



Effectiveness of Self-Management Educational Program on Quality of Life and Activities of Daily Living for Patients with Rheumatoid Arthritis

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ABSTRACT

Aims Rheumatoid Arthritis (RA) is a chronic inflammatory disease characterized by progressive articular damage of the joints with extra-articular manifestations. RA has a significant impact on the impairment of patients' quality of life and loss of physical function and is a leading cause of dependency and disability. The study aimed to assess the effectiveness of the Self-Management Educational program on Health-Related Quality of Life (HQoL) and Activities of Daily Living (ADL) in RA patients.

Materials & Methods This quasi-experimental study was carried out on 145 patients with RA from 10th March 2019 to 4th February 2020 at Rheumatology and Physical Rehabilitation Center. Participants were selected by simple random sampling and randomly divided into experimental (n=85) and control (n=60) groups. The study tools included the Health Assessment Questionnaire (HAQ), Barthel Index (BI), and World Health Organization Quality of Life-BREF (WHOQOL-BREF). Patients in the experimental group participated in a four-session self-management training program, while patients in the control group received only routine care. Data were analyzed by SPSS 22.0 software using Fisher's Exact test, Chi-square test, and Paired t-test.

Findings There was a significant improvement in the quality of life domains, ability to perform activities of daily living, and functional status after the educational program ($p < 0.01$). Also, the proportion of totally independent increased from 35.3% to 54.1% ($p < 0.05$).

Conclusion Self-management educational programs can be considered an effective intervention to improve the quality of life, perform activities of daily living and minimize functional disability in RA patients.

Keywords Rheumatoid Arthritis; Quality of Life; Activities of Daily Living; Self-Management

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Introduction

Rheumatoid Arthritis (RA) is a chronic, autoimmune multifactorial disease. It affects all populations, the prevalence rate ranging from 0.4% to 1.3%. Women are two to three times more likely to be affected than men increases with age and peaks between the fourth and sixth decade of life [1]. The most commonly involved joints are the knee, elbow, Metatarsophalangeal joints (MTP), Proximal Interphalangeal joints (PIP), toe PIP, lumbosacral phalangeal spine, and cervical spine [2]. Common features of RA include daily pain, depression, fatigue, physical disability, stiffness, and associated psychological features; in addition, inflammation and joint damage are the leading causes of disability [3]. Furthermore, mobility limitation, functional deterioration affect HRQoL and increase mortality and morbidity [4].

Moreover, RA may cause extra-articular signs and symptoms such as vasculitis, rheumatoid nodules, interstitial lung disease, cardiovascular disease, lymphoma, and amyloidosis. In addition, patients with RA may develop specific deformities, like ulnar deviation, swan neck deformity (hyperextension at PIPs), boutonniere deformity (flexion at PIPs), valgus or varus, Baker cyst in popliteal fossa [5].

Vicente-Herrero *et al.* [6] claimed that the central pathology of RA occurs in the synovial membrane; the joint limitation is a typical manifestation of the disease. In addition to the fact that most RA patients suffer from muscle loss, it is a progressive development that leads the patient to reduce his mobility, the capacity of displacement, and the social interaction, affecting the most elementary daily activities and contributing to decreased physical function and Quality of Life (QoL) in these patients. Consequently, it leads to self-care deficit; therefore, it is required to educate patients through self-management educational programs to take an active role in managing their daily life, enhancing their quality of life, and minimizing functional disability [7]. Although there is no cure for RA, the goals of management and treatment are to preserve joint function, prevent further deterioration, improve patient function and reduce pain. Therefore, extensive educational programs such as Arthritis Self-Management Program are recommended to enhance QoL, perform daily activities, functional status, reduce disability, medical costs, and the associated mortality risks [8].

The purpose of a self-management education program is to educate the patient on how to understand the disease, the availability of treatment options, improve self-efficacy, and provide the necessary skills and knowledge to improve their QoL [7]. This program enhances patient education about their condition, adherence to their medication, pain coping strategies, decision-making, and problem-solving [9]. Therefore, this study aimed to determine

the effectiveness of self-management training programs on rheumatoid arthritis patients' quality of life and daily life activities.

Materials and Methods

The present study was conducted at Rheumatology and Physical Rehabilitation Center, the largest and only rehabilitation center providing outpatient service for the rheumatologic patients in Sulaimani provenance /Kurdistan region/Iraq. A quasi-experimental design was used to recruit 145 patients with RA from 10th March 2019 to 4th February 2020. Participants were selected by simple random sampling method and randomly divided into experimental (n=85) and control (n=60) groups. Inclusion criteria were 1) patients 18 years and above, (2) patients willing to participate, 3) no mental illness or disturbance of consciousness. Exclusion criteria were 1) physically disabled conditions, 2) cancer patients, 3) autoimmune diseases other than RA or other joint diseases, 4) patients with other serious illnesses that affect the quality of life such as cardiovascular disease, diabetes, chronic respiratory diseases, and cerebrovascular accident, 5) pregnant women.

The researcher used a structured questionnaire to collect data using the face-to-face interview technique and the forms provided. The research questionnaire consisted of five parts which were distributed as follows:

Part I: Socio-demographic characteristics: age, gender, marital status, level of education, occupation, and financial status.

Part II: Patients' lifestyle and biomedical factors: which includes Body Mass Index (BMI), smoking, dining style, walking aids, and disease duration.

Classification of participants' BMI according to World Health Organization (WHO) guidelines for Asian populations was as follow: (<18.5-22.5 kg/m² underweight, 23-24.9 kg/m² normal weight, 25-29.9 kg/m² overweight and >30 kg/m² obese) [10].

Part III: The Barthel Index (BI)

Functional status can be described as the level of individual independence in performing ADL. A person's functional status can be assessed using the Activities of Daily Living (ADL) score [11]. In 1955, Dorothea Barthe and Mahoney introduced the Bartell Index to measure the severity of the disability. [12]. It is a good tool and a simple weight scale [13] that examines patients' ability to perform common basic ADLs [14].

The BI includes ten items: bathing, getting on and off the toilet, feeding, bladder control, dressing, bowel control, walking on a flat surface (or propelling a wheelchair if unable to walk) and ascending and descending stairs, personal toilet, moving from wheelchair to bed and returning. Each domain was scored in 1-point increments, with scores ranging from 0 to 20. It seems reasonable to choose BI

because it is easy to use, only takes a few minutes to get information from nurses or relatives; An easy method to describe the important disability area of many chronic diseases such as RA [15]. In the BI, the minimum score is 0, and the maximum is 20. The Interpretation of the scores is as follows: independent (20) and dependent (0-19). The level of dependency in BI is divided into categories: slight dependent (12-19), moderate dependent (9-11), severe dependent (5-8), and dependent (0-4) [11].

Part IV: The standardized Health Assessment Questionnaire (HAQ)

In 1978, Fries *et al.* at Stanford University developed the HAQ to assess dysfunction that occurs in RA and the functional capacity [16].

HAQ is most widely used to measure functional disability in RA and is a valid disability index. HAQ comprises eight sections: activities, hygiene, walking, grip, eating, reaching, getting up, and getting dressed. There are 2 or 3 questions for each section. Each section is scored from 0 (without difficulty) to 3 (unable to do). For each section, the score given to that section is the worst score within each section. i.e., if one question is scored one and another 2, the section's score is 2. In addition, if you use the device or help or need help from someone else, the minimum score for that section is 2. If the section score is already two or more, no modification will be made [17]. It consists of 20 items assessing the functional ability of patients in 8 domains of daily life, including eating, arising, hygiene, dressing, grooming, walking, usual activities, reaching, and gripping [18].

The questionnaire was answered in four score levels: 0 (without difficulty) to 3 (unable to do), and the highest score for each domain is averaged into a final score out of three, where higher scores indicate greater disability [19].

The questionnaire measures functional loss by measuring functional disability reliably and validly through observation or physical examination. Therefore, it is recommended that self-reported disability assessments be standardized in observational studies in clinical trials [20].

Part V: The WHO Quality of Life-BREF (WHOQOL-BREF)

WHOQOL-BREF is a 26-item instrument that consists of four domains: physical health (7 items), psychological health (6 items), social relationships (3 items), and environmental health (8 items); it also contains QOL and general health items. Each WHOQOL-BREF item is scored from 1 to 5 on the response scale, which is stipulated as a five-point ordinal scale. The scores are then transformed linearly to a scale of 0-100 [21].

The physical health domain includes items on mobility, daily activities, functional capacity, energy, pain, and sleep. Psychological domain measures include self-image, negative thoughts, attitudes, self-

esteem, mentality, learning ability, memory concentration, religion, and mental status. The social relationships domain contains questions on personal relationships, social support, and sex life. The environmental health domain covers financial resources, safety, health, social services, living physical environment, opportunities to acquire new skills and knowledge, recreation, general environment (noise, air pollution, etc.), and transportation [22].

The researcher modified and prepared a simplified booklet entitled "Information about Self-Management on Rheumatoid Arthritis" was modified and prepared by the researcher.

Patients in the experimental group were asked to participate in a four-session self-management training program. This program was one day a week for four weeks. Experimental participants received the program booklet and were presented in lectures and role-playing in four sessions. The sessions were held in small groups (5-7 patients). The first session consisted of 20-25 minutes. Initial evaluation was performed for patients, and the following week the program was structured weekly for 30-45 minutes; while there were no program, booklet, and lecture in the control group, they received only routine care.

Post-test was performed for both experimental and control groups after three months of self-management educational program. Patients who missed a session in the experimental group were not included in the post-test.

The program consisted of four chapters as follows:

The first chapter contained general information about RA, which includes: definition of RA, causes of RA, clinical manifestations, diagnosis, and treatments (names of medications, methods of taking them, and their side-effects). In chapter two, there was a piece of information about what are the other things to do to manage RA, how to care for painful joints such as using assistive devices for usual daily activities, using heat and cold therapy, massage, acupuncture, acupressure, using supplements and maintaining a positive attitude. Chapter three includes information about how to be a self-manger, how to manage flare, joint protection techniques to make daily routines easier and safer, maintaining good posture during walking, resting, sleeping, maintaining or using joints in a good alignment, balancing activity with rest and eating well. Finally, chapter four is composed of examples of exercises.

Descriptive and inferential statistics were used to identify participants' characteristics and the quality of life domains and HAQ scores presented in mean and standard deviation. Statistical analysis was performed by SPSS 22.0 software (IBM SPSS Statistics) using Fisher's Exact test, Chi-square test, and Paired t-test.

Findings

More than half of the experimental and control groups participants were between 40-60 years old. The majority of participants in both groups were female and married. More than half of the RA patients in both the experimental and control groups were illiterate, and their income was less than their expenditures. In addition, nearly one-third of both groups were either overweight or obese based on the BMI. The proportion of non-smoker in the experimental and control groups was almost the same. Most participants in both groups had their dining on the ground and did not use walking aids. Most experimental and control groups had regular medical follow-up visits. There was no significant difference between the two groups regarding socio-demographic and clinical characteristics at baseline ($p>0.05$; Table 1).

Table 1) Distribution of absolute and relative frequency of socio-demographic and clinical characteristics of participants in the experimental and control groups in the pre-test (numbers in parentheses are percentages)

Characteristics	Experimental group	Control group	P.
Age (years)			
<40	11 (12.9)	3 (5.0)	0.252 [†]
40-60	46 (54.1)	34 (56.7)	
>60	28 (32.9)	23 (38.3)	
Gender			
Female	82 (96.5)	58 (96.7)	0.830*
Male	3 (3.5)	2 (3.3)	
Occupation			
Paid employed	8 (9.4)	3 (5.0)	0.333*
Housewife	69 (81.2)	53 (88.3)	
Retired/Jobless	5 (5.9)	1 (1.7)	
Other	3 (3.5)	3 (5.0)	
Marital status			
Single	4 (4.7)	2 (3.3)	0.655 [†]
Married	68 (80.0)	46 (76.7)	
Widow/divorced	13 (15.3)	12 (20.0)	
Education			
Illiterate	44 (51.8)	35 (58.4)	0.46 [†]
Primary	24 (28.2)	17 (28.3)	
Secondary	13 (15.3)	6 (10.0)	
Institute/University	4 (4.7)	2 (3.3)	
Financial status			
Income>Expenditure	16 (18.8)	9 (15.0)	0.77 [†]
Income=Expenditure	26 (30.6)	17 (28.3)	
Income<Expenditure	43 (5.6)	34 (56.7)	
Body Mass Index (BMI)			
Normal	32 (37.6)	19 (31.7)	0.238
Overweight	32 (37.6)	29 (48.3)	
Obese	21 (24.7)	12 (20.0)	
Smoking			
No	82 (96.5)	58 (96.7)	0.830*
Yes	3 (3.5)	2 (3.3)	
Dinning style			
Ground	68 (80.0)	42 (70.0)	0.150
Dining table	17 (20.0)	18 (30.0)	
Walking aid			
No	74 (87.1)	48 (80.0)	0.238
Yes	11 (12.9)	12 (20.0)	
Follow-up			
No	14 (16.5)	12 (20.0)	0.152
Sometimes	14 (16.5)	16 (26.7)	
Regularly	57 (67.0)	32 (53.3)	
Diseaseduration (years)			
<5	34 (40.0)	21 (35.0)	0.816
5-10	19 (22.3)	14 (23.3)	
>10	32 (37.6)	25 (41.7)	

In the experimental group, the mean scores of general QoL, general health, and each of the domains of QoL and HAQ scores improved after the program compared to baseline, which changes were statistically significant ($p<0.01$), but no significant difference was observed in the control group ($p>0.05$; Table 2).

Table 2) Comparison of QoL and HAQ scores (mean±SD) between pre and post-program in the experimental (n=85) and control (n=60) groups.

Variables	Pre-test	Post-test	P.
General QoL			
Experimental group	52.00±16.16	59.23±14.41	0.0001
Control group	54.41±16.36	53.92±16.86	0.322
General health			
Pre-test	46.25±15.23	55.36±12.91	0.0001
Post-test	50.98±13.19	45.10±18.72	0.077
Physical domain			
Experimental group	50.66±13.25	56.42±14.55	0.0001
Control group	51.65±11.29	50.69±5.05	0.630
Psychological domain			
Experimental group	52.80±13.49	60.55±12.43	0.0001
Control group	53.67±10.33	53.10±11.27	0.411
Social domain			
Experimental group	60.30±13.86	64.39±11.72	0.0001
Control group	58.97±13.01	57.98±10.35	0.684
Environmental domain			
Experimental group	55.22±11.93	58.48±10.48	0.0001
Control group	54.47±10.76	53.39±8.39	0.527
HAQ			
Experimental group	1.02±0.86	0.76±0.84	0.002
Control group	0.98±0.83	1.06±0.85	0.424

According to the Barthel index, the proportion of totally independent patients in the experimental group increased from 35.3% in the baseline to 54.1% after the self-management educational program; Also, the percentage of both slight dependency and moderate dependency decreased, which was statistically significant ($p<0.05$). However, the changes in the control group were not statistically significant ($p>0.05$; Table 3).

Table 3) Comparison of the level of dependency in pre and post-program in both experimental (n=85) and control (n=60) groups

Dependency levels	Experimental group		Control group	
	No. (%)	Post-test	No. (%)	Post-test
Moderate dependency	31 (36.5)	21 (24.7)	21 (35.0)	22 (36.7)
Slight dependency	24 (28.2)	18 (21.2)	15 (25.0)	16 (26.7)
Total independent	30 (35.3)	46 (54.1)	24 (40.0)	22 (36.7)
Results*	$\chi^2=6.7$; $p=0.035$		$\chi^2=0.36$; $p=0.84$	

*Chi-square test

Discussion

The present study showed that most RA patients were between 40-60 years old. Most of them were female, housewives and married, and still living with their spouse, and most of them were illiterate and low-income. This is in line with the findings of Yang *et al.* [23] and Zhang *et al.* [24], the prevalence of RA was higher between the ages of 48-63 years, and women were 3 to 4 times more likely to develop RA than men. Furthermore, when monthly income was less than expenditure, a higher prevalence was observed among the lower socioeconomic status.

Moreover, the findings of the present study supported by a recent study conducted by Radwan and Borai [25] confirmed that the proportion of RA patients among illiterate is much higher (54.5%) than university graduates (4.1%). Another recent study conducted by Gamal *et al.* [26] found that the percentage of illiterates was higher in RA patients (33.5%) than in university graduates (22%).

At baseline, the proportion of overweight and obese in both experimental and control groups was higher than normal BMI. Almost all participants in both groups were non-smokers, the majority used the ground for dining and did not use walking aids, more than half of the participants followed regular medical visits, and most patients in both groups had RA for less than five years. There was no significant difference between experimental and control groups regarding clinical characteristics.

The association between obesity and increased risk of developing RA is claimed by epidemiologic studies, although these studies have shown conflicting results. Some studies proposed that obesity may be associated with more refractory inflammation through increased levels of inflammatory resistin, adipocytokines leptin, or visfatin or decreased levels of the anti-inflammatory adipocytokine adiponectin. This may affect the innate immune and adaptive immune system, activate monocytes and increase levels of inflammatory cytokines such as Tumor Necrosis Factor α (TNF- α), Interleukin 12 and 6 (IL-12, IL-6) [27]. Dining on the ground is common in Kurdish and other Eastern societies. According to our information, most participants were in the low socio-economical class, so they may not have a dining table or have deficit knowledge regarding the advantage of using a dining table for arthritis conditions. Since dining on the ground needs cross-legs sitting position, keeps joints and supportive structures (muscles, ligaments, etc.) under constant tension and can cause stiffness and discomfort. These symptoms may lead to extra stress on the joints [28]. The distal joints are more affected by the RA, the hands and wrist joints are more affected and can cause difficult grip [29]. This may be because patients with RA did not prefer to use walking aids during gait. The health care system is constantly improving in developing cities. Increasing patients' knowledge of their condition encouraged them to seek regular medical follow-up.

Both experimental and control groups were matched concerning general health, general QoL, physical health, psychological condition, social interaction, and environmental health at baseline (preprogram). The general health score was the lowest between the general QoL and QoL domains in the experimental and control groups. The score of physical, psychological, and environmental domains was below 60, which is considered a poor quality of life, while the score of the social domain was more

than 60 in both groups. The results of the present study indicated all QoL domains are below the WHOQoL-BREF cutoff point reported by Silva *et al.* [30, 31]; their results depicted that a critical value of 60 as the optimal cutoff point for assessing perceived QoL and health satisfaction, and they considered 60 as the minimal value for good QoL's domains, overall QoL and general health. The present study's finding on QoL was similar to the results obtained on the WHOQoL-Bref in RA patients by two previous cross-sectional studies in Iraq. Hussein [32] demonstrated that RA has a significant effect on HRQoL. The QoL was poor in general health perception (45.86 \pm 17.55). Physical functioning was most affected by RA (48.26 \pm 29.87), and social functioning was the least affected (53.04 \pm 26.759). On the other hand, Faiq *et al.* [33] found that quality of life was significantly affected by RA, physical domain scores were more affected, and social domain scores were least affected (42.5 \pm 12.0) and (55.1 \pm 11.9), respectively. Despite the development of the Iraqi environment after 2003, the health sector has not kept pace with global development, as there is a shortage of staff and resources, which reflects the poor quality of health services provided to patients [34].

Functional ability was another variable studied in the present study. Functional ability is the patient's ability to perform dressing, arising, eating, walking, hygiene, reaching, grip and activities. According to the HAQ scale, the score was 1.02, which considered the presence of moderate disability depending on the findings of a previous study conducted by Laure [35], who reported that HAQ's score below 0.5 is considered normal, 0.5-1 mild disability, 1.01-1.5 moderate disability and the score of above 1.5 indicates severe disability.

Patients with RA have a significantly higher prevalence of functional disability over RA disease duration, sex, and age than their non-RA counterparts. A previous study showed that participants with RA had a higher prevalence of functional disability at the RA incidence/index date (26%) compared to those without RA (11%), with persistent excess and no improvement over follow-up and calendar time [36]. Furthermore, another study in China reported that almost 15.8% of RA patients had a functional disability (HAQ-DI score \geq 1). A similar HAQ score (1.0 \pm 0.6) was stated by Ellegaard *et al.* [37] in samples with RA.

The main part of the study was to examine the impact of self-management education programs on improving QoL and functional ability to perform activities of daily living in RA patients and compare the results with RA patients who had only usual care (control). The study results indicated initial improvements in general QoL, general health, physical health, mental status, social interaction, environmental health, and functional ability to perform ADL in the experimental group. In contrast,

no improvement was observed in RA patients receiving routine care (control).

The present study's findings indicate a statistically significant difference between the baseline (preprogram) and post-program in the experimental group regarding general QoL, general health, physical health, psychological condition, social interaction, and environmental health. In contrast, no improvement in participants' QoL and ability to perform ADL was observed in the control group. As well as, participants in the experimental group improved their functional ability and ability to perform ADLs after the program. The self-management educational programs in the present study had a positive effect on RA QoL and the ability to perform ADLs, which led to the promotion of general health. This finding is in line with a study conducted by Turner *et al.* [38] to evaluate a group-based self-management program for patients with RA; This program was for seven weeks, 3 hours group-based for six months' follow-up. The results found that patients reported significant improvements in patient activation and HRQoL. Patients' anxiety and depression significantly improved, also there were significant improvements in self-management skills.

Patient education is very important for people living with chronic diseases such as RA because it enables them to adapt and cope with the effects of the disease and treatments. In contrast, research has identified a whole range of benefits such as improved disease knowledge, self-efficacy, concordance with treatment, and physical and psychological health status [39]. Research on the self-management program for patients with rheumatoid arthritis has focused primarily on patient education, self-expression, pain management, stress management, and depression management. The effectiveness of the Arthritis Self-Management Program (ASMP) has been confirmed. In general, self-management programs have many benefits and reduce medical costs in the long term. Self-management programs are currently recommended by the US National Arthritis Action Plan as an important component of rheumatic care [40].

A recent randomized control trial conducted by Shao *et al.* [41] to determine the effectiveness of a self-management program to protect joints and physical activity for patients with RA based on self-efficacy theory. The results showed that compared to the control group 6 months after the self-management program, participants in the intervention group significantly improved physical function, pain self-efficacy, and higher scores of self-management behaviors than the control group. Furthermore, participants in the intervention group had significantly lower scores for MHAQ (21.44±2.99) than the control group (24.75±8.28).

Another randomized control trial was conducted by Senara *et al.* [42] to evaluate the effect of the patient

education program in managing patients with RA for six weeks. The results showed that the educational program significantly improved the disability measured by the HAQ, pain intensity, and the number of painful and swollen joints measured by Disease Activity Score (DAS28).

Recently, Sarsak [43] reviewed the effect of the Joint Protection (JP) program on RA and summarized that subjects with RA benefit from JP, resulting in pain reduction, better joint adherence, and reduction in stiffness and better ADL functional ability.

In addition, Hevey *et al.* [44] conducted a pre-post-study to evaluate the effectiveness of the Chronic Disease Self-Management Program (CDSMP) delivered in routine clinical services on health, health behaviors, and healthcare utilization in patients with various chronic illnesses. The CDSMP ran for six weeks. The results showed that CDSMP participants reported statistically significant increases in activity levels, self-efficacy, energy, quality of life, and a significant decrease in depression scores.

To evaluate the effectiveness of a brief supervised education, self-management, and global upper extremity exercise training program, supplementing a home exercise regimen, for people with rheumatoid arthritis, Manning *et al.* [45] conducted a randomized controlled trial. The study results found that the program reduces upper extremity disability, function, handgrip strength, and self-efficacy in people with RA, with no adverse effects on disease activity.

The results of the present study are consistent with a study conducted by Ammerlaan *et al.* [46] to evaluate the feasibility of an online and face-to-face self-management program for young adults with RA. The program was once a week with a maximum of 10 minutes, for six weeks, and two weeks of follow-up, while the face-to-face version was for 12 hours in total during a weekend, in 3 days, and follow-up for three months. The results showed that both programs appeared to be feasible and well appreciated, especially in dealing with problems in daily life, and the participants indicated the time investment as worthwhile.

Conclusion

A self-management educational program can be considered an effective intervention to improve the quality of life, perform activities of daily living and minimize functional disability in rheumatoid arthritis patients.

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Ethical Permissions: This study was approved by the Ethical Committee at the College of the Medicine University of Sulaimani, and informed consent was obtained from all study participants.

Conflicts of Interests: The authors declared no conflict of interest.

Authors' Contribution: Ahmed K.M. (First author), Main researcher (50%); Rashid Amen M. (Second author), Assistant researcher (50%).

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