

Adolescents diagnosed with JIA: what they do not say to doctors (*psychological aspects*)

Margarita Tsitsi,
Psychologist, *Msc*

ENCA MEETING ATHENS,
SEPTEMBER, 2017



About JIA...



- JIA: multifactor disease with impacts on many aspects of patient's life
....Physical health, mental health, Quality of Life
- The age of onset is a determinant factor for the development of the disease
- Patient's adherence to drugs/physiotherapy is essential for the optimal prognosis of the disease.

Teenagers and JIA...



- What happens in adolescence?
- How a chronic disease impacts on teen's life?
- How do they feel/think about the disease?
- Do they express themselves to others (parents, doctors, friends)?
- Do they trust their doctors.... what do they say to them?
- Are the teens satisfied with the care they receive? What more do they need?



Why do we study adolescents?

- Adolescence is a very difficult and challenging period of human's life
- Many changes take place (physical, psychosocial, etc.)
- Teens have to deal with school achievement, activities, peer relations, self-conceptualization, family and social matters
- Self-esteem, body-image, future plans for studies and career, discovery of themselves, preparation for adulthood

Adolescence and JIA




An adolescent with JIA has extra difficulties to deal with:

- Impact on body image, self-esteem
- Impact on activities and social/peer relations
- Impact on anxiety and psychological factors
- Impact on goals and future plans





Adolescence and JIA

- Recent studies show that chronic diseases, such as JIA, might have a negative effect on adolescent's Quality of Life
 - The stress during puberty coming from several developmental changes, gets higher when there is a chronic disease to deal with
 - Difficulties in many domains, such as activities and school, socialization, self-belief, body image, future goals, etc. get higher too.
- 



Adolescence and JIA

Influence factors:

- Age
- Age of onset
- Gender
- Region of living
- Type of therapy
- Cooperation with doctors/ commitment to therapy

Aim-methods and type of the present study

- The impact of JIA on adolescents' life
- To detect the determining factors that we may control
- Material:

adolescents with established JIA

cared in the“ Pediatric Immunology & Rheumatology Referral Center, 1st Dept of pediatrics, Aristotle University, located in the Hippokrateio Hospital, Thessaloniki, GREECE

- Qualitative study (interviews with open questions), in order to have adolescents' pure beliefs and thoughts recorded.

Results- Patients enrolled

Characteristics	Results
No of pts (M:F)	20 (7:13)
Age	Early adolescence (12-14 years): 6 Middle adolescence (14-16): 9 Late adolescence (16-18): 5
Age of onset	< 5: 13 <10 5 >10 2
Diagnosis	15 JIA 5 disease control <i>Lupus 2</i> <i>Scleroderma 1</i> <i>Mixed Connective Tissue Disease 1</i> <i>Uveitis 1</i>
Residence	Thessaloniki 10 other cities 10



Adolescents replies

Group JIA

Disease activity:

- ▶ 16/20 adolescents (9 females, 7 males) claimed
“the disease has no or slight activity, at least for the last year, and they had no symptoms
- ▶ 4 Female adolescents claimed that....
“they have some symptoms (knee, elbow, eye inflammation) during the last months.

Disease activity and quality of life

16 asymptomatic adolescents said:

- they were very satisfied with their therapy (methotrexate), pain relief
- they had no side effects
- they had no difficulties in everyday life
- they were very satisfied with the medical team in the hospital, they felt close to them and they trusted them
- Shared Decision Making:
they felt that the Center's team takes them into account regarding therapy plans, but the doctors should be the final decisioners, because "they know better the JIA"





Disease activity and Quality of Life

4 adolescent girls → moderate disease activity in the last year

- ▶ Pain in elbow, knee, eye inflammation
- ▶ Difficulty in writing, weight lift, walking and running
- ▶ They felt secure and satisfied with the medical team and their treatment, but they needed a better adjustment of their medication to their symptoms




Disease activity and quality of life


Control group


- All 5 adolescents had no significant symptoms the last year
- No significant difficulty in every day life
- They were satisfied with their medication and treatment
- They felt very well with the doctors, they trusted them
- They found it easy to tell them anything they need

No difference between JIA and control group



School life-activities

- Essential role in adolescents' growth consists the school life and peer relationships ➡ acquisition of knowledge, self-perception, self-esteem, personal growth
 - Does JIA effects negatively on this area?
- 



School life-activities

JIA group:

- almost all 20 teens had a ***positive experience with school, had friends and social life***
- ***13 (10 girls, 3 boys)*** had a positive experience and high academic performance
- ***9/20 (8 had high performance)*** said “JIA has ***no effect on their studying***”
- ***11/20 (6 high performance, 5 moderate performance):*** pain, stretching, low mood, difficulty in writing influence on their studying

School life-activities



- 20/20 adolescents had at least 2 close friends and spent time with them
- 20/20 had free time for activities
- 11/20 had difficulty in socializing only in primary school (pain, fear of running, getting hurt, not going out)


School life-activities



Control group:

- ▶ **3/5 adolescents** had a positive **experience** and **high performance** in school and they found no disease-related effect on school life and studying
- ▶ **5/5 adolescents** had close friends and free time
- ▶ **3/5 adolescents** reported no disease-related effect on their social life

No difference between JIA and control group



School life-activities

In conclusion...

- We observed no significant effect of a chronic pediatric rheumatic disease (JIA or lupus, scleroderma, mixed CTD, uveitis) on adolescents' school and social life
- Adolescents think that this is important for their Quality of Life
- No effect detected probably due to the Center's policy of early intervention and treatment in pre-adolescence


Family relationships and JIA



- **20/20** adolescents reported that their **parents** played an **essential role** during the **diagnosis and treatment** and offered them **great support**
- **15/20** said that their **families** were **stressed** at the beginning but then **became stronger** and learnt to deal with
- **14/20** **asked for support** when they need it (parents, close friends)
- **14/20** would **appreciate professional help** for their **anxieties** in refer to their disease

Self-perception, self-esteem and JIA


- ▶ Most adolescents had a positive self- body image and self-esteem, according to their age
- ▶ They recognized both positive and negative elements of their personality and appearance
- ▶ **11/20** adolescents referred their ***appearance has been influenced by JIA (knee swelling, body height, body weight, body position, air growth, lack of exercise)***



Autonomy, goals, thoughts and JIA

- Most of the goals referred to future physical health, opportunity to study, friendship, independence
- These goals seemed to be in accordance with the ones of their peers without a disease

The goal of physical health seem to differentiate them from their peers



Autonomy, goals, thoughts and JIA

- **No adolescent** reported **lack of autonomy and significant difficulty in everyday life**
- **10/20** adolescents (6 girls, 4 boys) **no effect** of JIA on their **future goals**
- **7** adolescents (girls, 2 boys) ... JIA had **positive effect** on their **goals** (to be physiotherapists, doctors ,etc to help other people)
- **3** adolescents (2 girls, 1 boy) mentioned a **negative JIA-effect** on their **goals** (dance, athletics)

Thoughts and emotions about JIA

Most common thoughts recorded:

“I don’t want to be in pain any more”

“I’m afraid of having it in the future again”

“I don’t want any other medication”

“Medication costs a lot, I don’t want to bargain my family”

“I want a regular life, to run, do exercise”





Thoughts and emotions about JIA

In conclusion..

- Anxiety for the future
- Frustration for the medication and non-normal life
- Fear of pain
- Anger
- Responsibility for the family (cost and stress)



Adolescents mental health at risk




Take home message

- JIA has a certain impact on adolescents' life
- This impact is decreased by the age of onset (the younger they suffered the sooner they co-live with it)
- More impact on school life, self- perception, goals and thoughts
- Positive interaction with doctors, engagement to treatment
- Family gets stressed but in the end...becomes stronger
- Adolescents have friends and free time



Protecting factors

- Early diagnosis and treatment
 - Good engagement to treatment, positive interaction with medical team
 - Good support system (family, friends)
 - Sense of control (participation in treatment plans, future goals, activities, problem solving, independence)
 - No much impact on adolescence normal everyday life
- 



THANK YOU

FOR YOUR TIME, FOR YOUR ATTENTION