Assessment of mothers' practices toward children with steroid – sensitive nephrotic syndrome at pediatrics hospitals in Baghdad city

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المستخلص

الهدف: تهدف الدراسة إلى تقييم ممارسات الأمهات باتجاه الأطفال المصابين بمتلازمة التناذر الكلوي المتحسس للستيرويد، اللواتي يراجعن الوحدات الإستشارية لأمراض كلى الأطفال، وإيجاد العلاقة بين هذه الممارسات والصفات الديموغرافية للأم والطفل.
المنهجية: دراسة وصفية أجريت في الوحدات الإستشارية لأمراض كلى الأطفال في مستشفيات الأطفال (مستشفى الطفل المركزي، مستشفى حماية الأطفال، مستشفى الكاظمية التعليمي) للمُدّة من الثامن عشر من شهر شباط ولغاية نهاية شهر مايس ٢٠٠٩. عيّنة غرضية من (٨٠) أم مرافقة لطفلها. جُمعت المعلومات من خلال بناء استمارة استبيانية تكوّنت من قسمين؛ القسم الأول يخص الصفات الديموغرافية للأم والطفل، والقسم الثاني يخص ممارسات الأمهات عن متلازمة التناذر الكلوي المتحسس للستيرويد. أُستعمِلَ أسلوب المقابلة مع الأمهات لغرض ملء الاستمارة. تمّ تحديد مصداقية الاستبانة من خلال مجموعة خبراء. أمّا الثبات، فقد تمّ تحديده من خلال الدراسة الاستطلاعية وأجريَ تحليل المعلومات إحصائياً وفقاً لنظام التحليل الإحصائي الوصفي للعلوم الاجتماعية الإصدار (١٥) باستعمال التحليل الوصفي والاستنتاجي.
النتائج: أظهرت نتائج الدراسة أنّ ممارسات الأمهات ضعيفة بنسبة ٦١,٣%. كشفت نتائج الدراسة وجود علاقة إحصائية بين ممارسات الأمهات والمستوى الثقافي للام، ومُدّة إصابة الطفل بالمرض. بينما عمر الأم، وظيفة الأم، عمر الطفل، عمر الأم، جنس الطفل، تاريخ ظهور المرض، الأمراض السابقة للطفل، الوراثة لم تظهر أي علاقة ذات دلالة إحصائية معنوية.
التوصيات: أوصت الدراسة بالتثقيف الصحي حول المرض للأمهات والذي قد يحسن ممارساتهن.

Objective(s): To assess mothers' practices toward children with steroid – sensitive Nephrotic Syndrome (SSNS) who are visiting nephrology consultation units, and to find out the relationships between their practices and the demographical data for mother and child.

Methodology: A descriptive study was carried out at nephrology consultation units of Baghdad pediatrics hospitals (Child's Central Pediatric Teaching Hospital, Al-kadimiyia Teaching Hospital, and Welfare Teaching Hospital) started from February 18th to the end of July 2009. A purposive sample of (80) mothers who company their children were selected. The data were collected through a constructed questionnaire, with two parts; the first part is concerned with mother's and child's demographical characteristic, the second part is concerned with mothers' practices about steroid– sensitive nephrotic syndrome. An interview method was used to full questionnaire format. The validity was determined through a panel of experts. While, the reliability was determined through a pilot study. The data were analyzed by using descriptive and inferential statistical measures by using the statistical package of social science (SPSS) version (15).

Results: The findings of the study showed that mothers have poor practices (61.3%). The study results revealed that there is a significant association between mothers' practices and their educational level, and duration of the child's disease. While mother's age, occupation, child's age, child's sex, child's age at onset (years), child's previous disease and heredity have no association with their practices.

Recommendations: The study recommends that health education for mothers would improve their practices.

Keywords: **Assessment, mothers' practices, child with steroid – sensitive Nephrotic Syndrome**

Introduction:

Nephrotic syndrome (NS) is a group of symptoms and is a common type of kidney disorders occurs in children, which include protinuria, hypoprotinemia, especially hypo-albuminemia, edema, and elevated lipids. This group of symptoms occurs from increased glomerular capillary wall permeability to serum proteins. It may occur as a single episode or persist by many recurrences and remissions. It most common appear in ages 2-6 years and affects twice as many males as females [(1)]. The types of NS which can be divided in primary, when the syndrome related to glomeruli injury, and secondary due to and caused by systemic illness for this reason[(2)]. Most children with NS have the primary type, when their disease is not a companied by systemic disease. At the same time the primary form of NS also is classified into two types depending on response to steroid therapy. These types include steroid-sensitive and steroid-resistant [(3)]. Nephrotic syndrome is not a single disease entity. It may accompany any glomerular disease or injury, the underlying causes are unknown, but there is evidence which strongly supports the importance of the immune mechanism [(4-5)]. Most of the children with minimal change nephrotic syndrome (MCNS) are hospitalized for no more than a week at the time of diagnosis, and most of them don't require hospitalization again [(2)]. Hospitalization is important for first episode. Good family education and adequate communication enable them to recognize further problems and to obtain help and treatment for their children in an outpatient clinic [(6)]. Nursing consideration is very important for establishing a basic lines of care and family education, which includes: first monitoring intake and output in young children and weighing the diapers, second assessment of edema through observing swelling around eyes and dependent area, third diet should be restricted like salt and fluids and high protein during appearance of edema and fourth protected the child with NS from infection especially when the child is receiving corticosteroid therapy [(7)].

Methodology:

A purposive "non– probability" sample of (80) mothers having children with steroid–sensitive nephrotic syndrome were selected. The study conducted on consultation units at the pediatrics hospitals: Child's Central Pediatric Teaching Hospital, Al-kadimiyia Teaching Hospital, and Welfare Teaching Hospital from 18th of February to the 30th of July 2009. Assessment approach is used. Data were collected by interview with mothers having children with steroid-sensitive nephrotic syndrome. The investigator uses a constructive questionnaire format. A questionnaire format included two parts. The first part is related to the mother's and child's demographic variables, such as mother's age, educational level, occupation, and child's age, age at the onset of the disease, previous diseases and duration of the disease. The second part of the questionnaire format consists of structured items concerning mothers' practices toward children having steroid–sensitive nephrotic syndrome. This part consist of (5) main sections and comprises of (28) items, dealing with mothers' practices during edema, therapy, remission stage, child's food during acute phase and mothers' practices during the period of child's infection. The exclusion criteria of the study sample includes: Children with congenital nerphrotic syndrome, children <1year of age, and Children with steroid- resistance nephrotic syndrome (SRNS).

Results:

Table 1. Distribution of mothers' characteristic

Mothers' age (years)	Frequency	Percent
<20	1	1.3
20-24	11	13.8
25-29	**22**	**27.5**
30-34	**23**	**28.8**
35-39	19	23.8
40-44	1	1.3
≥ 45	3	3.8
Total	80	100%
Mother's educational level		
Illiterate	5	6.3
Read and write	13	16.3
Primary school graduate	**24**	**30.0**
Intermediate school graduate	**19**	**23.8**
Secondary school graduate	5	6.3
Institution school graduate	11	13.8
College graduate	3	3.8
Total	80	100%
Mother's occupation		
Housewife	**62**	**77.5**
Worker	18	22.5
Total	80	100%

This table indicates that (28.8%, 27.5%) of the mothers in the age group (30-34) years and (25-29) years respectively, (30.0%, 23.8%) graduated from primary and intermediate school respectively, and (77.5%) were housewives.

Table 2. Distribution of the characteristic of the nephrotic children

Child's sex	Frequency	Percent
Male	**48**	**60.0**
Female	32	40.0
Child's age (years)		
<5	**44**	**55.0**
6-8	14	17.5
9-11	22	27.5
Total	80	100%
Child's age at disease onset (years)		
<2 years	18	22.5
2 years	**13**	**16.3**
3 years	17	21.3
4 years	11	13.8
5 years and above	**21**	**26.2**
Total	**80**	**100%**
Duration of the disease (years)		
<1 year	**33**	**41.3**
1-2	23	28.8
3-4	13	16.3
≥ 5 years	11	13.8
Total	80	100%
Child's previous disease		
UTI	1	1.3
RTI	6	7.5
Flue	5	6.3
Others	11	13.8
None	**57**	**71.3**
Total	80	100%

Table 2. (Continued**)**

Renal Biopsy for the child	Frequency	Percent
Yes	5	6.3
No	**75**	**93.8**
Total	80	100%

This table shows that (60.0%) of nephrotic children were boys, (55.0%) at the age of < 5 years, onset of nephrotic syndrome takes high percentage at age ≥ 5 years and < 2 years (26.2%, 22.5%) respectively, (41.3%) of children have NS less than 1 year, (71.3%) have no previous diseases, and the majority of children (93.8%) have no renal biopsy.

Table 3. Distribution of child's family practices for their nephrotic children

Urine test by mother	Frequency	Percent
Yes	7	8.8
No	**73**	**91.2**
Weighing of the child by family		
Yes	11	13.8
No	**69**	**86.2**

This table indicates that (91.2% & 86.2%) of mothers don't practice urine test and weighing the child respectively.

Table 4. Distribution of mothers' practices according to (3) level likert Scale

Item	Always (2) No.	Percent	Sometimes (1) No.	Percent	Never (0) No.	Percent
Mother's practice if child have edema						
1. Avoid adding salt to the food	11	13.8	45	56.3	24	30.0
2. Take the child to the hospital for measuring his weight	**55**	**68.8**	22	27.5	3	3.8
3. Take the child to the hospital for urine exam	**56**	**70.0**	21	26.3	3	3.8
4. Allow child to act normally	**54**	**67.5**	24	30.0	2	2.5
5. Interrupting therapy without doctor order	22	27.5	17	21.3	**41**	**51.3**
6. Urine exam at home by urine strip	6	7.5	1	1.3	73	91.3
7. Weighing the child in the same scale and same clothes	10	12.5	-	-	70	87.5
8. Observe the decrease of urine with present froth	17	21.3	36	45.0	27	33.8
9. Fluid restriction	-	-	43	53.8	37	46.3
10. Allow the child to go to school	5	13.9	22	61.1	9	25.0
Mothers practice if child response to therapy						
11. Follow up absence edema from the body	**79**	**98.8**	1	1.3	-	-
12. Follow up absence of albumin in urine	5	6.3	7	8.8	68	85.0
13. Interrupting therapy without doctor order	21	26.3	25	31.3	**34**	**42.5**
14. Observe increase urine	35	43.8	32	40.0	13	16.3
15. Go to the hospital for decreasing therapy	**55**	**68.8**	21	26.3	4	5.0

Table 4. (**Continued**)

Item	Always (2) No.	Percent	Sometimes (1) No.	Percent	Never (0) No.	Percent
Mothers practice if child received corticosteroids						
16. Accurate doses as doctor order	**51**	**63.8**	17	21.3	12	15.0
17. Observe the side effect of the therapy	-	-	5	6.3	75	93.8
18. Undertake the times of the medications	4	5.0	53	66.3	23	28.8
19. Interruption of the therapy when the side effect appears	32	40.0	46	57.5	2	2.5
20. Protect the child from respiratory tract infection	18	22.5	33	41.3	29	36.3
21. Re-assurance of the doctor of giving vaccine	22	35.5	1	1.6	39	62.9
Mothers practice for the child's nutritional						
22. Give the child fish and chicken for compensating protein	**44**	**55.0**	31	38.8	5	6.3
23. Give the child eggs without yolk	7	8.8	35	43.8	38	47.5
24. Restricted fluid	2	2.5	37	46.3	41	51.3
25. Give the child milk	16	20.0	15	18.8	49	61.3
Mothers practice of committing to doctor order if the child has respiratory infection						
26. Protect the child from infected persons	5	6.3	25	31.3	50	62.5
27. Keep the child worm and dry	22	27.5	35	43.8	23	28.8
28. Give the child treatment as doctor order if child has respiratory infection	10	12.5	58	72.5	12	15.0

This table shows poor mothers' practices toward their children with SSNS except (2, 3, 4, 5, 11, 13, 15, 16, and 22).

Table 5. Association between mothers' practices and demographic characteristics of both the mother and the child

	Total mothers practice score about SSNS				P- value
	Poor		Acceptable and Good		
	Frequency	Percent	Frequency	Percent	
Mother's age (years)					
<20	-	-	1	100	
20-24	6	54.5	5	45.5	
25-29	12	54.5	10	45.5	0.387
30-34	14	60.9	9	39.1	
35-39	15	78.9	4	21.1	
40-44	1	100	-	-	
≥ 45	1	33.3	2	66.7	
Mother's education level					
Illiterate	4	80.0	1	20.0	
Read and writ	11	84.6	2	15.4	
Primary school graduate	13	54.2	11	45.8	0.029*
Intermediate school graduate	15	78.9	4	21.1	
Secondary school graduate	2	40.0	3	60.0	
Institution graduate	3	27.3	8	72.7	
College graduate	1	33.3	2	66.7	
Mother's occupation					
Housewife	41	66.1	21	33.9	0.096
Worker	8	44.4	10	55.6	
Child's sex					
Male	33	68.8	15	31.3	0.092
Female	16	50.0	16	50.0	

Table 5. (Continued**)**

	Total mothers practice score about SSNS				P- value
	Poor		Acceptable and Good		
	Frequency	Percent	Frequency	Percent	
Child's age onset (years)					
<2 years	6	33.3	12	66.7	0.139
2 years	8	61.5	5	38.5	
3 years	11	64.7	6	35.3	
4 years	8	72.7	3	27.3	
5 years	1	50.0	1	50.0	
6 years	5	100	-	-	
7 years	2	50.0	2	50.0	
8 years	3	100	-	-	
9 years	5	71.4	2	28.6	
Child's age (years)					
1-5	23	52.3	21	47.7	0.140
6-8	9	64.3	5	35.7	
9-11	17	77.3	5	22.7	
Duration of the disease (years)					
<1 year	13	39.4	20	60.6	0.003*
1-2	15	65.2	8	34.8	
3-4	12	92.3	1	7.7	
≥5 years	9	81.8	2	18.2	
child's Previous disease					
UTI	1	100	-	-	0.922
RTI	4	66.7	2	33.3	
Flue	3	60.0	2	40.0	
Others	6	54.5	5	45.5	
None	35	61.4	22	38.6	

	Total mothers practice score about SSNS				P- value
	Poor		Acceptable and Good		
	Frequency	Percent	Frequency	Percent	
Heredity					
Yes	15	68.2	7	31.8	0.433
No	34	58.6	24	41.4	

*Significant using Pearson chi-squared test at 0.05 level of significance

This table shows significant association between mothers' practices and their education level and duration of the child's disease (years)

Discussion:

Table (1) shows that more than half of the sample was in child bearing age and the minority were teenagers and old mothers, two third of the mothers were housewives.

Table (2) shows that males childe are more affected than females. It has been emphasized that NS occur in boys more than girls [8]. The most occurrence of NS is at the age of <5 years. It has been mentioned that around (80%) of cases of NS are almost present in preschool children [9-10]. In relation to the onset of NS, the study revealed that children at the age of 4 years and above and under 2 years are more affected. This finding comes in constant with another study which mentioned that "NS disease occurs at all ages, but most commonly between 2 and 5 years" [11]. Most children has the disease for less than (1) year with no previous diseases. It has been mentioned that "NS can be classified as primary when the syndrome is restricted to glomerular injury, or secondary when it develops as a part of systemic illness"[2]. The majority of children in this study have no renal biopsy who mentioned that "pre-adolescents who have NS without nephritis sings, hypocomplementemia or signs of systemic disease do not need a kidney biopsy before the imitation of therapy [4].

The findings of the result pointed out that most mothers didn't test the urine and weigh the child at home table (3), this finding disagrees with another study which stated that urine test is usually done while child receiving medication for NS [11]. Also, it has been indicated the parents should weigh their children daily [12].

In relation to family's heredity diseases, the result revealed that most children have no family history of diseases related to nephrotic syndrome. This result agreed with another study which mentioned that "family history present usually in 3.5% of parent's" [14].

Table (4) revealed that more than half (56.3%) of mothers sometimes avoid adding salt to the child's food. It has been emphasized that salt should be restricted and any food contain high sodium should be avoided during appearance of edema that associated NS [15].

The mothers have a satisfactory practices in items (2 and 3) which are related to measuring the weight and testing the child's urine and they present (68.8%, 70.0%) respectively. It has been mentioned that children with severe symptoms or newly diagnosed ones are hospitalized for assessment, checking and observation for evidence of infections, response to therapy and for mother education in relation to NS care [2].

Mothers who allow their children to act actively account (67.5%). This result agreed with another study which stated that "Bed rest does not need to be enforced" [16].

Half of mothers (51.3%) do not interrupt therapy without doctor advice; this result is in constant with a study which emphasized that the drug should be continued until the urine is free from protein and becomes normal [2].

The majority of mothers (91.3%) have never done urine exam at home. The urine test should be done by dipstick each void especially in the morning [14].

In regard to weighing the child, (87.5%) of mothers have never done so. This result disagrees with the study which indicated that the parents should be weigh the child daily using the same scale in the same clothing at the same time of the do mothers observe the urine amount sometimes [8].

Item (8) represent (45.0%) pointed that mothers observe the urine amount sometimes. While, (53.8%) sometimes does. Item (9) which is related to fluid restriction during appearance of edema. It has been reported that the parent notices the child's urination with frothy looking and the mother should restrict fluid from her child with NS during moderate and severe edema [17].

Mothers sometimes item (10) accounts (61.1%) let their children go to the school emphasized that "children with NS should attend school and can have full activity" [3].

Mothers' practices regarding child response to steroid-therapy show that the majority of them (98.8%) always follow up absence of edema from the child's body. (85.0%) of mothers never do item (12) which is related to checking albumin. More than third (42.5%) of mothers do not interrupt therapy without doctor order, (40.0%) of mothers sometimes observe increase in urine excretion. While, two third (68.8%) of mothers go to the hospital for the purpose of decreasing therapy. It is very important to teach the family the important steps of therapy and remission that occurs within (2-4) weeks after starting corticosteroids in MCNS [14].

(63.8%) of mothers always give accurate doses as doctor order. This result agrees with the study which indicated that the parent should know that therapy is to be continued according to the limited schedule and limited dose until urine becomes free of proteinuria [18].

The findings of the study pointed out that majority of mothers (93.8%) do not observe the side effects of therapy, especially corticosteroid. This result does not agree with the study which reported that the family should be aware of the side effects of steroid-therapy while the child receiving it [10]. Two third (66.3%) of mothers sometimes do items (18) which is related to times of the medication. This result pointed out that mothers have little information regarding times of medication. Therapy regimen consists of prednisone 60/mg/m^2/day in the three equally divided doses for 4 weeks, after that therapy becomes single does given every other day in the morning for 4-12 weeks [4].

In addition, the mother should not interrupt the therapy regimen by herself, more than half of mothers (57.5%) sometimes do so (item 19) they interrupt medication when side effects appear. This finding revealed mothers worries about child's condition or due to poor information that mothers have about the side effects of steroid-therapy.

In regard to the protection of child from getting diseases, (41.3%) of mothers sometimes protect their children from getting respiratory tract infection. Children with NS have decreased immunity and are highly susceptible to infection, two third (62.9%) of mothers never take doctor re-assurance of giving vaccine. This result agrees with the study which mentions that the mother does not know the contraindication of the vaccine on chronic disease, such as kidney diseases [12]. It has been emphasized that live vaccine is contraindicated in children with NS on daily corticosteroid therapy [7].

Diet is considered an important aspect of NS and children with nephrotic syndrome need special diet. Therefore, mothers' practices related to diet show that (55.0%) of them always give their children fish and chicken for compensation protein loss. This finding point out those mothers gets instruction from nurses or physician or from another source about the effects of diet with disease. While, (43.8%) of mothers sometimes give the child eggs without yolk and (51.3%, 61.3%) of mothers has never restricted fluid and give the child milk respectively. It has been emphasized that diet of the nephrotic child should be high in protein in order to compensate the protein loss in urine, in addition to much milk, meat and eggs [(2)].

Mothers should protect their children from infection such as flu and respiratory tract infection. Results revealed that (62.5%) of mothers do not protect their children from infected persons and (43.8%) of mothers sometimes keep them warm and dry. This result explains that mother might not know the effects of these infections on child with NS. It has been reported that the child with NS remains at risk to get infection due to loss of immunoglobulin in the urine and the parent should prevent the child's contact with infected persons during immunosuppressive therapy [(12)].

Table (5) shows mothers' practices have high significant association only with their educational level and the duration of the child's disease at $P \leq 0.05$ (level of significance).

Recommendations:

1. Mass media should take an action to provide the mothers with adequate information appropriate for mothers' educational such as films, pictures and real spots.

2. Nurses and health providers should take their roles in helping parents to understand nephrotic syndrome disease with psychological support.

3.The Ministry of Health would be helpful and responsible for providing special places in nephrology units for health education and providing the parents with pamphlets about the disease.

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