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

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Introduction:

- Juvenile idiopathic arthritis(JIA) is the most common rheumatic disease in children and constitute the bulk of pediatric rheumatology clinic patients.
- Parents of a children with JIA face challenges when caring for these children.
- Parents knowledge are important to help in the management of such a chronic disease and to prevent complications.
- Knowledge acquisition is a complex process and depends on teaching style and contents, parents intelligence, level of education and motivation.

objectives:

- ✓To investigate parents knowledge about their child's disease.
- ✓To focus on important role of health education in understanding this disease.
- ✓To establish a future plan for education program to the newly diagnosed patients and a general public health education program.

Patients & methods:

- A cross-sectional, descriptive study conducted at rheumatology department, Tripoli Children hospital over 6 months period from January to end of June 2017. A total of **100 parents** of children with JIA following in pediatric rheumatology clinic were assessed during their routine clinic visits by using a multiple choice questionnaire.
- The questionnaire addressed 6 main areas: 1)parental knowledge about child's diagnosis, 2)source of information and their satisfaction, 3)general knowledge about definition of arthritis, 4)knowledge regarding medical and physical treatment, 5)knowledge regarding participation in physical activities during school, 6)knowledge regarding vaccination.
- The level of education of parents was divided in to 5 levels:1-illeterate, 2-primary school education,3-secondary school education,4-university level and, 6-higher.
- ❖The main outcome in this study is the parental awareness about juvenile idiopathic arthritis in children and this was related to parents education using chi square(X2). Data was analyzed using SPSS-16.

Results:

The knowledge of 100 parents of children with JIA was studied, 94% were Libyan, 54% of them came from out side Tripoli. Mean duration of follow up in the rheumatology clinic was 4.4 ± 0.37 years, education level of assessed parents in table1. 68% of participant have no previous knowledge on JIA before diagnosis of their children. Majority ,97% aware of their child's diagnosis and this was not corresponding to their level of education as 97% with educational level 4&5 answered correctly compared with 98.1%with educational level 1&2 ($p=0.10$)

Table 1 parents characteristics

Characteristics	NO (%)
Nationality:	
Libyan	94(94%)
Non	6(6%)
Address	
Tripoli	46(46%)
out-side	54(54%)
Relation to patient	
mother	50(50%)
father	50(50%)
Educational level	
1-illeterate	10(10%)
2-primary school	42(42%)
3- secondary school	9(9%)
4-university	35(35%)
5-higher	4(4%)

Table 2 Source of information and parents satisfaction

Variable	NO(%)
Source of information	
physician	72(72%)
other source*	28(28%)
Adequacy of information	
satisfactory	56(56%)
Not	44(44%)
*Other sources: books, news paper ,TV, net work, friends and family members	

Table 3 parents knowledge about the disease

Character	NO(%)
Correct diagnosis	97(97%)
Definition of arthritis	51(51%)
Etiology of illness	63(63%)
JIA can remit spontaneously	41(41%)
JIA can be cured	48(48%)
NSAIDS is the main treatment	68(68%)
Steroid commonly used	83(83%)
Chemotherapy is used in treatment	46(46%)
Biological drugs are used in treatment	52(52%)
Drugs should not be stopped suddenly	72(72%)
Physiotherapy is important in treatment	78(78%)
Encourage to participate in school activities	76(76%)
Child can take all vaccination	46(46%)

Conclusion: questionnaire is simple way to investigate the parental knowledge regarding JIA, the result shows high level of knowledge in majority of parents of children with JIA compared with low level before starting follow up in rheumatology clinic which indicate need for general public heath education program.