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Factors Influencing Sleep Difficulty and Sleep Quantity in the Citizen Pscientist Psoriatic Cohort

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ABSTRACT

Introduction: Sleep is essential for overall health and well-being, yet more than one-third of adults report inadequate sleep. The prevalence is higher among people with psoriasis, with up to 85.4% of the psoriatic population reporting sleep disruption. Poor sleep among psoriasis patients is particularly concerning because psoriasis is independently associated with many of the same comorbidities as sleep dysfunction, including cardiovascular disease, obesity, and depression. Given the high

prevalence and serious consequences of disordered sleep in psoriasis, it is vital to understand the nature of sleep disturbance in this population. This study was designed to help meet this need by using survey data from Citizen Pscientist, an online patient portal developed by the National Psoriasis Foundation.

Methods: Our analysis included 3118 participants who identified as having a diagnosis by a physician of psoriasis alone or psoriasis with psoriatic arthritis. Demographic information, psoriasis severity and duration, sleep apnea status, smoking and alcohol consumption, itch timing, and sleep characteristics were included. Two separate multivariate logistic regression models in STATA were used to determine whether the presence of psoriatic arthritis, age,

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gender, body mass index, comorbid sleep apnea, psoriasis severity, timing of worst itch, smoking status, or high-risk alcohol consumption were associated with sleep difficulty or low sleep quantity, defined by the American Academy of Sleep Medicine as less than 7 h of sleep per night on average.

Results: Results from the multivariate logistic regressions found that sleep difficulty was associated with psoriatic arthritis (OR 2.15, 95% CI [1.79–2.58]), female gender (2.03 [1.67–2.46]), obese body mass index (BMI \geq 30) (1.25 [1.00–1.56]), sleep apnea (1.41 [1.07–1.86]), psoriasis severity of moderate (1.59 [1.30–1.94]) or severe (2.40 [1.87–3.08]), and smoking (1.60 [1.26–2.02]). Low sleep quantity was associated with obese BMI (1.62 [1.29–2.03]), sleep apnea (1.30 [1.01–1.68]), psoriasis severity of moderate (1.41 [1.16–1.72]) or severe (1.40 [1.11–1.76]), and smoking (1.62 [1.31–2.00]). Sleep difficulty and low sleep quantity were not associated with age, alcohol consumption, or timing of worst itch.

Conclusion: These results are potentially meaningful in several aspects. We identify an important distinction between sleep difficulty and sleep quantity in psoriatic disease, whereby having psoriatic arthritis and being female are each associated with sleep difficulty despite no association with low sleep quantity. Furthermore, there is conflicting evidence from prior studies as to whether psoriasis severity is associated with sleep difficulty, but this well-powered, large study revealed a strong, graded relationship between psoriasis severity and both sleep difficulty and low sleep quantity. Overall, our results show that both sleep difficulty and low sleep quantity were associated with multiple factors in this analysis of a large psoriatic cohort. These findings suggest that dermatologists may gather clinically useful information by screening psoriatic patients for trouble sleeping and low sleep quantity to identify potential comorbidities and to more effectively guide disease management.

Keywords: Comorbidities; Psoriasis; Sleep; Survey research

INTRODUCTION

Chronic sleep dysfunction can lead to a wide variety of adverse health outcomes, including cardiovascular disease, hypertension, obesity, type 2 diabetes mellitus, depression, and all-cause mortality [1, 2]. In addition to these long-term consequences, sleep disturbance can profoundly affect daily functioning, contributing to difficulty concentrating, impaired school or work performance, and driving or transportation accidents [3, 4]. Sleep is therefore essential for overall health and well-being [5], yet more than one-third of adults in the USA report inadequate sleep [6]. The prevalence is remarkably higher among people with psoriasis [5, 7–11]. For examples, a 2005 survey found that 49.5% of psoriasis patients experience sleep interference [7], a 2008 case-control study concluded that disordered sleep is a significant comorbidity in psoriasis [12], and a 2016 systematic review and meta-analysis reported sleep disruption in up to 85.4% of the psoriatic population [10]. Moreover, people with psoriasis are more likely to have diagnosed sleep-related conditions such as obstructive sleep apnea (OSA) (36.0–81.8% prevalence in psoriasis versus 2–4% in the general population), restless legs syndrome (15.1–18.0% versus 5–10%), and transient or chronic insomnia (5.9–44.8% versus 10–53%) [13].

Poor sleep among psoriasis patients is particularly concerning because psoriasis is independently associated with many of the same comorbidities as sleep dysfunction [12–14]. The consequences of each condition can thereby compound, with deadly results. In fact, a 2016 cohort study found that psoriasis patients with concomitant sleep disorders had significantly higher risks of ischemic heart and stroke events as compared to psoriasis patients without sleep issues [8]. In this way, disordered sleep does not merely reduce quality of life in psoriasis but can result in potentially lethal health outcomes.

Given the high prevalence and serious consequences of disordered sleep in psoriasis, it is vital to better understand the nature of sleep disturbance in this population. Contributing factors can be divided into two categories:

insufficient quantity of sleep and poor quality of sleep. The former is defined as less 7 h of sleep per day on average, as recommended by the American Academy of Sleep Medicine [4]. This measure can be readily assessed by directly asking an individual to quantify their average sleep. On the other hand, assessing sleep quality is far more complex. Sleep quality is determined by several factors, including but not limited to sleep latency, continuity, depth, and post-sleep restoration [15, 16]. An individual may have a subjective sense of their sleep quality and can be screened by asking if they experience difficulty or trouble sleeping on a routine basis, but many require objective evaluation using polysomnography and other specialized methods. Such evaluations are relatively simple and have been studied in association with many medical conditions, but it remains a critical need to more rigorously study sleep disturbance among large numbers of patients living with psoriatic disease [17].

This study was designed to help meet this need. Citizen Pscientist (CP) is an online patient portal developed by the National Psoriasis Foundation (NPF) that is designed to provide psoriatic patients with an opportunity to connect with each other by completing an optional survey with questions including demographic details, symptom and treatment histories, and quality of life topics such as the impact of their condition on diet, exercise, and of course sleep [18]. Participation in CP is completely voluntary. For those who opt in, CP participants can perform their own analyses of responses to the CP survey since all answers are posted to the CP website without any identifying information of those who provided it [18]. Participants also have the option to comment on survey results and engage in discussions with other members of the CP community, which has participants around the world [19].

Furthermore, clinicians and researchers can request access to this de-identified data to inform clinical care and research initiatives. The study described here used CP survey data as of July 2018 to examine what factors are associated with sleep difficulty and sleep quantity in this psoriatic cohort.

METHODS

Our analysis included data from 3118 participants who completed the CP survey and identified as having a diagnosis by a physician of psoriasis alone or psoriasis with psoriatic arthritis. Institutional review board (IRB) approval for CP was obtained from Genetic Alliance, which includes participants outside of the USA as included in this cohort. The study conformed with the Helsinki Declaration of 1964, as revised in 2013, concerning human rights. Participants had access to the Terms and Conditions of CP, including statements regarding the unlikely possibility that a breach of data confidentiality may occur and that their survey responses may be analyzed by researchers studying psoriatic disease and may be presented in written publications [18].

The most recent version of the CP survey contains 79 questions. A subset of 15 questions were selected for the scope of this analysis (Table 1). Demographic information, psoriasis severity and duration, sleep apnea status, smoking and alcohol consumption, itch timing, and sleep characteristics are provided (Table 2). Psoriasis severity was participant-reported by answering the survey question about psoriasis body surface (BSA) area involvement. Mild was defined as BSA less than 5%, moderate was defined as BSA of 5–10%, and a BSA greater than 10% was defined as severe. Sleep characteristics were derived from survey questions about hours of sleep per day on average and trouble sleeping. Participants who reported sleeping less than 7 h per day on average were categorized as having low sleep quantity, as defined by the American Academy of Sleep Medicine [4], and participants who responded “yes” to the question “Do you have trouble sleeping?” were categorized as having sleep difficulty.

STATA software (version 15) was used to tabulate frequencies, percentages, and means, and two separate multivariate logistic regression models were used to determine whether the presence of psoriatic arthritis, age, gender, body mass index (BMI), comorbid sleep apnea, psoriasis severity, timing of worst itch, smoking status, or high-risk alcohol consumption were

Table 1 Subset of Citizen Pscientist survey questions and response options

Question	Response options
Has a doctor diagnosed you with psoriasis?	Yes, No
Has a doctor diagnosed you with psoriatic arthritis?	Yes, No
How old are you?	Under 18, 18–25, 26–30, 31–35, 36–40, 41–45, 46–50, 51–55, 56–60, 61–65, Over 65
What is your sex?	Male, Female
How tall are you?	Under 4.5 ft, 4.5 ft–5 ft, Over 5 ft–5.5 ft, Over 5.5 ft–6 ft, Over 6 ft–6.5 ft, Over 6.5 ft
How much do you weigh?	Under 100 lbs, 100–120 lbs, 121–140 lbs, 141–160 lbs, 161–180 lbs, 181–200 lbs, 201–220 lbs, 221–240 lbs, 241–260 lbs, 261–280 lbs, 281–300 lbs, 301–320 lbs, 321–340 lbs, 341–360 lbs, 361–380 lbs, 381–400 lbs, Over 400 lbs
Do you have one or more of the following conditions?	Crohn's disease, Juvenile-onset diabetes (type 1), Rheumatoid arthritis, Lupus, Eczema, Cutaneous T cell lymphoma, Celiac disease, Sjogren's syndrome, Uveitis, Thyroid disease, Multiple sclerosis, Alopecia areata, Atopic dermatitis, High cholesterol, High triglycerides, High blood pressure, Coronary artery disease, Stroke, Adult-onset diabetes (type 2), Parkinson's disease, Liver disease, Cancer, Sleep apnea, Fatty liver disease
How much of your body is covered by psoriasis?	None or very little (body surface area, BSA < 5%), Only a few patches that could be covered by 1 or 2 palms of your hand (BSA < 5%), Could be covered by less than 5 palms of your hand (BSA < 5%), Between 5 and 10 palms of your hand (BSA 5–10%), Scattered patches (BSA 5–10%), Covered by more than 10 palms of your hand (BSA > 10%), Extensive psoriasis (BSA > 10%)
At what age did a doctor diagnose you with psoriasis?	I have never been diagnosed with psoriasis by a doctor, Under 18, 18–25, 26–30, 31–35, 36–40, 41–45, 46–50, 51–55, 56–60, 61–65, Over 65
At what age did a doctor diagnose you with psoriatic arthritis?	I have never been diagnosed with psoriatic arthritis by a doctor, Under 18, 18–25, 26–30, 31–35, 36–40, 41–45, 46–50, 51–55, 56–60, 61–65, Over 65
How many cigarettes do you smoke per day?	I don't smoke, I only smoke occasionally, 1–10 cigarettes, 11–20 cigarettes, More than 20 cigarettes
How many alcoholic drinks do you have per week? (one drink is 12 oz beer, 5 oz wine, 1 oz of liquor)	I don't drink alcohol, 1–3, 4–6, 7–9, 10 or more
At what time of day do you experience the most itch?	Morning, Midday, Afternoon, Evening, Night
Do you have trouble sleeping at night?	Yes, No
How many hours of sleep do you get per day on average?	Under 5 h, 5 h, 6 h, 7 h, 8 h, 9 h, 10 or more hours

associated with sleep difficulty or low sleep quantity (Table 3). The dependent variables listed above were chosen a priori, and both models were evaluated and adjusted for statistical interactions. For each outcome, *p* values of less than 0.05 were deemed significant, and odds ratios (ORs) with 95% confidence intervals (CIs) are reported.

RESULTS

Demographic results and clinical characteristics (Table 2) demonstrate that the CP population is almost equally composed of participants with psoriasis only (*n* = 1588, 50.9%) and those with psoriatic arthritis (*n* = 1530, 49.1%). As previously described, the CP psoriatic cohort is approximately 70% White/Caucasian [19]. This population is predominantly female (*n* = 2153, 69.1%), and the mean age is 45.2 (standard deviation 0.3). The average BMI is 27.6 (standard deviation 0.3), and 62.8% of participants have an overweight or obese BMI. With respect to disease duration, more than 10 years was reported by the majority of both psoriasis (80.3%) and psoriatic arthritis (69.5%) participants. In terms of sleep characteristics, over half of participants reported sleep difficulty (58.4%), and low sleep quantity was reported by 38.8% of respondents. More specifically, the proportions of participants endorsing each survey response option for sleep duration are illustrated in Fig. 1.

Results from the multivariate logistic regressions (Table 3) found that sleep difficulty was associated with psoriatic arthritis (OR 2.15, 95% CI [1.79–2.58]), female gender (2.03 [1.67–2.46]), obese body mass index (BMI \geq 30) (1.25 [1.00–1.56]), sleep apnea (1.41 [1.07–1.86]), psoriasis severity of moderate (1.59 [1.30–1.94]) or severe (2.40 [1.87–3.08]), and smoking (1.60 [1.26–2.02]). Low sleep quantity was associated with obese BMI (1.62 [1.29–2.03]), sleep apnea (1.30 [1.01–1.68]), psoriasis severity of moderate (1.41 [1.16–1.72]) or severe (1.40 [1.11–1.76]), and smoking (1.62 [1.31–2.00]). Sleep difficulty and low sleep quantity were not associated with age, alcohol consumption, or timing of worst itch.

DISCUSSION

These results are potentially meaningful in several aspects. First, we identify an important distinction between sleep difficulty and sleep quantity in psoriatic disease, whereby having psoriatic arthritis and being female are each associated with sleep difficulty despite no association with low sleep quantity. It is not possible to definitively account for these differences from this analysis, but various potential explanations can be considered. It is feasible that psoriatic arthritis contributes to musculoskeletal discomfort that causes more sleep difficulty than the cutaneous symptoms of psoriasis alone. Such physical discomfort might not reduce the number of hours slept on average but may cause trouble initiating and staying asleep or feeling rested after a sufficient quantity of sleep [7], which may be reported by CP participants as sleep difficulty despite adequate sleep quantity. With respect to gender, an extensive literature review indicates that this is the first study to report that female gender is uniquely associated with sleep difficulty in psoriatic patients. It is conceivable that women with psoriasis are more likely to report trouble sleeping because they tend to be more attuned to less restorative sleep, as reported in the general population [20]. Thus, even though women with psoriasis report similar quantity of sleep as their male counterparts, the former might not be sleeping as soundly as the latter who also may be less aware of any problem.

Second, there is conflicting evidence from prior studies as to whether psoriasis severity is associated with sleep difficulty [7, 9], but this is a well-powered, large study that revealed a strong, graded relationship between psoriasis severity and both sleep difficulty and low sleep quantity. These associations are reasonable given that more severe physical symptoms of psoriasis, especially pruritus [21], are more disruptive to a person's ability to sleep without difficulty, delayed onset, or premature cessation. Likewise, a 2008 study found that impaired sleep quality can partly mediate the association between pruritus and psychological symptoms in psoriasis, including anxiety and

Table 2 Clinical and sleep characteristics

Characteristic	Frequency (%)
Disease	
Psoriasis	1588 (50.9)
Psoriasis with psoriatic arthritis	1530 (49.1)
Age	
18–20	142 (4.6)
21–30	248 (8.0)
31–40	559 (17.9)
41–50	696 (22.3)
51–60	806 (25.8)
61–70	653 (20.9)
71–80	8 (0.3)
81–90	5 (0.2)
91–99	1 (0.1)
Gender	
Male	960 (30.8)
Female	2153 (69.1)
No response	5 (0.1)
Body mass index (BMI)	
Underweight (< 18.5)	137 (4.4)
Normal (18.5–24.9)	1021 (32.8)
Overweight (25–29.9)	875 (28.1)
Obese (\geq 30)	1085 (34.8)
Comorbid sleep apnea	
Absent	2735 (87.7)
Present	383 (12.3)
Psoriasis severity	
Mild (< 5% body surface area)	1328 (45.1)
Moderate (5–10% body surface area)	1053 (35.8)
Severe (> 10% body surface area)	564 (19.2)
Disease duration	
Psoriatic skin disease	
0–10 years	613 (19.7)
> 10 years	2505 (80.3)

Table 2 continued

Characteristic	Frequency (%)
Psoriatic arthritis	
0–10 years	466 (30.5)
> 10 years	1064 (69.5)
Smoking status	
Non-smoker	2416 (80.3)
Smoker	594 (19.7)
Alcohol consumption	
Low-risk	2710 (89.7)
High-risk	311 (10.3)
Timing of Worst Itch	
Frequency (%)	
Do not notice a difference	202 (6.5)
Morning	363 (11.6)
Midday	307 (9.8)
Afternoon	349 (11.1)
Evening	1048 (33.7)
Night	863 (27.6)
Sleep characteristics	
Frequency (%)	
Sleep quality	
No trouble sleeping	1213 (41.6)
Trouble sleeping	1704 (58.4)
Sleep quantity	
Less than 7 h per day	1166 (38.8)
7 h or more per day	1836 (61.2)

depression [22]. Such psychological comorbidities are more common in moderate and severe psoriasis and also independently associated with sleep disturbance [11, 23–26]. Therefore, sleep problems in psoriasis may be due to a combination of disease severity, as seen in this study, as well as closely related psychological factors that undoubtedly play a role in these associations but that were outside the scope of the CP survey.

Table 3 Factors associated with sleep difficulty or low sleep quantity by multivariate logistic regression

Variable	OR	95% CI	<i>p</i> value
Sleep difficulty^a			
Disease			
Psoriasis without psoriatic arthritis	–	–	–
Psoriasis with psoriatic arthritis	2.15	1.79–2.58	< 0.001*
Age	0.99	0.93–1.04	0.671
Gender			
Male	–	–	–
Female	2.03	1.67–2.46	< 0.001*
BMI			
Normal BMI	–	–	–
Underweight (< 18.5)	0.81	0.53–1.24	0.331
Overweight (25–29.9)	1.08	0.86–1.36	0.493
Obese (\geq 30)	1.25	1.00–1.56	0.047*
Comorbid sleep apnea	1.41	1.07–1.86	0.016*
Psoriasis severity			
Mild	–	–	–
Moderate	1.59	1.30–1.94	< 0.001*
Severe	2.40	1.87–3.08	< 0.001*
Timing of worst itch			
No difference	–	–	–
Morning	1.26	0.62–2.56	0.521
Midday	1.19	0.58–2.43	0.641
Afternoon	1.30	0.64–2.66	0.468
Evening	1.18	0.60–2.33	0.630
Night	1.34	0.68–2.65	0.403
Smoker	1.60	1.26–2.02	< 0.001*
High-risk alcohol consumption	0.79	0.59–1.05	0.105
Sleep quantity^b			
Disease			
Psoriasis without psoriatic arthritis	–	–	–
Psoriasis with psoriatic arthritis	1.08	0.91–1.29	0.371
Age	1.01	0.96–1.07	0.663
Gender			

Table 3 continued

Variable	OR	95% CI	<i>p</i> value
Male	–	–	–
Female	1.16	0.95–1.40	0.138
BMI			
Normal BMI	–	–	–
Underweight (< 18.5)	1.15	0.75–1.76	0.527
Overweight (25–29.9)	1.09	0.86–1.38	0.475
Obese (\geq 30)	1.62	1.29–2.03	< 0.001*
Comorbid sleep apnea	1.30	1.01–1.68	0.044*
Psoriasis severity			
Mild	–	–	–
Moderate	1.41	1.16–1.72	0.001*
Severe	1.40	1.11–1.76	0.004*
Timing of worst itch			
No difference	–	–	–
Morning	0.81	0.40–1.63	0.553
Midday	0.96	0.47–1.93	0.900
Afternoon	0.91	0.45–1.84	0.797
Evening	0.98	0.50–1.90	0.943
Night	0.84	0.43–1.65	0.618
Smoker	1.62	1.31–2.00	< 0.001*
High-risk alcohol consumption	1.34	0.70–2.58	0.372

OR odds ratio, CI confidence interval

**p* value of less than 0.05 was deemed to be significant

^a Defined as answering “yes” to the survey question “Do you have trouble sleeping at night?”

^b Defined as answering “Under 5 h,” “5 h,” or “6 h” to the survey question “How many hours of sleep do you get per day on average?”

– Indicates the reference group for each variable

Third, it is important to discuss the influence of OSA status and treatment on these results. Comorbid OSA was found to be associated with both sleep difficulty and low sleep quantity. These findings are consistent with literature on the relationship between OSA and psoriasis [9, 13, 27, 28]. At the same time, the CP survey did not include questions about treatment for OSA, such as continuous positive airway

pressure (CPAP), that could certainly influence the relationships between sleep difficulty, sleep quantity, and psoriasis. Similarly, high BMI was associated with both sleep variables, but given the association between being overweight or obese with OSA and psoriasis [29, 30], the link between high BMI and poor sleep may be explained by undiagnosed OSA. Relatedly, prior studies with smaller psoriatic cohorts have not

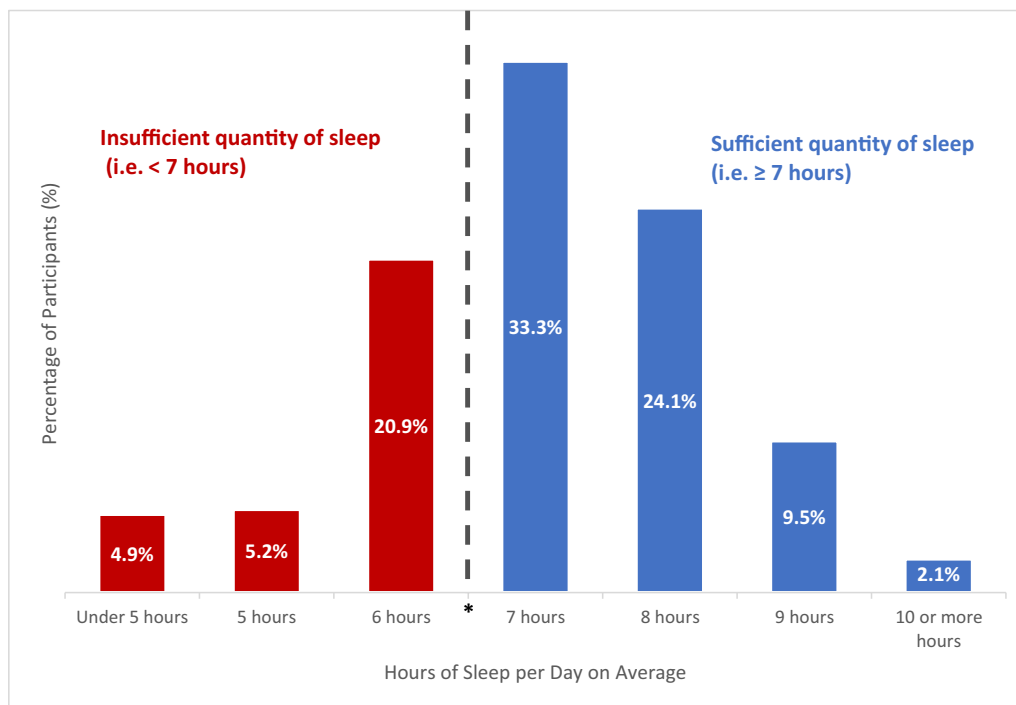


Fig. 1 Sleep duration responses. *American Academy of Sleep Medicine recommends 7 h as the amount of sleep needed to promote optimal health in adults [4]

found obesity to be predictive of sleep interference [7], but this analysis demonstrated a strong relationship between high BMIs and both sleep difficulty and low sleep quantity.

Limitations

All data used for this analysis were participant-reported and not physician-confirmed. For example, psoriasis severity was determined by patient-reported evaluation of BSA involvement rather than a physician's evaluation. Another example is that OSA status was reported by patients who may or may not have been formally evaluated for this key sleep-related comorbidity. This limitation could not be overcome given the web-based delivery of the CP survey and the de-identification of survey responses, making it not possible to link CP participant responses to physician-reported data.

Another limitation is that causality cannot be inferred from the reported associations. This

is a limitation inherent to data from observational cohort studies at a single time point like this one. A related limitation is that the design of this study as an online survey for patients living with psoriatic disease makes it not possible to compare the results from participants' responses to a control group.

An additional limitation is related to the survey instrument. As discussed, the full CP survey contains 79 questions that span many topics related to living with psoriatic disease. Only two of these questions relate to sleep difficulty and quantity. While both questions were included in the subset used for this analysis (Table 1), it would have been helpful to have more questions about sleep, such as asking about non-restorative sleep, sleep timing, or many other factors that influence sleep quality and duration. It would have been additionally helpful to include questions about psychological symptoms, such as anxiety or depression that could also directly impact sleep as described above. Using a more extensive, validated

instrument to evaluate sleep in psoriatic patients would be appropriate for future studies.

Lastly, the CP participant population lacks racial, gender, and age diversity. With particular respect to race, this cohort is approximately 70% White/Caucasian. Although psoriasis is most common in this group [31], a more racially diverse cohort would better capture a broader range of experiences with psoriasis and sleep.

CONCLUSIONS

Overall, our results show that both sleep difficulty and low sleep quantity were associated with multiple factors in this analysis of a large psoriatic cohort. These findings suggest that dermatologists may gather clinically useful information by screening psoriatic patients for trouble sleeping and low sleep quantity to identify potential comorbidities and to more effectively guide disease management. For example, if a patient endorses trouble sleeping or low sleep quantity, the physician could consider comorbidities such as obesity, OSA, and psychological symptoms. In some cases, a referral to a sleep specialist may be necessary for a more thorough evaluation of the many nuanced factors that influence sleep [16]. Incorporating such screening into routine dermatologic care seems not only manageable but also essential given the well-established high prevalence of sleep dysfunction in psoriasis as well as the severe health outcomes associated with this comorbidity in the psoriatic population [1, 5, 7–11, 13, 21].

Moreover, several studies have examined whether treatment of psoriasis alone is associated with improvements in sleep disturbance among this population. Results have shown that sleep problems can significantly improve with successful treatment of psoriasis, leading to reduced daytime fatigue and improved quality of life [32, 33]. However, sleep dysfunction may not remit entirely even when other psoriatic symptoms are well controlled, especially if there are sleep-related comorbidities such as OSA [34]. These findings reinforce the importance of screening psoriatic patients

for sleep problems and suggest that it may not be sufficient to only treat psoriasis in patients who endorse sleep disturbance.

In conclusion, this analysis helps fill the critical need to better understand the many associations of sleep disturbance in psoriasis and derives from an innovative approach to patient-centered research, whereby the psoriatic population is directly involved in the design, conduct, and analysis of the results [19]. While this study has several limitations as discussed, a key strength is overcoming selection bias that can occur in sleep research since CP participants were not selected on this basis, but rather identified through a select subset of CP survey answers. It is important to continue pioneering and advocating for research like this that make patients feel empowered and supported while also giving researchers and clinicians greater insight into many aspects of their lives with psoriatic disease, including the impact on sleep that has been thus far inadequately explored given its many consequences.

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Data Availability. The data sets generated and/or analyzed during the current study are available from the National Psoriasis Foundation on reasonable request. Please contact the corresponding author for more information.

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