

Exploring Social Health in Patients with Atopic Dermatitis: An Observational, Cross-sectional, Questionnaire Based Study on Social Participation and Emotional Support

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Atopic dermatitis (AD) is a common chronic inflammatory skin disease, which has significant impact on the life of those affected (1). While the impact of AD on physical and mental health has been frequently researched, social health has received limited attention. Social health is defined as perceived well-being regarding social activities and relationships, including the ability to relate to individuals, groups, communities, and society (2). In AD, this can be affected by factors such as fatigue, changes in physical appearance, and declining mental health. Therefore, to understand the full impact of AD on patients' lives, there is a need to measure social health as an outcome. In response, the Patient-Reported Outcomes Measurement Information System (PROMIS) developed a social health framework, which includes 2 primary sub-domains: social function and social relationships (3). The aim of this study is to evaluate the social health of patients with different AD severities in both sub-domains, in terms of ability to participate in social roles and activities, and emotional support.

MATERIALS AND METHODS

This observational, cross-sectional, questionnaire-based study was performed at the University Medical Center Groningen and the University Medical Center Utrecht (both tertiary referral centres) in the Netherlands between May 2022 and October 2022. In total, 2,066 adult patients with physician-diagnosed AD who visited the outpatient clinic between May 2020 and May 2022 received the questionnaire, which included questions on social health and other AD-related patient-reported outcome measures (PROMs). Social health was assessed by 2 x 8-item short forms from the PROMIS: ability to participate in social roles and activities (APS) and emotional support (3). For the scoring of the PROMIS questionnaires, T-scores are used. A T-score is a standardized score where the average score in the reference population (the general population of the United States for the forms in this study) is set at 50 with a standard deviation (SD) of 10. Higher T-scores indicate above-average social participation ability or perceived emotional support. AD control was assessed by the Atopic Dermatitis Control Tool (ADCT) (range 0–24) (4). AD severity was measured by the Patient-Oriented Eczema Measure (POEM) (range 0–28) (5). Weekly average pruritus was measured by the Numeric Rating Scale (NRS)-itch (range 0–10) and weekly average sleep disturbance was measured by the NRS-sleep (range 0–10) (6, 7).

Statistical analysis

An independent samples *t*-test and ANOVA were used to compare between different groups. Additionally, univariate and multivariate linear regression models were run. The multivariate regression

model was adjusted for age and sex. For usage of systemic treatment the multivariate model was also adjusted for AD severity (POEM). Statistical significance was set at $p < 0.05$. Analyses were performed using IBM SPSS Statistics for Windows (Version 28.0; IBM Corp Armonk, NY, USA).

RESULTS

In total, 863 patients responded to the questionnaire (response rate 41.8%). After excluding patients without information on sex ($n = 38$), those who did not respond to any PROMs ($n = 13$), and both PROMIS short forms ($n = 10$), 802 patients were included. The mean \pm SD age was 44.8 ± 16.7 years and 51.4% were female (**Table I**). Mean \pm SD PROMIS-APS score was 53.5 ± 8.7 and mean \pm SD PROMIS emotional support score 52.2 ± 8.7 .

Table I. Patient characteristics

Item	Total cohort ($n = 802$)
Age, years, mean \pm SD	44.8 \pm 16.7
Missing, n	5
Sex, n (%)	
Male	390 (48.6)
Female	412 (51.4)
PROMIS ability to participate in social roles and activities, mean \pm SD	53.5 \pm 8.7
Missing, n	2
PROMIS emotional support, mean \pm SD	52.2 \pm 8.7
Missing, n	3
ADCT, mean \pm SD	6.6 \pm 5.3
Controlled AD (<7)	475 (59.2)
Uncontrolled AD (≥ 7)	326 (40.6)
Missing, n	1
POEM, mean \pm SD	10.4 \pm 7.0
Mild (0–7)	308 (38.4)
Moderate (8–16)	302 (37.7)
Severe (17–28)	171 (21.3)
Missing, n	21
Weekly average NRS-pruritus, mean \pm SD	3.3 \pm 2.6
No/mild (0–4)	490 (61.1)
Moderate (5–7)	218 (27.2)
Severe/very severe (8–10)	79 (9.9)
Missing, n	15
Weekly average NRS-sleep disturbance, mean \pm SD	2.0 \pm 2.5
No/mild (0–3)	634 (79.1)
Moderate (4–7)	119 (14.8)
Severe (8–10)	33 (4.1)
Missing, n	16
Systemic treatment, n (%)	414 (51.6)
Biologics	323 (40.3)
JAK inhibitors	42 (5.2)
Conventional immunosuppressives*	49 (6.1)

n: number; SD: standard deviation; PROMIS: Patient-Reported Outcomes Measurement Information System; ADCT: Atopic Dermatitis Control Tool; POEM: Patient-Oriented Eczema Measure; NRS: Numeric Rating Scale; JAK: Janus kinase. *Conventional immunosuppressives included cyclosporine, methotrexate, mycophenolate mofetil, mycophenolic acid prednisolone, and tacrolimus.

Patients considering their AD as severe according to the POEM showed significantly lower PROMIS-APS scores than patients considering their AD as mild/moderate ($p < 0.001$) (Table SI). Similarly, patients with severe/very severe itch and patients with severe sleep disturbance showed significantly lower PROMIS-APS scores than patients with no/mild/moderate itch or sleep disturbance (both $p < 0.001$). Furthermore, patients with uncontrolled AD according to the ADCT showed significantly lower PROMIS-APS and emotional support scores than controlled AD patients (both $p < 0.001$).

In the univariate regression model, PROMIS-APS was positively associated with the use of systemic treatment, but inversely associated with higher POEM score, higher ADCT score, higher NRS-itch score, and higher NRS-sleep score (Table SI). PROMIS emotional support showed a positive association with the use of systemic treatment in the univariate model, while demonstrating an inverse association with higher POEM score, higher ADCT score, higher NRS-itch score, and higher NRS-sleep score (Table SI). Except for the use of systemic treatment, associations remained significant in the multivariate model.

DISCUSSION

In this study, we found that patients who considered their AD as severe had lower PROMIS-APS scores, indicating less ability to participate in social roles and activities compared with those with mild/moderate AD. PROMIS emotional support was significantly lower in patients with uncontrolled AD vs controlled AD. Additionally, both PROMIS-APS and PROMIS emotional support demonstrated a significant inverse association with higher scores of PROMs in the univariate and multivariate regression models. However, this association was weaker in the PROMIS emotional support scores compared with the PROMIS-APS scores.

The PROMIS social health questionnaires have not yet been used in AD. However, social health has been studied in AD patients. For social function, a cross-sectional, population-based study of 602 adults found that many AD patients reported that AD limited their lifestyle (51.3%), caused them to avoid social interaction (39.1%), and impacted their activities (43.3%) (8). These effects of AD were even more burdensome in individuals with self-reported moderate-to-severe AD, which was also the case in our study.

For social relationships, an international study that conducted in-depth telephone interviews with 1,098 adult patients with moderate-to-severe AD as defined by their treating physician reported that 21% struggled to form relationships, and 12% experienced relationship problems due to AD (9). A case-control study comprising 66 outpatients with AD found that patients with low

social support tended to have more frequent disease recurrence (10). Our study revealed that patients with uncontrolled AD according to the ADCT experienced less emotional support than patients with controlled AD. Nevertheless, no significant differences emerged from the severity categories of other PROMs. Additionally, emotional support did not emerge as a meaningful PROMIS domain in a cross-sectional study based on data from an internet survey (11). Therefore, the question arises regarding whether emotional support is a concern in patients with AD.

PROMIS measures are generic instruments designed to be applicable across populations and medical conditions. In the current study, AD patients who considered their itch as severe/very severe had PROMIS-APS T-scores of mean \pm SD 45.0 ± 8.5 , which is lower than the general Dutch population (50.6 ± 9.5) (12). No data are available on conditions comparable to AD. However, the score is comparable to patients with multiple sclerosis (45.2 ± 10.6), for example (13). Additionally, patients with uncontrolled AD had PROMIS emotional support T-scores of 51.0 ± 8.3 , which is higher than the general population of the United States (50 ± 10) (2). This emphasizes the impact of AD on social participation.

This study has a few limitations. The cross-sectional design prevented us from establishing causality. Furthermore, social health outcomes may be influenced by factors that we have not considered; for example, attitudes, personality, and finances. Lastly, selection bias may have occurred as not all patients responded, with potential bias in 2 directions: patients with limited social engagement may have been more likely to complete the questionnaire due to increased time at home, while, conversely, patients without energy to participate in social activities may have also lacked the energy to respond.

In conclusion, our study showed significantly lower PROMIS-APS scores among patients who perceived their AD as severe, based on all included PROMs. Additionally, the PROMIS emotional support score was possibly less relevant in this AD population. Further research is needed to assess how impaired social health affects overall health outcomes and to determine whether patients would benefit from additional support in this area.

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