

## ORIGINAL ARTICLE

# The impact of eczema involving visible areas of the skin on patients' quality of life

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## Abstract

**Rational:** Many studies have evaluated the impact of eczema according to the established severity. However, the specific impact of the location of eczema on the quality of life (QoL) has not been assessed.

**Objective:** In the present study, we focus on the burden of disease caused by the involvement of atopic dermatitis (AD) on visible areas of the face and hands.

**Methodology:** This study mobilized for each of the six countries where it was implemented (Canada, China, Italy, Spain, Germany and France), targeting a representative sample according to the quota method of their population aged 18 years and over. QoL was assessed through the QoL index (DLQI).

**Results:** We identified 801 people who reported having suffered exclusively from AD in the past 12 months. Overall, 31.7% ( $n = 257$ ) of the population considered their skin disease to be embarrassing with consequences in their personal life. Regarding stigmata, 15.7% ( $n = 126$ ) of people with eczema felt rejected, 15.5% ( $n = 124$ ) felt they were looked at with disgust and 33.1% ( $n = 265$ ) expressed a sense of discouragement. A significant impact was observed in 31.5% ( $n = 145$ ) of patients who had visible damage versus 12.3% ( $n = 42$ ) of patients with no visible damage ( $p < 0.0001$ ). The difference was also significant ( $p < 0.001$ ) when the average DLQI was assessed (6.6 vs. 4.8).

**Discussion:** The degradation of the QoL by AD is maximal when the hands and the face are affected simultaneously. The impact is also significantly higher when the hands are exclusively affected (compared to the face). The impact on the QoL is strongly linked to the experience and the lived experience of each patient, and the stigmata of the patients and their feelings of rejection are obvious. Surprisingly, exclusive hand involvement caused a higher impact in QoL than exclusive face involvement. Simultaneous involvement of the face and hands greatly amplifies the deterioration in QoL

## KEYWORDS

burden, eczema, stigma

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## INTRODUCTION

Atopic dermatitis (AD) in adults is often underestimated or excessively trivialized. In France, a study carried out on 20,012 individuals representative of the French adult population estimated the prevalence of AD at 4.65%.<sup>1</sup> In the United States, an observational study of 1278 adults estimated a prevalence of AD at 7.3% (range: 5.9–8.8%), with approximately 60% suffering from mild AD, 29% moderate AD and 11% severe AD.<sup>2</sup>

Since 2010, the notion of “burden” has been introduced by the World Health Organization (WHO) in the evaluation of the care and management of chronic diseases, including chronic skin conditions.<sup>3</sup> Regarding AD, the eCLA study showed that people with severe AD had a markedly deteriorated quality of life compared to those with mild to moderate forms of the disease. In addition, the disease has a relevant impact on the sexuality of patients and their partners.<sup>4</sup> Overall, AD in adults can cause major skin lesions and thus lead to discomfort, loss of confidence, withdrawal, social isolation and difficulty finding a job, thus meaning a strongly negative impact on the quality of life.<sup>5</sup>

Many studies have evaluated the impact of AD according to the established severity. However, the specific impact of the location of eczema on the quality of life has not been assessed. In the present study, we focus on the burden of disease caused by the involvement of AD on visible areas of the face and hands.

## METHODS

This study mobilized for each of the six countries where it was implemented (Canada, China, Italy, Spain, Germany and France), targeting a representative sample according to the quota method (age, sex, geographic location and income level) of their population aged 18 years and over.

Responders were asked about the presence of a skin disease in the past 12 months. For this analysis, we

identified patients who reported AD (confirmed by a health professional) as their only skin disease.

With the knowledge of national patient associations, participants were invited to complete a structured and consolidated digital questionnaire. Subjects who confirmed the presence of eczema were asked to specify their respective locations (hands, face and body) and self-assessed their severity. Only those individuals reporting eczema as their sole skin disease were retained.

Quality of life was assessed through the quality of life index (DLQI), which assesses the impact of a skin disease and its treatment on the quality of life of people with the disease. It is rated out of 30 (a score strictly lower than 6 shows a low impact of the disease on the patient's life, a score between 6 and 10 a moderate effect on the patient's life and finally, a score strictly greater than 10 shows a significant effect or even an extremely significant effect if it is greater than 20).<sup>6</sup>

Categorical values were described as numbers and percentages, and continuous variables as mean. Patients were compared according to the visible or nonvisible location of their dermatosis and according to the location (hand or face). Categorical variables were compared using the  $\chi^2$  test, and continuous variables using the *T* test.

Statistical analyses were performed on SAS Studio version 3.8.

## RESULTS

A total of 13,138 adult participants responded to the questionnaire (2011 Canadians, 3050 Chinese, 2000 French, 2000 Italians, 2040 Spanish and 2037 Germans). Of these, 26.2% ( $n = 3450$ ) had skin diseases, including eczema (9.74%;  $n = 1280$ ).

We identified 801 people who reported having suffered exclusively from eczema in the past 12 months (Table 1). Of these, approximately 57% ( $n = 460$ ) reported involvement of eczema in a visible area of their body. The

**TABLE 1** Description of the population according to the location of the visible dermatosis

	Global (N = 801)		Male (n = 369)		Female (n = 432)	
	n	%	n	%	n	%
Presence of a visible dermatosis	460	57.43	206	55.83	254	58.80
Presence of a visible dermatosis involving the hands	315	39.33	129	34.96	186	43.06
Presence of a visible dermatosis involving the face	191	23.85	92	24.93	99	22.92
Presence of a visible dermatosis involving both the face and hands	46	5.74	15	4.07	31	7.18
Presence of a visible dermatosis localized exclusively on the hands	269	33.58	114	30.89	155	35.88
Presence of a visible dermatosis located exclusively on the face	145	18.10	77	20.87	68	15.74

hands were involved in 39% ( $n = 315$ ), the face in 23.8% ( $n = 191$ ) and both the hands and the face in 5.7% ( $n = 46$ ). There was exclusive involvement of covered areas of the body in 42.6% ( $n = 341$ ). Finally, 33.6% ( $n = 269$ ) and 18% ( $n = 145$ ) of subjects declared an exclusive involvement of the hands and face, respectively.

Overall, 31.7% ( $n = 257$ ) of the population considered their skin disease to be embarrassing to their personal life with consequences in their personal life, without a significant difference according to gender. Of these, approximately 49% reported visible damage exclusively localized on the face, 45.3% only on the hands and 58.7% had simultaneous involvement of the hands and face.

Likewise, 46.9% ( $n = 376$ ) of the population considered their skin disease to be embarrassing to their professional life with consequences at work, without a significant difference according to gender. Approximately 29% of these reported visible damages exclusively localized to the face, 36.8% to the hands and 58.7% had simultaneous involvement of the hands and face.

In all, 23.5% ( $n = 60$ ) of the subjects considered their hand involvement to be a handicap in their professional activities, 24% ( $n = 62$ ) in their social relations, 20.2% ( $n = 53$ ) in their emotional and intimate lives, 28.1% ( $n = 71$ ) in their leisure activities and 26.2% in ( $n = 66$ ) their sports activities.

A total of 17.3% ( $n = 27$ ) of the subjects considered their facial impairment a handicap in their professional activities, 20.7% ( $n = 34$ ) in their social relations, 19.6% ( $n = 31$ ) in their emotional and intimate lives, 17.4% ( $n = 27$ ) in their leisure activities and 18% ( $n = 29$ ) in their sports activities.

Regarding stigmata, 15.7% ( $n = 126$ ) of people with eczema felt rejected, 15.5% ( $n = 124$ ) felt they were looked at with disgust and 33.1% ( $n = 265$ ) expressed a sense of discouragement. A total of 18.1% ( $n = 145$ ) of participants felt that others avoided touching them. Overall, 15.6% ( $n = 111$ ) of subjects considered that their sex life was affected, 35.3% ( $n = 283$ ) said they had sleeping difficulties and 38% ( $n = 305$ ) admitted being tired. These feelings are different depending on whether the attack is exclusively localized on the face, hands or simultaneously on the hands and face (Table 2).

Regarding the impact on daily life, among the patients declaring involvement of the hands (whether exclusive or not), 17.2% ( $n = 54$ ) admitted having difficulties using a smartphone or computer keyboard due to the skin condition of the hands; 22.2% ( $n = 70$ ) admitted being limited in their daily activities (holding a pen, cooking, tying their shoes or turning a key) because of skin involvement of the hands. Among those who felt concerned, 28.7% ( $n = 74$ ), 29.5% ( $n = 70$ ) and 22.4%

( $n = 54$ ) considered that their personal life would have been different, their professional life richer and their career development more promising, respectively, if their hands had not been affected.

Approximately 56% ( $n = 449$ ) of patients said that they had consulted a health care professional in the past 12 months (70% a dermatologist, 35.2% a general practitioner, 6.2% a pharmacist, 3.1% a homoeopathic or acupuncture doctor and 1.3% a plastic surgeon, respectively). Among the 44% ( $n = 352$ ) of patients who declared not having consulted a health care professional, 50% considered that their eczema was not serious enough, 60% thought they could manage it on their own and 2.6% stated the reason was lack of means.

In all, 20% ( $n = 164$ ) of patients admitted using alternative and complementary medicine. In this case, 34.8% ( $n = 57$ ) of patients preferred essential oils, 25.6% ( $n = 42$ ) herbal medicine and 13.4% ( $n = 22$ ) homoeopathy. A total of 22.6% ( $n = 37$ ) admitted practising yoga, 19.5% ( $n = 32$ ) acupuncture and 11% ( $n = 18$ ) meditation.

We assessed, for each of the identified populations, the DLQI by considering the mean score in the first instance and assessing the prevalence of a significant impact (DLQI > 109). Significance was assessed with the most relevant statistical test. According to the DLQI, among the general population, 62.4% ( $n = 500$ ) of them had a score that indicated a small impact of AD on the patient's quality of life (DLQI < 6) and 18.1% ( $n = 145$ ) had a score that indicated a significant impact of the disease on their quality of life (DLQI > 10).

As described in Table 3, there are differences depending on the visible area affected. In fact, a significant impact was observed in 17.2% ( $n = 25$ ) of patients who had visible damage exclusively on the face, 20.5% ( $n = 55$ ) of patients whose visible damage was localized exclusively on the hands and nearly 50% ( $n = 23$ ) of patients who declared involvement of both the hands and face. We also found this impact was significantly greater when the hands were exclusively affected (compared to the face) when we evaluated the impact through the average. The degradation of the quality of life is maximal when the hands and the face are affected simultaneously.

To complete our analysis, we identified two groups, a group with exclusively a non-visible area versus those with a visible area. (Table 4). The impact of the dermatosis was significantly greater in the latter group than in the former, whether measured in terms of average or of the importance of the impact on daily life. A significant impact was observed in 31.5% ( $n = 145$ ) of patients who had visible damage versus 12.3% ( $n = 42$ ) of patients with no visible damage ( $p < 0.0001$ ). The difference was also significant ( $p < 0.001$ ) when the average DLQI was assessed (6.6 vs. 4.8)

TABLE 2 Expression of stigmata by gender and location of the dermatosis

	Global		Visible impairment exclusive to the face		Visible impairment exclusive to the hands		Visible involvement of the hands and face	
	n	%	n	%	n	%	n	%
Feels left out or rejected by others	126	15.73	44	16.36	25	17.24	17	36.96
Feels others are looking at him/her with disgust	124	15.48	44	16.36	28	19.31	20	43.48
Has the impression that others avoid touching him/her	145	18.10	56	20.82	27	18.62	20	43.48
Has the impression that others avoid approaching him/her	110	13.73	40	14.87	22	15.17	16	34.78
Feels a sense of discouragement	265	33.08	98	36.43	47	32.41	33	71.74
Feels tired	305	38.08	109	40.52	55	37.93	29	63.04
Has difficulty falling asleep	283	35.33	91	33.83	51	35.17	27	58.70
Feels his/her sex life has been affected	111	15.57	41	17.15	16	12.21	19	44.19
<b>Male</b>								
Feels left out or rejected by others	59	15.99	20	17.54	14	18.18	6	40.00
Feels like others are looking at him with disgust	59	15.99	19	16.67	17	22.08	6	40.00
Has the impression that others avoid touching him	69	18.70	28	24.56	15	19.48	6	40.00
Has the impression that others avoid approaching him	51	13.82	21	18.42	11	14.29	5	33.33
Feels a sense of discouragement	101	27.37	37	32.46	24	31.17	11	73.33
Feels tired	119	27.37	44	32.46	25	31.17	9	60.00
Has difficulty falling asleep	121	32.79	41	35.96	28	36.36	6	40.00
Feels his sex life has been affected	52	15.76	25	25.00	9	12.68	5	35.71
<b>Female</b>								
Feels left out or rejected by others	67	15.51	24	15.48	11	16.18	11	35.48
Feels like others are looking at her with disgust	65	15.05	25	16.13	11	16.18	14	45.16
Has the impression that others avoid touching her	76	17.59	28	18.06	12	17.65	14	45.16
Has the impression that others avoid approaching her	59	13.66	19	12.26	11	16.18	11	35.48
Feels a sense of discouragement	164	37.96	61	39.35	23	33.82	22	70.97
Feels tired	186	37.96	65	39.35	30	33.82	20	64.52
Has difficulty falling asleep	162	37.50	50	32.26	23	33.82	21	67.74
Feels her sex life has been affected	59	15.40	16	11.51	7	11.67	14	48.28

**TABLE 3** Assessment of the quality of life according to whether the dermatosis is located on a visible area

	DLQI SCORE ( $p < 0.02$ ) <sup>a</sup>		DLQI > 10 ( $p < 0.001$ ) <sup>b</sup>	
	n	Mean	n	%
Visible impairment exclusive to the face	145	5.06	25	17.24
Visible impairment exclusive to the hand	269	6.60	55	20.45
Visible involvement of hands and face	46	10.96	23	50.00

Abbreviation: DLQI, quality of life index.

<sup>a</sup>The relationship between the DLQI score and membership of one of the three constituted groups (exclusive face, exclusive hand, face and hand) is statistically significant.

<sup>b</sup>The relationship between the impact on daily life as reported by the DLQI (DLQI > 10 = high impact) and membership of one of the three groups (exclusive face, exclusive hand, face and hand) is statistically significant.

**TABLE 4** Assessment of the quality of life according to whether the dermatosis is located in a visible or nonvisible area

	DLQI SCORE ( $p < 0.001$ ) <sup>a</sup>		DLQI > 10 ( $p < 0.001$ ) <sup>b</sup>	
	n	Mean	n	%
Visible involvement	460	6.55	145	31.52
No visible involvement	341	4.79	42	12.32

<sup>a</sup>The relationship between the DLQI score and membership of one of the two constituted groups (visible vs. no visible) is statistically significant.

<sup>b</sup>The relationship between the impact on daily life as reported by the DLQI (DLQI > 10 = high impact) and membership of one of the two groups (visible vs. no visible) is statistically significant.

## DISCUSSION

Our study in a sufficiently robust group of patients who suffer only from eczema shows that the impact of AD, in terms of quality of life and the daily burden of disease, in adults is far from negligible. The impact on the quality of life is strongly linked to the experience and the lived experience of each patient, and the stigmata of the patients and their feelings of rejection are obvious. Our study also shows the profile of suffering in patients with involvement of visible areas, which are of great importance for personal relations and performance of work activities. Hand involvement is especially troublesome at work, probably due to the functional handicap that hand involvement produces. Face involvement has an obvious impact in personal life. These results should be put into perspective with the many studies in which patients with AD considered that wearing a mask allowed them to hide from the gaze of others.<sup>7</sup>

Overall, the involvement of visible areas of the skin by eczema causes a higher impact on the quality of life than the involvement of nonvisible areas. Surprisingly, exclusive hand involvement caused a higher impact on quality of life than exclusive face involvement. Simultaneous involvement of the face and hands greatly

amplifies the deterioration in the quality of life. Involvement of visible areas by eczema also generated a frequent use of patient associations, which supports the essential role of such associations. Health care professionals should be aware of these concerns for a better care of their patients.

Our study confirms other previously reported important factors impacting the quality of life of patients and their families.<sup>8</sup> Our study also confirms the importance of sleep disturbances and difficulty in falling asleep in patients with AD.<sup>9</sup> In fact, almost one-third of our patients referred to having sleeping difficulties and just as many of them felt tired. These two elements are significantly deleterious for daily life activities and work, which are undoubtedly related to withdrawal.

One in three patients did not consult a health care professional, which poses a problem in the proper management of these patients. The use of alternative and complementary medicines has already been reported in other skin diseases; as an example, 21% of patients suffering from psoriasis had tried alternative and complementary medicine,<sup>10</sup> and we found a similar figure in our study for AD (20%).

Our study has limitations. We are faced with declarative data and at no time has a dermatologist been able to confirm the diagnosis of eczema. However, many recently published studies have used the same methodology and the same approach.<sup>11</sup> This approach makes it possible to interview patients regardless of their care path. A study where recruitment was done with health care professionals would not allow us to reproduce the experiences of the 44% of subjects who declared that they did not consult a health care professional, and we would have a restitution of the experience, which would ignore a large part of the affected population.

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### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### CONFLICTS OF INTEREST

Marketa Saint Aroman, Catherine Baissac and Ariadna Ortiz-Brugués are employed by Pierre Fabre. Antonio Torrelo has been advisor/lecturer/clinical trial investigator for Sanofi, Novartis, Viatrix, Pfizer, Lilly and Pierre Fabre. Charles Taieb has been employed by Pierre Fabre. The other authors declare no conflicts of interest.

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