

Effect of an Intervention Program on Maternal Knowledge about Juvenile Idiopathic Arthritis and Its Management

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Abstract

Background: Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in children. The course of JIA is chronic and relapsing-remitting with a complex treatment regimen. Mothers as the primary caregivers need regular review and ongoing information about the disease and its management.

The aim of the study: this study aimed to evaluate the effect of an intervention program on maternal knowledge about JIA.

Subjects and methods:

Research Design:

A quasi-experimental design (pre-posttest study) was used to conduct this study.

Settings:

The study was carried out at the Pediatric Rheumatology and Immunology Unit at Zagazig University Hospital and Al Harar Hospital (Outpatient Clinics).

Subjects:

The subjects of this study were 52 mothers and their children with JIA.

Tool of data collection:

A structured interview questionnaire was developed by the researchers and consisted of two main parts; **Part I:** Characteristics of the studied mothers and their children. **Part II:** Mother's knowledge about JIA.

Results: The total mean scores of knowledge and its domains (knowledge about JIA, complication, treatment, and care) were significantly improved in the post-intervention phase in comparison with the pre-intervention phase.

Conclusion: it can be concluded that the intervention program improved maternal knowledge about juvenile idiopathic arthritis.

Recommendations: Continuous educational programs should be conducted for children with JIA and their parents to provide them with essential knowledge about the disease, its treatment regimen, and care practices. Suitable booklets, brochures, posters, and health educational materials about JIA and its management should be available at the rheumatology unit for children with JIA in different age groups and their parents.

Key words: Juvenile idiopathic arthritis, Maternal Knowledge, intervention program, children, management

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Introduction

Juvenile idiopathic arthritis (JIA) is the most common type of arthritis in children and adolescents and can cause joint damage, chronic pain, and disability (Martini et al., 2022). It is a heterogeneous group of inflammatory conditions characterized by arthritis of unknown origin occurring in children and adolescents before the age of 16 years and persisting for more than 6 weeks (Prakken et al., 2011). JIA affects more than 2 million patients worldwide, with a prevalence of 16–50 cases per 100,000 individuals (Simon et al., 2020), with the condition being more prevalent among girls than boys (Thierry et al., 2014).

JIA types are autoimmune inflammatory diseases that can cause inflammation and/or pain in one or more joints, mainly in the hands, knees, ankles, elbows, and wrists, but may also affect other body parts (Martini et al., 2022). JIA affects the child's physical and psychological well-being, health-related quality of life, and social-educational attainments (Costello et al., 2019).

Persistent joint inflammation can lead to short or longer-term destruction of the joint, including cartilage loss and bony erosions. Among the other complications are osteopenia/osteoporosis, epiphyseal overgrowth, premature fusion of growth plates, or subluxated/unstable joints. Also, growth retardation, uveitis, blindness, and life-threatening macrophage activation syndrome are common complications that could occur in untreated patients. Thus, JIA treatment should be prompt and effective (Kasapçopur & Barut, 2015; Dağdeviren-Çakır et al., 2016).

The medical management of JIA aims to tamper down disease activity, normalize joint function, and prevent joint damage while attaining an optimum growth velocity (Hayward & Wallace, 2009). The new class of synthetic, targeted therapeutic agents, called biologic agents, transformed the landscape in JIA management (Warrie, 2022). Combination therapy of MTX with biologics is also recommended, for improved treatment efficacy (Klein, 2019).

Medical care and management of JIA requires parental involvement, particularly for young children (Yuwen, et al., 2018). Knowledge of the parents of children with chronic disease is an important determinant of health-related behavior. Education programs play an important role in the management of chronic diseases and represent a good tool for providing knowledge to patients and their parents about their disease. They are effective in many areas ranging from improvement of compliance, changing behavior, and to a lesser extent increase in knowledge (Khawaja et al., 2018).

The nurses play particularly key roles in follow-up monitoring of care and in supporting the specialist teams caring for patients with rheumatic diseases. recognizing poor disease control and the need for changes in treatment, providing a resource for ill children and their parents on treatment options and how to access additional support and advice, and identifying best practices with which to achieve optimal outcomes for patients and their families (Oliver, 2007).

Aim of the study

The current study aimed to evaluate the effect of an intervention program on maternal knowledge about Juvenile Idiopathic Arthritis.

Research hypotheses:

The intervention program improves maternal knowledge about JIA.

Subjects and methods

Research Design

A quasi-experimental design (pre-posttest study) was used to conduct this study.

Settings:

The study was carried out at the Pediatric Rheumatology and Immunology Unit at Zagazig University Hospital and Al Harar Hospital (Outpatient Clinics).

Participants:

The participants of this study were 52 mothers and their children who attended the previous settings and agreed to participate in the study.

The recruited children fulfilled the following criteria:

- Age 1-14 years with a confirmed diagnosis of Juvenile idiopathic arthritis (JIA) according to the criteria of the International League Against Rheumatism (ILAR).
- Children diagnosed with any subtype of JIA (ILAR classification) were included in the study.

Sample size:

The sample size was calculated based on the study carried out by Sunthornsup et al., (2022). Assuming the mean knowledge was 55 ± 10 vs. 70 ± 25 in pre vs. post-intervention respectively. At 80 % power and 95 % confidence level, the estimated sample was 52 cases using the Open Epi software program.

Tools of data collection:

Structured Interview Questionnaire.

It was developed by the researchers after a thorough detailed review of the literature and consisted of two main parts:

Part I: Characteristics of the studied mothers and their children

A: Characteristics of the studied mothers and their children such as mothers' age, educational level, and child's age, sex, and birth order.

B: General life activities such as practicing sports or activities, going to school regularly, whether is there a long distance between the home and the school, and how the child goes to school.

C: Disease profile: Medical history of the disease as the onset of the disease, time of disease diagnosis, other diseased family members, joint replacement surgery, and viral infections.

Part II: Mother's knowledge

This part of the questionnaire covered maternal knowledge about the disease, its complications, treatment, and care and was composed of 27 closed and open-ended questions that dealt with maternal' knowledge. Part II of the questionnaire was used as a pretest and posttest format.

The scoring system:

Each correct response was scored 1 point and zero for the incorrect or I don't know. The total score was (113). The scores of the items were summed up and the total was divided by the number of the items, giving the mean score. These scores were converted into percent scores as follows; satisfactory: if the percentage score was 60% or more with a corresponding score of 67.8 or more and unsatisfactory: if less than 60% with a corresponding score of less than 67.8.

Ethical consideration

Ethical approval for conducting the current study was obtained from the scientific research ethics committee at the Faculty of Nursing, Zagazig University. Informed consent for participation was taken from the studied mothers after a full explanation of the aim and process of the study. The researcher assured maintaining total anonymity and confidentiality of the participants' data and the collected data will be used for research purposes only. Also, mothers' right to withdraw from the study at any phase was assured.

Pilot study

It was carried out on a sample of six mothers and their children to test the applicability, consistency, clarity, and feasibility of the study tools as well as to estimate the exact time required for filling out the tools.

Fieldwork

The fieldwork of the current study went through the following steps:

Data collection took 8 months from January 2023 to the end of August 2023. At the first setting (the Pediatric Rheumatology and Immunology Unit at Zagazig University Hospital) the data was collected from January 2023 to the end of August 2023. The researcher attended the study settings 2 days per week (Tuesday and Wednesday) from 10:00 a.m. to 1:00 p.m.

At the second setting (Al Harar Hospital Outpatient Clinics) the data was collected from March to the end of August 2023. The researcher attended the study settings 3 days per week (Saturday, Sunday, and Monday) from 9:00 a.m. to 12:00 p.m. for data collection and implementation of the program.

The pilot study was done and analyzed after getting official permission. The assessment phase was performed before the implementation of the program by interviewing each mother individually to assess their knowledge about JIA (pretest) by using the structured interview questionnaire **part II** after identifying the mothers and their children who fulfilled the criteria of the study.

The researcher started by introducing herself, explaining the aim and process of the study, and obtaining their informed consent. The average number of interviewed mothers was between 1-2 mothers/day depending on their responses to the interviewer. Each interviewed mother took about 25-30 minutes to fill the questionnaire depending upon their understanding and response.

Assessment Phase:

The Program was constructed based on the educational needs of studied mothers that were derived from the results of the assessment phase. This assessment phase shed light and gave more

insight into deficits in maternal knowledge and helped in identifying their educational needs before the implementation of the program.

Planning Phase:

Based on the results obtained from the pilot study and assessment phase as well as reviewing the related literature, the intervention was planned and designed by the researchers. Detected needs, requirements, and deficiencies were translated into the aim and objectives of the program and set in the form of the web page and booklet that was prepared by the researcher its content was validated by a scientific committee and then planned to be distributed to the mothers to be used as a guide for learning.

The web page and the booklet contained information about the immune system, juvenile idiopathic arthritis, its complications, its treatment (NSAIDs, corticosteroids, and methotrexate), knowledge about eye follow-up, exercises and how to deal with joint pain, how to protect the child from infection, diet, and the role of the family members in helping children coping with their medical conditions.

The web page contains videos and pictures for illustration. The web page was designed to maintain continuity and sustainability of acquiring knowledge and skills related to disease management as well as, improve maternal knowledge about JIA and its management. At the end of each session, the mothers were informed about the web page, its URL, how to enter the web page, and the available information about the session on the web page <https://jia.sharqtech.com/>.

✓ **Teaching methods** were selected to suit teaching in small groups in the form of lectures, group discussions, brainstorming, and web demonstrations of some care practices.

✓ **Teaching materials** such as booklets (handouts), brochures, videos, and colored posters that covered theoretical and practical information were used. Also, the URL of the web page was disseminated to the participant mothers <https://jia.sharqtech.com/>.

✓ **Implementation phase:**

The program was implemented through seven sessions in which the mothers were given the program individually or in groups according to their availability. The length of each session varied according to the content of the session and the maternal's responses and it ranged 45-60 minutes.

Session (1): In this initial session the researcher introduced herself, and clarified the aim of the educational intervention. In this session, the mothers were informed about the web page, its URL, how to enter the page, and the available information about the sessions on the web page. The researcher arranged with mothers the dates of the next sessions based on their circumstances.

Session (2): This session included knowledge about the immune system and its functions, and about JIA, its types, causes, as well as, its signs and symptoms.

Session (3): This session involved providing knowledge about complications of juvenile idiopathic arthritis, diagnostic methods, and the importance of eye follow-up.

Session (4): This session focused on providing information about methods of treating JIA (medical and surgical procedures) types of medication, routes of drug administration, side effects of drugs, and how to deal with these side effects.

Session (5): This session included knowledge about dental care, physical therapy, and its types, how to deal with pain and stress, and how to use splints.

Session (6): This session focused on providing information about methods of protection from infection, a healthy diet for children with JIA, and methods of coping and support at home and school.

Session (7): This session was the termination of the program by summarization of knowledge that was given during the previous sessions. The researcher took feedback from mothers and acknowledged their role in completing this study.

Content validity and reliability

- For validity assurance purposes, tools were developed after a thorough review of the related literature and then submitted to a jury of three experts (one professor of pediatric nursing at the faculty of nursing, Alexandria University, one professor of Community health nursing at the faculty of nursing, and one professor of pediatrics faculty of Medicine at, Zagazig university. The recommended modifications were done and the final forms were ready for use.
- The reliability of tools was done by using Cronbach's Alpha test to measure the internal consistency of the components of tools.
- The reliability of the mothers' knowledge assessment tool (Interview Questionnaire Sheet) was 0.94.

Results:

Table 1 reveals that 51.9% of the studied children were from 7 to 12 years old with a mean age of 8.66 ± 3.56 years. Female children represented 55.8 % of the studied sample. Regarding birth order, 36.5% of studied children were the last child. Primary school represented 61.5% of the studied sample. Regarding characteristics of their mothers, it was observed that about 61.5% of mothers were from 24 to 34 years old with a mean age of 32.67 ± 6.31 years, and 34.6% of them

had completed their secondary education. Furthermore, most of the studied mothers (82.7% and 88.5%) were housewives, and from rural areas respectively.

Table 2 shows that 40.4% of the studied children were diagnosed with juvenile idiopathic arthritis less than one year ago. The highest percentage of studied children (82.7%) had a negative family history of JIA. Meanwhile, 17.3% of the studied children had a positive family history of the disease and 66.7% had an affected uncle. No one of the studied children had joint replacement surgery and only 5.8% had a viral infection that led to juvenile idiopathic arthritis which was Coronavirus (covid 19). Health insurance covered treatment expenses for 90.4% of the studied children.

As observed from Table 3 there was a highly statistically significant improvement in total mean scores of knowledge and its domains (knowledge about JIA, complication, treatment, and care) in the post-intervention phase in comparison with the pre-intervention phase ($P < 0.001$).

The relation between the demographic characteristics of participant mothers and their children and their total satisfactory knowledge score throughout the study phases is clarified in Table 4. This table revealed a statistically significant relation between the child's birth order, the mother's job, and the total satisfactory knowledge score in the pre and post-intervention phases ($P < 0.05$).

Table 5 shows statistically significant relations between positive family history of JIA, the degree of consanguinity, type of treatment support, and the total satisfactory knowledge score of mothers in both phases of the intervention ($P < 0.05$).

Discussion:

There was a significant improvement in mothers' knowledge regarding definition, causes, symptoms, and diagnosis in the post-phase compared to the pre-phase of the intervention. Maternal knowledge about NSAIDS' uses, common side effects, symptoms that required immediate medical care, and how to reduce side effects significantly improved in the post-phase compared to the pre-phase.

These results were in harmony with Jones et al. (2011) who found that There was a substantial improvement of between 22-48% in parental satisfaction in all education-related domains. The greatest improvements were in the disease (38%) and treatment (42%) domains.

In the same context, the decrease in maternal knowledge about JIA in the pre-phase of this study was supported by Pearce et al. (2021) who reported gaps in information areas parents feel are missing from JIA information, lack of awareness before diagnosis.

The low level of maternal knowledge about JIA in the pre-phase may be attributed to that most mothers were from rural areas where there may be a lack of connection facilities that help them to get information about the disease. Also, most cases were recently diagnosed and had no family

history. This led to a lack of maternal knowledge about JIA. additionally, mothers were not provided with sufficient information about the disease in the clinic.

This finding is supported by **Yuwen et al. (2018)** who reported that parents struggled to understand the disease, the cause, the options for treatment, and the impact of the disease on their child's future. Parents felt alone and in the dark. They tried to find resources from the internet, health care providers, friends, and relatives who may know about arthritis or have children with the same diagnosis, but found little available information.

The side effects of systemic glucocorticoids start early in therapy and are essentially unavoidable such as emotional lability, enhanced appetite, weight gain, or both, and insomnia. Enhanced in patients with underlying risk factors or concomitant use of another drug can cause glucocorticoid-related acne, diabetes mellitus, hypertension, and peptic ulcer disease. Delayed and insidious side effects are probably dependent on cumulative doses such as atherosclerosis, cataracts, fatty liver, growth retardation, osteoporosis, and Skin atrophy (**Alan & Alan, 2018**).

In this study, the intervention program significantly improved maternal knowledge about corticosteroids, disease management, and immunization compared to the pre-intervention phase. These results were in harmony with **Sunthornsap et al. (2022)** who conducted a randomized controlled trial about **the Effect of educational brochures compared with video on disease-related knowledge in patients with juvenile idiopathic arthritis** and demonstrated that the mothers had limited knowledge regarding various topics, including immunization, disease relapse management, and steroid usage. There was an improvement in disease-specific knowledge right after intervention.

The results of the current study indicated the effect of the intervention program on maternal knowledge about methotrexate. Nausea, vomiting, and upset stomach were reported as one of the most common side effects of methotrexate by 55.8% and 69.2% of the studied mothers before and after intervention respectively. The differences were statistically significant.

This goes in line with **Mulligan et al. (2013)** who conducted a study about **Mothers' Reports of The Difficulties That Their Children Experience in Taking Methotrexate for Juvenile Idiopathic Arthritis and How These Impact on Quality of Life** and reported that almost a third of children were reported to feel sick (upset stomach) every week after taking MTX and almost a quarter experienced weekly anticipatory nausea. Fifteen percent of children were reported to have vomiting every week after taking MTX.

Non-pharmacological approaches aim mostly at relieving pain, decreasing stiffness, and avoiding pain recurrence. It involves physiotherapy to help prevent malalignment and improve function. cognitive behavioral therapy, physical therapy exercise, and other approaches (massage) were promising therapies for relieving pain and constituted an important part of the treatment as

well as of the multidimensional approach to pain management. Other complementary or alternative treatments such as hot/cold aids, transcutaneous electrical nerve stimulation, natural medicine, and massage have been shown to improve comfort (Ramelet et al., 2014).

In the present study also, about one-fifth of mothers reported that their children practiced fitness exercises to improve heart and lung health in the pre-intervention phase. This percentage significantly raised to 86.5% in the post-intervention phase. Furthermore, joint pain was reported as a cause that prevents the child from exercising by 94.2% and 19.2% of the studied mothers before and after the intervention respectively. The difference was statistically significant. Regarding the application of warm compresses, in the morning on the painful area for a quarter of an hour or washing and showering with hot water, as the heat relaxes and invigorates the muscles' blood circulation was reported by 11.5% and 86.5% of the studied mothers, during pre and post-intervention phases respectively. The difference was statistically significant.

These findings agreed with Khawaja et al.(2018) who reported that the majority of participants recognize the importance of physiotherapy in treating patients with JIA, as well as physiotherapy was believed to reduce the occurrence and severity of deformities, increase the range of movement of joints and strengthen the muscles.

As regards the effect of the intervention program on maternal knowledge about protection from infection and the diet of their children with JIA. Implementation of the intervention program significantly improved maternal knowledge about avoiding live vaccines, as well as, cooking meat and poultry, and washing all foods properly in the post-phase compared to the pre-phase. Furthermore, the substantial role of a healthy diet and calcium in the management of JIA was emphasized by a high percentage of the studied mothers in the post-phase compared to the pre-phase. In the same context, Khawaja et al. (2018) reported that less than half of parents recognized that live attenuated vaccines should not be given to a child while he is on treatment.

Zandonadi (2022) observed that dietary aspects play essential roles in JIA patients' growth, body mass index (BMI), bone mineral density (BMD), inflammation, and recovery. Nutritional deficiency potentially affects JIA patients' general well-being and disease control and contributes to growth, inflammation, BMI, and BMD disturbances. Since nutritional status and nutrients play an important role in regulating immune function.

As regards the total mean scores of knowledge and its domains as reported by participant mothers of children with JIA throughout the study phases. It was observed that there was a highly statistically significant improvement in total mean scores of knowledge and its domains (knowledge about JIA, complication, treatment, and care) in the post-intervention phase in comparison with the pre-intervention phase. These results were in harmony with Sunthornsup et al. (2022) who reported improvement in disease-specific knowledge after intervention.

Also, Jones et al. (2011) reported a substantial improvement of between 22-48% in maternal satisfaction in all education-related domains. These findings supported the results of the present study which revealed that the percentages of mothers who had total satisfactory scores of knowledge and its domains significantly increased during the post-intervention phase in comparison with the pre-intervention phase.

khawaja et al. (2018) explained the good level of parent knowledge about JIA through a booklet that is routinely provided to the parent at the time of diagnosis and during each visit. Also, they were provided with information regarding the child's disease and progress by the treating physician. Teaching parents is time-consuming, and different approaches have been advised to increase parents' knowledge and compliance with education courses and booklet information. 72% of parents considered the treating physician as the absolute source of information and only 28% had other sources of information from books, media, and family members, which emphasizes more on the important role of the treating physician in providing parents with adequate information about the disease. However, one should not ignore the important role of the media (such as TV, books, newspapers...) and the need for specialized nurses to educate the parents given limited clinic time and lack of educational sessions.

Conclusions:

Based upon the findings of the present study, it can be concluded that the intervention program improved maternal knowledge about juvenile idiopathic arthritis.

Based upon the findings of the present study, the following are recommended:

1. Continuous educational programs should be conducted for children with JIA and their parents to provide them with essential knowledge about the disease, its treatment regimen and care practices.
2. Suitable booklets, brochures, posters and health educational materials about JIA and its management should be available at the rheumatology unit for children with JIA at different age groups and their parents.

Table 1: Demographic Characteristics of participant mothers and their children (n=52)

| Sociodemographic data | No. | % |
|-----------------------|-----|------|
| Child age (years) | | |
| 2- | 19 | 36.5 |
| 7-12 | 27 | 51.9 |

| | | |
|---------------------------|-------------|------|
| >12 | 6 | 11.5 |
| Mean± SD | 8.66 ±3.56 | |
| Sex | | |
| Male | 23 | 44.2 |
| Female | 29 | 55.8 |
| Birth order | | |
| First | 15 | 28.8 |
| Middle | 18 | 34.6 |
| Last | 19 | 36.5 |
| Educational Grade | | |
| kg | 11 | 21.2 |
| primary | 32 | 61.5 |
| preparatory | 9 | 17.3 |
| Mother age(years) | | |
| 24 - | 32 | 61.5 |
| 34-44 | 20 | 38.5 |
| Mean± SD | 32.67± 6.31 | |
| Level of education | | |
| Illiterate | 8 | 15.4 |
| Read and write | 14 | 26.9 |
| primary school | 3 | 5.8 |
| Secondary | 18 | 34.6 |
| University | 9 | 17.3 |
| Mother job | | |
| work | 9 | 17.3 |

| | | |
|----------------|----|------|
| house wife | 43 | 82.7 |
| Residence | | |
| Rural | 46 | 88.5 |
| Urban | 6 | 11.5 |
| Crowding index | | |
| ≤2 | 35 | 67.3 |
| >2 | 17 | 32.7 |

Table 2: Disease history of studied children with juvenile idiopathic arthritis (n=52)

| Disease history | No. | % |
|---|-----|-------|
| Duration of diagnosis | | |
| <1 year | 21 | 40.4 |
| 1- year | 15 | 28.8 |
| 4-8 year | 16 | 30.8 |
| Family history | | |
| Yes | 9 | 17.3 |
| No | 43 | 82.7 |
| If yes, what is the degree of consanguinity (n=9) | | |
| Brothers | 3 | 33.3 |
| Uncles | 6 | 66.7 |
| Type of treatment support | | |
| Insurance | 47 | 90.4 |
| At the country's expense | 5 | 9.6 |
| Doing any joint replacement surgery | | |
| No | 52 | 100.0 |

| | | |
|---|----|-------|
| Having any type of viral or other infection that led to juvenile idiopathic arthritis | | |
| Yes | 3 | 5.8 |
| No | 49 | 94.2 |
| If the answer was yes, what is the type of virus (n=3) | | |
| Corona virus (covid 19) | 3 | 100.0 |

Table 3: Total mean scores of knowledge and its domains as reported by participant mothers of children with juvenile idiopathic arthritis throughout the study phases (n=52).

| Total mean scores | pre | post | W | P-value |
|---------------------|-------------|-------------|--------|---------|
| | Mean± SD | | | |
| Knowledge about JIA | 7.98±5.11 | 19.40±5.39 | -5.539 | 0.001** |
| Complication | 1.65±1.92 | 4.46±2.03 | -4.344 | 0.001** |
| Treatment | 14.42±11.80 | 37.13±11.61 | -5.674 | 0.001** |
| Care | 10.86±5.59 | 21.98±5.14 | -5.570 | 0.001** |
| Total | 34.92±22.92 | 82.98±23.17 | -5.533 | 0.001** |

W: Wilcoxon signed ranks test, **: statistically highly significant (p<0.001)

Table 4: Relation between demographic characteristics of participant mothers and their children and their total satisfactory knowledge score throughout study phases.

| Socio-demographic data | Total satisfactory knowledge score | | | | χ^2 (¹ p-value) | χ^2 (² p-value) |
|------------------------|------------------------------------|-------|---------|------|-------------------------------------|-------------------------------------|
| | Pre =9 | | Post=42 | | | |
| | No. | % | No. | % | | |
| Child age (years) | | | | | | |
| 2- | 0 | 0.0 | 15 | 35.7 | 1.625 (0.444) | 10.078 (0.001**) |
| 7-12 | 9 | 100.0 | 21 | 50.0 | | |
| >12 | 0 | 0.0 | 6 | 14.3 | | |

| | | | | | | |
|-----------------------------|---|-------|----|------|-------------------|---------------------|
| Sex | | | | | | |
| Male | 3 | 33.3 | 18 | 42.9 | FET (0.714) | FET (0.734) |
| Female | 6 | 66.7 | 24 | 57.1 | | |
| Birth order | | | | | | |
| First | 3 | 33.33 | 15 | 35.7 | 6.547 (0.038*) | 21.504 (0.001**) |
| Middle | 0 | 0.0 | 18 | 42.9 | | |
| Last | 6 | 66.7 | 9 | 21.4 | | |
| Grade | | | | | | |
| kg | 0 | 0.0 | 9 | 21.4 | 2.836 (0.242) | 6.802 (0.033*) |
| primary | 9 | 100.0 | 24 | 57.1 | | |
| preparatory | 0 | 0.0 | 9 | 21.4 | | |
| Mother age(years) | | | | | | |
| 24 - | 6 | 66.7 | 27 | 64.3 | FET (0.99) | FET (0.480) |
| 34 - 44 | 3 | 33.3 | 15 | 35.7 | | |
| Level of mother's education | | | | | | |
| Illiterate | 0 | 0.0 | 6 | 14.3 | 5.554 (0.235) | 10.078 (0.039*) |
| Read and write | 0 | 0.0 | 12 | 28.6 | | |
| primary school | 0 | 0.0 | 3 | 7.1 | | |
| Secondary | 6 | 66.7 | 12 | 28.6 | | |
| University | 3 | 33.3 | 9 | 21.4 | | |
| Mother job | | | | | | |
| work | 6 | 66.7 | 3 | 7.1 | FET (0.001**) | FET (0.001**) |
| not work | 3 | 33.3 | 39 | 92.9 | | |
| Residence | | | | | | |
| Rural | 6 | 66.7 | 39 | 92.9 | | |

| | | | | | | |
|----------------|---|-------|----|------|----------------|------------------|
| Urban | 3 | 33.3 | 3 | 7.1 | FET (0.057) | FET (0.001**) |
| Crowding index | | | | | | |
| ≤2 | 9 | 100.0 | 27 | 64.3 | FET (0.467) | FET (0.023*) |
| >2 | 0 | 0.0 | 15 | 35.7 | | |

χ^2 : Chi-square test, FET: Fisher exact test, non-significant($p>0.05$), *: significant($p<0.05$), **: statistically highly significant ($p<0.001$), p^1 : for pre-intervention, p^2 : for post-intervention

Table 5: Relation between disease history of the studied children with juvenile idiopathic arthritis and mothers' total satisfactory knowledge score throughout the study phases.

| Disease history | Total satisfactory knowledge score | | | | χ^2 (¹ p-value) | χ^2 (² p-value) |
|---|------------------------------------|-------|---------|-------|-------------------------------------|-------------------------------------|
| | Pre =9 | | Post=42 | | | |
| | No. | % | No. | % | | |
| Duration of diagnosis | | | | | | |
| <1year | 3 | 33.3 | 18 | 42.9 | 8.880 (0.012*) | 0.679 (0.712) |
| 1- year | 6 | 66.7 | 12 | 28.6 | | |
| 4 -8 year | 0 | 0.0 | 12 | 28.6 | | |
| Positive Family history of JIA | | | | | | |
| Yes | 6 | 66.7 | 3 | 7.1 | FET (0.001**) | FET (0.001**) |
| No | 3 | 33.3 | 39 | 92.9 | | |
| If yes, what is the degree of consanguinity (n=9) | | | | | | |
| Brothers | 0 | 0.0 | 3 | 100.0 | FET (0.012*) | FET (0.012*) |
| Uncles | 6 | 100.0 | 0 | 0.0 | | |
| Type of treatment support | | | | | | |
| Insurance | 6 | 66.7 | 42 | 100.0 | FET (0.031*) | FET (0.001**) |
| Ministerial Decision | 3 | 33.3 | 0 | 0.0 | | |
| Having any type of viral or other infection that led to juvenile idiopathic arthritis | | | | | | |

| | | | | | | |
|-----|---|-------|----|------|------------|------------|
| Yes | 0 | 0.0 | 3 | 7.1 | FET (0.99) | FET (0.99) |
| No | 9 | 100.0 | 39 | 92.9 | | |

χ^2 : Chi-square test, FET: Fisher exact test, non-significant($p>0.05$), *: significant($p<0.05$), **: statistically highly significant ($p<0.001$), p^1 : for pre-intervention, p^2 : for post-intervention

No Conflict of interest.

References:

- [1] Costello R, McDonagh J, Hyrich K L and Humphreys J H (2021): Incidence and Prevalence of Juvenile Idiopathic Arthritis in The United Kingdom, 2000–2018: Results from The Clinical Practice Research Datalink. *Rheumatology*; 61:2548–2554 doi:10.1093/rheumatology/keab714.
- [2] Dağdeviren-Çakır A, Arvas A, Barut K, Gür E and Kasapçopur Ö (2016): Serum Vitamin D Levels during Activation and Remission Periods of Patients with Juvenile Idiopathic Arthritis and Familial Mediterranean Fever. *The Turkish Journal Pediatrics*; 58(1): 125-131.
- [3] Hayward K and Wallace C A (2009): Recent developments in anti-rheumatic drugs in pediatrics: Treatment of juvenile idiopathic arthritis. *Arthritis Research & Therapy*; 11, 216.
- [4] Jones J, Munro J, Williams T, Augustine A , Taylor K, Piper S et al., (2011): To evaluate the impact of a nurse-led JIA education program on parental satisfaction regarding knowledge of JIA and its management. *Pediatric Rheumatology*; 9(Suppl 1): O24
- [5] Kasapçopur Ö and Barut K (2015): Treatment in juvenile rheumatoid arthritis and new treatment options. *Turkish Archives of Pediatrics*; 50(1):1-10. doi: 10.5152/tpa.2015.2229.
- [6] Khawaja ES, Zletni MA, Abushhawia AM, Elmagrabi ZS, Sabei LT (2018): Parental knowledge and participation in the management of children with juvenile idiopathic arthritis at rheumatology department tripoli children hospital. *MOJ Orthopedics & Rheumatology*; 10 (3): 338–342.
- [7] Klein A (2019): Biologics in the treatment of juvenile idiopathic arthritis: A comparison of mono- and combination therapy with synthetic DMARDs. *Zeitschrift für Rheumatologie*;78: 599–609.
- [8] Prakken B, Albani S and Martini A (2011): Juvenile Idiopathic Arthritis. *Lancet*; 377(9783): 2138–2149.
- [9] Mulligan K, Kassoumeri L, Etheridge A, Moncrieffe H, Wedderburn L R and Newman S (2013): Mothers' reports of the difficulties that their children experience in taking methotrexate for Juvenile Idiopathic Arthritis and how these impact on quality of life. *Pediatric Rheumatology Online Journal*; 11: 23. doi: 10.1186/1546-0096-11-23.
- [10] Oliver S (2007): Best practice in the treatment of patients with rheumatoid arthritis. *Nursing Standard*; 21(42):47–56.

- [11] Pearce C, Newman S and Mulligan K (2021): Illness Uncertainty in Parents of Children with Juvenile Idiopathic Arthritis. *ACR Open Rheumatology*; 3(4): 250–259. doi: 10.1002/acr2.11238.
- [12] Ramelet A, Fonjallaz B , Rapin J, Gueniat C and Hofer M (2014): Impact of a Telenursing service on satisfaction and health outcomes of children with inflammatory rheumatic diseases and their families: a crossover randomized trial study protocol. *BMC Pediatrics*; 14:151. <http://www.biomedcentral.com/1471-2431/14/151>
- [13] Simon AT, Harikrishnan G P, Kawabata H, Singha S, Brunner H I and Lovell D J (2020): Prevalence of Co-Existing Autoimmune Disease in Juvenile Idiopathic Arthritis: A Cross-Sectional Study. *Pediatric Rheumatology*; 43(18): 1-12. <https://doi.org/10.1186/s12969-020-00426-9>.
- [14] Sunthornsup W , Vilaiyuk S and Soponkanaporn S (2022): Effect of educational brochure compared with video on disease-related knowledge in patients with juvenile idiopathic arthritis: A randomized controlled trial. *Frontiers in Pediatrics*; 10:1048949. doi: 10.3389/fped.2022.1048949.
- [15] Thierry S, Fautrel B, Lemelle I and Guillemin F (2014): Prevalence and Incidence of Juvenile Idiopathic Arthritis: A Systematic Review. *Joint Bone Spine*; 81(2):112–7.
- [16] Warriar K C (2022): A practical guide to using biologics in juvenile idiopathic arthritis. *Paediatric Child Health*; 32: 229–235.
- [17] Yuwen W, Lewis F M, Walker AJ and Teresa M. Ward (2018): Struggling in the Dark to Help My Child: Parents' Experience in Caring for a Young Child with Juvenile Idiopathic Arthritis. *Journal of Pediatric Nursing*; 37: e23–e29. doi: 10.1016/j.pedn.2017.07.007.
- [18] Zandonadi A R (2022): An Overview of Nutritional Aspects in Juvenile Idiopathic Arthritis. *Nutrients*;14(20):4412. doi: 10.3390/nu14204412.