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**Juvenile Idiopathic Arthritis Treatment Satisfaction and  
Quality of Life in Palestinian Patients**

**Ruba Mahmoud Abed Ja'afreh**

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# **Juvenile Idiopathic Arthritis Treatment Satisfaction and Quality of Life in Palestinian Patients**

**Prepared by:**

**Ruba Mahmoud Abed Ja'afreh**

**B.Sc. Pharmacy from Al-Quds University, Palestine**

**Supervisor: Dr. Hussein Hallak**

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## **Thesis Approval**

### **Juvenile idiopathic arthritis treatment satisfaction and quality of life in Palestinian patients**

Prepared by: Ruba Mahmoud Abed Ja'afreh

Registration No: 21711670

Supervisor: Dr.Hussein Hallak

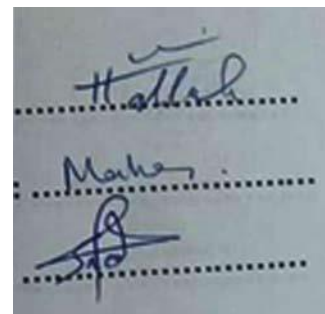
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The names and signatures of the examining committee members are as follows:

1-Head of committee: Dr.Hussein Hallak      signature: .....

2-Internal examiner: Dr.Maher Khdour      signature: .....

3-External Examiner: Dr.Sa'ed Zyoud      signature: .....



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## **Dedication**

I lovingly dedicate this thesis to my parents, who never stop giving of themselves in countless ways. To my sisters, who supported me each step of the way and have been my constant source of inspiration. They all have given me the drive and discipline to tackle any task with enthusiasm and determination.

Ruba Mahmoud Abed Ja'afreh

## Declaration

I certify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged and that this thesis has not been submitted for a higher degree to any other university or institution.

Signature: .....

A handwritten signature in blue ink, appearing to read 'Ruba', is written over a dotted line. The signature is stylized and includes a horizontal line underneath.

Ruba Mahmoud Abed Ja'afreh

Date: December 7, 2019

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## **Abstract**

Chronic diseases can affect patient's life in a very negative way; as such, it is important and necessary to measure the effects of those diseases and their impact in patient's life.

Juvenile Idiopathic arthritis (JIA) is one of chronic inflammatory diseases that affect joints all over the body and leads to several unwanted and maybe severe adverse events.

In Palestine, there are no studies about JIA or its impact on pediatric patients. As such, the aim of this study was to indicate and measure pediatric quality of life as well as measure satisfaction with the treatment they receive. In addition, to determine the factors that can affect quality of life and treatment satisfaction.

This study was conducted over a period of 8 months, which a total of 50 patients were included from two hospitals and a Specialized Pediatric Center in the West Bank under the supervision of their specialist pediatric rheumatologist doctor.

Two different questionnaires were administered to the 50 patients and their parents; one of questionnaire is to measure the pediatric quality of life (PedsQL) Generic Core Scales form. The other questionnaire was to measure patient's treatment satisfaction; we used Treatment Satisfaction Questionnaire for Medication (TSQM) version 1.4. In addition, the study evaluated factors that may affect PedsQL and TSQM including patient's place of living, family relationship with patients, parent's education level, type of house, family member's number, parent's monthly income, parents work status, and the cost of transportation to reveal the impact of JIA on the economic status. Furthermore, a correlation between PedsQL, TSQM scores with each subtype of JIA was determined. Finally, patient's weight, height, and BMI effect on with TSQM or PedsQL were evaluated.

Results indicate that all patients for all age groups have above average quality of life as well as treatment satisfaction scores. There was no significant effect except with TSQM global satisfaction domain, according to parent's scores, in which the lowest score of global satisfaction was observed in age group of 8-12 years while the 13-18 year old age group had the highest score with significant difference between age groups.

In case of the hypothesis and comparisons, the results indicated no significant effect except of the following cases:

Parents work status correlated with TSQM effectiveness domain, with the count of children's age groups. In addition, Parents work status correlated with TSQM convenience domain, without the count of children's age groups. The data indicates lower convenience score for working parents.

Family member numbers correlated with PedsQL social function domain in case of no counting of children's age groups. The data indicates relatively higher social function scores with increase in number of family members.

In case of children's weight and height correlation with PedsQL and TSQM, the results showed that both weight and height did not reveal any significant effect on PedsQL domains. On the other hand, there was a significant effect of height on TSQM global satisfaction domain, In which there was a positive relationship between them, that's mean the increase in height indicates higher global satisfaction.

In case of children's weight, there was a significant effect with TSQM side effects domain, in which there is a negative relationship between them, that means that the increase in weight gives lower side effect scores and vice versa.

For BMI, there was a significant effect on both PedsQL domains as well as TSQM. In case of PedsQL, there was a significant effect of BMI on emotional functioning and psychosocial functioning domains. In case of TSQM, there was a significant effect between BMI and the domain of convenience. In which there was a positive relationship between them; that means that the increase in BMI gives a higher scores with the mentioned domains.

According to the information obtained from patient's records, there were 4 patients with uveitis as a complication of JIA. For the medications used, the most commonly used medications were: Prednisone, Methotrexate, Ibuprofen, Folic acid. Biologics like infliximab, Etanercept, Abatacept, Tocilizumab, and Adalimumab were also utilized, occasionally.

In conclusion, all 50 JIA patients have above average quality of life and treatment satisfactions (scores were above 50), noting that the higher the scores the better HRQoL.



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## List of Abbreviations

ACR: American College of Rheumatology .....	1, 2
ANA: Anti-nuclear Antibody .....	passim
AS: Ankylosing spondylitis .....	7
BMD: Bone mineral density .....	13
BMI: body mass index .....	passim
CHQ: Child’s Health Questionnaire .....	28
COAs: Clinical outcome assessments.....	26
COX: Cyclo-oxygenase .....	17
CRP: C reactive protein .....	11
DMARDs: Disease-modifying anti-rheumatic agents.....	15, 33
ESR: Erythrocyte sedimentation rate.....	3, 11
EULAR: European League against Rheumatism.....	1, 2
FDA: Food and Drug Administration .....	24, 26
HLA: Human leukocyte antigen .....	3, 5, 11
HUI: Health Utilities Index.....	28
JAQQ: juvenile idiopathic arthritis quality of life questionnaire.....	27, 34
JIA: Juvenile idiopathic arthritis .....	passim
MRI: Magnetic Resonance Imaging .....	11
MTX: Methotrexate .....	passim
NSAIDs: Nonsteroidal anti-inflammatory drugs .....	passim
PedsQL: Pediatric Quality of Life Inventory .....	passim
RF: Rheumatoid Factor.....	passim
RMS: relapsing multiple sclerosis .....	29
TNF $\alpha$ : tumor necrosis factor $\alpha$ .....	21
TS: treatment satisfaction .....	29
TSQM: Treatment Satisfaction Questionnaire for Medication.....	passim

# **Chapter 1: Introduction**

## **1.1 Background**

Juvenile idiopathic arthritis (JIA) is a term that covers several categories (heterogeneous group), each of which covers characterized signs, symptoms and different genetic framework. JIA is considered as the most common cause of arthritis and its related problems in children whose age is less than 16 years old[1-3]. JIA leads to serious disabilities in short and long term[4], the estimated number of JIA patients around the world up to 1 per 1000 children[5]. JIA is featured by pain, inflammation, swelling and limitation of motion of joints[6] accompanied with heat, or tenderness that commonly leads to joint destructions that affects patients quality of life[2, 6]. Causes of JIA are unknown[7], but there is some evidence of it including a multifactorial autoimmune disease with environmental and genetic contributory factors[8]. The existence of several subtypes of JIA and the variation of classification systems of JIA make it difficult for studies to clear the environmental role in JIA[9]. The most common risk factors are infections in addition to genetic susceptibility. Many other factors, such as maternal smoking and stress, are thought to contribute to the pathogenesis[10]. In case of genetic susceptibility, gene involvement seems complex as the disease itself may involve multiple genes regarding immunity and inflammation [2, 11-13].

## **1.2 Classification of juvenile idiopathic arthritis**

The International League of Associations for Rheumatology (ILAR) systems[14], the European League against Rheumatism (EULAR) and the American College of Rheumatology (ACR), are three classification systems suggested over the last few decades for chronic arthritis in childhood[1, 2]. Despite the existence of more than one classification system, none are perfect, this is due to several reasons including the difficulty to classify some patients into any specific subgroup, in addition there were patients who attain criteria for more than one subtype[2]; the ILAR system refers such patients to undifferentiated arthritis patients[15]. Patients who suffer