

Original Article

Impact of an Educational Program on Parents' Knowledge, Attitude and Practice Towards Pediatric Nephrotic Syndrome.

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ABSTRACT

Introduction: Nephrotic syndrome (NS) is a chronic disease that is characterized by massive proteinuria, hypoalbuminemia, hyperlipemia, and edema. Inadequate parental knowledge about NS may prevent early detection of relapse or medications' side effects and delay the treatment .

Aim of the study: to measure the baseline level of knowledge, attitude and practice among parents of children with NS and to evaluate the effect of health education program on enhancing their knowledge, attitude and practice .

Methods: A prospective interventional study included 50 caregivers of children with confirmed diagnosis of NS recruited from the Pediatric Nephrology clinic Ain Shams, Egypt. The questionnaire covered socio-demographic data of children and their caregiver, anthropometric data and medical history of patients. Caregivers were evaluated for pre-intervention and 3-months-post- intervention for knowledge across 5 domains (the disease, nutrition, follow-up, psychological and physical aspects), attitude and practice across 4 domains (nutrition, follow-up, psychological and physical aspects) .

Results: The mean age of the studied children was 7.8 ± 3.1 years, males represented 58% of them. The mean mothers' age was 34.6 ± 6.1 years. Physicians were the primary source of data for all of them. Following interventional program, a significant improvement occurred in the mean knowledge score (from 72.8 ± 7.8 to 86.4 ± 5.7), the attitude score (from 14.6 ± 1.7 to 16.7 ± 2.1) and the practice score (from 17.6 ± 3.1 to 19.4 ± 3.5). Knowledge and attitude scores correlated with mother's education, the attitude score correlated with the gender of the patients and the practice score negatively correlated with the child's age .

Conclusion: knowledge, attitude and practice of mothers of children with NS significantly improved after the application of educational program. The study highlights the importance of applying a comprehensive interventional educational program for patients and their families, for better outcomes of the disease.

Key words: Knowledge; Attitude, Practice; Education; Nephrotic Syndrome

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INTRODUCTION

Nephrotic Syndrome is a chronic kidney disease that is relatively common in children that is characterized with massive proteinuria, hypoalbuminemia, hyperlipemia, and edema. It is basically caused by increased permeability through the abnormal glomerular basement membrane that can be primarily an intrinsic renal disease or secondary to congenital infections, diabetes, systematic lupus erythematosus (SLE), neoplasia or certain drug use [1]. The annual incidence rate of nephrotic syndrome (NS) is 2 to 7 cases per 100,000 children younger than 16 years old. Ninety percent of childhood NS is due to idiopathic cause of which eighty percent has minimal change disease [1,2,3]. NS tends to relapse; with 90% relapsing at least once and 50% of them are frequently relapsing or steroid dependent [4,5].

The chronic nature of NS and the possibility of relapses might lead to prolonged follow-up with frequent modifications in the treatment protocols and corticosteroids doses, with their potential risks such as stunted growth, obesity, hypertension and osteoporosis. Relapses increase the risk of infections, thrombosis, dyslipidemia and malnutrition [6]. This disease pattern requires the child and family members to make a relatively high level of adjustments in the social, emotional and physical aspects [2]. Inadequate parental knowledge of the disease course may prevent early detection of relapse in their children and subsequently delay treatment. Good education and adequate communication with the family is important especially during hospital admissions and the initial phase of the disease, to improve their attitude towards the dietary restrictions,

changes in the lifestyle and adherence to medications [6]. In an Indian study, knowledge of the parents about their children's NS was below average in 80% of them [7]. Parental knowledge on NS was positively related with their educational level and number of disease relapses [8]. In Egypt, a study that implement an educational program concluded that there was remarkable improvement of mothers' knowledge and health care practices about nephrotic syndrome [9]. While another study recommended that Pediatric nurses should provide educational sessions for school age children and their mothers about nephrotic syndrome to raise their level of health awareness about care of the disease [10]. Therefore, this study aimed to determine the baseline level of knowledge, attitude and practice among parents of children with NS, to evaluate the effect of health education program on them and to identify factors affecting their knowledge, attitude and practice.

METHODS

Study design and setting: This prospective interventional study was conducted on 50 mothers of pediatric patients with nephrotic syndrome (NS) and their children recruited from the Pediatric Nephrology clinic, Children's Hospital, Ain Shams University during the period from August 2023 to February 2024.

Inclusion criteria

- 1) Diagnosis of NS according to Kidney Disease Improving Global Outcomes guideline (KDIGO) 2021 clinical practice guideline for the management of glomerular diseases [11]
 - Nephrotic range proteinuria (first morning or 24 hours protein/creatinine ratio ≥ 2 g/g or ≥ 200 mg/ mmol or $\geq 3+$ dipstick). **and either:**

- Hypoalbuminemia (serum albumin < 30 g/l [3 g/dl]).
- Edema when albumin level is not available. It typically starts as periorbital edema in the early morning and subsides by the end of the day. Subsequently, bilateral pitting lower limb edema develops. In the advanced phase, edema becomes generalized with pleural effusion and ascites [12].

2) Both genders were included

3) The age of patients ranged between 3 and 16 years old.

4) Patients were on corticosteroids at time of enrollment and follow up

Exclusion Criteria: Patients with the following conditions were excluded:

- 1) Congenital NS
- 2) Associated autoimmune diseases
- 3) Associated renal impairment
- 4) Underwent kidney transplantation

Study Sampling: a convenience sampling technique was used to recruit the sample. The sample size was calculated using the PASS 15 program for sample size calculation, adjusting for a 10% dropout rate, a minimum sample size of 50 participants was determined to achieve 90.0% power and according to Abolwafa and Hossein, 2018 [9]. This sample size ensures the study's ability to reject the null hypothesis of no effect (effect size = 0) with a significance level (alpha) of 0.050, using a two-sided one sample t-test.

Study Tools: An Arabic interview questionnaire was used to collect data. The questionnaire is divided into 6 sections added to the educational interventional program. The questionnaire was adapted from Khider et al.[10]

The questionnaire was divided as following:

- **Section1: Sociodemographic data of the patients:** included 6 questions: age,

gender, birth order, number of siblings, school attendance.

- **Section2: Sociodemographic data of the main caregiver:** included 8 questions: residency, family income, maternal age, education and work, and family history of NS or other renal diseases.

- **Section 3: Medical history of children:** included 9 questions: age of disease onset, frequency of hospital admissions per year, cause of admission, the longest period of hospital stays, frequency of relapses per year, weight before illness and at admission and clinical manifestations including puffiness, edema, anorexia, vomiting, urine color, pallor, fatigue, postural hypotension, frothy urine, breathing difficulty and sleep disturbance.

- **Section 4: Assessment of knowledge regarding NS before and 3 months after intervention:** included 5 main domains (maximum score is 94):

- a) **The disease definition and criteria (maximum score is 49):** included 10 questions (knowledge source, definition, relation to kidney function, possible causes, symptoms, types, laboratory investigations for diagnosis and follow up, complications, associated problems, red flags of infection).

- b) **Nutrition (maximum score is 7):** included 5 questions about food ingredients and meals components.

- c) **Follow-up (maximum domain is 17):** included 6 questions related to the frequency of clinic visits, clinical and laboratory items.

- d) **Psychological aspects (maximum domain is 19):** included 3 questions to assess peer relationships and school achievement.

- e) **Physical aspects (maximum score is 2):** one question.
- **Section 5: Evaluation of parents' attitude towards:** nutrition (5 questions), follow-up (3 questions), psychological (2 questions) and physical aspects (1 question) (maximum score is 22).
 - **Section 6: Evaluation of parents' practice regarding the following domains:** nutrition (6 questions), follow-up (17 questions), psychological (4 questions) and physical aspects (1 question) (maximum score is 31).

All caregivers and their children were subjected to educational interventional program: Patients and their mothers were interviewed individually by the investigator before and 3 months after the educational program to assess their knowledge, attitude and practice towards NS. Questions were clarified by the investigator for every individual and the answers were recorded immediately. The education sessions were directed to the patients and their mothers through 2 main tools: educational session explained in a simple language after interviewing the participants in the first time and illustrating flyers. The educational program cover disease definition, types of NS, characteristics, complications, types, diagnosis, broad lines of treatment and their side effects, optimum nutrition, recommended vaccines, and precautions to protect from complications, written in simple Arabic language.

A pilot study was done to test questionnaire comprehension, duration of administration and intervention program among 10% of sample size and its results were not included in the final analysis.

Statistical Analysis

Analysis of data was done using SPSS program version 27. Quantitative data were presented using minimum, maximum, mean and SD, while qualitative data were presented using count and percentage. For calculation of knowledge, attitude and practice scores: true answer was scored as one, while incorrect answer (or I don't know answer) scored zero. Different knowledge, attitude and practice scores were calculated by adding scores for different questions of each item. The maximum total scores of knowledges, attitude and practice were 104, 22 and 31, respectively.

Inferential analyses were done for quantitative variables using Shapiro-Wilk test for normality testing. Paired samples t-test was used to compare quantitative data before and after intervention, while marginal homogeneity and McNemar's tests were used for qualitative data. Student t test and One-Way ANOVA tests were used to compare different scores between different independent groups. Pearson's correlation test was used to measure correlation between different quantitative data. P value less than or equal to 0.05 was considered statistically significant, otherwise is non-significant.

RESULTS

This study started with 50 mothers of children with NS and by the end of the study, 2 participants refused to continue, and one patient passed away due to serious pneumonia.

I. Description of participant's characteristics:

The mean age of the patients was 7.8 ± 3.1 years with a slight predominance of male gender (58%). The mean mothers' age was

34.6±6.1 years. Most of them (76%) were housewives and 30% of them had attended the secondary school. Residency of the patients was in slum areas in 48% and in rural areas in 36% of them, with generally a below average monthly income **Table 1**. The mean age of disease onset was 4.5±2.9 years. All of them were previously hospitalized, with the frequency of admission being one hospitalization/year in 42% **Table 2**. At the start of illness, puffiness and edema were reported in all patients

II. Description of participants' knowledge before and after the education program

The treating doctors were the main source of information about the disease, followed by the internet and social media among 22% of the participants. There was a significant improvement across all knowledge domains including knowledge about disease, nutrition, follow-up, psychological and physical aspects. The mean total knowledge score increased from 72.8±7.8 to 86.4±5.7 ($p < 0.001$) **Table 3,4,5**.

III. Parents' attitude towards NS before and after the education program

Participants showed positive attitude regarding adherence to the recommended diet (from 36% to 57.4%, p -value=0.01), and the interest in understanding the treatment plan (from 72% to 95.7%, p -value=0.01). **Table 6**.

The post-interventional attitude scores significantly elevated in the aspects of nutrition, follow up, psychological and physical concepts and the total attitude score increased from 14.6±1.7 to 16.7±2.1 (p -value<0.001) **Table 7**.

IV. Parents' practice regarding NS before and after the education program

The practice of participants changed to an acceptable level following the intervention, particularly in serving preservatives-free food (from 52% to 72.3%, p -value=0.02), care for skin creases (62% to 93.6%, p -value<0.001), turning from offering small quantities of food at short intervals (from 38% pre intervention to 10.6% post intervention, p -value=0.001) towards providing regular meals **Table 8**.

The practice of participants changed to better level following the intervention, improvement occurs in all domains except nutritional domain. The total practice score increased from 17.6±3.1 to 19.4±3.5 (p -value<0.001) **Table 9**.

V. Factor affecting knowledges, attitude and practice scores before intervention :

The initial knowledge score showed significant relation with the care giver's education (university educated had higher scores compared to illiterate and preparatory educated). The attitude scores were significantly related to both the gender of the patients (males achieve higher scores compared to females) and their mothers' education level (university educated had higher scores compared to illiterate and preparatory educated). The age of the patients was negatively correlated to their practice score **Table 10**.

Correlation between knowledge score and practice score before and after intervention showed significant but weak positive correlation between total scores for knowledge and practice in the pre intervention phase ($r=0.28$, p -value=0.05). However, this correlation disappeared in the post intervention scores ($r=0.07$, p -value=0.66) (results are not tabulated). This implies that altering practices is a multifaceted process that extends beyond mere knowledge acquisition.

Table 1: Socio-demographic characteristics of the studied participants.

Characteristics		N (50)	%
Age of children in years: mean ± SD (min- max)		7.8±3.1	(3-14)
Mothers' age in years: mean ± SD (min - max)		34.6±6.1	(25-49)
Family income: mean ± SD (min - max)		3458±1872.3	(300-8000)
Gender	Male	29	58%
	Female	21	42%
Birth order	First	16	32%
	Second	10	20%
	Third	15	30%
	Fourth	9	18%
Siblings	No siblings	1	2%
	One	12	24%
	Two	22	44%
	Three or more	15	30%
School	Public	42	84%
	Private	6	12%
	Not yet	2	4%
Mother's education	Illiterate	8	16%
	Read and write	5	10%
	Primary	4	8%
	Preparatory	9	18%
	Secondary/technical	15	30%
	University	9	18%
Mother's work	Housewife	38	76%
	Worker	9	18%
	Employee	3	6%
Residency place	Rural	18	36%
	Urban	8	16%
	Slum area	24	48%
Other sibling with NS	No	49	98%
	Yes	1	2%
Relatives with renal disease	No	45	90%
	Yes	5	10%

NS: Nephrotic syndrome, SD: Standard deviation

Table 2: Clinical characteristics of the studied patients

Characteristics		N (50)	%
Age at disease in years mean ± SD (min - max)		4.5±2.9	(1-13)
Longest admission period in days median ± IQR (min - max)		10(7-17)	(3-90)
Weight before illness mean ± SD (min - max)		18.1±10.1	(7-65)
Weight at admission mean ± SD (min - max)		22.5±10.8	(11-70)
Previous hospital admission	No	0	0%
	Yes	50	100%
Cause of admission	Nephrotic syndrome	50	100%
	Other cause	0	0%
No of admissions per year	One	21	42%
	Two	15	30%
	Three	11	22%
	Four or more	3	6%
No of relapses per year	No relapses	2	4%
	One	9	18%
	Two	24	48%
	Three	9	18%
	Four or more	6	12%

IQR: Interquartile range, NS: Nephrotic syndrome, SD: Standard deviation, *: Median and IQR

Table 3: Knowledge scores before and after the educational program

Characteristics	Intervention score	Min	Max	Mean	SD	t*	P value	
Disease domain	Before	27	50	40.6	4.9	8.4	<0.001	
	After	37	52	46.8	2.9			
Nutrition domain	Before	5	11	7.6	1.3	8.2	<0.001	
	After	8	10	9.3	0.7			
Follow up domain	Before	14	18	16.3	0.9	10.6	<0.001	
	After	16	19	17.7	0.5			
Psychological aspects domain	Before	0	14	4.8	3.5	4.8	<0.001	
	After	1	16	8.6	4.2			
Physical aspects domain	Before	1	4	3.4	1.1	4.1	<0.001	
	After	4	4	4	0			
Total Knowledge score	Before	51	92	72.8	7.8	10.5	<0.001	
	After	69	97	86.4	5.7			
Source of knowledge		N (50)				%		
Treating doctor		Yes				50		100%
Nurse		Yes				2		4%
Other guardians		Yes				3		6%
Radio and television		Yes				2		4%
Internet and social media		Yes				11		22%
All of them		Yes				1		2%

SD: Standard deviation, *: Paired samples t test.

Table 4: Parents’ knowledge regarding disease & proper nutrition pre- & post-intervention

Characteristics			Before N (%) 50 (100%)	After N (%) 47 (100%)	Before X̄ ± SD (min-max)	After X̄ ± SD (min-max)	P value [#]		
Total knowledge score					72.8 ± 7.8 (51-92)	86.4 ± 5.7 (69-97)	< 0.001		
The Disease	Kidney functions	Excretion of unwanted substances in urine	Yes	39 (78)	47 (100)	40.6 ± 4.9 (27-50)	46.8 ± 2.9 (37-52)	< 0.001	
		Produce an essential substance for erythropoiesis	Yes	12 (24)	40 (85.1)				
		Regulation of blood gases	Yes	17 (34)	34 (72.3)				
		BP regulation	Yes	37 (74)	46 (97.9)				
		Vitamin D activation	Yes	28 (56)	40 (85.1)				
	Definition of NS	Group of symptoms due to kidney pathology prevent proper blood purification and urinary excretion	Yes	37 (74)	46 (97.9)				
		Proteinuria and edema	Yes	49 (98)	47 (100)				
		Renal failure	Yes	11 (22)	1 (2.1)				
		Blood disease	Yes	10 (20)	4 (8.5)				
		Ascites	Yes	40 (80)	35 (74.5)				
	Causes of NS	Idiopathic	Yes	26 (52)	42 (89.4)				
		Renal basement membrane dysfunction	Yes	24 (48)	44 (93.6)				
		Congenital anomalies	Yes	34 (68)	40 (85.1)				
		Autoimmune diseases	Yes	29 (58)	37 (78.7)				
		Genetic	Yes	42 (84)	45 (95.7)				
	Types of NS	Kidney inflammation	Yes	46 (92)	46 (97.9)				
		Primary	Yes	3 (13.6)	30 (75)				
		Secondary	Yes	1 (4.5)	22 (55)				
		Congenital	Yes	18 (81.8)	39 (97.5)				
		I don't know	Yes	28 (56)	7 (14.9)				
	Symptoms of NS	Decreased UOP	Yes	49 (98)	46 (97.9)				
		LL edema	Yes	50 (100)	47 (100)				
		Periorbital edema	Yes	50 (100)	47 (100)				
		Abdominal swelling	Yes	47 (94)	47 (100)				
		Genital swelling	Yes	49 (98)	47 (100)				
		Anorexia, vomiting and sleep disturbance	Yes	40 (80)	43 (91.5)				
		Dark urine	Yes	4 (8)	0				
		Pallor	Yes	42 (84)	45 (95.7)				
		Fatigue	Yes	48 (96)	47 (100)				
		Postural hypotension	Yes	46 (92)	46 (97.9)				
		Frothy urine	Yes	48 (96)	47 (100)				
		Breathing difficulties	Yes	44 (88)	44 (93.6)				
		Urine analysis	Yes	50 (100)	47 (100)				
		Necessary laboratory investigations	Serum urea and creatinine	Yes	48 (96)				47 (100)
			Blood electrolytes	Yes	42 (84)				46 (97.9)
	Urinary protein		Yes	48 (96)	47 (100)				
	Urine color and amount		Yes	50 (100)	47 (100)				
	Lipid profile		Yes	31 (62)	42 (89.4)				
	Complications Of NS	Vitamin D level	Yes	45 (90)	46 (97.9)				
		Recurrent infections	Yes	45 (90)	47 (100)				
		Thrombosis	Yes	27 (54)	39 (83)				
		Immuno-dysregulation	Yes	47 (94)	47 (100)				
		Renal failure	Yes	38 (76)	45 (95.7)				
	Associated problems	Growth stunting and puberty delay	Yes	41 (82)	45 (95.7)				
		Hypertension	Yes	49 (98)	47 (100)				
Decrease school performance		Yes	33 (66)	19 (40.4)					
Growth arrest		Yes	36 (72)	24 (51.1)					
Recurrent infections		Yes	45 (90)	35 (74.5)					
Red flags of infection	Drug adherence difficulties	Yes	13 (26)	4 (8.5)					
	Fever	Yes	49 (98)	47 (100)					
	Anorexia	Yes	46 (92)	45 (95.7)					
	Night sweating and headache	Yes	48 (96)	43 (91.5)					
	Fatigue	Yes	48 (96)	47 (100)					
Nutrition	Eating habits	Lymphadenopathy	Yes	45 (90)	46 (97.9)				
		Overeating	Yes	7 (14)					
		No appetite	Yes	10 (20)					
	Preferred food	Average	Yes	33 (66)					
		Protein	Yes	36 (72)					
		Carbohydrates	Yes	23 (46)					
	Recommended diet	Fruits and vegetables	Yes	21 (42)					
		Change of eating habits	Yes	35 (70)	43 (91.5)				
		High protein diet	Yes	20 (42.6)	20 (42.6)				
		Salt free	Yes	46 (97.9)	47 (100)				
		Ordinary diet	Yes	5 (10.6)	0				
		High carbohydrate low protein	Yes	5 (10.6)	3 (6.4)				
		High fibers	Yes	26 (55.3)	45 (95.7)				
	Food should be avoided	I don't know	Yes	3 (6)	0				
		Salt	Yes	50 (100)	47 (100)				
Fast food		Yes	46 (92)	47 (100)					
Spices		Yes	43 (86)	44 (93.6)					
Preserved food		Yes	48 (96)	47 (100)					

Table 5: Parents’ Knowledge regarding follow-up, psychological & physical burdens of NS pre- & post- intervention.

Characteristics			Before N (%) 50 (100%)	After N 47 (100)	Before X̄±SD (min-max)	After X̄±SD (min-max)	P value [#]		
Follow up	Medications side effects	Increase body weight	Yes	48 (96)	47(%) (100)	16.3 ± 0.9 (14-18)	17.7 ± 0.5 (16-19)	< 0.001	
		Osteopenia	Yes	44 (88)	46 (97.9)				
		Hyperglycemia	Yes	35 (70)	41 (87.2)				
		High blood pressure	Yes	50 (100)	47 (100)				
		Recurrent infections	Yes	46 (92)	47 (100)				
		Myalgia	Yes	44 (88)	47 (100)				
	Follow up need follow up at home	Body swelling	Yes	40 (80)	6 (12.8)				
		Possibility of relapses	Yes	49 (98)	47 (100)				
		Knowing the child’s medications	Yes	46 (92)	47 (100)				
		Corticosteroids	Yes	50 (100)	47 (100)				
			Diuretics	Yes	-				1 (2.1)
			Antibiotics	Yes	1 (2)				
		Need to follow up of medications	Yes	43 (86)	47 (100)				
		Adherence to Disease follow up	Yes	50 (100)	47 (100)				
		Items that need follow up at home	Fluid input and output	Yes	50 (100)				47 (100)
Urinary protein	Yes		50 (100)	47 (100)					
Body weight	Yes		50 (100)	47 (100)					
Avoidance of infective persons	Yes		50 (100)	47 (100)					
Avoid adding salt to the food	Yes		50 (100)	47 (100)					
Drinking plenty of water	Yes		49 (98)	47 (100)					
Psychological aspect	Psychological effects of the disease	Fear of making any effort	Yes	24 (48)	13 (27.7)	4.8 ± 3.4 (0-14)	8.5 ± 4.2 (1-16)	< 0.001	
			Only during attack	1 (2)	17 (36.2)				
		Lack of self confidence	Yes	15 (30)	8 (17)				
			Only during attack	1 (2)	14 (29.8)				
		Isolation and depression	Yes	15 (30)	9 (19.1)				
			Only during attack	1 (2)	11 (23.4)				
	Fatigue	Yes	32 (64)	23 (48.9)					
		Only during attack	1 (2)	19 (40.4)					
	Fear of dealing with others	Yes	10 (20)	7 (14.9)					
		Only during attack	1 (2)	15 (31.9)					
		Incompliance to treatment	Yes	10 (20)	5 (10.6)				
	Change of daily activity during disease	Inability to participate in activities	Yes	17 (34)	9 (19.1)				
			Only during attack	2 (4)	26 (55.3)				
		Dependency on his mother	Yes	18 (36)	16 (34)				
			Only during attack	2 (4)	21 (44.7)				
Scholastic activity change	Decrease school performance	Yes	25 (50)	17 (36.2)					
	Decrease school attendance	Yes	27 (54)	26 (55.3)					
	Regression in his relationship with friends and teachers	Yes	13 (26)	6 (12.8)					
	Neglecting his homework	Yes	21 (42)	15 (31.9)					
Physical aspect	Level of activity allowed	Walking	Yes	36 (87.8)	47 (100)	3.4 ± 1.1 (1-4)	4.0 ± 0 (4-4)	< 0.001	
		Mild physical activity	Yes	36 (87.8)	47 (100)				
		Aggressive physical activity	Yes	3 (7.3)	0				
		Bed rest	Yes	1 (2.4)	0				
		I don’t know	Yes	9 (18)	0				

NS: Nephrotic syndrome, X̄: Mean, SD: Standard deviation, p: p-value >0.05: Non- significant; p-value <0.05: Significant; p-value < 0.01: highly significant.

Table 6: Attitude scores before and after the educational program

Attitude	Intervention score	Min.	Max.	Mean	SD	t*	P value
Nutrition domain	Before	0	3	1.5	0.9	4.8	<0.001
	After	0	4	2.5	1.5		
Follow up domain	Before	7	12	10.5	1.3	4.5	<0.001
	After	8	13	11.4	0.99		
Psychological and physical domain	Before	1	3	2.6	0.6	2.5	0.02
	After	1	3	2.8	0.4		
Total attitude score	Before	9	18	14.6	1.7	5.9	<0.001
	After	11	20	16.7	2.1		

SD: Standard deviation, *: Paired samples t test,

Table 7: Parents’ attitude pre- and post-intervention

Characteristics			Before N (%) 50(100%)	After N (%) 47(100)	P value*	Before X±SD (min-max)	After X±SD (min-max)	P value#
Total attitude score						14.6 ± 1.7 (9-18)	16.7 ± 2.1 (11-20)	< 0.001
Nutrition	Number of meals served	3 meals and 3 snacks	23 (46)	30 (63.9)	0.07	1.5 ± 0.9 (0-3)	2.5 ± 1.5 (0-4)	< 0.001
		When child feels hungry	24 (48)	16 (34)				
		Small frequent meals	3 (6)	1 (2.1)				
	Do you follow the required diet	Yes	18 (36)	27 (57.4)	0.01			
	Preventing salty, canned food and carbonated drinks	Yes	32 (64)	37 (78.7)	0.23			
Suitable nutrition	Yes	37 (74)	30 (63.8)	0.27				
Follow up	Regular follow up	Yes	47 (94)	44 (93.6)	1	10.5 ± 1.3 (7-12)	11.4 ± 0.99 (8-13)	< 0.001
	To avoid complications	Yes	42 (84)	44 (93.6)	0.23			
	To know treatment plan	Yes	36 (72)	45 (95.7)	0.01			
	Fluid input and output	Yes	35 (70)	41 (87.2)	0.07			
	Checking urinary protein	Yes	45 (90)	47 (100)	-			
	Checking body weight	Yes	45 (90)	42 (89.4)	1.0			
	Avoidance of infective persons	Yes	46 (92)	46 (97.9)	0.63			
	Avoid adding salt to the food	Yes	40 (80)	45 (95.7)	0.07			
	Drinking plenty of water	Yes	49 (98)	47 (100)	-			
	Taking medications in time	Yes	45 (90)	45 (95.7)	0.38			
	Never stop medications without doctor order	Yes	45 (90)	45 (95.7)	1.0			
Attention to hygiene	Yes	49 (98)	44 (93.6)	0.63				
Psychological and physical aspects	Encourage the child to have friends	Yes	41 (82)	43 (91.5)	0.34	2.5 ± 0.6 (1-3)	2.8 ± 0.4 (1-3)	0.02
	Encourage the child to take medications and attend follow up appointments	Yes	50 (100)	47 (100)	-			
	Encourage the child to exercise	Yes	36 (72)	43 (91.5)	0.07			

X̄: Mean, SD: Standard deviation, p: p-value >0.05: Non-significant; p-value <0.05: Significant; p-value < 0.01: highly significant.

Table 8: Practice scores before and after the educational program

Practice	Intervention score	Min	Max	Mean	SD	t*	P value
Nutrition domain	Before	2	8	5.3	1.8	1.1	0.28
	After	3	9	5.5	1.9		
Follow up domain	Before	4	13	8.4	2.2	2.3	0.02
	After	5	16	9.4	2.3		
Psychological and physical domain	Before	2	5	4.0	0.9	2.9	0.005
	After	2	5	4.6	0.7		
Total practice score	Before	11	24	17.6	3.1	3.1	0.003
	After	12	27	19.4	3.5		

SD: Standard deviation, *: Paired samples t test

Table 9: Parents’ practice pre- and post-intervention

Characteristics		Before N (%) 50 (100)	After N (%) 47 (100)	P value*	Before $\bar{X} \pm SD$ (min-max)	After $\bar{X} \pm SD$ (min-max)	P value#		
Total practice score					17.6 ± 3.08 (11-24)	19.4 ± 3.5 (12-27)	0.003		
Nutrition	Protein rich meals	Yes	42 (84)	44 (93.6)	0.13	5.3 ± 1.8 (2-8)	5.5 ± 1.9 (3-9)	0.28	
	Salt and spices free food	Yes	13 (26)	13 (27.7)	1.00				
	Small quantities at short intervals	Yes	19 (38)	5 (10.6)	0.001				
	Preservatives free food	Yes	26 (52)	34 (72.3)	0.02				
	Fruits and vegetables	Yes	46 (92)	45 (95.7)	1.00				
	Child feeding regimen	Family food		21 (42)	17 (36.2)				0.31
		Special food		2 (4)	1 (2.1)				
Family food with low salt			13 (26)	9 (19.1)					
All family eats low salt food			14 (28)	20 (42.6)					
Follow up	Weight	Yes	11 (22)	18 (38.3)	0.12	8.4 ± 2.2 (4-13)	9.4 ± 2.3 (5-16)	0.02	
	Daily BP monitoring	Yes	13 (26)	10 (21.3)	0.45				
	Following Temp daily	Yes	11 (22)	11 (23.4)	1.0				
	Urinary protein measuring	Yes	43 (86)	47 (100)	-				
	Taking medications in time	Yes	45 (90)	45 (95.7)	0.38				
	Noticing vital signs	Yes	46 (92)	47 (100)	-				
	Never stop medications without doctor order	Yes	45 (90)	45 (95.7)	1.0				
	Fluid restriction	Yes	1 (2)	1 (2.1)	1.0				
	Accurately assess fluid intake	Yes	7 (14)	9 (19.1)	0.75				
	Accurately assess urine output	Yes	9 (18)	7 (14.9)	0.77				
	Infection control measures	Yes	47 (94)	44 (93.6)	1.0				
	Brushing teeth daily	Yes	17 (34)	24 (51.1)	0.14				
	Care for skin	Yes	31 (62)	44 (93.6)	<0.001				
	Nail trimming	Yes	44 (88)	44 (93.6)	0.38				
Psychological and physical aspects	Not leaving the child alone	Yes	32 (64)	38 (80.9)	0.21	4.04 ± 0.9 (2-5)	4.6 ± 0.7 (2-5)	0.005	
	Does the child spend some time playing	Yes	43 (86)	45 (95.7)	0.06				
	Does the child have friends	Yes	41 (82)	43 (91.5)	0.34				
	Is the child motivated to take medications and attend follow up appointments	Yes	50 (100)	47 (100)	-				
	Does the child exercise	Yes	36 (72)	43 (91.5)	0.07				

Table 10: Factor affecting Knowledge, attitude and practice scores before intervention

Character		Knowledge score	P value	Attitude score	P value	Practice score	P value
		Mean± SD		Mean± SD		Mean± SD	
Gender	Male	74±8.2	0.29*	14.86±1.8	0.04*	17.3±2.8	0.41*
	Female	71.7±6.9		13.76±1.9		18.1±3.5	
Birth order	First	70.4±8.4	0.74**	14.1±1.9	0.73**	16.9±2.9	0.75**
	Second	78.8±7.1		14.8±2.4		17.7±3.7	
	Third	72.6±7.2		14.3±1.8		18.2±2.7	
	Fourth	72.1±5.4		14.8±1.5		17.6±3.8	
Siblings	No siblings	70±-	0.71**	14±.	0.82**	11±.	0.12**
	One	75±9.7		14.2±2.2		18.2±3.5	
	Two	70.6±6.2		14.3±1.7		18±2.8	
	Three or more	75.3±7.6		14.8±2.1		17±2.9	
School	Public	73±7.9	0.75**	14.3±1.9	0.65**	17.5±3	0.81**
	Private	74.3±7.7		14.7±2.3		17.5±4.7	
	Not yet	69.5±7.8		15.5±0.7		19±1.4	
Mother's education#	Illiterate	69.9±7.1	0.01**	14±1.8	0.02**	18.1±4.4	0.23**
	Read and write	71.2±2.8		14.8±1.3		17.8±1.9	
	Primary	73 ±8.1		14.5±1		16.7±2.8	
	Preparatory	68.6±9.2		13±2.1		16.7±3.2	
	Secondary/ technical	73.3±6.2		14.3±2		16.6±2.7	
	University	80.9±6.1		16.1±1.1		19.9±2.4	
Mother's work	Housewife	73.1±8.1	0.98**	14.7±1.7	0.08**	17.8±3.1	0.42**
	Worker	72.9±7.3		13.2±1.9		16.4±3.1	
	Employee	72.3±6.4		13.7±3.2		18.7±2.1	
Residency place	Rural	71.9±6.3	0.1**	14±2.2	0.12**	17.1±2.6	0.23**
	Urban	78.4±8.2		15.6±1.2		19.4±3.2	
	Slum area	72.1±8.1		14.3±1.8		17.4±3.3	
Age of patients in years		R= -0.9	0.53	R= -0.06	0.69	R= -0.29	0.05
Care giver's age in years		R= 0.17	0.23	R=0.16	0.26	R=0.06	0.68
Age at disease onset in years		R=-0.15	0.28	R=0.02	0.88	R=-0.01	0.96

SD: Standard deviation, *: Student t test, **One Way ANOVA test,
 #Post hoc test shows significant difference between illiterate vs university and prep vs university,
 r: Pearson Correlation, p: p-value >0.05: Non-significant; p-value <0.05: Significant; p-value < 0.01: highly significant

DISCUSSION

Nephrotic syndrome (NS) has several long-term consequences due to the underlying pathology and medications used to treat it. The key to effective management is pharmacological and nutritional therapies [13]. Given the link between level of knowledge and health

outcomes, there have been calls to prioritize patient-centered approaches that address the basic knowledge regarding the disease as well as providing specific information about prognosis, treatment, nutrition and the expected clinical course[14]. Due to the unique nature of NS being chronic diseases with frequent relapses, this study is one of the few

studies that investigated the impact of educational interventional program among NS patients in Egypt.

The study highlights many important points one of them was source of health information for patients; the treating physicians were the principal source of data about the disease for the patients and their parents, and due to the crowdedness, and lack of time for continued education and evaluation of the knowledge, attitude and practice of the parents during the follow up visits, it was expected to find many unanswered inquiries and confused data among the parents. That gap in the basic knowledge about NS was not completely fulfilled through social media and internet. Therefore, it is important to design other alternatives to continue the educational role of the physicians throughout the disease journey such as scheduled educational sessions, supporting audiovisual tools and rewarding the idol families to raise the spirit of competition.

Notably, in a study conducted in Sri Lanka on 94 parents of children with NS, 99.9% of the participants were dependent on the treating physicians and residents as the primary source of education initially and during the home follow up. Nurses were the second source for 59.1% of the parents, 6.4% depended on the dietitians and 3.2% preferred the media as a reliable source of information [15]. Another Malaysian study, involved 78 parents, showed that 85.9% of the parents got their primary knowledge from the healthcare professionals and 75.6% depended on the online educational sites [6]. It is recommended that the healthcare professionals provide the initial educational outlines, however, health education should be an ongoing process

with the participation of the nurses, dietitians, residents and specialists.

Through the designed audiovisual educational program in this study, there were a significant improvement across all knowledge domains about the disease including definition, nutrition, follow-up, psychological and physical aspects. The mean total knowledge score significantly increased from 72.8 ± 7.8 to 86.4 ± 5.7 . Raising awareness using audiovisual tools could leave a better impact on the children and their parents and make the information more digestible. The flyers could, also, save the time and effort of education, and work as a reference for the parents whenever they need.

The value of the parents' education about NS and its impact on their knowledge, attitude and practice was discussed in a study that was done in Egypt, in Minia governate, the study reported a significant improvement in the parents' knowledge about the disease, its causes, manifestations, complications, dietary restrictions, follow up investigations and the medications after a training program ($p=0.05$) [1]. Another Egyptian study adopted a 3-month-health-instructions-program for the newly diagnosed patients with NS and their families and achieved a significant improvement in the scores of knowledges from 2.4% to 96.5% [16]. Devi et al. [17] also revealed that the knowledge of caregivers regarding NS improved after providing an information booklet, from a mean score of 14.2 ± 3.1 , to 20.5 ± 1.7 (p -value < 0.001). This highlighted the importance of renewing the data of the parents about their children's disease, clarifying their cloudy thoughts, and answering the overcoming questions about the disease.

Attitude of the participants towards NS has improved significantly after the interventional educational program, the final scores of attitudes significantly elevated regarding nutrition, follow up investigations, psychological and physical domains; and the total attitude score increased from 14.6 ± 1.7 to 16.7 ± 2.1 ($p < 0.001$). Although the change in the practice scores was not as significant as the attitude scores, parents assured that they keep trying to improve their practice after their better awareness about the disease, its triggers and complications.

The practice of participants changed to better level following the intervention, improvement occurred in all domains except nutritional domain. Improving the practice of the families harboring a child with NS was achieved by many studies through different educational approaches. Sarika [7] studied the practices of 60 Indian parents of children with NS and found that 93.3% of parents exhibited poor practices regarding home management. The mean percentage for practice score was 26.2 ± 8.4 . The lowest mean percentage scores were in weight monitoring (10.4%) and urine examination (12.9%), followed by dietary modification (26.1%). Conversely, the highest mean percentage of practices was observed in daily living activities (55.3%) and emotional support (52%), followed by prevention of infections and complications (46.7%). Madhushani and Bandara [15] also reported that the practice score of 66% of parents ranged from 50 to 100, which was considered acceptable, while 34% had scores between 0 and 49. In Tawfique et al. [16], 37.6% of the caregivers had an initial average practice score, which increased to 62.4% after three months of the educational program, with special

improvement regarding edema monitoring, adherence to therapeutic protocols and nutritional regimen, compliance with the doctor's orders in case of respiratory infections, and the child's exercise routine.

Notably, the level of maternal education was significantly related to their baseline knowledge and attitude scores in a positive way. Whereas there was a statistically significant negative correlation between the age of child and total practice score. Moreover, the attitude initial scores exhibited significant relation with the gender of the patients. As the main source of information for children is often their mothers, who may already possess unsatisfactory knowledge, so the child gets wrong or incomplete information about self-care. This issue is exacerbated with low educational levels. This could be related to the fact that low educated parents cannot help their children to perform correct healthy practices [10]. This indicates the importance of the families' overall awareness with special attention to mothers, particularly when the affected child is younger in age, because the resistance to change their daily activities and the unhealthy life habits would be an obstacle to better practices.

Although knowledge and practice scores were positively correlated initially, that correlation was insignificant by the end of the study denoting the difficulty in applying the healthier pattern of life, which is a complex process that needs patience and persistence. This signifies the value of the well-organized educational training programs, as a core routine in the children's follow up, to simplify the information, overcome the fears of the children and their caregivers, achieve better adherence and follow up and

guarantee effective translation of the acquired knowledge into practice.

In agreement with our results, Saraswathi et al. [18] and Sarika [7] shared the findings of the positive relation between the maternal educational level and their knowledge scores. Ziyarah and Mua'ala [19] revealed a significant positive association between mothers' practices and each of the mothers' educational level and the duration of the child's disease.

Both Sarika [7] and Tawfique et al. [16] found a significant positive correlation between parents' knowledge scores and their practice scores concerning the home management of children with NS. This stands in contrast to the findings of Madhushani and Bandara [15], which revealed a negative correlation between parents' knowledge levels and their practices.

LIMITATIONS OF THE STUDY

This study was limited by the relatively small sample size, short duration of follow

up and hence unknown impact of improving knowledge on the clinical outcomes as wight gain, blood pressure, adherence to treatment, frequency of relapses and frequency of hospital admissions.

CONCLUSION

In conclusion, educating the mothers of children with NS using audiovisual tools could improve their knowledge about the disease and encourage better practice especially in the aspects related to the follow up, awareness about infections, orientation about the prescribed medications and their side effects.

RECOMMENDATIONS

We recommend applying the educational program on a larger scale of patients and to be available on regular intervals. Thereby, to evaluate the impact of such programs on the clinical outcomes as wight gain, blood pressure, adherence to treatment, frequency of relapses and frequency of hospital admissions.

ABBREVIATIONS

ANOVA	Analysis of Variance
KDIGO	Kidney disease improving global outcome
NS	Nephrotic syndrome
SD	standard deviation
SPSS	statistical package for social science

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STATEMENTS

Ethics approval and consent to participate

The study gained approval of the Research Ethics Committee of Faculty of Medicine. An informed consent was obtained from the parents or caregivers of participants after explaining the aim of the study and the study tools. Administrative approval was obtained from Pediatric Hospital, Faculty of Medicine, Ain Shams university.

Consent for publication

The contents and material of the manuscript have not been previously reported at any length or being considered for publishing elsewhere.

Availability of data and material

“applicable”

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