

# Parental knowledge and participation in the management of children with juvenile idiopathic arthritis at rheumatology department tripoli children hospital

## Abstract

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in children and constitute the bulk of pediatric rheumatology clinic patients, parents of children with JIA face challenges when caring for these children. Parents' knowledge is important to help in the management of such a chronic disease, and to prevent complications.

**The aim of this study is to:** investigate parents' knowledge about their child's disease in general, to focus on important role of health education in understanding this disease and to establish a future plan for an education program to the newly diagnosed cases and a general public health program.

**Methods:** descriptive, cross sectional design was adopted, one hundred(100) sets of parents of children with juvenile idiopathic arthritis were assessed by using a predesigned questionnaire that contains 27 multiple choice questions, the study was carried out in pediatric rheumatology clinic, Tripoli Children Hospital in the period from January to June 2017. The questionnaire addressed 6 main areas: Parental awareness about the child's diagnosis, Source of information and parents' satisfaction, General knowledge about definition of arthritis and disease etiology, Knowledge regarding medical and physical treatment, Knowledge regarding participation in physical activities during school days, and Knowledge regarding vaccination.

**Results:** 97% of parents answered the question of diagnosis of their children correctly, although 68% had no previous knowledge on juvenile idiopathic arthritis before start following in rheumatology clinic. In 72% of the participant the source of information was the physician, and in 56% of them this information is considered to be satisfactory.

**Conclusion:** Questionnaire is simple way to investigate the parental knowledge regarding juvenile idiopathic arthritis, the results showed high level of knowledge in majority of parents of children with JIA, although some wrong believes were discovered, and this possibly reflecting the good quality of educational program followed in the clinic. Reduced level of knowledge about the disease before start of follow up may reflect the community knowledge. general public health education programs to improve the awareness about chronic arthritis in children may help in the early referral of such cases.

**Keywords:** questionnaire, parental knowledge, juvenile arthritis

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**Abbreviations:** JIA, Juvenile idiopathic arthritis; ILAR, international league against rheumatism; RA, rheumatoid arthritis; DMARDS, disease modifying anti rheumatic drugs

## Introduction

Juvenile idiopathic arthritis(JIA) is defined by international league against Rheumatism (ILAR) as highly heterogeneous group of disorders that gathers together all forms of chronic arthritis that occurs before 16years of age<sup>1</sup> Although it considered being the most common rheumatic disease in children, the true frequency is not known, the incidence rates ranged from 1.6\100.000 to 23\100.00 and prevalence of 19.8\100.000.<sup>1</sup> JIA shows a substantial impact on the patient physical abilities, psychological functions and quality of life.<sup>2,3</sup>

Undoubtedly, 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<sup>4,5</sup> changing behavior and to less extent increase in knowledge.<sup>6-11</sup> But to be successful, programs must be planned with clearly defined, achievable objectives.<sup>4</sup> However, knowledge acquisition is a complex process and depends on teaching style and contents, patient and parents intelligence, level of education and motivation. Several studies have shown the beneficial effect of patient education in compliance and knowledge,<sup>3,4,11</sup> and many questionnaires have been developed for measuring patient knowledge in regard to rheumatic diseases.<sup>6,11</sup> Most of these studies were carried on adult rheumatology patients, to date

there are few studies that have done to assess the parents' knowledge in pediatric rheumatology patients in general<sup>12,13</sup> and to my knowledge nothing was done to assess the knowledge of parents of the patient with juvenile idiopathic arthritis in Arab countries.

In spite of the rapid progress and improvement in pediatric rheumatology service in Libya, many people are still un aware of pediatric rheumatic diseases in general and chronic arthritis in children especially. Although educational level of young parents has improved, however this is in turn did not affect the knowledge regarding rheumatic disease in children as was expected. One of the ways to empower the parents to deal with a child with juvenile idiopathic arthritis is through education, in order to achieve this the first step is to review and identify amount and level of parents knowledge.

### For these reasons we designed and implanted our study with an objective to

Investigate parents knowledge about their child's disease in general, with focus on important role of health education in understanding this disease in order to establish a future plan for education and training to the newly diagnosed cases and to initiate a general public health program to raise the awareness about the disease in the community.

### Patients and methods

Descriptive, cross sectional design was adopted. The study was conducted over 6months period from 1<sup>st</sup> of January to end of June 2017.

#### Inclusion criteria

All parents of children with juvenile idiopathic arthritis following in pediatric rheumatology clinic, Tripoli children hospital were assessed during their routine visits to the clinic during the period of study.

#### Exclusion criteria

We exclude answers from the first visit patients and from other relatives (rather than mother or father) that may accompany the patients at the visits.

#### Data collection process

Done by using pre structured multiple choice questionnaire, the first draft of the questionnaire was reviewed by two pediatricians and 10parents of children with JIA attending follow-up rheumatology clinic who suggest some changes in wording and style. A revised questionnaire was then applied.

A total of 100 parents were included in the study, 94 were Libyan and 6 were non Libyan, Arabic with Arabic as their native language. The questionnaire was self and interviewer administrated and the response was collected during the same visit. The purpose of the questionnaire which includes 27questions was explained to the parents and their verbal consent was taken to be included in the study. The questionnaire addressed 6 main areas:<sup>1</sup> parental awareness about the child's diagnosis,<sup>2</sup> source of information and their satisfaction,<sup>3</sup> general knowledge about definition of arthritis and disease etiology,<sup>4</sup> knowledge regarding medical and physical treatment,<sup>5</sup> knowledge regarding participation in physical activities during school days, and<sup>6</sup> knowledge regarding vaccination. The level of education of parents was divided in to 3 levels: low (primary school education), middle (secondary school education) and high (university and higher)

regarding data analysis it was conducted by using of SPSS software after cleaning and coding of data. Mean and SD used to describe quantitative variables, percentage used for other variables.

For the knowledge questions about the disease the correct answers were given one mark and the wrong one and non-answered questions were considered as lack of knowledge and given zero mark as. Then the total marks summated to have the total score for each participant. Total score is expressed as percentage, higher score reflects a greater knowledge. For inferential statistics we used Mann-Whitney U test and Kruskal-Wallis test to get the level of confidence of the association level of knowledge between different groups. a p-value<0.05 was used to indicate a statistically significant difference.

### Results

in this study, the knowledge of 100parents of children with JIA was studied. The mean duration of follow up in the rheumatology clinic was 4.4±0.37years, ranging from 0.5-16.3years. 94% were Libyan. more than 50% (54%) of our patients came from out-side Tripoli. Fifty two(52%) out of the total number interviewed were primary school level(education level 1), nine (9%) had secondary school(education level 2),thirty nine (39%) had university degree and higher (education level 3) (Table1).

Table 1 parents characteristics

Character	NO	Frequency
<b>Nationality:</b>		
Libyan	94	94%
Non Libyan	6	6%
<b>Address:</b>		
Tripoli	46	46%
Out-side	54	6%
<b>Relation with child</b>		
Mother	50	50%
Father	50	50%
<b>Education level:</b>		
1)Primary school	52	52%
2) Secondary school	9	9%
3) University &higher	39	39%
<b>Total</b>	100	100%

68% of participant have no previous knowledge about JIA before diagnosis of their children. Majority of parents (97%) were aware of their child's diagnosis and answered the question of diagnosis of their child's disease correctly, one(1) answered wrongly and no answer was obtained in 2 participant. The percentage of correct answer was unchanged with improvement of educational level, as 53.8% of participant with educational level 1 answered correctly compared with 44.4% and 48.7% of educational level 2 and 3 respectively (P= 0.61).72% of parents considered the treating physician as the absolute source of information while 28% had other sources of information from books, media and family members, and the information obtained from physician was considered to be satisfactory in 56% (Table 2).

Table 3 illustrates the impact of factors on the total knowledge score: regarding the parent who participate in the study and answer the questionnaire there was no difference between fathers and mothers, although mothers were found to be slightly more knowledgeable about the disease when compared to fathers (p=0.198), to be educated

or not has no significant effect on the score, but as expected parents with university level of education and above has slightly higher score than parents with low and middle level of education ( $p=0.120$ ), the number of non-Libyan parents was only 6 and their mean total score of knowledge is 15.8 which is un-significantly less than that of Libyan parents ( $P=0.907$ ), the parents who are living inside Tripoli have almost same mean knowledge score as those who live outside Tripoli ( $P=0.562$ ). More or less years of follow-up in our clinic gave no effect on the calculated score ( $P=0.698$ ) Table 4. Although majority had follow up more than 5years with mean follow up of  $4.4\pm 0.37$  years, and majority answered the question of diagnosis correctly, only 51% can define arthritis correctly, 44% had wrong answer and no answer in one(1) participant. 72% of participant recognize that juvenile idiopathic arthritis is different from rheumatoid arthritis (RA) in adult patients, 41% believe that the disease can remit spontaneously and can't be cured in 48 participant(48%).etiology of the disease is considered to be idiopathic in 63%,while 42% of participant believe that the disease is caused by cold weather (Table 5).

**Table 2** source of information and participant satisfaction

Variable	NO (%)
Source of information:	
Physician	72(72%)
Other sources*	28(28%)
Adequacy of information:	
Satisfactory	56(56%)
Non satisfactory	44(44%)
Total	100(100%)

\*Other sources: books, newspaper, T.V, network, friends and family members

**Table 3** Total mean score correlated with educational level

Education level	NO	Lowest score	Highest score	Mean score
1	52	20%	95%	63.2%
2	9	20%	90%	63.6%
3	30	23.3%	96.6%	69.7%

P=0.120

**Table 4** Total mean score correlated with duration of follow up

Duration of follow up	Lowest score	Highest score	Mean score
≤ 5years	16.6%	96.6%	65.6%
>5years-≤10 years	6.6%	95.3%	65.6%
>10years	43.3%	68.6%	65.8%

P= 0.698

**Table 5** parents knowledge on different items of the disease

	NO of participant who know	Frequency (%)
Correct diagnosis	97	97%
Definition of arthritis	51	51%
Etiology of illness	63	63%
JIA is different from RA	72	72%

Table continued

	NO of participant who know	Frequency (%)
JIA caused by cold weather	42	42%
JIA can remit spontaneously	41	41%
JIA can be cured	48	48%
Anti-inflammatory is the main treatment	68	68%
Steroid commonly used in treatment	83	83%
Chemotherapy is used in treatment	46	46%
Drugs should be taken regularly	67	67%
Drugs should not be stopped suddenly	72	72%
Physiotherapy is important in treatment	78	78%
Physiotherapy would eliminate arthritis	63	63%
Physiotherapy reduce incidence of malformations	68	68%
Physiotherapy increase range of joint motion & strength muscles	84	84%
Physiotherapy must be continued during disease activity	50	50%
Encourage to participate in school activities	76	76%
School activities guided by child's abilities	92	92%
Participate in sports even if affect joints strongly	75	75%
Can child take all vaccinations	46	46%
Should consult treating physician before vaccination	83	83%

Regarding treatment of JIA, 68% recognize that anti-inflammatory drugs are the main line of treatment in most cases,16% answered wrongly and 16% had no answer. 83% of participant knew that steroid commonly used at some time during the disease course, 12% had no answer. Only 46% of participant knew that chemotherapy can be used in treatment of JIA, 30(30%) answered wrongly and 24% had no answer. 67(67%) of participant believe that treatment should be taken regularly even if their children are a symptomatic, and 72(72%) knew that the treatment should not stopped suddenly.

Regarding physiotherapy, 78(78%) recognize the importance of physiotherapy in treating patients with JIA, despite their believe that physiotherapy will not eliminate the disease, in 63(63%) of participant. But physiotherapy will reduce the occurrence and severity of deformities as 68(68%) of participant believe and increase the range of movement of joints and strengthen the muscles as 84(84%) of participant believe. 50(50%) of participant believe that physiotherapy should be stopped during periods of disease activity.

Regarding participation in school physical activities and sports, 76(76%) believe that their children should be encouraged to participate in all school activities and sports, only 13% had wrong answers and 11% had no answer. In 92(92%) this participation should be according to the child's abilities. 75(75%) insist that children with JIA should

be encouraged to participate in sports even those that may affect their joints strongly.

Regarding vaccination of children with JIA, 46(46%) recognize that their children should not receive live attenuated vaccines while they are on medications, 37% had wrong answer and 17% had no answer. But 83(83%) of them recognize that treating physician should be consulted before giving any vaccines to their children.

## Discussion

Pediatric rheumatology is a new subspecialty especially in Libya which had started 20 years back and achieved excellent development over the last 10 years. Pediatric rheumatology department in Tripoli children hospital is the only center providing pediatric rheumatology service in west region of Libya. Our routine practice is to provide the parents of patients with JIA with a booklet that explain different types of the disease at the time of diagnosis and during each visit we provide them 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 parent's knowledge and compliance with education courses and booklet information the most commonly used.<sup>12,14,15</sup> The questionnaire was an easy and simple method to evaluate the parental knowledge, and can be used in future to evaluate changes in knowledge after any educational initiatives. Most parents found the questionnaire interesting, understandable and easy to be answered. Although the results suggested that majority of parents answered the question of diagnosis of their children correctly, 97% of participant, some of them have ambiguity and wrong believes on certain aspect of the disease as 42% of participant believe that JIA can be caused by cold weather and this might reflect the public believe on etiology of chronic arthritis in general. Most patients recognize that anti inflammatory drugs and steroids are commonly used in treating patients with JIA, 68% and 83% respectively. But only 46% recognize that methotrexate, the most commonly used disease modifying anti rheumatic drugs (DMARDs) in treatment of JIA is considered as chemotherapy.

Questions on physiotherapy showed a high level of understanding, as most participant understand the importance of physiotherapy to reduce deformities, increase range of movement of joints and to strengthen muscles although physiotherapist is not a component of our clinic team, unfortunately. Majority of parents can manage their children physical activities and sports in school according to their abilities. Only 46% of parents recognize that live attenuated vaccines should not be given to a child while he is on treatment but 83% prefer to consult the treating physician before giving any vaccine.

Our study showed that parents' knowledge is not significantly affected by level of education of parents as those with low education level had mean score of 63.2% compared with 63.6% and 69.7% for those with middle and high educational level but as expected parents with university level of education and above has slightly higher score than parents with low and middle level of education ( $p=0.120$ ). Also parents' knowledge is not affected by duration of follow up as those with follow up duration more than 10 years had mean score of 65.8% compared with 65.6% for those with follow up duration of 5 years or less ( $p=0.698$ ) although the lowest score was improved with longer follow up Table 4.

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 emphasize more on the important role of treating physician in providing parents with adequate information with regard to the disease. However one should not ignore the important role of the media (as T.V, books, news paper...) and the need for specialized nurse to educate the parents in view of limited clinic time and lack of educational sessions.

We can't find any similar work in the Arab countries for comparison except one study from Saudi Arabia<sup>13</sup> which was on parents knowledge around rheumatic disease in children in general and not on JIA patients. As most parents had a high level of knowledge with minimal wrong believes on specific aspects of the disease, **several conclusions can be drawn from these results:** the good level of knowledge observed may be attributed to the quality of consulting program followed in the rheumatology clinic as well as to the booklet which was written in a simple way allowing easy understanding of the subject. Finally, questionnaire is simple and easy method to investigate parental knowledge, and can be used as a sensitive method to detect changes in knowledge that may result from educational activities in future. The results showed that there is need for future general public health education programs plan to improve public awareness about juvenile idiopathic arthritis, that will lead to early referral of these cases.

## Recommendations

- i. Give more time to parents education using simple language and teaching aids as simple illustrated and colorful diagrams to explain.
- ii. Triaging parents according to how much educational support they need and request them to share in education programs.
- iii. Schedule education programs annually using possible available resources as T.V and social media to raise community awareness on chronic arthritis.
- iv. And further research project to observe parents behavior toward their children with JIA are needed.

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## Conflict of interest

The author declares no conflict of interest.

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