

Research Article

Assessment of Knowledge and Healthcare Related Practices of Caregivers Regarding Home Management of Children with Nephrotic Syndrome

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Abstract

Introduction: Nephrotic Syndrome (NS) is the commonest chronic glomerular disorder characterized by heavy proteinuria, hypoproteinaemia, oedema and hyperlipidaemia. Parental motivation and involvement are essential for home management of a child with NS. This study was conducted to assess caregivers' knowledge and healthcare related practices regarding home management of children with NS. **Methods:** A descriptive cross-sectional study was conducted among caregivers (n=94) attending the Paediatric Nephrology Clinic (PNC) at the Teaching Hospital Karapitiya, Sri Lanka. Data were collected through an interviewer-administered questionnaire. Data were analyzed using SPSS version 20. **Results:** The majority of the respondents (71.3%) were mothers. The majority of children with NS in the study sample were boys (70.2%), and their mean age was 7.6±3 years. About 40.4% of children had onset of disease at the age of 2-3 years. The majority of participants (53.2%) had scored more than 75 marks for knowledge. The practice score of the majority (66.0%) was between 50-100. The mean knowledge score was significantly higher in the participants who have managed their child with NS for 6-8 years (p=0.006) and for 9-11 years (p=0.019), compared to the participants who have managed their child with NS for 3-5 years. The mean knowledge score was significantly higher in the participants with the family history with NS in compared to the participants without family history of NS (p=0.001). A statistically significant association was found between mean practice score and the number of living children in the family (p=0.009). Mean practice score of the participants who had more than four living children was significantly higher than the participants who had two living children in their family (p=0.002). However, a significant negative correlation was observed between knowledge on NS and healthcare related practices of the participants (r= -0.240, n=94, p=0.020, 2-tailed). **Conclusions:** The overall knowledge and practices of parents/caregivers regarding home management of children with NS attending to the PNC, Teaching Hospital Karapitiya, Sri Lanka, was adequate and satisfactory.

Keywords: Home management, Paediatric, Nephrotic Syndrome, Knowledge, Practice

Introduction

Childhood survival helps the child to become a healthy adult in the future. Therefore, it is the responsibility of family members to improve children's health by strengthening the homecare for children [1]. In Sri Lanka, common renal diseases include; urinary tract infections, nephritis, nephrotic syndrome (NS), and calculus disease. All of these disease conditions are usually

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reversible but could be recurrent [2]. Among them, NS is the commonest glomerular disorder observed in childhood [3]. It is a chronic disorder characterized by heavy proteinuria, oedema hypoproteinaemia, and hyperlipidaemia. Before antibiotics were introduced, children with NS frequently died due to infections resulting from immunosuppression, a characteristic feature of the disease and poor nutrition [3].

In 2018, the World Health Organization notified that chronic kidney diseases of unknown etiology as a new threat in Sri Lanka [4]. According to the Annual Health Bulletin of Sri Lanka 2015, diseases of the urinary system are the eighth leading cause of hospital deaths in Sri Lanka and the tenth in the Galle District [5].

Proper home management of the children with NS by caregivers is essential in controlling the disease condition and preventing further complications [3]. Home management of children with NS is the management of children with NS at home concerning their diet, medication, investigation, immunization, follow up, and prevention of complications. Though the knowledge and practices about NS and its treatment have been assessed, there is no published data regarding caregivers' knowledge and practices related to home management of children with NS in Sri Lanka. Therefore, this study was aimed to assess caregivers' knowledge and practices related to home management of children with NS, attending the Paediatric Nephrology Clinic (PNC) of the Teaching Hospital Karapitiya, Sri Lanka.

Methods

Study design

A descriptive cross-sectional study was conducted at the PNC, Teaching Hospital Karapitiya, Sri Lanka, from August 2018 to September 2018.

Study population

The study was conducted among parents or other

caregivers of children with NS under 12 years attending the PNC of the Teaching Hospital Karapitiya, Sri Lanka. Calculation of the sample size ($n=95$) was done using the formula, $n=[p(1-p)Z^2]/d^2$ (n —sample size, p —expected proportion of subjects with the characteristics, d —margin of error, Z —standard normal deviate for the chosen confidence level) [6]. Since the chosen confidence level was 95%, Z was 1.96. The precision (d) was taken as 0.1, and p was 0.46 [7]. Any primary caregivers of the children with NS were included in the study and if the caregiver was not a parent of the child, he/she was referred to as “others”.

Parents or other caregivers of the children with NS but who do not have any other underlying diseases were included in the study. Caregivers of children who were with congenital anomalies, chronic illnesses, mental retardation, or other disabilities were excluded.

Study instruments

Data collection was carried out using a pre-tested interviewer-administered questionnaire developed based on an extensive review of related literature [7-10]. It included five main parts.

Part I included demographic data of the caregiver and the child. Part II was designed to assess the knowledge of parents/caregivers regarding NS. This part had questions about the nature of the disease, its' causes and clinical features, drug treatments and their side effects, available investigations and their side effects, diet, infections and protection from infections, immunization, urine examination at home, related activities and follow up. Part III consisted of questions to assess practices of caregivers regarding home management of children with NS. This section included questions regarding practices of the caregivers in situations when the child responds to therapy, receive corticosteroids and has oedema or respiratory infections. In addition, the practices regarding the child's

nutritional status and emotional support were assessed. Part IV was used to identify effective sources of information. Under this part, source of information, understandable source of information and satisfaction about the information received were assessed through different questions. Part V was used to obtain data regarding barriers to home management of a child with NS. The questionnaire was developed in English and was translated into the Sinhala language.

The questionnaire was pre-tested with ten volunteer parents of the same clinic. The length of the questionnaire, language comprehension, ambiguity of words, misinterpretations, sensitivity of questions, inability to answer and the practical issues were assessed during the pre-test interviews and modified accordingly.

Data collection

Data were collected by using an interviewer-administered questionnaire. Permission for data collection was obtained from the Director, Teaching Hospital Karapitiya, and the Consultant Pediatrician of the PNC, Teaching Hospital Karapitiya. Data were collected in a separated place of the clinic to minimize any external disturbances.

Statistical analysis

Knowledge scores (according to a marking scheme) and practice scores (according to a Likert scale) of the parents/caregivers regarding the home management of children with NS were calculated. Both knowledge and practice scores were categorized based on the questions asked. Knowledge scores were categorized as inadequate (below or equal to 50), moderate (51-75), and adequate (above 75), based on an in-house method. To assess the overall practice of the participants, scores were given according to a Likert scale (2, 1, and 0). A scoring system of the positive items was used: 0 for never, 1 for sometimes, and 2 for always, and those of the negative items were

reverse coded. The scores gained by each participant were converted to 100 for analysis and categorized as satisfactory (50-100) and unsatisfactory (00-49).

Data were coded, categorized, tabulated and analyzed using Statistical Package for Social Sciences (SPSS) version 20.0 and Microsoft Excel. Descriptive statistics were used to describe the characteristics of the population. To summarize data, frequency and percentages were used with mean (\pm SD), minimum and maximum values. Socio-demographic factors including age, educational qualification, occupation, ethnicity, duration of the management of the child and family history were compared with total knowledge score by performing a one-way ANOVA test and independent t-test. The mean practice scores of the different groups (based on the socio-demographic factors) were compared using an independent t-test and one-way ANOVA test. The association between the knowledge and practice scores was assessed using the Pearson correlation, and p values less than 0.05 was considered significant.

Ethical consideration

Ethical approval was obtained from the Ethics Review Committee, Faculty of Allied Health Sciences, University of Ruhuna, Sri Lanka (Ref: 14.02.2018:034). Before enrolling them into the study, informed consent was obtained in writing from all eligible participants (mother, father or other primary caregiver who has accompanied the child to the clinic) of the PNC, after explaining the aim of the study, its benefits and risks, duration of the study, and the data collection tools.

Results

The study included 95 caregivers of children with NS. One respondent had not answered the complete questionnaire. Therefore, the data analysis was done with 94 participants. The majority of the respondents, 67 (71.3%), were

mothers, and 19 (20.2%) were fathers. The majority of the participants (41.5%) were in the age group between 31-40 years, while a minority (10.6%) was in the age group >50 years. The highest educational qualification of the majority (67.0%) was the General Certificate of Education (G.C.E.) Ordinary Level. Only 24.5% had education up to G.C.E. Advanced Level and 4.3% of participants had never been to school. Among

the participants, 59.6% were unemployed. Most of the participants (94.7%) were Sinhalese. Most of them had two (38.3%) or three (38.3%) living children in their families, and 2.1% had more than four children. The monthly income of 37.2% of the respondents was between LKR 10,001-20,000, and (7.4%) had less than LKR 10,000 of monthly income. There were 20 (21.3%) urban residents, and the rest were living in rural areas (Table 1).

Table 1: Demographic characteristics of the caregivers of children with Nephrotic Syndrome (n=94)

	Characteristics	Frequency (n)	Percentage (%)
Relationship to the child	Father	19	20.2
	Mother	67	71.3
	Other caregivers	08	8.5
Age (in years)	21-30	18	19.1
	31-40	39	41.5
	41-50	27	28.7
	>50	10	10.6
Educational level	Never been to school	4	4.3
	Up to G.C.E. Ordinary level	63	67.0
	Up to G.C.E. Advanced level	23	24.5
	Graduates	4	4.3
Occupation	Non-professional	32	34.0
	Professional	6	6.4
	Unemployed	56	59.6
Ethnicity	Sinhala	89	94.7
	Tamil	2	2.1
	Muslim	3	3.2
Monthly income (LKR)	≤10 000	7	7.4
	10 001-20 000	35	37.2
	20 001- 30 000	27	28.7
	30 001- 40 000	9	9.6
	> 40 000	16	17.0
Number of living children	1	16	17.0
	2	36	38.3
	3	36	38.3
	4	4	4.3
	Other	2	2.1
Place of residence	Urban	20	21.3
	Rural	74	78.7

GCE- General Certificate of Education, LKR- Sri Lankan Rupee

In this study population, the majority of children with NS were males (70.2%), and the mean age of the children was 7.6 ± 3 years. The majority of children (40.4%) have had the onset of disease at the age between 2-3 years. The mean duration of management of NS was 3.5 ± 2.5 years, and 46.8% had no previous history of the diseases. Only 65 children (69.1%) had been immunized up to date, according to the Expanded Programme on Immunization in Sri Lanka. Among the children, 24 (25.5%) had not been vaccinated for Oral Polio Vaccine and the fifth dose of the Diphtheria and Tetanus Vaccine. Only five children (5.3%) had a family history of NS. Table 2 indicates the demographic characteristics of the children with NS.

Table 2: Demographic characteristics of children with Nephrotic Syndrome (n=94)

Characteristics	Frequency (n)	Percentage (%)
Gender		
Male	66	70.2
Female	28	29.8
Child's age group (years)		
1-3	7	7.4
4-6	33	35.1
7-9	23	24.5
10-12	31	33.0
Child's age at onset of disease (years)		
0-1	10	10.6
2-3	38	40.4
4-5	18	19.1
= or >6	28	29.8
Duration of management (in years)		
0-2	13	13.8
3-5	63	67.0
6-8	11	11.7
9-11	7	7.4
Childs' previous history of diseases		
None	44	46.8
Urinary Tract Infections	20	21.3
Respiratory Tract Infections	10	10.6
Flue	3	3.2
Other diseases	14	14.9
Urinary Tract Infections and other diseases	1	1.1
Respiratory Tract Infections, and other diseases	2	2.1
Immunization status (up to date)		
Incomplete	29	30.9
Complete	65	69.1
Family history of NS		
No	89	94.7
Yes	5	5.3

NS- nephrotic syndrome

The overall knowledge level of participants regarding home management of children with NS was adequate (Table 3). More than half of the participants had scored more than 76 (considered as an adequate level of knowledge), and 43.6% had scored 51-75 (moderate level of knowledge), and 3.2% had scored less than or equal to 50 (inadequate level of knowledge). The highest mean knowledge score of the caregivers' (97.87±14.51) was obtained for questions regarding drugs used for children with NS, and the lowest (37.59±29.02) was observed for the questions regarding the causes of disease.

Table 4 indicates the practice scores of the participants regarding the home management of children with NS. This study revealed that most participants, 62 (66.0%), had scored between the range of 50-100 (satisfactory) and 32 (34.0%) had scored between the 00-49 range (unsatisfactory). When considering the scores regarding participants' practices towards the home management of children with NS, the lowest mean scores (12.34±17.6) was observed for the emotional support, when the child is receiving corticosteroid therapy (34.04±9.7) and when the

child has oedema (37.13±9.3). The highest mean score obtained for practice (78.46±22.2) was reported regarding the management of the child when having respiratory infections.

There were statistically significant associations between the mean scores obtained for knowledge and duration of management. The results indicated that the mean knowledge score was significantly higher in the participants who managed their child for 6-8 years than the participants who managed their child for 3-5 years (82.09±9.58 vs 71.51±12.07, p=0.006). Further, the mean knowledge score was statistically higher in the participants who have managed their child for 9-11 years than participants who have managed their child for 3-5 years (82.43±4.20 vs 71.51±12.07, p=0.019). There was a statistically significant association between the mean knowledge score and family history with NS. The mean knowledge score was significantly higher in the participants with a family history with NS compared to the participants without a family history of NS (79.00±1.23 vs 73.98 ±12.38, p=0.001). But, there were no statistically significant associations between mean scores obtained for knowledge

Table 3: Level of knowledge of caregivers regarding home management of children with Nephrotic Syndrome

Level of knowledge	Score Range	Frequency (n)	Percentage (%)
Inadequate Knowledge	≤50	3	3.2
Moderate Knowledge	51-75	41	43.6
Adequate Knowledge	≥76	50	53.2

Table 4: Level of practice of caregivers regarding home management of children with Nephrotic Syndrome

Level of practice	Score Range	Frequency (n)	Percentage (%)
Satisfactory	50-100	62	66.0
Unsatisfactory	00-49	32	34.0
Maximum = 100			Minimum = 00

and categories of age groups ($p=0.498$), educational qualifications ($p=0.558$), ethnicity ($p=0.166$), and occupation ($p=0.681$).

Post Hoc analysis, using the least significant differences (LSD) criterion for significance, indicated that the average mean score for the practice of the participants who had more than four living children was significantly higher than the participants who had two living children in their family (96.88 ± 4.41 vs 50.17 ± 20.94 , $p=0.002$). The mean practice score was significantly higher in the participants who had more than four living children compared with participants who had one child in the family (96.88 ± 4.41 vs 55.86 ± 20.35 , $p=0.008$). The results indicated no statistically significant association between mean practice score and other demographic factors, including age groups, educational qualifications, occupation, ethnicity, duration of management and family history. A significant negative correlation was observed (using Pearson correlation) between the knowledge score and the practice score variables ($r=-0.240$, $n=94$, $p=0.020$, 2-tailed).

When considering the source of information for parents and other caregivers, the majority, 99.9% (93), had received information regarding home management of the child with NS from the Medical Officer of the ward. They had also received information from Nursing Officers of the ward (59.1%), the dietician (6.4%), mass media (3.2%), school teachers (1.1%), and other sources (6.4%).

Discussion

Home management of children with NS refers to the management at home regarding diet, skincare, medication, investigation, immunization, prevention of complications, and follow up. Patients and parents who clearly understand the disease better comply with treatments [10]. Proper practice for the management of NS at home by the parents is important to control the disease and

prevent complications.

In our study, most of the children with NS were males; 66 (70.2%) and 33 (35.1%) were in the 4-6 years old age group. The mean age of the children was 7.6 ± 3 years. Similar observations have been made by a study conducted by Rajasuriya et al. (2017) on the knowledge and practices about NS and its treatment in parents of affected children presenting to the Lady Ridgeway Hospital, Colombo, Sri Lanka [7]. They have reported that the majority of the children of their sample were boys, and their mean age was 7.9 ± 3.4 years. Similar to our study, they have also mentioned that 46.2% of parents had correctly answered more than 50% of knowledge questions regarding NS and about the treatment of affected children concluding that study participants' knowledge regarding NS was adequate. Furthermore, the majority (77.0%) from their sample had known the names of drugs used for NS.

In the present study, there were statistically significant associations between mean knowledge score and duration of management of NS ($p=0.008$) and family history of NS ($p=0.001$). However, there were no statistically significant associations between caregivers' knowledge scores and age, education, occupation, and ethnicity. However, a study conducted in a children's hospital in Sri Lanka had found that knowledge was positively associated with younger parents and was not significantly associated with education level, monthly income, and duration of disease [7]. A similar study carried out to access the knowledge of mothers of children with NS in India had revealed that there was a significant association ($p<0.05$) between knowledge scores and educational status, occupation, and religion of the mother [13].

When considering the parents' overall level of healthcare related practices, 66.0% ($n=62$) had scored between 50-100 and 34.0% had scored between the 00-49 range. However, similar studies

conducted by Ziyarah and Mua'ala in Baghdad city [8] and Sarika in India [9] have concluded that mothers had poor practices regarding NS.

In the present study, the lowest mean practice score (32.71 ± 11.01) was obtained for the questions on emotional support. However, it has been reported that both the child and caregivers need psychological support throughout the management of NS [12]. A study conducted in Egypt on knowledge and healthcare related practices on NS among school-age children and their mothers had shown that the mother's education, occupation, place of residence, and family income had a statistically significant relation with mothers' knowledge and health-related practices regarding the management of NS, and no statistically significant association between mothers' age and their knowledge [11]. Another study conducted at nephrology consultation units of Baghdad pediatrics hospitals also had reported no association between practices and mother's age, occupation, child's age, child's sex, child's age at onset (years), child's previous diseases, and heredity with regard to the management of their children having NS [8].

In the current study, a significant negative correlation was found between knowledge and healthcare-related practices ($p=0.020$). Therefore, the present study emphasizes the value of bridging the gap between knowledge and practice through an effective evaluation mechanism of behaviours and practices of the caregivers. A study conducted at the Lady Ridgeway Hospital, Colombo, Sri Lanka, in 2017 had also found a moderate negative association between knowledge and practices ($p<0.05$) of the parents regarding the home management of NS [7]. In contrast, a similar study conducted at selected hospitals in Haryana, India, has reported a positive correlation between knowledge scores and practices scores on a similar aspect [9].

In the present study, most participants had received information regarding the home management of the child with NS from the Medical Officer of the clinic or ward. They had understood the information provided by the Medical Officers more compared to other sources. This emphasizes the value of the involvement of the Medical Officers in the education/counselling of caregivers.

It is worth displaying posters with relevant information regarding home care management of children with NS in clinic settings and conducting health education sessions for caregivers by the healthcare team. Community healthcare team members such as Medical Officers of Health, Public Health Midwives, Public Health Nursing Sisters should pay more attention to children with NS and their immunization in the field settings. They can conduct secondary and tertiary health promotion programmes combined with home management of children with NS. Further studies with large samples are needed for a better generalization of the findings.

Limitations

As there was no validated questionnaire in Sri Lanka specific to assessing the knowledge and healthcare related practices regarding home management of children with NS, the researcher developed the questionnaire using the literature survey. Actual practices were not observed, and data were collected using an interviewer-administered questionnaire, and that score classification was also developed in-house. Recall bias could affect scores. Data were collected at a clinic at one teaching hospital; hence, the finding might not reflect children's overall home management status with NS in Sri Lanka.

Conclusions

The overall level of caregivers' knowledge regarding home management of children with NS attending a PNC, Teaching Hospital Karapitiya,

Sri Lanka was adequate. Caregivers' overall level of practice regarding home management of children with NS was satisfactory. Most participants had been educated about the management of NS at home by the Medical Officers of the respective wards or clinics. It is recommended to take necessary actions to improve the caregivers' knowledge regarding causes for NS, immunization, investigations, and nature of the disease and how the children could be emotionally supported.

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