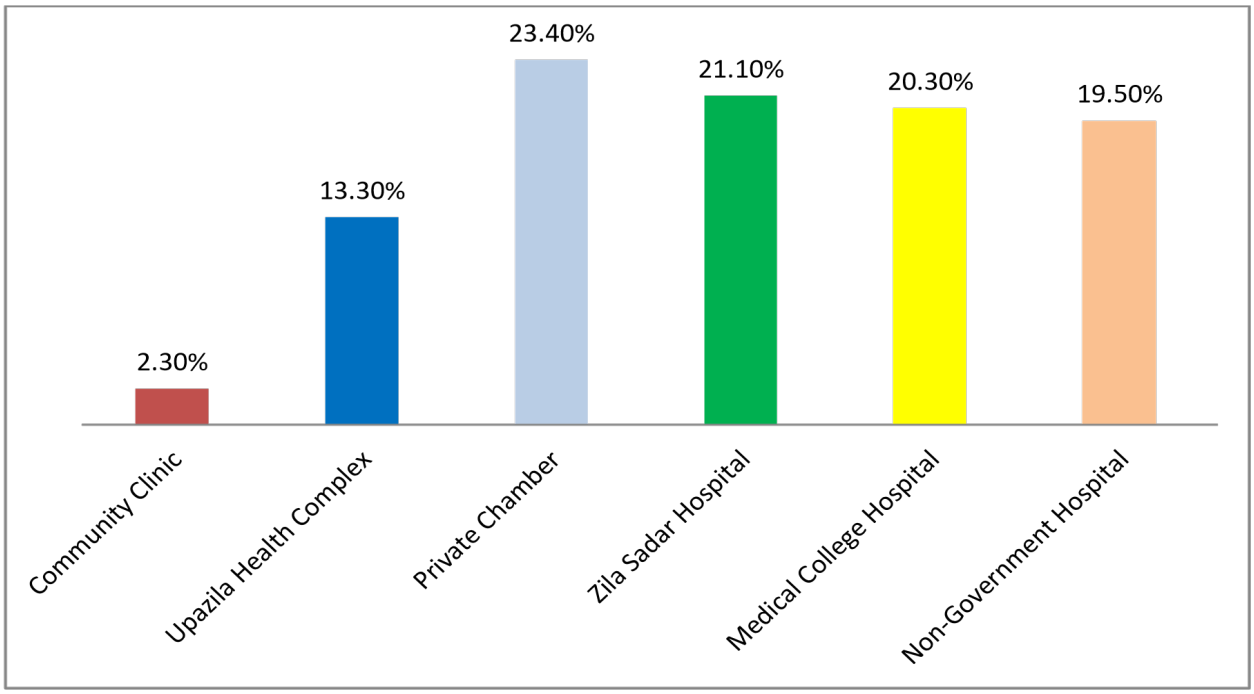

Figure 1. Distribution of the places of first diagnosis

From figure-1, we got some idea about the places of patients' first diagnosis. Private chambers of physicians diagnosed the highest number of patients [30 (23.4%)] in this study.

Table III: Distribution of medications for nephrotic syndrome n=128

Medications	Response	F (%)
Steroid	Yes	128 (100.0)
	No	0 (0.0)
Need for other medicines along with Steroid	Yes	38 (29.7)
	No	90 (70.3)
Other medications that are needed along with Steroid	Antihypertensives	6 (15.8)
	Anti-asthmatics	6 (15.8)
	Immunosuppressants	25 (65.8)
	Immunomodulators	1(2.6)

Table III demonstrates that all the children were steroid responsive and among them only 38 (29.7%) needed other medication along with Steroid. Of those 38, antihypertensive drugs were needed by 6(15.8%) children, anti-asthmatic drugs were taken by 6(15.8%), immunomodulator drugs were needed by 1(2.6%) child and most of the children 25(65.8%) were given immunosuppressant drugs.

Table IV: Level of Health-related quality of life (HRQoL) of parents having nephrotic syndrome children n=128

Level of HRQoL	F (%)	Mean±SD
Good (100-75)	8(6.3)	48.14±15.87, Minimum 11, Maximum 92.71
Average (50-75)	44(34.3)	
Below average (25-50)	68(53.1)	
Poor (25-0)	8(6.3)	

Table IV of Section C, describes8(6.3%) parents had good health related quality of life, 44(34.3%) parents had average health related quality of life, 68(53.1%) parents had below average health related quality of life and 8(6.3%) parents had poor health related quality of life.

Table V: Association between socio demographic traits and Level of Health related quality of life (HRQoL) n=128

Traits	Level of HRQoL				X^2	P value
	Good	Average	Below average	Poor		
	F (%)	F (%)	F (%)	F (%)		
Sex of the parents						
Mother	4(4.1)	30(30.9)	55(56.7)	8(8.2)	7.803	0.050*
Father	4(12.9)	14(45.2)	13(41.9)	0(0.0)		
Educational qualification of parents						
Illiterate	0(0.0)	0(0.0)	9(75.0)	3(25.0)	43.899	<0.001*
Primary	1(2.4)	11(26.2)	30(71.4)	0(0.0)		
SSC	1(2.2)	20(43.5)	20(43.5)	5(10.9)		
HSC	2(14.3)	7(50.0)	5(35.7)	0(0.0)		
Graduate	4(30.3)	6(51.5)	4(18.2)	0(0.0)		
Monthly income (BDT)						
≥5000	0(0.0)	2(6.3)	27(84.4)	3(9.4)	56.957	<0.001*
10000-30000	4(4.9)	35(42.7)	41(50.0)	2(2.4)		
31000-50000	2(18.2)	7(63.6)	0(0.0)	2(2.4)		
51000-70000	2(66.7)	0(0.0)	0(0.0)	1(33.3)		
Housing condition						
Pucca	6(14.6)	22(53.7)	9(22.0)	4(9.8)	29.345	<0.001*
Semi pucca	2(3.9)	16(31.4)	32(62.7)	1(2.0)		
Kacha	0(0.0)	6(16.7)	27(75.0)	3(8.3)		
Complication of illness						
Yes	3(4.2)	17(23.6)	46(63.9)	6(8.3)	11.422	0.010*
No	5(8.9)	27(48.2)	22(39.3)	2(3.6)		
Source of fund for health care expenditure						
Saved money	1(10.0)	1(10.0)	8(80.0)	0(0.0)	39.707	<0.001*
Monthly income	6(12.5)	27(56.3)	13(27.1)	2(4.2)		
Borrow	0(0.0)	13(33.3)	25(64.1)	1(2.6)		
Donation/Help	0(0.0)	2(10.5)	13(68.4)	4(21.1)		
Selling of property	1(8.3)	1(8.3)	9(75.0)	1(8.3)		
Family Type						
Nuclear family	4(4.6)	28(32.2)	50(75.5)	5(5.7)	2.641	0.450
Joint Family	4(9.8)	16(39.0)	18(43.9)	3(7.3)		
Age of child (in completed years)						
<4	3(6.0)	15(30.0)	27(54.0)	5(10.0)	27.932	0.02*
4-6	2(4.5)	21(47.7)	20(45.5)	1(2.3)		
7-9	3(12.5)	4(16.7)	17(70.8)	0(0.0)		
10-12	0(0.0)	2(40.0)	3(60.0)	0(0.0)		
13-15	0(0.0)	1(25.0)	1(25.0)	2(50.0)		
>15	0(0.0)	1(100.0)	0(0.0)	0(0.0)		

*Statistically significant

Table V shows the Association between socio demographic traits and Level of Health related quality of life (HRQoL).

Discussion

Parents of nephrotic syndrome children experienced a tough life which was exhausting, time consuming and continuous, requiring constant follow up during the day and night.The study revealed from the gender perspective, majority (76%) were female respondents and 24% respondents were male. This variation of findings may be due to fathers had to continue their job for financial management and mothers remain with the child almost 24hours for taking proper care of the child. There were significant differences between respondent sex in relation to the HRQoL. Respondent's sex had a significant effect on HRQoL (p=0.05). HRQoL declined for female respondent than male. The average score of HRQoL was more for male respondent. When exploring other variables affection HRQoL of parents, the difference between mothers' and fathers' level of involvement in taking care and parent's gender needs necessary adjustment.[10] The results of studies on parental adjustment in relation to parents' gender are inconsistent. Some of them have shown the parenting stress is higher in mothers than in fathers[11], while other researchers have detected no such differences[12] or even found that fathers experienced more stress.[13]Mothers report poorer physical and mental health, as well as other aspects of quality of life.[14]

The present study did not show any statistical significance between age of parents and their HRQoL. The mean±SD age of the parents was 24.19±4.67 years while the range of age was 18-52years.A study conducted in Malaysia revealed that the mean age of parents was 40.86 years (SD 7.24) range 24 to 58 years.[3]This variation of findings may be due to social context of early marriage in our country.In this study, that parents' educational qualification had a highly significant effect on HRQoL ($p<0.001$). Respondents who completed postgraduate degree, had a better health related quality of life than illiterate respondents. Here, the graduate parents had average (51.5%) and illiterate parents had below average (25.0%) health related quality of life. Good education and adequate communication to the family is important especially during hospital admission on initial diagnosis. This helps them to recognize the problem that may arise in future and getting treatment from doctor at outpatient clinic.[3] Increased parental knowledge via education can reduce the number of relapses. Parental knowledge on nephrotic syndrome was associated with parental education level and number of disease recurrence.[15] By the type of family, most(68%) of the parents were from nuclear family and 32% were from joint family. A study conducted in Kolkata revealed that majority (76.1%) were from nuclear family.[5] This finding may be explained by the realities of urbanization, lifestyle change and imitation of western culture. Type of family had no statistical significance on any domain of health-related quality of life in this study. Intensity of the initial steroid therapy and the duration of illness were not different between two groups. One study concluded that children from nuclear family relapsed 3times more than children from joint families.[16]The P- value showed that respondent house condition has highly significant effect on each and every domain of HRQoL ($p<0.001$). The socio-economic condition of Bangladesh has improved during past decades and majority people lives in semi-pucca and pucca houses in urban area. The HRQoL increased with good housing condition (pucca or semi pucca house), which suggested a positive relationship between respondent income and their quality of life. The study revealed that parent's source of fund for health care expenses had highly significant effect on HRQoL ($p<0.001$). The substantial amount of caregiving required by nephrotic children may increase parents' vulnerability to emotional, physical and psychological consequences, which are typically high in resource limited countries.[17] This vulnerability is due to the shortage of health care professionals, and in

some instances institutions, making it necessary for the parents to provide formal and informal care for nephrotic kids at home and in the hospitals.[18] Previous studies have also reported that parents of chronically ill children face greater financial burdens as they need to pay for the health care and therapy services for their children.[19] Parents have to place the special needs of the children above their own needs.[20] Thus, parents' psychological quality of life may be indirectly lowered. Parents may have guilt and pessimism. This will severely negatively affect their psychological health.In Nigeria, as in other low-income countries, the unavailability of basic resources and the limited health care infrastructure and personnel often delays treatment and increase the burden for the parents.[21]Our study showed mean HRQoL of the parents according to their children's gender had no significance differences. By age of children, the study revealed that there was significant effect of nephrotic children's age on HRQoL of parents. The more the age of children the less the HRQoL of parents. Age affects intellectual, social and emotional developments, thus affect the children's perception of their quality of life and eventually thus further affect parents' health related quality of life.[22] The study found negative correlation between child's complications status and health related quality of life of parents. Among the complications in our study, 27.9% children suffered from infections of various body system e.g., cellulitis, peritonitis, gastritis, meningitis, pneumonia, urinary tract infection etc.; 19.7% children suffered from Steroid induced complications e.g. hypertension, cataract, diabetes, obesity etc.; 8.6% children suffered from hematological complication e.g. septicemia, anemia. Child's disease related complication had highly significant effect on HRQoL (p= 0.010) of parents. Majority children were first diagnosed at tertiary care facilities because in primary care facilities there are little access of relevant investigations. Treatment costs in the government hospitals are less than specialist chamber. Pediatric nephrologist, diagnostic and other facilities are available mainly in government and semi-government hospitals. (Fig-1) This study found majority (53.1%) of the parents had below average health related quality of life, 34.3% parents had average, 6.3% had poor and 6.3% had good health related quality of life (Table IV). Enhancing the comprehensive knowledge about these issues should be used to improve low-cost but highly effective programs that will meaningfully attenuate the burden.

Conclusion

Nephrotic syndrome is a common disease in the Asian subcontinent. It has an excellent long-term outcomefor the majority of patients. But the prolonged course causevarious complications within the condition and its treatment. Though, nephrotic syndrome is a relatively benign and potentially curable chronic disorder in children, it can deteriorate the quality of life of parents in multiple domains of functioning. Physicians should not be complacent with the therapeutic remission of the nephrotic syndrome, until the parental worries are duly addressed with adequate social support system. Apart from competent medical management, these domains also need to be investigated and support systems designed in order to provide true holistic care. Special measures like counseling of the parents as well as all family members should be organized to boost up emotional wellbeing. Efforts to make all pediatricians aware of the disease; its treatment, monitoring and complications; and to provide clear guideline for referral.

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