

Evaluation of parental knowledge of Pediatric Rheumatic Diseases

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ABSTRACT

Objective: To investigate the parental knowledge of pediatric rheumatic diseases in general, and in particular information regarding their children's diseases. To focus on the important role of health education in understanding these chronic diseases, and formulate a future plan for establishing a general public education program.

Methods: One hundred sets of parents, of children with established rheumatic diseases with mean duration of illness, (4.1 ± 2.83), a mean child age (9.9 ± 3.15) years, were given a 20 multiple choice questionnaire during their routine visit to the Pediatric Rheumatology Clinic and Physiotherapy Department or to the pediatric ward at King Faisal Specialist Hospital and Research Center, Riyadh, Saudi Arabia, over a 6-month period between December 1998 and June 1999. The questionnaire addressed 4 main areas: 1. parental awareness regarding their children's diagnosis and duration, 2. source of information and parental satisfaction, 3. general knowledge about

rheumatic diseases and 4. knowledge about medical and physical therapy. The total possible score is 23.

Results: The overall mean score is 11.6. The mean total score is not affected by the parental education level. The majority of parents have wrong beliefs, regarding rheumatic diseases. The treating physician is the main source of parental information and in the majority of the parents, this information is satisfactory.

Conclusion: The questionnaire is a simple and easy test to investigate parental knowledge regarding pediatric rheumatic diseases. The survey shows the need for health education programs and a future general public health education plan to improve awareness of pediatric rheumatic diseases and maybe other chronic illness.

Keywords: Questionnaire, parental knowledge, Pediatric Rheumatic Diseases.

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Patient education is the foundation upon which to build treatment programs. Several studies have shown the beneficial effect of patient education on compliance and knowledge.^{4,6,7,12} Many questionnaires have been developed for measuring patient's knowledge with regards to rheumatic diseases.^{3,8,9} In spite of the rapid progress and improvement in medical services in the Kingdom of Saudi Arabia, many people are still unaware of pediatric rheumatic diseases. Although education level has improved however, this in turn did not affect the level of knowledge regarding these diseases, as was expected. For these reasons our study is conducted using a

questionnaire to evaluate the parental knowledge of pediatric rheumatic disease in general and their awareness with regards to their children's specific diseases among parents who attended the pediatric Rheumatology Clinic and Physiotherapy Department or Pediatric ward at King Faisal Specialist Hospital & Research Center (KFSH&RC) and to establish a future plan for a general public education program.

Methods. A total of 102 parents of children with established rheumatic diseases with a mean duration of illness of 4.1 ± 2.83 years ranging from 0.25 to 12

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years and a mean child age of 9.9 ± 3.15 years ranging from 1.5 to 16 years were given a 20 multiple choice questionnaire (Appendix I) during their routine visit to the Pediatric Rheumatology Clinic and Physiotherapy Department or to the pediatric ward at KFSH & RC. The study was conducted over a 6-month period between December 1998 and June 1999. All parents were Saudi with Arabic as their native language. One parent answered the questionnaire. We excluded answers from the first visit patient and from other relatives not regularly accompanying the child. The level of parental education is divided into 5 levels 1. illiterate education 2. primary school education 3. intermediary school education 4. secondary school education 5. university or higher education. The survey was self and interviewer administered and the response was collected during the same visit. The purpose of the survey was explained to the parents and 20 questions were written in both Arabic and English, the parents completed themselves and those who were illiterate were helped to complete the questionnaire. The questionnaire addressed 4 main areas 1. parental awareness about their children's diagnosis and duration 2. source of information and parental satisfaction 3. general knowledge, comprising definition of arthritis, etiology and parental beliefs 4. knowledge regarding medical and physical therapy. All questions were selected by the treating physician and the senior physiotherapist. The questionnaire was pre-tested for feasibility and comprehensibility. The score is one point for each correct answer and the total possible score is 23. Questions 2-4 are not scored as these are direct questions dealing with parental awareness regarding pediatric rheumatic diseases in general, parental source of information, and if the information given was satisfactory or not. One point is given for the correct diagnosis and accurate disease duration (question 1). The questions have one or multiple

correct answers (Appendix 1). We considered the best single answer that defines arthritis is joint swelling (question 5), however statement "a and b" together scored as one point if both were chosen as per the definition of arthritis of the American College of Rheumatology (ACR) criteria.² Although antibiotics are used for treating some rheumatic diseases such as lyme disease and rheumatic fever, we considered only drugs that suppress inflammation and the immune response as the principal drug therapy for pediatric rheumatic diseases (question 9).

Statistical Method The main outcome in this study is the parental awareness of rheumatic diseases in children. This was related to other factors such as parental education level and disease duration using Chi-square test (X^2 test). The p-value of <0.05 was used to indicate a statistically significant difference.

Results. The 102 questionnaires were collected from 102 parents. Fourteen (14%) out of the total number interviewed were illiterate [education level 1], 10 (10%) had primary school [education level 2], 18 (18%) had intermediary school [education level 3], 28 (27%) had secondary school [education level 4] and 32 (31%) had University or a higher degree [education level 5]. Their answers scored and analyzed are shown in (Table 1). All parents found the questionnaire easy and interesting. The overall mean score is 11.6. No parent achieved the full score. The total mean score by education level for all parents is between 10.1-12.8 and was not associated with the significant difference between the levels of education ($P=0.075$). The mean score is not affected by disease duration, as those with disease duration more than 4 years had mean score of 12.07 compared with 11.3 in those with disease duration of 4 years or less. The majority of parents (86%) were aware of their child's disease and the percentage of correct diagnosis was improved with the improvement in the

Table 1 - Parental knowledge about Pediatric Rheumatic Diseases and their Children's Diseases.

Level of Education	Total No. (%)	Correct Diagnosis (%)	Awareness of Rheumatic Diseases in Children (%)	Mean of Total Score
Level 1	14 (14)	9 (64)	3 (21)	11.5
Level 2	10 (10)	7 (70)	5 (50)	10.1
Level 3	18 (18)	17 (94)	9 (50)	10.5
Level 4	28 (27)	26 (93)	16 (57)	12.8
Level 5	32 (31)	29 (91)	16 (50)	11.7
Total	100 (100)	88 (86)	49 (48)	11.6
P value*		0.033	0.287	0.075

* P value < 0.05 is considered statistically significant

Table 2 - Source of information and parental satisfaction.

Variable	No (%)
Source of Information:	
Treating physician	98 (96)
Other sources*	4 (4)
Total	100
Adequacy of Information:	
Satisfactory	75 (74)
Not satisfactory	22 (21.5)
Not provided	5 (5)
Total	102 (100)
*Other sources: Books, newspaper, media or family member	

education level ($P=0.033$). Fifty-three (52%) of the parents were not aware of the existence of rheumatic diseases in children while 49 parents (48%) were aware of these diseases in children. The level of awareness was not affected by the level of education ($P=0.287$). Ninety-eight (96%) of parents considered the treating physician as the absolute source for their information while 4 (4%) parents had other sources of information from books, media or family member. The information provided by the treating physician was satisfactory to 75 (74%) of the parents and was not satisfactory to 22 (22%) parents while 5 (5%) of the parents stated that no information was provided (Table 2). The majority of parents (69%) believed that cold damp weather is the cause of arthritis. Thirty-five (35%) of the parents' response was that all rheumatic diseases are curable while 20 (20%) parents considered arthritis of both children and adults similar. Seventy-five (74%) of the parents response was that the medications should be taken regularly even in the absence of pain, while 13 (13%) of the parents believed that medications should be taken only when pain is severe. The minority of the parents (7%) considered medications to be addictive. Steroids were chosen correctly as a drug used for treating rheumatic disease in 60 (59%) of the parents and 22 (22%) of the parents selected chemotherapy, while 26 (25%) of the parents considered antibiotic as drugs used for treating rheumatic diseases. The majority of parents (78%) believed that the purpose of the exercise program is to increase the range of motion and muscle strength and 54 (53%) of the parents identified the importance of continuing the exercise program with an adjustment to the patient tolerance during acute arthritis. The majority of the parents (74%) selected a once daily exercise program for children with arthritis and 20 (20%) of the parents

were aware that the joint should be used as much as possible. For relieving morning stiffness and muscular pain, a warm bath and massage were the response of 46 (45%) and 41 (40%) of the parents. However the purpose of a wrist splint was correctly answered by 48% of the parents only.

Discussion. Pediatric Rheumatology is a new subspecialty in the Kingdom of Saudi Arabia, which has achieved excellent development and maturity over the last 10 years. The Pediatric Rheumatology section at KFSH & RC is the only center in the Kingdom that provides a tertiary care service. Our routine practice during each visit is to provide the parents with information regarding the child's disease and his progress by the treating physician and the senior physiotherapist. A booklet that explains the exercise program is provided to help the parents to do regular daily physiotherapy. Teaching patients is time consuming and different approaches have been devised to increase the patient's knowledge and compliance with education courses and information booklets among the most commonly used.^{10,11,13} The questionnaire was an easy and simple method to evaluate parental knowledge. It can be used in the future to evaluate changes in knowledge after any educational initiatives. Although the results suggested that the majority of the parents were aware of their children's diseases, average information regarding pediatric rheumatic diseases in general, states some of the parents having ambiguity and wrong beliefs on certain aspects of rheumatic diseases such as arthritis caused by cold damp weather. The survey showed that parental knowledge was not affected by the education level or disease duration which emphasizes more on the important role of the treating physician and the physiotherapist in providing parents with adequate information with regard to the disease. However, one should not ignore the important role of the media (TV, newspaper, books and pamphlets) and the need for specialized nurses to educate the parent during each encounter. In the view of limited clinic time and the lack of the teaching sessions, the patient education programs play an important role in the management of chronic diseases and providing knowledge to the patients regarding their diseases. A few studies conducted in the Kingdom of Saudi Arabia stressed the need for general public education programs that will help to improve patient compliance.^{1,5} After establishing educational programs, the study can be re-conducted again to detect changes in parental knowledge with regards to these chronic diseases.

In conclusion, the questionnaire is a simple and easy method to investigate parental knowledge regarding pediatric rheumatic diseases. The results showed that there is a need for health education programs and education courses with information booklets as an important component of managing these chronic diseases, and it also stressed on the

need for a future general public health education plan to improve public awareness with regard to pediatric rheumatic disease, and maybe other chronic diseases.

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