ORIGINAL RESEARCH

The Impact of Prolonged Home Care on Nursing Adherence and Overall Quality of Life Among Pediatric Patients Diagnosed with Nephrotic Syndrome

Ying Wang, BM; Fang Liu, BM; Danhong Ni, BM; Jingjing Liu, BM

ABSTRACT

Background • Nephrotic syndrome is characterized by prolonged duration, frequent relapses, various comorbidities, and complex management. Although children with nephrotic syndrome generally adhere well to medical protocols during hospitalization under close supervision, post-discharge adherence to care plans often poses challenges.

Objective • This study aims to investigate the impact of continuous home care on nursing compliance, immune function, and quality of life among pediatric patients diagnosed with nephrotic syndrome.

Methods • A retrospective analysis was conducted on ninety-eight cases of discharged children with nephrotic syndrome admitted to our hospital from January 2020 to January 2023. Based on different nursing programs, the children were divided into two groups: 54 cases in the observation group and 54 cases in the comparison group. The observation group received continuous home care involving assessment of nursing problems, care, and effect evaluation, while the comparison group received conventional pre-discharge health education and regular telephone follow-up after discharge. Nursing care compliance, immune function, and quality of life were compared between the two groups.

Results • The observation group demonstrated significantly higher compliance rates in areas such as diet, fluid intake, medication, dialysis regimen, daily life, and exercise compared to the control group ($P < .05$). Aftercare, the observation group showed greater disease cognitive ability, disease-related behaviors, beliefs about the disease, and overall scores compared to the control group, with statistical significance ($P < .05$). Moreover, the quality-of-life index scores of children in both groups improved aftercare, with the observation group showing higher scores in behavioral ability, physical function, psychological function, and social function compared to the control group, and these differences were statistically significant ($P < .05$).

Conclusions • Implementing ongoing home care for children diagnosed with nephrotic syndrome significantly enhances their overall quality of life, particularly in terms of familial dynamics, self-perception, and adherence to medical treatment. (*Altern Ther Health Med.* 2023;29(8):144-149).

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INTRODUCTION

Pediatric nephrotic syndrome is a chronic condition that requires primarily pharmacological management, particularly the administration of glucocorticoids.[1] Previous research has demonstrated the effectiveness of sustained glucocorticoid treatment in managing the ailment and reducing the likelihood of relapse within two years.[2] However, the prolonged use of hormonal drugs and their associated adverse effects raise significant concerns for children and their parents.[3] Moreover, children's reduced inclination to participate in caregiving efforts and limited knowledge in managing the condition can lead to higher recurrence rates and more frequent complications, affecting their long-term prognosis.[4] Therefore, there is a substantial demand for post-discharge care for these patients.[4,5]

The extended home care approach is currently experiencing rapid development worldwide, and with the increased incidence of various chronic diseases, it is gaining significant attention.[5] Extended home care refers to expanding nursing services beyond the duration of hospitalization, thereby breaking free from the confines of care solely within the hospital setting. This approach utilizes all available resources to extend the provision of nursing care, enhancing the scope of support to adequately address the healthcare requirements of the child upon discharge

from the hospital.[6] Continuing home care aims to offer care for the child outside the hospital setting, promoting their active involvement in the care process. Moreover, continuing home care strengthens the bond of trust between the child, parents, and healthcare providers, thereby bolstering parental confidence. This form of care also eliminates adverse consequences, such as the child's apprehension towards hospital wards, leading to improved adherence to nursing protocols.[7]

Therefore, we investigated the changes in adherence, immune function, and quality of life among children with nephrotic syndrome before and after receiving nursing care. Our objective was to explore the impact and prognosis of continuous home care on the management of nephrotic syndrome. The study aims to provide a stronger theoretical basis for nephrotic syndrome care and to develop innovative ideas and approaches for its management.

PATIENTS AND METHODS

Study Design and Participant Selection

This retrospective analysis involved the case data of 98 discharged children with nephrotic syndrome who were admitted to our hospital between January 2020 and January 2023. Based on different nursing programs, the children were divided into two groups: 54 cases in the observation group and 54 cases in the comparison group.

Inclusion and Exclusion Criteria

Inclusion criteria were as follows: (1): Children diagnosed with nephrotic syndrome, possessing detailed clinical data and basic information; (2): Children with normal intellectual development, thinking and language skills, communication abilities, and clear consciousness; and (3): Children aged 9 to 18 years old who received hormone therapy until they met the discharge criteria.

Exclusion criteria were as follows: (1): Children who couldn't be followed up after discharge, those with combined mental illness or depression, and children with concomitant secondary diabetes mellitus; (2): Children with serious primary diseases like cardiovascular and hematopoietic disorders; and liver function ALT or AST levels exceeding 1.5 times the upper limit of normal. Children whose parents are unable to provide long-term care or whose hospitalization was interrupted for various reasons; and (3): Individuals with intellectual disabilities, physical disabilities, and those whose parents suffer from mental disorders or mental retardation.

Implementation of Family-Centered Care and Follow-Up Strategies

Continuity of Family Care Model in the Observation Group. In the observation group, the continuity of family care model was employed to assess care problems and their effects. This method involved registering follow-up information, including the child's name, sex, age, treatment process, contact information, and home address on the day of discharge.

Comprehensive Health Information Booklet. A comprehensive health information booklet on nephrotic syndrome was disseminated to the families. The nursing staff diligently implemented holistic care measures for the children, conducting monthly follow-up telephone visits and SMS guidance to the parents after the children's discharge from the medical facility.

Addressing Nursing Problems and Outcome Evaluation. At each follow-up visit, the main nursing problems that existed at each stage after the child's discharge from the hospital were addressed, and the degree of improvement of each problem of the child was evaluated using the outcome evaluation system.

Empowering Parents for Technical Care. In addition to participating in the routine care of the child, parents were also trained to master and instruct the child in technical care, including measurement methods, normal ranges, and precautions for the thermometer, blood pressure meter, and perineal cleaning of urine protein.

Psychological Support and Emotional Guidance. After discharge, the child's psychological status was evaluated, and timely guidance was provided to express emotions, communicate with parents and friends, and actively participate in outdoor activities.

Medication Adherence and Complication Management. The observation group monitored medication adherence, identified any recurrence during medication, and managed complications and adverse drug reactions with appropriate guidance and advice.

Family Follow-Up Visits. Family follow-up visits were conducted once a month to observe the children's mental status and emotional reactions, maintain close communication with parents, and indirectly assess recent hormone use of the children through parents.

Comparison Group: Routine Pre-Discharge Health Education

Routine pre-discharge health education and regular post-discharge telephone follow-up were implemented in the comparison group. The medical and nursing staff provided information to the children about their medication and dosage, reminding them to take the medication on time and as prescribed. Additionally, the children were advised to pay attention to relevant matters and informed about the importance of scheduling regular check-ups to keep the medical and nursing staff updated on their condition.

Observed Indicators

Relevant Scores. The Knowing, Believing, and Acting survey was used.[8] This questionnaire consisted of 45 entries, including cognitive ability about the disease (18 entries), disease-related behaviors (18 entries), and beliefs about the disease (9 entries). Each entry was scored on a scale of 1 to 5, resulting in a total score ranging from 45 to 225 points. Higher scores indicated that the children had a clearer understanding of the disease. The Cronbach's coefficient of the questionnaire was 0.925, indicating good reliability and validity.

Table 1. Comparison of Baseline Information between the Two Groups of Patients

Group	Average Age (years)	Gender (Male/ Female)	Body Mass Index (kg/m²)	Average Duration of Illness (years)	Clinical Typing	
					Simplexity	Nephrosis type
Comparison Group (54)	11.06 ± 1.71	34/20	23.05 ± 2.23	1.35 ± 0.29	18	36
Observation Group (54)	10.98 ± 1.62	33/21	23.40 ± 2.03	1.10 ± 0.31	17	37
t	0.377	0.039	-0.821	-0.480	0.042	
P value	.051	.843	.414	.632	.837	

Note: Values are presented as mean ± standard deviation. "*t*" represents the Student's *t* test value, and "*P*" represents the corresponding *P* value for each variable.

Nursing Compliance Scores. A self-developed nursing compliance scale was employed for children with chronic kidney disease.[9] The scale encompassed various aspects, including diet, fluid intake, medication, dialysis regimen, daily life, and exercise. Compliance was considered achieved when the children fully adhered to the medical regimen. The adherence rate was calculated as follows:

$$\text{Adherence rate} = (\text{Number of adherence cases} / \text{Total cases}) \times 100\%.$$

Quality of Life Scores. The concise health status survey scale was used to evaluate the quality of life of the children in both groups before and after care.[10] The scale mainly consisted of four dimensions: behavioral ability, physical function, psychological function, and social function, with a total score of 100 for each dimension. A higher score indicated a higher quality of life for the children.

Statistical Analysis

All statistical data in this study were entered into Microsoft Excel, and Statistical Package for Social Science (SPSS) version 28.0 (IBM, Armonk, NY, USA) was utilized for statistical calculations. Measurement data following normal distribution were expressed as Mean ± SD. Independent samples *t* test was used for comparison. Count data were compared using the chi-square test, while rank data were compared using the rank sum test. A significance level of $P < .05$ was considered statistically significant.

RESULTS

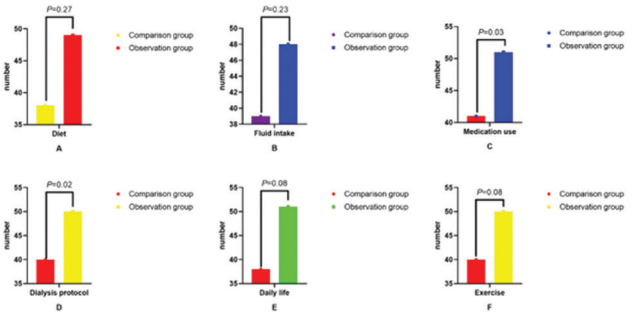
Comparison of Clinical Data of Study Subjects

The mean age, gender, body mass index, average disease duration, and clinical staging of patients in the Observation group were not statistically significant compared to the comparison group ($P > .05$). Refer to Table 1 for details.

Comparison of Nursing Compliance

In the observation group, the compliance rate of diet, fluid intake, medication, dialysis regimen, daily life, and exercise was significantly higher than that of the comparison group, with a statistically significant difference ($P < .05$). See Figure 1 for a graphical representation.

Figure 1. Comparison of Daily Life Self-Care Ability Scores between Observation Group and Control Group



Note: The figure presents the comparison of daily life self-care ability scores between the observation group and the control group. The data were analyzed using Epidata and SPSS 28.0 and mean ± standard deviation values are shown. Independent samples *t* tests were conducted, revealing that the diet compliance rate, fluid intake compliance rate, medication compliance rate, dialysis protocol compliance rate, daily life compliance rate, and exercise compliance rate of the observation group were higher than those of the control group. The observation group exhibited higher scores in daily life self-care ability compared to the control group, with statistically significant differences (*$P < .05$).

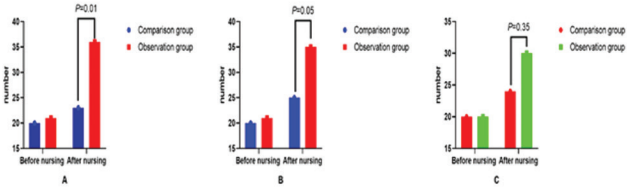
Comparison of Correlation Scores

There was no statistically significant difference between the two groups in comparing pre-care-related scores ($P > .05$). However, aftercare, the disease cognitive ability, disease-related behaviors, and beliefs about the disease scores of the observation group were higher than those of the comparison group, with a statistically significant difference ($P < .05$), refer to Figure 2.

Comparison of Quality-of-Life Indicators

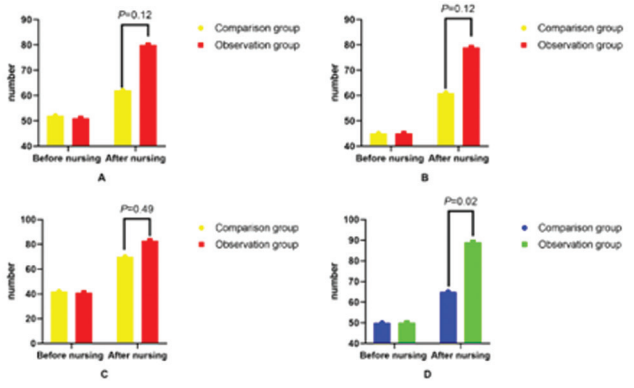
There was no statistically significant difference in the quality-of-life scores between the two groups of children under care ($P > .05$). However, aftercare, the quality-of-life index scores of children in both groups were higher than those before care. Additionally, the behavioral ability scores, physical function scores, mental function scores, and social function scores of children in the observation group were higher than those in the comparison group aftercare, with a statistically significant difference ($P < .05$), see Figure 3.

Figure 2. Comparison of Relevant Scores between Observation Group and Control Group



Note: The figure illustrates the comparison of relevant scores between the observation group and the control group; (A): disease-related behavior; (B): and disease belief scores; (C): compared to the control group, with statistically significant differences ($P < .05$). Daily life self-care ability score comparison data were entered using Epidata, and then statistical processing was performed using SPSS 28.0. The data were entered into a computer database by two individuals, and the results are expressed as mean ± standard deviation. Independent samples *t* tests were conducted, showing no statistically significant differences ($P > .05$). However, after nursing, the observation group displayed higher cognitive ability.

Figure 3. Comparison of Quality-of-Life Indicators between Observation Group and Control Group



Note: The figure presents the comparison of quality-of-life indicators between the observation group and the control group. The observation group exhibited higher scores in (A): behavioral ability; (B): physiological function; (C): psychological function; and (D): social function compared to the control group, with statistically significant differences ($P < .05$). However, after nursing, the quality-of-life index scores in both groups increased compared to before nursing. Daily life self-care ability score comparison data were entered using Epidata, and then statistical processing was performed using SPSS 28.0. The data were entered into a computer database by two individuals, and the results are expressed as mean ± standard deviation. Independent samples *t* tests were conducted, showing that the nursing life quality scores of the two groups were not statistically significant ($P >$v.05).

DISCUSSION

Pediatric nephrotic syndrome is a group of clinical syndromes caused by increased permeability of the glomerular basement membrane due to various causes, leading to significant protein loss from the urine into the plasma.[11] Clinically, it is characterized by massive proteinuria, hypoproteinemia, hyperlipidemia, and pronounced edema, with massive proteinuria and hypoproteinemia being essential for diagnosis.[12] The primary treatment approach for these conditions is currently pharmacological, focusing on glucocorticoids and cytotoxic drugs.[13] Glucocorticoids are the most utilized drugs in treating kidney diseases.[14]

Medication administration for nephrotic syndrome typically follows the principle of "appropriate initial dosage, gradual tapering, and extended maintenance." Prednisone is the prototypical drug used in this context, and in cases of hepatic impairment and significant edema, it may be substituted with an equivalent oral or intravenous dose of prednisolone.[5] Numerous studies have now demonstrated the positive impact of extended home care on treatment compliance in nephrotic syndrome.[16] Literature studies have also shown that extended home care interventions effectively improve compliance with hormone therapy in children with nephrotic syndrome, reducing their relapse and complication rates.[17]

Studies have confirmed the significant improvement and effective reduction in the recurrence of nephrotic syndrome after extended home care interventions.[18] A recent study investigating treatment adherence among children discharged from the hospital with nephrotic syndrome reported a remarkable compliance rate of 100% in the test group, whereas the control group exhibited a lower rate of 79.3%.[19] These findings demonstrate the clinical applicability and benefits of continuous home care interventions.

Our study revealed that the observation group demonstrated significantly higher compliance rates in various aspects, including dietary, fluid intake, medication, dialysis regimen, daily living, and exercise, compared to the comparison group, and these differences were statistically significant. Additionally, aftercare, the observation group exhibited higher scores in disease cognitive ability, disease-related behaviors, beliefs about the disease, and overall scores compared to the comparison group, and these differences were also statistically significant. Furthermore, the post-care quality of life index scores for children in both groups showed improvement compared to their pre-care scores.

The observation group also exhibited significantly higher scores in behavioral ability, physical function, psychological function, and social function compared to the comparison group. This finding strongly suggests extended home care can significantly enhance quality-of-life satisfaction among children diagnosed with nephrotic syndrome. Continuing home care primarily focuses on intervening in the child's post-hospital treatment.[20] It was observed that by providing appropriate and effective nursing interventions, emotional tension in the child could be alleviated, leading to positive cooperation with treatment and enhancing the confidence of parents in overcoming the disease.[21]

Additionally, the presence of gentle and kind healthcare personnel tends to foster reliance and trust in patients and their families, thereby improving treatment compliance.[22] As a source of stress, the hospital ward often generates negative emotions in the child, thereby impacting their treatment compliance.[23] However, extended home care offers children the opportunity to receive standardized and effective follow-up treatment at home, eliminating the negative effects of the hospital ward and enhancing their treatment adherence.[24]

In our study, we observed that the treatment compliance rate of patients in the observation group was higher than that of the comparison group. The data strongly suggest that psychological care, combined with comfort care for patients with nephrotic syndrome, contributes to improving treatment compliance rates. This positive outcome can be attributed to the efficacy of communication during nursing interventions, which fosters trust among patients and their families, strengthens the nurse-patient relationship, and ultimately facilitates enhanced treatment adherence.[25]

In this study, patients in the observation group had superior quality-of-life scores in all dimensions compared to those in the comparison group. This finding indicates that integrating psychological care and comfort care for patients diagnosed with nephrotic syndrome yields favorable outcomes in enhancing their quality of life.[26] This improvement can be attributed to providing patients with guidance on daily life precautions and dietary care during the intervention.[27] Assisting patients in developing favorable dietary habits and facilitating the process of disease amelioration proves advantageous in mitigating the occurrence of complications and recurrent events, ultimately enhancing the long-term quality of survival for patients.[28] A correlated study discovered that providing uninterrupted care for individuals undergoing hemodialysis can effectively alleviate anxiety and depression, enhance their quality of life, promote treatment adherence, and increase nursing satisfaction.[29] These findings further support our results.

Study Limitations and Future Implications

Our study has identified several limitations. Since nephrotic syndrome is a prevalent chronic kidney disease in children, treating and caring for this condition, entail a lengthy and intricate process. Consequently, future studies should consider extending the duration of the intervention to obtain a more comprehensive understanding of the effects of nursing intervention. Moreover, it is important to acknowledge that the current sample size remains insufficient to reflect the impact of the intervention accurately. Therefore, increasing the sample size in future studies can help reduce random errors and increase the reliability of the results.

In addition, the age range of the children selected for the nursing intervention in our study was 9 to 18 years old, which falls within the school age and adolescence. Since the onset of nephrotic syndrome is typically between 2 to 7 years old, the older age of the children in our study could have influenced the impact of the intervention. Furthermore, various factors such as the prolonged duration of the disease, the different cognitive comprehension abilities of each child, the varying disease development stages, and individual differences might have affected the intervention outcomes.

For forthcoming research, we recommend enhancing the precision of subject selection to refine the study's scope and account for these influencing factors. A more targeted and specific approach to subject selection would help obtain more accurate and valuable insights into the effects of nursing intervention in children with nephrotic syndrome.

CONCLUSION

In conclusion, this study provides valuable insights into the effectiveness of continuous home care for children diagnosed with nephrotic syndrome. The findings demonstrate that such an approach positively impacts various aspects of the children's lives, particularly in improving their quality-of-life satisfaction, especially in family life, self-awareness, and compliance with care. The implementation of continuous home care has been shown to enhance the overall quality of life of these children significantly. By providing standardized and effective follow-up treatment at home, the negative effects of the hospital ward can be eliminated, and this alleviates stress and negative psychology in the child, ultimately enhancing treatment adherence. Additionally, integrating psychological care and comfort care fosters trust among patients and their families, strengthens the nurse-patient relationship, and facilitates enhanced treatment compliance. Future research should consider extending the duration of the intervention and increasing the sample size to obtain a more comprehensive understanding of the effects of nursing intervention on children with nephrotic syndrome.

CONFLICT OF INTEREST

The authors have no potential conflicts of interest to report relevant to this article.

AUTHORS' CONTRIBUTIONS

YW and FL designed the study and performed the experiments; FL and DN collected the data; DN and JL analyzed the data; YW prepared the manuscript. All authors read and approved the final manuscript.

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