



SUMMARY

Nephrotic syndrome is an a clinical state characterized by edema, massive proteinuria, hypoalbuminemia, and altered immunity. Approximately 90% of children with nephrotic syndrome have a type of primary disease called MCNS that is steroid responsive. Childhood NS can occur at any age but is usually occurs in children between the age 2-7 years .The estimated incidence of NS ranges between 2-7cases in children per 100,000 children per year in the united states. It seems to affect boys more often than grils.This high rate of affected individuals posses a significant public health problem. Mothers play an important role in providing care to their children includes administer medications reported potential side effects, daily urine analysis for protein, monitoring the child's weight, and prevent infection or protect their children from infection.

Aim of this study:

The study aims to assess maternal management of children with nephrotic syndrome and their quality of life .

Subjects and Methods:

A) Research Design:

A descriptive design was used in this study

B)Research settings:

This study was conducted at Benha University Hospital and Children Specialized Hospital .



(C) Sample:

All children with nephrotic syndrome and their mothers were Recruited the previously mentioned setting was included in this study during the period of 6 months was (from october2009 to March2010) with the number of 100

C)Tools:

Data was gathered using two tools interview questionnaire sheet. It was designed by researcher after reviewing related literature and composed of (4)parts .

Part (1): Socio-demographic data of the studied mothers such as (age, level of education, occupation, and number of children in the family)

Socio demographic characteristics of the children such as (age ,sex and birth order).

Part (2): Mothers knowledge about nephrotic syndrome such as definition, causes, sign and symptoms, complication.....etc.

Part (3) :Care provided by mothers to their children with nephrotic syndrome such as skin care ,prevention of infection, nutritional and fluids needs, urine analysis for albumin,.....etc.

Part (4): Mothers knowledge about quality of life of their children with nephrotic syndrome it included child daily living such as (physical, social, emotional status of children,...etc).



Finding of this study can be summarized as follows:

- The mean age of studied mothers was 20.7 ± 0.256 years. The mean age of studied children with NS was 4.85 ± 0.868 years.
- Three quarters of mothers of the (74%) didn't know the definition of NS and the majority of them (98%) reported incomplete answer about signs and symptoms while the majority of them (93%) don't know the complication of the disease.
- The majority of mothers (89%) had incomplete don regarding technique of skin care , while as slightly more than three quarter of them (78%) didn't know how to prevent child infection and about 2/3 of them (63%) didn't know the importance of skin care .
- The present study revealed that the majority of mothers (94%) did urine analysis and measure child weight for their children at the time of follow up visit.
- The present study revealed that two thirds of mothers (66%) did regular follow up for their children .
- The present study revealed that all of the children studied go to school alone and 37% absence from school as the nature of the disease and nearly half (46.30%) of them lack in academic achievement.
- The present study revealed that there was statistically significant between total score of mothers knowledge about quality of life, sociodemogarghic characteristics and their education, occupation and age of child and their quality of life ($P < 0.05$)



- The present study revealed that there was a highly statistically significant difference between total score of mothers practice, their sociodemographic characteristics and their age, education, occupation, residence and care provided to their children ($P < 0.001$)
- The present study revealed that there was statistically significant difference between total knowledge, practice of mothers and the quality of life total scores

CONCLUSION:

It can be concluded from the present study that:

1. Male more affected than female and their age between (4-6) years old.
2. The majority of mothers had deficit in their knowledge and unsatisfactory incomplete practice regarding care of their children suffering from nephrotic syndrome.
3. Mothers perceived that their children have low QOL.

RECOMMENDATION:

In the light of the previously findings the following recommendation are suggested:

1. Periodical educational training program for mothers at hospital by using booklets and other audio visual aids
2. Provision of periodic health teaching to mothers about how to monitor urine analysis for protein daily, check the child's weight weekly to assess the fluid retention.
3. Reinforce mothers of the importance of follow up.

Orientation program for mothers to improve their performance care and the quality of life for children with nephrotic syndrome .