Exploring health practitioners’ personal models of psoriasis:
“We understand but we forget”

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Psoriasis is...

- **Common** – 2% population / 1.8million in UK\(^1\)
- A systemic **inflammatory** condition mainly involving skin
- Associated with high levels of **distress**
- A **Long-term** condition associated with **co-morbidities**\(^2\)
- Associated with **lifestyle cardiovascular disease risk factors**\(^3-5\)

A complex condition...

**Psoriasis:**
onset, flares, severity, unpredictable occurrence

**Lifestyle factors:**
smoking, alcohol, obesity, physical inactivity

**Psychological distress:**
anxiety, stress, depression & suicidal ideation

**Co-morbidities:**
Psoriatic arthritis, Inflammatory bowel disease, metabolic syndrome, cardiovascular disease
FOR EXAMPLE...
Psoriasis: onset, flares, severity, unpredictable occurrence

Psychological distress: anxiety, stress, depression & suicidal ideation

Lifestyle factors: smoking, alcohol, obesity, physical inactivity

Co-morbidities: Psoriatic arthritis, Inflammatory bowel disease, metabolic syndrome, cardiovascular disease
Psoriasis:
onset, flares, severity, unpredictable occurrence

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ALTERNATIVELY...
Psoriasis: onset, flares, severity, unpredictable occurrence

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Psychological distress: anxiety, stress, depression & suicidal ideation

2.
Psoriasis: onset, flares, severity, unpredictable occurrence

Lifestyle factors: smoking, alcohol, obesity, physical inactivity

Psychological distress: anxiety, stress, depression & suicidal ideation

Co-morbidities: Psoriatic arthritis, Inflammatory bowel disease, metabolic syndrome, cardiovascular disease
ONE MORE...
Psoriasis:
- onset, flares,
- severity,
- unpredictable occurrence

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Personal models of illness

Cognitions, emotions, knowledge and experiences of illness (Hampson et al 1995)

Leventhal et al.’s Self-Regulatory/Common Sense Model
Illness representations: Cause, Identity, Consequences, Timeline, Cure/Control, Coherence + emotional representations: anxiety, depression, anger = patients ‘personal model’ of illness

Patients’ personal models predict:
Mood, adherence self-management, health seeking behaviour and functioning

In psoriasis personal models predict:
Visits to outpatient clinics, physical and mental health, pathological worry, social functioning

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## Models of psoriasis

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cause</strong></td>
<td>Stress / genes / poor lifestyle</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>Red scaly plaques / itching / flaking / pain</td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td>Low self confidence / limited work options / comments by members of the public</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
<td>Life long / comes and goes / will resolve with treatment</td>
</tr>
<tr>
<td><strong>Control/Cure</strong></td>
<td>Nothing apart from biologics / maintaining healthy lifestyle / avoiding stressful situations</td>
</tr>
<tr>
<td><strong>Emotions</strong></td>
<td>Sadness / fear / anger / guilt / frustration</td>
</tr>
<tr>
<td><strong>Behaviour</strong></td>
<td>Seek treatments / engage in self-management behaviours / social withdrawal</td>
</tr>
</tbody>
</table>
Healthcare providers’ understanding of psoriasis...

- GPs viewed and managed psoriasis episodically
  - a ‘rash’ not a complex long-term condition\(^\text{13}\)

- Practitioners (primary & secondary care) do not discuss lifestyle & CVD risk in the context of psoriasis\(^\text{14}\)

- Patients report frustration with care that only focuses on skin\(^\text{15,16}\)

\(^{13}\text{Nelson, Barker et al., 2013; }^{14}\text{Nelson, Keyworth, et al., 2014; }^{15}\text{Nelson, Chew-Graham et al., 2013; }^{16}\text{Richards et al, 2004}\)
Healthcare practitioners’ personal models of psoriasis?

Simple skin complaint or complex inflammatory condition?
Methods

Participants

• Specialist and generalist healthcare providers who consult with people with psoriasis (n = 23)
• Recruitment through dermatology and primary care membership lists/organisations and snowballing sampling

Procedure

• In-depth qualitative interviews face-to-face or via phone
• Topic guide: Experiences of consulting about psoriasis; awareness of complexities of psoriasis; management strategies

Analysis

• Principles of framework analysis and constant comparison
• Coding – cognitive representation of psoriasis (illness beliefs), affective response to managing the condition (emotions), and clinical management (behaviours)

17 Richie & Spenser, 1994
Results

1) Identifying complexity of psoriasis: Practitioners often recognised complex links between psoriasis, co-morbidity, psychological and lifestyle factors.

- I have seen stress and psoriasis linked many times, and obviously I know as a GP when people are stressed they do tend to drink and smoke more (GP 4)
- If you’re drinking and smoking and overweight and demotivated, you’re not going to treat your psoriasis (SN 4)
- It’s very difficult to give up something or to take on a new approach to life. So no matter what the cause of depression or low mood – it would be very difficult to change your lifestyle, because you’ve not got the capacity to do it (DSN 4)

- Smoking and alcohol are absolutely paramount. The interplay between alcohol and psoriasis is extremely complex but pivotal to disease management (CD 3)
2) **Skin first:** Although practitioners understood these complexities they simultaneously demonstrated skin condition-focused thinking and limited clinical management.

I’m not interested in doing that [discussing lifestyle], I’ve got too much complex dermatology to be dealing with (CD 2)

Once you’ve cleared the skin...*then you can discuss other things [lifestyle behaviours]* (CD 15)

I have seen a lot of misery now, with psoriasis...so my approach is to try to make their skin better as soon as possible. So that if I do this, maybe I can make them feel better...

Yes and now that she’s got better she hasn’t gone and done sport or all these other things, she’s very happy about her skin but it hasn’t widened her horizons which is quite interesting, and she keeps her skin covered still (CD 1)

Many times I ask them, ‘why are you unhappy’? And they tell me, no I’m not unhappy with my skin, but why, I wonder why the DLQI [Dermatology Life Quality Index] is so high! (CD 7)
3) **Patient first:** Minority with sophisticated personal model recognised psoriasis-related complexity *and* emphasised professionals’ responsibility for addressing this.

I’ll be explaining about lifestyle changes they may want to aim...I'll want to have an idea of what's going on with their joints and what's going on with their life and addressing those issues as well. (CD 6)

Our role is more to help them understand that their general health is relevant to the skin and that improving general health, getting enough sleep, avoiding stress, eating healthily is all going to benefit both their health and their skin and, sort of, trying to see it as more whole holistically for them and their psychological well-being, you know, it all, sort of, is interlinked. (SN 1)
4) Episodic care: Patients discharged after skin improvement, not managed as long-term condition.

Send them to the specialist nurse for review and support and education after which time they’re meant to be discharged (CD 2)

There’s a lot of times where you’re not seeing them as the primary consultation, so they come in for something else in general practice and they need a top up of medication or a slight enquiry. (GP 4)

I will continue to carry on with the message about lifestyle changes, smoking and alcohol and all that...but also about what it feels now to not have psoriasis and also to be mindful of the possibility of recurrences (CD 6)

Rare that practitioners described a long-term approach to care
5) **Practitioner empathy with psoriasis:** Practitioners with ‘skin first’ models frustrated with psoriasis patients consultations. Those with elaborate personal models reported positive affect towards patient improvement.

I personally feel less control and more sorry for patients with psoriasis because I haven’t got the power to completely clear their skin (SN 8)

We see a change in those people who it does help; their confidence increases, they start to do more...you see them sort of blossoming, it’s a lovely job for that (SN 1)
Discussion

• First study to explore healthcare practitioners’ personal models of psoriasis and how this may relate to clinical management

• Practitioners personal models are varied and are often mismatched with their reported management approach (skin versus patient)

• Some awareness of psoriasis as complex long-term condition but skin-focused thinking and management reported.

• Guidelines on psoriasis may not be translating knowledge to practice\(^\text{18}\)

• Further research needed to investigate the impact of different personal models upon observable care provision and the impact of training to address this.

\(^\text{18}\)NICE, 2012 (CG 153)
Next steps

Pso Well interventions

Practitioner training

Patient materials

Broaden understanding of psoriasis and improve care for patients
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