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**Title:** Understanding the experience of sleep disturbance in psoriasis: A qualitative exploration using the Common Sense, Self-Regulation Model

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#### **What is already known about this topic?**

- Sleep disturbance is common in psoriasis, characterised by difficulties initiating sleep and maintaining sleep, and short sleep duration
- Sleep disturbance in people with psoriasis is associated with pre-sleep cognitive and somatic arousal, itch and low mood

#### **What does this study add?**

- First qualitative study of sleep in psoriasis
- Sleep disturbance in people living with psoriasis is perpetuated by intrusive thoughts and worries about the condition, its symptoms, and counterproductive coping strategies
- Psoriasis and sleep disturbance interact, influencing physical and psychological aspects of the disease
- Perceived control of sleep is problematic, and desire to obtain control may maintain sleep difficulties and distress

#### **What are the clinical implications of this work?**

- Clinicians should give greater attention to sleep as part of psoriasis management
- Identified potential treatment targets for improving sleep
- Addressing sleep problems may improve psoriasis management

## **ABSTRACT**

### **Background**

Psoriasis is associated with significant morbidity which negatively impacts upon quality of life. Sleep disturbance is reported by patients to be common in psoriasis and is associated with physical and psychological variables, although there is little published work in this area. Understanding sleep and the factors involved in its disturbance in psoriasis is a potentially important clinical area given the role of sleep in health and disease processes.

### **Objective**

To explore the experience of sleep and sleep disturbance in psoriasis using the Common-Sense-Self-Regulation Model (CS-SRM).

### **Method**

Semi-structured interviews were conducted with adults diagnosed with psoriasis. Interview questions were informed by the CS-SRM and previous research. Framework analysis was applied, including coding data into the CS-SRM dimensions and allowing additional inductive themes to emerge.

### **Results**

Seventeen people with psoriasis (9 female, 8 male; aged 19-86) were interviewed about sleep and sleep disturbance. Seven themes emerged, with six accounted for by the CS-SRM: characteristics of sleep disturbance, change in sleep patterns, thoughts about and symptoms of disease disturbing sleep, impact of poor sleep on daily life, attempts to improve sleep, a daily battle for control and a seventh relating to metacognitive processes. A reciprocal relationship between sleep and psoriasis was evident across themes with interactions between key sleep-related thoughts, emotions and behaviours.

### **Conclusion**

This study showed that sleep disturbance is a persistent concern for people with psoriasis, it has a 24-hour impact, and interacts with psychological and physical aspects of psoriasis. The distress and frustration felt when managing sleep disturbance perpetuated problematic sleep. Addressing this with currently available sleep treatments may therefore confer sleep and psoriasis-related benefits for people living with this condition.

## INTRODUCTION

Psoriasis is a long-term immune-mediated inflammatory skin condition affecting approximately 2% of the population.<sup>1</sup> Aside from characteristic demarcated plaques and other dermatologic sequelae, psoriasis is associated with significant comorbidity, namely: diabetes,<sup>2</sup> psoriatic arthritis,<sup>3</sup> cardiovascular disease<sup>4</sup> and depression and anxiety.<sup>5</sup>

Mounting evidence suggests links between psoriasis and sleep disturbance.<sup>6</sup> Recent research indicates that sleep disturbance is common in psoriasis, characterised by difficulties initiating and maintaining sleep, early waking and an inability to resume sleep, as well as short sleep duration (<7h).<sup>7</sup> Itch, pre-sleep cognitive and somatic arousal, depression and pain have been associated with sleep disturbance in psoriasis.<sup>6-10</sup> Sleep has an important role in the functioning of physiological and psychological systems.<sup>11</sup> Beyond the noticeable consequences of sleep disturbance (e.g. tiredness, low mood, daytime dysfunction)<sup>12</sup> other effects include dysregulation of metabolic,<sup>13</sup> immune<sup>14</sup> and cardiovascular functioning,<sup>15</sup> which, over time increase the propensity for illness and impact upon disease processes.<sup>11,16, 17</sup>

Insight into the aetiology and maintenance of sleep disturbance can be obtained from models of insomnia. The 3P model (*predisposing, precipitating* and *perpetuating* factors) proposes that biopsychosocial factors (altered neurotransmitter functioning, ruminative tendencies or social pressures) *predispose* to sleep difficulties which are often *precipitated* by illness or stress.<sup>18</sup> Unhelpful cognitions and behaviours used to promote sleep and/or manage the consequences of poor sleep (e.g. excess caffeine use, increasing time in bed) paradoxically *perpetuate* sleep difficulties.<sup>18,19</sup> Whilst the 3P model helps conceptualize how chronic sleep disturbances manifest it may not account for interactions between sleep disturbance and disease-specific beliefs about the causes of poor sleep and illness. The Common Sense Model of Self-Regulation (CS-SRM) identifies illness perceptions (beliefs about an illness/health threat) based upon six domains: illness identity, timeline, cause, consequences, coping and controllability.<sup>20</sup> These, along with the parallel processes of emotional representations inform coping responses and predict health outcomes in psoriasis.<sup>21-23</sup> The CS-SRM has been used to explore the experience of psoriasis,<sup>24</sup> and psoriatic arthritis (PsA).<sup>25</sup>

Qualitative methodology provides context, allowing participants to describe an experience in their own words and facilitates an in-depth exploration a particular phenomenon.<sup>26-28</sup> Therefore, we set out to obtain an in-depth participant-led account of psoriasis-specific

factors that contribute to and maintain sleep disturbance using the CS-SRM framework, and to evaluate the utility of the model in this context.

## **METHODS**

### **Sampling and recruitment**

Participants were  $\geq 18$  years old, had a diagnosis of psoriasis and were recruited from a specialist psoriasis clinic, a research database, posters in community settings and on social media. Due to the systemic nature of psoriasis, patients with psoriasis and PsA were included. Purposive sampling using a maximum variation approach<sup>29</sup> was used to gain perspectives across variables including age, gender, ethnicity and self-reported sleep disturbance.

### **Data collection**

Following written consent, face-to-face or via telephone semi-structured interviews were conducted between February 2016 and April 2017 by ALH. Interviews facilitated understanding of individuals' own experiences in detail using the CS-SRM framework. The topic guide (see Supplementary file 1: Topic guide) was based upon the CS-SRM and piloted with a research user group. Interviews were digitally recorded, with field notes made following interviews to document emerging salient patterns. Interviews were transcribed verbatim and anonymised.

### **Data analysis**

Framework analysis<sup>30</sup> tested the utility of the CS-SRM and allowed emergent themes not accounted for by the model to be identified. Following familiarisation, data were initially coded according to the six CS-SRM dimensions and a working analytical framework of themes and subthemes was developed. In an attempt to reduce subjectivity, multiple coding was used.<sup>31</sup> Analysis was led by the first author (ALH), and supported by other authors (CB, AC), both of whom are health psychologists and experienced qualitative researchers. A constant comparison approach was used.<sup>32</sup> Further details on the analysis can be found in the supplementary files (see Supplementary file 2: Qualitative data analysis). The study was approved by NHS ethics (15/NE/0424).

## **RESULTS**

Seventeen participants (9 [53%] female) completed interviews (10 face-to-face and 7 by telephone), lasting between 26 and 133 minutes (Mean=52 min; SD=25.5). Ages ranged from 19 to 86 years (Mean=40.4; SD=16.9) and the age of psoriasis onset from 2 to 59 years (Mean=22.9 years; SD=16.4). Three participants were of South Asian ethnicity, 13 were white British, and one was white Eastern European. Participant characteristics are displayed in Table 1.

[Insert Table 1 here]

## Themes

Analysis produced seven themes, six of which were accounted for by the CS-SRM (Identity, Timeline, Cause, Consequences, Coping and Control) and one was not (Metacognitive processes).

### Theme 1: Identity – symptoms of sleep disturbance

Participants' sleep problems were characterised by three distinct experiences.

**1.1 Can't get to sleep:** Sleep onset often took many hours. Participants sometimes anticipated when sleep would require significant effort.

*“So as much as it takes me a little bit of time to fall asleep, I can definitely tell the difference between when I'm just taking a while to get to sleep, and when I'm actually struggling to cue sleep, overall, yeah. [P10]”*

**1.2. Can't stay asleep:** Difficulties returning to and maintaining sleep were experienced along with night-time awakenings which was frustrating. Duration of awakenings were significant; some described *“watching the clock go all the way through four to five [P8]”*. Others gave up attempting to sleep and engaged in a productive task.

*“I do go to sleep quickly but then I'll wake up, it can be an hour, it can be a few hours and I can wake up several times in the night. Sometimes I go back to sleep. Sometimes I can be up at four o'clock in the morning ironing. So it's...you know, 'cause you lie there for a while and you think, bloody hell, I'm wasting my time and, like, I'll get up and do something useful...[P11]”*

**1.3. Lighter sleep:** Participants perceived sleep as lighter, believing they remained partially awake throughout the night and described being woken easily by external stimuli. Sleep was viewed as a skill they had lost over time.

*“You lose the ability to sleep. How I slept before was sound and now it’s a lighter sleep. It’s not a sound sleep. [P1]”*

## **Theme 2: Timeline - Change in sleep patterns**

The history and change in sleep patterns varied across participants.

**2.1. Marked Change:** Many reported experiencing sleep problems for so long they could not recall the last time they slept well. Some attributed this change to a precipitating event, such as disease onset or a stressful life event, while others experienced a gradual change over time. Descriptions of the history and patterning of sleep problems were predominantly neutral, suggesting acceptance or resignation that little could be done to improve their sleep.

*“It just seems to be the way it is now and at some time...like I say, years ago I was...I don’t remember it being like this. But I’ve been like this for so long that I don’t know when it started. [P11]”*

**2.2. Variability of sleep:** For some sleep was variable, better during the winter, or on weekends due to greater opportunity for sleep. Temporal links between sleep and the condition of their skin were made, as sleep deteriorated as a function of time since the last treatment which was attributed to increased skin agitation which they would have to manage by applying treatments during the night.

*“Some nights are worse than others, it depends on how the skin is. My skin’s not too bad at the moment. But as it’s getting closer to my injection, so my injection’s due in a couple of weeks, so my skin’s now starting to flare up. So my sleep patterns are getting worse, because I’m up again putting cream on. [P6]”*

## **Theme 3: Cause - Thoughts and symptoms disturbing sleep**

Sleep disturbance was associated with psychological and physical intrusions relating to psoriasis. Some believed that psoriasis was intrinsically associated with sleep problems.

*“I think if I haven’t had psoriasis, my sleep would improve, absolutely, and it would improve the quality of life in everywhere else, absolutely. [P5]”*

**3.1.1. Thoughts/worries:** Intrusive thoughts, worry and rumination inhibited sleep and could occur before sleep and during night-time awakenings. Content was predominantly negative, often distressing and could relate to everyday concerns including family or work or centre on psoriasis. Psoriasis-specific thoughts included previous or future adverse treatment effects, appointments, obtaining clear skin, treatment effectiveness, how skin would look the following day and how others would perceive them.

*“When I’m finding it difficult to sleep, that’s probably the time when my mind refocuses back to my illness and the condition I have, and it kind of magnifies the whole thing, and I kind of delve into different areas about my appointments, about the past, about the future, so I’ll kind of think about different things in different ways. [P2]”*

**3.1.2. Lack of distraction:** The intensity of psoriasis-related thoughts at night was noticeably amplified, possibly due to the lack of distractions relative to daytime when participants were busier with social and occupational activities. Many stated that although psoriasis was always present, night-time mentation was dominated by psoriasis and was when they were *“faced with the reality of the situation [P2].”*

*“I think they [thoughts] probably are worse at night because I’m not distracted whereas during the day you’re distracted with work, other people but at night time there’s no real distraction so the mind is playing games. [P5]”*

**3.1.3. Difficult to control:** Thoughts at night were challenging to control. Participants struggled to inhibit or change the content of thoughts regardless of the effort expended. The lack of effective coping strategies further prevented sleep, which was associated with frustration, a sense of defeat and perceived lack of control. The inability to control thoughts often resulted in feelings of guilt and self-blame as participants believed they were responsible for unwanted cognitive activity.

*“...I do struggle with that [controlling thoughts]. You know, if I’m thinking of something I can’t just be like, it’s alright, I’ll just stop thinking about that. It does get to a certain point where you’re just like, wow, I can’t stop this. You know, I really want to and I’m really trying but I just can’t. [P12]”*



**3.2. Psoriasis symptoms:** Symptoms including itching, burning skin, and pain from skin and joints were worse at night, making it difficult to sleep and find a comfortable sleeping position. Poor sleep was also anticipated during flares. Participants reported scratching which interfered with sleep and could occur while awake or during sleep, often realising they had scratched during sleep in the morning as blood would be present on pajamas and bedsheets.

*“Yeah, if I'm having a really bad flare-up and my skin's really red and irritated, I know before I go to bed that I'm going to wake up at least once during the night, because it's just so irritable that you can't focus on sleep. I don't know if that makes sense but you just can't go to sleep because you're constantly thinking, my God, that's so itchy, or, that's so irritable, what can I do to make that not feel that way. [P12]”*

**3.3. Goal conflict: sleep vs. treatment:** Participants debated between sleeping at the risk of irritated skin or purposefully waking throughout the night to apply treatments to reduce skin agitation and dryness. This trade-off left participants feeling conflicted and frustrated at the lack of consolidated and restful sleep.

*“...I take it [medication] at night time, and I think it works over a period of 16 hours, so by around four, five o'clock the next day I have to top it up with some paracetamol based painkillers which last two to four hours, so by night time I'm sort of in quite a lot of pain, which is the time that I go to bed, but then the sustained release inflammatories which I take to keep me going through the day, they take time to sort of work, so it's usually during the night that I'm having the problems, and I can't really do that during the day because that's when I go to work, so I need to be pain free during the day, so I have to sort of compromise on the sleep. [P2]”*

Some tried ignoring symptoms as long as possible due to the desire for a good night's sleep, however eventually had to apply treatments as they could no longer tolerate skin irritation.

*“...there have been a couple of nights where I've thought I'm not getting up, I'm just not getting up. But then I've had to get...and I might have done that for about an hour or so. But then I've had to get up, because I just can't stand it anymore. [P6]”*

#### **Theme 4: Consequences - Impact of sleep disturbance on daily life**

Daytime consequences of sleep disturbance were characterised on intrapersonal and interpersonal levels.

**4.1. Intrapersonal:** Daytime tiredness, exhaustion, unproductivity and a lack of energy impacted upon attention, motivation, concentration, anxiety management and social activities. Participants thought they were different from others who sleep well engendering a sense of isolation and abnormality, which was compounded by their inability to perform everyday tasks. This was associated with negative self-perceptions and self-blame.

*“I think there is a degree of sort of blame and guilt and why me, why can't I stop this, why can't I just have a good night's sleep like everybody else; not that everybody else has a good night's sleep. So it's one of them, yeah, I suppose I do get those sort of thoughts, you know, why the hell can't I stop this and just get on with it, come on, be normal. [P8]”*

Disease exacerbation (skin and joint flares, pain, itchiness and fatigue) and worries about appearance were experienced in the days following poor sleep. Participants described a vicious cycle whereby sleep disturbance resulted in increased stress, leading to disease exacerbation and subsequently impaired sleep.

*“It would definitely flare up, but it wouldn't be the next day, it would be...it would take place...I would be getting very little sleep and it would be over a period of days and it would be causing me stress, and on top of that I would be flaring up slowly, and that will be adding another stress, and now the fact my sleep, and so it would be a part of not getting enough sleep, stressful about it, noticing the flare up, stressing about that and then that would feed into not getting a good sleep because I would be thinking about it at night. [P5]”*

**4.2. Interpersonal:** Poor sleep negatively affected mood and social relationships, which led to irritability and disconnection from friends and family. Adjustments were made by others to help participants sleep or apply treatments due to their exhaustion or flares which they attributed to sleep disturbance.

*“But then I'll say to them, God, I've not...and they will say mum, you're really not well today, there's no reason why you shouldn't sleep. But in myself it makes me feel really guilty because then I wake up and things will have been done, and my husband works all week and he works nights, so then I don't think it's fair that he should have to come home and start cleaning up or going shopping...[P6]”*

Participants felt stigmatised and isolated when discussing sleep problems with others including health professionals, who often dismissed concerns as insignificant. Some felt they

were perceived as lazy due to napping or when cancelling plans due to tiredness. Participants expressed jealousy and envy towards others who slept well, and could not understand why sleep came so easily to others, intensifying feelings of abnormality and isolation.

*“I’ve spoken to my GP about it in the past, as well, but I didn’t really, he didn’t really pick up on it particularly, he just said, oh I’m sure your sleep will improve, and that was kind of it really, he didn’t take it particularly seriously. [P17]”*

### **Theme 5: Coping - Attempts to improve sleep and manage the consequences of sleep disturbance**

Coping with sleep disturbance was a 24-hour effort, involving both night-time and daytime strategies which had limited effectiveness.

**5.1. Night-time coping:** Participants described forcing sleep, hoping for sleep, distracting themselves from intrusive thoughts and frustration and increasing sleep opportunity by going to bed earlier. Although these strategies were ineffective, and in some cases counterproductive, participants persisted. Meditation, breathing exercises, listening to music, and mindfulness were effective for some. Use of prescription and over-the-counter sleep medication was common, yet these were used sparingly due to concerns about dependence and desire to obtain “control” over sleep.

*“I’m thinking, oh God, the alarm is on for half six, come on, push yourself, make yourself sleep; and that’s virtually impossible; sometimes I get to that point and, do you know what, I might as well just get up that one hour early. [P8]”*

*“Probably more frustrated, because I mean, I’ve gone to bed earlier, because I feel tired. And I’ve gone to bed and I can’t sleep. [P13]”*

**5.2. Daytime coping:** Caffeine and physical activity were used to reduce daytime tiredness, however this could cause or exacerbate sleep difficulties.

*“if I haven’t slept well, I’ll suddenly fill myself full of caffeine the next day and drink tea, but then again, I didn’t even think about the fact that drinking tea could be why I didn’t sleep very well...[P9]”*

**5.3. Acceptance/passive normalisation:** Despite sleep difficulties at night resulting in distress, participants also expressed acceptance, resignation or passive normalisation of current sleep.

*“I can’t say I’m happy with it, no because I would love to sleep all night and get up in the morning. But I’m accepting of it. It’s...it is what it is. It doesn’t distress me. I’m not upset about it. It’s just the way it is. [P11]”*

### **Theme 6: Control - A constant battle for control over sleep**

Perceptions of control over sleep and the ability to improve/manage sleep ranged from limited control, to absolute lack of control which varied from day to night.

**6.1. Limited control:** Those reporting limited control believed their coping strategies had some influence, that they could be doing more to improve sleep, or thought they were in control when they slept well.

*“I think I’d have a little bit [of control], maybe just using the techniques that I use, but ultimately, probably, not a lot. [P3]”*

**6.2. Absolute lack of control:** Others reported an absolute lack of control, believing that sleep was controlled by external factors they could not influence. Participants were disappointed when they were unable to sleep when desired.

*“I’m very disappointed with myself. I feel like this is my body, I should be able to fall asleep when I want to. [P5]”*

**6.3. Day vs. Night:** Control varied between day and night-time. Sleep could be inhibited relatively easily during the day as participants could cope with tiredness. However, at night, they could not sleep no matter how much effort they put in, thus believing they had no control over sleep at night.

*“Maybe it doesn’t control me as much as I think it does actually, because if I allowed it to I would go to sleep in the day. But I don’t always allow myself to. So in that respect I’m control it then in the daytime. But in the night time, no. [P6]”*

### **Theme 7: Metacognitive processes: Paradoxical effect of metacognitive coping strategies**

A theme not accounted for by the CS-SRM related to the use of metacognitive processes or attempts to think about thinking at night-time as a way of coping with sleep. Although intended as a coping strategy to reduce engagement with unwanted thoughts, these often further exacerbated sleep disturbance by intensifying thoughts.

**7.1. Metacognitive techniques:** Participants described attempting to 'clear their mind' to suppress intrusive thoughts and diverting or replacing thoughts to more positive or neutral and relaxing cognitions.

*"...I try to stop myself going off onto other things, but what I find sometimes is the more I try and stop myself the more I actually do end up thinking about these things, I don't want to sound too stupid, but I just think, I'm not going to think about it, and the of course I do think about it and so it goes on really. [P17]"*

**7.2. Paradoxical effect:** Metacognitive coping strategies often had the paradoxical effect of thought rebound and increased arousal thereby perpetuating wakefulness. Some identified this as contradictory and ineffective towards the desired goal of sleep.

*"...those to me are, sort of, almost like trying to fool yourself a little bit, you know, like, a relaxation method is trying to make yourself relax and to make that...that seems like a contradiction in terms and I have that same, sort of, problem with suppressing thoughts, because that would be a contradiction...[P9]"*

## DISCUSSION

The CS-SRM was useful in describing complex and dynamic interactions between thoughts (e.g. lack of control over sleep/intrusive thoughts), emotions (e.g. frustration/guilt/worry) and behaviours (e.g. increasing time in bed/distraction) associated with sleep disturbance in psoriasis.

The cognitive processes described in narratives are similar to those documented in insomnia,<sup>33</sup> but specific content centered around psoriasis rather than sleep-related issues.<sup>34,35</sup> This may be due to biased attention towards symptoms and negative illness-related thoughts and worries which further increase arousal and distress<sup>36-42</sup> and exacerbate sleep difficulties. Nocturnal itch and scratching was reported and may occur during sleep,<sup>43</sup> or during brief awakenings, thus interrupting sleep.

These findings suggest that sleep disturbance may exacerbate psoriasis, possibly via dysregulation of the Hypothalamic-Pituitary-Adrenal axis, immune dysfunction, altered melatonin secretion, increased distress and Sympathetic Nervous System arousal. Melatonin, implicated in immune functioning and sleep timing displays reduced secretion and altered circadian rhythmicity in psoriasis which may contribute to psoriasis flares.<sup>44,45</sup>

Despite acceptance of poor sleep, perceived lack of control and a desire for control were common across themes. Sleep is tightly regulated by circadian and homeostatic processes,<sup>46</sup> however participants increased sleep effort to promote successful sleep. This is a common trait in poor sleepers,<sup>47</sup> and along with counter-productive thought control strategies paradoxically maintains arousal.<sup>48,49</sup> The absence of effective night-time coping strategies and increased arousal may bias attention towards indicators of wakefulness or disease symptoms and increase cognitive load.<sup>47</sup> Poor control over nocturnal sleep may be compounded by attention driven towards sleep and sleep-related threats, reinforcing the inability to sleep.<sup>35</sup>

Increased arousal following thought suppression attempts is well documented in poor sleepers<sup>50-52</sup> and other clinical populations.<sup>53</sup> Combined mindfulness and cognitive behavioural therapy for insomnia can improve sleep<sup>54</sup> and CBT for insomnia more broadly has proven effective in a range of clinical populations.<sup>55-57</sup> Whether this is effective in psoriasis warrants investigation.

Studies of primary insomnia samples have also found isolation and stigma resulting from the lack of attention and legitimacy given to sleep difficulties, suggesting it is widespread<sup>12,33,58</sup> Given the importance of sleep for health and the current emphasis on comprehensive assessments of psoriasis (i.e. lifestyle/quality of life and skin functioning) addressing sleep as a health behaviour provides opportunities to improve health broadly.<sup>59,11</sup>

Given the sampling strategy used, these findings cannot be generalised to all individuals with psoriasis. Although a diverse sample was achieved, participants were not screened for sleep problems as our aim was to allow participants to define them. This methodology reveals important aspects of sleep experience that could not be explored using quantitative methods,<sup>60,61</sup> supporting and building upon previous findings.<sup>7</sup> Despite efforts to ensure the trustworthiness of our findings, we recommend a future prospective study investigate the temporal associations between night-time sleep and a wider range of daytime variables including symptoms in people with psoriasis.

These findings suggest that sleep disturbance has a significant impact on people with psoriasis, underscored by the 24-hour impact on their lives. The relationship between sleep disturbance and psoriasis appears to be reciprocal, involving psychological and physical aspects of disease. Assessing and treating sleep disturbance should be part of standard clinical care for people with psoriasis.

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## **Supplementary file 1**

### **Topic guide**

1. Identity (how patients describe their symptoms of poor sleep, can be too much or too little)
  - It would be great if you could tell me a bit about what your sleep is like
  - Can you describe a typical bad/good night's sleep?
  - What kind of problems do you have?
    - Sleep duration: too short / too long
    - Waking up during the night
    - Falling asleep/waking up early
    - Is sleep timing / schedule consistent?
    - Is sleep restorative / refreshing?
  
2. Timeline (how long have they had trouble sleeping)
  - Could you tell me about what your sleep has been like throughout your life?
  - When you were younger?
  - How was your sleep before you had psoriasis?
  - Tell me a bit about when your sleep problem started
    - Persistent
    - Cyclical
    - Infrequent
  
3. Cause (how patients identify why they have poor sleep)
  - Could you have a think about what you think causes you to sleep poorly/well?
  - Internal causes:
    - Mood/anxiety
    - Symptoms
    - Thoughts/worries
  - External:
    - Work/family life
    - Environmental factors
  
4. Consequences (how participant's believe sleep impacts on functioning)
  - So you've had a good/bad night's sleep; how does that make you feel the next day?
  - How does it affect social, relational, occupational, physical, psychological/emotional functioning?
  - Tell me about what effect a bad night's sleep has on your ability to carry out day-to-day tasks?
  
5. Action planning/coping strategies (How participant's attempt to cope with sleep disturbances)

- I was wondering if now you could tell me how you cope/deal with your sleep problem?
- What techniques do you use to try and improve your sleep?
- Do you try the same things every night or use different strategies?
- How do you feel when coping strategies aren't working?
- How do you know if what you're doing is working?

6. Curability/Controllability (How curable do participants believe their sleep problem is/what would improve their sleep)

- How much control do you have over your sleep/how well are you able to improve your sleep?
- I want to know more about whether you think you can control/improve your sleep?

## **Supplementary file 2**

### **Qualitative data analysis**

Three members of the analysis team (ALH, CB, AC) independently coded the first three interview transcripts. The codes were then discussed and compared within the research team to reduce the influence of subjective biases on analysis. This provided an opportunity to discuss initial labels and refine themes and subthemes. Constant comparison methods were used in parallel with data collection and iteratively allowing the developing analysis to inform subsequent interviews and vice versa,<sup>31</sup> conducted by the first author. Data not accounted for by the model were coded by grouping emergent patterns of data into defined categories and were discussed between the analysis team until a consensus on emergent themes was reached. Subsequently, overarching categories of data from within and without the CS-SRM were organised into super-ordinate themes and sub-themes. Meetings between analysis team members occurred throughout data analysis and allowed refinement of themes and sub-themes throughout. Any inconsistencies were resolved following discussion. Independent coding and subsequent discussions helped reduce subjectivity in analysis and ensured consistency throughout the analytic process. Data collection and analysis ceased when the research team agreed thematic saturation was achieved (i.e. interview data no longer added new insight to the emergent themes/sub-themes and no new themes emerged from the data).