

## **SUMMARY**

Nephrotic syndrome is one of the most, chronic kidney disease in Egypt. The estimated incidence of nephrotic syndrome ranges between 2-7 childhood cases per 100,000 children per year. Childhood nephrotic syndrome can occur at any age but nephrotic syndrome is most common between the ages of 1.5 and 5 years. It seems to affect boys more often than girls throughout the world. This condition is due to inflammation of renal parts, infection, toxics, tumors, hereditary and idiopathic. It's also accounting for many days of school absenteeism and many hospital admissions each year. However, education for children and their mothers about nephrotic syndrome self-management skills including; steroids medication program, follow up of child with doctor according to child appearance, weight increase or oedema, amount of urine, color and protein analysis daily, breathing and coughing exercises and physical exercises; all these skill enable children and their mothers to cope with the disease and make nephrotic syndrome more controllable.

The aims of this study were to assess mothers' knowledge and practice about care of their children with nephrotic syndrome, design and implement a discharge guide program for mothers about care of their children with nephrotic syndrome, and evaluate the effect of the discharge guide program on mothers' knowledge and practice.

### **Research hypotheses:**

- Mothers are lacking knowledge and practice about care of their children with nephrotic syndrome.
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- Mothers after attending the training program will show an improvement in their knowledge and practice related to care provided to their children with nephrotic syndrome.

### ◆ **Research design:**

The present study follows a quasi-experimental research design to achieve its purpose. This design is a mean for examining casual relationships and manipulation of the independent variable. It is like true experiments, it involves the manipulation of an independent variable, which is the institution of an experimental treatment. However, the quasi-experimental design lacks of a control group.

### **I. Technical Design:**

The technical design included the setting, subjects as well as tools of data collection.

#### **Setting:**

This study was conducted at the Pediatric Departments in Benha University Hospital and Specialized Pediatric Hospital in Benha City.

The designated setting for data collection of this study was Benha University Hospital as demonstrated in the protocol but as a result of the unavailable of a suitable number of the study age group 2 to 12 years, the researcher selected another, the Specialized Pediatric Hospital in Benha City this hospital to complete the sample needed as they give medication to children with nephrotic syndrome for free.

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**Subjects:**

A representative sample of mothers of children with nephrotic syndrome (diagnosed by a physician) was included in the study from the previously mentioned settings, their total number was 80. In addition, the children were included in the study according to the following criteria from both sexes, their ages ranged from 2 to 12 years, free from any other chronic diseases such as; DM, liver diseases and diagnosed nephrotic syndrome.

**Tools of data collection:**

The following tools were designed and used by the researcher after reviewing a related literature and under supervision of the supervisors of the study.

**I Pre/post Assessment Questionnaire Format (Appendix I):**

It included the following parts:

**♦ Part One:**

1. Characteristics of children, it includes; age, sex, birth order and educational level.
  2. Nephrotic syndrome characteristics, it includes; time of child's complaints, symptoms felt by the child, seasonal effect of nephrotic syndrome relapse, relatives' complaints from kidney disease and then the relative relation's degree for the child, effect of nephrotic syndrome on child's health, number of nephrotic syndrome relapses during a year and the most common period of nephrotic syndrome relapse.
  3. Characteristics of mothers, it includes; age, level of education and occupation.
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4. Data from mothers about their child's medication, it includes; name and type of the prescribed drug, method and dose as recommended, regularity of the mother toward giving this medication for children.

♦ **Part Two:**

- 1- Mothers' knowledge regarding to nephrotic syndrome as definition, causes, symptoms (mild, moderate & severe), complications, medication and care of children during nephrotic syndrome relapse.
- 2- Mothers' knowledge regarding nephrotic syndrome triggering factors it includes; nutritional triggers, psychological, environmental, respiratory infection, playing and additional efforts and the relation between them toward nephrotic syndrome relapse occurrence and performing breathing, coughing and body exercises, collecting method of urine, urine analysis, assessment of edema degree care of children (skin & mouth), personal hygiene, treatment program and intake and output chart for the child and nutritional program.

**II Pre/post Mothers' Practice Checklist (Appendix II):**

It was prepared by the researcher to observe mothers' practice related to care of their children during nephrotic syndrome disease and care given by them to avoid relapse from occurrence, it includes;

***First;*** Mothers' interventions toward dealing with their children during relapse occurrence such as; avoiding exhausting exercises, putting the child in comfortable position, providing complete relaxation and complete bed rest, performing regular breathing exercise, providing mouth and skin care, giving special meals and providing regular follow-up (urine colour and

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amount, urine analysis, level of edema or increasing of abdominal cavity measurement, vital signs and skin condition) for the child

**Scoring system:**

The score of knowledge was divided into two levels: Mothers whose knowledge scores 60 grades or more were, they considered on the satisfactory level and those whose scores below 60 grades are on unsatisfactory level. Knowledge content was divided into 8 questions and each questions was assigned a score; three score level if the participant final score obtained is considered complete; below the final score it is considered incomplete knowledge, and if participant do not know the knowledge it is considered as incorrect. The total score of questionnaire responses was 24, accordingly, more than 75% was considered complete knowledge, 60-<75 was considered incomplete knowledge and less than 60% was considered incorrect knowledge. Meanwhile, the score of practice was divided into two levels, where mothers whose practice scores equal 80 grades, they or more are considered on the satisfactory level, and those whose scores are below 80 grades are on unsatisfactory level.

**III Discharge Guide Program (Appendix III):**

It was prepared by the researcher under supervision of the supervisors after reviewing the related literature, based on mothers' knowledge and practice deficit about nephrotic syndrome and care of their children during nephrotic syndrome relapse.

**II. Operational Design:**

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### **1) Preparatory phase**

A review of the current and past local and international related literature using books, magazines periodicals and internet was done to get acquainted with various aspects related to nephrotic syndrome definition, its causes, incidence, pathophysiology, triggering factors, its impact on child health and school activities, management, role of the nurse and its prognosis and then to develop the study tools and the content of the program.

### **2) Pilot study;**

A pilot study was carried out during January, 2010. It involved eight mothers of children with nephrotic syndrome and their children to test the applicability of the study tools and suitability of the setting and to determine the time needed to fill in the sheets no modifications were done or the forms by adding or omitting any questions.

### **3) Field work**

The field work was carried out in January, 2010 to April, 2011. The purpose of the study was explained by the researcher to all mothers of children with nephrotic syndrome who agreed to be included in the study. The average time needed for the completion of each interview (with a mother) was around 45-60 minutes.

A trust relation was established quickly between the researcher and the mothers during the initial interview. Mothers were openly and comfortably speaking about their educational experiences. Mothers expressed a sincere appreciation for nephrotic syndrome education and

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handouts provided to them before the beginning of first session making pre assessment and then orientation to the program. After each session, a feedback on the previous session was done and after completing all sessions, a post immediate assessment and follow up of the program through oral questions three months later was done using pre/ post tests.

#### **4) Program Construction**

The program was constructed based on the actual results obtained from the pre-program assessment using the interviewing questionnaire, practice checklist as well as literature review which aimed to satisfy the studied mothers' knowledge deficit and unsatisfactory practice regarding the care of their children with nephrotic syndrome.

#### **Steps of Program Construction:**

##### **A. General objectives**

The aim of this program was to improve the mothers' knowledge and practice regarding the care of their children with nephrotic syndrome.

##### **B. Specific objectives;**

By the end of this program, each mother should be able to:

*(According to the given handout and questionnaire)*

1. Define nephrotic syndrome.
  2. Determine classification of nephrotic syndrome
  3. Enlist types of nephrotic syndrome categories.
  4. Mention the triggering factors for nephrotic syndrome.
  5. Enumerate symptoms of nephrotic syndrome.
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6. Identify symptoms that refer to worsen nephrotic syndrome.
7. Determine lines of nephrotic syndrome treatment.
8. List types and doses of nephrotic syndrome medication.
9. Discuss methods that should be followed to avoid nephrotic syndrome.
10. Determine the nutritional requirements that should be given to the child.
11. Perform collecting method of urine, urine analysis, assessment of edema degree care of children and personal hygiene, treatment program, breathing, coughing and body exercises and intake and output chart for the child.
12. Apply interventions for the child during nephrotic syndrome relapse (nutritional program, care of edema, care of skin, care of mouth or general personal hygiene, follow up of the child with nephrotic syndrome (urine analysis, amount and colour of urine, level of edema, intake and output chart) and try to prevent the child with nephrotic syndrome from infection and relapse.

### **Program implementation:**

Implementation of the program was carried out at the previously mentioned settings. The subjects' material used has been sequenced through the 19 sessions, 10 sessions for theory and 9 sessions for practice. The duration of each session ranged from 45 to 60 minutes including periods of discussion according to mothers' achievement, progress and feedback. Sessions started according to mothers' suitable time, usually at 9.00 am.

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Mothers were divided into small groups, each group included about 4 to 5 mothers (depending on mothers' circumstances), in each session and the content was implemented for each group at every session separately for 9 weeks (3 days/week), in addition to one week for post test.

At the beginning of first session, an orientation to the program and its purpose took place. After each session, a feedback about the previous session was done and the objective of the new topics. Simple Arabic language was used to suit the mothers' level of understanding. Methods of teaching varied including lectures, group discussion, demonstration, re-demonstration and role play. Instructional media were used these include: booklet, colored posters and real objects, which include medication tablet, dipstick, container of dipstick and tape to measure level of edema or abdominal cavity

All mothers who were included in the study were cooperative with the researcher. They were interested in the contents of the study especially with the handouts that will remember them with all sessions' contents when they forget them.

During implementation of the study, all mothers who were included in the study reported that their children were in need for special care from them all the time.

### **Program evaluation**

After the implementation of the program, the post-test was done to test of the studied mothers' knowledge and practice by the same format of the pre-test to evaluate the effectiveness of the implemented program, this was done immediately after the intervention and showed differences between

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pretest and post-test.

### **5) Ethical considerations:**

A written consent was obtained from all study subjects;

- 1- All mothers' rights secured.
- 2- Each study subject should be informed with the nature process on expected outcomes of the study.
- 3- All data will be confidential and informed with the purpose.
- 4- Each study subject is informed time throughout the study.

## **III. Administrative Design**

The necessary approvals to conduct the study were obtained from the chairman of the selected settings through formal letters from Dean of the Faculty of Nursing at Benha University, with the title and objectives of the study

## **IV. Statistical Design**

The collected data were organized, categorized, tabulated and verified prior to computerized entry; statistical analysis was done by using The Statistical Package for Social Science (SPSS) version 7. Data were presented in tables using mean, standard deviation, number, percentage distribution, correlation coefficient and paired t-test.

According to the findings of the exploratory phase, mothers' knowledge deficit about nephrotic syndrome and care needs of their children with nephrotic syndrome were determined. Accordingly, the general and specific objectives of the program were stated. Program content was developed as well as teaching methods were prepared. The study tools used

for assessment (questionnaire sheet and observation sheet) were used to evaluate the effect of the program.

**\*The findings of this study can be summarized as follows:**

1. The mean age of children was  $6.29 \pm 2.41$  years, half of them were females with the highest percentage (67.5%) of children in primary schools.
2. The mean age of the studied mothers was  $28.80 \pm 5.61$  years. More than two fifths of mothers (43.8%) had technical education and less than three quarter of them (72.5%) are working.
3. The study reflected that there was more than one quarter (26.3%) of children had their nephrotic syndrome symptoms from 4-6 years. Meanwhile, two fifths (40%) of children their relatives were suffering from kidney disease, where 37.5% of them were relatives from the first degree for the child.
4. Regarding source of mothers' information about their child's nephrotic syndrome, for less than two thirds (65%) of them, they had their information from doctors. Meanwhile, the minority (2.5%) of nurses were providing mothers with information about nephrotic syndrome.
5. During pre-program implementation, 92.5% of children had relapsed four times or more per year, for 53.75% of children the average period of relapses was 5-8 years.
6. After program implementation, 48.2% of children their relapses occurred once per year.
7. Pre-program implementation all (100%) of mothers didn't know the exact name and type of prescribed drug for their children. Moreover,

the majority of those mothers were giving medication for their children only during relapse. After implementation of the program, there were improvement in mothers' knowledge about medication.

8. Mothers' mean scores of knowledge and practice improved significantly in relation to their child with nephrotic syndrome at the post-program implementation rather than pre-program implementation
9. There was a highly statistically significant difference ( $P < 0.001$ ) between total mothers' knowledge during pre and post program implementation.
10. There were highly statistically significant differences ( $P < 0.001$ ) between total mothers' practice during pre/ post program implementation.
11. No relations found between mothers' characteristics and their knowledge immediately after program implementation phase, as well no relation with their practice at pre- program implementation phase .

**\*Conclusion:**

In the light of the study findings, it was concluded that mothers' knowledge and practice related to care provided to their children with nephrotic syndrome was deficient as none of them had a pre-program satisfactory knowledge or adequate practice. That would have a negative impact in their ability to care of their children. Several socio-demographic factors had their reasonable impact on mothers' knowledge and practice, such as age, level of education and their working status. The developed discharge guide program to significant improvements in mothers' knowledge and practice. This means that the research hypothesis that mothers' knowledge and practice will be improved after implementation of the

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discharge guide program and the presence of positive correlation between their knowledge and practice was achieved throughout the study.

**\*Recommendations:**

Based on the findings of the current study, the following recommendations are proposed;

1. Provide mothers of children with nephrotic syndrome by updated pamphlets, posters and Arabic booklets about nephrotic syndrome which contain an action plan suitable for each child's nephrotic syndrome nature in order to facilitate improving their knowledge as they considered the main member in children's care team.
2. Socio-demographic factors of caregivers especially mothers should be taken into account in designing a nephrotic syndrome educational program such as their ages and educational level.
3. Mothers' knowledge and practice should be evaluated continuously through nurses to ensure the effectiveness of the provided care for their child and to achieve nephrotic syndrome control outcomes.