A qualitative study of patients’ experiences of screening for psoriatic arthritis

DOI: 10.1111/bjd.21825

DEAR EDITOR, Psoriatic arthritis (PsA) is a chronic inflammatory arthritis which can cause pain, fatigue, swelling and stiffness in the joints, and can result in limited physical function and a high psychosocial burden. Patients with psoriasis are at greater risk of developing PsA than those without.

There is no definitive test for PsA. A diagnosis is made by rheumatologists after referral from primary care based on the patient’s medical history, a physical examination, blood tests, a magnetic resonance imaging (MRI) scan and X-rays. Delays can be due to patient-related factors (e.g. reluctance to seek medical help) and clinician-related factors (e.g. the lack of autoimmune diagnostic markers). Even a 6-month delay from symptom onset can result in worse long-term physical function.

The PROMPT programme (National Institute for Health Research grant: RP-PG-1212-20007) is investigating the clinical and cost benefits of early detection of PsA. The main study is a two-arm parallel-group cluster randomized controlled trial (RCT) of screening (known as TUDOR), using enhanced surveillance for PsA in primary care vs. standard care. Screening included an examination of participants’ skin, joints, hands, feet, scalp, physical tests (e.g. touching toes), height and weight measurement, blood tests, X-rays, MRI scans and questionnaires. An important aspect of TUDOR is understanding whether screening would be acceptable to patients with psoriasis, some of whom will be diagnosed with PsA as a result and some of whom will not. The aim of this study was to understand the experience of screening from the perspective of participants with psoriasis recruited to the enhanced surveillance arm in the TUDOR RCT.

The study was approved by the Proportionate Review Subcommittee of the North East–Newcastle & North Tyneside 1 Ethics Committee (reference 16/NE/0393) and the Health and Applied Sciences Faculty Research Ethics Committee of the University of the West of England (reference: HAS.17.03.129). A qualitative design was used. Data were collected in one-to-one, semistructured, telephone interviews and analysed using framework analysis. Twenty-four participants were recruited from two sites in the TUDOR RCT (Table 1). Three main themes represent the data.

Theme 1 reports participants’ views on screening as part of healthcare. Participants described a range of feelings from apprehension and mild anxiety through to excitement and optimism. Overall, screening was a well-conducted, positive experience for participants and was viewed as an opportunity for early detection.

Theme 2 reports patients’ views on the examination process. Participants described the examination as a positive experience, with most participants finding the examination process to be comfortable and not distressing.

Theme 3 reports patients’ views on the impact of screening. Participants described the impact of screening as positive, with most participants finding the screening process to be informative and educational.

Table 1 Participant data

| Diagnosis | Male/female sex | Age (years) | Time with psoriasis (years) | Heard of PsA | Site | Interview date |
|-----------|----------------|-------------|------------------------------|--------------|------|---------------|
| PsA       | Male           | 71          | 54                           | No           | 1    | 11 November 2019 |
| PsA       | Female         | 39          | 22                           | No           | 1    | 15 November 2019 |
| PsA       | Female         | 70          | 60                           | Yes          | 1    | 20 November 2019 |
| OA        | Female         | 58          | 6                            | No           | 1    | 22 November 2019 |
| PsA       | Male           | 40          | 30                           | No           | 1    | 25 November 2019 |
| None      | Female         | 59          | 15                           | No           | 1    | 2 December 2019 |
| OA        | Female         | 73          | 50                           | Yes          | 1    | 6 December 2019 |
| PsA       | Male           | 39          | 12                           | No           | 2    | 11 December 2019 |
| PsA       | Female         | 70          | 30                           | Yes          | 2    | 12 December 2019 |
| PsA       | Male           | 49          | 24                           | No           | 2    | 12 December 2019 |
| PsA       | Male           | 58          | 57                           | Yes          | 1    | 13 December 2019 |
| None      | Female         | 72          | 30                           | No           | 1    | 10 January 2020 |
| None      | Female         | 56          | 51                           | No           | 2    | 15 January 2020 |
| OA        | Female         | 66          | 38                           | Yes          | 1    | 15 January 2020 |
| PsA       | Male           | 43          | 22                           | No           | 1    | 24 January 2020 |
| None      | Male           | 62          | 43                           | Yes          | 2    | 2 March 2020 |
| None      | Female         | 40          | 24                           | No           | 2    | 3 March 2020 |
| None      | Female         | 56          | 38                           | No           | 2    | 5 March 2020 |
| Crohn disease | Female | 71          | 20                           | Yes          | 1    | 6 March 2020 |
| PsA       | Male           | 72          | 7                            | No           | 2    | 15 May 2020 |
| None*     | Female         | 56          | 38                           | Yes          | 2    | 15 May 2020 |
| PsA       | Female         | 61          | 55                           | Yes          | 2    | 18 May 2020 |
| PsA       | Male           | 55          | 20                           | Yes          | 2    | 18 May 2020 |
| None      | Female         | 35          | 18                           | Yes          | 2    | 21 May 2020 |

OA, osteoarthritis; PsA, psoriatic arthitis. *Awaiting diagnosis at time of interview.
and reassuring experience. Participants appreciated the thoroughness of the examination and the time to talk with specialists, including having the opportunity to talk about the impact of their condition on their mental health. This was the case both for participants who screened positive for PsA and for those who did not. Some felt that if it were not for the screening, they would still be experiencing pain and fatigue and living with undiagnosed PsA. For some participants screening resulted in other conditions being diagnosed (e.g. osteoarthritis, Crohn disease) and they were able to receive advice and help for these conditions.

Theme 2 reports participants’ thoughts on how screening enhanced a sense of control over their health. Participants who screened positive for PsA valued the help they were given in treating their condition, while those who screened negative gained an awareness of symptoms to watch out for and the need to seek advice quickly and initiate treatment if necessary. For some, diagnosis was a ‘lightbulb moment’ where the reason for their stiff, achy joints became clear. Participants referred to having made changes that were beneficial to their health following screening, for example making changes to diet and exercise, and adapting the way they did things and talked to others (including employers) about their PsA.

Theme 3 reports views on optimizing screening. Suggested improvements include using case studies, signposting to support groups and information provision. Participants mentioned barriers to attending screening, including location, parking and time of appointments. Other potential barriers included embarrassment (especially if clothing needed to be removed) and concerns about what to expect.

These findings showed that screening was acceptable to participants whether they were diagnosed with PsA or not. This supports a systematic review and thematic synthesis of qualitative studies which found that participants felt empowered when they understood the link between psoriasis and PsA. In addition to possible diagnosis, screening appointments provided an environment to support participants’ self-management by communicating advice about the nature and treatment of PsA, addressing negative illness beliefs and unhelpful coping strategies that participants may have developed to deal with their psoriasis, and by encouraging participants’ ownership of their health condition. This contrasts with participants’ experiences of being diagnosed with PsA in the current healthcare context, where those who had experienced disbelief and misdiagnoses could arrive in rheumatology already anxious, in pain and distrustful of healthcare providers.

This qualitative study indicates that screening is acceptable and a potentially valuable method to increase the early detection of PsA in patients with psoriasis and improve their clinical outcomes.

Christine A. Silverthorne 1, Clive Bowen, 2 Jane Lord, 2 Neil McHugh, 3 William Tillett, 1 Emma Dures 1 and Anya Lissina 1, 4

1 University of the West of England, Bristol, UK, 2 University of Bristol Academic Rheumatology Group, Bristol, UK, 3 University of Bath, Bath, UK, and 4 on behalf of the PROMPT study group.

Correspondence: Christine A. Silverthorne
Email: chris.silverthorne@uwe.ac.uk

Funding sources: This report is independent research funded by the National Institute for Health Research (NIHR), Programme Grants for Applied Research [Early detection to improve outcome in patients with undiagnosed PsA (PROMPT), RP-PG-1212-20007]. This report presents independent research commissioned by the NIHR. The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the National Health Service (NHS), the NIHR, NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), the Programme Grants for Applied Research programme or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, Medical Research Council, Central Commissioning Facility, NETSCC, the Programme Grants for Applied Research programme or the Department of Health.

Conflicts of interest: the authors declare they have no conflicts of interest.

Data availability statement: the data that support the findings of this study are available from the corresponding author upon reasonable request.

References
1 Gladman DD, Antoni C, Mease P et al. Psoriatic arthritis: epidemiology, clinical features, course, and outcome. Ann Rheum Dis 2005; 64 (Suppl. 2):ii14–ii17.
2 Tillett W, Charlton R, Nightingale A et al. Interval between onset of psoriasis and psoriatic arthritis comparing the UK Clinical Practice Research Datalink with a hospital-based cohort. Rheumatology (Oxford) 2017; 56:2109–13.
3 Haroon M, Gallagher P, FitzGerald O. Diagnostic delay of more than 6 months contributes to poor radiographic and functional outcome in psoriatic arthritis. Ann Rheum Dis 2015; 74:1045–50.
4 Gale NK, Heath G, Cameron E et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol 2013; 13:117.
5 Symptom D, Kelly A, Tunnicliffe DJ et al. Patients’ perspectives and experience of psoriasis and psoriatic arthritis: a systematic review and thematic synthesis of qualitative studies. Arthritis Care Res 2020; 72:711–22.
6 Chisholm A, Pearce CJ, Chinoy H et al. Distress, misperceptions, poor coping and suicidal ideation in psoriatic arthritis: a qualitative study. Rheumatology 2016; 55:1047–52.
7 Howells L, Chisholm A, Cotterill S et al. Impact of disease severity, illness beliefs, and coping strategies on outcomes in psoriatic arthritis. Arthritis Care Res 2018; 70:295–302.
Progression of in situ and early invasive cutaneous squamous cell carcinomas concurrent with successful target tumour response to a programmed death-1 inhibitor

DOI: 10.1111/bjd.21831

Dear Editor, The treatment of locally advanced and metastatic cutaneous squamous cell carcinoma (cSCC) is challenging. In many cases, the burden of disease is beyond what can be managed with surgery and radiation therapy. The medical management of unresectable tumours has historically defaulted to head and neck SCC protocols, resulting in unfavourable outcomes. In September 2018, the anti-programmed cell death protein 1 (PD-1) antibody, cemiplimab, received an indication for unresectable, advanced cSCC by the US Food and Drug Administration, followed by pembrolizumab in June 2020. PD-1 inhibitor therapy is quickly becoming the new gold-standard treatment for advanced cSCC through its ability to achieve higher and more durable response rates, as well as a more favourable side-effect profile compared with chemotherapy and epidermal growth factor receptor inhibitors.

As the use of PD-1 inhibitors for high-risk cSCC increases, an interesting phenomenon has been observed. Among responders, target tumours recede while superficial cSCCs remain unaffected and patients continue to develop new superficial and early invasive cSCCs on successful treatment. It appears that PD-1 checkpoint inhibition generates an adequate immune response in deep and/or metastatic cSCCs but permits the persistence and growth of new in situ and early invasive cSCCs.

We observed this phenomenon in our case series of four patients (four male; average age 76 years, range 72–80). The patients were followed in clinic through the completion of their PD-1 inhibitor courses, with infusions every 3 weeks. All four patients experienced a complete clinical and radiological response in their locally advanced or metastatic cSCC tumours within 1 year of treatment. However, during PD-1 inhibitor treatment, all four patients had new or persistent growth of SCC in situ (SCCis) and early invasive cSCCs. Patient 1 developed two new invasive cSCC lesions (Figure 1a) and had no response in pre-existing SCCis and actinic keratoses (AKs) of his head and neck. Patient 2 developed two SCC, keratoakanthoma type lesions on his hand and three SCCis lesions on his face and neck, one of which progressed to an early invasive cSCC (Figure 1b). Patient 3 developed one hypertrophic AK on his neck during treatment and one minimally invasive basosquamous cell carcinoma upon completion of therapy, with durable response in the target tumour. Patient 4 had complete clinical and radiological response on positron emission tomography of his stage IV left occipital scalp SCC after six PD-1 inhibitor infusions, but developed new SCCis lesions on the face and scalp on preinfusion visits 3 and 6. All four patients required a second form of therapy including cryotherapy, electrodesiccation and curettage, photodynamic therapy and topical 5-fluorouracil for the superficial lesions while showing complete response at the advanced SCC.

Our experiences suggest that PD-1 inhibitor therapy effectively targets deep dermal, perineural and subcutaneous cSCC tumours but fails to generate immune clearance of superficial cSCC and epidermal dysplasia. These observations raise questions about the immunogenicity of cSCC by stage and the

Figure 1 (a) Development of two early invasive squamous cell carcinomas on the left ear of patient 1 during treatment with a programmed death (PD)-1 inhibitor. New growths appeared after 13 doses of the PD-1 inhibitor. (b) Development of two squamous cell carcinomas, keratoakanthoma subtype on the left dorsal hand of patient 2 during PD-1 inhibitor treatment.