

The Effectiveness of Family- Centered Education on Quality of Life and Readmission in Children with Nephrotic Syndrome

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Abstract

Background

Children with Nephrotic Syndrome (NS) experience frequent hospitalizations, and readmission affects the quality of life of the patient and family. We aimed to investigate the effectiveness of family-center education on quality of life and readmission in children with nephrotic syndrome.

Materials and Methods

This quasi-experimental study was performed in two groups the pediatric ward of Ali Ebn Abitalib Hospital, Zahedan, Iran, in 2018. Ninety-six children with Nephrotic Syndrome were selected by convenience sampling and were randomly into two groups: intervention (n = 48) and control (n = 48) groups. In the intervention group, family-centered education was held for 4 sessions. Eight weeks after training, readmission and quality of life were assessed. The Pediatric Quality of Life Inventory (PedsQL 4.0), and demographic information were used before and after intervention.

Results

The mean age of children with NS in the intervention group was (8.06 ±2.10), and in the control group it was (8.58 ± 2.87) (P>0.05). The mean of quality of life in the intervention group after the intervention (56.02 ±192.28) was significantly higher than before the intervention (51.73 ± 164.71) (P<0.001, t= 7.54). The mean of quality of life after intervention was significantly different between the intervention and control groups (P= 0.03, t= -3.03). There was also a significant difference between the two groups in terms of mean readmission (P < 0.001).

Conclusion

The results suggest that family-centered education effected on quality of life and readmission; so we propose that nurses can use family-centered education as a cost-effective and acceptable method for families of children with chronic illness.

Key Words: Children, Education, Family, Readmission, Quality of life, Nephrotic syndrome.

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1- INTRODUCTION

Nephrotic syndrome (NS) is most common disorder in pediatrics that is caused by glomerular disease (1). This disease is divided into primary (intrinsic to the kidney), and secondary (with systemic diseases) classes. This disease in childhood is more prevalent in boys (boys are effected than girls the ratio is 2 to 1) and its age of incidence is reported to be 2 to 6 years (2, 3). The prevalence of primary NS is 2 -7 cases per 100,000 children under 16 annually (4, 5). NS is a chronic renal disease with alternating periods of clinical symptoms such as proteinuria, edema, hypoalbuminemia (albumin deficiency less than 2.5 gr/ dl), and hyperlipidemia (> 200 mg/ dl) (6, 7). It causes poor psychological status for the patients and families, and causes long-term concerns (8).

Children with NS experience inappropriate social behaviors, psychological stress, underperforming academically, and repeated readmissions. They must follow restrictive dietary and fluid regimes (9). Children with NS experience the recurrence as 3 to 4 times per year and hospitalized frequently because of recurrence, so that it reaches 30-40% after the first relapse. Frequent readmissions in hospitalization, led to more changes such as aggression, and more fatigue in children. The children who hospitalized, becomes more fragile and sensitive emotionally. More over readmissions schedules are burdensome and interfere with school attendance and participation in peer-related activities, so compromising opportunities for attaining academic and psychosocial potential. Also, frequent readmissions leads to additional stresses, maternal deprivation, financial and psychological burdens on the mothers and other family members (3, 9, 10). Repeated readmissions led to increased dependency of the patient on others and associated with poor quality of life (11, 12). Steroids are widely used as the

primary treatment for this disease (13). These medications have adverse effects such as body growth retardation, bone deformity, and edema. In addition, adverse effects of corticosteroids on the cardiovascular system, immune system, and central nervous system revealed. These adverse effects affected on the quality of life of the children (9, 14). Quality of life means optimal levels of physical, mental, and social functioning communication, perception of health, life satisfaction, and well-being (15). Presenting in school, gaining academic successes, and communicating with classmates are effective factors in achieving of child's quality of life (16). Chronic kidney disease (CKD) have significant impacts on different aspects of children's lives such as their lifestyle and their social and psychological development. These conditions are such that if these children can live a long life with the medications, they and their families face many difficulties (17).

Nguyen et al. (2018) concluded that long periods of NS decrease the quality of life of the child with NS (18). Patient education increases perception of the disease, so, leading to learning, self-care, increasing of quality of life and reducing morbidity and costs. Education led to ability of the patient and family to accomplish home and outpatient cares after hospital discharge. So, reduce readmission of these patients (9, 19, 20). A study conducted by Jamali et al. (2019) indicated that education increases the dimensions of quality of life (physical, emotional, psychological, social, and school dimensions (21). Due to critical role of family in care of children at home, so education to family can increase adapting to the illness (22). Family-centered education is a process in which increase parents' perception of efficacy, well-being, and improving developmental and functional outcomes in children with

special health needs. Moreover, family-centered education increases their knowledge and skills for care of child, so leading to increase the quality of life, and parenting skills (23, 24). Family-centered education achieves developmental-motor, and play in children, also leading to effective functioning of family in care and reducing psychological stress, and frequent relapse in children (9, 23, 25, 26). Hasanpour-Dehkordi et al. (2016), concluded that family-centered education increased quality of life and reduced readmission, as decreased medical costs for the patient and hospital (15). Considering the importance of family-centered education and its effect on self-care behaviors and quality of life in patients with NS, the limitation of studies on family-centered education, complications and symptoms of the disease and frequent readmission, this study was implemented to investigate the effectiveness of family-centered education on quality of life and readmission of children with Nephrotic syndrome.

2- MATERIALS AND METHODS

2-1. Study design and population

This quasi-experimental study included 96 children with NS who were admitted to the pediatric unit of Ali Ebn Abitaleb Hospital in Zahedan, Iran, in 2018. The subjects were selected by sequential sampling and were randomly divided into two groups: 1, the intervention groups (48 subjects), and 2, control group (48 subjects). The researcher selected the eligible participants for the sampling. The subjects were chosen using simple random sampling with a lottery method. First, envelopes containing cards with numbers one and two were given to the participants, if the number one chosen, they assigned to the intervention group. Otherwise, they assigned to the control group. Total sample size was calculated as 96 people (48 in each group) based on the study of Hakim

et. al (2015) with 95% confidence and 80% power (26). Based on the formula ($Z_{1-\alpha/2} = 1.96$, $P_1=0.26$, $q_1=0.74$, $Z_{1-\beta} = 0.85$, $P_2 =0.06$, $q_2=0.94$). To ensure the adequacy of the sample size and to consider the sample attrition in this study, 50 subjects were assigned in each group with a total of 100.

$$n = \frac{\left(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta}\right)^2 [P_1(1 - P_1) + P_2(1 - P_2)]}{(P_1 - P_2)^2}$$

2-2. Inclusion and exclusion criteria

Inclusion criteria for the family were as follows: 1, being the primary caregiver among family members; 2, not having formal education about Nephrotic Syndrome at the time of research; 3, having minimal literacy. Inclusion criteria for the child were as follows: 1, aged between 2 and 16 years of age with all types of NS; 2, no history of renal transplantation; 3, maximum 6 months had passed since the onset of disease. Exclusion criteria were as follow: 1, resistance to steroids during the research; 2, having renal failure and need for dialysis.

2-3. Measurement tools

Data were collected through a demographic questionnaire and the PedsQL (Pediatric Quality of Life Inventory™) questionnaire. Demographic questionnaire included 7 items (age, gender, birth order, length of admission, duration of Nephrotic Syndrome, child's educational level, and education of primary caregiver). The PedsQL 4.0™ generic questionnaire is a standard scale. It measure the quality of life of children with aged between 2 and 16 years of age. The scale consists of 23 separate items. In this questionnaire, child performance is evaluated in 4 separate subscales: the Physical Function subscale (8 items), the Emotional Function subscale (5 items), the Social Function subscale (5 items) and the School Function subscale (5

items). The PedsQL 4.0™ generic is designed in such a way that each item examines the existence of a specific problem in the past month. The answers are as Likert Scale including 5 options: Never (4), rarely (3), sometimes (2), often (1) and always (0). The score for each subscale is between 0 and 100. A score of less than 25 indicates a low quality of life, a score between 25 and 75 indicates a moderate quality of life, and a score above 75 indicates a high quality of life (27). The PedsQL 4.0™ generic is used in previous studies and its reliability has been confirmed (17, 27, 28). In the study by Khanjari et al. (2018) the PedsQL™ 4.0 generic core questionnaire used at the Persian. The reliability of the questionnaire was $\alpha = 84\%$ through Cronbach's alpha; and validity of whole subscales were reported 80%-88 % (28). In the study by Mohammedian et al. (2015), the content validity of the inventory in the whole instrument was 0.84, and 0.80 in physical function subscale, 0.86 in emotional function, 0.83 in social function, and 0.88 in school function (27). In the present study, Cronbach's alpha was calculated to determine the reliability of the PedsQL 4.0™ generic. Cronbach's alpha was obtained as 0.77 on physical function subscale, 0.84 on emotional function, 0.85 on social function, and 0.61 on school function. The reliability of the scale was obtained as 0.88.

2-4. Intervention

The researcher selected eligible children from those admitted in the pediatric unit. Written and verbal parent's consent was obtained after adequate explanations to the subjects and parents. They were assured that the information would remain confidential. In the intervention group, the demographic questionnaire was completed by the researcher using interview with the parents. The researcher completed the PedsQL 4.0™ generic by interview with the child. Then, the researcher presented 4

sessions as lecture, and face-to-face education to the primary caregivers and children for 4 consecutive days (**Table.1**). The duration of each session was 30-45 minutes, which in some subjects was longer depending on the age group. The sessions were implemented after nursing and medical procedures, such as medication, visiting and sleeping time, and medical examinations. At the end of the fourth session, the education was given to the primary caregiver of child in the form of a pamphlet and educational booklet which provided by the researcher. In addition, the researcher's contact number was given to caregiver to contact him in case of any questions. Eight weeks after the end of the last educational session, the child referring to the child's home completed PedsQL 4.0™ generic questionnaire again, and the researcher investigated readmission. The numbers of readmission were asked from the child and inserted in demographic questionnaire. In the control group, there was no educational sessions except routine care in in the pediatrics unit. Quality of life and readmission of the child were assessed at the mentioned times.

2-5. Ethical Considerations

The Ethics Committee of Zahedan University of Medical Sciences under the code of ethics IR.ZAUMS.REC.1397.378 approved this research). Informed consent was obtained verbally and in written from parents.

2-6. Statistical Analysis

Data were analyzed using SPSS software version 21.0 (SPSS, USA, IBM), and by using Chi-square, independent, and paired t-test samples. Chi-square was used to control qualitative demographic variables. Independent t-test was used to compare means and changes of quality of life and readmission before and after intervention in each group and between the two groups. Paired t-test samples was used to compare

the means in each group before and after the intervention. A K-S test was used to check normal distribution. Data are

presented as mean \pm standard deviations (SD). Significance levels in this study were less than 0.05.

Table-1: Educational content.

Time	Content	The methods of training
First session	Definition of NS symptoms and complications of the disease, medications	Lecture
Second session	How to use drugs, side effects, and Training in physical activity, cares in home and diet	Lecture
Third session	Training about prevention of readmission, recommended to communicate with friends	Lecture
Fourth session	Review the contents and answer the students' questions	Lecture, Pamphlet, Booklet

NS: Nephrotic Syndrome.

3- RESULTS

3-1. Demographic Characteristics

Findings of this study showed that the mean age of children with NS in the intervention group was (8.06 \pm 2.10 years) and in the control group it was (8.58 \pm

2.87 years) ($P > 0.05$). **Table.2** shows the main demographic characteristics of the study in two groups. There were no significant difference between the two groups in terms of demographic characteristics ($P > 0.05$).

Table-2: The Main Characteristics Studied in Both Groups, n=96.

Variables	Intervention group, n=48	Control group, n= 48	P-value
Age (Mean \pm SD)	8.06 \pm 2.10	8.58 \pm 2.87	0.31 [†]
Gender			0.06 [‡]
Girl	26 (54.2)	17 (35.4)	
Boy	22 (45.8)	31 (64.6)	
Birth orders			0.75 [‡]
1-2	27 (56.2)	22 (45.8)	
3-4	21 (43.8)	26 (54.2)	
The number of hospitalization	2.18 \pm 1.26	2.81 \pm 1.69	0.44 [†]
Educational level of caregiver			0.77 [‡]
Diploma	29 (60.5)	25 (42.1)	
Bachelor	13 (27)	17 (35.4)	
Master	6 (12.5)	6 (12.5)	
Educational level of child			0.27 [‡]
Primary school	40 (83.3)	38 (79.2)	
Secondary school	8 (16.7)	10 (20.8)	
Family income			0.26 [‡]
Sufficient	31 (64.6)	36(75)	
Insufficient	17 (35.4)	12(25)	

[†] T-test, [‡] Chi-square test. SD: Standard deviation.

3-2. Quality of life

The results in **Table.3** indicated that the mean of quality of life in the intervention group after the intervention (56.02 ±192.28) was significantly higher than before the intervention (51.73 ± 164.71) (P <0.001, t = 7.54). However, the results of the paired t-test revealed no significant difference in quality of life in control group after cares (P= 0.2, t =3.24). Independent t-test showed that the mean differences of quality of life was significantly different between the intervention and control groups after intervention (P = 0.03, t = -3.03). However, the mean of quality of life did

not significantly different between the intervention and control groups before intervention (P = 0.34, t = 0.95). Therefore, it can be said that family-centered educational intervention caused changes in the quality of life in the intervention group.

3-3. Readmission

The results in **Table.4** regarding readmissions showed that readmission was 1.70±0.45 mean and SD in the intervention group. It's mean and SD was 1.22±0.42 in control group. Results of independent t-test indicated that there was a significant difference between the two groups in terms of mean readmission (p< 0.001).

Table-3: Changes of the Mean of quality of life before and after family- center education in both groups.

Quality of life	Before intervention Mean± SD	After intervention Mean ± SD	Mean differences Mean ± SD	P-value
Intervention group	51.73±164.7	56.02±192.28	4.29±25.31	P < 0.001 t = 7.54 df ‡ = 47
Control group	54.69±177.03	57.61±158.35	2.92±18.67	P = 0.2 t = 3.24 df ‡ = 47
P-value †	t = 0.95 df = 94 P = 0.34	t = -3.03 df = 94 P = 0.03*	t = -6.78 df = 94 P <0.0001*	

Values are expressed as mean ±SD, † Independent sample T-test, ‡ Degrees of freedom, the score of quality of life were considered between 0 and 100 (27), SD: Standard deviation, DF: Degree of freedom.

Table-4: Changes of the mean of readmission after family- centered education in both groups.

Readmission	Intervention group Mean± SD	Control group Mean± SD	P-value †
	1.70±0.45	1.22±0.42	P <0.001 t=-5.30 df= 94

Values are expressed as mean ±SD, † Independent sample T-test, DF: Degrees of freedom, SD: Standard deviation.

4- DISCUSSION

The aim of this study was to investigate the effect of family-centered education on quality of life and

readmission of children with NS. This study showed that the mean of quality of life in the intervention group after education was significantly higher than from that of pre-education, which can be

related to the role of family-centered education on the quality of life of children with NS. Researchers have made significant findings about the considerable effects of education on the quality of life in children (29-31). Khanjari et al. (2018) investigated “the effect of combined education on the quality of life of children with NS”. They concluded that combined education could improve the quality of life in children with chronic diseases, so, they recommended that parents of these children be trained to raise adaptive skills (28). Tong et al. (2008) concluded that despite the increasing number of patients with CKD diseases and due to the long-term needs of these patients, education was effective to raise their quality of life (29).

The findings by Cai Rong and Liu (2009), showed that the use of evidence-based approach for health education of children with NS improves the quality of life of these children (30). The results of these studies were consistent with the results of the present study. The results of some studies indicate that informed participation of families in health-care services increase the adaptability as the quality of life of the patients, families, and caregivers (32, 33). Ghavidel et al. (2015) examined ‘the effect of family-centered education on quality of life after coronary artery bypass graft surgery’. The results showed that family-centered education increased the quality of life of patients (31). They have written that Family-based education seems to be positive-effects on the life style in these patients and their families, which strengthens family relationships and reduces the negative effects of child’s disease on the family. Moreover, the findings of the present study showed that readmission after intervention decreased significantly in the intervention and control groups. The results by Charnaya et al. (2019) showed that a standardized approach to educate patients and families of children with NS could reduce

readmission (34). Cai Rong and Liu (2009) concluded that education reduced readmission (30). The results of these studies were consistent with the results of the present study. However, the findings of some studies indicate that educational supportive intervention did not affect readmission rate. The findings by Hakim et al. (2015) indicated that the follow-up care model could not influence the readmission control of patients (26). The reasons for non-effective of this educational model in Hakim et al.’s study were culture differences, the living environment, diet, and medication of the patients, and the duration of training times. The results of Hakim et al.’s study was inconsistent with the results of the present study. The limitations of this study include the difference between the levels of learning of the subjects and the education provided by nursing staff, which could be effect on results of education by researcher.

5- CONCLUSION

The findings of the current study indicated that family-centered education for 4 session (30-45 min) and in 4 consecutive days for the primary caregivers and children increased the quality of life and decreased readmission of children with Nephrotic Syndrome. One of the key roles of nurses is patient education. Education to family raises awareness, self-care and the quality of life of the child. Increasing the quality of life also improves patient and family comfort. Also, self-care leads to less recurrence of the disease by following a treatment regimen. Considering care of children with NS depend on their family members and the family has an important role to play in adapting them, so nurses can use family-based education as a cost-effective method to guide the patient and their family members in their efforts to achieve to the care goals. Thus, it is suggested that this

approach be implemented in the pediatric unit of the hospitals.

6- AUTHOR CONTRIBUTORS

Mehdi Rezaei Nejad, Alia Jalalodini, Dr Mahnaz Ghaljeh, and Dr Simim Sadeghi conceived the study and contributed in the design of the study and the drafting of the manuscript; Mehdi Rezaei Nejad conducted the protocol; Alia Jalalodini and Dr Mahnaz Ghaljeh advised on the method of education, and Dr Ali Navidian advised on data analysis; Alia Jalalodini revised and approved the manuscript.

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8- CONFLICT OF INTEREST: None.

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