

FAMILY PERSPECTIVES ON THE FEASIBILITY OF

A CORTICOSTEROID INDUCTION REGIMEN TRIAL IN JUVENILE IDIOPATHIC ARTHRITIS

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1. Introduction & Background

- Current delivery routes of corticosteroid treatment for juvenile idiopathic arthritis (JIA) are based on physician and patient preference, rather than scientific evidence.
- This qualitative study aims to inform the development of

PARTICIPANTS' CONCERNS

• Participants tended to describe being more willing to participate at diagnosis than at flare-up. Parents reported diagnosis to be an intensely emotional time, at which they would prefer treatment certainty.

a future trial that will evaluate the most effective routes and doses of CS. In particular, we explored treatment preferences, acceptability of randomisation, willingness to participate, and deliberations regarding outcomes.

2. Methodology

- Semi-structured interviews with a purposive sample of patients and parents (N = 28) recruited via rheumatology clinics at four UK sites (9 children and 19 parents).
- Eligible families had children aged 1-16 years (although for children aged 7 years or less only the parents were interviewed), with recent experience (< 12 months) of CS treatment and either recent JIA diagnosis or flare.
- Interviews were audio recorded and transcribed. Data analysis drew on thematic analysis techniques.

VIEWS ON DELIVERY ROUTES

Participants typically reported being less willing to participate at flare-up. Prior experience of delivery routes influenced perceptions of future treatment efficacy.

Five overarching themes emerged as key trial concerns:

Treatment suitability "He had inflammation in about 36 joints... they said... 'give him some kind of aggressive treatment'. So that's what they addressed [IV] as - aggressive treatment" (Parent 9)

•Treatment interactions "I don't know, would they stop the Methotrexate or would they just carry it on?" (Parent 4)

Randomisation "Computers wouldn't [know] what it's doing... whereas a person... they'd know themself if they'd trained for years"

Travel/time "I work full time... they're very restricted of what time you can have off" (Parent 6)



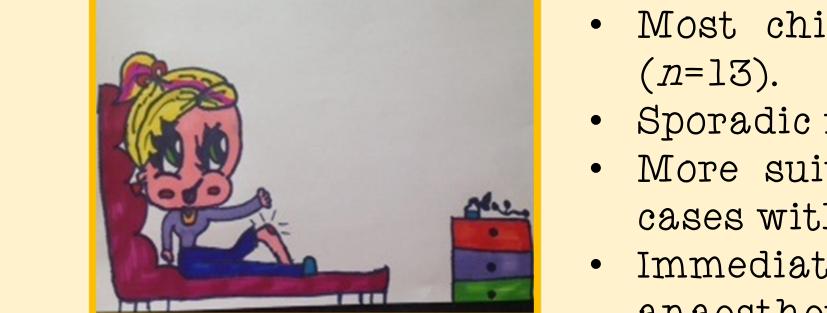


Quality of care

"I'd kind of probably take part in it... 'cause think if something didn't work on me I know that they'd just like, if I needed to they'd just put me on something else like in the end...?" (Child 9)

4. Conclusion





Intra-articular injection (IA)

- Most children had first-hand experience
- Sporadic relief.
- More suitable for severe joint flares and cases with few affected joints.
- Immediate effect but trepidation about anaesthetic.

Methylprednisolone (tablets)

- Most children had first-hand experience (*n*=10).
- Often deemed ineffective.
- Less intensive and unsuitable for severe flares. Convenient but side effects were a concern.



• No family appeared in equipoise regarding the delivery routes, largely due to previous treatment experiences.

- Recruitment of patients with flaring disease to a future trial will likely be challenging; treatment experience-based rather preferences were typically than anticipated.
- A key question clinicians will need to answer is: "If it's not worked this time, what makes them think it's going to work the second time?" (Parent 6).
- Confidence and reassurance from clinicians regarding treatment credibility and trial legitimacy could be key



Intravenous Injection (IV)

- Half of children had first-hand experience.
- More intensive, fast-acting but sporadic in its relief.
- Those with experience reported facial puffiness and weight gain.
- Those without experience queried its suitability for young children.

Intra-muscular Injection (IM)

- Three children had first-hand experience (all >10 years old).
- Reported and perceived as fast-acting.
- One child said it was painful.
- No reported or perceived side effects.



to participation willingness in a future trial.

About Juvenile Idlopathic Arthritis (JIA)

JIA is a heterogeneous collection of diseases affecting 15,000 children in the UK. Common symptoms include: joint pain, swelling and stiffness. Corticosteroids (CS) can help to achieve rapid disease control in children presenting with new or flaring JIA.

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