

## Effect of a Supportive Training Program on Anxiety in Children with Chronic Kidney Problems and their Mothers' Caregiver Burden

### Abstract

**Background:** Chronic problems have a long course of treatment and are one of the important causes of the childhood hospitalization. The aim of this study was to determine the effect of a supportive training program on the children's anxiety and their mothers' caregiver burden. **Materials and Methods:** This study was a randomized controlled clinical trial, performed on two groups in three stages in the autumn of 2017 on 112 individuals. The study population consisted of all children with chronic kidney problems who hospitalized in Emam Hossein Hospital (Isfahan, Iran) and their mothers. Sampling selection method was convenient. Participants were randomly assigned to experimental ( $n = 56$ ) and control ( $n = 56$ ) groups and the supportive training program, that was a self-regulating program, was done for the experimental group. The Face Anxiety Scale and the Zarit Caregiver Burden Scale were completed by both groups before, after and 1 month after the intervention. Statistical significance was set at 5%. **Results:** There was a significant difference in the mean scores of anxiety and caregiver burden in the experimental group preintervention [anxiety: ( $t_{54} = 0.31, p = 0.75$ ); caregiver burden: ( $t_{54} = 1.34, p = 0.18$ )], postintervention [anxiety: ( $t_{54} = 5.30, p < 0.001$ ); caregiver burden: ( $t_{54} = 2.72, p = 0.009$ )], and follow-up [anxiety: ( $t_{54} = 2.39, p = 0.01$ ); caregiver burden: ( $t_{54} = 3.06, p = 0.003$ )], whereas there was no significant difference in the mean scores of anxiety and caregiver burden in the control group. In order to controlling for pretest scores, the repeated measure analysis of covariance was adopted. **Conclusions:** The results showed that the supportive training program can reduce children's anxiety and their mothers' caregiver burden and suggesting to nurses, an effective program to reduce the negative effects of hospitalization on children and their mothers.

**Keywords:** Anxiety, burden of care, chronic disease, Iran, training

### Introduction

Medical developments in recent decades have caused significant reduction in the deaths and also increase in survival of the majority of children with chronic illnesses.<sup>[1]</sup> Chronic illnesses and their accompanying problems are considered as a crisis for children and their families.<sup>[2]</sup> Among chronic problems, chronic kidney problems have a high prevalence in children. Chronic kidney disease has been suggested to affect 74 children per million globally, a number that will continue to increase as therapies allow for longer survival.<sup>[3]</sup> Children with chronic disease, in addition to illness and treatment problems, such as prolonged treatment, dietary and activity restrictions, changes in body image, inability to participate in their age-specific programs, and specific daily care, require frequent or prolonged hospitalization.<sup>[4-6]</sup> Repeated

hospitalization can lead to negative experiences in children that recurrence of these experiences is a factor for creating mental health problems such as anxiety.<sup>[7]</sup>

The illness and hospitalization of the child also change the family's daily routines and parental roles.<sup>[8]</sup> Prolonged illness, numerous treatment complications, unexpected costs, and sometimes loss of work position impose heavy burdens on caregivers and create many problems, like physical and mental problems, neglecting of other family members, family and marital conflicts, and impact on the social life of the parents.<sup>[9-11]</sup> Parents of children with chronic diseases try to adapt to existing conditions using adaptive behavioral. Tak and McCubbin have classified these adaptation behaviors into three patterns: (1) behavioral pattern of understanding the child's health status through communication with other parents

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with similar children and consulting with the medical staff, (2) behavioral pattern of family preservation and desirability of the situation, and (3) behavioral pattern of social support and mental stability.<sup>[12,13]</sup>

Numerous studies have been carried out on children's anxiety and parental caregiver burden in Iran and abroad; however, so far, no holistic study has been designed based on physical, psychosocial, and evolutionary needs based on the principle of family-based care. Thus, the present study was conducted with the aim to design a program based on the adaptive behaviors presented by Tak and McCubbin and determine the effect of this program on the children's anxiety and their mothers' caregiver burden.

## Materials and Methods

This study was a randomized controlled clinical trial (IRCT20171028037045N1), performed with two groups in three stages (pretest, posttest, and follow-up) in the autumn of 2017 on 112 individuals. The study population consisted of all 6–12-year-old children with chronic kidney problems who hospitalized in Emam Hossein Hospital (Isfahan, Iran) and their mothers. These children were admitted with a diagnosis of nephrological disorders including chronic kidney diseases, end-stage of renal disease, nephrotic syndrome, urinary tract infection at the time of conducting the study (from September, 29, 2017 to February, 3, 2018). The inclusion criteria for the children in the study were have passed at least 3 months since their diagnosis,<sup>[14]</sup> accepted to participate in the study, authorization of parents as proposed in informed consent, have no confirmed medical diagnosis of neurological and/or cognitive disorder, and lack of use of sedative and analgesic drugs based on medical records. The mothers' inclusion criteria were having at least elementary education, not being a member of the medical staff, lack of psychiatric illnesses according to their own statements, and lack of use of psychoactive drugs. Children who were in isolation were excluded because they could not participate in group class. The other study exclusion criteria included the child's and family's reluctance to continue cooperation at each stage of the study, discharge of the child before the end of the program, and lack of regular participate at the training sessions (having more than two absences).

Sampling selection method was convenient. From among the children admitted to the internal wards of Emam Hossein Hospital (Isfahan, Iran), 120 children and their mothers who had the inclusion criteria were selected. After obtaining informed written consent forms from the mothers, they were randomly assigned to experimental ( $n = 60$ ) and control ( $n = 60$ ) groups. The confidence coefficient of  $Z_1$  was 0.95, i.e., 1.96; power factor of  $Z_2$  was 0.80, i.e., 0.84; and  $s$  was the minimum estimation of standard deviation for each variable that was considered seven based on similar studies<sup>[15,16]</sup> and  $d = 5.5$  was the minimum mean difference for each of the variables between the two groups.

Hence, the required sample size in each group, assuming a 15% dropout rate, was estimated at 30 individuals. Thus, 120 children and their mothers were selected and were randomly divided into experimental and control groups. For this purpose, cards with the odd and even numbers were placed in a box and each participant was asked to randomly select a card. The odd numbers were related to experimental group and even numbers for control group. Eventually, eight mothers and children were excluded during the study due to lack of completion of the program. In total, data analysis was performed on 112 subjects, i.e., 28 children and 28 mothers in the experimental group, and 28 children and 28 mothers in the control group [Figure 1].

The data collection tool was a three-part questionnaire. The first part was a demographic characteristics form consisting of items on the child's gender, parents' education and occupation, insurance status, membership in a support organization, fixed caregiver, age of the child and mother, duration of diagnosis, and the rate of admission. The second part was the Faces Anxiety Scale (FAS) for the children which consists of five cartoon faces and a numerical scale of 1–5 that indicating 1:lack of anxiety, 2:low anxiety, 3:moderate anxiety, 4:high anxiety, and 5:severe anxiety. The psychometric properties of Persian version have been reported by Borhani *et al.* Persian version of this scale with a good reliability ( $r = 85\%$ ) has been used in various studies.<sup>[17,18]</sup> And the third part was Zarit Caregiver Burden Scale (ZBS) for the mothers with 22 items scored on a scale ranging from 0 to 4 (never, rarely, sometimes, mostly, and always, respectively). A total score of 0, less than 30, 30–60, 61–88, and 88 indicated no, slight, moderate, severe, and the highest caregiver burden, respectively. The ZBS is global standardized tool which was designed by Steven H Zarit in 1980. The reliability and content validity of this scale were obtained as  $\alpha = 0.79$ – $0.93$  and  $89.5\%$ , respectively, and the reliability of the scale has been reported in the study by Navidian as  $r = 94\%$ .<sup>[19]</sup> Also, reliability of the scale was calculated using test–retest method on 10 caregivers as a pilot study ( $r = 0.94$ ). After the questionnaires were distributed among the subjects for completion, the supportive training program was implemented. The supportive training program was a self-regulated program that the contents of which were developed based on the needs of the subjects, review of articles and scientific texts, and opinion of psychiatry professors, and psychologists of the children, and psychiatric groups. The program was held for five sessions daily<sup>[12,13]</sup> each for 45–50 minutes for the experimental. A group comprised six to eight children and mothers and the program was held for children and their mothers at same time but separately. At the end of each session, the materials covered on the same day were printed and given to the mothers. For the control group, a 20-minute question and answer session was considered before discharge and

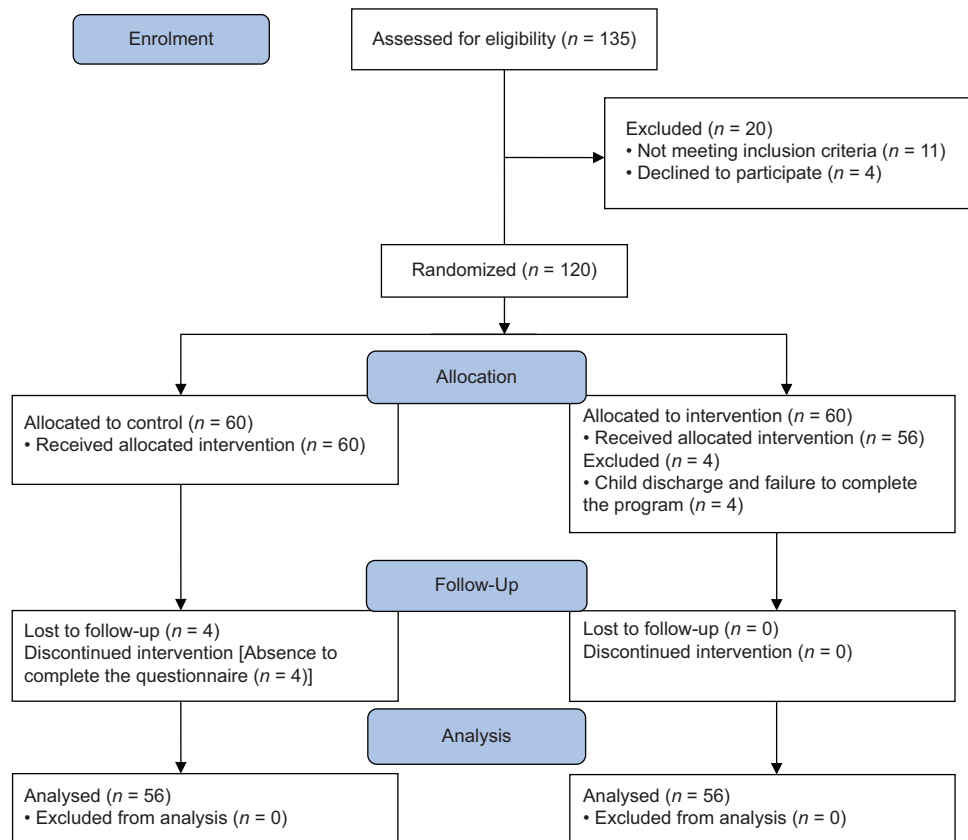


Figure 1: CONSORT flow diagram for the study

they were also provided with the printed materials. Other caretaking measures were performed as the ward routine. After and 1 month after the intervention the FAS and ZBS questioners was completed by children and their mothers in both groups. In order to complete the questionnaires 1 month after the intervention, participants were called to the hospital by telephone. The order, objectives, and content of the mothers' and the children's sessions have been summarized in Tables 1 and 2, respectively. The collected data were analyzed using descriptive and inferential statistic, including Chi-square test, independent *t*-test, repeated measures analysis of variance (ANOVA), and repeated measures analysis of covariance (ANCOVA) in Statistical Package for the Social Sciences software (version 18.0, SPSS Inc., Chicago, IL, USA).

### Ethical considerations

To observe ethical principles, an approval and introduction letter was obtained from the Research Deputy of the Faculty of Nursing and Midwifery of Isfahan University of Medical Sciences and presented to the related authorities. Moreover, written informed consent forms were obtained from the subjects and they were assured of the confidentiality of their information and statements, their freedom to participate in the treatment sessions and leave the sessions if unwilling to continue and the sessions being free of charge. This article was derived from a Nursing Master Dissertation. The

ethical code is 396445 and was approved by the Research Deputy of Isfahan University of Medical Sciences, Faculty of Nursing and Midwifery in September, 23, 2017.

### Results

Analysis of the demographic characteristics using the statistical tests indicated that no significant differences existed between the two groups in terms of the demographic characteristics of the child's gender, parents' education and occupation, insurance status, membership in a support organization, fixed caregiver, age of the child and mother, duration of diagnosis, and the rate of admission.

The results of independent *t*-test showed no significant difference between the two groups in terms of before the intervention [children: ( $t_{54} = 0.31, p = 0.75$ ), mothers: ( $t_{54} = 1.34, p = 0.18$ )]. However, after the intervention and 1 month after the intervention, the mean children's anxiety and their mothers' caregiver burden score of the control group was significantly higher than the experimental group [Table 3].

Furthermore, the results of repeated measures ANOVA showed that the mean children's anxiety and their mothers' caregiver burden in the control group did not differ significantly before, after, and 1 month after the intervention [anxiety: ( $F_{(1,45)} = 0.69, p = 0.60$ ); caregiver burden: ( $F_{(1,45)} = 1.70, p = 0.07$ )]. Nevertheless, significant

**Table 1: Supportive training program's sessions set for mothers**

Sessions	Objectives and Content*
First session	Familiarity of mothers with the researcher, research, goals, and content
Second session	Getting information and upgrading knowledge about their child's illness Communicating with families with children with similar conditions
Third session	Familiarity of mothers with the principles and importance of self-care Teaching stress coping methods and adaptive skills
Fourth session	Maintaining family integrity and optimizing the situation Upgrading the spiritual dimension
Fifth session	Familiarity with community and supportive social organizations Formation of small groups of participating families and continuing connections in the future if desired Summarizing the content and receiving feedback

\*Method: Compilation of lecture, question and answer, sharing experiences, decision-making method, displayed, and problem-solving method

**Table 2: Supportive training program's sessions set for children**

Sessions	Objectives and Content*
First session	Referrals and acquaintances Performing a game of Ice breaking series to prepare the children
Second session	Drawing a painting with the desired theme Reducing isolation by attending a classroom Drawing a painting titled "Hospitalized child" Providing an explanation of what they have drawn
Third session	Indirect instructional adaptation strategies by storytelling Performing a story show by a researcher and fellow pedagogue using fingerprints Expression of children's opinions and feelings in relation to the story
Fourth session	Showing the desired equipment for children (syringes without needle, medical gloves, and etc.) Preparation of work with existing equipment, with the help of the coach
Fifth session	Preparation of children for the termination of the group Asking children about what they have learned and leading conversations to positive experiences from being hospitalized

\*Method: Compilation of lecture, question and answer, sharing feelings, storytelling and role playing, practical activity

differences were observed in mean children's anxiety and their mothers' caregiver burden score in the experimental group before, after, and 1 month after the intervention [anxiety: ( $F_{(1,45)} = 2.03, p = 0.03$ ); caregiver burden: ( $F_{(1,45)} = 19.48, p = <0.001$ )]. In order to controlling for pretest scores, the repeated measure ANCOVA was adopted with these assumptions including Normality of anxiety and care burden variables using the Shapiro–Wilk test, Equivalence of variances using Levene test, homogeneity of variance of covariance using Box test [Table 4].

## Discussion

The present study investigated the effectiveness of the supportive training program on anxiety score in hospitalized children with chronic kidney problems and their mothers' caregiver burden. The results showed that this program decreased the level of children's anxiety and their mothers' caregiver burden. This finding is consistent with the results of previous studies on this subject. AsghariNekah *et al.* found that structured cognitive-behavioral group play therapy has influence on reducing the anxiety and depression in children with cancer.<sup>[20]</sup> Similarly, other researchers have investigated the effect of supportive training programs, including painting therapy, story therapy and play therapy, on the children's anxiety. For example, Mohammadi *et al.*,<sup>[21]</sup> Sheikhzakaryae *et al.*,<sup>[22]</sup> Karami *et al.*,<sup>[23]</sup> Kunchan *et al.*,<sup>[24]</sup> HamedTavassoli *et al.*<sup>[25]</sup> and Li *et al.*<sup>[26]</sup> All these studies showed that the anxiety of children reduced significantly in experimental group after the intervention. In the present study, children's anxiety increased again during the follow-up 1 month after the intervention. This finding can be explained by using of the FAS in hospital for checking the children anxiety in 1 month after the intervention and probability being the negative effect of the environment. In this regard, Khodabakhshi Koolae *et al.* performed a study to determine the effect of painting therapy on aggression and anxiety among children with cancer showed a significant anxiety reduction that this decrease continued in the 1-month follow-up with a lower slope.<sup>[27]</sup> This disparity may be due to differences in sample age and the nature of the disease.

Also, a study was conducted on children with cancer under chemotherapy by Ajourloo *et al.* The results indicated a significant reduction in posttest anxiety compared to pretest. However, with fixed changes, the intervention was not statistically significant in the posttest-follow-up period.<sup>[28]</sup> This disparity may be due to the duration of the intervention and the nature of the disease. The present finding suggests a significant reduction in the children's anxiety after and 1 month after the intervention in the experimental group. In contrast, Silva *et al.* found no significant differences in the degree of anxiety in hospitalized school age children before and after Dramatic Therapeutic Play technique.<sup>[29]</sup> This lack of significant results may be due to using of the Child Drawing: Hospital instrument and the sample size.

**Table 3: Comparison of the mean scores of children's anxiety and their mother's caregiver burden between the experimental and control groups**

	Mean (SD)		<i>t</i>	df	Mean difference ( <i>p</i> *)
	Control	Experimental			
Child's anxiety					
Pre-intervention	3.70 (1.40)	3.80 (1.10)	0.31	54	(0.75)
Postintervention	3.80 (1.50)	1.90 (1.10)	5.30	54	-2.10(<0.001)
1 month-follow-up	4.10 (1.30)	3.20 (1.30)	2.39	54	-0.86 (0.01)
Mother's caregiver burden					
Preintervention	42.90 (18.50)	36.60 (17.10)	1.34	54	(0.18)
Postintervention	40.40 (17.70)	29.20 (12.70)	2.72	54	-3.30 (0.009)
1 month-follow-up	41.80 (17.90)	29.40 (11.90)	3.06	54	-5.80 (0.003)

SD: Standard deviation, *t*: Independent *t*-test, df: degree of freedom, *p*\*: *p* value using *t*-test

**Table 4: Comparison of the mean scores of child's anxiety and mother's caregiver burden between three time periods of intervention in two groups**

Groups	Repeated measures ANOVA	Repeated measures ANCOVA		
		<i>p</i> <i>F</i> <sub>(df)</sub>	<i>p</i> time <i>F</i> <sub>(df)</sub>	<i>p</i> between groups <i>F</i> <sub>(df)</sub>
Child's anxiety				
Experimental	0.03 <i>F</i> <sub>(1,45)</sub> =2.03	0.695 <i>F</i> <sub>(1,45)</sub> =0.15	< 0.001 <i>F</i> <sub>(1,45)</sub> =74.60	< 0.001 <i>F</i> <sub>(1,45)</sub> =16.59
Control	0.60 <i>F</i> <sub>(1,45)</sub> =0.69			
Mother's caregiver burden				
Experimental	<0.001 <i>F</i> <sub>(1,45)</sub> =19.48	0.25 <i>F</i> <sub>(1,45)</sub> =1.35	<0.001 <i>F</i> <sub>(1,45)</sub> =25.80	0.04 <i>F</i> <sub>(1,45)</sub> =3.55
Control	0.07 <i>F</i> <sub>(1,45)</sub> =1.70			

df: Degree of freedom

Based on the results of the current study, the mothers' caregiver burden was reduced after and 1 month after the intervention in the experimental group. The result of the study by Rezaee *et al.* showed that group-based supportive training program significantly decreased caregiver burden of mothers of children with thalassemia major.<sup>[30]</sup> This is in agreement with the results of the studies by Ghane *et al.*,<sup>[15]</sup> Etemadifar *et al.*,<sup>[31]</sup> Torabi *et al.*,<sup>[32]</sup> Ashghali Farahani *et al.*,<sup>[33]</sup> Navidian *et al.*,<sup>[34]</sup> and Manne *et al.*<sup>[35]</sup> In contrast, McMillan *et al.* found no significant differences in the care burden of caregivers of patients with heart failure after coping-based intervention.<sup>[36]</sup> This lack of significant results may be due to the nature of the disease. The present study also found that mothers' caregiver burden increased gradually over the three measurements (preintervention, postintervention, and follow-up) in control group; however, this change was not significant. It is in line with the finding of study by Farahmandnia *et al.* on family burden of adolescence with type 1 diabetes.<sup>[37]</sup> This finding may be related to the progressive and chronic nature of these diseases. Despite the growing recognition of the burden and adverse effects of chronic kidney problems on caregivers, very little evidence is available about the

effect of supportive training interventions on their physical or psychosocial well-being. The lack of evidence may be due to inadequate advocacy, funding and support resources available to develop, implement, and evaluate support and information interventions for caregivers.

However, the sample size limited the results of this study, since perhaps more evidence would have been identified if it were larger, with a greater power of generalization. Consequently, it is recommended that further studies be conducted with a greater number of school children and in different diseases. Another limitation of the present study was the voluntary participation in the supportive training program. Therefore, some of the effects observed in the present study may have been due to the participants' enthusiasm to take part in such a program; thus, in order to control this factor, other sampling methods can be used in future studies. Moreover, further studies need to increased number of the sessions and gradual separation of children from the program. In addition, the data collection tool for mothers was one questionnaire and the use of only one tool may not be able to reflect the mental experience of subjects. Therefore, it is suggested that in future studies, variables such as mother's quality of life are also examined.

Another important issue was the use of the FAS in hospital for checking the children anxiety in 1 month after the intervention and probability being the negative effect of the environment and it is suggested that the anxiety questionnaires be completed in an environment other than the hospital.

## Conclusion

The results of this study showed that the designed supportive training program can be helpful in reducing the children's anxiety and their mothers' caregiver burden. It seems that presence of this program and a trained nurse in internal wards are necessary to provide a holistic care of children who hospitalized with chronic kidney problems.

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## Conflicts of interest

Nothing to declare.

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