

Original Article

Effects of family-centered care on children with primary nephrotic syndrome

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Abstract: Objective: To explore the effects of family-centered care (FCC) on children with primary nephrotic syndrome (PNS). Methods: Eighty-five pediatric patients with primary nephrotic syndrome admitted to our hospital from October 2018 to September 2019 were enrolled. They were alternately included into group A (43 cases, routine care) and group B (42 cases, FCC) upon admission. The following parameters were compared: behavioral score, compliance rate, relapse rate, quality of life, and parental satisfaction of child's care. Results: Group A exhibited significantly lower behavioral scores within 5 months after discharge, higher compliance rates with follow-up and adherence rates, lower recurrence rates within 6 months after discharge, higher ISLQ scores within 3 months after discharge, and better parental satisfaction of child's care ($P < 0.05$). Conclusion: FCC can improve behaviors, increase the compliance rate, reduce the recurrence rate, and improve the quality of life and parental satisfaction from nursing pediatric patients with PNS.

Keywords: Pediatric primary nephrotic syndrome, family-centered care, nursing, quality of life

Introduction

Nephrotic syndrome is a common type of kidney disease seen in pediatric care, with PNS accounting for 21%, and this proportion is gradually increasing [1, 2]. Nephrotic syndrome is a type of chronic kidney disease that progresses slowly but is difficult to heal, and is prone to recurrent episodes, which may be life threatening in children [3].

The clinical treatment of pediatric PNS usually has a long course, and corresponding adverse reactions will negatively affect the growth and development of children. The quality of life of the pediatric patients will also be decreased accordingly [4]. Therefore, in order to obtain satisfactory outcomes, nursing intervention needs to be emphasized. Currently, due to changes in nursing concepts and medical service models, nursing care now not only focuses on disease treatment, but also involves many individual aspects, such as the family interactions and social support [5, 6]. Considering that the quality of life of pediatric patients with PNS

will be significantly reduced, care intervention not only emphasizes the control of disease progression, but also focuses on improving quality of life, so that the children maintain a good physical and mental state.

Family-centered care (FCC) increases the performance results of high-quality nursing service in hospitals. This mode of care emphasizes communication, coordination and cooperation between caregivers, children and parents in order to achieve better information sharing and provide comprehensive nursing care for the children [7, 8]. FCC is commonly used in pediatric nursing, but so far has not centered on PNS. Its application value has not been fully clarified [9]. In this study, 85 pediatric patients with PNS were enrolled to analyze the performance of FCC to provide more references for the development of pediatric FCC nursing.

Materials and methods

A total of 85 children with primary nephrotic syndrome were enrolled from October 2018 to

September 2019. They were divided into group B (42 cases) and group A (43 cases) according to the order of admission. The parents of all the pediatric patients signed an informed consent, and the study was approved by the ethics committee of our hospital. (1) Inclusion criteria: patients who meet the diagnostic criteria for PNS [10]; age ≤ 12 years; normal cognitive and mental status; received immunosuppressive or hormonal therapy; and lived with parents for a long period. (2) Exclusion criteria: patients combined with other serious systemic diseases; severe complications; patients from single-parent families; and parents with mental disorders.

Treatment methods

Group B received routine care for six months, including ward rounds, daily monitoring of the conditions, sharing nursing knowledge with parents, and health education. Follow-up by telephone was conducted every week after discharge.

Group A was given the same care as group B as well as FCC. Establishment of the FCC team: The team members included a highly qualified pediatrician, and nursing staff that holds psychological certification, as well as two nurses with more than 5 years of pediatric nursing experience, and three other responsible nurses. All members of the team received professional training before the beginning of nursing to understand the FCC targets, the methods of formulating the nursing strategies during hospitalization as well as after discharge, and psychological intervention methods for pediatric patients and their parents.

Training for parents: In the implementation of nursing, team members provided health training for the parents, strengthened communication with parents, and built a harmonious relationship between nurses and patients. The team's responsibilities, as well as disease causes, symptoms, treatment methods, rehabilitation process, and prognosis of children with PNS were explained to the parents. Team members cooperated with parents to compile a highly portable manual of pediatric PNS, which covers disease symptoms, dietary and exercise choices, daily care priorities and methods, renal puncture-related care methods and medication guidance. Nurses with psychological certificates are responsible for assessing psycho-

logical conditions of patients and their family, determining their actual nursing needs, and accordingly selecting the appropriate education methods. Nursing staff guided the parents to be proficient in child care, including measuring blood pressure and temperature, and taking urine samples, etc.

Establishment of mutual help groups for family caregivers. Members of mutual help groups included parents, a nephrotic syndrome expert and the nurses. Every week, meetings were organized in the hospital to share treatment and nursing experience. By providing social, emotional, and informational support for families, mutual support groups helped individuals build confidence and acquire skills in nursing. The nurses and experts summarized key points and gave feedback during meetings, and answered questions raised by parents. Out-of-hospital follow-up care: Before discharge, the home-based care plan was formulated with the parents. The nurses conducted telephone follow-ups at an interval of 2 weeks. During the follow-up, the nurses communicated with the parents to understand the child's recent state of illness and psychological status, and provided corresponding guidance for the implementation of home care.

Outcome measurements

1) Behavioral scores: The Conners Parent Rating Scale was used to better understand certain behavioral issues in the children [11] in terms of 6 aspects: hyperactivity, anxiety, impulsive-hyperactivity, psychosomatic disorders, learning problems, and behavioral problems. A total of 48 questions were each scored from 1 to 4 points. One point means none, 4 means a lot, and the total score ranged from 48-192 points, the higher the score, the more children had behavioral problems. Evaluation was performed upon admission, and at 1, 2, 3, 4, and 5 months after discharge.

2) Compliance rate: The two groups were followed up for 6 months after discharge. The adherence rate and follow-up compliance rate between the two groups were compared. Criteria for adherence: patients did not take their medications or not enough medicine at least twice; patients discontinued the medicine before reaching the prescribed course of treatment; any of the above conditions were recorded as non-compliance with medicine. The fol-

Table 1. Baseline data ($\bar{x} \pm s$)/[n (%)]

Data		A (n=43)	B (n=42)	t/X ²	P
Gender	Male	23 (53.49)	25 (59.52)	0.315	0.575
	Female	20 (46.51)	17 (40.48)		
Age (year)		8.23±3.16	7.59±3.24	0.922	0.359
Age	< 6 years	15 (34.88)	17 (40.48)	0.283	0.595
	≥ 6 years	28 (65.12)	25 (59.52)		
Duration of disease	< 6 months	13 (30.23)	14 (33.33)	0.094	0.759
	≥ 6 months	30 (69.77)	28 (66.67)		
Single child	Yes	18 (41.86)	16 (38.10)	0.126	0.723
	No	25 (58.14)	26 (61.90)		

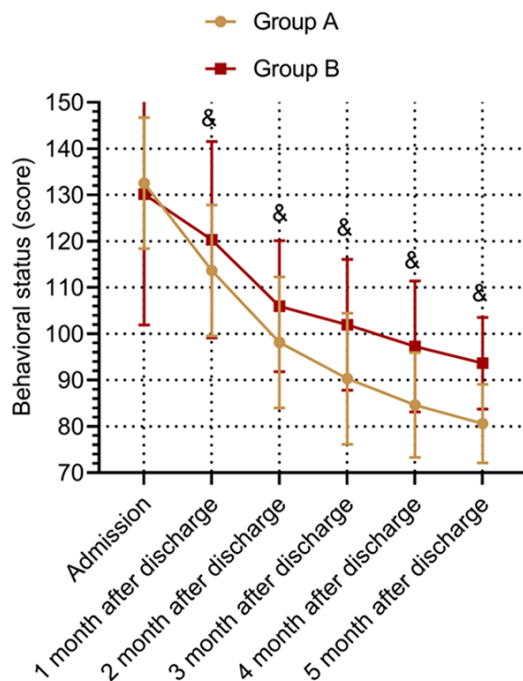


Figure 1. Comparison of the behavioral scores between the two groups. The behavioral scores of group B upon admission were not significantly different from group A ($P > 0.05$). At 1 to 5 months after discharge, scores of group A were significantly lower ($P < 0.05$). & $P < 0.05$.

low-up compliance criteria: the number of follow-up visits was missed at least 2 times, 2 months after discharge.

3) Recurrence rate: The recurrence rates of the two groups during the 6-month follow-up were compared. The recurrence criteria [12]: 24 h urine protein > 50 mg/kg in the complete remission period, or the urine protein was ≥ 2 mg/kg and this occurred 3 times within one week. Frequent recurrence criteria: 2 or more relapses within 6 months.

4) Quality of life assessment: Inventory of subjective life quality questionnaire (ISLQ) [13] was used for evaluation. There are 52 items each scoring 1-4 points. One point means that there is no such idea; 2 means sometimes; 3 indicates often; 4 means always. The 52 questions can be divided into school life (8), living environment (5), family life (7), anxious experience (5), depression experience (8), self-knowledge (6), somatic emotion (5), and peer interaction (6). A higher score indicates a higher quality of life. Evaluation was performed upon admission and 3 months after discharge.

Parental satisfaction of the child's care: Based on the Boston Children's Hospital's resources [14], a family-centered nursing satisfaction scale was developed, with a total of 10 items, specifically: a relatively fixed nurse provided services during the hospitalization; the nurse can explain nursing services; nurses offered good care; nurses can help parents understand the conditions of the children; nurses can inform about the changes in the condition; nurses explained to parents the significance of participating in nursing; nurses teach parents to take care of the children; nurses help parents to participate in the care of the children; nurses make parents feel the importance of participation in the care of the children; nurses let parents understand the methods of child care and follow-up after discharge. Each item is scored on a scale of 0-3, which indicates complete disapproval, basic disapproval, half approval, and full approval, respectively. A higher score indicates the higher satisfaction.

Statistical methods

Statistical analysis was performed with SPSS 22.0, measurement data was expressed as ($\bar{x} \pm s$), and comparison between groups was performed using independent sample t test; count data was expressed as [n (%)] and was examined using chi-squared test, and ANOVA analysis and F test were used for intra-group and inter-group multipoint comparisons. $P < 0.05$ indicated that the difference was statistically significant.

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Table 2. Compliance rates [n (%)]

Grouping	Medicine		Follow up	
	Yes	No	Yes	No
A (n=43)	35 (81.40)	8 (18.60)	33 (76.74)	10 (23.26)
B (n=42)	26 (61.90)	16 (38.10)	23 (54.76)	19 (35.24)
χ^2	3.983		4.568	
P	0.046		0.033	

Table 3. Comparison of recurrence rates [n (%)]

Grouping	Case	recurrence	Frequency of recurrence
A	43	4 (9.30)	1 (2.33)
B	42	11 (26.19)	6 (14.29)
t		4.170	4.022
P		0.041	0.045

Results

Baseline data

There was no statistical difference in gender ratio, average age and range, duration of disease, and proportion of single child families between the two groups ($P > 0.05$) (**Table 1**).

FCC improves behavioral scores

There was no significant difference in the behavior upon admission between the two groups ($P > 0.05$). The behavioral scores of group A from the 1st to 5th month after discharge were significantly lower than those of group B ($P < 0.05$) (**Figure 1**).

FCC increases compliance rate

The medication adherence and follow-up compliance rates of group A were significantly higher than those of group B ($P < 0.05$) (**Table 2**).

FCC reduces recurrence rate

Group A expressed lower recurrence rates and frequency of recurrence rates within 6 months after discharge compared with group B ($P < 0.05$) (**Table 3**).

FCC improves quality of life

The quality of life scores in group A at 3 months after discharge were significantly higher than those in group B ($P < 0.05$) (**Figure 2**).

FCC improves parental satisfaction

Group A expressed better parental satisfaction towards care compared with group B (**Figure 3**).

Discussion

FCC is an innovative method for the formulation and implementation of nursing care as well as the evaluation of the nursing performance. This nursing model is based on a mutually beneficial partnership between nurses and patients' families [9, 15]. Under FCC, nursing staff not only focused on each children's illness but also strengthened the role of the family [16, 17]. Patients are from different cultural backgrounds and this should be considered when providing comprehensive nursing services [18, 19].

Nursing implementation centered on the needs of the children in many aspects, such as emotions, growth and development, school education, social interaction, and family relationships, etc. in FCC. This mode of care emphasizes the role of parents and the value of family support in nursing [20, 21].

The FCC philosophy includes 8 core values, covering authorization, choice, information, flexibility, respect, cooperation, strength, and support. It values enduring family harmony, and includes family members as participants in the nursing process to meet the psychological needs of children who need parental care, and helps to give parents guidance to enable them properly care for children. In this study, the behavioral scores of children in group A from 1-5 months after discharge were lower than those of group B. The medication and follow-up compliance rates in group A were higher than those of group B. The recurrence rate and frequency of recurrence rate in group A were lower than those of group B, suggesting that FCC can improve children's behavioral scores and reduce their adverse behaviors, thus children have a higher rate of compliance with medication and follow-up visits, so as to guarantee better disease control effect. The reason may be that FCC treats human being with a combination of psychology, physiology, and societal care, which jointly affects the individual's health. The family plays a psychological support role for children in disease treatment and rehabilitation.

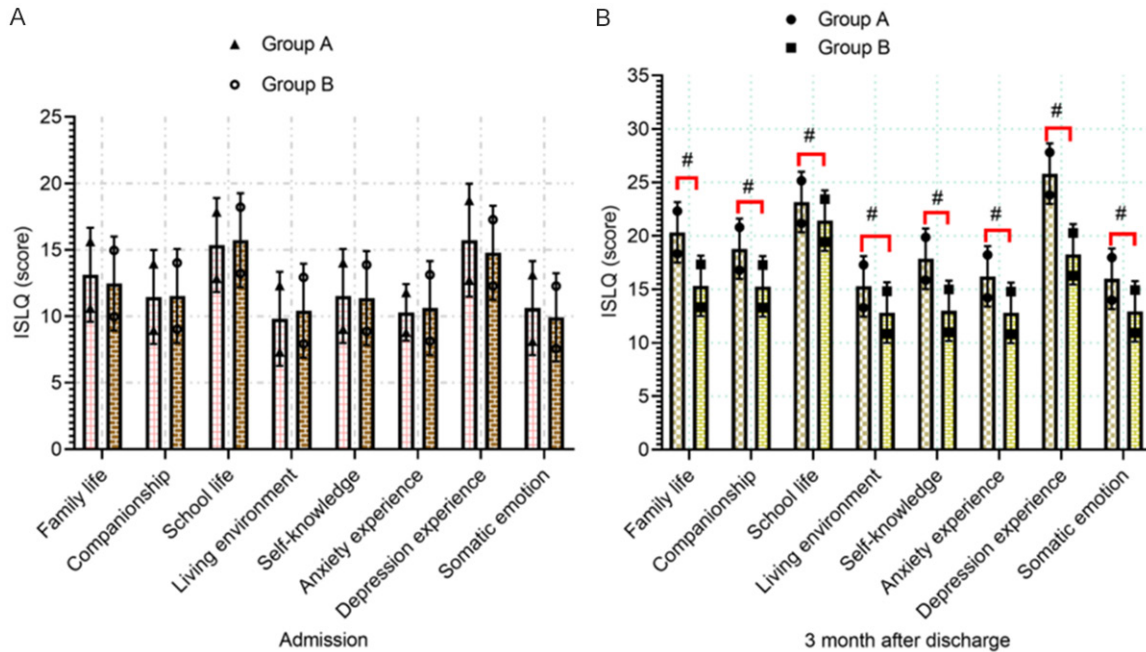


Figure 2. Comparison of quality of life. Upon admission, ISLQ scores of group A were not different from group A. Group A showed higher ISLQ scores at the 3rd month after discharge ($P < 0.05$). # $P < 0.05$.

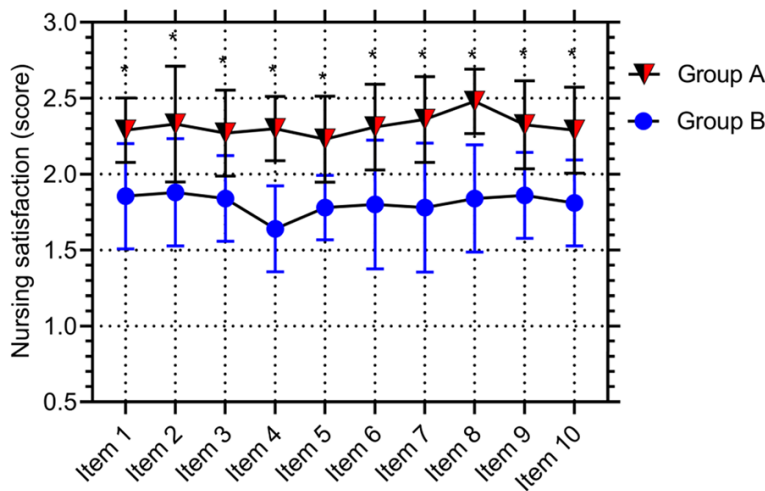


Figure 3. Comparison of nursing satisfaction between the two groups. Group A exhibited significantly higher satisfaction towards the level of care ($P < 0.05$).

A study of stunted children showed that the more harmonious the relationship between the mother and the child, the greater the improvement effect of the child's development [22]. In this study, the average scores of quality of life and parental satisfactory in group A at the 3rd month after discharge were higher than those of group B. The reason may be that under the

FCC model, parents were not just onlookers but participants in the care. They have a stronger sense of self-satisfaction, self-worth, and more confidence for the rehabilitation. Their enthusiasm and initiative were sparked to smooth the care process. Studies suggested that the FCC mode is a very applicable nursing mode for hospitalized children [23]. Another study indicated that FCC is not just for children, but also for patients of all ages [24].

In summary, FCC for pediatric PNS care can improve behavioral scores and compliance rates, reduce recurrence rates, and increase children's quality of life and parental satisfaction. However, this study only included a small size sample, so the analysis of the research results lacks comprehensiveness. In addition, the follow-up time is short. In the future, we will increase the sample size and follow-up time to obtain more comprehensive conclusions.

Disclosure of conflict of interest

None.

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