ORIGINAL ARTICLE

Impact of Atopic Dermatitis on Patients and their Partners

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Atopic dermatitis is a chronic, relapsing and inflammatory skin disease. The impact of atopic dermatitis on the partners living with patients has been poorly investigated. The objective of this study was to evaluate the impact of atopic dermatitis in the daily lives of adult patients and to assess the burden of the disease on their partners. A population-based study was conducted on a representative sample of the general population of French adults aged 18 years of age using stratified, proportional sampling with a replacement design. Data were collected on 1,266 atopic dermatitis patient-partner dyads (mean age of patients 41.6 years, 723 (57.1%) women). The mean age of partners was 41.8 years. Patient burden, measured by the Atopic Dermatitis Burden Scale for Adults (ABS-A) score, was closely related to the objective atopic dermatitis severity: the mean score in the mild group (29.5) was significantly lower than in the moderate (43.9) and severe groups (48.6) ($p < 0.0001$). Partner burden, measured by the EczemaPartner score, was highly related to atopic dermatitis severity ($p < 0.0001$). Daytime sleepiness, measured by the Epworth Sleepiness Scale, showed a mean score of 9.24 in patients and 9.01 in their partners, indicating impaired sleep. Atopic dermatitis was found to decrease sexual desire in 39% and 26% of partners and patients respectively.

Key words: atopic dermatitis; partners; burden; quality-of-life; sleep.

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SIGNIFICANCE

Atopic dermatitis can impart a profound burden on patients and their partners including sleep disturbance and sexual health impairment. This is not surprising, considering that partners share a significant part of the challenges faced by the affected individuals. These results merit particular attention for future patient-centred care provision. Indeed, the burden of atopic dermatitis on partners should be taken into consideration by physicians when implementing education programmes dedicated to patients and their loved ones. Targeting partners with education and psychosocial support can eventually decrease the burden.

Atopic dermatitis (AD) is a chronic, relapsing and inflammatory skin disease. In France, the prevalence of AD in the general population over 15 years of age is estimated at 4.6% (1) and prevalence of adult AD is estimated at around 2–10% (2, 3). Although AD is not a life-threatening disease, it has profound impact on quality of life (QoL) (4, 5). Pruritus, the main symptom of AD, often leads to frequent scratching, skin pain, and skin infections. AD has been shown to significantly impair sleep quality (6). Moreover, whether the patient is a child, teenager or adult, AD may have a secondary negative impact on the physical, emotional, social, and economic elements of the patient's family life (7, 8). The term "greater patient" was coined by Basra & Finlay (9) to describe the immediate close social group affected by a person having skin disease. Since AD is probably a lifelong illness, its negative impact on the lives of patients and their families occurs throughout the lifespan. Previous studies on AD have focused mainly on children (10). However, adult patients with AD may also share the psychosocial burden of their disease with family members and partners (5, 11). Different burdens of AD arise as patients enter adulthood, including adverse effects on sexual health and affective relationships (12–14). Partners of patients with chronic diseases face multiple challenges, and may have to adjust their activities of daily living.

Although studies have focused on the health-related QoL and burden of AD in patients themselves, data regarding the impact AD has on the partners living with them are scant (15). A few studies have focused on the impact of AD on an individual's sexuality, but information regarding the difficulties experienced by the partners is very limited (16, 17).

The aim of this study was therefore to evaluate the impact of AD in the daily lives of adult patients in the French population and to assess the burden of the disease on their partners.

MATERIALS AND METHODS

Study design

This was an observational, cross-sectional study. The study was approved by a local ethics committee at CHU de Grenoble, France (reference number 20.04.18.61210) and was conducted according to the principles of the Declaration of Helsinki.

Study population

Survey participants were recruited between January and April 2021, from a representative sample of French adults recruited by a polling institute (HC Conseil Paris, France) from the general adult population above 18 years of age using stratified, proportional sampling with a replacement design. Respondents who reported being diagnosed with AD by a physician were invited to participate in the study. The inclusion criteria were: ability to understand French; provision of consent to participate in the study after receipt of written information about the study; age above 18 years. Participants also gave consent for their partner's participation in the study. The patient and spouse were asked to respond separately, with the spouse having to respond within a maximum of 2 or 3 days.

Study procedures

Patients were asked to complete a questionnaire regarding sociodemographic and personal information, including age, sex, and relationship duration. Partners were asked to complete a different questionnaire regarding sociodemographic and personal information, including age but not sex.

Patients were asked to self-evaluate the global clinical severity of their AD (into mild, moderate, or severe). Partners were also asked to evaluate the global clinical severity of their partner's AD (as mild, moderate, or severe). Objective clinical severity of AD was assessed by the patient using the Patient-Oriented Eczema Measure (POEM) (18). POEM is a self-assessment tool used to monitor disease activity in children and adults with AD. The questionnaire asks about the frequency of occurrence of 7 symptoms during the preceding week (itching, sleep, bleeding, weeping, skin cracking, skin flaking off, and skin dryness). It is rated out of 28. The previously proposed banding for POEM scores were used to create 3 groups: mild (0–7), moderate (8–16), and severe (17–28) (19).

Patients and partners were asked to complete several questionnaires on QoL and burden, as well as a non-validated questionnaire about sexuality, which was used in a previous study (13).

The burden of AD was assessed by the patient using the Atopic Dermatitis Burden Scale for Adults (ABS-A) (20). The ABS-A questionnaire is a validated tool that assesses the burden of AD in adult patients. The questionnaire consists of 18 items grouped into 4 domains ("daily life", "economic constraints", "care and management of disease", and "work and stress"). It is rated out of 90. A higher ABS-A score reflects a higher AD burden.

The burden of AD was assessed by the partner using EczemaPartner (21). It is a validated questionnaire that evaluates the burden of partners of patients with AD.

It is structured around 5 factors (Perceived strain by social reactions, Strain caused by cleaning, Acute emotional strain, Restrictions of social life, General emotional strain) cover the following areas: social, emotional, leisure domain. It is comprised of 15 items and is rated out of 60. A higher EczemaPartner score reflects a higher AD burden on the partner.

The Epworth Sleepiness Scale, is a questionnaire that evaluates daytime sleepiness, and thus indirectly measures sleep disorders (22). It is comprised of 8 items and is rated out of 24. The higher the score, the higher the likelihood for a subject to fall asleep. If the Epworth score is ≤ 6, sleep is considered sufficient. A score ≥ 10 implies the presence of a sleep disturbance.

All the questionnaires were anonymous. The patients and their partners' questionnaires were linked by a code to form a dyad.

Statistical methods

Categorical values are described as numbers and percentages, and continuous variables as means, ranges and standard deviations (SD), or median and quartiles. Categorical variables were analysed using the $\chi 2$ test. The mean scores of the different instruments were compared for different levels on different variables using the Jonckheere-Terpstra test. Statistical analyses were preformed using the SAS software version 9.4 (SAS Institute, Cary, NC, USA).

RESULTS

A total of 2,530 patients with atopic dermatitis confirmed by a physician were identified and recruited. Of these, 1,722 declared that they were living as a couple. A total of 1,266 spouses completed the questionnaire, i.e. a joint response rate of 73.5%. Data were collected on 1,266 AD patient-partner dyads. Their characteristics are detailed in **Table I**. The mean age of the patients was 41.6 years (range 18–83 years), and 723 (57.1%) patients were women. The mean age of partners was 41.8 years (range 16–79 years). The median duration of the relationship was 12 years (range 6–20 years).

Severity

According to the POEM scores of the respondents, 560 (44.23%) presented mild AD, 561 (44.31%) moderate AD, and 145 (11.45%) severe AD (Table I). Patients' self–reported severity matched the severity established by the POEM score in 55% of cases; 25% overestimated their severity and 18% underestimated it. Partners' reported severity matched the severity established by the POEM score in 52% of cases, and the patients' self-reported severity in 70% of cases (**Table II**).

Table I. Description of the study population: patients with atopic dermatitis (AD) and their partners

Variable	Patient with AD ($n = 1,266$)	Partner ($n = 1,266$)
Age, years mean (SD)	41.6 (12.3)	41.8 (12.3)
Age categories *n* (%)		
18–25 years	75 (5.9)	74 (6.4)
25–35 years	390 (30.8)	336 (28.9)
35–50 years	527 (41.6)	493 (42.4)
51–65 years	211 (16.7)	194 (16.7)
> 65 years	63 (5.0)	66 (5.7)
Sex (*n*, %)		
Men	543 (42.9)	NA
Women	723 (57.1)	NA
Relationship duration, years, mean (SD)	15.5 (11.9)	
Median (quartiles), years	12 (6, 20)	
Severity of AD in patient		
Patient-Oriented Eczema Measure, *n* (%)		
Mild	560 (44.23)	
Moderate	561 (44.31)	
Severe	145 (11.45)	

SD: standard deviation; NA: not applicable.

Table II. Comparison between the partners regarding the atopic dermatitis (AD) severity assessment

	Mild N (%)	Moderate N (%)	Severe N (%)	No opinion N (%)
Global ($p = 0.6636$)				
Partner	412 (32.54)	711 (56.16)	115 (9.08)	28 (2.21)
Patient	441 (34.83)	690 (54.50)	110 (8.69)	25 (1.97)
Mild (POEM) ($p = 0.2195$)				
Partner	259 (46.25)	277 (49.46)	11 (1.96)	13 (2.32)
Patient	290 (51.79)	242 (43.21)	13 (2.32)	15 (2.68)
Moderate (POEM) ($p = 0.6787$)				
Partner	125 (22.28)	360 (64.17)	62 (11.05)	14 (2.50)
Patient	128 (22.82)	368 (65.60)	56 (9.98)	9 (1.60)
Severe (POEM) ($p = 0.8647$)				
Partner	28 (19.31)	74 (51.03)	42 (28.97)	1 (0.69)
Patient	23 (15.86)	80 (55.17)	41 (28.28)	1 (0.69)
Concordance between POEM and self-reported severity				
	Matching N (%)	Underestimation by the partner N (%)	Overestimation by the partner N (%)	One or neither of them has an opinion N (%)
Global ($p = 0.3121$)				
Partner	661 (52.21)	227 (17.93)	350 (27.65)	28 (2.21)
Patient	699 (55.21)	231 (18.25)	311 (24.57)	25 (1.97)
Mild (POEM) ($p = 0.1424$)				
Partner	259 (46.25)	–	288 (51.43)	13 (2.32)
Patient	290 (51.79)	–	255 (45.54)	15 (2.68)
Moderate (POEM) ($p = 0.6787$)				
Partner	360 (64.17)	125 (22.28)	62 (11.05)	14 (2.50)
Patient	368 (65.60)	128 (22.82)	56 (9.98)	9 (1.60)
Severe (POEM) ($p = 0.9916$)				
Partner	42 (28.97)	102 (70.34)	–	1 (0.69)
Patient	41 (28.28)	103 (71.03)	–	1 (0.69)
Concordance between patients' and partners' reported severity ($p = 0.0174$)				
Total	880 (69.51)	155 (12.24)	185 (14.61)	46 (3.63)
Mild	407 (72.68)	49 (8.75)	79 (14.11)	25 (4.46)
Moderate	374 (66.67)	82 (14.62)	86 (15.33)	19 (3.39)
Severe	99 (68.28)	24 (16.55)	20 (13.79)	2 (1.38)

POEM: Patient-Oriented Eczema Measure.

Burden

Patient burden, as measured by the ABS-A, was closely related to the objective AD severity: The mean (SD) score in the mild group was 29.5 (15.03) vs 43.9 (17.06) and 48.6 (18.52) in the moderate and severe groups, respectively ($p < 0.0001$) (**Table III**). A third of partners (420/1,266) believed that AD was contagious (**Fig. 1**). Patient burden was higher when the partner believed AD was contagious [50.78 (17.42) vs 31.76 (14.85); $p < 0.0001$].

Partner burden, as measured by the EczemaPartner, was highly related to AD severity. The mean (SD) score in the mild group was 20.00 (14.38) vs 31.06 (14.72) and 32.98 (14.48) in the moderate and severe groups, respectively ($p < 0.0001$) (Table III). The scores for each item on the Eczema Partners are described in Table SI.

Table III. Quality-of-life and burden of disease scores according to atopic dermatitis (AD) severity in 1,266 adult patients and their partners

	N (%)	ABS-A Mean (SD)	Eczema Partner Mean (SD)	Patient ESS Mean (SD)	Partner ESS Mean (SD)
Global score	1266 (100)	38.07 (18.11)	26.39 (15.61)	9.24 (5.01)	9.01 (4.83)
POEM					
Mild	560 (44.23)	29.50 (15.03)	20.00 (14.38)	7.73 (4.74)	7.91 (4.78)
Moderate	561 (44.31)	43.89 (17.06)	31.06 (14.72)	10.29 (4.63)	9.54 (4.46)
Severe	145 (11.45)	48.64 (18.52)	32.98 (14.48)	11.05 (5.77)	11.23 (5.33)
p-value		< 0.0001	< 0.0001	< 0.0001	< 0.0001
Patient self-reported severity					
Mild	441 (34.83)	30.54 (16.64)	19.11 (14.45)	8.10 (4.80)	8.29 (4.88)
Moderate	690 (54.5)	41.16 (16.75)	29.92 (14.48)	9.70 (4.91)	9.39 (4.65)
Severe	110 (8.69)	50.55 (18.58)	35.51 (14.25)	11.35 (5.03)	9.56 (4.99)
No opinion	25 (1.97)	30.80 (22.55)	17 (16.64)	7.40 (6.07)	9.00 (6.71)
p-value		< 0.0001	< 0.0001	< 0.0001	< 0.0001
Partner self-reported severity					
Mild	412 (32.54)	30.35 (16.40)	19.44 (14.44)	8.42 (4.79)	8.21 (5.05)
Moderate	711 (56.16)	40.88 (16.86)	29.41 (14.57)	9.57 (4.93)	9.42 (4.42)
Severe	115 (9.08)	50.23 (19.52)	35.90 (15.12)	10.66 (5.64)	9.83 (5.49)
No opinion	28 (2.21)	30.39 (19.58)	12.64 (12.16)	7.07 (5.02)	7.21 (6.66)
p-value		< 0.0001	< 0.0001	< 0.0001	< 0.0001

p-values were calculated using the Jonckheere trend test.
SD: standard deviation; ABS-A: Atopic Dermatitis Burden Scale for Adults; ESS: Epworth Sleepiness Scale.

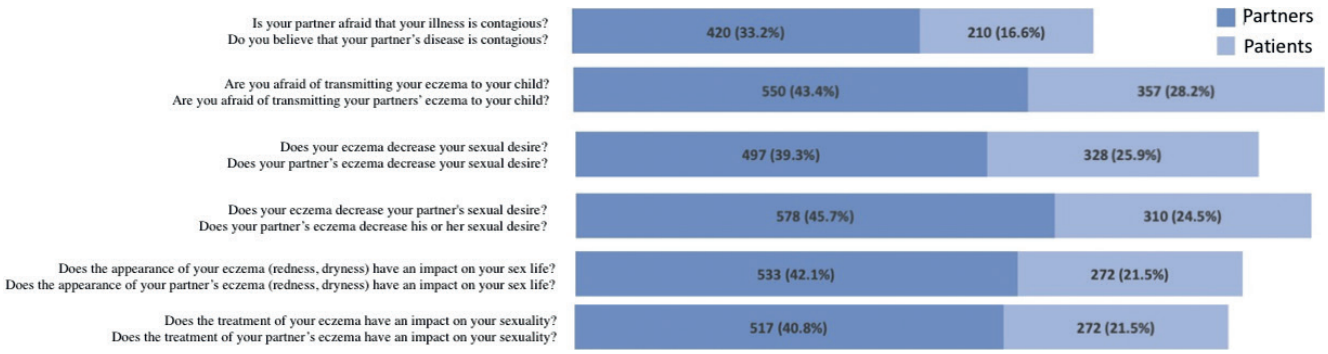

Fig. 1. Impact of atopic dermatitis on atopic dermatitis on sex life according to the patients and the partners.

Similarly, partner burden was higher when he or she believed AD was contagious [50.80 (SD17.40) vs 20.40 (SD13.70); $p<0.0001$].

The mean length of the couple relationship is 15.5 (±11.9). For both the patient and the spouse the burden is greater the more recent the relationship $p<0.001$ (Table SII).

Sleep

Daytime sleepiness, as measured by the Epworth Sleepiness Scale (ESS), showed a mean score of 9.24 (SD 5.01) in patients and 9.01 (SD 4.83) in their partners, indicating impaired sleep. Analysis by severity of atopic dermatitis demonstrated significantly more daytime sleepiness with increasing AD severity in both groups (Table III). Patients slept on a mean of 6.68 (SD 1.52) h a night, and their partners slept 6.84 (SD 1.45) h. Hours of sleep decreased significantly as AD increased in severity, in both patients and their partners (**Table IV**). Among the 1,266 patient-partners dyads, 420 (33.2%) had both members with an ESS score>9. This proportion was raised to 49.7% when AD was severe (Table IV).

Impact of AD on couple's sex life

Fig. 1 depicts the answers of AD patients and their partners regarding the impact of atopic dermatitis on their sex life. AD had a negative impact on patients and their partners, which was more pronounced in partners. AD decreased sexual desire in 39% and 26% of partners and patients, respectively. Nearly half (46%) of partners believed that AD decreased his or her partner's sexual desire, and a quarter of patients (25%) believed that their eczema decreased their partner's sexual desire. A negative impact of AD on sex life was associated with higher ABS-A and EczemaPartner burden scores in patients and their partners respectively (**Table V**).

DISCUSSION

This real-world study on 1,266 AD patient-partner dyads in France is one of the very rare studies to have evaluated the impact of AD on partners beyond sexual health (17). The results suggest that AD has a detrimental effect on the QoL of affected individuals and their partners, including sleep disturbance and sexual health impairment. Whether in patients or in their partners, the burden increases with increasing severity of AD, regardless of how severity is measured. It is noteworthy that variations in QoL scores in partners mirror those of patients. Three real-world studies (2 in the USA and 1 in France, Germany the UK and the USA) have also demonstrated that a more severe AD, whether self-reported or assessed by POEM, has a higher impact on the QoL of patients (4, 23, 24). In 1 report, severe AD was 8 times more likely to cause a moderate-to-severe effect on DLQI compared with mild AD (24).

Table IV. Impact of atopic dermatitis on sleep

Mean hours of sleep per night according to AD severity as assessed by POEM (SD)	Global	Mild	Moderate	Severe	*p* value
In patients	6.68 (1.52)	7.00 (1.33)	6.52 (1.59)	6.27 (1.77)	<0.0001
In partners	6.84 (1.45)	7.10 (1.27)	6.68 (1.51)	6.48 (1.65)	<0.0001
Sleep quality according to AD severity as assessed by POEM ($n=1,266$)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	
In patients					<0.0001
Good sleep (ESS ≤6)	366 (28.91)	220 (39.29)	110 (19.61)	36 (24.83)	
Problematic sleep (ESS 7–9)	289 (22.83)	146 (26.07)	120 (21.39)	23 (15.86)	
Sleep disturbance (ESS ≥10)	611 (48.26)	194 (34.64)	331 (59.00)	86 (59.31)	
In partners					<0.0001
Good sleep (ESS ≤6)	380 (30.02)	230 (41.07)	124 (22.10)	26 (17.93)	
Problematic sleep (ESS 7–9)	286 (22.59)	116 (20.71)	145 (25.85)	25 (17.24)	
Sleep disturbance (ESS ≥10)	600 (47.39)	214 (38.21)	292 (52.05)	94 (64.83)	
Sleep disturbance (ESS ≥10) in the patient-partner dyad	420 (33.18)	130 (23.21)	218 (38.86)	72 (49.66)	<0.0001

AD: atopic dermatitis; SD: standard deviation; POEM: Patient-Oriented Eczema Measure; ESS: Epworth Sleepiness Scale.

Table V. Impact of atopic dermatitis on sex life and burden according to the patients and their partners

	ABS-A scores						EczemaPartner Scores					
Answer	Yes			No			Yes			No		
Patient responses	N	Mean	Median	N	Mean	Median	N	Mean	Median	N	Mean	Median
Does your eczema decrease your sexual desire?	328	54.3	54	938	32.4	29	328	37.7	39	938	22.4	21
Does your eczema decrease your partner's sexual desire?	272	57.0	57	994	32.9	30	272	39.5	41	994	22.8	21
Does the appearance of your eczema (redness, dryness) have an impact on your sex life?	310	55.1	54	956	32.6	29	310	37.9	39	956	22.7	21
Does the treatment of your eczema have an impact on your sexuality?	272	56.0	54	994	33.2	30	272	38.3	40	994	23.1	21
Partner's responses												
Does your partner's eczema decrease your sexual desire?	497	50.6	51	769	30.0	26	497	38.34	39	769	18.7	17
Does your partner's eczema decrease his or her sexual desire?	578	48.8	49	688	29.1	25	578	36.40	38	688	18.0	16
Does the appearance of your spouse's eczema (redness, dryness) have an impact on your sex life?	533	50.4	51	733	29.1	25	533	38.03	39	733	17.9	16
Does the treatment of your partner's eczema have an impact on your sexuality?	517	50.8	51	749	29.3	25	517	38.35	39	749	18.1	16

ABS-A: Atopic Dermatitis Burden Scale for Adults.

More than half of patients in this study had moderate-to-severe disease according to the self-administered objective POEM instrument. When patients and their partners were asked to globally evaluate AD severity (using the mild-moderate-severe scale), their assessment matched the severity established by the POEM in a little more than half of patients (55%) and partners (52%). Nevertheless, the perception of AD severity by partners was aligned with that of patients in 70% of cases. This excellent agreement between patients' and partners' global assessment, but relatively low agreement between the latter and the POEM scale, has also been described in a recent study in children with AD and their parents (25). Authors suggested a reasonable explanation for this inconsistency: the severity measured by POEM is related to symptoms occurring during the preceding week, whereas in patients and their relatives the assessment probably corresponds to a much longer timespan.

Patients and their partners had excessive daytime sleepiness, which worsened with AD severity. Hours of sleep also decreased significantly as AD increased in severity. Sleep disturbances are very common and burdensome in AD. They have been extensively explored in children with AD, and to a lesser extent in adults (6, 26–28). Increased disease severity is associated with reduced sleep quality, increased sleep-onset latency and reduced sleep efficiency (26). Sleep disturbances in AD is associated with increased psychological burden. In children with AD, sleep disorders have been shown to significantly reduce their QoL and that of their caregivers and other family members (26, 26). While patients and their partners were not asked whether they were living under the same roof, or sharing the same bed, bed sharing is a common practice. There is growing evidence suggesting that a sleep disorder in 1 partner may increase risk for a sleep disorder in the other partner, all the more so when 1 partner is affected by a condition associated with a sleep disorder (26, 29–31).

This study confirms and expands on the results of a previous study that found a decrease in sexual desire due to AD in both patients (39%) and their partners (26%) (13). Skin appearance of AD patients, location of lesions on visible or genital area, the presence of itch or pain are all factors that can have a negative impact on sexual life (9, 14). Sexual dysfunction in a relationship can in turn impart profound strain on a couple. One study determined that AD is associated with higher rates of separation and divorce, and AD patients are less likely to be living with a partner (32).

Strength and limitation

The large-scale and population-based approach, which allows for generalization of results to the French population contribute to the strength of our study. The study includes several limitations. Clinical severity of AD was measured using the POEM, a patient-reported outcome measure, and was not assessed by dermatologists. This study also lacked a control group; a comparison would have been helpful in discriminating whether these results are specific to AD, or are characteristic of any couple with another (or no) dermatological condition. Moreover, this study did not evaluate all the patients and partner-related parameters, such as level of education and marital status. Lastly, questions about how AD impacted the relationship on a daily basis, including sexual dysfunction, were not specifically asked.

Conclusion

AD can impart a profound burden on patients and their partners. This is not surprising, considering that partners share a significant part of the challenges faced by the affected individuals. These results merit particular attention for future patient-centred care provision. Indeed, the burden of AD on partners should be taken into consideration by physicians when implementing education programs

dedicated to patients and their loved ones. Targeting partners with education and psychosocial support can eventually decrease the burden.

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