Effect of Supportive Care Activities on Negative Emotional Feelings of Children with Nephrotic Syndrome

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Abstract

Nephrotic syndrome is a collection of symptoms due to kidney damage. This includes protein in the urine, low blood albumin levels, high blood lipids, and significant swelling. Other symptoms may include weight gain, feeling tired, and foamy urine. Complications may include blood clots, infections, and high blood pressure.

Aim of the study: This study was aimed to assess the effect of supportive care activities on negative feelings of nephrotic syndrome children. **Setting**: The study was carried out at medicine department of children's hospital affiliated to Ain Shams University Hospitals. **The subjects:** The subject of this study was purposive sample composed of (50) children were attended to the previously mentioned setting and accompanying mothers. **Tools of data collection:** An Interviewing Questionnaire, Children's Assessment of Participation and Enjoyment (CAPE),multidimensional Scale of Perceived Social Support (MSPSS).

Results: Less than half of the studied children having negative Emotional Feelings.

Conclusion: The study concluded that the studied children with Nephrotic Syndrome have negative feelings need Supportive Care.

Recommendations: This study recommended the importance of Encourage use of Supportive care activities programs to help them to prevent the negative feelings of Nephrotic syndrome children.

Keywords: *Children, Emotional, Supportive, Negative, Nephrotic Syndrome.*

Introduction

Nephrotic syndrome may occur when the filtering units of the kidney are damaged. this damage allows protein normally kept in the plasma to leak into the urine in large amounts, which reduces the amount of protein in your blood. Since the protein in the blood helps keep fluid in the bloodstream, some of this fluid leaks out of the bloodstream into your tissues, causing swelling, called edema.[14]

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Nephrotic syndrome is a problem where too much protein called albumin is released from the body into the urine. it means that one or both kidneys are damaged. the kidneys contain many coils of tiny blood vessels. each of these is called a glomerulus. glomeruli filter substances from the blood into the urine. nephrotic syndrome occurs when the glomeruli stop working normally. [10]

Glomerular disease may be caused by an infection or a drug it may be caused by a disease that affects the entire body, like diabetes or lupus. Many different diseases can cause swelling (inflammation) or scarring (sclerosis) of the glomerulus. Sometimes glomerular disease is idiopathic, meaning it happens without any cause that can be found, the glomerular diseases that cause nephrotic syndrome generally can be divided into primary and secondary Nephrotic Syndrome. [16]

Primary nephrotic syndrome is known as Idiopathic nephrotic syndrome its associated with glomerular disease without an identifiable causative disease or drug. Idiopathic nephrotic syndrome includes multiple histologic types such as : minimal change disease, mesangial proliferation, focal segmental glomerulosclerosis, Secondary nephrotic syndrome refers to an etiology extrinsic to the kidney. approximately 10% of children with nephrotic syndrome have secondary nephrotic syndrome**.** [19]

Childhood nephrotic syndrome is a group of symptoms that occur because of damage to the kidneys. nephrotic syndrome can occur in children at any age, but usually is found in children between 18 months and 5 years of age. you should check with your child's pediatrician or a pediatric kidney disease specialist if your child has signs of nephrotic syndrome, [21]

Supportive care is an important aspect of managing children with nephrotic syndrome. Patient and Parent Education Adequate information about the disease, associated complications and the expected course should be provided. Parental motivation and involvement are essential in management of a child with nephrotic syndrome. measures are emphasized such as Urine examination for protein at home, maintain a diary showing proteinuria, medications received and intercurrent infections, Ensure normal activity and school attendance. [13]

Negative emotional for children with Nephrotic syndrome has biological, behavioral, and social manifestations that have implications on the mental health, social and personality development of the child, and family coping. Nephrotic syndrome in children has a significant impact on intellectual functions and behavioral aspects, including anxiety and depression. Parents of children with nephrotic syndrome are more likely to develop psychosocial problems, have less social adjustment, and have a poorer quality of life compared with parents of healthy children. [9]

The Role of the nurse is very important to aiding mother in acceptance of their child's condition, encourage the mother to know diagnosis and teach them how they can support their children by living normal life and accept negative emotion feelings, nurses should provide educational classes for the mothers and their children about nephrotic syndrome to elevate their level of health awareness about disease and its care. as well provide children and their mothers with useful source of information at home, in addition to mass media should provide educational mass media programs for such diseases.[1]

Significance of the study: Pediatric Nephrotic syndrome is the most common renal disorder, in childhood and adolescences; pediatric Nephrotic syndrome prevalence is 4-5% worldwide and in Egypt ranged from 11-12%. (National Center of Biological Information's NCBI ., 2017) . Also no one provide supportive care for children with Nephrotic syndrome at pediatric care setting.

Aim of the Study: This study aimed to assess the effect of supportive care activities on negative emotional feelings of Nephrotic syndrome children

Subjects and Method

I. Research Design: A quasi-experimental design was used to conduct this study.

Study Setting: The study was carried out at medicine department of children's hospital affiliated to Ain Shams University Hospitals

Subjects: The subject of this study was purposive sample composed of (50) children were attended to the previously mentioned setting and accompanying mothers

II. Technical Design: Tools of data collection: Data were collected through use of the following tools:

I. Interview Questionnaire:

I. An Interviewing Questionnaire: It was designed by the researchers after reviewing the related literature:

(1): Characteristics of children

(2): Characteristics of mothers of children and their knowledge.

Scoring System: Scores used to evaluate Mother's knowledge regarding nephrotic syndrome. The correct answer was taken score one and for the incorrect answer was taken zero scores. The total knowledge score interpreted as follows:

- Satisfactory knowledge was considering from 60 to 100%
- Unsatisfactory knowledge less than 60%

II. Children's Assessment of Participation and Enjoyment (CAPE): It was designed to examine how children and adolescence participate in everyday activities outside of their school classes. It measures children's participation in recreation and leisure activities outside of mandated school activities

Scoring System: Scoring system was done by allocating to each sentence a score (0) for No and (1) Yes. The score of items was summed-up and the total divided by a number of the items, giving a mean score of the part. These scores were converted into a percent score was classified as the following:

- < 60% Not participated in activity from zero < 33
- ≥ 60% Participated in activity from 34 – 55

III. Multidimensional Scale of Perceived Social Support (MSPSS), it was used to measure perceived social support.

Scoring System: Scoring system was done using three points Liker scale ranging from Zero to 2 respectively as (0) Rarely; (1) Sometimes; and (2) Always. The score of items was summed-up and the total divided by a number of the items, giving a mean score of the part. These scores were converted into a percent score was classified as the following:

- < 50% Low perceived social support from zero <12
- 50 %< 75% moderately perceived social support from 12 <18
- ≥ 75% highly perceived social support from 18 – 24

III. Operation Design: The operational design for this study consisted of three phases, namely preparatory phase, pilot study, and fieldwork.

Preparatory Phase: The researcher reviewed the literature and prepared the data collection tools including the socio-demographic and clinical data parts, as well as children`s emotional negative feelings scale, children's assessment of participation and enjoyment and multidimensional scale of perceived social support among children having nephrotic syndrome. This was served to develop the study tools for data collection. During this phase, the researcher also visited the selected place to get acquainted with the personnel and the study settings. Development of the tools was under supervisors' guidance and experts' opinions were considered

Pilot Study: A pilot study was carried out in the first half of July 2018, before data collection. The pilot study included 10% of the study subject fulfilling the previously mentioned criteria; it was conducted to evaluate the simplicity, practicability, legibility, understandability, feasibility, validity and reliability of the tool, it was also used to find the possible problems that might face the researcher and interfere with data collection to estimate the time needed to fill in the sheets. According to the results of the pilot study, no modifications were done in the tools. Those who shared in the pilot study were included in the main study sample

Fieldwork: Once permission was granted to proceed with the study, the researcher visited the study setting and met with mothers/children having nephrotic syndrome who fulfilled the inclusion criteria. The purpose of the study was explained to mothers/children. The researcher started the interview with the mothers/ children individually using the data collection tools. The researcher read, explained the steps of the study and choices were recorded for illiterate mothers, while educated mothers read and full the questionnaire by themselves.

The time consumed to fill out the full questionnaire ranged from 35 to 45 minutes for one questionnaire, each Saturday, Monday, and Thursday from 9:00 am to 12:00 pm in previously mentioned sitting

IV. Administrative Design: An official letter requesting permission to conduct the study was submitted from the Dean of Faculty of Nursing, Ain Shams University to obtain permission from the general director of children's hospital affiliated to Ain Shams University Hospitals to collect the data of the study. The agreement of each relative was obtained after explaining the aim and nature of the study

Ethical Considerations: Approval was obtained from the ethical committee to conduct this study. The researcher explained the study aim in a simple and clear manner to be understood by eligible mothers/children. Verbal consent was obtained by each participant before collecting any data. Participants were informed about their right to withdraw from the study at any time without giving any reason. Data were considered confidential and not be used outside this study without mothers approval.

V. Statistical Analysis: Data collected from the studied sample was revised, coded and entered using. PC. Computerized data entry and statistical analysis

were fulfilled using the statistical package for social sciences (SPSS) version 20. Data were presented using descriptive statistics in the form of frequencies, percentages. Categorical data were tested with the Chi-square test (X2) for qualitative variables and independent sample t-test for quantitative variables. Statistical significance was considered at p-value <0.05.

Results

Table (1) shows that, near to two thirds (64.0%) of the studied children were males, 32.0% of them their age ranged between 8<10 years old with mean± SD 8.1±1.4. Regarding to educational level, nearly to two thirds (60.0%) of the studied children were in primary school.

Table (2) shows that, more than one third (40%) of the studied children were fathers age ranged between 35<40 years old with mean± SD 37.1±2.9, while nearly to two thirds (60.0%) of the studied children fathers were age ranged between of 40<45 years old with mean± SD 42.6±2.4.

Table (3) shows that, more than one third (38.0%) of them were had illness for 2<4 years with mean± SD 2.3±0.8, near to three quarters (70.0%) of the studied mothers were discovered disease through signs and symptoms and the majority (94.0%) of them were treated with immunosuppression.

Table (4) shows that, nearly to half (42.0%) of the studied children were overweight, 46.0% of them were shorter than normal, 56.0% of them had normal head circumference, while 34.0% of them were had large arm circumference than normal

Table (5) clarifies that, there were statistically significant differences between the studied mothers regarding their knowledge in relation to meaning, causes and signs & symptoms of nephrotic syndrome throughout the pre and post intervention respectively (p<0.05).

Table (6) clarifies that, there were statistically significant differences between the studied mothers regarding their knowledge in relation to treatment & precautions of nephrotic syndrome throughout the pre and post intervention respectively (p<0.05).

Table (1): Number and percentage distribution of the studied children according to their characteristics (no= 50)

Items	No	%
Gender		
Male	32	64.0
Female	18	36.0
Age in years		
<6	2	4.0
6<8	13	26.0
8<10	16	32.0
10<12	9	18.0
12<14	7	14.0
14<15	3	6.0
Mean ±SD	8.1±1.4	
Level of Educational		
Read and write	8	16.0
Primary school	30	60.0
Preparatory education	14	28.0
Secondary school	2	4.0
Technical school	1	2.0

Table (2): Number and percentage distribution of the parents according to their socio-demographic characteristics (no=50)

Items	Mother		Father	
	No	%	No	%
Age in year				
25 < 35	13	26.0	4	8.0
35 < 40	20	40.0	10	20.0
40 < 45	12	24.0	30	60.0
45 <50	4	8.0	5	10.0
≤ 50	1	2.0	1	2.0
Mean ± SD	37.1±2.9		42.6±2.4	
Educational level				
Illiterate	3	6	2	4.0
Read & write	5	10.0	4	8.0
Primary	11	22.0	10	20.0
Preparatory	10	20.0	9	18.0
Secondary	20	40.0	22	44.0
University	1	2.0	3	6.0
Job				
Working	30	60.0	41	82.0
Did not working	20	40.0	9	18.0

Table (3): Number and percentage distribution of the studied children according to their illness history (no=50)

Items	No	%
Duration of illness in year		
< 2	17	34.0
2 < 4	19	38.0
4< 6	9	18.0
≤ 6	5	10.0
Mean ± SD	2.3±0.8	
Disease discovered through		
Accidental	2	4.0
Regular follow-up	4	8.0
Complications of other disease	9	18.0
Signs & symptoms	35	70.0
Type of treatment		
Immunosuppression	47	94.0
Antihypertensive	39	78.0
Antibiotics	28	56.0

Table (4): Number and percentage distribution of the studied children according to their anthropometric measurement (no= 50)

Items	No	%
Weight		
Over weight	21	42.0
Normal	17	34.0
Under weight	12	24.0
Height		
Shorter	23	46.0
Normal	16	32.0
Longer	11	22.0
Arm circumference		
Smaller	9	18.0
Normal	14	28.0
Larger	27	34.0

Table (5): Distribution of mothers regarding their knowledge about meaning, causes and signs & symptoms of nephrotic syndrome throughout the pre and post intervention (no=50)

Items	Pre		Post		X^2	P Value
	No	%	No	%		
Meaning of nephrotic syndrome						
Known	19	38.0	29	58.0	4.0	*0.04
Unknown	31	62.0	21	42.0		
Causes of nephrotic syndrome						
Known	22	44.0	33	66.0	4.88	*0.03
Unknown	28	56.0	17	34.0		
Signs & symptoms of nephrotic syndrome						
Known	9	18.0	27	54.0	14.06	**0.002
Unknown	41	82.0	23	46.0		

Table (6): Distribution of mothers regarding their knowledge about diagnosis, complications, treatment and precautions of nephrotic syndrome throughout the intervention (no=50)

Items	Pre		Post		X^2	P Value
	No	%	No	%		
Diagnosis of nephrotic syndrome						
Known	28	56.0	37	74.0	3.56	0.6
Unknown	22	44.0	13	26.0		
Complications of nephrotic syndrome						
Known	21	42.0	25	50.0	0.64	0.4
Unknown	29	58.0	25	50.0		

Items	Pre		Post		X^2	P Value
	No	%	No	%		
Treatment of nephrotic syndrome						
Known	20	40.0	33	66.0	6.78	*0.01
Unknown	30	60.0	17	34.0		
Precautions for nephrotic syndrome						
Known	15	30.0	26	52.0	5.00	*0.02
Unknown	35	70.0	24	48.0		

(*) Statistically significant at $p < 0.05$

Discussion

Nephrotic syndrome is a problem where albumin is released from the body into the urine. It means that one or both kidneys are damaged. The kidneys contain many coils of tiny blood vessels. Each of these is called a glomerulus. Glomeruli filter substances from the blood into the urine. Nephrotic syndrome occurs when the glomeruli stop working normally. A child with nephrotic syndrome may have: (very high levels of protein "albumin" in the urine, low levels of protein in the blood, tissue swelling all over the body "edema" especially in the belly "ascites", weight gain from excess fluid, high cholesterol levels in the blood and less urine) [2] .

The most common type is called Minimal Change Nephrotic Syndrome (MCNS). With MCNS, a child has times when symptoms get worse (relapses). But the condition can be managed over time. In rare cases, a child may develop kidney failure and need dialysis. Most children with this problem have idiopathic nephrotic syndrome. Idiopathic means that it occurs with no known cause. [18]

In rare cases, a nephrotic syndrome may occur in the first week of life. This is called congenital nephrotic syndrome. It is inherited by an autosomal recessive gene. This means that boys and girls are equally affected. A child inherits 1 copy of the gene from each parent, who are carriers. Carrier parents have a 1 in 4 chance of having a child with this syndrome with each pregnancy. The outcome for this type of nephrotic syndrome is very poor. [8]

This was supported by [5], who studied "Nephrotic syndrome in childhood "mentioned that, one third of the studied children were in the age group (8-10 years old), were the first child in their families and two thirds of them were males.

But this was not in accordance with [6] who conducted a study about "Psychiatric adjustment in children with nephrotic syndrome" showed that, one third of the studied children were in the age group (6-8years old) and were males.

The current work mentioned that, more than one third of the studied children mothers were in the age group (35<40 years old), while two thirds of their fathers were in the age group (40<45 years old). As regards their education level it was found that, less than half of them had secondary educational level. Also two thirds of the studied children mothers were working and the majority of their fathers were working (table 2).

This was in agreement with[15] whose study was about "Long-term outcome of children with steroid-sensitive idiopathic nephrotic syndrome" clarified that, regarding the educational level of the studied children parents less than half of them had moderate educational level, the majority of their fathers were working while two thirds of their mothers were working mothers .

In the study of[20], which was about "Treatment of idiopathic nephrotic syndrome: regimens and outcomes in children" showed that, two thirds of the studied children were shorter than normal and it was clear from this study that there was significant correlation between the growth retardation and nephritic syndrome.

Having knowledge and health related practice regarding chronic illness such as nephritic syndrome improve child and family health outcomes by promoting recovery, speeding return to school, promoting health behavior, and appropriately involving the child on his

or her own care decisions. Important strategies for helping child to cope include providing information within the child's cognitive ability, and helping parent to understand what choices they have [7]

This was in accordance with [4] whose study was about "How mothers perceive their children with the nephrotic syndrome" mentioned that, there was statistically significant difference between knowledge of mothers about nephrotic syndrome in relation to treatment, complications and follow up pre and post intervention.

This was supported by [12], who conducted " A study about knowledge of mothers of children with nephrotic syndrome toward recurrence of disease " clarified that, there was statistically significant difference between mothers of the studied children regarding their total knowledge in relation to nephrotic syndrome.

The study of [22], which was about "Assessment of mothers' practices toward children with steroid-sensitive nephrotic syndrome at pediatrics hospitals in Baghdad city college of nursing, university of Baghdad " showed that, there was highly statistically significant difference between perceived social support to nephrotic syndrome children in relation to (there is family that tries to help, have friends with whom can share joys and sorrows and can talk about problems with friends) pre and post intervention.

This was in agreement with [3] whose study was about "Psychological status of both children with the nephrotic syndrome or acute glomerulonephritis and their parents" clarified that, there was statistically significant difference between the studied children regarding their self-improvement activities in relation to (reading and doing homework) and their physical activities in relation to (performing activities and team sports).

This was supported by [17] who studied "Health-related quality of life and psychosocial adjustment in steroid-sensitive nephrotic syndrome" mentioned that, there was statistically significant difference between the studied children regarding their participation and enjoyment throughout the pre and post intervention .

This was supported by [11], who studied "Correlations between performance on neuropsychological tests in children with nephrotic syndrome "mentioned that, there was statistically significant difference between the studied children regarding their emotional negative feelings pre and post intervention.

Conclusion

The result of the present study concluded that Supportive care activities as, social support, recreational Activities, Social Activities, Self-improvement Activities, Active Physical Activities, Skill-based Activities intervention prevent the negative emotional feelings of Nephrotic syndrome children, namely, Emotion liability, Negativity dimension and Emotion Regulation dimension.

Recommendations

In the light of the study findings, the following recommendations are suggested:

1. Encourage use of Supportive care activities programs periodically for children with nephrotic syndrome disease and their mothers based upon their actual assessment to help them to prevent the negative emotional feelings of Nephrotic syndrome children.
2. Further studies should be conducted to study risk factors of rapid progression of the negative emotional feelings of Nephrotic syndrome children.
3. Availability of multidisciplinary team of supportive care as well as follow-up out-patient clinic that include pediatric nurses, renal physicians, social workers, dietitian, psychotherapists and physiotherapist to assist children and their families in maintaining near normal lifestyle at highest possible level of emotional feeling.

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