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Effectiveness of a Support-Training Program based on the Orem's Self-Care Deficit Theory on the Quality of Life of Children Undergoing Hemodialysis

Fahimeh Khazaei[1], Naghmeh Razaghi[2*], Hamidreza Behnam Vashani[3]

Abstract

Background: Most children undergoing hemodialysis (HD) are burdened with some deficits to practice self-care, causing poor quality of life (QoL). Orem's Self-Care Theory (SCT) is known as one of the nursing models involving patients in care and putting much more emphasis on self-care.

Aim: This study aimed to investigate the effectiveness of a support-training program developed based on Orem's SCT on QoL among Iranian children undergoing HD.

Method: This quasi-experimental study with a pretest-posttest research design was conducted using the census method on a total number of 27 children aged 8-15 undergoing HD at Dr. Sheikh Hospital, Mashhad, Iran, in 2019. For this purpose, the Self-Care Measurement Scale (Shintani, 2009) and the KIDSCREEN-52 quality of life questionnaires were completed before the inclusion of the study participants, and then, universal self-care and health-deviation self-care needs were identified. The data were further analyzed in the SPSS Statistics software (version 16).

Results: The total mean scores of QoL were obtained at 24.9±0.118 and 27.3±0.177 before and immediately after the intervention program, respectively. The results of the Bonferroni posthoc test showed a significant difference between the total mean scores of the pretest-posttest stages (P<0.001). Moreover, the difference between the total mean scores was significant 2 and 6 weeks after the implementation of the given program and immediately after it (P<0.001).

Implications for Practice: Since, in this study, the self-care support-training program practiced was developed based on Orem's SCDT, the study findings can be utilized in planning to improve the QoL of children undergoing HD.

Keywords: Children, Hemodialysis, Orem's self-care theory, Quality of life

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Introduction

With an increase in life expectancy, chronic diseases have today become a focus of attention as a major health problem. Chronic kidney disease (CKD) is known as a condition, which makes a person continuously play the role of a patient in life because of poor health status, the disease itself, and the treatment complications (1). The overall statistics released by the World Health Organization show that the incidence of this disease in children aged < 16 in the world varies between 1.5 and 3 in every 1 million cases (2). Moreover, the hemodialysis (HD) treatment rate among children and adolescents aged < 20 is about 9 people in every 1 million in the peer population and this value is by 15.5% in the United States (3). According to the reports published by the Management Center for Transplantation and Special Diseases, affiliated with the Ministry of Health and Medical Education in Iran, the population of patients with CKD across the country is 458,000 cases, including 148,000 children (4).

Children with CKD also face the risks of other illnesses and mortality, as well as low levels of quality of life (QoL) (5). The results of several studies have further indicated that self-care activities by children undergoing HD have been inadequate in comparison with other normal counterparts in society (6). Concerning the effects of CKD on patients' physical, mental, and social health status (7), it is important to measure QoL in patients. Evidence shows that various treatments can make significant changes in the QoL of patients with CKD (8). Hadi et al. (2010) conducted a study to investigate eight dimensions of QoL in a group of patients undergoing HD, in comparison with healthy controls. Accordingly, a significant difference was observed in all dimensions of QoL, especially in terms of physical functioning and role limitations due to physical health problems, bodily pain, and mental health issues (9).

Currently, self-care represents a basic concept of care and it is assumed as the main philosophy in nursing (10), which maintains and improves life and health in a person (11). The use of self-care can thus lead to desirable outcomes, such as minor complications, reduced hospitalization, higher levels of patient satisfaction, patient autonomy, improved adaptation to illnesses, increased well-being and performance, higher QoL, and better symptom control (12).

Orem's Self-Care Theory (SCT) is among the models with a special approach towards humans and healthcare issues, wherein humans are regarded as creatures endowed with the power of thinking and reasoning that should be involved in their own care. In this line, Orem has further reiterated that self-care is one of the main concepts of his theory. According to this model, self-care is a learned behavior in general that can meet the numerous needs of patients during diseases or once health deviations occur (13). Orem also proposes three levels for lack of self-care, including the wholly compensatory (complete dependence), the partly compensatory (partial dependence), and the supportive-educative nursing systems. Depending on patients' conditions, such systems can be practiced for care or support (14).

Nursing models are valuable guidelines to demonstrate the structure of professional nursing care and aid nurses in reviewing measures and evaluating such care. Regarding this, the application of Orem's SCT is a standard way that enables individuals to build up a more active role in their care and treatment, and thereby, improve their self-care, reduce fear and dependence, and increase motivation, self-confidence, and a sense of autonomy (15). Since the goal of nursing is to satisfy the needs of patients in terms of self-care accompanied by responsibilities in this domain, to boost patient autonomy, and to maintain compatibility of these individuals in the face of changes, children can also be assumed responsible for self-care (6). Therefore, it is of importance to reflect on the effectiveness and advantages of this model among this age group in the Iranian context. The present study aimed to evaluate the effectiveness of a self-care support-training intervention program developed based on Orem's SCT on QoL in children undergoing HD.

Methods

This one-group quasi-experimental study was fulfilled with a pretest-posttest research design. The study was conducted at Dr. Sheikh Hospital, Mashhad, Iran, because of convenient access to the samples; as a result, a relatively very reasonable sample size was obtained. The statistical population included all children aged 8-15, referring to Dr. Sheikh Hospital within 2018-2019. The study sample consisted of 27 children undergoing HD, selected from a population of 32 children admitted to this hospital. Moreover, the inclusion criteria were being at the age range of 8-15 years old, undergoing

HD, undergoing at least 1 year of HD treatment, lacking the occurrence of severe stressful events over the past 3 months (e.g., the death of close relatives), lacking major physical illnesses preventing them from participating in the study (e.g., fractures, surgeries, and hospitalization in the last 6 months), and lacking mental disorders (i.e., known mental illnesses and use of antidepressants). On the other hand, the cases with an acute physical and mental problem and a stressful event (e.g., the death of close relatives) during the study, and absent in more than one session of the training program, and unwilling to cooperate at any stage of the study were excluded from the research. Informed consent was obtained from parents and children.

Since all children undergoing HD in a particular period were examined in this study, their inclusion was based on a non-random, convenience, and purposive sampling method. The sample size was also determined using the formula of "Comparison of mean/standard deviation (SD) of two populations" with paired variables. Afterward, the mean/SD scores were calculated based on the findings of a pilot study. The sample size for the QoL scores was further estimated to be nine cases. The total number of children undergoing HD in the city of Mashhad, meeting the inclusion criteria in this study was 27 patients. In this respect, the confidence level (CL) of the study results was desirable.

The required data were collected using three questionnaires, namely a demographic characteristics information form, the KIDSCREEN-52 quality of life, and the Self-Care Measurement Scale (Shintani et al., 2009). The 52-item standardized KIDSCREEN-52 quality of life is designed in 4 subscales (i.e., emotional, physical, social, and academic) and 10 dimensions and used for children aged over 8. Shahraki-Sanavi et al. (2011) had reported the content validity ratio and the content validity index for this questionnaire as 0.69 and 0.88, respectively. The reliability of this tool was confirmed using the test-retest method, rendering for 0.93 (16). In this study, the Cronbach's alpha coefficients for the subscales of physical, emotional, social, and academic functioning were respectively 0.89, 0.77, 0.76, and 0.82, as well as 0.79 for the overall QoL. The responses to this questionnaire were rated on a five-point Likert scale from never (1 point) to always (5 points) and from never (1 point) to very high (5 points) in some items. The maximum and minimum scores for each item were five and one, respectively. Moreover, the highest and lowest scores of QoL were 260 and 52, respectively, with higher scores indicating more desirable QoL of the child.

To assess the needs of patients undergoing HD, the Self-Care Measurement Scale, developed by Shintani et al., 2007, was practiced (17). For this purpose, the questionnaire was initially translated into Persian and its validity was approved by seven experts. In this questionnaire, universal self-care needs and health-deviation self-care needs were specified. The growth and development of self-care needs were also removed since the target population was not at a specific age range. The scale of universal self-care needs included 5 criteria of diet adjustment (12 items), stress prevention (9 items), food safety (5 items), sports activities regulation (5 items), and habits (4 items). The health-deviation self-care needs also contained 3 criteria, namely care for shunt (10 items), nutrition and pharmaceuticals (8 items), and observation of care instructions (7 items) with Yes/No responses. If the answer was No, they were regarded as children's self-care needs.

To evaluate the reliability of this scale, the internal consistency method was employed. The Cronbach's alpha coefficients for the dimensions of diet adjustment, stress prevention, food safety, sports activities regulation, and habits were respectively 0.94, 0.86, 0.79, 0.83, and 0.77; in the same line, it was 0.88 for the total score of the universal self-care needs.

The first stage of the study was performed to determine the children's deficits in self-care. The universal self-care needs and the health-deviation self-care needs for each child were thus assessed using the two parts of the Self-Care Measurement Scale by the researchers through interviews with the children and their caregivers, before the start of the support-training program sessions. In this study, the health-deviation self-care needs in children included care for shunt, proper diet, treatment/care, 24-hour urine volume, blood pressure measurement, rigorous adherence to HD sessions, as well as the use of medications and control of complications. At this point, KIDSCREEN-52 quality of life was completed prior to the inclusion of the participants into the study.

At the second stage, based on the self-care needs determined in the previous stage, the self-care support-training intervention program was designed based on Orem's SCT, which involved a supportive-educative program. At this stage, some programs were developed to meet the patients' self-care needs, and then, the approvals of the children and their caregivers were obtained. Finally, a care need list was provided for each patient, resulting in need-based training. This program included

making the patients sensitized to adopting healthy behaviors, giving safety tips to families, providing notes about fistula-induced infection prevention, highlighting the importance of HD dose prescribed, guiding on how to take medications, having safe and adequate nutrition, performing proper physical activities, and practicing relaxation techniques and breathing exercises.

At the third stage, the self-care support-training program was designed for each person (based on their needs and abilities) and held during HD by the researchers using lectures, question and answer, role-plays, video clips, and pamphlets, individually, for 8-10 sessions of half an hour in 4 weeks (2-3 times a week). The researchers also attempted to compensate for the deficits in the ability of the patients and their caregivers involved in providing care through different methods (e.g., guidance, physical/mental support, and education). The children also received the required training while their caregivers simultaneously attended the training program sessions. Immediately after the completion of the sessions, 2 and 6 weeks after the intervention, the KIDSCREEN-52 quality of life was administered for each participant (Figure 1).

As this study was one-group research with a pretest-posttest design and the dependent variables were measured within three stages, the data were analyzed via the repeated measures analysis of variance (ANOVA) or its non-parametric equivalent, namely the Friedman test. Moreover, paired t-test was performed for intragroup comparisons at two stages through Bonferroni posthoc test or its non-parametric equivalent, namely Dunn's test. The data analysis was also accomplished using the SPSS Statistics software (version 16) and the 95% CL was assumed in data interpretation.
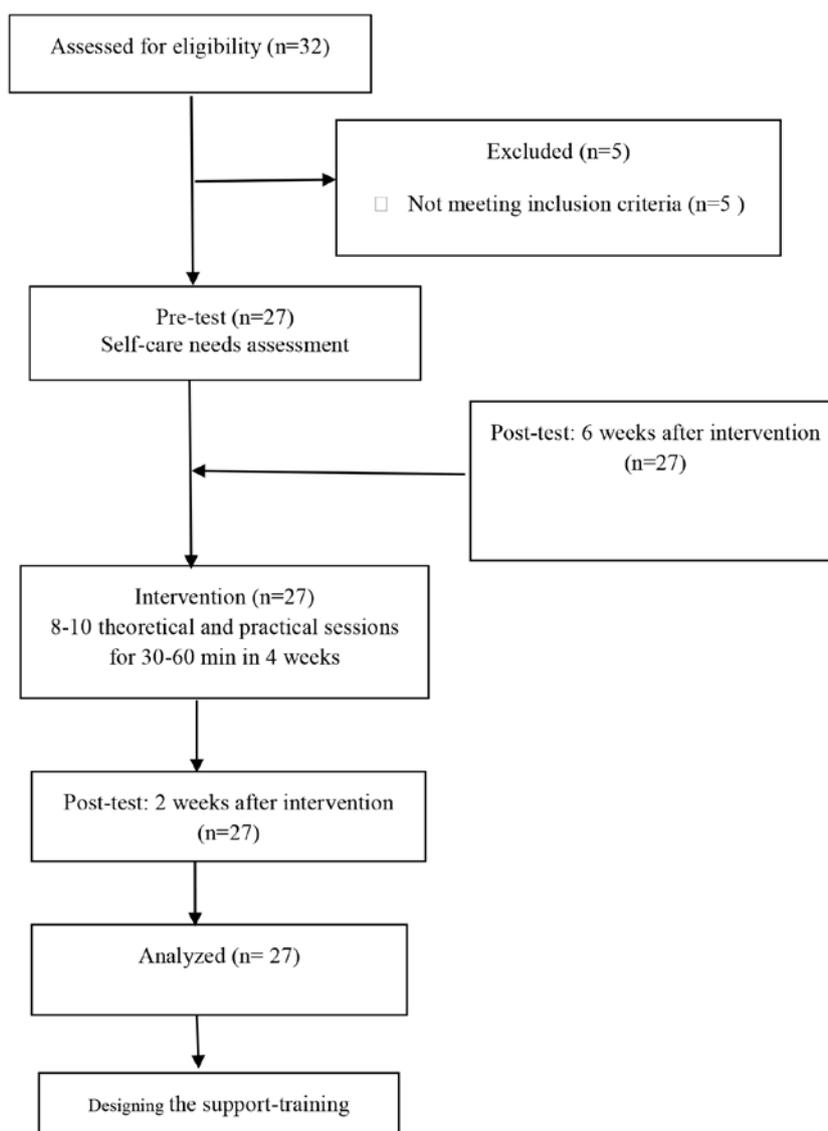
Figure 1. Research procedure diagram

Results

The children investigated in this study were in the age range of 8-15 years old. The age ranges of developing CKD and diagnosing underlying diseases were also 4-13 and 2-8 years old, respectively. Furthermore, the duration of HD was 1-7 years and the total number of HD sessions was 2-3 times per week. In this research, the majority of the children were male (Table 1).

The results of the repeated measures ANOVA with regard to the effect of the self-care support-training program based on Orem's SCDT on the total score of QoL for the children undergoing HD showed a statistically significant difference among the study stages in terms of the total score of QoL ($P<0.001$). The total mean/SD scores of the QoL before and immediately after the intervention were obtained at 118.0±24.9 and 177.0±27.3, respectively. The results of the Bonferroni posthoc test also revealed a difference between the total mean/SD scores before and immediately after the intervention ($P<0.001$). The total mean/SD scores of QoL 2 and 6 weeks after the intervention were estimated 166.1±21.0 and 140.8±19.2, respectively. The Bonferroni posthoc test results correspondingly showed a significant difference between the total mean/SD scores 2 and 6 weeks after the intervention and before it ($P<0.001$) and 2 and 6 weeks following the intervention and immediately after it ($P<0.001$) (Table 2).

Table 1. Quantitative descriptive characteristics of children

Quantitative variables	Mean±SD
Age (year)	12.6±2.0
Age at developing CKD (year)	9.7±2.0
Age at diagnosing underlying diseases (year)	4.2±2.7
Duration of HD (year)	2.9±1.8
Family size	4.9±1.6
HD sessions (times per week)	2.9±0.4

CKD: Chronic kidney disease, HD: Hemodialysis

Table 2. Total score and dimensions of quality of life in three intervals, namely after the intervention and 2 and 6 weeks after intervention

Dimensions of quality of life	Before intervention Mean±SD	After intervention Mean±SD	2 weeks after intervention Mean±SD	6 weeks after intervention Mean±SD	Intragroup test results
Physical	9.3±3.0	15.7±2.6	15.02.7	12.8±2.5	χ^2=73.7 df=3 P<0.001 Friedman test
Emotional	41.3±6.4	65.1±8.9	60.5±8.4	51.0±7.3	F=2.111 df=1.8, 2.46 P<0.001 Repeated measures ANOVA
Social	54.8±11.3	78.2±14.8	73.3±14.1	63.0±12.0	F=2.188 df=2.4, 56.7 P<0.001 Repeated measures ANOVA
Academic	12.5±3.0	18.1±2.9	17.2±3.3	14.5±3.3	F=141.3 df=8.59, 3.2 P<0.001 Repeated measures ANOVA
Total score of quality of life	118.0±24.9	177.0±27.3	166.1±21.0	140.8±19.2	F=454.1 df=1.9, 46.4 P<0.001 Repeated measures ANOVA

The ratio of increase in each dimension of QoL at the stage immediately after the intervention was further evaluated compared with that before it. These ratios were 68.8, 57.6, 42.7, and 44.8 for the subscales of physical, emotional, social, and academic functioning, respectively, and in general, it was concluded that the greatest change was related to physical functioning (Table 2).

Concerning the paired intragroup comparisons at two stages, the results of the Dunn's test demonstrated a statistically significant difference among all stages before, immediately after, and 2 weeks after the intervention in physical functioning (P<0.05). However, no significant difference was observed among the study stages immediately after and 2 weeks after the intervention. Based on the results of the Bonferroni posthoc test, a statistically significant difference was revealed among the emotional, social, and academic functioning in all stages before, immediately after, and 2 weeks after the intervention (P<0.05). Nevertheless, no significant difference was found among the stages immediately after and 2 weeks after the implementation of the intervention program. Additionally, there was an inverse correlation between the duration of HD and the total score of QoL in children aged 8-15 with CKD undergoing HD (r=-0.53); in other words, a longer duration of HD in these children led to a lower QoL. Consequently, the results of the Pearson correlation coefficient showed that the given correlation was statistically significant (P<0.004).

Discussion

The present study confirmed the hypothesis that the children receiving the self-care support-training intervention program developed based on Orem's SC-T had better QoL at the post-test stage, compared to the pre-test one. Considering the research hypothesis, the results showed that the children receiving the intervention had noticeable progress in all dimensions of QoL (the physical, emotional, social, and academic sub-scales) at the post-test stage and 2-6 weeks after the intervention, compared to the pre-test one. In line with the results of this study, El-Tawab quotes from Henkel that self-care could reduce physical problems, and consequently, improve QoL and a sense of autonomy (18). Regarding this, self-care activities for children undergoing HD are supposed to be highly important in increasing their capacity to perform their daily life activities (6).

According to the results, the self-care support-training intervention program based on Orem's SCT could improve the total score of QoL of children undergoing HD. These findings were in line with those reported by Zain ELdin et al. (2018), examining the impact of a self-care intervention program on the QoL of children undergoing HD. In the mentioned study, the total mean/SD score of QoL of children at the pre-test stage was 61.161±5.66, compared to those at the post-test and follow-up stages estimated at 34.33±0.88 and 33.66±2.32, respectively. Therefore, it was concluded that the implementation of the self-care training program improved the QoL of children undergoing HD (19). However, the follow-up of the children in the research conducted by Zain ELdin et al. (2018) lasted 3 months after the intervention, which was longer than that in the present study. The questionnaire used to measure QoL in both studies was different from each other, meaning that lower scores indicated a better level of QoL in the study performed by Zain ELdin et al. (2018).

In the present study, the academic dimensions of QoL were further considered, which significantly improved after the intervention. In addition, the results of this study were in agreement with those of research carried out by Hossein (2017) on the effectiveness of self-management programs on QoL of children undergoing HD. He had further indicated that the QoL of children had been enhanced after the implementation of the training program (6). With regard to the effectiveness of the intervention program developed based on Orem's SC-T, it can be argued that the use of this model provides nurses with the possibility to describe children's behavior objectively to provide them with training in case of any deficits in self-care in that dimension or support them. Furthermore, the impact of the intervention can be associated with different training strategies adopted by the researchers in the form of diverse lectures, question and answer, role-plays, video clips, and pamphlets, which had consequently improved their QoL.

The children undergoing HD (assigned to the intervention group) received much attention from the researcher during the study and caring responsibility was entrusted to them. As a result, their morale was much more affected and this emotional bond made them listen to the talks and training issues by the researchers, leading to the promotion of all dimensions of their QoL. Nonetheless, these results were inconsistent with those of research conducted by Abd El Tawab (2010), in which the majority of the children undergoing HD had poor levels of QoL after the intervention since they failed to establish

communications with others (18). Nevertheless, in the present study, the children had no problems communicating with the researchers. For this reason, they received good training, and the significant changes in their QoL evidenced that they had been able to apply what they had learned in their self-care.

Naroie et al. (2012) carried out a semi-experimental study on Orem's SCT and its effect on the QoL of 35 patients undergoing HD with the mean age of 38 using the 36-item Short-Form Health Survey (SF-36). They found a considerable improvement in the mean scores of QoL in the overall domains of health, including physical functioning, role emotional, mental health, social functioning, and general health perception (20). The findings of this study were also in line with the results reported by Bahadori et al. (2014), investigating the impact of an intervention program based on Orem's SCT on QoL in children undergoing HD. He indicated that the use of the self-care model could have significant effects on all dimensions of the QoL, including physical functioning, bodily pain, general health perception, vitality, social functioning, mental health, and role emotional, compared to that before the intervention (21).

In the present study, the intervention based on Orem's SCT also affected all dimensions of QoL, especially physical functioning, apparently due to more focus on training and removal of self-care deficits in physical aspects. Accordingly, the practice of the self-care model increases the awareness of one's capabilities that can meet the needs faster and better and encourage clients to take part in their own self-care, ultimately leading to the improvement of their QoL (2, 3). The results of the mentioned study revealed the effectiveness of this model in children and adolescents with poor physical characteristics to take care of themselves. Therefore, it seems that the given model can be implemented in this age group like adults. It should be noted that the use of larger samples ensures the generalizability of the results.

Based on the results of this study, QoL enhanced immediately after the intervention program, compared to that 2 and 6 weeks after it, denoting that the passage of time could decrease the effect of training. Consequently, it is suggested to recruit a full-time consultant and an experienced nurse trained according to Orem's SCT with educative-supportive roles or partial compensatory roles in HD centers (at least once a week) to rehearse the training and institutionalize the practices in the long run. In this regard, Zain ELdin et al. (2018) had recommended self-care interventions as parts of the routine care of children undergoing HD (19).

It was also found that the patients undergoing HD for longer years had low levels of QoL. These findings were in agreement with those reported by Nayak and Khare (2017), observing a significant relationship between the duration of HD in each year and self-care among adolescents (22). Zain ELdin et al. (2018) also showed that children aged 4-6 undergoing HD had lower self-care activities (19), indicating that the patients required a self-care model, leading to the improved QoL in all social, emotional, and physical dimensions. As the target group is children, it is suggested to start training from the time of diagnosing to institutionalizing it and build a proper lifestyle to form a new habit and finally improve QoL.

Concerning the results of this study, it is recommended to hold self-care training courses in all HD centers routinely to increase the levels of knowledge and awareness in children about self-care and provide them with mental support. At the same time, it is required to examine barriers to the implementation of support-training intervention programs with reference to Orem's SCT. Since the number of eligible samples was inadequate in this study, the pretest-posttest design was used, and the lack of a control group was one of the limitations. Therefore, it is recommended to conduct further studies with a control group to determine the impact of the given intervention with more certainty. The follow-up duration of 6 weeks was also another limitation of the present study, suggesting to have a longer follow-up in future research.

Implications for Practice
The results of this study showed that training based on Orem's SCT was effective in improving the QoL of children undergoing HD. Accordingly, this model can be a focus of attention among policymakers and stakeholders of nursing management. Given the results of the research, it is recommended to establish support-training centers to improve self-care in children and adolescents undergoing HD. With regard to the importance of childhood and adolescence, preparing educational self-care packages and distributing them among children and their caregivers can lead to higher levels

of QoL and boost their self-care. The application of this model in this study provided valuable information in the field of research on children and adolescents, which can be utilized in nursing, as well as examining, understanding, and evaluating care systems for children undergoing HD.

Acknowledgments

Conflicts of Interest

The authors declare no conflict of interest in the publication of this article.

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