"Comparison of the effect of patient-centered and family-centered education on quality of life in patients with rheumatoid arthritis referred to rheumatologic clinics of educational centers affiliated to Shahid Beheshti University of Medical Sciences, Tehran"



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### **Original Research Article**

COMPARISON OF THE EFFECT OF PATIENT-CENTERED AND FAMILY-CENTERED EDUCATION ON QUALITY OF LIFE IN PATIENTS WITH RHEUMATOID ARTHRITIS REFERRED TO RHEUMATOLOGIC CLINICS OF EDUCATIONAL CENTERS AFFILIATED TO SHAHID BEHESHTI UNIVERSITY OF MEDICAL SCIENCES, TEHRAN Samira Rezaei Ghadi<sup>1</sup>, Maryam Janatolmakan<sup>2</sup>, Hiva Azami<sup>3</sup>\*

- 1..MSc of Medical Surgical Nursing, Clinical Research Development Unit of Loghman Hakim Hospital, Shahid Beheshti University of medical sciences, Tehran, Iran
- 2. MSc of Medical Surgical Nursing, Clinical Research Development Center, Imam Reza Hospital, Kermanshah University of medical sciences, Kermanshah, Iran
- \*3. MSc of critical care nursing, Kermanshah university of medical sciences, Imam reza hospital, Kermanshah,

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For Correspondence

Email ID:

hiva64@gmail.com

#### **Abstract:**

**Introduction:** Rheumatoid Arthritis Chronic illness with various degrees of inflammation, swelling and pain in the joints. Because the disease is associated with impotence, the family plays an important role in the care of these patients. The aim of this study was to determine the relationship between family-centered education and quality of life in a patient with rheumatoid arthritis.

**Methods & Material:** In this research, a clinical trial study was performed on 96 patients with rheumatoid arthritis in Shahid Beheshti University hospitals. Patients in 6 groups of 16 patients, each group in 3 sessions, each session, 45-30 minutes, for 3 weeks with the presence of a patient and a family member in the family and patient group, with the presence of the patient in the patient group and with the presence of only one family member In the family group. Then they took part in the training classes. The first session, familiarity with the patients and about the disease of rheumatoid arthritis and drugs for patients by the researcher was given and the demographic questionnaire and the questionnaire sf-36 were completed.

In the second session, a proper diet was prescribed and in the third session, appropriate exercises were trained. At the end of each session, the educational booklet was provided to the patients. Four weeks after the completion of the classes, the quality of life questionnaire (36sf) was completed by the patients.

**Results:** The quality of life before education in the family and patient group is 26 and in the group 35 and in the group is only 34. The quality of life after education in the family and patient group is 74 and in the patient group are 57 and in the group are only 38 families. The findings showed that before the intervention, the quality of life score was low in all three groups, but after intervention, the mean scores of quality of life in two groups of the family, patient and patient group were significantly higher than the pre-intervention group, and in the group only the family There was no significant difference between the scores of the three groups of the family and the patient and the patient group and the family group in the quality of life score, and the quality of life in the family and patient group was much higher than that of the patient group and the family group. And the quality of life score later the intervention in the patient group was much more than the family group.

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**Conclusion:** The role of the family with the patient has been emphasized on improving the quality of life. Based on this research, family planning nursing interventions and family members' participation with the patient are recommended for the care of a patient with rheumatoid arthritis.

Keyword: Training, Rheumatoid arthritis, Patient-centered, Family-centered, Quality of life

#### **Introduction:**

In the last decade, with the advent of science and technology and lifestyle changes, health has changed in terms of illness and death[1] .In this regard, infectious and contagious diseases are controlled and chronic and metabolic diseases have been replaced. Chronic diseases are currently the cause of major health problems in developed countries[2] Bone and joints are common diseases in developed and developing countries, as described in the international action of the 2000 to 2010 period as the "Decade of Bone and Arthropods"[3]In the US in 2020, the prevalence of rheumatoid arthritis is estimated to be over 18% due to increased life expectancy[4].Rheumatoid arthritis has a significant impact on the quality of life of patients[5]. Studies show that patients with rheumatoid arthritis have a lower quality of life than healthy people[6].Chronic diseases affect interactions of patients[7]. With preventive means, up to 70% of attacks can be prevented, One of the ways of controlling is training[8]After training, clients will be able to achieve the best level of health and can prevent and manage health problems and minimize their disabilities by educating people[9]. So that they can make informed decisions about their health and wellbeing and take responsibility personally[10], and if they deviate from health, they can effectively manage their lifestyle changes[11, 12]. Currently, improvements to the health problems of patients and family carers have replaced caregivers[12]. The family is considered as a social place to educate and change the behavior of the

community[13]. It seems that teaching patients along with family members and family involvement in educational programs increases the ability of individuals to create and sustain lifestyle changes[14]. Nowadays, attention to quality of life is one of the most important issues in the international community and researchers[15]. The World Health Organization has been focusing on quality of life in recent years[16]. The aim of this study was to compare the effect of patient-centered and family-centered education on quality of life in patients with arthritis rheumatoid referred rheumatologic clinics of educational centers affiliated to Shahid Beheshti University of Medical Sciences, Tehran, It is hoped that with this research, a small step can be taken to improve nursing knowledge and reduce the suffering of patients.

#### **Methods:**

The present research is semi-experimental. The research environment of the rheumatologic clinic of Loghman Hakim Hospital and Taleghani Hospital in Tehran. The population of this study was all patients with rheumatoid arthritis who were diagnosed with the disease based on the protocol of the International Association of Rheumatoid Arthritis and the physician of the Rheumatologic Clinic. The sample number is 96.Criteria for entering research into patients with rheumatoid arthritis, age group 25-65, lack of other connective tissue and musculoskeletal diseases, willingness to participate in research, resident in Tehran or suburbs, lack of education (patient or family member), By the organization or organ of the patient, the fluency in the Persian language, the reading and writing of the visual impairment of hearing loss (the patient or family member). Exit criteria: The patient's and family's reluctance to

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continue cooperation, the absence of patient and family participation in one of the training sessions, the patient company and the family during the formal training sessions of other centers, the patient or the active member of the Selected samples were gradually for five months.A questionnaire was used to collect data. The instrument for collecting data was two demographic questionnaires and SF-36 quality of life questionnaire .The Quality of Life Questionnaire (SF-36) has 36 questions and consists of 8 sub-scales and each subscale consists of 2 to 10 items. The eight subsamples of this questionnaire are: Physical Function (PF), Role Disruption Due to Physical Health (RP), Disruptive role for emotional health (RE), Energy / Fatigue (EF), Emotional wellbeing (EW)Social function (SF), Pain (P) and general health (GH) Also, from the integration of sub-scales, there are two subsamples with the names of physical health and mental health .In this questionnaire, lower scores represent lower quality of life and vice versa .Score questionnaire for quality of life 36 questions (SF-36): To get 8 sub-scales, add questions to each subscale and then divide them by the number of questions. Therefore, scores for each sub-scale will range from 0 to 100 :Physical Function (PF): Questions 3-4-5-6-7-8-9-10-11-12 Divided by 10 .Role Disruption due to Physical Health (RP): Questions 13-14-15-16 divided by 4 ,Disruptive role for emotional health (RE): questions 17-18-19 divided by 3, Energy / Fatigue (EF): Questions 23-27-29-31 divided by 4 Emotional Welfare (EW): Questions 24-25-26-28-30 Divided by 5 Social Function (SF): Questions 20 and 32 divided by 2, Pain (P): Questions 21 and 22 divided by 2, General Health (GH): Questions 1-33-34-35-36 divided by 5, To obtain a subset of the subscale of the subscale of physical health, the following sub-scales of physical function (PF), role disorder are performed due to physical health (RP), pain (P), general health (GH) And for the subset of mental health: the subset of the role of disorder is performed due to emotional health (RE), energy / fatigue (EF), emotional wellbeing (EW), social function (SF). The validity of the content was used to determine the validity of the research Also, a study was conducted on the

reliability and validity of the SF-36 standard Persian standard questionnaire which was conducted by Ali Montazeri in 2005. This study was designed to translate and determine the reliability and validity of the SF-36 international standard instrument for measuring quality. Liferelated health was designed and carried out. The results of this study showed that the SF-36 standard Persian instrument has a reliable and reliable validity in assessing the quality of life associated with health. After obtaining a referral from the Faculty of Nursing and Midwifery of Islamic Azad University, Tehran Medical Branch, and submitting it to the Research Unit of Shahid Beheshti University Hospitals (Loghman and Taleghani), eligible samples were selected. Patients were enrolled in 4 classes of 16, each group in 3 sessions, each session in 30-45 minutes, for 3 weeks. The first session, familiarity with patients, and how to complete the questionnaires, the disease of rheumatoid arthritis and drugs for patients by the researcher were given. In the second session, on the proper diet And at the third session, appropriate sports were trained. At the end of each session, the educational booklet was provided to the patients. Four weeks after the completion of the classes. the SF-36 quality of life questionnaire was completed by the patients. In this study, independent variables (patient-centered and family-centered education) and dependent variable (quality of life)To analyze the data, descriptive statistics were used: frequency tables as well as bar graphs of central indicators (such as average) and dispersion indices (such as standard deviation). In this research, in order to study the effect of patient-centered and familycentered education on quality of life in patients with rheumatoid arthritis, inferential statistics (ttest) were used to remove the pretest effect on post-test.

#### Findings:

The highest percentage of gender is in the "family and patient" group of women (62.5%), in the "female patient group" (75%) and women (71%) in the "family only" group. Chi-square test was used to test the differences between the groups and the calculated p-value was 0.5. Considering this issue, it was found that there is no statistically significant difference between the

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three groups. The level of education in the family and patient group is below the diploma (50%), and in the patient group under the diploma (43.8%) and in the 'family only' category under the diploma (59.4%). It was found that there was no statistically significant difference between the three groups. Marital status is married (75%) in the family and patient group, and married (37.5%) in the "sick group" and married (59.4 percent) in the "family only" group. There was no significant statistical difference between the three groups. The income level in the "family and patient" group is less than the cost (68.8%), and in the patient group the income is less than the cost (68.8%) and in the "family only" group the income is less than the cost (75.0%). It was found that there was no statistically significant difference between the three groups. The age of the research units in the family and patient group was between 35-45 (37.5%), and in the "patient group" (35-35 years old), and in the "family only" age range of 35-45 (50) Percent). It was found that there was no statistically significant difference between the three groups .The frequency distribution and percentage of smoking in the studied patients in the study groups (Table 1) showed a significant difference between the three groups (p-value = 0.004). Also, the frequency distribution and percentage of perception of the patient with rheumatoid arthritis with their family members showed a significant difference between the three groups (Table 2). Frequency distribution and percentage of joints involved in rheumatoid arthritis showed a significant statistical difference between the three groups (Table 3.)

Table 1: Frequency distribution and percentage of smoking intake

group	Family and patient		Just sick		Just family	
Cigarette	Frequency	percent	Frequency	percent	Frequency	percent
Less than 10 in a day	1	100%	7	100%	4	50%
10 and more per day	0	0.0%	0	0.0%	4	50%
	df= 2 p-value=0/004					

**Table 2.** Frequency distribution and percentage of perception of the patient with rheumatoid arthritis with members Your family

group	Family and patient		Just sick		Just family		
References	Frequency	percent	Frequency	percent	Frequency	percent	
Parents	1	3.6%	8	32.0%	4	13.8%	
sister and brother	4	14.3%	3	12.0%	7	24.1%	
Child	8	28.6%	5	20.0%	3	10.3%	
Spouse	15	53.6%	9	36.0%	15	51.7%	
	p-value=0/07						

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**Table 3** Frequency distribution and percentage of joints involved in rheumatoid arthritis in the studied groups

group	Family and patient		Just sick		Just family		
References	Frequency	percent	Frequency	percent	Frequency	percent	
A joint	13	40.6%	8	25.8%	15	48.4%	
Two joints	11	34.4%	16	51.6%	3	9.7%	
Three joints	3	9.4%	3	9.7%	9	29.0%	
Four joints and more	5	15.6%	44	12.9%	4	12.9%	
	p-value=0/015						

In this study, in the patient group before and after education, in terms of quality of life in terms of physical function, role impairment due to physical health, role impairment due to emotional health, energy / fatigue, emotional well-being, social function, pain, general health, physical health, There is a significant statistical difference between mental health. There was a significant difference in the quality of life in the family and patient group before and after

education.In the group, only the family before and after education in terms of quality of life, in terms of physical function, role disorder due to physical health, role impairment due to emotional health, energy / fatigue, emotional well-being, social function, pain, general health, physical health, There was no statistically significant difference in mental health. (Table 4).

**Table 4** Comparison of Quality of Life in Patients with Rheumatoid Arthritis in Patients, Patients and Families, Family

group	Components of quality of life	Mean before interventio n	Standard deviation before intervention	Average after interruptio n	Standard deviation after intervention	Т	Df	p- value
Patient	Quality of Life	35.58	20.62	57.99	18.41	-10.20	31	.000
Sick and family	Quality of Life	26.78	15.76	74.4482	12.49564-	-17.21	31	.000
Family	Quality of Life	34,22	22, 025	38.76	14.78	1.28	31	p>0/05

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Quality of life in two groups of patients in the patient and family groups before intervention indicates that there is a significant difference between the this two groups component. Comparison of quality of life in two groups of patients and patient and family groups shows that there is a significant difference between the two groups of patients and in the patient and family groups after education, and as the family patient group that has a mean score of lower quality of life before intervention After training, they have a much higher score, so the statistical difference before intervention is unaffected by the result of education. Quality of life in the two groups of patients and in the family only group indicates that there is no significant difference between the two groups in this component and the quality of life before intervention. Quality of life in two groups of patients and only the family group indicates that there is a statistically significant difference between the two groups of patients and in the patient and family groups

education. Evaluation of quality of life in two groups of only the family and in the patient and family groups before intervention indicates that there is a significant statistical difference between the two groups. Comparing the quality of life in both the patient and family groups and the family-only group indicates that there is a statistically significant difference between the two groups only in the family and in the patient and family groups after the training. Comparison of the quality of life topic in the three groups of patients and the group only in the family and patient and family groups indicates that there is a statistically significant difference between the three groups of patients in the patients and the family, and the group of patients and the family before the education. To compare the quality of life in the three groups of patients and only the family and patient and family groups, there is a statistically significant difference between the three groups of patients and the patient and family groups and the patient and family groups after the training (Table 5).

**Table 5:** Comparison of Quality of Life in Patients with Rheumatoid Arthritis in Patients, Patients and Families and Families after Intervention

Group	Patier	nt group	Patient and family group		The only patient group			
Quality of Life	Average after interven tion	Standard deviation after interventi on	Average after interventio n	Standard deviation after intervention	Average after interventi on	Standard deviation after intervention	df	p- valu e
57/99	18/41	74/44	74/44	-12/49	76/38	78/14	42/ 90	/000

#### **Discuss:**

Rheumatoid arthritis is a chronic multi-systemic disease[17].In most patients, the disease is continuously associated with varying degrees of articular anomalies and functional disorders[18], and within 10 years, approximately 50% of patients will develop a disability.The life expectancy of people with rheumatoid arthritis is reduced by a median of 3-7 years.The mortality rate is 2.5 times that increase and rheumatoid arthritis is 15 to 30 percent of its own [19]In this study, in relation to demographic characteristics, the findings showed that the research units were

divided into three groups: 1- Family and patient group 2- Only patient group 3- Family group only in terms of gender, marital status, education, age, weight, occupation, Income, smoking, duration of smoking, consumption of meat, consumption of tea, amount of tea per day, personality type, awareness of disease, percentage of family members, living with family members, beginning of illness in pregnancy, use of pills There is no significant difference in the way of contraception, the duration of the disease, the number of joints affected and drug use, and are homogeneous.

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However, in terms of the number of smoking per day, the feeling of being close to the family was statistically significant. The quality of life of patients with rheumatoid arthritis before training is 58/35, From the results it can be concluded that quality of life in these patients is undesirable. Naderiand et al., In a study conducted in Yazd in 2008, entitled "Investigating the relationship between quality of life, health status and self-care behaviors in patients with rheumatoid arthritis, Findings showed a positive and significant correlation between quality of life, health status and selfcare behaviors (p <0.01). The subjects under study had a relatively low quality of life and the average percentage of their maximum quality of life scores was 36.8%. His results are consistent with the results of this study [6]In this study, the findings showed that the average quality of life after education to the patient was 58.199. This indicates an increase in the average score of quality of life by 50%, which indicates the effect of education on quality of life in the form of education The patient is. In a study by Gronning et al. In 2012 entitled "Investigating the Impact of an Educational Program Including Individual and Group Training in Patients with Orthostatic Bridge Using A Randomized Controlled Method", the findings showed that education in both groups was effective Which is consistent with the present study[19]. The mean score of life quality before training in this study increased from 35.8 to 58.59 after training, which indicates improvement in quality of life. In assessing the quality of life of the patient and the family before the training, the findings showed that it was 22/33. From the results of this research, it can be concluded that the quality of life in this group was undesirable. In a study by Frozen and colleagues in 2007, the quality of life in patients with rheumatoid arthritis was performed. The findings showed that 50% of the patients considered their quality of life to be desirable and in the least desirable, and 50% considered it unfavorable. In terms of quality of life dimensions, the results indicated that 50% of patients considered their quality of life to be desirable and generally desirable, and 50% considered unfavorable in their physical, social, economic, psychological, social, and social

dimensions. There was a significant relationship between age, marital status, employment status, duration of illness, physiotherapy, family income adequacy and quality of life. There was no significant relationship between sex, exercise therapy and quality of life. His research findings are in line with this research [20]In the present study, the findings showed that the mean score of life quality before education in the group was 37.29 and the mean score of life quality after education was 38.77. This finding reflects a very poor quality of life in a group that has only received training in that family. In a study conducted by Professor Kelly and colleagues in 2011 entitled "The Effect of 8-Week Aerobic Exercise on the Quality of Life and Pain in Patients with Rheumatoid Arthritis" Shiraz, The results showed that there was a significant difference between the quality of life scores at the beginning of the intervention vans in the test group (P <0.01). Also, the pain intensity in the test group was significantly lower than the control group. His findings are consistent with the results of this study, which shows the effect of education on the quality of life of patients with rheumatoid arthritis [4]The findings of this study showed that in the patient education group and in the group to the family, the quality of life before education was 35.58 and 34.22, respectively. Quality of life after education in case group is 57/99 and 38/76 in family education group respectively. So, we conclude that patient education has a greater impact on patient quality of life than in-patient education. A study by Michael and colleagues in 2009 entitled "Positive Impact of Nursing Interventions on Family-based Care in Adult Care with Critical Situation in the Internal and Surgical Division" at two educational hospitals in Queensland and Australia. The type of intervention was primary care of patients. In the intervention group, care was provided by their families .Nursing care was given to the control group. The results showed that participants in the intervention group received twice as much control over the control group as the control group.They showed 1.5 times cooperation. Families with a prior experience of caring for a patient with a critical illness were 1.5 times more likely than those who did not

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have such an experience. In addition, the intervention group received 1.51 times more support than the control group and understood 1.5 times more than the general family-based care control group. His results are consistent with the results of this study[20]. The findings of this study showed that patients had a significant difference in the components (physical function, role disorder due to physical health, role impairment due to emotional health, social function, pain, general health, mental health) in the patient education and family education group But in the area of emotional exhaustion, physical exhaustion, and quality of life, there is a significant statistical difference.In a study conducted by Smarr et al in their 2011 self-care study on patients with rheumatoid arthritis using a patient-centered model, Smarr et al. Found that self-care can provide easy, effective, and permanent health care services in the event of access limitation Provided to the clinics. You can use a software program to extend the benefits of self-care programs to many audiences.It can also be used as a model for the emerging generation of delivery and clinical management systems on the Internet.His findings regarding the effect of self-care on patients with rheumatoid arthritis are consistent with the present study[21]. At the end of the research and other researchers' findings, the results showed that both patient and family education simultaneously have a greater impact on the quality of life of patients than on education for the family alone.

#### **Conclusion:**

The role of the family with the patient has been emphasized on improving the quality of life. Based on this research, family planning nursing interventions and family members' participation with the patient are recommended for the care of a patient with rheumatoid arthritis.

#### **Limitations:**

From the limitations of this study, we can point out the individual and cultural differences of patients, the attitude of patients towards themselves and the disease.

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