Nephrotic Syndrome Knowledge and Health Care Related Practices among School Age Children and their Mothers

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Abstract

Background: Nephrotic syndrome is documented as a common chronic disease in childhood. The knowledge of parent from different angles of the disease is vital to increase the parental awareness about therapeutic facilities to treat children and to enhance the quality of life and the health of the community.

Aim of the Study: The current study was designed to assess nephrotic syndrome knowledge and health care related practices among school age children and their mothers.

Subjects and Methods: A descriptive exploratory research design was utilized in this study. A convenient sample includes 50 school age children aged 8-12 years old with nephrotic syndrome and their mothers. The settings were the Pediatric Medicine Inpatient Departments and Outpatient Clinic at two Pediatric Hospitals affiliated to Cairo University. The required data was collected through structured interview questionnaire which developed by the research investigator. Nephrotic syndrome knowledge sheet and health related practices questionnaire were developed to assess knowledge and health care related practices among school age children with nephrotic syndrome and their mothers.

Results: The current study revealed that the highest percentages of the children who suffer from nephrotic syndrome and their mothers had unsatisfactory level of total knowledge and health related practices.

Conclusion: Mother education, occupation, place of residence and family income had a high statistical significant relation with mothers’ total knowledge and health related practices, however there were no statistical significant relation between mothers’ age and their knowledge. In addition, children age, education and place of residence and family income had statistical significance relation with children total knowledge.

Recommendations: 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.

Key Words: Nephrotic syndrome – School age children – Mother – Knowledge – Health related practices.

Introduction

TODAY’s children’s are tomorrow’s citizens, a well-developed child adds to the nation welfare and children are the precious resources of the nation. The most precious resources of any country are children. It is our responsibility to protect them against all forms of exploitation and discrimination. Each new child offers humanity another chance for survival, a child is considered as the future hope of the family and as an individual he will determine the kind of status the family would gain in the future [1].

Nephrotic Syndrome (NS) or nephrosis is the most common presentation of glomerular injury in children. NS is characterized by massive proteinuria, hypoalbuminemia, hyperlipidemia and edema as a result of increase glomerular permeability to plasma protein result in massive urinary protein loss [2,3]. NS is a disease that can be seen all over the world the annual incidence rate of NS in children aged below 16 years is 2 to 7 new cases per 100 000, with a prevalence rate of 16 cases per 100 000. Incidence peaks between 2-5 years old. Male are more affected than female the ratio is 2:1. The incidence rate of NS in children is 15 times higher than in adults [4,5]. Amongst Egyptian children 243 deaths annually are due to NS, this ranks Egypt as the second country in the world in this regard, preceded only by Japan which tallies up to 447 deaths, the united states follow closely behind Egypt with 153 deaths [6,7].

Primary (Idiopathic) NS is the most common type about (90%) of children who present with the
typical features of nephrotic syndrome [8,9]. The exact cause of NS is unknown and it cannot be prevented, however many diseases and conditions can cause glomerular damage and lead to NS. It may be primary (idiopathic) NS (90%) as MCNS, membranous nephropathy or congenital NS, as congenital syphilis or secondary NS as use of certain drugs or certain immune diseases, after infections as hepatitis B and C, Human Immune Deficiency Virus (HIV) [10,11].

Edema is the presenting symptom in about 95% of children with NS. Early on, the edema is intermittent and insidious noted mostly in the periorbital, scrotal, and labial regions, symptoms of infection can be diagnosed, such as fever, lethargy, irritability, or abdominal pain weight gain and ascites while hypertension and gross hematuria are uncommon [12].

The main aim of therapeutic management is reducing excretion of protein in urine, reducing retention of fluids in tissues preventing infection and minimizes complication related to therapies [13], treatment for NS includes initial treatment as starting treatment with prednisolone and nonspecific treatment as antihypertensive therapy. Immunosuppressive drugs, antibiotic prophylaxis, and supportive treatment as include diet, high in protein and fiber but low in saturated fat and salts children with mild to moderate edema may be managed in outpatients clinics [14,15].

Nurses should assess child's condition but the first priority is to assess the child’s fluid status as the hypoalbuminemia predisposes the child to the risk of developing hypovolemia. Whereas nursing interventions involves administering medications which are diuretics, antibiotics and corticosteroids as prescribed. Asking dietitian to plan a low sodium diet with moderate amount of protein, instructing children in restricting fluid intake, providing meticulous skin care to combat edema, encouraging activity and exercise, monitoring and document the location and character of edema, monitoring intake and output hourly and stressing the importance of adhering to the special diet [4].

Many school age children with nephrotic syndrome were hospitalized frequently with relapse of disease; the factors related to these relapses were respiratory infection, skin infection, taking steroid irregularly, and high salt diet. Therefore, relapse and infection among these school-age children with nephrotic syndrome might reflect either improper self-care practices of the child or inappropriate children care management by the families, in addition to hospitalization causes certain changes in routine, such as change in family dynamics, the disruption or delay in education [16].

Hospitalization causes certain changes in routine, such as change in family dynamics, the disruption or delay in education, the affective deficiencies, maternal deprivation, physical and psychological aggression, so that the child, who is ill and hospitalized, becomes more fragile and sensitive emotionally. In this sense, the impact of NS can be reflected in several areas of the child’s life, possibly interfering on the chances for a healthy socio-emotional development and sharing in children activities, limiting the independence of the child, since parents usually control the habits of children and contact with other children, in order to protect them, for fear that the child can get infections. This limitation affects the understanding and acceptance of the disease by the child [17,18].

Having knowledge and health related practice regarding chronic illness such as NS 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 [19].

Aims of the study:
The aims of the current study were to:
- Assess NS knowledge and health care related practices among school age children.
- Assess NS knowledge and health care related practices among mothers of school age children.

The research questions:
- What is NS level of knowledge and health care related practices among school age children?
- What is NS level of knowledge and health care related practices among mothers of school age children?

Subjects and Methods
Research design:
A descriptive exploratory research design was utilized to carry out this study.
Setting:
The current study was conducted at the pediatric medicine departments (2nd & 4th floor) at Cairo University Specialized Pediatric Hospital (CUSPH) and at the medicine departments (5th & 6th floor) and outpatient clinic at Pediatric University Hospital (EL-Moniera Hospital) affiliated to Cairo University. Data collection was conducted over six months period extended from January 2014 till June 2014.

Study subject:
A convenient sample of 50 school age children with nephrotic syndrome and their mothers will be included in the study.

Inclusion criteria:
1- Children with confirmed diagnosis of NS.
2- Age 8-12 years old.
3- Both gender.

Exclusion criteria:
1- Children with congenital anomalies or other chronic illness.
2- Children with mental retardation or other disabilities.

Tools for data collection:
Structured interview schedule was developed by the researcher based on extensive review of related literature and consultation of the experts and composed of 115 questions under five parts:

I- Personal health related data about the child it contained 6 questions such as (age, gender, birth rank, school and number of other siblings).

II- Personal health related data about the mother it contained 12 questions such as (age, education level, occupation, family income and number of other children).

III- Medical history of the studied children it contained 21 questions about previous illness of child, previous admission, child's age at disease onset (years), past medical history of child's family, nutritional status, urine amount in the last 12 hours, clinical signs noticed before admission and treatment received before.

IV- Knowledge assessment sheets: This sheet consisted of two sections each section contains 32 questions for each mother and 32 questions for each child which cover their knowledge regarding definition of disease, causes, signs and symptoms, investigations done to the child, NS specific diet, early signs of infection, oral medication and side effects.

V- Health related practice sheet: This sheet consisted of two sections each section contains 6 questions for each mother and 6 questions for each child which cover their reported practice regarding management of NS such as general hygiene practices, regular follow-up measures such as (measuring weight, intake and output, measuring temperature, blood pressure and check protein in urine), administration of medication, proper following of nutrition and psychological reassurance of the child.

Scoring system:
Scoring system for mothers or their children regarding their knowledge and reported health related practices about NS: Scoring system was graded according to the items of the interviewing questionnaire sheet; mother or child answers were evaluated using model answer sheet prepared by the researcher. Each correct answer took two scores, incomplete answer took one score and wrong answer took zero. The total score of mothers' or their children regarding their knowledge and reported health related practices about NS was 76 score 64 score for knowledge of mothers or their children about NS and 12 scores for reported health related practices about NS). The total mothers or their children knowledge was scored as less than 50% was considered as unsatisfactory (less than 38) while score of 50% and more is considered as satisfactory (up to 38).

Field work:
Before conducting the study an official permission had been obtained from the directors of at two Pediatric Hospitals as well as permission from the heads of pediatric medicine departments and outpatient clinics. Through an interview the researcher explained the questionnaire to each mother and her child individually; the researcher started to ask the mother and her child about personal data and medical history. After that the child was asked first about his or her knowledge about nephrotic syndrome and later on about his or her practices regarding self-care. And then the mother was asked about her knowledge about NS and later on about her health care related practices regarding her child. After finishing interview, the researcher appreciated the child and his mother for participation. The procedure toke one session in a closed room, each session take from 40-45 minutes.
Content validity:
The study tools were revised by 5 expert professors in fields of pediatric nursing and pediatrics who reviewed the content for clarity, relevance, comprehensiveness, understanding, applicability and easiness for administrative. Minor modifications were required. The content validity of this tool was checked by the researchers and correction was carried out accordingly.

Tool reliability:
The internal consistency was measured to identify the extent to which the items of tools measure the same concept and correlate with each other. Internal consistency estimates reliability by grouping questions in questionnaire that measure the same concept. One common way of computing correlation value among the question instruments is by using Cronbach’s alpha. Regarding to the reliability of this study tools coefficient alpha of questionnaire sheet was 0.7.

A pilot study:
A pilot study had been done on 5 of children and their mothers to test the feasibility of the study, application of tools, clarify of sentences and to estimate the time required to collect required data and needed modifications will be done.

Administrative and ethical consideration:
Ethical approval was obtained from the relevant Research Ethical Committee in the Faculty of Nursing, Cairo-University, to approve the study. A written formal consent is obtained from the mothers of children after explaining to them the aim of the study, its benefits and risks, duration of the study and the data collection tools. The researcher informed the mothers and children that all data gathered during the study considered confidential. The researcher also informed them about their rights to withdraw from the study at any time without giving any reason and without any effect on the care of provided to the child.

Statistical design:
The collected data were coded, categorized, tabulated and analyzed by personal computer using SPSS windows statistical package for social science Version 21. Frequency and percentage were used for numerical data as well as mean ± standard deviation, minimum and maximum. For finding the differences between numeric data, t-test was used. In addition, correlation coefficient was used to describe association between variables in the same group. Correlation coefficient (r) of 0.5 was considered fair correlation, if more than 0.5 to 0.75, it was considered good correlation, and if more than 0.75, then it was considered as very good correlation. Probability (p-value) less than 0.05 was considered significant and less than 0.001 considered as highly significant.

Results
Fig. (1) revealed that, less than three quarters of the studied children (74%) were in the age group 8 to less than 9 years old while, the minority (8%) of children age was between 11-12 years old with a mean of age 8.56±1.07 years.

Considering children gender, more than three quarters of them (76%) was male while 24% were females. The majority of the studied children were in primary school (88%) while 12% of them were in preparatory school. Regarding children' rank, it was found that less than half of the children, (48%) ranked as middle child, followed by 28% were the first child and 24% were the last child.

Table (1) indicated that, 46% of mothers were in the age group between 30-39 years old, while, the minority (16%) was in the age group more than 40 years old with a mean of age 33.70±6.37 years. As regards educational level of the studied mothers, 32% of them finished secondary school education and only (10%) finished higher education. Regarding working status of the mothers, the majority (86%) was house wives. Considering place of residence, it was found that 78% of mothers live in rural areas while the minority of them (22%) live in urban areas. As regards family income, half of the families (50%) had hardly sufficient income, less than half (46%) of the families had insufficient income and the minority (4%) had sufficient income.

Table (2) showed that, the vast majority of the studied mothers (92%, 92% and 94% respectively) had unsatisfactory level of knowledge about NS, diet and follow-up. Less than two thirds of the mothers (62%) had unsatisfactory knowledge about treatment, while the vast majority of mothers (94%) had unsatisfactory score in their total knowledge. As well as less than three quarters of them (74%) had unsatisfactory score in their reported health care related practices. For the children' knowledge about NS; the vast majority of them (94% and 90% respectively) had unsatisfactory level of knowledge about NS, diet. The majority of the studied children had unsatisfactory knowledge about follow-up, and treatment of NS. (96% and 86%, respectively)
regarding their total knowledge score about NS and their reported health care related practices; the majority of them (90%, 92% respectively) had unsatisfactory scores of knowledge.

Table (3) illustrated that, the mean scores of children, knowledge about NS was 21.60±6.08 and it was 3.84±1.84 for their reported health care related practice. While the mean score of mothers' knowledge about NS was 23.18±5.23 and it was 5.18±2.04 for their reported health care related practice. There was a highly statistically significant differences between total children and mothers' knowledge scores of reported health related practice \((p=0.000)\). On contrast, there is no statistically a significant difference between total scores of, child and mother knowledge.

Table (4) revealed that, there was highly statistical significant positive correlation between mother knowledge and reported health care related practice \((p=0.000)\).

Table (5) indicated that, there was a highly statistically significant positive correlation between children total knowledge scores and knowledge about health care practice \((p=0.000)\).

There was a highly statistical significant positive correlation between mothers total knowledge and reported health care related practices and their level of education, family income, place of residence and working status. However there is no statistical significance relation between mothers' total knowledge or reported health care related practices and their age. Regarding children with NS, there was a highly statistical significant positive correlation between children total knowledge and reported health care related practices and their age, level of education, family income and place of residence.

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**Table (1): Demographic characteristics of mothers of children with NS (N=50).**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (in years):</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>19</td>
<td>38.00</td>
</tr>
<tr>
<td>30-39</td>
<td>23</td>
<td>46.00</td>
</tr>
<tr>
<td>40 and more</td>
<td>8</td>
<td>16.00</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>33.70±6.37</td>
<td></td>
</tr>
<tr>
<td><strong>Educational level:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>15</td>
<td>30.00</td>
</tr>
<tr>
<td>Can read and write</td>
<td>6</td>
<td>12.00</td>
</tr>
<tr>
<td>Primary school</td>
<td>6</td>
<td>12.00</td>
</tr>
<tr>
<td>Preparatory school</td>
<td>2</td>
<td>4.00</td>
</tr>
<tr>
<td>Secondary school</td>
<td>16</td>
<td>32.00</td>
</tr>
<tr>
<td>Higher education</td>
<td>5</td>
<td>10.00</td>
</tr>
<tr>
<td><strong>Occupation:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>7</td>
<td>14.00</td>
</tr>
<tr>
<td>House wife</td>
<td>43</td>
<td>86.00</td>
</tr>
<tr>
<td><strong>Place of residence:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>39</td>
<td>78.00</td>
</tr>
<tr>
<td>Urban</td>
<td>11</td>
<td>22.00</td>
</tr>
<tr>
<td><strong>Income:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td>2</td>
<td>4.00</td>
</tr>
<tr>
<td>Hardly sufficient</td>
<td>25</td>
<td>50.00</td>
</tr>
<tr>
<td>Insufficient</td>
<td>23</td>
<td>46.00</td>
</tr>
</tbody>
</table>

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**Table (2): Mothers and children level of knowledge and health care related practice about NS.**

<table>
<thead>
<tr>
<th>Items</th>
<th>Mothers (N=50)</th>
<th>Children (N=50)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Satisfactory</td>
<td>Unsatisfactory</td>
</tr>
<tr>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Knowledge about NS.</td>
<td>4 8.00</td>
<td>46 92.00</td>
</tr>
<tr>
<td>Knowledge about diet.</td>
<td>4 8.00</td>
<td>46 92.00</td>
</tr>
<tr>
<td>Knowledge about treatment.</td>
<td>19 38.00</td>
<td>31 62.00</td>
</tr>
<tr>
<td>Knowledge about follow-up.</td>
<td>3 6.00</td>
<td>47 94.00</td>
</tr>
<tr>
<td>Total knowledge level.</td>
<td>3 6.00</td>
<td>47 94.00</td>
</tr>
<tr>
<td>Reported health care related practices level.</td>
<td>13 26.00</td>
<td>37 74.00</td>
</tr>
</tbody>
</table>
Table (3): Comparison between total means score of mothers and children knowledge and health related practice about NS.

<table>
<thead>
<tr>
<th>Item</th>
<th>Min-max</th>
<th>Mean±SD</th>
<th>t</th>
<th>p  (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total knowledge of child about NS</td>
<td>11-34</td>
<td>21.60±6.08</td>
<td>–1.673</td>
<td>0.101</td>
</tr>
<tr>
<td>Total knowledge of mother about NS</td>
<td>1-8</td>
<td>23.18±5.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reported health related practice of child about NS</td>
<td>14-37</td>
<td>3.84±1.84</td>
<td>–3.809</td>
<td>0.000**</td>
</tr>
<tr>
<td>Reported health related practice of mother about NS</td>
<td>2-12</td>
<td>5.18±2.04</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**: Statistical significant at p≤0.01.

Table (4): Correlation between mothers knowledge about NS and health care related practice.

<table>
<thead>
<tr>
<th>Item</th>
<th>General knowledge of mother about NS</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Knowledge about health related practice of mother about NS</td>
<td></td>
<td>0.605</td>
<td>0.000**</td>
</tr>
</tbody>
</table>

**: Correlation is significant at p<0.01 level (2-tailed).

Table (5): Correlation between children knowledge about NS and health care related practice.

<table>
<thead>
<tr>
<th>Item</th>
<th>General knowledge of children about NS</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>* Knowledge about health related practice of children about NS</td>
<td></td>
<td>0.545</td>
<td>0.000**</td>
</tr>
</tbody>
</table>

**: Correlation is significant at p<0.01 level (2-tailed).

Discussion

Regarding to personal data of children; it was found that, less than three quarters of the children were in between 8 years->9 years with mean age 8.56±1.07 years. So most of children were in primary school this result at the same line with [20]. Who studied behavioral changes among 60 Egyptian children with NS, the authors indicated that the mean age of children with NS in Egypt was 8.38±0.75.

As regards children' gender, the current study revealed that more than three quarters of the studied children were male which is compatible with most of literature that NS male children more than female. In the same field, [7] studied NS in Egyptian children: They found that male to female ratio was 2.5:1. In the same context, [21] concluded that there is a male predisposition with ratio 2:1 male to female. In contradictory with [8], who studied patterns of childhood steroid- sensitive and steroid-resistant NS in kingdom of Saudi Arabia on 87 child results of his study showed that the male to female ratio was almost 1:1 in children with NS.

Regarding to personal data of the studied mothers, more than one quarter of them were illiterate so that as expected mothers educational level effect their level of knowledge which reflect on their care for their children with NS, this result is similar to [22] who studied mothers’ care for children having NS and indicated that mother with higher education were more responsive to information about herself and her child health care. On contrary, [23] studied knowledge of 66 parents of children with NS toward recurrence of disease at specialized clinic of nephrology of medical-professional center in Iran and stated that however the low level of education of the studied mothers, they were with the favorable knowledge towards the disease.

Regarding to mothers of children with NS age, the highest percentage for their age is between 30-39 years old with mean age 33.70±6.37. However, it is observed that mothers aged from 30-39 years old had more knowledge than younger or older age and that this may be due to their age they are able more to learn and gain information than other age group in the same context, [28] assessed 80 mothers’ practices toward children with steroid sensitive NS at pediatric hospitals in Baghdad city college of nursing, they found that more than quarter of the mothers in the age group (30-34 years old).

The current study illustrated that, more than one quarter of the studied mothers had satisfactory level of knowledge about treatment of NS. However, most of the mothers and their children had unsatisfactory knowledge about NS, diet, treatment and follow-up. In relation to mothers’ total knowledge and health care related practice. There was highly statistical significant positive correlation between mothers’ knowledge about their children with NS and their reported health care related practice so that mothers who had unsatisfactory knowledge about NS had unsatisfactory reported health care related practice and this might be a result of illiteracy, low economic status. Most of the mothers were housewives and live in rural areas that may be outreach health care delivery system which can be a barrier for delivery of...
The current study showed that, there was highly statistical significant correlation between mothers' knowledge regarding NS and their level of education, working status, place of residence and family income as mothers' knowledge was increased with highly educated mothers, with housewife's mothers, and mothers who live in urban areas than rural areas and by increased family income. Meanwhile there were no statistically significant relation between mothers' age and their knowledge and their reported practices. This result was supported by [24] and [22] who studied the behavioral abnormalities in children with NS. They concluded that mothers had unsatisfactory level of knowledge due to their demographic characteristics as age, education, occupation, place of residence and family income.

Regarding to children' level of knowledge, the majority of them had unsatisfactory knowledge about NS, diet, treatment and follow-up. For their total knowledge and health care related practice most of them had unsatisfactory level of knowledge and this may be a result of cognitive abilities which is still developing and also the main source of their information was their mothers who are already had unsatisfactory knowledge, so the child gets wrong or incomplete information, this was at the same line with [16] who indicated that the risk of children low knowledge level about self-care increases with low educational levels and this could be related to the fact that low educated parents cannot help their children to perform correct healthy practices. There was highly statistically significant correlation between children knowledge and reported health care related practice. There was statistically significant correlation between child level of knowledge and their age, education, place of residence and family income as older children, higher grade children, children who live in urban areas and higher income had more knowledge.

Regarding to comparison between mothers and their children knowledge and reported health related practice. There was statistically significant difference between total mean score of children and mothers of health related practice. On contrast, there was no statistically significant difference between total child and mother knowledge. While, higher knowledge and reported practices observed with mothers than children however mothers knowledge and health related practices was scored as unsatisfactory.

Based on the study's results, the majority of mothers and their children with NS need health education programs for raising their level of knowledge and health related awareness this result is in congruent with [18] who perform a qualitative study on how mothers perceive their children with the NS. The authors suggested that formation of groups with mothers of children with NS in the days of consultations to clarify more and more about the aspects of the disease and the importance of actions in their child’s daily life; would be important to strengthen mothers' knowledge, at the time of the meetings in hospitalizations.

Conclusion:

It was concluded from the current study results that the highest percentages of the mothers had unsatisfactory level of total knowledge regarding care for NS. Mother's education, occupation, place of residence and family income had high statistical significance with mothers' total knowledge, however there were no statistical significance between mothers' age and their knowledge. In addition, the highest percentage of the studied children who suffer from NS had unsatisfactory level for total knowledge about NS. Children' age, education, place of residence and family income had statistical significance with children total knowledge.

Recommendations:

On the light of the findings of the current study, the following were recommended: 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 Arabic leaflet as useful source of information at home.in addition to mass media should provide educational mass media programs for such diseases.

References

NS Knowledge & Health Care Related Practices among School Age Children


