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Effect of Intervention Program on Maternal Participation for Management and Nutritional Status of Children with Juvenile Idiopathic Arthritis

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Abstract

Background: Juvenile idiopathic arthritis (JIA) is a common rheumatic disorder in children with a chronic relapsing-remitting course that affects physical growth and requires frequent adjustment of the treatment regimen. **The study was aimed** to evaluate the effect of an intervention program on maternal participation for the management and the nutritional status of children with JIA. **A quasi-experimental design** was conducted at the Pediatric Rheumatology and Immunology Unit at Zagazig University Hospital and Al Ahrar Hospital on a sample of 52 mothers and their children. **Three tools were used as follows;** a structured interview questionnaire, the maternal participation in the management of their children questionnaire, and the nutritional assessment sheet. **Results:** the total mean scores of maternal participation in the management of their children with JIA and the means of weight, height, and body mass index (BMI) of the studied children were significantly improved after the implementation of the intervention. **(P<0.001). Conclusion:** the intervention program was effective in improving maternal participation in the management of their children with JIA. The study findings also revealed a statistically significant increase in the percentage of healthy-weight children after the implementation of the intervention. **Recommendations:** Providing continuous training, counseling, and support for mothers is essential to maintain their participation in the management of their children with JIA. Moreover, tailored nutritional programs that address the specific needs of children with JIA are needed to maintain normal physical growth and boost immunity.

Keywords: Children, Intervention program, Juvenile idiopathic arthritis, Maternal participation & Management, Nutritional status.

Introduction

The International League of Associations for Rheumatology (ILAR) defines JIA as arthritis of unknown cause, that begins before the age of 16, and persists for more than 6 weeks, after the exclusion of all other possible diagnoses **(Petty et al., 2004)**. Juvenile idiopathic arthritis (JIA) is the most prevalent chronic multifactorial rheumatic disease in children. It is an inflammatory condition characterized by persistent joint inflammation that results in swelling, pain, and limitation of movement (**Dağdeviren-Çakır et al., 2016).** Extra-articular structures; eyes, skin, and internal organs are also affected by JIA leading to disability and even associated fatality **(Zaripova et al., 2021).**

JIA significantly affects the child's life, by impacting their physical and psychological health, quality of life, and social-educational achievements **(Tollisen et al., 2018).** Persistent joint inflammation can result in fatigue, pain, abnormal growth, joint damage, and deformities (**Lunt et al., 2020).**

Untreated inflammatory arthritis can result in short or longer-term joint damage, including cartilage loss and bony erosions. Other complications may include osteopenia/osteoporosis, epiphyseal overgrowth, premature fusion of growth plates (leading to brachydactyly), subluxated/unstable joints (often at wrists or atlantoaxial joints), or eventual fusion/ ankyloses of joints. Involvement of both temporomandibular joints (TMJ) can rapidly destroy the growth center for the mandible, with subsequent micrognathia and retrognathia **(Shenoi, 2017).**

Many non-joint-related complications could develop in untreated patients such as; impaired physical growth, uveitis, blindness, and life-threatening macrophage activation syndrome. Therefore, treatment of JIA should be prompt and effective. But it is important to consider the adverse effects of medications e.g. osteoporosis, growth retardation secondary to glucocorticoids, etc. (**Kasapçopur & Barut, 2015; Dağdeviren-Çakır et al., 2016).**

Poor growth and malnutrition are often associated with JIA and these occur due to systemic inflammation, corticosteroid use, or inadequate nutrition (reduced appetite due to chronic inflammation or from drugs with gastrointestinal side effects like methotrexate). Protein/energy

malnutrition is common in children with JIA and is associated with the severity of the disease **(McErlane et al., 2018).** JIA can cause many short- and long-term health impairments during childhood and early adulthood **(Abdelaleem et al., 2021),** with nearly half of the affected children continuing to have active joint disease into adulthood **(Knafl et al., 2015)**.

As in all rheumatic disorders treatment of JIA necessitates a collaborative approach. The treatment team should include a pediatric rheumatologist, physiotherapist, ophthalmologist, orthopedic specialist, pediatric psychiatrist, and the patient's family. The primary medical goals are to relieve pain, reduce disease activity, and restore the limited range of motion **(Kasapçopur & Barut, 2015).**

Mothers often take on the primary caregiver role, responsible for monitoring, preparing, and administering treatments **(Venter, 2011).** They share many of their child's illness experiences and frequently undergo similar continuous adjustments required for managing a chronic condition. After dealing with their child's initial symptoms and diagnosis, many mothers develop the skills and knowledge needed to manage chronic symptoms and flare-ups, such as administering medication and supervising exercises **(Mulligan et al., 2013)**. They also adapt interventions based on the illness stage and balance the needs of other family members **(Knafl et al., 2015; Waite-Jones et al., 2020).**

Mothers tend to perceive the experience of living with childhood chronic conditions differently. Nurses often focus on the illness and the technical skills required to manage the illness. They tend to dwell on deficits and negative aspects of the situation. While knowledge of potential problems a caregiver may encounter is useful, nurses must realize that each family's experience with chronic conditions is unique **(Potts & Mandleco, 2012).**

Parents of chronically ill children can often feel helpless, vulnerable, and unqualified due to the complexity of their child's illness. In such situations, staying informed and advocating for their child may be the only actions within their control. For that reason, they need education and training to enhance their ability and performance **(Iowa State University, News Service, 2017).**

Significance of the study

Parenting a child with JIA involves many challenges, such as managing the child's pain, distress, and physical limitations; handling medications and frequent hospital visits; addressing the impact on schooling; dealing with financial issues like taking time off work; and coping with uncertainty about the future. Additionally, in some healthcare systems, medication costs can be significant **(Mulligan et al., 2022).**

Medical care and management of JIA often requires active parental involvement, especially for younger children. Parents commonly experience confusion, emotional distress, guilt, anxiety, anger, frustration, and fear. The demands of caregiving can interfere with various aspects of family life, and many parents feel a lack of social support **(Knafl et al., 2015).**

Parents' knowledge about their child's chronic disease significantly influences health-related behaviors. Educational programs are crucial in managing chronic diseases, providing valuable information to patients and their parents. These programs are effective in improving compliance, changing behaviors, and to a lesser extent, increasing knowledge **(Khawaja et al., 2018).**

Aim of the study

This study was aimed to evaluate the effect of an intervention program on maternal participation for the management and the nutritional status of children with JIA.

Research hypotheses:

H1: Maternal participation for the management of their children with JIA is expected to be improved after the implementation of the intervention program

H2: The nutritional status of children with Juvenile Idiopathic Arthritis is expected to be improved after implementation of the intervention program.

Subjects and Method

Research design

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

Setting

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

Subjects

A purposive sample of 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 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

Three tools were used for data collection as follows;

Tool I: Structured Interview Questionnaire

It was developed by the researchers and consisted of two main parts:

Part 1: Characteristics of the studied mothers and their children including; mothers' age, educational level, and child's age, sex, and birth order.

Part 2: 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**.**

Tool II: The Maternal Participation in The Management of Their Children Illness Questionnaire (MPMCIQ):

It was developed by the researchers, guided by Arthritis Self-Efficacy Scales **(Lorig K & Holman H, 1998)** and The Pediatric Rating of Chronic Illness Self-Efficacy (PRCISE) (**Emerson et al., 2018)** to evaluate the maternal participation in various aspects of child care and was used as (a pretest and posttest format). It consisted of six subscales that assess maternal management of their children's pain, symptoms, disease, and exercise, as well as maternal ability to get help from family, friends, and doctors and maternal ability to control their mood.

The scoring system:

The maternal participation in the management of their children's illness questionnaire includes 17 items, which are rated on a 5-point Likert scale: (1) very uncertain, (2) somewhat uncertain, (3) uncertain, (4) certain, and (5) very certain, with higher scores indicating higher participation in the management.

Tool III: Nutritional Assessment Sheet

It was developed by the researchers and consisted of the following parts:

Part 1: Physical Growth Assessment:

It included data such as; the child's birth date, date of visit, child's weight and height as well as the presence of edema.

Physical growth was assessed by measuring weight and length/height then the measurements were entered into the WHO Anthroplus software **(WHO, 2009).** The WHO Anthroplus enabled the researcher to drive nutritional status information, expressed in z-scores and percentiles, using the WHO standards for preschool children and WHO reference for older children for the following indicators; length/height for age, weight for age, and BMI for age.

Physical growth assessment was done through the following steps: -

1- Measuring the weight (by the electronic scale) and height/recumbent length (by the measuring tape) of the studied children. Recumbent length was measured in children less than 24 months and in those who are too weak to stand. Standing height was measured for children older than 24 months of age and for children who could stand up or were willing to stand.
2- Data entry: the required variables were the child's birth date, date of visit, age, weight, edema status (yes/no), and length/height (recumbent or standing).
3- Edema: it always indicates if the child has edema or not.
4- The nutritional status was derived in terms of weight-for-age, height-for-age, and BMI-for-age

The scoring system:

Percentiles specific to age and sex were used to classify BMI as follows:

BMI-for-age categories	corresponding percentiles
Underweight	< 5th percentile
Healthy weight	5th percentile to the 85th percentile
Overweight	85th to ≤ 95th percentile
Obesity	> 95 th percentile

The nutritional status was classified as follows:

- Stunting – height-for-age ≤-2 SD of the WHO Child growth standards median.
- Wasting – weight-for-height ≤-2 SD of the WHO Child growth standards median. **(WHO, 2024)**

Part 2: Clinical Assessment of Nutritional Status Checklist

It was developed by the researchers and guided by **Hockenberry & Wilson's (2015)** clinical assessment of nutritional status to assess signs of possible nutritional deficiency. It included clinical examination of skin, hair, head, neck, eyes, teeth, gums, lips, tongue, and eyes … etc. by inspection. This tool was used as a pretest and posttest (6 months after implementation of the program) format.

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 needed to complete the tools. Since no modifications were necessary for the data collection tools, the mothers and children who participated in the pilot study were included in the final study sample.

Content validity index (CVI)

CVI was determined to ensure tool validity, by creating the tools, following a comprehensive review of relevant literature, and then submitted to a panel of three experts in the fields of pediatric nursing, pediatrics, and community health nursing. The suggested modifications were made, and the final versions were ready for use.

Reliability of the study tools:

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 maternal participation in the management of their children's illness questionnaire was 0.73
- The reliability of the nutritional assessment tool was 0.79

Ethical considerations

Ethical approval for this study was granted by the scientific research ethics committee at the Faculty of Nursing, Zagazig University. Informed consent was obtained from the participating mothers after thoroughly explaining the study's aim and process. The researcher guaranteed the complete anonymity and confidentiality of the participants data. Additionally, the mothers were assured of their right to withdraw from the study at any phase.

Study framework

The intervention program was executed through four phases as follows:

Assessment Phase:

The program was developed 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 participation in the management of their children with JIA as well as, the nutritional status and physical growth of their children and helped in identifying their educational needs.

Planning Phase:

Drawing from the pilot study results, the assessment phase, and a review of related literature, the researchers planned and designed the intervention. Identified needs, requirements, and deficiencies were translated into the program's aim and objectives, which were then developed into a web page and booklet. The content was validated by a scientific committee and prepared for distribution to the mothers as a learning guide.

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-based was designed to maintain continuity and sustainability of acquiring knowledge and skills related to disease management as well as, improve maternal participation in the management of their children with JIA. 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 be suitable for small groups including lectures, group discussions, brainstorming, and web demonstrations of some care practices.

Teaching materials such as booklets (handouts), brochures, videos, and colored posters were utilized to cover both theoretical and practical information. Also, the URL of the web page was disseminated to the participant mothers https://jia.sharqtech.com/.

Implementation phase:

The program was delivered over seven sessions, with the mothers receiving the program individually or in groups based on their availability. The length of each session varied depending on the content of the session and mothers' responses, ranging from 45 to 60 minutes.

Session (1): In this initial session the researcher introduced herself, and explained 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 definition of immunity, the function of the immune system, and immune system organs. Definition of JIA, types, causes, 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, and methods of coping and support at home and school.

Session (6): This session focused on providing information about methods of protection from infection, healthy diet for children with JIA and foods that should be avoided, as well as important nutrients for children with JIA.

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.

Teaching activities during the sessions:

- At the beginning of each session, the researchers introduced the session title to the studied mothers (two minutes).
- The researchers asked mothers: what they knew about the session's topic.
- The time allowed for brainstorming was three minutes, and then each mother was allowed to list her ideas (five minutes).
- Then the researchers introduced a simple lecture about JIA or its care according to each session topic (30-40 minutes).
- At the end of each session, the researcher summarized what was given in the session and conducted an interactive group discussion to receive the mother's feedback about what was given in the session (ten minutes)
- The researcher used the Arabic language appropriate to the mother's educational level. Motivation and reinforcement were employed during the session to enhance the mothers' learning experience.

Evaluation phase (post-test):

In this phase, maternal participation in the management of their children's illness and the nutritional status of studied children were reassessed after 6 months from the end of the intervention by using **tool II** and by measuring weight and height as well as using nutritional status chick list respectively.

Fieldwork

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

Data collection took 10 months from the beginning of January to the end of October 2023. The researcher attended the study settings 5 days per week 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 participation in the management of their children with JIA (pretest) using tool II and the nutritional status and physical growth of children with JIA using tool III after identifying the mothers and their children who met the study criteria (the clinical assessment of nutritional status was performed by the attendant physician).

The researcher began by introducing herself, explaining the study's aim and process, and obtaining informed consent. On average, 1-2 mothers were interviewed per day, depending on their responses. Each interview took about 10-15 minutes to complete the questionnaire, depending on the mothers' understanding and responses.

Statistical analysis

All data were gathered, organized, and statistically evaluated using SPSS 20.0 for Windows (SPSS Inc., Chicago, IL, USA 2011). Quantitative data were presented as mean ± SD and range, while qualitative data were presented as absolute frequencies (number) and relative frequencies (percentage). The McNemar test, Wilcoxon signed ranks test, paired t-test, and Spearman correlation coefficient were employed. A p-value < 0.05 was deemed statistically significant, a p-value < 0.001 was considered highly statistically significant, and a p-value ≥ 0.05 was regarded as statistically non-significant.

Results

Table (1): Precentage distribution of studied mothers and their children according to their demographic characteristics (n=52)

Demographic data	No.	%
Child's 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		
Nursery school	11	21.2
Primary	32	**61.5**
Preparatory	9	17.3
Mother's 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's working condition		
Working	9	17.3
Housewife	43	**82.7**
Residence		
Rural	46	**88.5**
Urban	6	11.5
Crowding index		
≤2	35	**67.3**
>2	17	32.7

Table (2): Percentage distribution of the studied children with JIA according to their medical history (n=52)

Disease history	No.	%
Duration of diagnosis		
<1year	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**

Disease history	No.	%
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 maternal participation in the management of their children and its domains throughout study phases (n=52).

Total mean scores of maternal participation in the management of their children's illness	Pre	post	Paired t-test	P-value
	Mean± SD			
Pain management	8.61±2.59	16.55±2.06	-19.660	0.001**
Symptoms	10.19±3.53	16.48±1.68	-13.701	0.001**
Disease management	4.36±2.11	13.26±2.67	-17.324	0.001**
Exercises	2.01±0.75	3.40±1.17	-7.342	0.001**
Help from family, friends, and doctors	6.34±2.09	15.90±3.24	-17.201	0.001**
The mood	2.11±0.81	3.67±1.02	-8.417	0.001**
Total	33.65±5.42	69.28±5.27	-40.490	0.001**

***: highly statistically significant (p<0.001)*

Table (4): Nutritional status of studied children with juvenile idiopathic arthritis throughout study phases (n=52).

Nutritional status	Pre	Post	W	P-value
	Mean± SD			
Weight in kg	27.30±11.91	28.11±10.22	-3.647	0.001**
Height in cm	123.77 ±17.61	126.95±17.43	-6.321	0.001**
BMI	17.30±5.12	17.04±3.62	-1.412	0.001**
Weight Z-score	-0.066±0.53	0.04±0.67	-0.727	0.467
Height Z-score	-0.34±1.39	-0.54±1.19	-4.214	0.001**
BMI Z-score	-0.76±1.69	-0.32±1.98	-2.841	0.001**
Weight percentile	47.90±17.13	50.83±19.03	-0.830	0.001**
Height percentile	43.17±35.41	37.55±31.93	-4.719	0.001**
BMI percentile	34.60±29.67	47.04±33.27	-2.670	0.001**

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

Table (5): Body mass index scores of studied children with juvenile idiopathic arthritis throughout study phases (n=52).

BMI	Pre		Post		MH p
	No.	%	No.	%	
Underweight	14	26.9	9	17.3	0.001**
Healthy weight	29	55.8	40	76.9	
Obese	9	17.3	3	5.8	

***: statistically highly significant (p<0.001)*

Table (6): Stunting and wasting among studied children with juvenile idiopathic arthritis throughout study phases (n=52).

BMI	Pre		Post		MC p
	No.	%	No.	%	
Stunting					0.250
Stunting	9	17.3	6	11.5	
No stunting	43	82.7	46	88.5	
Wasting					0.500

Wasting	11	21.2	9	17.3	
No wasting	41	78.8	43	82.7	

MC: Mc Nemar Test, statistically non-significant (p>0.05)

Table (7): Signs of malnutrition among the studied children with juvenile idiopathic arthritis throughout study phases (n=52).

Symptoms of malnutrition	Pre		Post		MC p
	No.	%	No.	%	
Skin					
Scaling	20	38.5	19	36.5	0.987
Dermatitis	7	13.5	7	13.5	0.99
Dry or rough	13	25.0	11	21.2	0.890
Petechiae	10	19.2	9	17.3	0.99
Wrinkled skin	16	30.8	13	25.0	0.543
Poor turgor	30	57.7	27	51.9	0.554
Edema	38	73.1	33	63.46	0.062
Pallor	25	48.1	23	44.2	0.876
Hair					
Weak and friable	41	78.8	36	69.2	0.125
Stringy	21	40.4	19	36.5	0.234
Dry	15	28.8	12	23.1	0.456
Alopecia	10	19.2	9	17.3	0.987
Pigmentation	7	13.5	6	11.5	0.897
Head					
Softening of cranial bones	10	19.2	8	15.4	0.567
Prominence of the frontal bones	7	13.5	6	11.5	0.985
The skull is flat and depressed toward the middle	6	11.5	5	9.6	0.996
The presence of hard, tender lumps in occiput	3	5.8	0	0.0	0.999
Neck					
Enlargement of the thyroid gland	6	11.5	2	3.8	0.125
Enlarged lymph nodes	**36**	**69.2**	**15**	**28.84**	0.001**
Eyes					
Eye redness	18	34.6	16	30.8	0.876
Night blindness	0	0.0	0	0.0	---
Eye infections	9	17.3	7	13.5	0.675
Cataracts	0	0.0	0	0.0	----
Ears					
Hearing impairment	0	0.0	0	0.0	---
Nose					
Irritation and cracks at nasal angle	7	13.5	5	9.6	0.234
Mouth					
Fissure and inflammation at corners	24	46.2	20	38.5	0.125
Gums					
Spongy and friable	3	5.8	3	5.8	0.999
Swollen	6	11.5	5	9.6	0.897
Bluish red or black	5	9.6	3	5.8	0.345
Bleeds easily	40	76.9	35	67.3	0.089
Tongue					
Diminished taste sensation	0	0.0	0	0.0	---
Cracks	6	11.5	5	9.6	0.986
Teeth					
Brown mottling	15	28.8	12	23.1	0.234

Symptoms of malnutrition	Pre		Post		MC p
	No.	%	No.	%	
Pits	3	5.8	2	3.8	0.876
Fissures	13	25.0	11	21.2	0.453
Caries	36	69.2	32	61.5	0.123
Chest					
The depressed lower portion of the rib cage	0	0.0	0	0.0	---
A sharp protrusion of the sternum	0	0.0	0	0.0	---
Enlarged costochondral junctions	0	0.0	0	0.0	---
Delayed breast development in adolescent girls	3	5.8	3	5.8	0.999
Abdomen					
Distended	25	48.1	11	21.2	0.001**
Flabby	15	28.8	9	17.3	0.04*
Weak abdominal muscles	12	23.1	7	13.5	0.061
A prominent or large potbelly	21	40.4	10	19.2	0.001**
Musculoskeletal					
General weakness	42	80.8	35	67.3	0.031*
Tremors in the extremities	9	17.3	8	15.4	0.786
Deformities in the back (kyphosis, lordosis, scoliosis)	3	5.8	3	5.8	0.999
Bowing in extremities	2	3.8	2	3.8	0.999
Knock- knees	0	0.0	0	0.0	---
CNS (behavior)					
Irritable	52	100.0	48	92.3	0.124
Anxious	17	32.7	16	30.8	0.876
Lethargic	9	17.3	8	15.4	0.885
Mentally slow	9	17.3	9	17.3	0.999
Confused	0	0.0	0	0.0	---
Mask like facial expression	3	5.8	3	5.8	0.999
Blurred speech	3	5.8	3	5.8	0.999
Involuntary laughing	2	3.8	2	3.8	0.999
Convulsions	6	11.5	6	11.5	0.999
Unsteady gait	36	69.2	35	67.3	0.897

MC: Mcnemar test, non-significant (p>0.05), ***: highly statistically significant (p<0.001)*

Table (8): Correlation between mothers' participation in the management of their children with JIA, and the BMI percentile of the children throughout the study phases.

Pre-phase	BMI percentile		Post-phase	BMI percentile	
	r	p		r	p
Maternal management	0.097	0.492	Maternal management	0.185	0.189

r: correlation coefficient, non-significant(p>0.05), ***: statistically highly significant (p<0.001)*

Table (1): Shows 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. Primary school represented 61.5% of the studied sample. Regarding characteristics of their mothers, it was observed that about 61.5% were aged from 24 to 34 years with a mean age of 32.67± 6.31 years, and 34.6% had completed their secondary education. Furthermore, 82.7% and 88.5% of the studied mothers were housewives, and from rural areas respectively.

Table (2): Reveals that 40.4% of the studied children were diagnosed with juvenile idiopathic arthritis for less than one year. The highest percentage of studied children (82.7%) had a negative family history of JIA. 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.

Table (3): Reflects highly statistically significant improvements in total mean scores of maternal participation in the management of their children with JIA and its domains in the post-intervention phase in

comparison with the pre-intervention phase **(P<0.001).**

As observed from Table (4): The means of weight, height, and BMI of the studied children significantly improved after implementation of the intervention program **(P<0.001).**

Table (5): Shows that the percentage of healthy-weight children increased from 55.8% before the intervention to 76.9% after the intervention. The difference was highly statistically significant **(P<0.001).**

As observed from Table (6): The percentage of stunted and wasted children decreased from 17.3% and 21.2% before the intervention to 11.5% and 17.3% after the intervention respectively. But the difference was not statistically significant **(P>0.05).**

Table (7): Represents a statistically significant decrease in the percentage of children who had signs of malnutrition including enlarged lymph nodes of the neck, distended, flabby, and prominent or large abdomen, and general weakness after implementation of the intervention program **(P<0.05).**

Table (8): Shows no statistically significant correlation between mothers' participation in management and the BMI percentile of their children in both phases of the intervention **(P>0.05).**

Discussion

An educational intervention was planned, designed, and implemented in the current study and its effect on maternal participation in the management of their children with JIA, and the nutritional status of the studied children was assessed.

The total mean scores of maternal participation for management of their children with JIA and its domains significantly improved after the implementation of the educational intervention. The pre-intervention reported maternal feelings of uncertainty in their abilities to care for their children changed to more positive feelings in their abilities to effectively manage children's pain, symptoms, disease, exercises, getting help from family, friends, and doctors, as well as controlling mood after the intervention.

Yuwen et al., (2017) in a study of parents' experiences in caring for 2–5-year-old children with JIA described similar pre-intervention parents' feelings of uncertainty about knowing how to help while witnessing their child suffer and made every effort to manage their child's condition and care. Also, **Currie et al., (2023)** in their research on parent and youth perspectives on managing JIA reported negative parents' feelings about their abilities to do anything while watching their child suffer.

Consistent with the findings of the present study **Pearce et al., (2021)** reported parental uncertainty regarding how to manage the condition medically and uncertainties around how to parent effectively. While initial uncertainties for parents were tied to a shortage of information and comprehension about JIA, acquiring more information did not necessarily alleviate all concerns especially issues related to worries for their child's long-term wellbeing and the need for more support in coping with the emotional challenges posed by JIA.

The improvement in maternal participation in the management of their children with JIA after the educational intervention in the present study and the frequent evidence underscores the importance of providing parent education programs, particularly for those lacking support, to help manage and cope with their children's chronic health issues more successfully **(Sanyod et al., 2021; Kieckhefer et al., 2013; Mawani et al., 2013)**.

As regards to nutritional status of studied children with JIA. It was observed the means of weight, height, and body mass index (BMI) of the studied children were significantly changed after the implementation of the intervention ($p<0.001$). Moreover, the findings of the present study revealed that more than one-quarter of the studied children were underweight, and nearly one-sixth were obese before the intervention these percentages decreased and the percentage of healthy-weight children increased significantly at the end of the study (6 months after implementation of the intervention).

Zare et al., (2023) reported variations in height and weight values among children with JIA in comparison with healthy controls across studies ($p = 0.029$). They also reported suggestive evidence of reduced height and weight in studies on Juvenile Idiopathic Arthritis (JIA). This evidence supports the findings of the present study regarding the significant negative change in the height percentiles and height Z-scores of the studied children throughout the study.

In agreement with the current study **McErlane et al., (2018)** who mentioned a significant decrease in the height z-score from baseline to 3 years ($p \leq 0.0001$) in a prospective study of growth patterns in early juvenile idiopathic arthritis. Moreover, **Grammatikopoulou et al., (2023)** who concluded that height and body mass index (BMI) z-scores are suboptimal in children with JIA.

The results of the current study revealed that slightly more than one-sixth of the studied children were stunted and more than one-fifth were wasted these percentages decreased at the end of the study with no statistically significant difference. The prevalence of short stature in JIA children ranges between 10.4% in children who have polyarticular disease to 41% in those with systemic forms **(d'Angelo et al., 2021)**. **Lofthouse et al., (2002)** in a study to assess the

nutritional status of children with JIA reported a higher percentage of stunted children and a lower percentage of wasted children.

There was no statistically significant correlation between mothers' participation in disease management, and the BMI percentile of their children either before or after the intervention. Because poor growth in JIA is influenced by multiple factors and may be associated with the severity of systemic inflammation, corticosteroid use, nutritional factors; chronic inflammation, or the gastrointestinal side effects of medications like methotrexate that can reduce dietary intake **(Grammatikopoulou et al., 2023; McErlane et al., 2018)**. The degree of growth impairment can differ based on the subtype of JIA and tends to be more pronounced in children with polyarticular and systemic JIA **(Souza et al., 2008)**.

Children with systemic arthritis, uncontrolled disease, or on long-term corticosteroid therapy, face an increased risk of growth impairment **(Guzman et al., 2017)**. Nutritional deficiency can significantly impact overall health, and disease management, and contribute to disturbances in growth, inflammation, BMI, and bone mineral density among JIA patients. Since nutritional status and nutrients play an important role in modulating immune response **(Zandonadi, 2022)**. Children and adolescents with JIA particularly those with polyarthritis, are more susceptible to malnutrition compared to their healthy peers **(Więch et al., 2018)**. Protein/energy malnutrition in children with JIA has been found to correlate with disease severity **(Simon, 2010)**.

In general, the educational intervention was effective in improving maternal participation in the management of their children with JIA. Despite the presence of some limitations including; the absence of a control group, weak response of the studied mothers to the web page, and lack of repeated assessment of nutritional status (more than two measurements).

Conclusion

The intervention program had a positive effect on improving maternal participation in the management of their children with JIA. The study findings also revealed a statistically significant increase in the percentage of healthy-weight children following the intervention. Moreover, a significant negative change in the height percentiles and height Z-scores of the studied children was observed throughout the study phases.

Recommendations

- Providing continuous training, counseling, and support for mothers is essential to maintain their participation in the management of their children with JIA. This may include regular educational programs, workshops, and involvement in support groups.
- Design and implement tailored nutritional programs that address the specific needs of children with JIA to maintain normal physical growth and boost immunity.
- Further controlled trials are needed to assess the effectiveness of the educational web page on children and parents' knowledge, and participation in management.
- Further prospective longitudinal studies are needed to assess and follow the nutritional status of JIA children through real-time observations and allow insight into cause-and-effect relationships.

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Conflicts of interest

The Authors declare that there is no conflict of interest.

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