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The Effect of Parent Training and Telephone Follow-up on Adherence to Medication Program of Children with Epilepsy

Shirin Ranjbar [1], Firozeh Hosseini [2], Tayebeh Hasan Tehrani [3*], Soodabeh Aghababaei[3], Leili Tapak [4], Mohammad Hossein Sattari [5]

Abstract

Background: Epilepsy is a common chronic neurological disorder in paediatrics. Most of the children with epilepsy do not properly adhere to medication regimen which leads to a lack of control over seizure and increased mortality and morbidity rate in these patients.

Aim: This study was conducted with aim to evaluate the effect of parent training and telephone follow-up on adherence to the medication program of children with epilepsy.

Method: This quasi-experimental study was conducted with participation of 72 parents of children with epilepsy who were referred to Besat Hospital of Hamadan in 2019-2021. The samples were assigned to two experimental and control groups by using random block permutation. During the first 24 hours of admission, the participants completed the researcher-made medication adherence questionnaire. A face-to-face training program and follow-up by phone were provided for the experimental group and no intervention for the control group. The questionnaire was also completed after two months. Data were analysed using SPSS software (version 22). $p<0.05$ was considered statistically significant.

Results: After the intervention, the control group showed a non-significant increase of 47.10±15.07 in medication adherence ($p>0.05$). However, the intervention group experienced a significant increase of 88.83±4.68 in medication adherence ($p<0.001$).

Implications for Practice: Parental education and telephone follow-up can be recommended as an independent action in nursing care services to improve medication adherence in children with epilepsy.

Keywords: Children, Epilepsy, Medication adherence, Telephone follow-up, Training

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1. Research Center for Nursing and Midwifery Care, Non-communicable Diseases Research Institute, School of Nursing and Midwifer, Shahid Sadoughi University of Medical Sciences,Yazd, Iran
2. Department of Pediatrics, Hamadan University of Medical Sciences, Hamedan, Iran
3. Mother and Child Care Research Center, Institute of Health Sciences and Technologies, Avicenna Health Research Institute, Hamadan University of Medical Sciences, Hamadan, Iran
4. Modeling of Noncommunicable Diseases Research Center, Institute of Health Sciences and Technologies, Avicenna Health Research Institute, Hamadan University of Medical Sciences, Hamadan, Iran
5. Department of Nursing, Hamedan Branch, Islamic Azad University,Hamadan, Iran

* Corresponding Author Email: t.tehrani@umsha.ac.ir

Introduction

Epilepsy is a common chronic neurological disorder that impacts the lives of 50–70 million individuals globally with a higher incidence rate in developing countries (1,2). Approximately half of all epilepsy cases manifest in childhood, with 10.5 million children under the age of 10-15 years being affected (3, 4). The prevalence of epilepsy in Iran was estimated as 1-3% of the entire population (5). Individuals with chronic illnesses must manage their conditions, often through medications effectively. This is important to minimize the disease's impact and prevent additional disability (6).

The primary method used by individuals with epilepsy to control their condition is antiseizure medications, which are the best line of defense against seizure attacks (7). These drugs can control seizures by up to 67% (8). Epilepsy is associated with complex psychological and social complications. Furthermore, the diagnosis of epilepsy and drug therapy is insufficient for managing it. Therefore, evaluating the level of adherence to medication among epilepsy patients should be a typical part of the treatment management process (9).

Medication adherence is defined as the degree of individual drug use behavior following the recommendation healthcare providers agreed upon (10). One of the reasons for the failure of drug therapy for this disease is the lack of treatment adherence. Up to 50% of people with epilepsy have poor adherence due to the prolonged treatment period and the simultaneous use of multiple drugs (11). Inadequate compliance with antiepileptic medications results in treatment failure, heightened mortality and morbidity rates, increased healthcare expenses, additional medical complications, and a diminished quality of life (12, 13). Alsous et al. in their study stated that adherence to antiepileptic drug therapy in Jordanian children with epilepsy is 55.6%, indicating a need for clinical interventions aimed at overcoming high levels of non-adherence and striving to increase adherence to more acceptable levels in these children (14). Modi et al. in their study also showed that non-adherence to antiepileptic drugs is a significant problem for children with epilepsy and their families, with nearly 60% showing poor adherence to treatment (15).

Medication adherence in children's care is a multifaceted process that requires collaboration between patient and health care professional, likewise between the child and parent, and the parent and health care professional; therefore, parents can play a supportive role for children (16). The results of a meta-analysis suggest that the adherence of families with children suffering from chronic diseases to medical interventions is associated with their performance related to family challenges, flexibility, communication, and problem-solving. Regularly assessing the functioning of the family as a whole, providing family-based self-management services, and offering support can lead to positive outcomes, such as enhanced adherence to treatment regimens. Screening for family functioning creates opportunities for prevention and integration of support for family self-management (17). However, limited studies have been conducted on the knowledge and actions of physicians, nurses, and families in enhancing medication adherence in children (18). Ensuring adherence to medication regimens is crucial for effective medical and healthcare interventions. Non-adherence to prescribed medications leads to the limited treatment outcomes for children with epilepsy (9). Important consequences of non-adherence to treatment regimens in children with epilepsy include increased and recurring seizures, incorrect clinical decision-making, and poor quality of life (15, 19) . The information and training provided to parents of sick children in pediatric wards regarding medication regimen and follow-up by healthcare providers are usually too general due to the high number of patients and lack of time and are not well-executed or monitored due to overcrowding in these wards (20, 21).

Telephone intervention may be a suitable approach to address the problem-solving needs of patients with chronic disease and enhance medication adherence (22). Telephone nursing in providing care is not only cost-effective and facilitates access to adequate care, but also saves time, reduces emergency department visits, and increases communication between patients and nurses (23). Despite the known impact of non-adherence to treatment in children with epilepsy, few interventions have been implemented to improve their adherence to treatment regimens (15). Evaluating barriers to treatment adherence over time leads to identifying effective interventions and improving adherence and care (4). Consequently, combining in-person training with telephone follow-up can enhance treatment adherence in children with epilepsy (22, 24). The present study was conducted with aim to investigate the impact of telephone training for parents on medication adherence in children with epilepsy in order to characterize the treatment gap associated with parent training by nurses and their telephone follow-up.

Methods

This pre-and post-intervention quasi-experimental study was conducted on patients who were hospitalized in the Besat Educational and Medical Center of Hamadan pediatric wards from December 2019 to February 2021. The sample size was calculated based on the research by Mousavi et al. (19) and according to the Cochrane sample size formula for comparing two means (by considering the 95% confidence level of the test , power equal to 80% and loss rate=10%) (25), and considering the common variance of medication compliance in the two groups equal to 1.59 and taking into account at least 1.2 significant difference between the two groups; therefore, the sample size was estimated to be at least 36 subjects in each group.

The participants were selected using a convenience sampling method based on inclusion criteria and were allocated to the intervention group (n=36) and the control group (n=36) using random block permutation. In this way, a permuted block randomization method with blocks of size 4 was used to randomly allocate the participants into two groups of control and intervention (Figure 1). The inclusion criteria were children aged 1 to 7 years with confirmed diagnosis of epilepsy by a physician and having a medical record, access to and ability to use a mobile phone by the parents of the child, absence of other physical and mental illnesses in children, and a minimum six-month use of antiepileptic drugs. The exclusion criteria included the emergence of other physical or mental health problems during the study and the unwillingness to continue participating in the study.

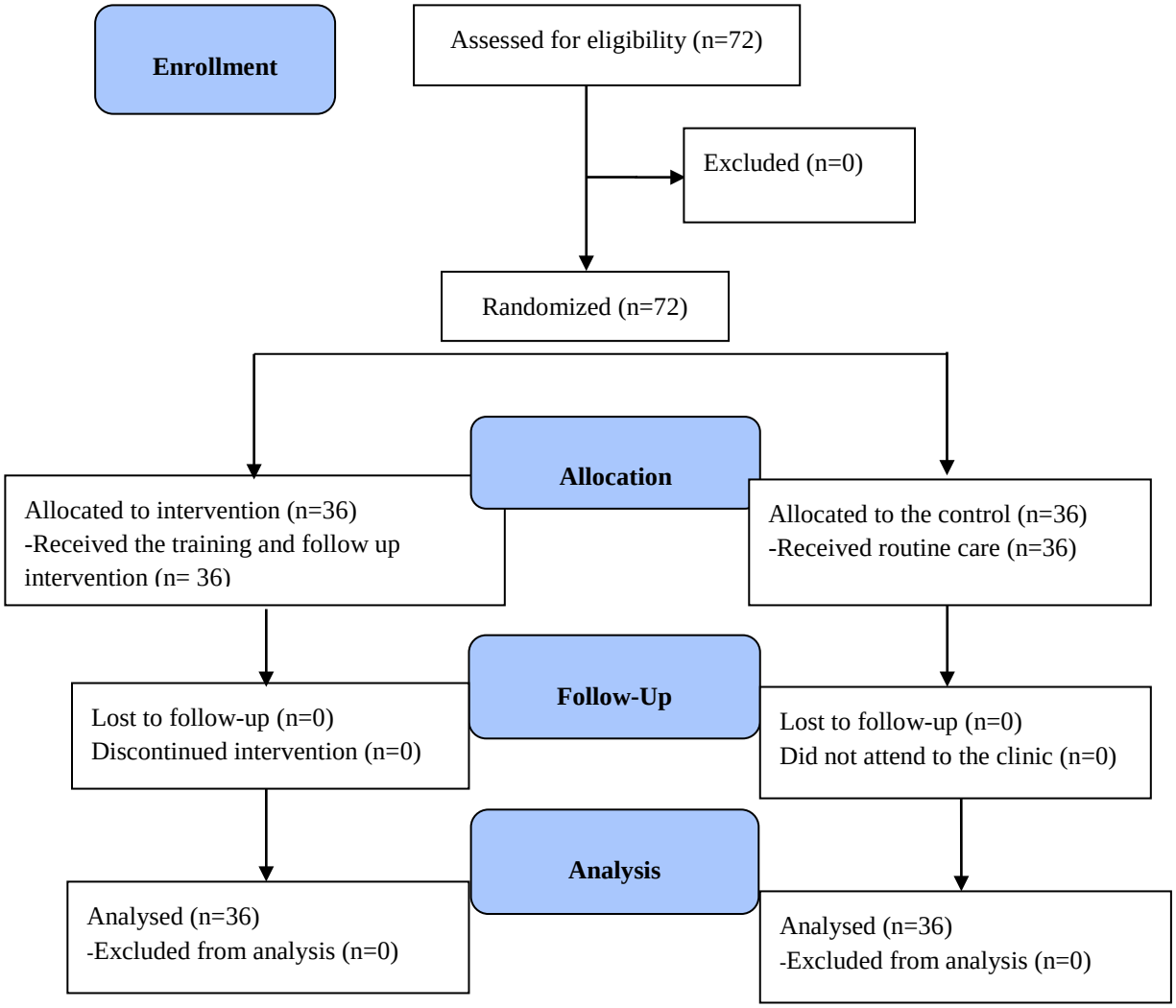

Figure 1. CONSORT flowchart of the study process

To collect data, the researcher developed a medication adherence questionnaire based on similar studies and relevant resources. This questionnaire comprised 32 items divided into four domains: knowledge and awareness (5 phrases/5-25 points), barriers (12 phrases/12-60 points), beliefs and

attitudes (8 phrases/8-40 points), and performance and adherence (7 phrases/7-35 points). The minimum score is 32 and the maximum score is 160. In order to facilitate the presentation of the results, the scores were changed to a scale of 0 to 100. The questionnaire was scored based on the person's response to the questions with a score of 5-1 (5 means the most desirable answer and 1 means the least desirable answer). The scoring of some questions was reversed (questions 6, 7, 9, 10-17, and 23-25 are reversely scored). A high score indicated greater adherence. The validity of the questionnaire was confirmed by ten experts in the fields of nursing and medicine.

Psychometric of the tool was done through qualitative face validity, qualitative and quantitative content validity. To check the qualitative formal validity, one of the 10 participants in the research had a face-to-face discussion about the difficulty of understanding, appropriateness and relationship of the items with the dimensions of the questionnaire and the possibility of misinterpretations of the phrases and inadequacy in the meanings of the words, and the necessary corrections were made. Quantitative and qualitative methods were used to determine content validity. In this study, 10 experts in different fields (pediatric nursing and pediatricians) were asked to comment on the grammar, the use of appropriate words, the spelling of words, the clarity of the concepts of the items and the ease of completing the questionnaire. Then, based on their opinions, the items were revised and modified. CVI content validity index and CVR content validity ratio were used to check content validity. To determine the CVR, a questionnaire was sent to 14 experts in the fields of pediatrics and instrument making. The mentioned index was calculated and then the resulting number was compared with the critical point of the adjusted Lawshe table based on the number of evaluator experts. Finally, I-CVI value of CVI was calculated for each of the items and S-CVI value for all items was calculated as 0.81. Finally, to check the reliability, internal consistency was done with a sample of 30 participants by calculating Cronbach's alpha coefficient. The reliability of the medication program adherence tool from four areas of awareness and knowledge, obstacles, beliefs and attitude, performance, adherence and reliability of the whole tool were calculated 0.92, 0.73, 0.81, 0.83 and 0.85, respectively.

The research participants were enrolled after obtaining written consent and explaining the study's objectives and procedures. The parents in both groups were invited to complete the questionnaire (before the intervention and two months after the intervention). For the intervention group, the interventions began with holding training in three sessions, every other day during one week (30-45 minutes) of face-to-face training before discharge. The training content included the definition of epilepsy, its care, the role of drug therapy, emphasizing and encouraging adherence to the medication regimen, avoiding discontinuation of medication, following safety precautions, and familiarity with drug side effects based on the latest medical and pediatric nursing sources. The sessions were organized in a question-and-answer format, and the parents in the intervention group were provided with a booklet at the end of each session. After discharge from the hospital, communication was maintained through phone calls lasting 10-15 minutes. In the first week, two phone calls were made, followed by one phone call per week during the rest of the study period, at pre-arranged times, to address any questions or concerns of the families of these patients. The last phone call was made in the fourth week after discharge, during which necessary coordination for follow-up visits and re-completion of the medication adherence questionnaire was done.

Following the intervention period, eight weeks after discharge, both groups visited the clinic to complete the medication adherence questionnaire under the supervision of a researcher who was not involved in the training. It is worth mentioning that the control group received routine care (a brochure containing educational tips as well as answers to questions that some patients randomly asked by the ward staff) while hospital discharge.

Data analysis was performed by SPSS software (version 22). Paired t-test was used to compare the means before and after the intervention in each group (experimental and control groups). Independent t-test was also used to compare the means in two intervention and control groups before and after the intervention. In addition, chi-square test was used to compare qualitative parameters between the two groups. $p<0.05$ was considered statistically significant.

Ethical Consideration

An informed written consent was obtained from all participants. The study was approved by the ethics committee of the Research Deputy of Hamadan University of Medical Sciences (ethical code: IR.UMSHA.REC:1398.002). Patients were also informed that if they experienced any

problems during the treatment, they should inform the researchers through telephone or in-person communication; moreover, they were informed that they could withdraw from the study at any stage if they wished. At the end of the study, the training materials were also provided to the control group to observe the ethical considerations.

Results

The mean age of patients in the control group was 42.55 ± 23.58 months and in the intervention group was 50.16 ± 38.11 months. Additionally, the mean duration of the disease in the control group was 31.08 ± 16.66 months, while in the intervention group, it was (27.11 ± 25.21) months. Moreover, the mean weight in the control group was 14.59 ± 4.03 kg, while in the intervention group, it was 17.01 ± 8.13 kg. According to the results of data analysis, it was found that in both intervention and control groups, a majority of the patients were male, with a rate of (58.3%) and (66.7%), respectively. Furthermore, in the intervention group, a proportion of the patients (16.7%) had a family history of epilepsy in first-degree relatives. In comparison, a larger proportion (44.4%) had a family history of epilepsy in second-degree relatives. In contrast, the corresponding percentages in the control group were (13.9%) and (50%) for first-degree and second-degree relatives, respectively.

Table 1: Demographic characteristics of the participants in the two groups

Variables	Intervention N (%)	Control N (%)	*p*-value*
Gender of child			
Male	15 (41.7)	12 (33.3)	0.62
Female	21 (58.3)	24 (66.7)	
Caregiver			
Mother	29 (80.6)	31 (86.1)	0.56
Father	7 (19.4)	5 (13.9)	
Job status (Mother)			
Housewife	30 (83.3)	30 (83.3)	1.00
Employed	6 (16.7)	6 (16.7)	
Job status (Father)			
Self-employed	27 (75)	30 (83.3)	0.56
Employed	9 (25)	6 (16.7)	
Education level (Mother)			
Under diploma	14 (41.7)	20 (55.5)	0.27
Diploma	14 (38.9)	10 (27.8)	
Academic	8 (19.4)	6 (16.7)	
Education level (Father)			
Under diploma	16 (44.5)	20 (55.5)	0.56
Diploma	13 (36.1)	10 (27.8)	
Academic	7 (19.4)	6 (16.7)	
Residence			
City	20 (55.5)	15 (41.7)	0.03
Countryside	11 (30.6)	6 (16.7)	
Village	5 (13.9)	15 (41.7)	
Drug side-effect			
Yes	13 (36.1)	14 (38.9)	1.00
No	23 (63.9)	22 (61.1)	

*Chi-square test

As the Chi-square test results indicated, no significant difference was found between the two groups regarding demographic variables (p>0.05) (Table1).

Before the intervention, the highest mean score of adherence to the medication plan in both intervention and control groups was related to performance and adherence. Also, the lowest mean score in each group was related to the field of awareness and knowledge (Table 2). After the intervention, the highest mean score of adherence to the medication plan in both the intervention and control groups was related to the performance area. After the intervention, the lowest mean score in

both the intervention and control groups was related to the area of barriers (Table 2).
Before the intervention, there was no significant difference between the two groups regarding adherence to the treatment program in knowledge, barriers, beliefs, attitude, and adherence (p>0.05). However, after the intervention, there was a significant difference between the two groups regarding adherence to the treatment program in the aforementioned areas (p=0.001) (Table 2).

Table2: Comparison of mean score of adherence to the medication plan in the intervention and control groups before and after the intervention

Dimensions of medication adherence	Group	Before intervention	After intervention	Mean change	p-value*
Awareness and knowledge	Intervention	31.25 ± 14.21	83.19 ± 6.22	51.94 ± 17.12	<0.001
	control	36.11 ± 16.26	37.63 ± 16.19	1.52 ± 4.11	0.032
	p-value**	0.18	<0.001		
Barriers	Intervention	31.31 ± 12.94	67.63±6.37	36.32 ± 11.81	<0.001
	control	33.47 ± 14.93	33.75±14.92	0.28 ± 2.45	0.50
	p-value**	0.51	<0.001		
Beliefs and attitudes	Intervention	53.81 ± 13.99	85.93 ± 5.66	32.11 ± 15.51	<0.001
	control	57.55 ± 14.08	57.20 ± 13.91	-0.34 ± 2.08	0.32
	p-value**	0. 26	<0.001		
Performance and adherence	Intervention	58.73 ± 12.14	93.15 ± 5.68	34.42 ± 11.83	<0.001
	control	63.19 ± 11.85	63.88 ± 11.09	0.69 ± 2.22	0.07
	p-value**	0.11	<0.001		
Adherence to the medication plan (Total score)	Intervention	42.12 ± 14.15	88.83 ± 4.68	46.70 ± 13.71	<0.001
	control	46.58 ± 15.47	47.10 ± 15.07	0.52 ± 1.92	0.11
	p-value**	0.20	<0.001		

*Paired t-test, **Independent t-test

Discussion

This study aimed to investigate the effect of parent training and telephone follow-up on adherence to the medication program of children with epilepsyBehavioral interventions, such as reminders and telephone follow-up, have proven to be more effective in promoting adherence. The intervention groups, which received education and follow-up, exhibited improved adherence compared to the control groups. These findings align with the study by Majd et al. on Iranian children and adolescents with epilepsy that showed a direct correlation between patients' self-efficacy and their ability to manage their illness. Training programs increased adherence to medication regimens and self-efficacy (26). Other researchers also reported similar results (27,28). Moreover, the research by Liu et al. showed a significant increase in medication knowledge and adherence to medication regimens in epilepsy patients after reading a medication booklet (29). Therefore, telephone follow-up and remote care can be recommended as fundamental methods to increase adherence to medication programs.
Park et al. conducted a study on children with epilepsy and demonstrated that patients' self-efficacy is directly linked to their ability to manage their condition. They suggest that training programs targeted at epilepsy patients effectively improve their self-efficacy and ability to manage their disease (30). The research conducted by May et al. on individuals with epilepsy in Sweden indicated that patients' grasp of their illness improved after receiving training intervention, which successfully enhanced patients' self-care practices and improved their overall quality of life (31). In clinical practice, interventions can be carried out in two different ways. Similar to ther studies (2,32), in the present study, we implemented two methods for addressing the issue. First, educational interventions were provided to the relevant personnel, including patients and families. Second, behavioral interventions, such as the use of intensive reminders, were implemented (2, 32).
The secondary treatment gap refers to patients who were diagnosed and initiated on Antiepileptic drugs but discontinued their medication prematurely, in addition to poor adherence. Frequent non-adherence and doubts about the effectiveness of treatment may lead to a secondary treatment gap, so we tried to reduce this problem by following up on the phone and reminding the use of medicine and the taught materials (33). Furthermore, other studies indicated that care follow-up by nurses could

result in increased adherence to treatment programs in chronic patients (5, 19, 34). The studies by Akhu-zaheya et al. and Khonsari et al. on patients with acute coronary syndrome, aiming to improve medication adherence through a text message reminder system, align with the current research. However, it should be noted that the disease studied in the present research is different from the mentioned studies (35, 36).

However, the results of the present study are not in line with the findings of Bikmoradi's research, which showed an increase in medication adherence among the control group following a telephone intervention compared to before the intervention (37). However, it should be noted that the disease studied in Bikmoradi's research differed from that of the current study, as the patients in the former study had undergone coronary artery bypass surgery and were in an acute and life-threatening condition, which may have increased their sense of obligation to take their medication. Furthermore, the study by Unk, which utilized multimedia-based education, found no statistically significant difference in medication adherence and treatment acceptance between the two groups of computer-based education and brochure-based education. The reason for the discrepancy in the results can be attributed to the type of disease or the target population in this study (38).

However, there are different factors affecting treatment adherence or non-adherence; the most important factors that influence adherence in children are patient/caregiver-related factors, therapy-related factors, condition-related factors, health system-related factors, and socioeconomic factors (39).

The present study results showed that after the intervention, there was a statistically significant difference in the average medication adherence of the two groups of intervention and control in four areas of knowledge and awareness, barriers, beliefs and attitudes, and performance and adherence. This suggests that training and telephone follow-up can lead to improving medication adherence in children with epilepsy, as parents are more likely to comply with the medication regimen. This can also prevent the recurrence of the disease and hospitalization of the child and reducing the financial burden on the family and society.

The limitation of this study was the potential influence of individual differences among participants on their responses, leading to uncertainty about the accuracy of the data. Additionally, personal beliefs and differences can impact learning and the implementation of individual training, potentially affecting uncontrollable outcomes. On the positive side, this study provides patients with cost- and time-saving benefits. However, the lack of blinding is a weakness of this study.

Implications for practice

According to the results of the present study, aprental education and telephone follow-up can be recommended as an independent action in nursing care services to improve medication adherence in children with epilepsy. Telenursing has been able to improve the quality of life of parents and their children through continuous educational interventions and also reduce the complications of the diseases in the community with continuous educational interventions while increasing parental independence and quality of life. For this purpose, it is expected that after the development of legal, professional, and ethical infrastructures, nurses' experiences will be used to consider a separate unit called planning and follow-up unit in hospitals and medical centers.

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Conflicts of interest

The authors declared no conflict of interest.

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Authors' Contributions

Shirin Ranjbar Ghanei: conceptualization, investigation, methodology, administration, supervision,

writing-review & editing. Firozeh Hosseini: conceptualization, administration, and methodology. Tayebeh Hasan Tehrani: supervison and revising the manuscript. Soodabeh Aghababaei: Writing review & editing. Leili Tapak: data analysis. Mohammad Hosein Sattari: data collection. All authors contributed to the writing of the manuscript and discussed on the manuscript.

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