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Effect of Implementing Family-centered Empowerment Model on the Quality of Life in School-age Children Diagnosed with Rheumatoid Arthritis

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Abstract

Background: Rheumatoid arthritis is the most prevalent chronic rheumatologic disease of children. The quality of life (QOL) in these individuals is affected by physical pain, discomfort, treatment complications, and frequent absences from school leading to academic failure. No research similar to the present investigation was performed in this area.

Aim: We aimed to evaluate the problems of children with rheumatoid arthritis. Moreover, we assessed the effect of family-centered empowerment on the QOL of these children.

Method: This randomized clinical trial was performed on 60 children aged 8-12 years diagnosed with rheumatoid arthritis in Akbar Pediatrics Hospital, Mashhad, Iran in 2018. The subjects were divided into test and control groups. The four stages of family-centered empowerment model, namely improvement of knowledge, self-efficacy, self-esteem, and assessment were executed for the test group. After a month, the inventory of pediatric quality of life was completed again. Data analysis was performed by Mann-Whitney U test, independent t-test, and paired t-test using SPSS version 16.

Results: No significant difference was observed between the groups regarding age ($P=0.351$). In addition, the post-intervention QOL of the test group was significantly higher than the control group ($P=0.004$). There was a significant difference between the pre- and post-intervention QOL in the test group ($P < 0.001$).

Implications for Practice: This study indicated the effect of family-centered empowerment model on the physical, emotional, educational, and social dimensions of QOL of children aged 8-12 years diagnosed with rheumatoid arthritis. As a result, this model is recommended to empower the children with this disease or other chronic diseases and their caregivers.

Keywords: Child, Family-centered nursing, Quality of life, Rheumatoid arthritis

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Introduction

Rheumatoid arthritis of children is the most prevalent chronic rheumatologic disease in children and one of the most common chronic diseases during childhood (1). According to the criteria presented by the International Union of Rheumatology, this disease is characterized by the inflammation of the joints lasting for a period of at least six weeks, disease onset before the age of 16 years, and rule out of other causes of arthritis (2).

The global incidence of the disease varies from 0.8-22.6% per 100,000 children with the prevalence of 7-400 per 100,000 children. This wide difference is due to the variations in populations, environment, and genetic predisposition (3). Any type of chronic and limiting disease has unfavorable effects on the mental health of the patients and their families. On the other hand, chronic diseases affect the quality of life (QOL) in patients (4).

It is clear that children need concentration, self-control, and autonomy. In addition, the lack of physical activity may prevent the involvement of children with chronic diseases in school and extracurricular activities creating a sense of humility and inadequacy. Therefore, one of the most important care goals for the patients at this age must be to improve their QOL (5).

Children are dependent on their parents due to the need for care and control of their health (6). In addition, the chronic diseases and disability of children exert considerable impacts on the function of the family. This problem puts huge burdens on the shoulders of their family, such as responsibilities and concerns regarding the care needs of children, educational requirements, medical services, treatment costs, vague future, social isolation, losing social opportunities, many absences from work, as well as physical, financial, and emotional problems (5). Consequently, families must be more prepared and active to take care of their children.

On the other hand, nursing interventions for children must also address the participation of their families. In other words, family involvement in childcare is one of the key principles of the family-centered empowerment model. As a result, giving an opportunity to the patients and family members by nurses might help them to become aware of their abilities required to meet the needs of children (7). Currently, the concept of patient empowerment has gained remarkable importance in nursing and medical research making the recognition of this issue as a necessity for the nursing profession (8, 9). In addition, family-centeredness is a philosophy accepted in nursing. Nurses play an important role in improving the level of health and QOL of individuals through empowering (10). Regarding care philosophy, family-centered care officially recognizes the importance of family as a central point of concentration in all health cares (11).

The two key concepts of family-centered care include enabling and empowering. In this regard, enabling is interpreted as creating an opportunity for all family members to show their current abilities and competencies. Empowering explains the professional interactions with families in a way that the family can have a sense of control over life (12).

One of the effective methods in empowering patients with chronic diseases is implementing the family-centered empowerment model, which is an Iranian model designed by Alhani in 2002 (7). Various studies were performed to assess the efficacy of this model on other patients with diverse diseases (13, 14). It is noteworthy that the model consists of four stages, including improving knowledge (understanding the threat), increasing self-efficacy, raising self-esteem through educational participation, and assessment (7).

The mentioned model involves the empowerment of patients and their families by dealing with the impacts and complications of the disease and better controlling of the condition to achieve a higher QOL (10). In this context, Teymouri et al. (2011) marked that executing the family-centered empowerment model played an important role in increasing the QOL of school-age children with Asthma (15).

Family-centered care considers family as the center and main core of cares. Despite numerous advantages, this type of care is less emphasized and is overlooked in Iran in professions that deal with patients. In this respect, a reason could be the lack of sufficient awareness and training about family-centered services. Furthermore, there is not a sufficient applied educational content and medical education based on a medical model in Iran (16).

The QOL of children with rheumatoid arthritis is influenced by their disease due to pain, discomfort, complications, frequent absences from school, academic failure, feeling of difference from their peers, and low self-esteem. Nonetheless, few studies have been conducted on this topic in Iran and the

prevalence of this chronic disease is high in children (1). With this background in mind, we implemented the family-centered empowerment program to take a step toward QOL improvement. Moreover, this study aimed to determine the impact of family-centered empowerment model on the QOL of the children with rheumatoid arthritis.

Methods

This randomized clinical trial was conducted on 60 children aged 8-12 years and affected by rheumatoid arthritis, as well as their family caregivers in the rheumatology ward of Akbar Pediatrics Hospital, Mashhad, Iran. The subjects were divided into two groups of intervention and control.

In order to calculate the sample size, ten subjects were selected from each of the control and intervention groups for a pilot study based on which the final sample size was determined. The mean and standard deviation (SD) of QOL was 57.46 ± 8.92 in the intervention group and 46.9 ± 9.89 in the control group. Therefore, the minimum sample size was estimated as 23 cases per group with a confidence interval of 95% and a test power of 80%. However, considering the possibility of sample drop out, 30 participants were allocated to each group (i.e., a total of 60 subjects).

The inclusion criteria were the age range of 8-12 years, diagnosis of rheumatoid arthritis by a physician from at least three months ago, no specific psychological problems, ability to complete the questionnaire and attend the empowerment program, and having no chronic diseases other than rheumatoid arthritis. The exclusion criteria entailed the lack of willingness of children and their caregivers to cooperate with the researcher, stressful events affecting QOL (e.g., violence and fight in the family, the divorce of the parents, and unpleasant events), and diagnosis of known psychological disorders or diseases.

It should be noted that the family members of the patients attending the research were the main guardians of the children, including father, mother, sister, brother, aunt, and others. In order to prevent the distribution of information, the subjects were allocated to the intervention and control groups in time blocks assigned to each group randomly and by a coin toss. In this regard, the subjects were assigned to the control group and then the intervention group.

The data collection tools were the Pediatric Quality of Life Inventory (PedsQL), demographic characteristics questionnaire, and subject selection form. The validity and reliability of the demographic characteristics questionnaire and subject selection form were assessed based on the opinions of seven experts. Moreover, the validity and reliability of the PedsQL were evaluated by Mohammadian et al. (2014) in children in Kashan, Iran (17).

In the latter research, the content validity index of the whole tool was estimated as 0.84, while it was calculated as 0.8, 0.86, 0.83, and 0.88 for the subscales of physical, emotional, social, and educational performance, respectively. The PedsQL contains 23 items covering the four dimensions of physical, social, educational, and emotional performance. The questionnaire was scored as 0-100 for each subscale and the total score was obtained by calculating the sum of the scores and dividing by 23. In this respect, the higher score was indicative of a higher QOL, whereas the lower score demonstrated a lower QOL.

First, research objectives were explained to the families and their children in-person. Afterwards, written informed consents were obtained from the families and their children. The eligible individuals were enrolled in the study. In the next stage, the questionnaires were completed by the children of the intervention and control groups. However, the routine training program of the ward, including educational pamphlets along with 15 min of explanations by a nurse was executed for the subjects in the control group.

On the other hand, the participants in the intervention group received the family-centered empowerment model encompassing the four steps of improving knowledge, raising self-efficacy, enhancing self-esteem, and assessment. The model was taught through group training, practical demonstration, educational participation, and the provision of educational booklets (8). Each group contained 3-4 families, children of whom were hospitalized at the same time.

The family-centered empowerment model has four stages. Stage one is improving knowledge or understanding the threat at which the perceived severity and sensitivity of family members are boosted through improving the knowledge level by training (7). At this stage, two educational sessions were held for at least 45 min to cover the topics of rheumatoid arthritis physiology, symptoms, complications, prognosis, medications, nutrition, activity, and exercise. At the end of this

stage, the topics were explained again in case of ambiguity. At the beginning of the next session, questions were asked about the topics presented in the former session to ensure the comprehension of the content by learners.

The second stage was self-efficacy enhancement with the goal of elevating self-efficacy through increasing the ability of individuals to perform their self-care actions. At this stage, the necessary skills were trained by the researcher in the field of care and control of rheumatic arthritis disease in children.

The aim of this stage was achieved through the practical demonstration of correct syrup taking by a syringe, accurate dividing of tablets into required pieces of quarter or half, method of measuring axillary temperature with a mercuric thermometer, correct reading of the temperature, and training of exercises for the joints of children in accordance with the discretion of physicians. Afterwards, the families were requested to practice and repeat the skills to become proficient (7). At least one 45-min session was held at this stage. Understanding and performing the acts by the caregivers and motivating by the researcher augmented the self-efficacy of the individuals.

The third stage was known as self-esteem boosting through pieces of training for the participants. At this stage, the family caregivers were asked to teach what they had learned in the past two stages to their children and other family members while providing them with educational cards. We requested the family members to ask the children to write everything they had learned on a piece of paper along with any questions they had about the content and deliver them to the researcher the next stage. Therefore, all the notes of patients and caregivers were received and evaluated the next sessions so that the quality of former meetings could be assessed and the researcher would know about the defects to eliminate them.

The benefits of transferring the educational content from caregivers to patients include: 1) augmenting the knowledge of caregivers and they can increase their self-efficacy in implementing the educational program, 2) elevating the sense of accountability in family caregivers, 3) giving the family caregivers the chance to select and decide, and 4) improving self-esteem in the family caregivers attending this training (7). At least one 45-min session was held at this stage.

The fourth stage of the program was the assessment step. At this stage, the evaluation was carried out during the intervention and eventually at the end of the process. The assessment was made in order to examine the steps of empowerment plan using questions and answers at the end of each session and at the beginning of the next session. One month after the intervention, the QOL questionnaire was completed again by the children of the case and control groups (7).

In this research, the researcher followed all the codes of ethics defined by the Ethical Committee of the research vice-chancellor of Mashhad University of Medical Sciences. A letter was presented to the research authorities of the Nursing and Midwifery School of Mashhad. Furthermore, the research methods and objectives were explained by the researcher to the participants and informed consents were attained from the subjects and their families.

It should be noted that the patients were allowed to leave the research and were ensured regarding the confidentiality of their personal information. At the end of the research, the educational booklets were provided to the subjects in the control group and the results were provided to the patients in case they requested. In addition, The results would be published to be used by other researchers and enthusiast people. A copy of the project will be available in the library of Nursing and Midwifery School of Mashhad.

After coding, the data were analyzed using SPSS software version 16. Descriptive statistics included mean, SD, and frequency distribution. The Kolmogorov-Smirnov test and Shapiro-Wilk test were utilized to assess the normal distribution of the quantitative variables. Moreover, the Chi-Square test was applied to evaluate the homogeneity of the groups for the qualitative variables. In order to examine the homogeneity of the groups regarding the quantitative variables, the independent t-test or Mann-Whitney U test were used.

In addition, the two groups were compared in terms of normal quantitative variables applying the independent t-test. The variables with non-normal distribution and ordinal variables were compared between the two groups by the Mann-Whitney U test. The nominal variables were also assessed using the Chi-Square test, precise Chi-Square, and Fisher's exact test. For the intragroup comparison between the two pre- and post-intervention times, the paired t-test and Wilcoxon test were used for normal and non-normal variables, respectively. The probability factor was considered as 95% for all tests.

Results

The mean and SD of children age in the intervention and control groups was 10.5 ± 1.6 and 10.6 ± 1.0 years, respectively. In addition, the weight of the children was found as 32.8 ± 9.5 kg in the test group and 33.8 ± 10.3 kg in the control group. The mean and SD of children height in the case and control groups was reported as 137.4 ± 16.0 and 139.8 ± 15.0 cm, respectively (Table 1).

In terms of gender, 60% of the subjects in the intervention group (N=18) and 63.3% of the participants in the control group (N=19) were female (Table 2). Our findings showed that the mean and SD of the age of the children caregivers was 36.1 ± 7.2 and 37.4 ± 7.5 years in the test and control groups, respectively (Table 1). In addition, 80% of the caregivers in the intervention group (N=24) and 93.3% of the caregivers in the control group (N=28) were mothers. In the case and control groups, 30% (N=9) and 50% (N=15) of the children were demonstrated to have caregivers with a diploma degree (Table 2).

Furthermore, the mean and SD of the pre-intervention total QOL score of the children with rheumatoid arthritis was revealed as 42.4 ± 13.1 and 43.2 ± 19 in the test and control groups, respectively. According to the results of the independent t-test, this difference was not significant ($P < 0.511$) (Table 3). On the other hand, the mean and SD of the post-intervention total QOL score of the children with rheumatoid arthritis was 73.7 ± 10.8 and 46.5 ± 19.6 in the case and control groups, respectively. In this regard, the results of the independent t-test were indicative of a significant difference between the two groups ($P=0.004$) (Table 3).

The total score of QOL increased to 31.4 ± 7.4 in the intervention and to 3.3 ± 2.4 in the control group after the test. The findings of the Mann-Whitney U test showed that these augmentations were significantly different ($P < 0.001$) (Table 3). Concerning the intragroup comparison, the paired t-test

Table 1. Frequency distribution of children based on demographic characteristics in the two intervention and control groups

Variable	Group		Test Result
	Intervention N (%)	Control N (%)	
Gender of children			
Female	18 (60)	19 (63.3)	P = 0.79
Male	12 (40)	11 (36.7)	Chi-square
Age of children (year)	10.1 ± 5.6	10.1 ± 6	P = 0.35 Independent t-test
Height of children (cm)	137.16 ± 4	139.15 ± 8	P = 0.43 Independent t-test
Weight of children (kg)	32.9 ± 8.5	33.10 ± 8.3	P = 0.39 Independent t-test
Age of caregiver (year)	36.7 ± 1.2	37.7 ± 4.5	P = 0.51
Relation of caregivers with children			
Father	0 (0)	0 (0)	
Mother	24 (80)	28 (93.3)	
Sister	1 (3.3)	2 (6.7)	P = 0.13
Brother	0 (0)	0 (0)	Precise Chi-square
Aunt (mother's sister)	2 (6.7)	0 (0)	
Aunt (father's sister)	3 (10)	0 (0)	
Level of the education of caregivers			
Illiterate	2 (6.7)	0 (0)	
Elementary	6 (20)	7 (23.3)	
End of elementary school	10 (33.3)	4 (13.3)	P = 0.17
Diploma	9 (30)	15 (50)	Mann-Whitney U
BSc and higher	3 (10)	4 (13.3)	
Total	30 (100)	30 (100)	
Involved joints of children			
Wrist, elbow, or knee	7 (23.3)	5 (16.7)	P = 0.51
Ankle, knee, or hip	23 (76.7)	25 (83.3)	Chi-square
Total	30 (100)	30 (100)	

Table 2. Mean and standard deviation of the quality of life in children pre- and post-intervention in the intervention and control groups

	Group		Type of test	Intergroup test result
	Intervention (N=30)	Control (N=30)		
	Mean±standard deviation	Mean±standard deviation		
Physical dimension of the quality of life				
Pre-intervention	37.8±15.3	38±2.17	Independent t-test	P = 0.71
Post-intervention	69.5±14.1	40.8±21	Independent t-test	P = 0.004
The difference compared to pre-intervention	31.7±7.3	2.8±1.4	Mann-Whitney U	P < 0.001
Intergroup test result	P < 0.001	P = 0.42	Paired t-test	
Emotional dimension of the quality of life				
Pre-intervention	44.2±17.6	46.3±22.7	Independent t-test	P = 0.21
Post-intervention	74.7±14.5	47.3±23.1	Independent t-test	P = 0.001
The difference compared to pre-intervention	30.5±7.9	1.0±3.3	Mann-Whitney U	P < 0.001
Intergroup test result	P < 0.001	P = 0.11	Paired t-test	
Social dimension of the quality of life				
Pre-intervention	45.8±16.8	46.5±26.8	Independent t-test	P = 0.46
Post-intervention	78.7±13.9	47.8±26.6	Independent t-test	P = 0.006
The difference compared to pre-intervention	32.8±9.3	1.3±2.9	Mann-Whitney U	P < 0.001
Intergroup test result	P < 0.001	P = 0.12	Paired t-test	
Educational dimension of the quality of life				
Pre-intervention	44.3±16.5	44.2±19.7	Independent t-test	P = 0.39
Post-intervention	74.7±14	45.5±23.9	Independent t-test	P = 0.009
The difference compared to pre-intervention	30.3±11.1	3.3±10.7	Mann-Whitney U	P < 0.001
Intergroup test result	P < 0.001	P = 0.72	Paired t-test	
Total score of the quality of life				
Pre-intervention	42.4±13.1	43.2±19	Independent t-test	P = 0.51
Post-intervention	73.7±10.8	46.5±19.6	Independent t-test	P = 0.004
The difference compared to pre-intervention	31.4±7.4	3.3±2.4	Mann-Whitney U	P < 0.001
Intergroup test result	P < 0.001	P = 0.47	Paired t-test	

showed that the change in the overall QOL score was significant in the test group, compared to the pre-intervention score ($P < 0.001$). On the other hand, the results of the paired t-test demonstrated that the pre- and post-intervention overall scores of QOL were not significantly different in the control group ($P=0.476$) (Table 3).

The pre- and post-intervention scores of various QOL dimensions in children are mentioned in Table 3. Regarding the fact that a test group was compared with a control group in this study, Cliff's Delta formula was used to estimate the effect size. As a result, the effect sizes for overall score of QOL, physical, emotional, social, and educational dimensions were estimated as 1.39, 1.37, 1.19, 1.16, and 1.22, respectively. Given that these effect sizes were greater than 0.8, there was a significant difference between the two test and control groups in all cases.

Discussion

In the post-intervention stage, the QOL score in terms of physical dimension was significantly higher in the intervention group, compared to the control group. Moreover, in the intragroup comparison, the paired t-test showed a significant difference regarding the physical aspect of QOL in the test group. The latter result demonstrates that the family-centered empowerment model increased the physical dimension of QOL of children with rheumatoid arthritis.

Alhani et al. (2006) evaluated the effect of family-centered empowerment on the QOL of the school-age children with thalassemia. These authors reported a significant enhancement in the physical context of QOL of the subjects in the test group, which is consistent with our findings(14). In another study by Zieh et al. (2006) on asthmatic children in Iran, there was a significant difference between the mean QOL of the subjects in the case and control groups pre- and post-intervention in terms of physical activity, which is in line with our findings (18).

In the current study, after the intervention, the score of the emotional feature of life quality was

significantly higher in the test group than the control group. In addition, the intragroup evaluation of the intervention group by paired t-test indicated a significant difference concerning the emotional dimension of QOL between the pre- and post-intervention stages. In other words, the family-centered empowerment model enhanced the emotional aspect of QOL in children with rheumatoid arthritis.

Teymouri et al. (2011) investigated the impact of family-centered empowerment model on the life quality of school-age children with asthma. In the mentioned study, the mean and SD of QOL score in the participants changed significantly post-intervention, specifically in the emotional context. Therefore, the results of these authors are consistent with our findings. It should be noted that the research method in both studies was the same and consisted of implementing the four stages of the family-centered empowerment model. In addition, all the participants were children aged 8-12 years that is similar to the present investigation (15).

Our post-intervention findings showed that the score of the social dimension of life quality was significantly higher in the test group, compared to the control group. Moreover, the intragroup comparison by paired t-test in the intervention group indicated a significant difference regarding the social dimension of life quality between the pre- and post-intervention times. In other words, the applied model was able to enhance the social aspect of QOL in children with rheumatoid arthritis.

Alhani et al. (2006) carried out a research on school-age children with thalassemia. They demonstrated a significant difference between the pre- and post-intervention scores of the social dimension of QOL in the subjects of the test group, which is in line with our findings (14).

Following the intervention, the educational feature of the case group was significantly higher, in comparison with the control group. In addition, the intragroup evaluations in the intervention group showed that the educational dimension of life quality changed significantly after the test. The latter result was indicative of the family-centered empowerment model influence on elevating the score of the educational dimension of QOL in the children with rheumatoid arthritis.

In the study performed by Teymouri et al. (2011), there was a significant difference between the mean and SD of emotional context scores in the children with asthma pre- and post-intervention, which is in congruence with our findings (15). Alhani et al. reported that the mean scores of school performance aspect were not significantly different between the QOL of the children in the test and control groups before and after the intervention. This lack of consistency between the results regarding the educational performance might be related to the variation in the nature and complications of thalassemia and rheumatoid arthritis (14).

The total post-intervention score of QOL was significantly higher in the intervention group, compared to the control group. Moreover, the intragroup comparison in the case group demonstrated a significant difference between the pre- and post-intervention scores meaning that the family-centered empowerment model increased the total QOL score in the children with rheumatoid arthritis.

According to McKlindon and Heller, power and control are vital issues in families. The power factor in a family is affected by empowerment and the family system is influenced by changes in one person due to interactive communication. Therefore, it can be expected that the empowerment of a family member affects the ability of the family system to access health goals. Finally, the ability of families will lead to more efficient care and will help the patients with chronic diseases to receive care of higher quality resulting in improved health.

Family caregivers of chronic patients are under a lot of pressure as those at risk of disease are often referred to as a hidden disease. Interventions, such as empowerment model will consider the educational and therapeutic needs of these individuals to help change the attitudes toward the disease, symptoms, and behavioral changes. Furthermore, these practices reduce the psychological stress of family members and promote their QOL and self-efficacy. Owing to their benefits, including cost-effectiveness, safety, and efficacy, this type of interventions can help the caregivers of the patients, especially those with chronic diseases (e.g., multiple sclerosis) to raise their specialized care quality.

Our findings could be generalized to multiple sclerosis because it is a chronic disease similar to rheumatoid arthritis (19). It is noteworthy that the diversities in the participants concerning culture (urban or rural), beliefs, economic status, values, individual differences, and intrinsic abilities affected their learning ability. Consequently, these personal differences might be recognized as limitations for the present study.

Implications for Practice

According to the results of this study, the implementation of the family-centered empowerment model can improve the physical, emotional, educational, and social contexts of QOL in the children aged 8-12 years and diagnosed with rheumatoid arthritis. As a result, execution of the empowerment model by nurses is recommended for the children with other chronic diseases and their families. Moreover, further studies regarding the effect of this model on the care performance of caregivers and their QOL, as well as the frequency of disease complications and duration of re-hospitalization of the children due to the side effects are suggested.

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Conflicts of Interest

The authors of this study declare no conflicts of interest regarding the publication of this paper.

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