

Parental Knowledge on Nephrotic Syndrome and Disease Relapse in children

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ABSTRACT

Introduction: Parental knowledge on nephrotic syndrome and disease relapse is important for early recognition and treatment of relapse to prevent the complications. Parental knowledge on nephrotic syndrome was reported to be inadequate from published studies. To date, there is no study on parental knowledge on childhood nephrotic syndrome in Malaysia. This study is thus aimed at to determine the level of knowledge on NS and disease relapse among parents of children with nephrotic syndrome and determine factors that influence knowledge on nephrotic syndrome and disease relapse. **Study Design and**

Methods: This was a cross-sectional study conducted in Paediatric Nephrology Clinic, Hospital Selayang from November 2016 to November 2017. Seventy-eight parents were recruited based on universal sampling. Self-administered questionnaire in Bahasa Malaysia and English was designed through focus group discussion with five subject matter experts and validated through content validity. Data was analysed using IBM SPSS Statistics 23.0.

Results: Majority of parents or guardians (91%) were able to answer more than 50% of the questions correctly. Of these, 56% were able to answer more than 75% of the questions correctly. A 'cut-off' of 75% was defined as good knowledge. Parents of children with frequent relapses had higher parental knowledge and this was statistically significant ($p=0.025$).

Conclusion: Parental knowledge on nephrotic syndrome and disease relapse was still inadequate as only 56% parents had good knowledge. The main areas of deficit in parental knowledge were related to medications, infections, home urine dipstick monitoring, and recognition of warning signs during relapse.

KEY WORDS:

Nephrotic syndrome; disease relapse; parental knowledge

INTRODUCTION

Nephrotic syndrome (NS) is one of the glomerular diseases occurring in children with the presence of proteinuria (urine protein/creatinine ratio $\geq 200\text{mg}/\text{mmol}$ or urine protein excretion more than $40\text{mg}/\text{m}^2/\text{hour}$ on a timed urine

collection), low albumin level (less than $25\text{g}/\text{L}$) and oedema.^{1,2}

Nephrotic syndrome is usually seen among three to nine year-old children who present with sudden onset of gravity-dependent oedema.³ Nephrotic syndrome can be due to primary (idiopathic) cause or secondary causes such as infections and medications.³ The annual incidence rate of nephrotic syndrome is two to seven cases per 100,000 children younger than 16 years old.⁴ Ninety percent of childhood nephrotic syndrome is due to the primary idiopathic cause of which eighty percent has minimal change disease.^{3,5,6} However, a diagnosis of non-minimal change nephrotic syndrome should be highly suspected if a child presents at less than one year of age.³

Corticosteroids are the mainstay of therapy for nephrotic syndrome.^{1,3} Majority of patients with minimal change disease (up to 95%) achieved remission after receiving eight-weeks course of corticosteroid.^{1,4} Remission is defined by urinary protein excretion of less than $4\text{mg}/\text{m}^2/\text{hour}$, or urine dipstick for protein negative or trace for three consecutive days.²

A relapse is defined by urine dipstick for protein of 2+ or more for three consecutive days or urine albumin excretion more than $40\text{mg}/\text{m}^2/\text{hour}$.² Based on the Kidney Disease Improving Global Outcomes (KDIGO) Clinical Practice Guideline for Glomerulonephritis (2012), the definition of infrequently relapsing nephrotic syndrome is one relapse within six months of initial response, or one to three relapses in any 12-month period. Frequently relapsing nephrotic syndrome is defined by two or more relapses within six months of initial response, or four or more relapses in any 12-month period. Steroid dependent nephrotic syndrome is defined by two consecutive relapses during corticosteroid therapy, or within 14 days of stopping therapy. Steroid resistant nephrotic syndrome is diagnosed when a patient fails to achieve complete remission after eight weeks of corticosteroid therapy.⁷

Unfortunately, nephrotic syndrome tends to relapse; with 90% relapsing at least once and 50% of them are frequently relapse or steroid dependent.¹ This leads to multiple visits and prolonged follow-up at the clinic with frequent changing of drug dosage and sometimes even requiring admission to the

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hospital. This disease pattern requires the child and family members to make a relatively high level of adjustment in the social, emotional and physical aspect.⁸ Furthermore, multiple courses of corticosteroids have potential side effects such as stunted growth, obesity, high blood pressure and osteoporosis.⁹ Relapses of nephrotic syndrome also increases the chance of getting complications such as infection, thrombosis, dyslipidaemia and malnutrition.¹⁰ However, the frequency of relapses reduce with increasing age of the child in which 58% to 90% no longer have relapse after the age of 18 years.¹¹

Inadequate parental knowledge on the disease course may prevent early detection of relapse in their children and it leads to delayed treatment. Good education and adequate communication to the family is important especially during hospital admission on initial diagnosis. This helps them to recognise the problem that may arise in future and getting treatment from doctors at the outpatient clinic.¹²

A study by Sarika, amongst 60 parents regarding their knowledge and practices on home management of children with nephrotic syndrome at three selected hospitals in Haryana, India, found that the majority of the parents (80%) had below average knowledge regarding home management of children with nephrotic syndrome.¹³

Chao et al., concluded that the disease-related knowledge among parents of children with nephrotic syndrome needed to be improved. Increased parental knowledge via education can reduce the number of relapses. Parental knowledge on nephrotic syndrome was associated with parental educational level and number of disease recurrence ($p < 0.05$).¹⁴

Hakim et al., concluded that only 18.2% of 66 parents of children with nephrotic syndrome had good knowledge about their child's recurrence of symptoms. Therefore, it is necessary to increase their knowledge level through various educational programme which will enhance the level of quality of care.¹⁵

Parental knowledge on nephrotic syndrome and disease relapse is important especially on early recognition and treatment of disease relapse to prevent complications.

In Malaysia, the current approach in education of parents with nephrotic syndrome children regarding the disease is given verbally during the initial diagnosis and on subsequent clinic visits. However, no assessment has been done on parental knowledge on nephrotic syndrome in addition to disease relapse and treatment.

This study is thus aimed at determining the level of knowledge on NS and disease relapse and to determine factors that influence the level of knowledge on NS and disease relapse among parents of children with nephrotic syndrome in Malaysia as a basis on formulation of educational tools or training programme.

MATERIALS AND METHODS

This study was a prospective, questionnaire based descriptive study examining parental knowledge of a child with nephrotic syndrome about the disease and recurrence. It was conducted in the Paediatric Nephrology Clinic, Hospital Selayang between 21st November 2016 to 17th November 2017.

All nephrotic syndrome patients from the age of one to eighteen years old who had a follow-up appointment in Nephrology Clinic Hospital Selayang from 21st November 2016 to 17th November 2017 were identified from the electronic appointment scheduling system. Patients with other chronic diseases and secondary nephrotic syndrome were excluded.

A questionnaire was designed through a focus group discussion with five subject matter experts: four paediatric nephrologists and one trainee in paediatric nephrology. Content validation was performed and 32 questions out of 56 questions were chosen based on acceptable content validation ratio to form the questionnaire to test on parental knowledge. This was pretested on five parents from the target group. It was available in Bahasa Malaysia and English. The questionnaire consisted of two sections. The first section comprised demographic data of parents or legal guardians, date of birth, ethnicity, highest education level, occupation and total monthly family income. The second section was on parental knowledge on nephrotic syndrome and disease relapse; it was further divided into three components: (i) four questions on parental general knowledge on nephrotic syndrome; (ii) eleven questions on parental knowledge on management of nephrotic syndrome; and (iii) seventeen questions on home monitoring and disease relapse. Each question with a correct answer was given a score of "1", while each question that had an incorrect answer or a "don't know" response was given a score of "0". If all the questions were answered correctly, the total score was "32". Good knowledge was defined by a 'cut-off' of 75% of correct answers.

During the clinic visit, the parents or legal guardians were asked to participate in the study by the researcher or staff nurses and written consent was taken from those who agreed to participate. Only one of the parents was recruited to participate in the study if both were present. The self-administered questionnaire was answered by them in the common waiting area of the clinic while waiting for their children's turn to be seen by the doctor. Parents who had difficulty in answering questions were helped by the researcher or by consulting doctors in the consultation room. The researcher collected the questionnaires after the clinic and questions that were not answered were completed via a telephone conversation with the parents. Demographic data and clinical parameters of patients were filled-in by the researcher which included date of birth, sex, date of diagnosis, first relapse from diagnosis, number of relapses since diagnosis, category of diagnosis in relation to steroid sensitiveness and relapse as well as status of whether the child was in remission or relapse upon study recruitment and whether kidney biopsy was done.

Table I: Socio-demographic profile of 78 parents of children with nephrotic syndrome

Socio-demographic profile	Frequency	Percentage (%)
Relationship with patient		
Father	20	25.6
Mother	55	70.5
Legal guardian	3	3.8
Ethnicity		
Malay	55	70.5
Chinese	8	10.3
Indian	10	12.8
Orang Asli	1	1.3
Others	4	5.1
Highest educational level		
Primary	5	6.4
Secondary	31	39.7
Certificate/ diploma	23	29.5
University degree	19	24.4
Occupation		
Professional	35	44.9
Non-professional	43	55.1
Monthly total family income ^{a,b}		
Lower Income (< RM 3000)	31	43.1
Middle Income (> RM 3000 - 7000)	33	45.8
Higher Income (>RM7000)	8	11.1

a. Based on national household income 2015

b. 6 parents' income were not revealed

Table II: Parental source of information on nephrotic syndrome

Source	Frequency	Percentage %
Healthcare workers	67	85.9
Consultant/specialist	58	74.4
Internet	59	75.6
Medical officer	40	51.3
Friends/ relatives	29	37.2
Books/ magazines	17	21.8
Pamphlets	15	19.2
Staff nurse	15	19.2
House officer	10	12.8
Others (i.e. parents of NS patients, journals)	3	3.8
TV/ Radio	2	2.6

Statistical Analysis

Data entry and analysis was done using SPSS version 23 for Windows, student version. Mean and standard deviations, median and interquartile range were calculated for continuous variables, and frequency and percentages for categorical variables. For categorical data, Mann-Whitney U test was used to test levels of significance. Kruskal-Wallis Test was used when there was more than two categorical data. Multiple linear regression test was used to test for any correlation between parental knowledge and independent variables. Significance was taken at a p value of less than 0.05.

RESULTS

In this study, 107 nephrotic syndrome patients were identified from the electronic appointment scheduling system and all of them were eligible to be recruited into the study. Of the 107 patients, 78 (73%) parents (75 parents and three

legal guardians) consented and completed the questionnaire; while parents of 23 patients were missed from sampling during clinic appointments, and six patients defaulted follow up throughout the study period.

Patients

The median age of patients was eight years old (interquartile range (IQR): 7, range: 2-18 years). Majority were male patients (67.9%) with a male to female ratio of 2:1. The average age at diagnosis was 35 months (IQR: 32, range: 6-155 months). The median duration of disease from first diagnosis to patient recruitment was 52 months (IQR 74, range: 3-192 months). The median number of relapses since diagnosis was 8.5 (IQR: 8, range: 1-40). The majority of patients were in the infrequently relapsing group (39.7%), followed by frequently relapsing and steroid resistant group which constituted 21.8% and 20.5% respectively, and steroid dependent group (18%).

Table III: Percentage of parental response for individual questions:

Questions	Correct [Frequency (%)]	Incorrect [Frequency (%)]	Don't know [Frequency (%)]
General knowledge on nephrotic syndrome			
B1.4. For children with nephrotic syndrome, what leaks in large amount into the urine?			
B1.4.a Sugar	57 (73.1)	2 (2.6)	19 (24.4)
B1.4.b Protein	77 (98.7)	0	1 (1.3)
B1.5. What is the common symptom present in children with nephrotic syndrome?			
Oedema	78 (100)	0	NA
B1.6. Majority of children (more than half) with nephrotic syndrome who responded to treatment will eventually develop kidney failure.			
No	34 (43.6)	16 (20.5)	28 (35.9)
Management of nephrotic syndrome			
B2.1. What are the possible effects of prednisolone?			
a. Increased appetite	67 (85.9)	9 (11.5)	2 (2.6)
b. High blood pressure	42 (53.8)	17 (21.8)	19 (24.4)
c. Lower immunity	54 (69.2)	15 (19.2)	9 (11.5)
d. Higher risk of infection	60 (76.9)	9 (11.5)	9 (11.5)
e. Weaker or thinner bones	37 (47.4)	17 (21.8)	24 (30.8)
f. Height stunted	48 (61.5)	21 (26.9)	9 (11.5)
g. Risk of cataract	45 (57.7)	10 (12.8)	23 (29.5)
B2.2. What would you do if your child develops high fever AND severe abdominal pain while taking prednisolone?			
See doctor immediately	73 (93.6)	5 (6.4)	NA
B2.3. You should seek medical attention if your child is on prednisolone and exposed to others who suffer from:			
a. Measles	55 (70.5)	8 (10.3)	15 (19.2)
b. Chicken pox	53 (67.9)	8 (10.3)	17 (21.8)
B2.4. When should your child take prednisolone?			
On empty stomach	75 (96.2)	3 (3.8)	NA
Home monitoring and disease relapse			
B3.1. With regards to relapse nephrotic syndrome:			
a. Majority of children with idiopathic nephrotic syndrome will have relapse	60 (76.9)	4 (5.1)	14 (17.9)
b. Infection can trigger a relapse	66 (84.6)	3 (3.8)	9 (11.5)
B3.2. Definition of relapse nephrotic syndrome:			
Urine dipstick for protein 2+ or more for 3 consecutive days	64 (82.1)	14 (17.9)	NA
B3.3. Home urine dipstick monitoring whilst your child is on treatment for nephrotic syndrome:			
a. Daily urine dipstick checking is needed during treatment of nephrotic syndrome to monitor the response	75 (96.2)	2 (2.6)	1 (1.3)
b. When your child is well and has no body swelling whilst on treatment, urine dipstick monitoring can be reduced to few days once	32 (41)	42 (53.8)	4 (5.1)
c. The best urine sample to test for protein is the first one obtained in the morning	78 (100)	0	0
B3.4. Home urine dipstick monitoring whilst your child is in remission:			
a. When your child is unwell or catches a 'cold', you should check his/her urine dipstick more frequently for a period of several days	58 (74.4)	17 (21.8)	3 (3.8)
b. It is not necessary to check urine dipstick for protein at all if your child is well	50(64.1)	25 (32.1)	3 (3.8)
Correct action to do based on the result of your child's urine dipstick for protein:			
B3.5. 1+ for 3 consecutive days: observe first and seek treatment if there is body swelling	55 (70.5)	23 (29.5)	NA
B3.6. 2+ for 2 consecutive days: observe first and seek treatment if there is body swelling	32 (41)	46 (59)	NA
B3.7. 2+ for 3 consecutive days: seek medical attention	68 (87.2)	10 (12.8)	NA
B3.8. When your child is unwell or has infection, protein may be present in the urine.			
Yes	67 (85.9)	4 (5.1)	7 (9)
B3.9. Most relapses of nephrotic syndrome rarely require admission if relapses are treated early.			
Yes	66 (84.6)	8 (10.3)	4 (5.1)
B3.10. Below are warning signs of a child with relapse nephrotic syndrome, of which immediate medical attention is needed:			
a. Cold hands and feet	30 (38.5)	32 (41)	16 (20.5)
b. Reduced urination	69 (88.5)	5 (6.4)	4 (5.1)
c. Vomiting	40 (51.3)	30 (38.5)	8 (10.3)
d. Diarrhoea	42 (53.8)	27 (34.6)	9 (11.5)

Table IV: Factors that influence parental knowledge on nephrotic syndrome and disease relapse

Factors	Mean Rank	p value
Parental educational level		
-Non tertiary educated	33.01	0.01
-Tertiary educated	45.06	
Parental age		
-Younger (less than 40 years old)	42.54	0.13
-Older (above 40 years old)	35.05	
Ethnicity		
-Malays	41.04	0.35
-Non Malays	35.83	
Occupation		
-Non Professionals	36.93	0.26
-Professionals	42.66	
Duration of disease		
-Less than 12months	46.25	Kruskal-Wallis Test 0.28
-12 to 35 months	44.09	
-36 to 59 months	42.56	
-Equal to or more than 60 months	33.90	
Current status of patient		
-Remission	41.23	0.26
-Relapse	34.81	
Category of relapse group		
-Infrequent Relapse	30.68	0.005
-Frequent Relapse	45.32	
Total Family Income Group		
-Lower Income (<RM3000)	33.82	Kruskal-Wallis Test 0.22
-Middle Income (RM 3000 - 7000)	36.20	
-Higher Income (> RM 7000)	48.13	

Table V: Multivariate linear regression tests for correlation between parental knowledge with parental education, parental age group and frequency of relapse group

Model	Unstandardized Coefficient		Unstandardized Coefficient	Sig	95% CI for B		Adjusted R Square	Sig
	B	Std Error	Std Error		Lower bound	Upper bound		
1 (Constant)	21.25	1.18		<0.01	18.89	23.60	0.10	0.01
Tertiary Educated	1.74	1.04	0.19	0.09	-0.33	3.82		
Frequent Relapse	2.36	1.03	0.25	0.02	-0.30	4.42		
Older Age Group	-0.83	1.03	-0.09	0.42	-2.89	1.23		

Dependent variable: Total Marks

Parents

Majority of the parents were mothers (70.5%) and Malays (70.5%). The mean age of the parents was 40.86 years old (standard deviation (SD):7.24, range: 24 to 58 years). Majorities were Malays. In terms of their level of education, 53.9% were diploma and degree holders and 46.1% were secondary school and below. For parental occupation, 44.9% of parents were in the professional group and the remaining were in the non-professional group such as skilled worker, labourer and others. Most of the parents (45.8%)were of the middle-income group (RM3000-7000)(Table I).

All of the parents knew of the diagnosis of nephrotic syndrome in their children except for one parent. All of them said that they were informed by the treating doctor on what was nephrotic syndrome.

The main parental source of information was healthcare workers (85.9%) with consultant or specialist constituting the majority (74.4%). This was followed by the internet (75.6%). Pamphlets as a source of information was relatively less frequent which constituted only 19.2% (Table II).

Parental knowledge on nephrotic syndrome was assessed in several aspects, such as general knowledge, knowledge related to management, knowledge on home monitoring and disease relapse, and lastly on their practice of adjusting prednisolone dosage on their own.

The highest total score of correct answers was 30 and the lowest was 10 (total score 32), with median total score of 24 (IQR 5). This study showed that the majority of parents (91%) were able to answer more than 50% of the questions

correctly. From this, 56% were able to answer more than 75% of the questions correctly. Only 9% had below average knowledge, i.e., less than 50% of the questions were answered correctly.

General knowledge on nephrotic syndrome

Parents knew that protein leaks in large amount into urine and oedema is the most common symptom in nephrotic syndrome except for one who did not know about urinary protein leakage.

Knowledge on management of nephrotic syndrome

Parental knowledge on possible effect of prednisolone on bone health was poor of which only 47.4% of parents knew that prednisolone may cause the bones to be weaker or thinner, and 30.8% admitted that they did not know about it. On the other hand, parents had good knowledge on the negative effect of prednisolone on height and increased appetite which constituted 61.5% and 85.9% respectively. Approximately one third of parents did not know that immediate medical attention is needed when their children were exposed to patients with measles (19.2%) or varicella (21.8%) while the former were still taking prednisolone.

Parental knowledge on home monitoring and disease relapse

There were 17.9% of the parents who did not know the most crucial knowledge on disease relapse i.e. the definition of relapse nephrotic syndrome. More than half of the parents (53.8%) thought that urine dipstick monitoring can be reduced to once every few days when their children had resolved symptoms and body swelling whilst on treatment; however, they should have monitored the urine dipstick daily despite disappearance of symptoms and body swelling. Majority (59%) thought immediate medical attention is needed if urine protein is 2+ for two consecutive days. They are not aware that they need to observe at home and only if there is associated body swelling or puffiness, further medical attention is needed.

Only 38.5% of the parents knew that cold hands and feet were one of the warning signs of hypovolaemia in a child with relapse nephrotic syndrome, for which immediate medical attention is needed. (Table III)

One of the questions was to assess the parent's practice of adjusting their children's prednisolone dosage on their own. A total of 12.8% of parents actually adjusted the prednisolone dosage on their own. The reasons given included parental concern regarding the side effects of prednisolone. There was another occurrence whereby the parent was trying to avoid her child being admitted if were to get medical attention, thus she increased the prednisolone dose on her own initiative when her child's urine dipstick for protein became positive on tapering prednisolone.

Factors that influence parental knowledge on NS and disease relapse

There was a statistically significant difference in parental knowledge between non-tertiary educated parents (mean rank of 33.01) and tertiary educated parents (mean rank of 45.06, $p=0.01$). Parents of children in the frequent relapse group had a higher knowledge score with mean rank of 45.32

compared with parents of children in the infrequent relapse group with mean rank of 30.68 ($p=0.005$). However, there was no statistically significant difference in parental knowledge with regards to parental age, ethnicity, occupation, total family income, duration of disease and current status of patient (whether in remission or relapse) (Table IV).

Multiple linear regression test was used to test for correlation between parental knowledge and age group of parents, education level of parents and category in relation to relapse. Analysis showed that parents of children with frequent relapse had higher parental knowledge compared with infrequent relapse group in which they had 2.36 marks higher in knowledge score (95% CI: -0.31, 4.42, $p=0.02$) (Table V).

DISCUSSION

In our study, the main source of information on nephrotic syndrome was healthcare workers followed by the internet. Pamphlets as the source of information was relatively less frequent which constituted only 19.2%. To date there is no educational pamphlet available locally for parents on nephrotic syndrome. The available pamphlet sources were from other countries which were accessible through the internet. Study by Mamatha et al., amongst 60 parents concluded that there were significant increase in parental knowledge scores after administering the information booklet ($p<0.05$).¹⁶ Information booklets or pamphlets in different local languages can be considered as one of the channels to convey information to parents especially for those with lower educational level or has limitation in accessing information through the internet and it can be used as a tool that parents can always refer to for reference.

In this study, the majority of the parents (91%) were able to answer more than 50% of the questions correctly. Of these, 56% were able to answer more than 75% of the questions correctly which is classified as good level of knowledge. This finding is in contrast to other published studies. The study by Sarika in 2017 at three selected hospitals of Haryana, India, showed that the majority of the parents (80%) had below average knowledge (defined by parents answered less than 50% of the questions correctly) on home management of children with nephrotic syndrome.¹³ In a study by Hakim et al., in 2013 at a specialised clinic of nephrology in Ahvaz, Iran, only 18.2% of parents had good knowledge on nephrotic syndrome disease recurrence (defined by parents answered more than 75% of the questions correctly).¹⁵ A study by Zyah and Mua'ala at the nephrology units in Baghdad showed that 61.3% of mothers had poor practices,¹⁷ and knowledge scores and practice scores showed positive correlation as shown by Sarika ($r=0.51$, $N=60$, $p<0.05$).¹³

Lower educational level of the study populations in the three aforementioned studies may be the contributing factor to the differences in parental knowledge score between our study and the aforementioned studies. Only 18% of the parents had higher secondary education and 93% of the parents did not have exposure to information regarding nephrotic syndrome in the study by Sarika.¹³ Only 7.6% of parents had tertiary

education in the study by Hakim et al.¹⁵, whilst only 17.8% had higher secondary education in the study by Ziyarah and Mua'ala.¹⁷ In our study, 53.9% of the parents had a higher education level (diploma or degree holders). Furthermore, our study was conducted in the specialised paediatric nephrology clinic where there was more emphasis on parental education.

The parental knowledge on other chronic diseases was reported as inadequate as well. A study by Zhao et al., in 2013 on 2485 parents of children with asthma in China found that only a small number of parents (18.31%) were able to answer at least 60% of the questions correctly.¹⁸ Ghafoor et al., concluded that parental knowledge on thalassaemia was also inadequate.¹⁹ However, a more recent study by Kolahi et al., in 2017 on 206 mothers of children with epilepsy concluded that maternal level of knowledge on epilepsy was good.²⁰

From our study, the main area of deficit in parental knowledge was medications, i.e., the possible effects of prednisolone in particular effect on bone health. The emphasis on steroid toxicity was mainly on short stature and development of glaucoma and cataracts. These are common steroid toxic effects and hence focus was given to educate parents on these and alert them. There was less emphasis on bone health, and this explains why there is lack of knowledge on this area. Several studies have reported that children on oral corticosteroids had reduced bone density. Furthermore, study by Van Staa and colleagues in United Kingdom revealed that the risk of fracture was shown to increase in children who received four or more courses of oral corticosteroids as compared with those taking non-systemic corticosteroids (adjusted OR: 1.32; 95%CI: 1.03, 1.69).²¹

Another area of deficit in parental knowledge was infections (in particular exposure to measles or varicella), home urine dipstick monitoring, actions in relation to different urine dipstick results, and recognition of warning signs of relapse. The area with maximum deficit in knowledge score as shown by study of Sarika was medication, urine examination, infections and complications which is consistent with our study.¹³ This information is crucial in educating our parents with emphasis on areas found to be deficient. It is important to pay attention at areas with poor parental knowledge. The first step in education process is to identify the needs and requirement, following it an appropriate education programme can be designed and implemented.¹⁵

In our study, 12.8% of the parents actually adjusted the prednisolone dosage on their own, the main reason being their concern regarding the side effects of prednisolone. In a study by Ziyarah and Mua'ala, 57.5% of the mothers interrupted the therapy regimen themselves based on appearance of side effects, possibly due to their concern regarding the child's condition, or lack of understanding on the side effects of therapy.¹⁷ However, it is important to emphasize to our parents that they are not allowed to self-adjust the prednisolone dosage; this will interfere with the prescribed treatment course and may cause more disease relapses due to the lower than prescribed prednisolone doses. Prolonged prednisolone courses due to recurrent relapses will increase the risk of steroid side effects.

In our study, parents with tertiary education had higher parental knowledge ($p = 0.019$). Based on a study by Abu-Ouf et al., in 2016 on 121 parents about parental perceptions of their child's kidney disease, there was an association between perceived knowledge and understanding of the condition with caregiver level of education ($p < 0.0001$).²² However, the study conducted by Hakim et al., showed that there was no significant correlation between maternal educational level with knowledge scores.¹⁵

Our study concluded that parents of children with frequent relapse had higher parental knowledge from both univariate analysis and multiple linear regression test. Chao et al., also found that parental knowledge on disease was related to educational background, and the frequency of recurrence ($p = 0.05$).¹⁴ Parents of children with frequent relapse are exposed to more opportunities to clinic visits or hospital admissions which increase their chance of obtaining information on the disease from healthcare provider or through their effort in reading online information with the opportunity to understand more about the disease or provide better care for their children. Parents acquired more knowledge with more relapses in their children, however we should aim for all parents to have good knowledge regardless of the frequency of relapses as knowledgeable parents from beginning of their children's disease course is important. Chao et al., emphasised that the number of relapses can be reduced with increased parental knowledge through education.¹⁴ Parental knowledge on nephrotic syndrome and disease relapse is important especially on early recognition and treatment of disease relapse to prevent complications.

LIMITATIONS

The questionnaire was answered by parents in the common waiting area at the paediatric clinic before their children's turn to see the doctor in the consultation room. Parents might be distracted by noisy surrounding which will affect their concentration in reading, understanding and answering the questionnaire properly. There was however no time limit for parents to complete the questionnaire, as long as parents submitted the answered questionnaire before they left the clinic. There is also a possibility that both parents had discussed the questionnaire together, although only one was required to participate in the study. These factors might influence parental knowledge level reflected in the questionnaire.

CONCLUSION

Parental knowledge on nephrotic syndrome and disease relapse was inadequate as only 56% of the parents had good knowledge, who answered more than 75% of the questions correctly. The main areas of deficit in parental knowledge were related to medications, infections, home urine dipstick monitoring, and recognition of warning signs during relapse. Parents of children with frequent relapse were shown to have higher parental knowledge.

RECOMMENDATION

A checklist can be created containing important topics on nephrotic syndrome, especially on areas noted to be deficient in our study i.e. medications, infection, home urine dipstick monitoring, and recognition of warning signs of relapse. This checklist should be filled-in by parents during clinic visits before consultation with doctors in order to disclose which topic that needs to be reinforced during clinic consultation. Parental knowledge can be improved through this process.

ETHICAL APPROVAL

Ethical approval was obtained from the Research and Ethics Committee of National University of Malaysia (UKM PPI/111/8/JEP-2017-042) and the Medical Research Ethics Committee of the Malaysian Ministry of Health (NMRR-16-1973-32015 IIR).

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