



## The Relationship between Education Based on Orem's Self-Care Model and Caregiver's Quality of Life: A Quasi-Experimental Study in Patients with Multiple Sclerosis

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### Abstract

Caregivers of patients with Multiple Sclerosis (MS) often experience a decreased quality of life due to the physical and emotional strain of caring for these patients. Orem's self-care model offers a unique approach to addressing the needs of both patients and caregivers in the health care setting.

This study aimed to assess the impact of an educational program based on Orem's self-care model on improving the quality of life of caregivers of MS patients.

This quasi-experimental study included 76 primary family caregivers of MS patients in Bandar Abbas, who were randomly assigned to either a control or intervention group. The intervention group participated in a 7-sessions educational program based on Orem's self-care model, each lasting 40 minutes. The quality of life of caregivers was assessed using the SF-36 questionnaire before and after the intervention in both groups. Data analysis was conducted using SPSS-26 software, including statistical tests such as chi-square, t-test and covariance analysis, with a significance level set at less than 0.05.

The mean age of caregivers in the intervention group was  $39.74 \pm 11.34$  and  $38.94 \pm 11.32$  in the control group. The overall mean quality of life score in the intervention group increased from  $52.31 \pm 8.47$  before the study to  $61.10 \pm 12.8$  after the intervention, while in the control group it changed from  $57.04 \pm 14.01$  to  $55.23 \pm 10.20$ . These differences were statistically significant ( $P < 0.05$ ) in the intervention group.

Nurses can play a vital role in supporting caregivers of MS patients by enhancing their abilities to cope with the challenges of this chronic disease. Educational programs based on models like Orem's self-care model can significantly improve the quality of life of caregivers of MS patients overtime.

**Keywords:** Caregiver, Orem's self-care model, Multiple sclerosis

## Introduction

Chronic diseases are increasingly becoming the leading cause of disability and mortality worldwide. The prevalence of chronic diseases is on the rise, accounting for about 60% of deaths and 46% of the global burden of disease. It is expected that by 2030, these diseases will be responsible for 73% of deaths and 60% of the global burden of disease (1). Multiple Sclerosis (MS) is a chronic non-traumatic, autoimmune, and demyelinating disease of the central nervous system that most commonly affects individuals between the ages of 20 and 50, specifically in the third and fourth decades of life. MS is one of the most debilitating chronic neurological diseases in young adults. The course of the disease is unique and unpredictable and the exact cause and definitive treatment for it have not been well established (2). The disease affects 2.5 million people worldwide (3). According to the World Health Organization, its prevalence is 80, 14.9, 8.3, 5, 2.8 and 0.3 per 100000 people in Europe, the Eastern Mediterranean, the Americas, the Western Pacific, Southeast Asia and Africa, respectively (4). The prevalence of MS is very high in different geographical areas of Iran. In a survey conducted in 2013, researchers found that the overall prevalence ranged from 5.3 to 74.28 per 100000 people in Iran (5). Common symptoms of this disease include sensory impairment, weakness, muscle cramps, visual impairment, cognitive impairment, fatigue, tremors, impaired urination and defecation, sexual dysfunction, imbalance, forgetfulness, hearing loss, numbness, blurred vision, and speech disorders (2). It threatens the independence and ability of the individual to be effective in the family and society, affecting all aspects of the patient's daily life (4). The increasing trend of MS disease in Iran highlights the importance of addressing the issues and medical problems faced by these patients (6). Approximately 30% of MS patients require supportive care at home, with 80% of this care is being provided by informal

or unpaid caregivers. Caring for MS patients is a significant concern, as the disease is often diagnosed between the ages of 20 and 30, requiring several years of care. As the disease progresses, patients need increasing levels of care, placing heavier responsibilities on caregivers. Studies have shown that caregivers of MS patients experience numerous psychological, physical, social and economic challenges during the caregiving process. Caregivers are exposed to the patient's suffering, pain, and the fear of their death, which can impact their own quality of life. Since the well-being of caregivers directly influences the quality of life of patients, it is crucial to provide them with more support. While there have been many studies on MS disease and its impact on patients, there is limited information available on the support provided to caregivers of MS patients (7). Health-related quality of life is a multidimensional structure that includes aspects of quality of life and function affected by health status, such as symptoms, physical health, psychosocial factors and psychological conditions. Criteria for health-related quality of life include people's perceptions of their overall health and how it impacts their daily lives, including physical, mental, and social functioning (8). Complications of care are another important factor affecting quality of life. Care-related stress can contribute to disease in caregivers, as those under stress have higher levels of stress hormones. This long-term physical and emotional response to high stress may increase caregivers' risk for hypertension, diabetes, and other diseases (9).

Being a caregiver has both physical and stressful consequences. The specific characteristics of certain diseases are likely to determine their effect on the caregiver. Caregivers' suffering is a multidimensional response to the physical, emotional, psychological, social, and financial pressures associated with caring for another person (10). Families of MS patients are vulnerable in need of attention due to the long-term care required

for patients and the enduring high levels of stress. Because of the unpredictable nature of the disease, the activities of families of MS patients are often unplanned, and spouses many feel pressure due to their limited involvement in life.

In order to address the numerous problems and challenges faced by patients and their families, it is crucial to provide educational and supportive services. This should start with patients, then extend to caregivers and families after the diagnosis and commencement of drug treatment. The goal is to enhance the understanding of families and caregivers about the disease and the patient's condition, improve social skills for better communication with patients, promote acceptance the disease, facilitate emotional expression, encourage self-care, and strengthen optimism and spiritual well-being (11).

Orem's self-care model is a valuable clinical guide for planning and implementing self-care principles. This model serves used as a conceptual framework for self-care programs (12). Orem's self-care model is considered one of the most comprehensive theories of self-care. She argues that humans are the only beings with the ability to care of themselves. Orem defines self-care as the activities individuals engage in to maintain or improve their life, health, and prevent and treatment or treat diseases. Orem's self-care model is centered on the idea that individuals require self-care activities, and nurses assist individuals in maintaining their life, health and well-being (13).

Given the situation and needs of patients when facing health changes and the role of the nurse in this model, three types of care systems have been designed: complete compensation system, partial compensation system and supportive-educational system. The supportive-educational system is utilized when the patient is willing to learn and do something, but requires assistance. In this system, the nurse primarily acts as a consultant. The self-care education program for MS patients in this study is based on

Orem's self-care model within the supportive-educational nursing system (6). Considering the high prevalence of MS in Iran and the adverse consequences such as loss of income, health care costs, and limited research in this area, the present study aimed to investigate the impact of self-care education based on Orem's self-care model on the quality of life of caregivers for MS patients.

## Methods

### Statistical population

This quasi-experimental study was conducted from March 2020 to January 2021. The statistical population of this study included caregivers of MS patients referred to the MS clinic in Bandar Abbas.

### Sampling method

Samples were selected using convenience sampling method. After selecting them, they were randomly allocated into intervention and control groups. The researcher contacted the MS clinic for assistance in selecting samples based on inclusion criteria. Upon introducing themselves and obtaining written consent from the patients to participate in the study, they were allocated to either the intervention or control group based on a random list generated by the randomization software. Inclusion criteria included: being a first-degree family member, aged 18 or older, having a history of at least 6 months of caring for the patient, not having participated in similar training courses in the past (3), and not suffering from mental illnesses (2). Exclusion criteria included: not attending more than two training sessions, experiencing acute stress or crisis during the intervention period (4), unwillingness to continue cooperation in any part of the study (2), and having a private caregiver at home (14).

### Implementation Method

Both groups were presented with the demographic characteristics questionnaire and quality of life questionnaire to complete. Additionally, patients in the intervention group completed the self-care needs assessment form. This form, designed by Khodaveisi et.al

(2018), includes questions about the patient's knowledge and attitude towards the disease, their skill level and performance, pain level, learning\_ability, memory problems, disease symptoms, and willingness to participate in a self-care plan (2).

Educational interventions were conducted over 7 sessions lasting 40 minutes each, once a week, with the caregiver present, for a period of 2 months at the MS center. Participants were required to perform the tasks taught in each session, and were followed up with phone calls. The content of the educational program is outlined in table 1, and the process of sampling and implementing the intervention is shows in Diagram 1. A total of 76 individuals were included in the study, with 7 participants withdrawing for various reasons. Two individuals left due to migration, three due to unwillingness to continue cooperating, and two due to missing more than two training sessions, resulting in their exclusion from the study.

At the end of the sessions, educational materials were presented in the form of written booklets approved by 10 faculty members and research advisors. Since the self-care needs of each patient were different from the others, the method of education was individualized and face-to-face. Three months after the intervention, a quality of life questionnaire for caregivers in both control and intervention groups was completed.

#### Analysis Method

The results of the research were analyzed with SPSS-26 software and statistical tests such as chi-square, t-test and covariance analysis. A significant level of less than 0.05 was considered. It should be noted that during this period, the control group samples received only the routine interventions of the MS clinic. To observe the principle of justice in research, a complete booklet was also donated to the caregivers in the control group after conducting the study.

#### Results

The results of the present study showed that the majority of caregivers in the control group (61.8%) and intervention group (80%) were patients' spouses. The mean age of caregivers was  $38.94 \pm 11.32$  years in the control group and  $39.74 \pm 11.34$  years in the intervention group. Most caregivers in the control group (88.2%) and intervention group (91.4%) were married. The mean duration of care given to patients in the control and intervention groups was  $4.86 \pm 3.61$  and  $7.94 \pm 5.31$  years respectively.

There was no statistically significant difference between the two groups in terms of the distribution of variables such as age, gender, level of education, marital status, income, current job, type of family relationship with the patient, insurance status, housing status, chronic disease of caregiver, membership in the MS association, number of caregivers, duration of care given to the patient, number of people with chronic disease in the family and the grade of disease ( $P > 0.05$ ). Some demographic characteristics of the subjects are described in Table 2.

The difference between the means of quality of life in the control and intervention groups before the intervention was not statistically significant ( $P > 0.05$ ). The total score of quality of life in the intervention group before the intervention was  $52.31 \pm 8.47$ , which increased to  $61.10 \pm 12.81$  three months after the intervention, and this increase was statistically significant ( $P < 0.05$ ). This improvement was significant in all aspects of quality of life in the intervention group. The score of quality of life in the dimension of role disorder due to physical health in the intervention group before the intervention was  $58.03 \pm 23.7$  and increased to  $69.39 \pm 29.9$  after the intervention, which was statistically significant ( $P < 0.05$ ).

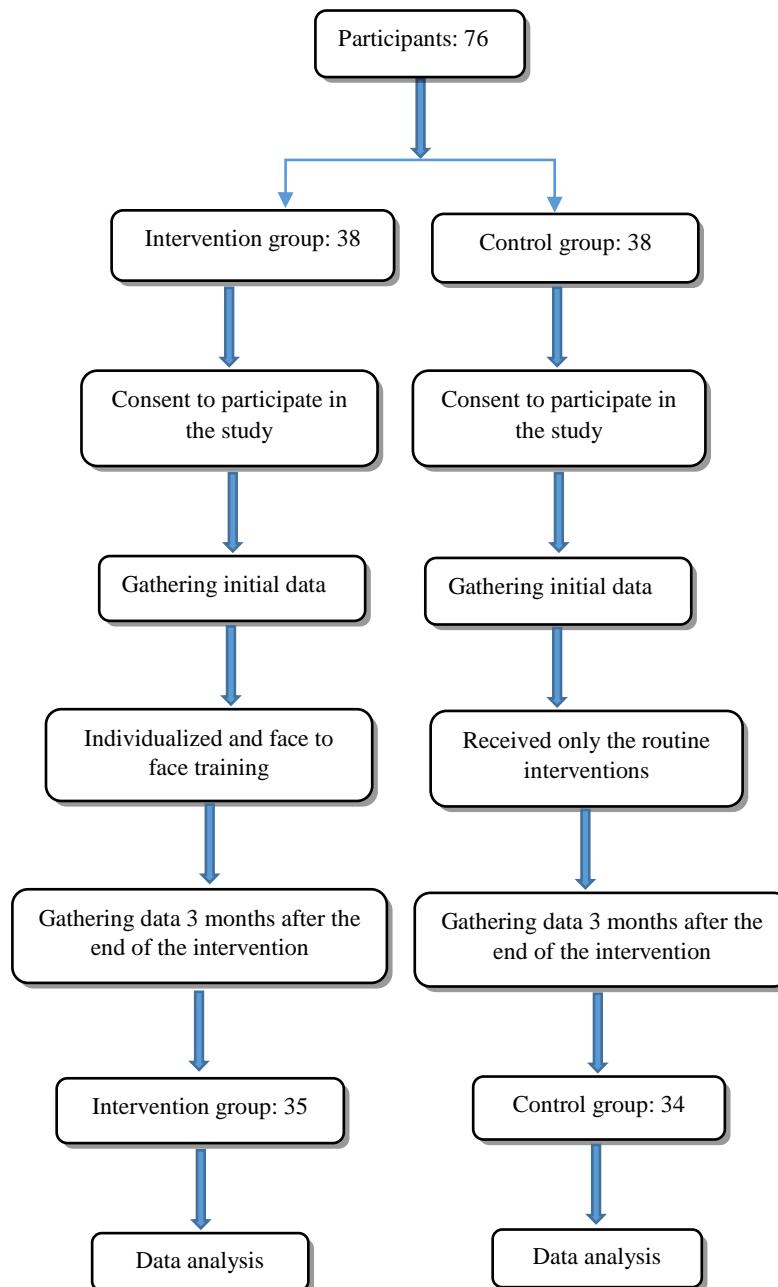
The score for quality of life in the physical function dimension in the intervention group was  $64.5 \pm 25.6$  before the intervention and  $82.5 \pm 24.9$  after the intervention, showing a statistically significant increase ( $P < 0.05$ ). The mean and standard deviation of quality of life

in the dimension of role disorder due to emotional health in the intervention group was  $64.8 \pm 25.8$  before the intervention and  $79 \pm 35.1$  after the intervention, also showing a statistically significant increase ( $P < 0.05$ ). The score for quality of life in the energy/fatigue dimension in the intervention group was  $49.6 \pm 13.9$  before the intervention and  $63.3 \pm 20.1$  after the intervention, with this

increase being statistically significant ( $P < 0.05$ ). The paired t-test also showed a statistically significant difference ( $P < 0.05$ ).

The mean for quality of life in the emotional well-being dimension in the intervention group was  $48.2 \pm 11.4$  before the intervention and  $57.8 \pm 13.7$  after the intervention, with this increase also being statistically significant ( $P < 0.05$ ).

**Diagram 1. The consort diagram illustrating the study levels.**



**Table 1. Contents taught to caregivers in educational sessions.**

Sessions	Content
1	Definition of multiple sclerosis, symptoms and complications of the disease, self-care behaviors and maintaining health in controlling complications
2	fatigue (training of exercise program, prioritization of tasks, teaching energy conservation methods and environmental design)
3	urinary incontinence (such as bladder training, use of incontinence absorption pads, pelvic floor muscle exercises, habitual training of defecation time, and the Valsalva maneuver method)
4	defecation incontinence (regulating defecation time, diet training, training to regulate fluid intake), constipation (training for exercise and mobility planning, regulation of defecation time, training of pelvic floor muscle massage and diet training)
5	training and familiarity with the movement problems created and reducing its complications (patient transfer and movement, prevention of blood accumulation in the arteries of the lower limbs, exercises for range of motion of the joints, prevention of deformity of the limbs and placement in a proper position), familiarity with equipment and assistive devices to prevent bed sores (improving skin blood flow, improving nutritional status, reducing friction and tensile force and minimizing bed and seat moisture)
6	visual disturbances (training the way of using the colors), muscle weakness, muscle cramps and imbalance (relaxation and coordination exercises, training the way of using assistive devices)
7	familiarity with the psychological problems after the lesion in MS patients, financial and social resource management (using insurance services and support institutions)

**Table 2. The demographic characteristics of the participants in both the control and intervention groups.**

	Variable	Group		P value
		Intervention	Control	
Gender	Levels	N (%)	N (%)	0.267
	Female	16 (%45.7)	20 (%58.8)	
	Male	19 (%54.3)	14 (%41.2)	
Level of education	Illiterate	0 (%0.0)	3 (%8.8)	0.179
	High school	11 (%31.4)	9 (%26.5)	
	Diploma	19 (%53.3)	14 (%41.2)	
	Bachelor's degree	4 (%11.4)	8 (%23.5)	
	higher	1 (%2.9)	0 (%0.0)	
Marital status	Married	32 (%91.4)	30 (%88.2)	0.660
	Single	3 (%8.6)	4 (%11.8)	
Income level	Less than adequate	13 (%37.1)	11 (%32.4)	0.537
	Adequate	21 (%60.0)	23 (%67.6)	
	More than adequate	1 (%2.9)	0 (%0.0)	
Current job	Housewife	14 (%40.0)	15 (%44.1)	0.371
	Employee	16 (%45.7)	18 (%52.9)	
	Unemployed	2 (%5.7)	0 (%0.0)	
	Retired	3 (%8.6)	1 (%2.9)	
Type of family	Spouse	28 (%80.0)	21 (%61.8)	0.535
	Parents	4 (%11.4)	7 (%20.6)	

relationship with patient	Children	1 (%2.9)	3 (%8.8)	
	Sister	1 (%2.9)	2 (%5.9)	
	Brother	1 (%2.9)	1 (%2.9)	
Insurance status	Insured	35 (%100.0)	33 (%97.1)	0.307
	Non-insured	0 (%0.0)	1 (%2.9)	
Housing status	Personal	18 (%51.4)	17 (%50.0)	0.906
	Rental	17 (%48.6)	17 (%50.0)	
Membership in MS association	Yes	23 (%65.7)	17 (%50.0)	0.186
	No	12 (%34.3)	17 (%50.0)	
Age (Mean $\pm$ SD)		39.745 $\pm$ 11.3458	38.941 $\pm$ 11.3269	0.851
duration of care given for patient (Mean $\pm$ SD)		7.943 $\pm$ 5.3134	4.868 $\pm$ 3.6162	0.052
Disease grade (Mean $\pm$ SD)		1.850 $\pm$ 0.7844	1.655 $\pm$ 0.6548	0.080

**Table 3. Mean scores of quality of life dimensions before and 3 months after the intervention in control and intervention groups**

Dimensions of quality of life	Group	Before	after	Paired t test results
		Mean $\pm$ SD	Mean $\pm$ SD	
<b>Physical function</b>	Intervention	64.57 $\pm$ 25.66	82.57 $\pm$ 24.94	<0.0001 0.565
	Control	72.91 $\pm$ 18.86	70.38 $\pm$ 22.01	
<b>Role disorder due to physical health</b>	Intervention	58.03 $\pm$ 23.74	69.39 $\pm$ 29.91	0.014 0.362
	Control	84.25 $\pm$ 118.73	67.08 $\pm$ 28.26	
<b>Role disorder due to emotional health</b>	Intervention	64.84 $\pm$ 25.87	79.69 $\pm$ 35.13	0.003 0.855
	Control	65.13 $\pm$ 29.38	64.16 $\pm$ 29.36	
<b>Energy / Fatigue</b>	Intervention	49.69 $\pm$ 13.97	63.33 $\pm$ 20.18	<0.0001 0.600
	Control	53.75 $\pm$ 17.90	55.83 $\pm$ 17.09	
<b>Emotional well-being</b>	Intervention	48.24 $\pm$ 11.48	57.81 $\pm$ 13.71	0.004 0.337
	Control	49.77 $\pm$ 16.60	52.44 $\pm$ 15.38	
<b>Social function</b>	Intervention	38.00 $\pm$ 14.69	47.12 $\pm$ 10.68	<0.0001 0.906
	Control	41.66 $\pm$ 10.95	41.38 $\pm$ 13.76	
<b>general health</b>	Intervention	56.66 $\pm$ 14.82	66.21 $\pm$ 14.52	0.004 0.127
	Control	62.22 $\pm$ 12.33	63.61 $\pm$ 14.07	
<b>Pain</b>	Intervention	22.93 $\pm$ 09.90	31.42 $\pm$ 10.27	0.002 0.280
	Control	29.65 $\pm$ 09.16	24.79 $\pm$ 08.77	
<b>Total quality of life score</b>	Intervention	52.31 $\pm$ 08.47	61.10 $\pm$ 12.81	0.002 0.529
	Control	57.04 $\pm$ 14.01	55.23 $\pm$ 10.20	

In the social function dimension, the mean and standard deviation in the intervention group were  $38.00\pm14.6$  before the intervention and  $47.1\pm10.6$  after the intervention, with the paired t-test showing this increase significant to be significant ( $P<0.05$ ).

In the general health dimension, the mean in the intervention group was  $56.14\pm6.8$  before the intervention and  $66.2\pm14.5$  after the intervention, with this increase being statistically significant ( $P<0.05$ ). In the pain dimension, the mean and standard deviation of pain in the intervention group were  $22.9\pm9.9$  before the intervention and  $31.4\pm10.2$  after the

intervention, which was also statistically significant (Table 3).

## Discussion and Conclusion

This study has demonstrated that self-care education based on Orem's self-care model can enhance the quality of life for caregivers of patients with MS. Researchers recommend increasing social support for caregivers to alleviate their suffering and improve their mental health and overall quality of life (8). In a study by Rivera-Navarro et al. focusing on the perceived suffering of caregivers of MS patients, it was found that the health-related

quality of life of patients is closely linked to the suffering experienced by their caregivers (15). Therefore, it can be conducted that self-care education based on Orem's model can also benefit caregivers by reducing their suffering.

Jahan Bakhshian's research revealed that caregiver participation in educational-support programs can effectively reduce emotional stress, boost self-confidence, enhance problem-solving skills, improve communication, and decrease the occurrence of mental disorders in patients (11). McMillan et al. also found that just three educational sessions can significantly enhance caregivers' quality of life and alleviate family suffering (16). Alshubaili et al. found that special attention must be paid to caregivers who are vulnerable, less educated, unemployed, and afraid of contracting the disease. Their patients suffer from longer periods of illness (17). This highlights the importance of training caregivers.

In the study by Polin et al, it was found that spouses who care for chronic patients, experience significant pressure. This pressure can lead to a decrease in their quality of life and the quality of care they provide (18). Brandon's study suggest that nurses can assist caregivers in regarding control. With advances in medical care, more people are living longer with chronic illnesses or disabilities, or disabilities, requiring assistance from family and friends. Nurses can empower these caregivers through education, resources, support, and interventions (19).

Nurses are in a unique position to assist caregivers in expressing their emotions, encouraging realistic perceptions, facilitating adjustment to the evolving illness, and alleviating burdens. Assessing caregiver burden enables nurses to gain a deeper understanding of the family's requirements and capabilities allowing family members to sustain in their caregiving responsibilities and ensure positive outcomes for the patient. Therefore, it can be conducted that empowering the individual responsible for

caring for a patient with MS can significantly enhance the quality of care provided to patients by lessening caregivers' burthen (10).

Orem's self-care model has the potential to improve the quality of life for caregivers of MS patients. However, there is a lack of research on the application of Orem's self-care model specifically for those caring for MS patients. Existing studies in this area have focused on a diverse group of patients requiring home care. In a study by Waldron-Perrine et al. examining predictors of life satisfaction among caregivers of MS patients, it was found that social support plays a crucial role in increasing caregivers' life satisfaction. The researchers concluded that lower levels of social support may be linked to decreased levels of assistance and support, as well as increased caregiver distress (20).

The results of this study indicate that self-care activities by MS patients and their caregivers are quite possible. With education and implementation of a self-care program based on Orem's self-care model, a significant difference is created in their quality of life. The implementation of a self-care program is associated with an increasing in the quality of life of caregivers of patients. If the implementation of the self-care program continues based on patients' self-care needs and is designed in accordance with their level of understanding, it can lead to positive results in health performance. Therefore, the use of models that can persuade caregivers and focus on patients' participation in self-care can enhance the quality of life. Additionally, the use of this model provides valuable information and can be applied in examining, identifying, and evaluating the care system of MS patients.

Due to the Covid-19 outbreak, sampling and intervention were conducted, but subjects did not fully cooperate out of fear of infection. Communication was also challenging. Despite efforts to control sampling conditions and collect data properly, distractions and the usual difficulties with patients and caregivers may have affected responses to the questionnaire.

Caregivers often develop skills over time caring for patients, which could impact the study results. Additionally, patient care is typically a family effort, not solely one person's responsibility. This study only focused on the most effective individual, neglecting the influence of other family members. The extensive questionnaire may have caused boredom, which was unavoidable due to its standardized format.

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### Author's Contributions

N.D: Initial design of the article, data collection and analysis, initial and final editing and writing of the manuscript

E.I: Initial design of the study, initial and final writing and editing of the manuscript

A.A.N: Initial design and final editing of the manuscript

S.H.T: data analysis, final editing of the manuscript

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### Ethical considerations

The protocol of this study was approved by the Ethics Committee of Hormozgan University of Medical Sciences under the reference code of IR.HUMS.REC.1399.518.

### Conflict of interest

The authors of this study declared no conflict of interest for writing or publishing this article.

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