

Effect of Self-Management Program on Self-efficacy and Quality of Life for School Age Children with Juvenile Rheumatoid Arthritis

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Abstract :**Back ground**: Effective self-management behaviors program have the potential to improve health outcomes, quality of life, self-efficacy and diminish morbidity. A better understanding of self-management interventions that help with managing symptoms, treatment, physical and psychological consequences is necessary for accomplishing a positive effect on health. **Aim of the study** was to evaluate the effect of self-management program on self-efficacy and quality of life for school age children with juvenile rheumatoid arthritis. **Setting**: The study was carried out at Inpatient Pediatric Rheumatology unit in Benha University Hospital and Benha Specialized Pediatric Hospital in association with Ministry of Health and Population. **A quasi experimental design** was used for carrying out the present study. **Subjects**: A purposive sample of (55) child was chosen from the previously mentioned setting. **Tools of data collection**: Five tools were utilized; personal and medical data assessment sheets, knowledge assessment questionnaire, self-management behaviors questionnaire, self-efficacy scale and quality of life inventory. **Results**: There was a highly statistical significant difference in children' knowledge, self-management behavior, self-efficacy and quality of life pre and post program implementation ($p < 0.001$). **Conclusion**: Based on the results of the present study, it can be concluded that, the self-management program was an eminently effective technique to improve children' self-management behaviors, self-efficacy and quality of life. **Recommendation**: Encourage continuous self-management program for children experiencing juvenile rheumatoid arthritis to improve quality of life, self-efficacy and thus reduce negative consequences of the disease.

Key words: Self-management program, self-efficacy, quality of life, juvenile rheumatoid arthritis and school age Children.

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I. Introduction:

Chronically ill children such as those with juvenile rheumatoid arthritis (JRA) must handle with taking medication, taking part in everyday physical activity, maintaining a healthy diet and an appropriate disease management to decrease the negative effects of the disease on quality of life¹. JRA is a common systemic inflammatory disease characterized by the presence of destructive polyarthritis with a predisposition for affecting the small joints of the hand and feet². According to the International League of Associations for Rheumatology (ILAR), JRA is any arthritis lasting at least 6 weeks and developing before the age of 16 years in the absence of a known cause³.

Globally, incidence of JRA ranges between 2 and 22 per 100,000 Children populations, while The estimated prevalence show figures somewhere in the range of 7 and 150 per 100,000^{4,5}. The prevalence among European and North American children extends from 16 to 150 per 100,000⁶. In Australian, came to up to 400/100,000⁷. In Sweden, the yearly incidence is around 15 for every 100 000 children. In Chinese children, the prevalence was 3.8 per 100,000. Outside Africa, the prevalence ranges from 0.0038% to 0.004%⁸ and in Oman, the prevalence is 20⁹. This wide distinction is because of the varieties in populations, environment, and hereditary predisposition¹⁰.

The most widely recognized manifestations of all types of JRA incorporate joint pain and swelling, which may come and go but are most often persistent; joint stiffness in the morning; limping; and unpredictable changes in symptoms from asymptomatic periods (remission) to flare-ups and pain. The long-term impacts of JRA incorporate joint contracture and joint damage. Moreover, diagnostic procedures, stays in hospital, and side effects induced by drugs used in JRA treatment are sources of additional stress¹¹.

Juvenile rheumatoid arthritis is more typical among girls than boys and considered a significant reason of short and long-term disability. The disease affects physical functioning, mental health, school and home working. As children arrive at adulthood, they experience a continuous disease activity, medication-associated

morbidity, life-long disability, an expanded danger of emotional and social dysfunctioning¹². Quality of life (QOL) is a multidimensional construct covering physical, mental, social, behavioral components of well-being and function as perceived by the children feelings associated with health¹³.

Juvenile rheumatoid arthritis has negative consequences for child development, including increased dependence on parents, problems developing autonomy, inadequate peer relations and adjustment problems¹⁴. Besides, family factors can ruin the child's adjustment to the illness. In addition, increasingly parental depression and family pressures predict more psychosocial problems among chronically ill children and this demonstrated an expansion in the need of child to accomplish adaptation and improve QOL¹⁵.

Self-management (SM) is the 'individual's ability to manage the symptoms, treatment, physical, psychosocial consequences and life style changes inherent in living with a chronic condition¹⁶. SM is a task for the children themselves requires a multidisciplinary approach but in practice is often provided by nurses who have insight about the impact of a chronic condition on a children's life and are therefore designated to coach children in self-management for maintaining life roles, as well as address the psychological impact of disease^{17,18}.

Self-efficacy alludes to personal's judgments or beliefs about their abilities to perform successfully specified tasks. According to American psychologist Albert Bandura, Self-efficacy theory focused on that human activity and achievement rely upon how profound the cooperation between one's personal thoughts and a given task. So, children with greater self-efficacy have been shown to practice more self-management behaviors, leading to better disease control, better physical function and better quality of life¹⁹.

Significance of the study:

Juvenile rheumatoid arthritis is the most widely cause of chronic arthritis in children²⁰. The prevalence in Egypt is 3.43 per 100,000²¹. Despite medical advances in understanding the etiology and treatment of juvenile rheumatoid arthritis, it can still result in considerable physical, social disability for school-age children and can have a serious impact on child development²². Furthermore, it places self-care and psychosocial demands on the child and on the family caregivers. In this regard, effective educational interventions should extensively address the particular skills and behaviors required of children. One way that has been proved to be successful in ensuring this focus is to use self-management education that attempts strengthened children's self-efficacy perception, facilitate the adoption of self-management behaviors, enable them to cope with the disease and thus to prevent disability^{23,24}. Accordingly, improving self-management behaviors, quality of life and self-efficacy toward JRA through program are fundamental.

Aim of the study

The aim of the present study was to evaluate the effect of self-management program on self-efficacy and quality of life for school age children with juvenile rheumatoid arthritis.

Research Hypothesis:

There will be a significant improvement of children's self-management behaviors after implementation of program than before.

There will be a significantly higher children's quality of life after implementation of program than before.

There will be a significantly greater children's self-efficacy after implementation of program than before.

There will be a positive correlation between total self-management behaviors, total self-efficacy with total quality of life pre and after implementation of program.

Subjects and Methods:

Research design:

A quasi experimental design was used to achieve the aim of the study.

Setting:

The study was conducted at Inpatient Pediatric Rheumatology unit in Benha University Hospital and Benha Specialized Pediatric Hospital in association with the Ministry of Health & Population. Inpatient pediatric rheumatology unit in Benha University Hospital is constructed from 2 rooms, each room consisted of 8 beds, while at Benha Specialized Pediatric Hospital; the unit is constructed from three rooms, each room consisted of 4 beds, so the total bed capacity at both hospitals is 28 beds.

Subjects:

A purposive sample of (55) child from both sex was chosen as follow; (37) of them from Benha University Hospital and the others (18) from Specialized Pediatric Hospital after fulfilled the following criteria.

Inclusion criteria:

- Children diagnosed with juvenile rheumatoid arthritis
- Age ranged from 8-12 years
- Capable to comprehend instructions
- Willing to take part in the study

Exclusion criteria:

- Children with other chronic disease or psychological problems.

Tools for data collection:

Five tools were used to collect the data of this study:

Tool (I): Personal and medical data assessment sheet: It was developed by the researchers based on recent literature review and written in simple Arabic language to assess the children's personal and medical data. It included two main parts:

Part I: Personal characteristics of children as; age, gender, level of education, hospital setting, residence and attend any previous intervention program related to JRA. **Part II:** Medical data of children such as; height, weight, age of onset/ years, time from symptom onset to diagnosis/months, duration of illness/ months and joints affected by disease.

Tool (II): Knowledge assessment questionnaire: It was developed by the researchers based on recent literature review as **Kyle and Carman,(2013)²⁵; Kjekken et al., (2015)²⁶ and Zuidema et al., (2015)²⁷**. Then translated into Arabic language to assess children knowledge regarding juvenile rheumatoid arthritis. It included (12) multiple choice questions related to definition, etiology, risk factors, symptoms, diagnostic procedures, treatment, complications and nursing care.

Scoring system: Children responses were measured by giving a score of (1) for the correct answer and (zero) for the wrong answer. Total scores were ranged from (0-12), cut point was done at 60%=7.2 grade score and the value was calculated and scoring system developed by the statistician as follow; Knowledge was considered satisfactory if the percent score was 60% or more and unsatisfactory if less than 60%.

Tool (III): Self-Management Behaviors Questionnaire (SMBQ):

It was adapted by researchers based on **Nadrian et al., (2011)²⁸** to evaluate self-behaviors of children regards management of JRA. Then translated into Arabic language. It consisted of (12) self-behaviors related to exercise regimens, joint warming, joint protection, adequate rest, adaptation with disease, food supplement, healthy diet, massage, stress management, relaxation, drug management, regular follow up.

Scoring system: Using a three point Likert scale as follow: (3) always, (2) sometimes, and (1) never. The total score were ranged from (12-36), cut point was done at 60%=22. The total scores were summed up and converted to percent score. Level of self-behaviour is considered **Good** if the percent ($\geq 75\%$) of total behaviors score = ≥ 27 point, **fair** (60% - < 75%) score = 22- < 27 point and **poor** (< 60%) score = < 22point.

Tool (IV): Quality of Life Inventory (QOL; version 4.0): It was adopted from **Varni et al., (2001)²⁹** to assess quality of life for children suffering from juvenile rheumatic arthritis. It consisted of 23 items covering the four dimensions; physical functioning (8items), emotional (5items), social (5items), and school functioning (5items). A physical health summary score was based on eight items and equal to the physical functioning dimension. A psychosocial health summary score was based on the 15 items from the emotional, social and school functioning dimensions.

Scoring system: A 5-point Likert response scale from 0= never a problem, 1= almost never a problem, 2= sometimes a problem, 3= often a problem to 4= almost always a problem. These response scales was converted to 0-100, being (0=100, 1=75, 2=50, 3=25, 4=0). The score is calculated by counting the points given to the items for each dimension. The total score was obtained by calculating the sum of the scores and dividing by 23. In this respect, the higher score was indicative of a higher QOL, whereas the lower score demonstrated a lower QOL.

Tool (V): Children's Arthritis Self-Efficacy Scale (CASES): It was designed by **Barlow et al., (2001)³⁰** to measure children's perceived ability to control or manage aspects of life with juvenile arthritis. The scale consists of 11 statements grouped under 3 subscales; self-efficacy of activity (4 items), self-efficacy of symptoms (4 items), and self-efficacy of emotions (3 items). Internal consistency of each subscale via Cronbach's alphas was (0.90) for activity, (0.87) for symptoms and (0.85) for emotion.

Scoring system: 5-point Likert scale ranges from 1 (not at all sure) to 5 (very sure). Each subscale is scored separately, taking the mean of subscale items. Total scores was range from 11 to 55 on each subscale. Higher scores indicate greater self-efficacy.

Methods:

The study was executed according to the following steps:

Preparatory phase: It involves the following; looking into the national and international related literatures using journals, periodicals, textbooks, internet and theoretical knowledge of the different aspects concerning the topic of the study so as to gather the tools of the study.

Content validity and Reliability:

Tools Validity: Tools of data collection were translated into Arabic and investigated for their content validity by three juries (two in Pediatric nursing from the Faculty of Nursing Benha University, and one in Rheumatology from the Faculty of Medicine Benha University) who are experts' in the related field and selected to test the content validity of the instruments and to Judge its clarity, comprehensiveness, relevance, simplicity, and accuracy. All of their remarks were taken into consideration; some items were re-phrased to arrive at the final version of the tools. The tools were regarded as valid from the experts' point of view.

Tools Reliability: The tools were tested for reliability by the test-retest technique by 5 children from the two hospitals who were interviewed at an interval of one week period and data were analyzed and compared. The reliability was evaluated in a pilot study by estimating their internal consistency utilizing Cronbach's alpha coefficient method. This turned to be ($\alpha = 0.91$) for personal and medical data assessment sheet ($\alpha = 0.86$) for knowledge assessment questionnaire, ($\alpha = 0.89$) for SMBQ, and ($\alpha = 0.85$) for QoL inventory. This indicates a high degree of reliability for the study tools.

Administrative and Ethical Considerations:

All the relevant principles of ethics in research were pursued. Before starting the practical work an official letter clarifying the purpose of the study was obtained from the dean of the faculty of nursing to the two hospitals directors to conduct the study and collect the necessary data. Participants' (All children and their parents) consent to participate was obtained after telling them about their rights to participate, refuse, or withdraw at any time. Total confidentiality of any obtained data was guaranteed. The study maneuver could not involve any unsafe effects on participants.

The Pilot Study:

A pilot study was conducted to test the clearness and applicability of the study tools and estimate the time needed for each tool. It was done on 10% of the total subjects, (5) children (3 from Benha University Hospital, and 2 from Specialized Pediatric Hospital) who excluded in the present study to avoid sample bias and contamination. In the light of pilot study analysis, modification was done accordingly and the last form was developed.

Field Work:

The following phases were adopted to achieve the aim of the current study; assessment, planning, implementation, and evaluation phases. These phases were conveyed from the earliest starting point of October 2018 to the end of July 2019 covering ten months.

Assessment phase:

This phase involved interviews with children to collect baseline data, at the beginning of interview; the researchers welcomed each child, explained the purpose, duration, and activities of the study and took written consent from their parents. After that, Pre-test was done to assess personal and medical data, children knowledge, self-management behaviors, self-efficacy and quality of life regarding juvenile rheumatoid arthritis by using pre-test tools (I, II, III, IV &V).The data obtained during this phase comprised the baseline for further comparison to evaluate the effect of self-management program. The average time required for finishing each questionnaire was around (10-15 minutes).

Planning phase:

Based on baseline data obtained from pre-test assessment and relevant review of literatures, the self-care management program was developed by the researchers as indicated by children' level of comprehension in simple Arabic language

Implementation phase:

Self-management program was implemented through sessions. Children were divided into 20 groups (2-3 children in each group), the program has taken from 4-5 hours for each group, distributed as the following; 5 sessions, each session kept going from 45-60 minutes, 5 days/week in the morning shift, and were

implemented according to children readiness. These sessions were repeated to each subgroup of children. In this way, the program took (20) weeks.

The **first session** of program focused on general knowledge about juvenile rheumatoid arthritis (definition, etiology, symptoms, risk factor, diagnostic procedure, treatment & complications) and the other sessions focused on self-care behaviors as the following, **the second session** included (exercise regimens, joint warming, joint protection, adequate rest & massage). Then, **third session** included (importance of healthy diet & food supplement). After that **fourth session** included (stress management & relaxation). Finally, **fifth session** (drug management & regular follow up). Toward the start of the program sessions, a direction to the motivation behind program took place and the children were informed about the time and place of sessions which were carried out at the hematology department lecture room. Different methods of teaching were used such as modified lecture, and group discussion. Suitable teaching media were included an educational booklet that distributed to all children in the first day of the program as well as audio-visual aids and role play. The researchers continued to reinforce the gained information, answered any raised questions and gave clear explanation.

Evaluation phase:

Children's knowledge was evaluated instantly after implementing the program. While, SMB, Qol and CASE were assessed after three months of program implementation by utilizing the same tools of the pre-test. This helped to evaluate the effect of the implemented self-management program.

Statistical design: The collected data organized, tabulated and statistically analyzed using statistical package for social science (SPSS) version 21 for windows, running on IBM compatible computer. Descriptive statistics were applied (e.g. frequency, percentages, mean and standard deviation). Test of significance, Chi-square "X²", paired t test, and correlation coefficient (r) were applied to test the study hypothesis. Reliability of the study tools was done using Cronbach's Alpha. A significant level value was considered when $p < 0.05$ and a highly significant level value was considered when $p < 0.001$. No statistical significance difference was considered when $p > 0.5$.

II. Result:

Table (1): Personal characteristics of the studied children (n=55)

Personal characteristics	No	%
Age:		
8- <10 years	31	56.4
10-12 years	24	43.6
Mean ± SD	10.36 ± 1.87	
Gender:		
-Male	20	36.4
-Female	35	63.6
Educational level:		
-Illiterate	4	7.2
-Primary schools	51	92.8
Hospital setting:		
-Benha University Hospital	37	67.3
-Benha Specialized pediatric Hospital	18	32.7
-Residence:		
Urban	19	34.5
Rural	36	65.5
Attend any previous intervention program related to JRA:		
Yes	0	0.0
No	55	100.0

Table (1): shows personal characteristics of the studied children. It was found that more than half of children (56.4%) were aged ranged from 8 to less than 10 years, with a mean of age 10.36 ± 1.38 years. There was a slight preponderance of female (63.6%). As far as educational level, the vast majority of them (92.8%) were enrolled in primary education level. More than two thirds of them (67.3%) were from the Benha University

hospital. Regarding residence, less than two thirds (65.5%) of children was from rural area compared to 34.5% from urban one. All of the studied children (100%) not attend any previous intervention program related to JRA.

Table (2): Medical data of the studied children (n=55)

Medical data	No	%
Weight of children(kg): Mean ± SD	33. 6±5.8	
Height of children(cm): Mean ± SD	137.26±3	
Age at onset (years): Mean ± SD	9.1 ±4.0	
Time from symptom onset to diagnosis/months:		
< 3 month	7	12.8
3- 6 months	13	23.6
> 6 months	35	63.6
Mean ± SD	8.2 ±2.0	
Duration of illness (months):		
< 12 month	10	18.2
12-< 24 months	37	67.3
≥ 24 months	8	14.5
Mean ± SD	22.8 ±15.7	
Joints affected by the disease:		
-Wrist, elbow, or knee	17	30.9
-Ankle, knee, or hip	38	69.1

It is clear from **table (2)** that the mean weight of the studied children was found as 33. 6±5.8kg and the mean height of them were reported as 137.26±3cm. The mean age at onset of disease was 8.1 ±4.0years. More than half (63.6%) of children showed that the time from symptom onset to diagnosis was longer than six months and the mean was 8.2 ±2.0months. The mean duration of illness was 22.8 ±15.7months. Concerning the joints affected by the disease, more than two thirds (69.1%) of children involved ankle, knee, or hip joint, and 30.9% of them involved Wrist, elbow, or knee.

Table (3): Distribution of the studied children according to their total knowledge level scores about juvenile rheumatoid arthritis thorough program phases (n=55).

Total knowledge level	Pre-program (n=55)		Immediately Post-program (n=55)		X ²	P- value
	No	%	No	%		
Satisfactory	12	21.8	41	74.5	36.56	<0.000*
Unsatisfactory	43	78.2	14	25.5		

*A highly statistical significant difference (P ≤0.001)

Table (3): Illustrates that there was a highly statistical significant improvement in the level of knowledge scores about juvenile rheumatoid arthritis among the studied children, whereas, whereas, only 21.8% of the studied children had satisfactory level of knowledge pre-program, and this level increase to nearly three quarters (74.5%) of them had satisfactory level of knowledge immediately post-program implementation.

Table (4): Distribution of the studied children regarding their self- management behaviors scores through program phases (n=55)

Self- management behaviors items	Self-management behaviors Pre-program(n=55)						Self-management behaviors After 3 months Post-program(n=55)						X ²	P
	Never		Sometimes		Always		Never		Sometimes		Always			
	No	%	No	%	No	%	No	%	No	%	No	%		
Exercise regimen	41	74.5	10	18.2	4	7.3	3	5.5	9	16.4	42	76.4	6.250	<0.005*
Joint warming	24	43.6	17	30.9	14	25.5	6	10.9	15	27.3	34	61.8	18.129	<0.001**
Joint protection	40	72.7	10	18.2	5	9.1	9	16.4	12	21.8	34	61.8	4.871	<0.005*

Adequate rest	38	69.1	11	20.0	6	10.9	6	10.9	17	30.9	32	58.2	2.832	<0.005*
Adaption with disease	40	72.7	8	14.5	7	12.7	6	10.9	12	21.8	37	67.3	28.767	<0.001**
Healthy diet	41	74.5	8	14.6	6	10.9	4	7.3	9	16.4	42	76.4	2.31	<0.005*
Food supplement	25	45.5	18	32.7	12	21.8	6	10.9	17	30.9	32	58.2	24.762	<0.001**
Massage	41	74.5	10	18.2	4	7.3	3	5.5	10	18.2	42	76.4	21.989	<0.001**
Stress management	40	72.8	7	12.7	8	14.5	3	5.5	14	25.5	38	69.1	9.227	<0.005*
Relaxation	29	52.7	17	30.9	9	16.4	4	7.3	19	34.5	32	58.2	19.163	<0.001**
Drug management	45	81.8	7	12.7	3	5.5	2	3.6	6	10.9	47	85.5	3.841	<0.005*
Regular follow up	45	81.8	3	5.5	7	12.7	4	7.3	9	16.4	42	76.4	7.616	<0.005*

*Statistical significant difference (p<0.05) **A highly statistical significant difference (P ≤ 0.001)

Table (4): Demonstrates children self-management behaviors about juvenile rheumatoid arthritis. It was found that (81.8%, 81.8%, 74.5%, 74.5% and 74.5%) of children had never done activities pre-program regarding (drug management, regular follow up, massage, exercise regimen and healthy diet), these activities changed to always done with percentage (85.5%, 76.4%, 76.4%, 76.4%, and 76.4%) respectively after 3 months post-program implementation. There was a statistical and highly statistical significant difference (p<0.05 & p<0.001) respectively.

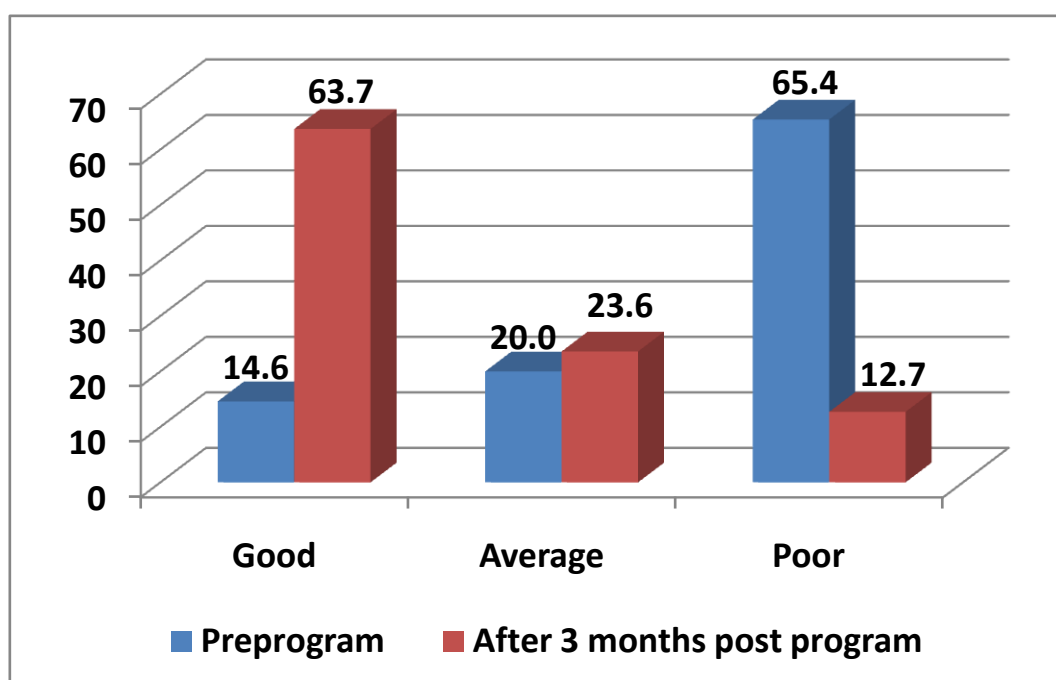


Figure (1): Total level of self-management behaviors among studied children through program phases (n=55).

Figure (1): Displays that less than two thirds (63.7%) of children had a good level scores of self-management behaviors after three months post-program implementation compared to 14.6% pre-program.

Table (5): Mean scores for quality of life domains thorough program as reported by children (n=55)

Quality of life domains	Pre-program Mean ± SD	3 months Post-program Mean ± SD	Paired t-test	P-Value
Physical health summary	41.7±1.99	79.6±0.55	33.29	**0.000
Psychosocial health summary	44.5±0.72	80.8±0.35	87.10	**0.000
Emotional functioning	44.3±0.48	74.9±1.20	40.75	**0.000
Social functioning	43.8±0.78	75.2±1.34	51.44	**0.000
School functioning	37.3±1.27	59.6±0.48	22.80	**0.000
Total	42.32±1.32	74.02±1.12	70.49	**0.000

**A high statistical significant difference (P ≤ 0.001)

Table (5): Presents that, the total mean scores for all domains of quality of life was statistical significantly higher among children at three months post-program implementation compared to pre-program (74.02±1.12 verses 42.32±1.32, P<0.001) respectively, including higher physical health (79.6±0.55), psychosocial health (80.8±0.35), emotional functioning (74.9±1.20), Social functioning (75.2±1.34) and school functioning (59.6±0.48).

Table (6): Mean scores for self-efficacy subscales thorough program as reported by children (n=55)

Self-efficacy subscale	Pre-program Mean ± SD	3 months Post-program Mean ± SD	Paired t-test	P-Value
Self-efficacy in activity	6.32±10.65	12.32±0.55	6.556	** .000
Self-efficacy in symptoms	6.15 ± 0.72	14.85±0.35	7.427	** .000
Self-efficacy in emotions	4.38±0.48	9.49±1.20	5.154	** .000
Total	16.85±4.21	36.66±2.01	9.85	** .000

****A high statistical significant difference (P ≤ 0.001)**

Table (6) reveals that, there was highly statistical significant differences in the total self-efficacy mean scores among children after 3 months post-program implementation compared to pre-program (36.66±2.01 versus 16.85±4.21, p<0.000) respectively. Moreover, the greatest self-efficacy mean scores were respectively related to symptoms and activity subscales (14.85±0.35 & 12.32±0.55), while the lowest self-efficacy mean scores was related to emotions subscale (9.49±1.20).

Table (7): Correlation between total self-management behaviors, total self-efficacy with total quality of life through program phases.

Variable	Total quality of life Pre-program		Total quality of life 3 months Post-program	
	r	p-value	R	p-value
Total self-management behaviors	0.383	<0.001**	0.492	<0.001**
Total self-efficacy	0.495	<0.001**	0.538	<0.001**

**** Significant at the 0.01 level (-tailed).**

It is evident from **table (7)** that there was a highly statistical significant positive correlation between total self-management behaviors, total self-efficacy with total quality of life pre and three months post-program implementation (p <0.001) respectively.

III. Discussion

Effective self-management behaviors program have the potential to improve health outcomes, quality of life, self-efficacy and reduce morbidity³¹. A better understanding of self-management interventions that help with managing symptoms, treatment, physical and psychological consequences is necessary for accomplishing a positive effect on health³². It was reported that children who actively participated in training benefited more from these programs than those who did not³³. So absolutely, the aim of the study was to evaluate self-management program on Self-efficacy and quality of life for school age children with juvenile rheumatoid arthritis.

As for the studied children's age, the findings of the current study demonstrated that more than half of the children's age ranged from eight to less than ten years and the mean age at onset of disease was 9.1±4.0. This finding was in the same context with **Mendelson et al., (2017)**¹⁴ who studied Comics as an educational tool for children with rheumatic arthritis and found that the age of the children ranged from 8–14 years and the mean age at onset of disease was 9.8 ± 4.6 years.

According to gender, the findings of the current study showed that more than half of the children were females. The researchers noticed a reasonable female predominance of JRA in this study. In this regard, **Ellis and Munro, (2010)**³⁴ mentioned that gender is a known risk factor, with girls more likely to develop JRA than boys. This result matched with **Abu AL-Fadl et al., (2014)**³⁵ who evaluated health-related quality of life, anxiety and depression in patients with early rheumatoid arthritis and found that the majority of patients were female. Conversely, this result contrasted with another epidemiological study conducted by **Malievskiy, (2011)**³⁶ who assessed prevalence and incidence of juvenile idiopathic arthritis for children in the republic of Bashkortostan (Russia), and reported that JRA in boys was higher than in girls.

As regard children's residency, the present study result show that less than two third of children were from rural area compared to more than one third from urban one. The inconsistency between urban and rural children with JIA could be because of numerous variables incorporate geographic distribution, genetic

background, infectious agents and environmental factors. This is in concurrence with **Abou El-Soud et al., (2013)**²¹ who determined the prevalence of juvenile idiopathic arthritis (JIA) in Sharkia Governorate, Egypt and found that more than half of children with JRA from the rural area compared to two fifth from urban one.

Early diagnosis and treatment of JRA are essential in preventing irreversible joint damage and accomplishing good long-term outcomes. Evidence shows that the sooner an accurate diagnosis is made and suitable medication is taken, the better results are probably going to be. In spite of the significance of early diagnosis, delays in diagnosis and referral for JIA are common³⁷. In the current study result, more than half of the children displayed time from symptom onset to diagnosis was longer than six months. This could be due to lack of parents' awareness about JRA and more than half of the children live in rural area and need to travel great distances to access pediatric rheumatologists; alternatively, children are overseen by other specialists who are not ideally prepared to convey best-practice care for JRA and this leads to delays in diagnosis. This finding is in agreement with survey conducted by **Arthritis Queensland (2012)**³⁸ who showed that the time from symptom onset to diagnosis for 41% children was longer than six months.

Concerning children's knowledge regarding JRA, the result of present study revealed that there was a highly statistical significant improvement in the level of knowledge scores. Whereas, nearly three quarters of them had satisfactory knowledge immediately post-program compared to less than one quarter pre-program. From the researcher's perspectives, this could be ascribed to the effectiveness of the program in increasing the ability of children to comprehend and gain knowledge easily. Also, the children show more interest and good readiness for learning about JRA. The result of present study was in harmony with the study done by **Gurjar et al., (2018)**³⁹ who assessed the Effectiveness of supportive educational intervention on knowledge, self-care behavior, disease activity and health status among arthritis patients and showed that there was a highly statistical significant difference in the mean pretest and post test scores of knowledge among arthritis patients (p-value <0.001).

Correspondingly, this finding was in agreement with **Breedland et al.,(2011)**⁴⁰ who studied the Effects of a group-based exercise and educational program on physical performance and disease self-management in rheumatoid arthritis and found that most of children showed statistical significant improvement of knowledge regarding JRA after implementing of the educational program(p<0.001). Similarly, the present result was consistent with **Stinson et al., (2010)**⁴¹who conducted a study about; An internet-based self-management program with telephone support for adolescents with arthritis which revealed higher levels of disease knowledge among adolescents after the program implementation.

On assessing self-management behaviors for children with juvenile rheumatoid arthritis, the present finding demonstrated that majority and nearly three quarters of children had never done activities before program implementation regarding (drug management, regular follow up, exercise regimens and healthy diet). This could be duo to the fact that all of children not attend any intervention program related to JRA and more than three quarters of them had unsatisfactory level of knowledge pre-program. This finding was congruent with **Seyam et al., (2018)**⁴² who assessed health needs and self-efficacy for rheumatoid arthritis patients and revealed that most of patients have educational needs, especially in areas of disease follow up, medications and diet. Furthermore, **Poh et al., (2015)**⁴³ mentioned that patients have inadequate information in these areas. Besides, this result coincided with **Zuidema et al., (2015)**²⁷ who showed that rheumatoid arthritis patients have informational needs for various topics as exercise and medication.

In any case, the present study finding was in the same context with **Smolen et al., (2014)**⁴⁴ who conducted study about; Recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying anti rheumatic drugs and pointed out to the fact that the management of rheumatoid arthritis for children must adjust more than 90% of self-care behaviors particularly exercise and drug management which was performed less than the ideal.

Following three months of the program implementation, there was a highly statistical significant improvement of self-management behaviors which clarified that less than two thirds of children had good level. This could be due to the capability of the management program to increase children's knowledge of the necessity of self-care behaviors modification to achieve a healthy lifestyle. This finding was consistent with **Gurjar et al., (2018)**³⁹ who found that 65% of patients in the posttest had good level of self-care behavior, and there was a highly statistical significant difference (p<0.001). In this respect, **Polluste et al., (2014)**³³ added that the patient education regarding JRA is very important to perform self-care behaviors effectively particularly medication management. This result was in compatible with **Conn et al., (2013)**⁴⁵ who assessed the effect of arthritis self-management program on outcome in African Americans with rheumatoid arthritis and pointed out that more than half of the children used self-care behaviors especially massage therapy and healthy diet post-program implementation to decrease the problems associated with rheumatoid arthritis and to improve health status.

On investigating children's quality of life, the present study finding indicated that all the dimensions of quality of life mean scores were lower pre-program implementation. This could be due to lack of management

programs that play a significant role in enhancing QoL. The present result was in the same line with **Kwon et al., (2015)**⁴⁶ who assessed relation between functional ability and health-related quality of life of children with juvenile rheumatoid arthritis and found that health-related quality of life scores were significantly lower in the JRA group than in the control group (68.39 versus 85.17, $p < 0.001$). Meanwhile, the present finding was similar with **Malm et al., (2017)**⁴⁷ who assessed quality of life in patients with established rheumatoid arthritis and reported a reduction of all QoL dimensions.

On the other hand, the current study result reflected that there was a highly statistical significant increase in the total quality of life means scores after 3 months of the program implementation. This could be due to the fact that the improvement of self-management behaviors had the potential ability to make the children adapt and cope with the effects of the disease which reflected upon improving QoL. This finding was in accordance with **Pilevar et al., (2019)**⁴⁸ who studied the effect of implementing family-centered empowerment model on the quality of life in school-age children diagnosed with rheumatoid arthritis and found that the total QOL scores were significant increase in the test group post intervention compared to the pre-intervention scores ($p < 0.001$). Likewise, **Małgorzata et al., (2016)**⁴⁹ who investigated health-related quality of life in children with rheumatic arthritis; child's and parent's point of view and revealed that all quality of life domains was statistical significant improved after intervention implementation ($p < 0.05$). Additionally, the present finding was in correspondence with **Békési et al., (2011)**⁵⁰ who evaluated health-related quality of life changes of children and adolescents with chronic disease after participation in therapeutic recreation camping program and showed significant improvement of all QoL dimensions in children and adolescents living with JRA after the therapeutic recreation camping program ($p < 0.001$).

Interestingly, the present finding revealed that, there was a highly statistical significant improvement in the total self-efficacy mean scores among children after 3 months post-program compared to pre-program. This result could be referred to the effectiveness of management program for enhancing self-efficacy in children with JRA. This finding was in accordance with **Sedghi-Goyaghaj et al., (2019)**⁵¹ who evaluated the effect of self-care program training on self-efficacy in veteran with spinal cord injury and revealed that self-care program training is effective in increasing self-efficacy mean scores. Nonetheless, this finding was in agreement with **Marks, (2014)**⁵² who studied Self-efficacy and arthritis disability: An updated synthesis of the evidence base and its relevance to optimal patient care and confirmed that the training courses could enhance the self-efficacy and subsequently, self-care skills.

Self-efficacy is important for effective disease management. Research has demonstrated that self-efficacy predicts adherence, health behavior, and disease management which are relied upon to be significant for quality of life⁵³. Concerning the correlation between total self-efficacy with total quality of life among studied children with juvenile rheumatoid arthritis, the current study finding indicated that there was a highly statistical significant positive correlation pre and after 3 months post-program. This might be due to the fact that self-management program help children gain a satisfactory level of knowledge, modify their self-behaviors as well as increase their self-efficacy which subsequently has a positive impact on improving the quality of life. The present finding parallels with **Cramm et al., (2013)**⁵⁴ who investigated the importance of general self-efficacy on quality of life outcomes over time among adolescents with type I diabetes or juvenile rheumatoid arthritis and revealed that there was a highly statistical significant positive correlation between total self-efficacy and total quality of life ($p \leq 0.001$).

Importantly, the present study finding revealed that there was a highly statistical significant positive correlation between total self-management behaviors and total quality of life pre and after 3 months post-program. This implies that higher self-management behaviors lead to higher children's quality of life. The present finding goes in line with **Nadrian et al., (2011)**⁵⁵ who assessed the relationship between quality of life, health status and self-care behaviors in patients with rheumatoid arthritis in Yazd and showed that there was a significant positive correlation between total quality of life and total self-care behaviors of RA patients ($p < 0.01$).

IV. Conclusion

Based on the results of the present study, it can be concluded that, the self-management program was an eminently effective technique to improve children' self-management behaviors, self-efficacy and quality of life. Hence, these results support the proposed hypotheses.

V. Recommendation

In view of the findings of the present study, the following recommendations can be suggested:

1. Encourage continuous self-management program for children experiencing juvenile rheumatoid arthritis to improve quality of life, self-efficacy and thus reduce negative consequences of the disease.
2. Encourage children to adopt correct and proper self-care behaviors which contribute to successful management of the disease.

3. Disseminate a simplified illustrated Arabic booklet about juvenile rheumatoid arthritis to increase children and parent's awareness for healthy life.
4. Inform parents that early diagnosis, timely referral to proper hospital is most important for better long term outcomes.
5. Recommend replication of the current study on larger probability sample in different setting to achieve wider utilization of the program.

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References

- [1]. **Cramm JM, Strating MMH, Sonneveld HM, Nieboer AP. (2013):**The longitudinal relationship between satisfaction with transitional care and social and emotional quality of life among chronically ill adolescents. *Applied Research Quality of Life*; 8:481–91. doi:10.1007/s11482-012-9209-3.
- [2]. **Hakim A, Clunie GP, and Haq I.(2011):** Oxford handbook of rheumatology, 3rd ed., Oxford University Press, Oxford, UK, p. 1321.
- [3]. **Giancane G, Consolaro A, Lanni S, Davi S, and Schiappapietra B. (2016) :** Juvenile idiopathic arthritis: Diagnosis and treatment. *Rheumatology Therapy*; 3:187-207.
- [4]. **Gowdie PJ, and Tse S. (2012):** Juvenile Idiopathic Arthritis. *Pediatric Clinics of North America*; 59: 301-327. <https://doi.org/10.1016/j.pcl.2012.03.014>.
- [5]. **Prakken B, Albani S, and Martini A. (2011):** Juvenile Idiopathic Arthritis. *The Lancet*; 377: 2138-2149. [https://doi.org/10.1016/S0140-6736\(11\)60244-4](https://doi.org/10.1016/S0140-6736(11)60244-4).
- [6]. **Eisenstein EM, and Berkun Y. (2014):** Diagnosis and Classification of Juvenile Idiopathic Arthritis. *Journal of Autoimmunity*; 48: 31-33. <https://doi.org/10.1016/j.jaut.2014.01.009>.
- [7]. **Australian Institute of Health and Welfare. (2008):** Juvenile arthritis in Australia. Canberra: Australian Institute of Health and Welfare; Arthritis Series Number 7. [Google Scholar].
- [8]. **Thierry S, Fautrel B, Lemelle I, and Guillemain F. (2014):** Prevalence and incidence of juvenile idiopathic arthritis: A systematic review. *Joint Bone Spine*; 81: 112-7.
- [9]. **Abdwani R, Abdalla E, Al Arawi S, and Al-Zakwani I. (2015):** Epidemiology of Juvenile Idiopathic Arthritis in Oman. *Pediatric Rheumatology*; 13: 33. <https://doi.org/10.1186/s12969-015-0030-z>
- [10]. **Malek A, Aghighi Y, Parvisy B, Reza Raeeskarami S, and Ziaee V. (2014):** Epidemiologic investigation of juvenile rheumatoid arthritis: a ten-year study. *Tehran University Medicine Journal*; 72(3):187-93.
- [11]. **Consolaro A, Negro G, and Lanni S. (2012):** Toward a treat-to-target approach in the management of juvenile idiopathic arthritis. *Clinical Exp Rheumatology*; 30(4 Suppl 73):157–162. [PubMed]
- [12]. **Moorthy LN, Peterson MG, Hassett AL, and Lehman TJ (2010):** Burden of childhood onset arthritis. *Pediatric Rheumatology Online Journal*; 8:20.
- [13]. **Tong A, Jones J, and Craig JC, (2012):** Children’s experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. *Arthritis Care Res (Hoboken)*; 64:1392–1404.
- [14]. **Mendelson A, Rabinowicz N, Reis Y, Amarilvo G, Harel L, Hashkes PJ and Uziel Y. (2017):** Comics as an educational tool for children with juvenile idiopathic arthritis. *Journal of pediatric rheumatology*; 15(1):69.
- [15]. **Hockenberry MJ, and Wilson D. (2018):** Wong's nursing care of infants and children-E-book, 1st ed., Elsevier Health Sciences, Philadelphia, P. 907-8.
- [16]. **Lindsay S, and Kingsnorth S. (2013):** A systematic review of self-management interventions for children and youth with physical disabilities and rehabilitation early online; 1:13. DOI: 10.3109/09638288.2013.785605
- [17]. **Alleyne G, Hancock C, and Hughes P. (2011):** Chronic and non-communicable diseases: a critical challenge for nurses globally. *International Nursing Review*; 58(3): 328–331. Doi:10.1111/j. 1466-7657.2011.00912.x.
- [18]. **Elissen A, Nolte E, Knai C, Brunn M, Chevreur K, Conklin A, Durand-Zaleski I, Eler A, Flamm M, Frolich A, Fullerton B, Jacobsen R, Saz-Parkinson Z, Sarria-Santamera A, Sonnichsen A, and Vrijhoef H. (2013) :** Is Europe putting theory into practice? A qualitative study of the level of self-management support in chronic care management approaches. *Biomedical Central Health Services Research*; 13(1): 117. doi:10.1186/1472-6963-13-117.
- [19]. **Bandura A. (2009):** Cultivate self-efficacy for personal and organizational effectiveness, *Handbook of principles of organization behavior*, 2nd ed., Wiley Company, New York. P. 143–164. [Google Scholar]
- [20]. **Olaosebikan BH, Akintayo RO, Animashaun BA, and Adelowo OO. (2017):** Juvenile Idiopathic Arthritis in a New Rheumatology Clinic in Nigeria. *Journal of Advanced Rheumatology Science*; 1(1):1-7.
- [21]. **Abo-El-Soud AMA, El-Najjar AR, and El-Shahawy EE. (2013):** Prevalence of Juvenile Idiopathic Arthritis in Sharkia Governorate, Egypt: Epidemiological Study. *Rheumatology International*; 33, 2315: 2322. <https://doi.org/10.1007/s00296-013-2707-2>.
- [22]. **Vanoni F, Suris JC, and von Scheven-Gête A. (2016):** The difference of disease perception by juvenile idiopathic arthritis patients and their parents: analysis of the JAMAR questionnaire. *Pediatric Rheumatology Online Journal*; 14:2.
- [23]. **Kendall E, Ehrlich C, Sunderland N, Muenchberger H, and Rushton C. (2011):** Self-managing versus self-management: Reinvigorating the socio-political dimensions of self-management. *Chronic Illness*; 7(1): 87–98. doi:10.1177/1742395310380281.
- [24]. **Jonsdotir H. (2013):** Self-management programs for people living with chronic obstructive pulmonary disease: a call for a reconceptualization. *Journal of Clinical Nursing*; 22(5–6): 621–637. doi:10.1111/jocn.12100.
- [25]. **Kyle T, and Carman S. (2013):** Essentials of pediatric nursing, growth and development of newborn and infant, 2nd ed., Lippincott Williams & wilkins company, China, pp. 71- 88.
- [26]. **Kjeken I, Dagfinrud H, Heiberg T, and Kvien TK . (2015):** Multidisciplinary approach to rheumatoid arthritis. In: Weisman MH, editor. *Rheumatology*. 6th ed. Philadelphia, Content Repository Only, p. 809–14.

- [27]. **Zuidema RM, Repping-Wuts H, Evers AWM, Van Gaal, BGI, and Van Achtenberg T. (2015):** What do we know about rheumatoid arthritis patients' support needs for self- management? A scoping review. *International Journal of Nursing Studies*; 52(10):1617-1624.
- [28]. **Nadrian H, Morowati sharifabad MA, and Bahmanpour K. (2011):** Development of rheumatoid arthritis education program using the PRECEDE_PROCEED model. *Health Promotion Perspectives*; 1(2): 118-129.
- [29]. **Varni J, Seid M, and Kurtin P. (2001):** PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*; 39(8):800-812.
- [30]. **Barlow JH, Shaw KL, and Wright CC. (2001):** Development and preliminary validation of a Children's Arthritis Self-Efficacy Scale. (*Arthritis Rheumatism*) *Arthritis Care Res*; 45:159-66.
- [31]. **Drus B, Zhao L, and von Esenwein S. (2010):** The health recovery peer (HARP) program for persons with serious mental illness. *Schizophrenia Research*; 118:264-70.
- [32]. **Du S, and Yuan C. (2010):** Evaluation of patient self-management outcomes in health care: a systematic review. *International Nurses Review*; 57: 159-67.
- [33]. **Polluste K, Kallikorm R, and Lember M. (2014):** Level of knowledge and sources of information about the rheumatoid arthritis in Estonian patients. *Rheumatology International*; 34:675-81.
- [34]. **Ellis JA, and Munro JE. (2010):** Possible environmental determinants of juvenile idiopathic arthritis. *Rheumatology*; 49: 411-425.
- [35]. **Abu AL-Fadl EM, Ismail MA, Thabit M, and El-Serogy Y. (2014):** Assessment of health-related quality of life, anxiety and depression in patients with early rheumatoid arthritis. *The Egyptian Rheumatologist*; 36(2):51-56.
- [36]. **Malievskiy VA. (2011):** Prevalence and incidence of juvenile idiopathic arthritis in children in the republic of Bashkortostan: The epidemiological study. *Pediatric Rheumatology*; 9(Suppl 1):145.
- [37]. **Foster H, and Rapley T. (2010):** Juvenile idiopathic arthritis: improved outcome requires improved access to care. *Rheumatology*; 49: 401-403
- [38]. **Arthritis Queensland, (2012):** Stakeholder surveys: Report of survey findings to inform action planning for juvenile idiopathic arthritis in Queensland.
- [39]. **Gurjar NR, Thomas KT, and Tiwari M. (2018):** Effectiveness of supportive educational intervention on knowledge, self-care behavior, disease activity and health status among arthritis patients. *International Journal of Research in Orthopaedics*; 4(5):771-777.
- [40]. **Breedland I, Van Scheppingen C, and Leijmsa M. (2011):** Effects of a group-based exercise and educational program on physical performance and disease self-management in rheumatoid arthritis: a randomized controlled study. *Physical Therapy*; 91:879-93.
- [41]. **Stinson J, McGrath P, and Hodnett E. (2010):** An internet-based self-management program with telephone support for adolescents with arthritis: a pilot randomized controlled trial. *Journal of Rheumatology*; 37:1944-52.
- [42]. **Seyam MH, Sobeh DE, and Qalawa SA. (2018):** Health needs and self-efficacy for rheumatoid arthritis patients. *Port Said Scientific Journal of Nursing*; 5(2):44-62.
- [43]. **Poh LW, He HG, Lee CSC, Cheung PP, and Chan W. (2015):** An integrative review of experiences of patients with rheumatoid arthritis. *International Nursing Review*; 62(2): 231-247.
- [44]. **Smolen JS, Landewé R, and Breedveld, FC, (2014):** EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying ant rheumatic drugs: update. *Ann Rheum Dis* 2014; 73:492-509.
- [45]. **Conn DL, Pan Y, Easley K A, Comeau D L, Carlone J P, Culler S D, and Tiliakos A.(2013):** The effect of the Arthritis Self-Management Program on outcome in African Americans with rheumatoid arthritis served by a public hospital. *Clinical Rheumatology*; 32(1):49-59 <http://dx.doi.org/10.1007/s10067-012-2090-5>.
- [46]. **Kwon HJ, Kim YL, and Lee SM. (2015):** Relation between functional ability and health-related quality of life of children with juvenile rheumatoid arthritis. *Journal Physical Therapy Scientific*; 27:837-840.
- [47]. **Malm K, Bergman S, Andersson M, Bremander A, and Larsson I. (2017):** Quality of life in patients with established rheumatoid arthritis: a phenomenographic study. *SAGE Open Med*; 5:1-8.
- [48]. **Pilevar N, Ramezani M, Malek A, and Vashani HB. (2019):** Effect of Implementing Family-centered Empowerment Model on the Quality of Life in School-age Children Diagnosed with Rheumatoid Arthritis. *Evidence Based Care Journal*; 9 (2): 65-73.
- [49]. **Malgorzata M, Lidia R, Sak, Filip R. (2016):** Health-related quality of life in children with juvenile idiopathic arthritis – child's and parent's point of view; 54(5): 243-250.
- [50]. **Békési A, Török S, and Kökönyei G. (2011):** Health-related quality of life changes of children and adolescents with chronic disease after participation in therapeutic recreation camping program. *Health Quality of Life Outcomes*; 9:43.
- [51]. **Sedghi Goyaghaj N, Pishgooe AH, Aliyari S, Zareiyani A. (2019):** The Effect of Self-Care Program Training on Self-Efficacy in Veteran with Spinal Cord Injury: A Randomized Clinical Trial Study, *Arch Neurosci*. Online ahead of Print; 6(3):e89001. doi: [10.5812/ans.89001](https://doi.org/10.5812/ans.89001).
- [52]. **Marks R. (2014):** Self-efficacy and arthritis disability: An updated synthesis of the evidence base and its relevance to optimal patient care. *Health Psychology Open*; 23:1-18. [PMC free article] [PubMed] [Google Scholar]
- [53]. **Luszczynska A, Cao D S, Mallach N, Pietron K, Mazurkiewicz M, Schwarzer R.(2010):** Intentions, planning, and self-efficacy predict physical activity in Chinese and polish adolescents: two moderated mediation analyses. *International Journal Clinical Health Psychology*; 10(2):265-78.
- [54]. **Cramm JM, Strating MM, and Nieboer AP. (2013):** The importance of general self-efficacy on quality of life outcomes over time among adolescents with type I diabetes or juvenile rheumatoid arthritis. *Frontiers in pediatrics*; (40):1-8.
- [55]. **Nadrian H, Morova Sharifabad MA, Mirzaei A, Bahmanpur K, Moradzadeh R, and Shariati AM.(2011):** Relationship between quality of life, health status and self-care behaviors in patients with rheumatoid arthritis in Yazd. *Journal Ilam University Medicine Scientist*; 19:15-25.[Google Scholar]

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