



Rapport från PREs 28 september – 1 oktober 2023 i Rotterdam. Även detta år fanns det möjlighet att delta på plats och digitalt. Här kommer några korta återblickar från konferensen.

**Adolescent care: time for a rethink?**

**Janet McDonagh**

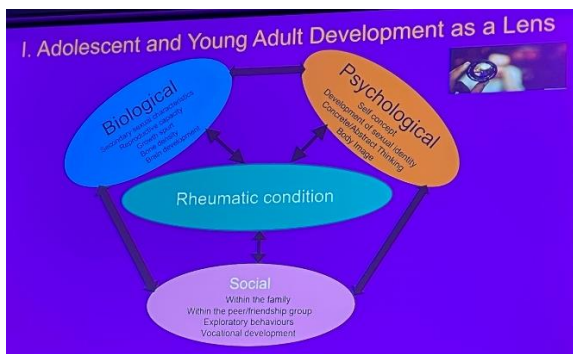
Vi måste tänka på att vara välkomnande för tonåringarna. Viktigt att tänka på vems frågor det är som lyfts i rummet och låta ungdomarna ta sin tid för att formulera sina frågor.

När man arbetar med ungdomar är det viktigt att man lyfter blicken och ser till helheten. Hur fungerar det med den reumatiska sjukdomen i förhållande till biologiska, Psykologiska och sociala aspekter. Det är också av stor vikt att man har kunskap om hjärnans utveckling under ungdomsåren. Detta för att ha förståelse för hur ungdomar agerar i olika situationer. Det är också viktigt att lära sig hur man på bästa sätt kommunicerar med ungdomar. För att underlätta att prata med ungdomar om känsliga saker är det viktigt att prata med dem och tystnadsplikt och sekretess. Det finns olika instrument man kan använda i samtal med ungdomar tex. HEADSSSSS H= home E= Education/Exercise/ Eating A= Activities/ambitions D= drugs and alcohol S= sexual health S= suicide and mental health S= sleep S= Safety S= social media. Ett annat instrument som kan användas är STEPP S= sexual maturation and growth T= Thinking E= Education/employment P= Peers/Parents.

Ungdomar med JIA avskyr att vara annorlunda och strävar efter att passa in och vara "normala". Ungdomarna önskar ofta att få information och kunskap om sin sjukdom.

Transition handlar om att lära sig att ta ansvar för sin sjukdom och behandling samt att lära sig att leva med detta.

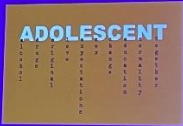
"Transition - it's not about arthritis it's about living with it" *Young person, Shaw KL et al. 2004*



### III. Evidence re: how health professionals can enhance communication with young people to improve health outcomes

3 themes

- Challenges of addressing sensitive aspects of YP lives
- Trust and emotional safety as a prerequisite for effective communication
- Importance of a sense of inclusion and autonomy




Kim B & White K. 2018 (systematic review)

### Growing Up with... JIA

Systematic review of qualitative literature  
27 studies, 542 participants

Main themes:

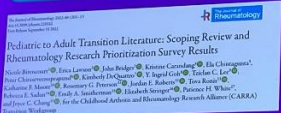
- aversion to being different
- striving for normality
- stigma and misunderstanding
- suspension in uncertainty
- desire for knowledge
- managing treatment



Tong A et al 2012

### Young People have been telling us what we need to know for a long time!

"Transition - it's not about arthritis - it's about living with it" - Young person, Shaw RL et al. 2004



- The transitional care needs of young people, health care teams and caregivers are well described in the literature
- Young people and their caregivers ranked research priorities re: work, school or social function HIGHER than healthcare teams

Bitencourt N, 2022


### Managing Treatment (Tong A 2012)

"We may have effective meds, but if they don't take them...."



- Biological**
  - Brain development
- Psychological**
  - self-concept
  - cognitive thought
  - body image
- Social**
  - relationships with parents, peers, others
  - exploratory behaviours
  - vocation

### Psychosocial screening – the 8<sup>th</sup> vital sign Getting Into Adolescent HEADS<sup>+</sup>



IAAH, Istanbul, 2013

<https://www.health.nsw.gov.au/kidsfamilies/youth/Pages/heedsss-videos.aspx>

- H - Home
- E - Education/Exercise/Eating
- A - Activities/Ambitions
- D - Drugs/alcohol
- S - Sexual health and relationships
- S - Suicide and mental health
- S - Sleep
- S - Safety
- S - Social Media

### STAPP Developmental Assessment

Sexual maturation and growth

- Is the intellectual, pubertal and growth stage appropriate for his/her chronological age?

Thinking

- Is the young person using concrete or abstract constructs?
- Does he/she have sufficient self-esteem and/or future prospect?

Education/Employment

- Is the young person involved in an education/training activity that is, in the cultural context, appropriate for his/her age?

Peers/Parents

- How connected is the young person to the peers and parents?
- Who is responsible for the young person's health care decisions?

## Physical exercise and health outcomes

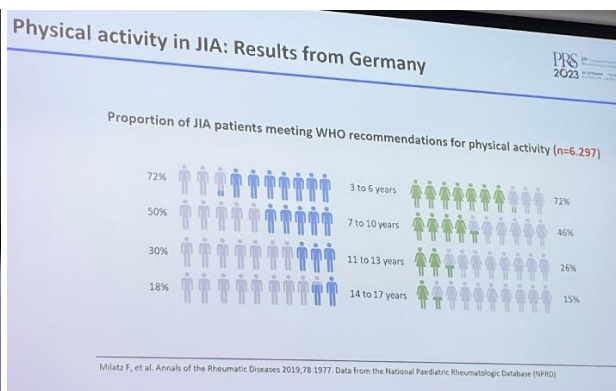
Florian Milatz

Skilj på fysisk aktivitet och fysisk träning. Fysisk aktivitet är alla rörelser även de som man gör i sin vardag. Till exempel gå till bussen eller går i trappor. Rekommendationen är 60 minuters fysisk aktivitet varje dag. Många barn och ungdomar möter inte upp mot dessa rekommendationer. Studien som presenteras visar att ungdomar i Tyskland som har JIA är långt ifrån att leva upp till dessa rekommendationer. Endast 18 % av pojkarna och 15 % av flickorna i åldern 14-17 år når upp till rekommendationen.



- Globally, about 81% of adolescents aged 11-17 years are insufficiently physically active
- 85% of girls and 78% of boys not meeting WHO recommendations on physical activity

[www.who.int/news-room/fact-sheets/detail/physical-activity](http://www.who.int/news-room/fact-sheets/detail/physical-activity)






Tonåringar rapporterar problem med illamående 6 gånger oftare än vuxna. Många för patienten jobbiga biverkningar kommer aldrig fram eftersom ingen frågar. Många har till exempel problem med nedsatt aptit.

### Problem:

- Use of methotrexate ↑ in JIA(U).
- No national (UK) guidelines for use of validated tool for evaluating methotrexate intolerance.
- Gaps in documentation for audit purposes.
- Biologic therapy escalation >10% = side effects. (Falvey et al. 2017, Amin et al. 2015).
- Subjective assessment: Clinician's experience & contemporary knowledge.
  - UK population Rheumatology CNS's = 600, 60% approaching retirement (BSR 2019, HSCIC 2018)
  - 10% specialised in paediatric rheumatology (Livermore 2020).



### Solution:

- Proposed Tool: Methotrexate Intolerance Severity Score** (Bulatović et al. 2011)
  - the only validated method for objective assessment of methotrexate intolerance for paediatric rheumatology.
- However...**
  - Results of UK Paediatric Rheumatology CNS survey (87.5% response rate)
    - Only 17.5% have heard of MISS
    - 0% use MISS
    - Intolerance subjectively assessed in a variety of settings inc. telehealth.
    - Not all side effects reported captured using MISS
  - ↑ risk to patients, service provision and continuity of care.
    - especially when relying on experience to make a subjective assessment.

### Side effects

- Nausea, vomiting, ↓ appetite, fatigue, headaches, diarrhoea, crying, irritability, classic conditioning, anticipatory nausea and refusal (BNFc 2020-21, Kearsley-Fleet et al. 2019, Khan et al. 2019, Bulatović et al. 2011, RCH 2021).
- Routine monitoring (toxicity) (BNFc 2021-22, Ferrara et al. 2018)
- 75% Intolerance = physical & psychological (Kearsley-Fleet et al. 2019, Kyrgaard et al. 2020, Falvey et al. 2017)
- ↑ Intolerance JIA (Kyrgaard et al. 2020, van Dijkhuizen et al. 2015, Bulatović et al. 2011).
- x6 Adolescents vs Adults = ↑ nausea (Falvey et al. 2017),
- Results in ↑ levels of non-adherence. (Falvey et al. 2017, Mulligan et al. 2013)

### Summary:

**Conclusion:**

- The MISS (2011) tool:
  - ✓ The only validated & published tool available.
  - ✓ provides structure to intolerance assessments.
  - ✓ lends itself for use during telehealth consultations.
  - ✗ Didn't capture 5/9 most common side effects. (BNFc 2021-22)
  - ✗ Didn't capture pharmacokinetic & toxicity profile.
  - ✗ Didn't capture 7/11 side effects reported by parents.
  - ✗ Didn't identify 30% intolerant children.

**Recommendations:**

- An improved methotrexate intolerance assessment tool is needed.
- Modifications to incorporate objective measures of methotrexate intolerance (e.g., hepatotoxicity) and subjective patient experience.

## Pain and fear related to long-term needle injections


Kari Sorensen

### Background

**Needle-related pain and fear**  
 The interaction and communication between the child and adults  
 How the procedure is managed  
 The use of evidence-based coping strategies

**Lack of research into long-term injection-based treatment**

Potential risk of non-adherence to treatment based on needle-related pain and fear



Guzman et al., 2015, Becharis et al., 2014, McLennan & Rogers, 2018; McMurtry et al., 2015

### Aims

UNIVERSITY OF OSLO  
 Kari Sorensen  
 Just a little needle stick

To explore:

- The expressions and experiences of needle-related pain and fear in children with rheumatic diseases
- The child-parent-nurse interaction in training sessions
- The families handling of the needle injections at home
- Nurses' perception of their educational role and prerequisites to perform the training sessions

### Design and Methods

An exploratory qualitative design

**Sub-study I**  
 Video observations (9)  
 Children (8), parents (11), nurses (7)  
 How are pain and fear communicated and managed during training sessions and performance of the first medical injection?

**Sub-study II**  
 Individual interviews (15)  
 Focus Groups (4)  
 Children (16), parents (16)  
 How do regular needle injections affect children with RDs and their families in their daily living?

**Sub-study III**  
 Focus groups (3)  
 Nurses (14)  
 How do nurses perceive their educational role, competence and practice in performing patient education for these families?

Thematic Analysis; Interaction Analysis

Braun & Clarke, 2006, Terry et al., 2017, Jordan & Henderson 1995

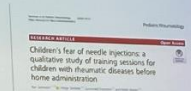
### Paper I - Findings

Children often feared the needle-stick

The stinging pain related to the injection was more bothersome

Children commonly expressed fear indirectly as cues and nonverbal signs

Acknowledging communication, addressing pain and fear, tended to involve the child in decision-making



## Paper II - Findings

Challenges related to technical struggle and emotional distress

- Lacking information and guidance
- Children continued to fear the needle stick
- Coping strategies were used randomly
- Fixed and repetitive routines

## Summary of the findings

Short hospital stays limit the combination of conducting the first injection and patient education at the same time

### Administrating the first injection

- Coping strategies
- Acknowledging communication

### Patient education

- Individual needs
- Web-based information channels

### Nurses' need for pedagogical competence and communication skills

- The child-nurse-parent relationship

Här kommer även några spännande postrar.

### DETERMINANTS OF PARENT/PATIENT OVERALL WELL-BEING POOR RATINGS IN JUVENILE IDIOPATHIC ARTHRITIS PATIENTS WITH INACTIVE DISEASE

Roberta Nadeau<sup>1</sup>, Marco Barroero<sup>2</sup>, Francesca Ribella<sup>3</sup>, Chiara Trifanetti<sup>4</sup>, Cristina Herrera Mora<sup>5</sup>, Clara Malagon<sup>6</sup>, Amparo Iturriz<sup>7</sup>, Olga Arguedas<sup>8</sup>, Nicolò Ruperto<sup>9</sup>, Angelo Ravelli<sup>10</sup>, Alessandro Consolaro<sup>11</sup>

**Background:**

- The patient/parent global assessment of well-being (PAGaW) is one of the outcome measures (PROs) in the management of juvenile idiopathic arthritis (JIA).
- However, its use as a proxy indicator of disease activity in JIA is controversial since PAGaW can be affected by several factors.
- Aim of this study was to identify the determinants of poor PAGaW ratings in patients with inactive disease according to the physician.

**Methods:**

Patients with a physician global assessment indicating inactive disease, enrolled in the epidemiology, treatment and Outcome of Childhood Arthritis (ETOCAR study) were recruited.

- Demographic and clinical features and PROs were compared between subjects with PAGaW 1 and 2.
- To identify variables independently associated with PAGaW 1, a multiple logistic regression analysis was performed, controlling respiratory variables showing significant results in univariate tests ( $p < 0.05$ ).
- A dominance analysis was conducted to rank predictors in terms of their contribution to the overall ranking of the outcome.

**Results:**

- 1177 patients out of the 3,537 (33.3%) had a PAGaW 1.
- An univariate analysis on other age of disease onset and of the visit, LAR category, CRP and morning side effects (SEs) were associated with PAGaW 1 (Table 1).
- Independent associations with a PAGaW 1 were identified for age at visit  $> 7$ , subsequent onset of fever (Ost)  $\geq 10$ , pain VAS  $\geq 4$ , disease activity VAS  $> 7$ , presence of morning stiffness, reduced functional status and quality of life, and presence of at least one SE (Table 1).
- The dominance analysis showed that the most important predictors of poor PAGaW 1 and a quality-of-life score  $> 7$  were the presence of pain VAS  $\geq 4$ , accounting for the 19.5%, the SEs, and the presence of at least one SE (Figure 2).

**Conclusion:**

- Many patients rank the PAGaW 1 in absence of active disease, showing that the patients not always acknowledge of inflammation means remission.
- Pain and impairment of quality of life appear to be the main determinants of this occurrence.
- PAGaW reflects many aspects of the disease burden, including non-inflammatory pain, functional ability, burden, and psychosocial aspects.

**References:**

1. Nadeau R, Barroero M, Ribella F, Trifanetti C, Herrera Mora C, Malagon C, Iturriz A, Arguedas O, Ruperto N, Ravelli A, Consolaro A. Determinants of parent/patient overall well-being poor ratings in juvenile idiopathic arthritis patients with inactive disease. *Ann Rheum Dis*. 2023;72(11):e2023. doi:10.1136/annrheumdis-2023-223023

### Does 'One-Stop' Clinician Ultrasound Scanning Streamline Patient Management in Paediatric Rheumatology Clinics?

Abstract Number: P1022

**Introduction:**

Ultrasound with imaging standardisation by the UMERIC group, has emerged as an indispensable tool in paediatric rheumatology. It:

- Increases UK paediatric rheumatologists in conducting these scans in clinic.
- With survey data shed light on their views, the impact of clinician scanning on patient management is less explored.

**Objectives:**

1. Evaluate effects of in-clinic ultrasound performed by paediatric rheumatologists, focusing on improved communication and patient management.
2. Demonstrate how musculoskeletal ultrasound can expedite diagnosis, hasten treatment decisions and reduce the demand for external scans.

**Methods:**

- Brief anonymous survey filled out by paediatric rheumatologists in a tertiary centre who performed an ultrasound scan in clinic.
- 7 weeks of data collection from analysis in IBM SPSS.

**Results:**

- 38 surveys were collected over 7 weeks
- Mean of 2.8 joints scanned per patient

**Conclusion:**

- Overall, substantial benefits to in-clinic scanning, improved communication between paucity, patients and the paediatric rheumatologist.
- Reduced radiology requests and saved NHS resources.
- Expeditious treatment and minimised patient education disruptions by reducing the number of appointments required.
- Fostered patient understanding and acceptance by educating them about their condition and treatment.
- Enhanced patient confidence which positively influenced treatment adjustments.

**References:**

1. Gattuso J, Noyes L, Wain JG, et al. Standardised musculoskeletal ultrasound in Pediatric Rheumatology: Normal Age-Related Ultrasound Findings. *Arthritis Care Res (Hoboken)*. 2016;28(2):318-36. doi:10.1002/acr.22801

2. Roubicek S, Serrano L, et al. Application of the UMERIC standardised ultrasound scoring system in juvenile idiopathic arthritis: a multicenter reliability exercise. *Rheumatology*. 2020;19(9):1974-87.

