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

Running head: Screening for JPsA

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What's already known about this topic?

- NICE guidelines recommend annual screening for psoriatic arthritis for all patients with psoriasis
- Validated screening tools, such as the Psoriasis Epidemiology Screening Tool (PEST), have been developed for use in adult dermatology clinics
- No screening tools are currently recommended for use in paediatric dermatology clinics
- The Paediatric Gait Arms Legs Spine (pGALS) is a quick simple validated musculoskeletal 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 standardised
- 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
- Guidance on how to screen for psoriatic arthritis in children based on the authors' clinical experience.

Abstract

Introduction

National Institute for Health and Care Excellence (NICE) guidelines recommend annual screening for psoriatic arthritis in all patients with psoriasis. Currently, no validated assessment tools have been recommended for screening for juvenile psoriatic arthritis (JPsA). Our first objective was to determine dermatologists practice when assessing children's joints. Second, we aimed to explore the challenges dermatologists experience when looking for joint disease 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 categorised responses were calculated. Thematic content analysis was used to generate a set of core themes across the interview data.

Results

Twenty three of the 41 consultant dermatologists contacted agreed to be interviewed. Seventy eight percent (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 (3). The two key barriers described for detecting arthritis were 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 standardised approach for screening and to increase their confidence in paediatric musculoskeletal examination. Based on the authors' experience, guidance is provided on screening for psoriatic arthritis in children.

Introduction

Psoriasis affects patients of all ages. The estimated prevalence of psoriasis amongst children is between 0.5 and 2.15% [1]. Psoriatic arthritis is a known associated disease in patients with psoriasis [2,3] and is considered less common in children compared to adults. National Institute for Health and Care Excellence (NICE) psoriasis guidelines recommend annual assessment for psoriatic arthritis [4]. In adults validated screening tools are available, for example the Psoriasis Epidemiology Screening Tool (PEST) questionnaire [5], however currently no validated tools are recommended for use in paediatric dermatology.

Juvenile psoriatic arthritis (JPsA) is defined as an idiopathic inflammatory arthritis diagnosed in a child under 16 years and the presence of psoriasis or two supporting features: family history of psoriasis in a first degree relative, nail pitting, onycholysis, dactylitis [6] (Figure 1). Published literature on JPsA is limited and the presentation can include oligoarticular, polyarticular and enthesitis-related arthritis [7-9]. It is recognised that JPsA is a destructive arthropathy, can lead to permanent damage if left untreated and a delayed diagnosis of an inflammatory arthropathy can result in poorer long-term outcomes and disability[3,10-12]. Negative outcomes in JPsA include poorer physical health and a greater need for disease modifying medications as well as poorer 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 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 that 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. Ethical approval was not sought as this survey of current practice and opinion and falls within a dermatologist's role as a health professional.

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

Analysis

Quantitative

The interview guide included questions on: i) dermatologists routine practice; ii) reasons why detecting JPsA may be difficult and suggestions for improvement; iii) clinical presentation, implications for management and long-term health outcomes. The responses were categorised 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)). All quantitative data was analysed using basic descriptive statistics (Microsoft Excel 2010).

Thematic analysis

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 familiarisation, followed by generating initial codes, searching for themes, reviewing themes, and defining and naming themes. This is an established method often used in eliciting rich data that quantitative analysis cannot do alone [15].

Results

Quantitative

A total of twenty three consultant dermatologists were interviewed. A good geographical distribution across the UK was achieved: England (18), Wales (2), Scotland (2) and Northern Ireland (1). Seventeen dermatologists (74%) were female. Sixteen dermatologists (70%) were clinical lead for paediatric dermatology at their centre. Twelve (52%) worked in a secondary referral

centre, two (9%) in a tertiary referral centre, and nine (39%) in both. The average number of children seen by each dermatologist with psoriasis per month was four (range 1 to 10). Nine dermatologists currently have children with psoriasis and psoriatic arthritis under their care.

Routine assessment (Table 1)

In total 18 (78%) dermatologists routinely ask children with psoriasis about joint disease. Of participants who worked solely in a secondary referral centre (n=12), 7 (58%) routinely ask children with psoriasis about joint disease compared to all of those who work in a tertiary centre or both (n=11). Of these, 13/18 (72%) ask new patients, but only four (22 %) always ask about joint disease at every visit and one replied often (4%). About half, 12/23 (52%), ask about a family history of psoriatic arthritis. The number who routinely examine for arthritis is low (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 to cover for axial disease. 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 joint disease in children with psoriasis (Table 1)

Inexperience and lack of training in musculoskeletal examination were identified as reasons why detecting arthritis may be difficult. Addressing these were the two main suggestions for improving detection. On average dermatologists rated

their confidence in assessing joint disease in children at 3 (response range 1 to 7).

Presentation of JPsA, implications for management of the skin and long-term outcomes health outcomes (Table 2)

Most dermatologists (70%) felt that psoriasis presents before arthritis, but many commented that their perception might reflect referral bias. Overall participants were often unsure or felt no particular pattern was associated with the presentation of skin (8 (35%)) or joint disease (12 (52%)).

The majority (16, (70%)) of dermatologists said that the presence of JPsA would change their management of psoriasis. Three (13%) participants said they would initiate more aggressive management if JPsA was present.

A relatively high proportion of participants (15, (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; iv) age specific differences in managing children compared to adults with psoriasis. The themes are presented in Table 3. Respondent quotations are used to substantiate each theme and subtheme. 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) a limited personal experience of managing children with JPsA; ii) limited long-term follow-up of children with psoriasis; iii) limited published evidence about the relationship between psoriasis and psoriatic arthritis in children.

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

Discussion

This research is the first study to detail dermatologists experiences of assessing for JPsA in children with psoriasis. The interviews demonstrate that whilst most clinicians routinely ask about joint disease their assessment focuses on new patients, asking about joint pain and relying 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 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 assessment tool/guideline and to improve clinical training/experience of joint assessment.

Dermatologists commonly associate inflammatory arthritis with pain or soreness; however these are not the most important differentiating symptoms. Joint swelling or loss of function are often more indicative of the presence of joint inflammation. Clinicians would therefore benefit from clearer guidance about core questions to ask when assessing for inflammatory arthritis in the history. We recommend that dermatologists include the questions listed in Figure 2 when asking about joint disease.

Currently there are no validated assessment tools recommended to screen for JPsA in paediatric dermatology clinics. Paediatric rheumatologists recommend the use of Paediatric Gait Arms Legs Spine (pGALS) tool to screen for all types of joint disease in children [16]. pGALS is a quick simple validated musculoskeletal assessment to be used by non-specialists to distinguish abnormal from normal joints in children, that might not be apparent from the history alone. On average pGALS takes 2 minutes to perform and specific manoeuvres to cover juvenile idiopathic arthritis are included [17]. There is a full educational support package available online or through DVD to teach clinicians how to perform a pGALS examination [18]. When participants were asked directly about screening or assessment tools to look for JPsA in children none suggested pGALS. Due to dermatologist's lack of awareness of an examination based tool and low confidence in assessing joint disease, successful implementation of pGALS would

benefit a national strategy for dissemination and education amongst paediatric dermatologists.

The Psoriasis Epidemiology Screening Tool (PEST) questionnaire [5] or a modified PEST had been used by five dermatologists. Its sensitivity and specificity as a screening tool for JPsA is unknown, and JPsAs distinction from adult psoriatic arthritis is supported by a different genetic basis and clinical presentation[6,19]. However, further evaluation of the PEST questionnaires utility as a screening tool, especially for adolescents, should be considered since there has already been early adoption amongst dermatologists.

The absence of screening tool specifically designed or validated for JPsA is a current evidence gap. It is unknown whether a questionnaire 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 (Figure 2).

Published literature is also extremely limited on the clinical presentation of skin and joint disease in JPsA, and the long-term outcomes for children with both diseases. The evidence about the temporal relationship between the onset of psoriasis and arthritis is varied and it is unclear if associations such as intergluteal/perianal, scalp and nail psoriasis with psoriatic arthritis hold true in the paediatric population [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.

The interviews were undertaken with a geographically diverse and institutionally varied group of dermatologists, suggesting that 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[14]. However, it is likely that those who participated in the interviews are more likely to have a specialist interest in childhood psoriasis and therefore implement best practice. The effect of this difference would be to minimise rather than augment the conclusions of these interviews. No specific data was collected on non-responders, but geographical and gender (74% vs 67% female) representation was similar between both groups.

In conclusion, our findings support the need for a standardised approach for 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.

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Interview question	Responses	Number of responses, n=23 (%)
How would you ask a child or their parents, about joint disease?	Ask about symptoms: • Pain or soreness • Swelling • Redness • Stiffness • Morning stiffness • Specific sites of symptoms eg hands, heel	19 (83%) 19 (83%) 9 (39%) 4 (17%) 3 (13%) 1 (4%) 5 (22%)
	Limitations on activity	7 (30%)
	Not meeting expectations	6 (26%)
	Open question '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%)
	More difficult communication with children	4 (17%)
	Alternative diagnoses for joint symptoms	4 (17%)
	Other: eg rely on rheumatology, time limited 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: eg education through national meetings, simple investigations, improved identification of at risk children	5 (22%)
	No suggestion given	1 (4%)

Table 1: Responses to questions asked about how joint disease is routinely assessed, difficulties experienced when assessing for joint disease and suggestions to improve the detection of joint disease in children with psoriasis

Interview question	Response	Number of responses, n (%)
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: localised, 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%)

Table 2: Responses to questions about the clinical presentation of juvenile psoriatic arthritis and long-term health outcomes. *More than one response possible

Theme	Subtheme	Example participant quotations
Identity and 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 is recognised	'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 associated with 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** 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 is 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** Reliance on a history of joint symptoms to prompt examination	'if they've had any joints that are sore, swollen or red' [P9] 'if the specifically said one joint was troublesome then I would look more carefully at that' [P7]
	Set-up of paediatric services Variation in the working relationship between specialties and opportunity for training	'we do a joint paediatric rheumatology-dermatology clinic every three months' [P6] '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 localise 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]

Table 3: Main themes and subthemes from thematic analysis of interviews

Figure 1: A summary of the International League of Associations of Rheumatology (ILAR) diagnostic criteria for juvenile psoriatic arthritis [6]

Age at onset is under 16 years, disease duration is 6 weeks or greater, and other known conditions are excluded
AND psoriasis
OR two of the following dactylitis, nail pitting, onycholysis, and/or family history of psoriasis (in a first-degree relative)
EXCLUDING Ankylosing spondylitis, enthesitis-related arthritis, sacroiliitis with inflammatory bowel disease, Reiter's syndrome, acute anterior uveitis

Figure 2: 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 day to day activities and taking part in sport Difficulties holding a pen or developing 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 [16,17] 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) [5]
Refer to paediatric rheumatology if any signs or symptoms elicited