Early recognition and detection of juvenile psoriatic arthritis: a call for a standardized approach to screening

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Summary

Background. National Institute for Health and Care Excellence (NICE) guidelines recommend annual screening for psoriatic arthritis (PsA) in all patients with psoriasis. Currently, no validated assessment tools have been recommended for screening for juvenile PsA (JPsA).

Aim. To determine dermatologists’ practice when assessing children’s joints and explore the challenges dermatologists experience when looking for joint disease, in order to inform future strategies to improve early detection of arthritis.

Methods. Structured telephone interviews were undertaken with dermatologists identified through the British Society of Paediatric Dermatology. Percentages for binary and categorized responses were calculated. Thematic content analysis was used to generate a set of core themes across the interview data.

Results. Of the 41 consultant dermatologists contacted, 23 agreed to be interviewed. Of these, 78% (18/23) reported they routinely ask about joint disease. Only 13% (3/23) routinely examine the joints of children with psoriasis. Overall, assessment for JPsA lacked a structured, evidence-based approach. The average confidence rating for assessing joint disease was low (score of 3). The two key barriers described for detecting arthritis were a lack of experience and training, and subtle or difficult to detect signs. The two main suggestions for improving detection were the introduction of an assessment tool/guideline and increased clinical experience and training.

Conclusion. There is a clear need for dermatologists to use a standardized approach for screening and to increase their confidence in paediatric musculoskeletal examination. In this article, we provide guidance on screening for psoriatic arthritis in children based on our clinical experience.

Introduction

Psoriasis affects people of all ages. The estimated prevalence of psoriasis in children is 0.5–2.15%.1 Psoriatic arthritis (PsA) is known to be associated with psoriasis,2,3 and is considered less common in children than in adults. National Institute for Health and Care Excellence (NICE) psoriasis guidelines recommend annual assessment for psoriatic arthritis.4 For adults, validated screening tools, such as the Psoriasis Epidemiology Screening Tool (PEST) questionnaire,5 are available, but currently there are no validated tools recommended for use in paediatric dermatology.

Juvenile PsA (JPsA) is defined as an idiopathic inflammatory arthritis diagnosed in a child aged < 16 years in the presence of psoriasis or two or more supporting features: presence of nail pitting, onycholyisis, dactylitis, or a family history of psoriasis in a first-degree relative6 (Table 1). Published literature on JPsA...
is limited, and the presentation can include oligoarticular, polyarticular and enthesis-related arthritis.7–9 It is recognized that JPsA is a destructive arthropathy, which can lead to permanent damage if left untreated. A delayed diagnosis of inflammatory arthropathy can result in poorer long-term outcomes and disability.3,10–12 Negative outcomes in JPsA include impaired physical health and a greater need for disease-modifying medications as well as reduced quality of life and higher unemployment.3,10,13 Therefore, early detection of JPsA in at-risk populations is important.

Our first objective was to determine dermatologists’ routine practice when screening for JPsA. Second, we aimed to explore the challenges dermatologists experience when assessing joints in children, in order to inform future strategies to improve early detection of arthritis.

Methods

Elite interviews were undertaken with consultant members of the British Society of Paediatric Dermatology (BSPD).14 To ensure a good geographical distribution of participants and only one response per paediatric dermatology department, 41 consultant dermatologists were contacted. These members had previously confirmed in a BSPD audit or survey to be the consultant contact for paediatric psoriasis at their centre. An email invitation was sent explaining the format, purpose and intended audio recording of the interview. No incentive was offered for participation. A telephone appointment was made with those who responded.

Verbal consent was obtained at the beginning of each recording and to ensure anonymity, a unique identifier was assigned in place of the participant’s name. Ethics approval was not sought as participation in this survey of current practice and opinion was consistent with a dermatologist’s role as a health professional.

All interviews were conducted by one author (EBT) between March and July 2015. The interviews took between 15 and 30 min each, and followed a written interview guide containing open and closed questions. Audio recordings were transcribed as intelligent verbatim transcription.

Statistical analysis

Quantitative

The interview guide included questions about: (i) the dermatologist’s routine practice; (ii) reasons why detecting JPsA may be difficult and suggestions for improvement; and (iii) clinical presentation of JPsA, implications for management and long-term health outcomes. The responses were categorized and percentages calculated for these and binary responses. We calculated a mean average Likert response for dermatologists’ confidence when assessing for joint disease (1 = not at all confident to 10 = very confident).

Thematic

Thematic content analysis, using the five steps described by Braun and Clarke,15 was applied to the transcripts to identify common themes across the interviews. The first stage was familiarization, followed by generating initial codes, then searching for, reviewing, defining and naming themes. This is an established method often used to elicit rich data that quantitative analysis cannot do alone.15

Results

Quantitative results

Of the 41 consultant dermatologists contacted, 23 agreed to be interviewed. A good geographical distribution across the UK was achieved: England (18), Wales (2), Scotland (2) and Northern Ireland (1). Of the 23 dermatologists who participated, 17 (74%) were female and 16 (70%) were the clinical lead for paediatric dermatology at their centre. Twelve dermatologists (52%) worked in a secondary referral centre, two (9%) in a tertiary referral centre, and nine (39%) in both. The average number of children with psoriasis seen by each dermatologist per month was 4 (range...
Routine assessment

In total, 18 (78%) dermatologists routinely ask children with psoriasis about joint disease (Table 2). Of participants who work solely in a secondary referral centre \((n = 12)\), 7 (58%) routinely ask children with psoriasis about joint disease compared with all (100%) of those who work in a tertiary centre or in both \((n = 11)\). Of these, 13/18 (72%) ask new patients about joint disease, but only four (22%) always ask about joint disease at every visit and one (4%) replied that they often ask. About half (52%; 12/23) ask about a family history of PsA. The number who routinely examine for arthritis is low \((n = 3; 13\%)\).

Six clinicians (26%) have used or know of a screening/assessment tool; of those, four mentioned PEST and one cited a locally modified PEST that includes assessing for axial disease. The three dermatologists who routinely examine for arthritis described their assessment as ‘move and feel’ with particular focus on the small joints; however, no systematic approach was described.

Barriers to assessing for joint disease in children with psoriasis

Inexperience and a lack of training in musculoskeletal examination were identified as reasons why detecting arthritis may be difficult (Table 2). Addressing these were the two main suggestions for improving detection. On average, dermatologists rated their confidence in assessing joint disease in children as 3 (response range of 1–7).

Presentation of juvenile psoriatic arthritis and management implications

Most dermatologists (70%) felt that psoriasis presents before arthritis, but many commented that their perception might reflect referral bias (Table 2). Overall, participants were often unsure or felt that no particular pattern was associated with the presentation of skin \((n = 38; 35\%)\) or joint \((n = 312; 52\%)\) disease in JPsA.

The majority \((n = 316; 70\%)\) of dermatologists said that the presence of JPsA would change their management of psoriasis. Three participants \((13\%)\) said they would initiate more aggressive management if JPsA was present.

A relatively high proportion of participants \((n = 315; 65\%)\) were unsure about the long-term health outcomes for children with psoriasis and psoriatic arthritis.

Thematic analysis

The qualitative analysis generated four main themes: (i) identity and attitudes, (ii) knowledge, (iii) barriers to action and (iv) age-specific differences in managing children compared with adults with psoriasis. The themes are presented in Table 3. Respondent quotations were used to substantiate each theme and sub-theme. Saturation of themes was achieved.

Confidence was an important subtheme. Low confidence often related to limited training and guidance. As a consequence, participants felt they did not have a systematic approach to their assessment. Uncertainty was also an important subtheme. Clinicians were unsure about the clinical presentation of JPsA and the long-term health outcomes. Uncertainty appeared to originate from: (i) limited personal experience of managing children with JPsA, (ii) limited long-term follow-up of children with psoriasis, and (iii) limited published evidence about the relationship between psoriasis and PsA in children.

In specific regard to the subtheme set up of paediatric services, none of the dermatologists interviewed offer a combined paediatric dermatology/rheumatology clinic at their centre. Many share care between the two specialties for children with skin and joint disease. Direct contact between consultants varies from referral by letter to direct contact.

Discussion

To our knowledge, this research is the first study to detail dermatologists’ experiences of assessing for JPsA in children with psoriasis. The interviews demonstrate that although most clinicians routinely ask about joint disease, their assessment focuses on new patients, asking about joint pain and with a reliance on symptoms to prompt an examination. However, no structured and consistent approach to assessment was described.

Dermatologists rated their confidence in assessing for arthritis as low. Low confidence was also an important subtheme in the qualitative analysis. In part, low confidence may originate from a lack of experience and a concern that the physical signs of arthritis may be subtle or difficult to detect; these were the two main reasons dermatologists described as to why detecting JPsA may be difficult. The two key suggestions to improve detection were the introduction of an
Table 2 Responses to questions about assessment for juvenile psoriatic arthritis.

| Interview question                                                                 | Responses                                                                 | n (%)  |
|------------------------------------------------------------------------------------|---------------------------------------------------------------------------|--------|
| How would you ask a child or their parents about joint disease?†                  | Ask about symptoms:                                                      | 19 (83)|
|                                                                                   | Pain or soreness                                                          | 19 (83)|
|                                                                                   | Swelling                                                                  | 9 (39)|
|                                                                                   | Redness                                                                   | 4 (17)|
|                                                                                   | Stiffness                                                                  | 3 (13)|
|                                                                                   | Morning stiffness                                                         | 1 (4)|
|                                                                                   | Specific sites of symptoms eg hands, heel                                  | 5 (22)|
|                                                                                   | Ask about limitations on activity                                          | 7 (30)|
|                                                                                   | Ask about not meeting expectations for mobility                            | 6 (26)|
|                                                                                   | Ask an open question, eg ‘any problems’?                                   | 2 (9)|
| In your experience are there any reasons why you may find detecting psoriatic arthritis in children with psoriasis difficult?† | Lack of experience or training in joint assessment                         | 11 (48)|
|                                                                                   | Physical signs may be subtle or difficult to detect in children            | 6 (26)|
|                                                                                   | Lack of awareness of the association between psoriasis and juvenile psoriatic arthritis by family and clinicians | 4 (17)|
|                                                                                   | Communication with children more difficult                                 | 4 (17)|
|                                                                                   | Alternative diagnoses for joint symptoms                                   | 4 (17)|
|                                                                                   | Other: e.g. reliance on the rheumatology department; limited time in clinic; limited investigations | 5 (22)|
|                                                                                   | No difficulties experienced                                                | 2 (9)|
| Can you make any suggestions about what would help you detect joint disease in children with psoriasis?† | Assessment tool/guideline                                                 | 14 (61)|
|                                                                                   | Clinical training or experience                                            | 8 (35)|
|                                                                                   | Other: e.g. education through national meetings; simple investigations; improved identification of at-risk children | 5 (22)|
|                                                                                   | No suggestion given                                                        | 2 (9)|
| In your experience, do you feel skin signs or joint signs develop first in children with psoriatic arthritis?† | Psoriasis first                                                            | 16 (70)|
|                                                                                   | Unsure about order of presentation                                         | 5 (22)|
|                                                                                   | Joints first                                                               | 1 (4)|
|                                                                                   | Simultaneous presentation                                                  | 1 (4)|
| In your experience do you feel there are any particular skin patterns in children with psoriatic arthritis?† | Unsure or no pattern associated                                            | 8 (35)|
|                                                                                   | Acral                                                                     | 3 (13)|
|                                                                                   | Nail                                                                      | 3 (13)|
|                                                                                   | Severe psoriasis                                                          | 3 (13)|
|                                                                                   | Chronic plaque                                                            | 2 (9)|
|                                                                                   | Scalp                                                                     | 2 (9)|
|                                                                                   | Less likely to occur with guttate psoriasis                               | 2 (9)|
|                                                                                   | Other: localized, flexural, correlation between sites of psoriasis and arthritis | 3 (13)|
| In your experience do you feel there are any particular joint patterns in children with psoriatic arthritis?† | Unsure or no pattern associated                                            | 12 (52)|
|                                                                                   | Small joint disease                                                       | 5 (22)|
|                                                                                   | Monoarthritis                                                             | 3 (13)|
|                                                                                   | Enthesitis                                                                | 3 (13)|
|                                                                                   | Knee                                                                      | 2 (9)|
|                                                                                   | Other: elbow, ankles, dactylitis, widespread, mutilating                  | 5 (22)|
| In your experience, what are about the long-term outcomes in children with psoriasis and psoriatic arthritis?† | Unsure                                                                    | 12 (52)|
|                                                                                   | More likely to have severe and persistent psoriasis                       | 11 (48)|
|                                                                                   | Poorer compared to children with psoriasis alone                          | 6 (26)|
|                                                                                   | Increased concern about comorbidities                                     | 4 (17)|
|                                                                                   | Psoriasis is likely to do well on rheumatological drugs                   | 4 (17)|
|                                                                                   | Other: increased need for aggressive treatment, joint disease can be disabling, poorer quality of life | 6 (26)|

*From 23 dermatologists; †more than one option possible.
assess tool/guideline and increased clinical training/experience of joint assessment.

Dermatologists commonly associate inflammatory arthritis with pain or soreness, but joint swelling or loss of function are often more indicative of joint inflammation. Clinicians would therefore benefit from clearer guidance about core questions to ask in the history when assessing for inflammatory arthritis.

| Theme                  | Subtheme                                                                 | Example participant answers                                                                 |
|------------------------|--------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| Identity/attitudes     | Confidence: low confidence due to limited training and guidance          | 'I'm not that confident' [P3]                                                               |
|                        |                                                                         | 'I don't think I would ever be confident examining joints or be confident clinically' [P9]  |
|                        |                                                                         | 'I don't regard myself as doing a proper musculoskeletal examination' [P1]                |
| Awareness              | opinions on ease of detecting juvenile psoriatic arthritis varied, but the need for vigilance by clinicians and families for juvenile psoriatic arthritis was recognized | 'I think we would be able to tell if there is a serious inflammatory joint problem' [P4]   |
|                        |                                                                         | 'You may not see inflammation as easily [P6]                                               |
|                        |                                                                         | 'I do highlight to parents at the first visit that there can be a link and it is important if they develop any joint symptoms or signs to check it' [P6] |
| Division of roles      | joint assessment and examination was strongly considered the role of paediatric rheumatology | 'If there is evidence of arthritis I hand them off to the rheumatologists' [P3]              |
|                        |                                                                         | 'Because we work so closely I've never really taken it on board (assessment of joints)' [P1] |
| Knowledge              | Uncertainty: participants were unsure about the clinical presentation and long-term health outcomes | 'I don't know, I haven't seen enough to give a valid answer for that' [P17]                |
|                        |                                                                         | 'I don't think I can answer that because I am not involved enough in follow-up' [P1]       |
|                        |                                                                         | 'what information about psoriatic arthritis starting in children and how is the natural history of this condition progressing on to adulthood, I don’t think there is hardly any data' [P3] |
| Treatment              | choice of treatment was influenced by knowledge and understanding of the disease | 'Much more likely to go to methotrexate early if they have arthritis rather than phototherapy' [P2] |
|                        |                                                                         | 'In the long term their skin does better than children who are not treated early with a systemic' [P1] |
| Disease impact         | disability and challenging management                                    | 'I have seen some horrible permanent joint deformity with very, very, significant impact on function' [P6] |
|                        |                                                                         | 'you know these are going to be difficult cases for life' [P22]                            |
| Barriers to action     | Signs and symptoms                                                      | 'if they've had any joints that are sore, swollen or red' [P9]                             |
|                        |                                                                         | 'if they specifically said one joint was troublesome then I would look more carefully at that' [P7] |
|                        | Set-up of paediatric services                                           | 'We do a joint paediatric rheumatology-dermatology clinic every 3 months' [P6]  |
|                        | Variation in the working relationship between specialties and opportunity for training | 'They aren’t geographically particularly close .... I know the name of the paediatric rheumatologist but I’ve never met them’ [P8]. |
| Age-specific differences | Differences in consultation requirements and presentation of disease     | 'Children won’t necessarily localize pain or be able to describe joint pain in the same way as an adult’ [P4] |
|                        |                                                                         | 'I think often the parental anxiety and involvement can be really difficult' [P5]          |
|                        |                                                                         | 'You may not see inflammation as easily particularly if they are chubby, little tiny ones’ [P6] |
Therefore, we recommend that dermatologists include the questions listed in Table 4 when screening for arthritis.

Currently, there are no validated assessment tools recommended to screen for JPsA in paediatric dermatology clinics. Paediatric rheumatologists recommend the use of the Paediatric Gait Arms Legs Spine (pGALS) tool to screen for all types of joint disease in children.\textsuperscript{16} pGALS is a quick, simple and validated musculoskeletal assessment to be used by non-specialists to distinguish abnormal from normal joints in children, which might not be apparent from the history alone. On average, pGALS takes 2 min to perform, and specific manoeuvres to check for juvenile idiopathic arthritis are included.\textsuperscript{17} There is a full educational support package available online or on DVD to teach clinicians how to perform a pGALS examination.\textsuperscript{18} When dermatologists were asked directly about screening or assessment tools for JPsA in children, none suggested pGALS. Owing to dermatologists’ lack of awareness of an examination-based tool and their low confidence in assessing joint disease, successful implementation of pGALS would benefit from a national strategy of dissemination and education among paediatric dermatologists.

PEST\textsuperscript{5} or a modified PEST had been used by five dermatologists. However, the sensitivity and specificity of PEST as a screening tool for JPsA is unknown, and the distinction of JPsA from that of adult PsA is supported by a different genetic basis and clinical presentation.\textsuperscript{6,19} Further evaluation of the utility of PEST as a screening tool, especially for adolescents, should be considered, as there has already been early adoption of this tool by dermatologists.

The absence of a screening tool specifically designed or validated for JPsA is a current evidence gap. It is unknown whether a questionnaire-based or examination-based approach is best for use in paediatric dermatology clinics. In view of this lack of guidance, until further research is conducted, we have laid out a structure for assessing for joint disease in children with psoriasis based on our clinical experience (Table 4).

The published literature on the clinical presentation of skin and joint disease in JPsA and on the long-term outcomes for children with both diseases is extremely limited. The evidence about the temporal relationship between the onset of psoriasis and arthritis is varied, and it is unclear if associations such as intergluteal/peri-anal, scalp and nail psoriasis hold true in the paediatric population.\textsuperscript{20,21} This correlates with dermatologists’ uncertainty, and supports the genuine need for further studies to evaluate the clinical presentation and potential risk factors for developing psoriatic arthritis in childhood.

These interviews were undertaken with a geographically diverse and institutionally varied group of dermatologists, suggesting that the participants’ views and practices are likely to be representative of paediatric dermatologists in the UK. Interviews with 23 participants provided a rich and detailed dataset and saturation of themes was achieved; this sample size is accepted for elite interview qualitative research.\textsuperscript{14} However, it is likely that those who participated in the interviews are more likely to have a specialist interest in JPsA and therefore implement best practice. The effect of this difference would be to minimize rather than augment the conclusions of these interviews. No specific data was collected on nonresponders, but geographical and sex (74\% vs. 67\% female) representation was similar between both groups.

**Table 4** Recommendations for assessing for juvenile psoriatic arthritis in children with psoriasis.

| Focus on the following questions in the clinical history |
|----------------------------------------------------------|
| Swelling and stiffness of joints                          |
| Difficulties getting up and moving in the mornings or after a period of rest |
| Any problems with daily activities or taking part in sport |
| Difficulties holding a pen, or development of a swollen ‘sausage’ finger/toe |

Ask about a family history of psoriasis and psoriatic arthritis

Consider performing a Paediatric Gait Arms Legs Spine (pGALS) assessment if undertaken relevant training\textsuperscript{16–18}

Gait: observe the patient walking

Arms: upper limb movements with specific movements for the hands

Legs: lower limb movements including the hips

Spine: movement of the whole spine

Consider using the Psoriasis Epidemiology Screening Tool (PEST) in young people (12–18 years old)\textsuperscript{5}

Refer to the paediatric rheumatology department if any signs or symptoms are elicited.
Conclusion

Our findings support the need for a standardized approach to annual screening for JPsA. There is a need to evaluate current screening tools used outside dermatology (pGALS) or in adults (PEST) for their suitability to be used in paediatric dermatology clinics. In the interim, we have provided recommendations for the assessment of JPsA and encourage a closer working relationship with colleagues in paediatric rheumatology.

What’s already known about this topic?

- NICE guidelines recommend annual screening for psoriatic arthritis in all patients with psoriasis.
- Validated screening tools, such as PEST, have been developed for use in adult dermatology clinics.
- No screening tools are currently recommended for use in paediatric dermatology clinics.
- pGALS is a quick, simple and validated musculo-skeletal assessment to be used by non-specialists to distinguish abnormal from normal joints in children.

What does this study add?

- This study shows that dermatologists are asking about joint disease, but the current approach is not structured or standardized.
- Dermatologists suggested an assessment tool/guideline and training to improve early detection of juvenile psoriatic arthritis.
- There is a need to increase dermatologists’ confidence in paediatric musculoskeletal examination; this will be of particular importance if an examination-based screening tool such as pGALS is recommended.
- We provide guidance on how to screen for JPsA based on our clinical experience.

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