ORIGINAL REPORT

Counselling Needs in Atopic Dermatitis: Perspectives on Pregnancy and Treatment

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Atopic dermatitis (AD) is a common inflammatory skin disease affecting 5–8% of adults, with many being of reproductive age and potentially experiencing AD- and treatment-related challenges during family planning and pregnancy (FPP). This study examined whether patients with AD receive FPP-related information from their dermatologist and their concerns about pregnancy and breastfeeding. A cross-sectional questionnaire study was conducted among 18–45-year-old patients with AD treated at dermatology departments in university hospitals or private dermatology clinics in Denmark, all undergoing either topical or systemic treatment. A total of 121 patients participated in the study. The most pronounced concern was the heritable nature of AD (88.4%), followed by concerns about the teratogenicity of their treatments (29.8%). Additionally, 37.1% of women expressed concern about their ability to breastfeed. One-third of patients with AD had discussed FPP with their dermatologists prior to pregnancy, and 15% reported having fewer biological children than they desired due to their disease. Adult patients with AD have significant unmet informational needs regarding FPP. Addressing these concerns at appropriate stages in their lives, potentially through structured communication, could provide patients with better opportunities to address their concerns and plan their family life based on comprehensive and accurate information.

Key words: atopic dermatitis; family planning; pregnancy.

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SIGNIFICANCE

Atopic dermatitis is a chronic skin disease affecting both children and adults. This study examined concerns about pregnancy and breastfeeding among patients with atopic dermatitis aged 18–45, as well as their discussions with dermatologists regarding family planning and pregnancy. Most patients expressed concerns, one-third had discussed family planning and pregnancy with their dermatologist, and 15% reported having fewer children than desired due to their disease. These findings underscore the need to provide patients with atopic dermatitis with comprehensive family planning and pregnancy information to support informed family planning and minimize the impact of their condition on reproductive decisions.

Atopic dermatitis (AD) is a heterogeneous, chronic inflammatory skin disease characterized by pruritus, xerosis, and chronic or chronically relapsing eczema lesions. The clinical manifestation of AD can vary widely, with factors such as age, persistence, global region, and severity (1–4). AD affects approximately 20% of children and 5–8% of adults (4–6). Approximately 85% of patients are diagnosed with AD before the age of 5, with fewer than 5% of cases persisting into adulthood. Conversely, 25% of adult AD patients have acquired the disease later in life (2, 7).

Considering that AD can persist into or develop in adulthood, patients of reproductive age must navigate their skin disease and medication during family planning and pregnancy (FPP). Some systemic treatments for AD can affect the foetus (8). Women with AD appear to decrease their use of both topical and systemic treatments during pregnancy (9). However, those affiliated with a specialized dermatology hospital department tend to increase their use of topical treatments during pregnancy (9).

In 2019, The European Task Force on Atopic Dermatitis (ETFAD) published recommendations on how to treat male and female patients with AD while conceiving, being pregnant, and during breastfeeding (8). Recommendations for both topical and systemic treatments for AD during FPP are limited to only a few systemic options for severe disease. This makes treating and advising patients with AD during FPP challenging for the dermatologist, not only because of the lack of substantial evidence, but also due to an inadequate understanding of the informational needs and concerns of patients with AD related to FPP.

This study investigates the informational needs of patients with AD of reproductive age in relation to FPP, and furthermore explores potential concerns that these patients might have about pregnancy and breastfeeding.

MATERIALS AND METHODS

Study design

The study was designed as an anonymous, questionnaire-based, cross-sectional study. The questionnaire was developed by the authors and validated in a pilot test on 10 patients. The questionnaire included the 4 following domains: (*i*) sociodemographic data and disease-specific questions, (*ii*) current family status, 3(*iii*) concerns related to the impact of AD on pregnancy and breastfeeding, and (*iv*) information received from healthcare professionals concerning FPP. Questions regarding breastfeeding were exclusively addressed to female participants.

The questionnaire was implemented in REDCap (https://projectredcap.org/), from which a QR code was generated to facilitate online completion by the patients.

As the questionnaire was anonymous, no ethical approvals were necessary.

Study population

Patients were recruited at Department of Dermatology, Aarhus University Hospital and Bispebjerg Hospital, as well as at 2 private dermatological clinics in Aarhus.

Inclusion criteria were: (*i*) a diagnosis of AD, (*ii*) age between 18 and 45 years, (*iii*) treated with either topical and/or systemic medication.

Data collection

Patients were asked about their willingness to participate either before or after their consultation with the dermatologist. Questionnaires were collected between April 2022 and February 2023.

Study data were collected and managed using REDCap electronic data capture tools hosted at Aarhus University Hospital (10, 11). REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing (*i*) an intuitive interface for validated data capture; (*ii*) audit trails for tracking data manipulation and export procedures; (*iii*) automated export procedures for seamless data downloads to common statistical packages; and (*iv*) procedures for data integration and interoperability with external sources.

Statistical analysis

All statistical analyses were conducted using STATA/SE 17.0 (StataCorp LLC, College Station, TX, USA). For all continuous data, means and 95% confidence intervals (95% CI) were calculated. The χ^2 test was used for statistical analyses with a significance threshold set at $p<0.05$. When subgroups in the analysis were equal to or fewer than 5 subjects, Fisher's exact test was used instead of the χ^2 test. Due to the limited number of respondents in several subgroups, further subgroup analyses were not feasible.

RESULTS

*Characteristics (***Table I***)*

In this study, 121 patients met the inclusion criteria and completed the questionnaire. Among these patients, 70 (57.9%) were female. Mean age for all participants was 29.8 years (95% CI: 28.5–31.2). The mean age of onset of AD was 5 years (95% Cl: 3.7–6.2), and the mean age at diagnosis was 7 years (95% Cl: 5.5–8.6). Most participants were in a partnership (relationship, engaged, married) (75.2%), and reported "I do not have children, but I want children in the future" (43.8%). Among the

Table I. Patient demographics

Characteristics	Total	Female	Male
Gender, *n* (%)	121 (100)	70 (57.9)	51 (42.1)
Age, mean (95% CI)	29.8 (28.5–31.2)	29 (27.3–30.7)	30.9 (28.7–33.2)
Civil status, *n* (%)			
Partnership (relationship, engaged, married)	91 (75.2)	54 (77.1)	37 (72.5)
Single	28 (23.1)	15 (21.4)	13 (25.5)
Divorced	2 (1.7)	1 (1.4)	1 (2)
Highest level of education, *n* (%)			
Public school	10 (8.3)	6 (8.6)	4 (7.8)
High school	26 (21.5)	19 (27.1)	7 (13.7)
Technical education	18 (14.9)	8 (11.4)	10 (19.6)
Higher education – short (2–3 years)	15 (12.4)	8 (11.4)	7 (13.7)
Higher education – middle (3.5–4.5 years)	28 (23.1)	16 (22.9)	12 (23.5)
Higher education – long (5–6 years)	24 (19.8)	13 (18.6)	11 (21.6)
Household income (yearly), *n* (%)			
≤300,000 DKK	41 (33.9)	27 (38.6)	14 (27.5)
300,001–500,000 DKK	33 (27.3)	20 (28.6)	13 (25.5)
>500,000 DKK	47 (38.8)	23 (32.9)	24 (47.1)
EASI score, *n* = 69, mean (95% CI)	4.6 (2.8–6.4)	4.6 (2.4–6.8)	4.6 (1.5–7.7)
Age of onset of atopic dermatitis, mean (95% CI)	5 (3.7–6.2)	5.3 (3.3–7.2)	4.5 (2.9–6.1)
Age at diagnosis of atopic dermatitis, mean (95% CI)	7 (5.5–8.6)	7.6 (5.3–9.8)	6.2 (4.1–8.3)
Comorbidities, *n* (%)			
Asthma	55 (45)	29 (41.4)	26 (51)
Conjunctivitis	12 (10)	6 (8.6)	6 (11.8)
Allergic rhinitis	72 (60)	40 (57.1)	32 (62.7)
Food allergy	35 (29)	18 (25.7)	17 (33.3)
Psychological diseases (anxiety, depression, ADHD)	36 (30)	27 38.6)	9 (17.6)
Alopecia	2 (2)	1 (1.4)	1 (2)
Diabetes	1 (1)	1 (1.4)	0 (0)
Hypertension	6 (5)	2 (2.9)	4 (7.8)
Current treatment, *n* (%)			
Topical treatment only	15 (12.4)	13 (18.6)	2 (3.9)
Systemic treatment	103 (85.1)	57 (81.4)	46 (90.2)
Other treatment	4 (3.3)	0 (0)	4 (7.8)

Table II. Information regarding patients' biological children

Factor	Do you have biological children?			
	Yes, *n* (%), *n* = 45		No, *n* (%), *n* = 76	
	Women	Men	Women	Men
Total	25 (55.6)	20 (44.4)	45 (59.2)	31 (40.8)
Number of biological children prior to diagnosis of AD, mean (95% CI)	0.1 (−0.005;0.3)	0.08 (−0.08;0.2)	–	–
Number of biological children after diagnosis of AD, mean (95% CI)	1.4 (1;1.8)	1.3 (0.9;1.7)	–	–
Age				
18–26 years	0 (0)	1 (5)	31 (68.9)	16 (15.6)
27–31 years	3 (12)	4 (20)	9 (20)	8 (25.8)
32–45 years	22 (88)	15 (75)	5 (11.1)	7 (22.6)
Highest level of education				
Public school	2 (8)	1 (5)	4 (8.9)	3 (9.7)
High school	1 (4)	0 (0)	18 (4)	7 (22.6)
Technical education	3 (12)	5 (25)	5 (11.1)	5 (16.1)
Higher education – short (2–3 years)	3 (12)	4 (20)	5 (11.1)	3 (9.7)
Higher education – middle (3.5–4.5 years)	6 (24)	5 (25)	10 (22.2)	7 (22.6)
Higher education – long (5–6 years)	10 (40)	5 (25)	3 (6.7)	6 (19.4)
Current family situation				
Planning pregnancy within a year	3 (12)	0 (0)	6 (13.3)	4 (12.9)
Pregnant/my partner is pregnant	1 (4)	3 (15)	4 (8.9)	2 (6.5)
Breastfeeding	2 (8)	–	0 (0)	–
Fertility treatment	0 (0)	1 (5)	0 (0)	0 (0)
No biological children, wants children later	0 (0)	0 (0)	31 (68.9)	22 (71)
Have biological children, do not know if I want more	2 (8)	6 (30)	0 (0)	0 (0)
Do not want biological children	0 (0)	0 (0)	4 (8.9)	3 (9.7)
Have got the children I want	17 (68)	10 (50)	0 (0)	0 (0)

AD: atopic dermatitis.

participants, 45 (37.2%) had biological children, with most of these patients being between 32 and 45 years (37 [82.2%]) (**Table II**). The mean EASI score was 4.6 (95% CI: 2.8–6.4), with 85.1% of participants receiving systemic treatments, while 12.4% were treated exclusively with topical treatment (Table I).

Concerns

Among the 121 respondents, 89% expressed concerns related to AD in relation to pregnancy and/or breastfeeding. The most common concerns were potential heritability of AD (88.4%) and teratogenic side effects of treatment (29.8%), with fewer concerns about the miscarriage risk associated with AD (6.6%). Women were more likely to express concerns, particularly about teratogenicity (60.2% vs 39.8% in men).

Significant age-related differences were observed in concerns about teratogenicity ($p = 0.002$), heredity ($p = 0.042$), and the ability to breastfeed ($p = 0.029$), with the most pronounced concerns observed among patients aged 18–26 years. Additionally, patients without biological children were more concerned about permission to conceive (95.8%) and teratogenic risks (83.3%) compared with those with biological children (95.8% vs 4.2%, $p < 0.0001$ and 83.3% vs 16.7%, $p = 0.002$, respectively). Concerns about breastfeeding due to AD were reported by 37.1% of women, with a significant difference between those with and without biological children ($p = 0.009$) (**Table III**).

Information from dermatologist

Of the patients who received systemic treatment, 66 (58.4%) reported discussing FPP with their dermatologist, with the majority of discussions (56 [84.8%]) being initiated by the dermatologist. A statistically significant gender difference was noted, with more women (46 (69.7%)) than men (20 [30.3%]) engaging in these discussions ($p < 0.0001$) (**Table IV**).

Access to information

Patients' perceived access to information about FPP was distributed as follows: "to a low degree" (30%), "to some degree" (32.5%), and "to a high degree" (37.5%).

Table III. Concerns regarding pregnancy and breastfeeding

Item	Total *n* = 121	Gender			Biological children		
		Women	Men	*p*-value	Yes	No	*p*-value
Concerns regarding pregnancy, *n* (%)							
Any concern	108 (89.2)	65 (60.2)	43 (39.8)	0.134	37 (34.3)	71 (65.7)	0.055
Am I allowed to conceive on my current treatment?	24 (19.8)	14 (58.3)	10 (41.7)	0.957	1 (4.2)	23 (95.8)	< 0.001
Is my treatment harmful to the foetus?	36 (29.8)	25 (69.4)	11 (30.6)	0.093	6 (16.7)	30 (83.3)	0.002
Will my child inherit my skin disease?	107 (88.4)	65 (60.8)	42 (39.3)	0.074	37 (34.6)	70 (65.4)	0.100
Is the risk of miscarriage higher?	8 (6.6)	7 (87.5)	1 (12.5)	0.079	1 (12.5)	7 (87.5)	0.256
Can I take care of my child due to eczema? *n* = 120	20 (16.7)	15 (75)	5 (25)	0.083	5 (25)	15 (75)	0.312
Will I be able to breastfeed my child? Women only	26 (37.1)	26 (100)	–	–	4 (15.4)	22 (84.6)	0.009

Table IV. Information from dermatologist concerning family planning and pregnancy

	Did you have a conversation with your dermatologist about FPP when you started systemic treatment? $n = 113$			
Factor	Yes	*p*-value	Conversation was initiated by the dermatologist	*p*-value
Total, *n* (%)	66 (58.4)		56 (84.8)	
Gender, *n* (%)		< 0.001		0.156
Women	46 (69.7)		41 (89.1)	
Men	20 (30.3)		15 (75)	
Age, *n* (%)		0.863		0.398
18–26 years	25 (37.9)		23 (92)	
27–31 years	23 (34.9)		10 (43.5)	
32–45 years	28 (42.4)		23 (82.1)	

Women reported significantly less access to information than men ($p = 0.033$) (**Table V**).

Impact on number of children

Regarding family planning, 15.7% of patients reported having fewer children than desired due to their disease. The primary reasons cited included the hereditary transmission of AD (79%), exacerbation of AD during pregnancy (46.2% among women), and the need to discontinue AD treatment (36.8%) (**Table VI**).

A significant association between level of education and having biological children was identified ($p < 0.001$), with patients in the lowest educational level having fewer children, predominantly in the 18–26 age group.

DISCUSSION

This study highlights a previously underexplored issue concerning the intersection of AD and family planning. The findings demonstrate that concerns related to FPP are widespread among patients with AD, particularly regarding heritability of AD, teratogenic risks of treatments, and challenges with breastfeeding. These concerns align with patterns observed in studies on other chronic inflammatory diseases, such as inflammatory bowel disease (IBD), where similar apprehensions exists (12). However, whereas miscarriage was highlighted as a major concern for patients with IBD, it was the least prominent concern in our study.

Several studies among patients with chronic inflammatory diseases have also documented primary concerns regarding teratogenicity of treatments, heredity of the disease, the ability to care for a child, disease exacerbation during pregnancy, and miscarriage (13–15). Our findings corroborate that many of these concerns are similarly prevalent among patients with AD.

Patients without biological children expressed significantly greater concerns regarding permission to conceive during treatment, teratogenic effects of medication, and, for women, the ability to breastfeed, compared with those with children. This pattern mirrors findings from studies on IBD, where patients without children or those contemplating pregnancy reported heightened concerns compared with those who already had children (13, 14). A Danish study similarly found that rheumatological patients without biological children expressed greater concerns than those with children (15).

Patients without children may lack firsthand experience in managing family planning alongside a chronic disease. Insufficient guidance from dermatologists or uncertainty regarding where to obtain information could exacerbate these concerns.

When examining the information provided by dermatologists to patients with AD regarding FPP, we found that only 60% of those receiving systemic treatments discussed FPP at the initiation of treatment. This indicates that 40% did not receive information on FPP, despite many treatments for AD having limitations or contraindications related to conception, pregnancy, and/or breastfeeding (8). In most cases, the discussion regarding FPP was initiated by the dermatologist (84.8%), contrasting with a study involving patients with IBD, where only 52.5% of discussions were gastroenterologist-initiated (14).

A notable gender difference was observed in the provision of FPP information, with significantly more women receiving this information compared with men. Addressing this disparity is crucial to ensure equitable care for all patients with AD, regardless of gender.

Table V. Access to information regarding family planning and pregnancy

	To what degree did you feel that you had access to:							
	Information and precautions on FPP as a patient with AD ($n = 80$)				Information on treatment options during pregnancy and breastfeeding (women, $n = 44$)			
Factor	To a low degree	To some degree	To a high degree	*p*-value	To a low degree	To some degree	To a high degree	*p*-value
Total, *n* (%)	24 (30)	26 (32.5)	30 (37.5)		17 (38.6)	11 (25)	16 (36.6)	
Gender, *n* (%)				0.033				–
Women	19 (79.2)	11 (42.3)	18 (60)		17 (100)	11 (100)	16 (100)	
Men	5 (20.8)	15 (57.7)	12 (40)		–	–	–	
Age, *n* (%)				0.185				0.023*
18–26 years	5 (20.8)	7 (26.9)	15 (50)		2 (11.8)	1 (9.1)	9 (56.3)	
27–31 years	7 (29.2)	5 (19.2)	5 (16.7)		5 (29.4)	4 (36.4)	1 (6.3)	
32–45 years	12 (50)	14 (53.9)	10 (33.3)		10 (58.8)	6 (54.5)	6 (37.5)	

Patients who did not find the question relevant have been removed from the statistics in this table.
AD: atopic dermatitis.

Table VI. Impact of atopic dermatitis (AD) on how many children the patients have had

Item	Total $n = 121$	Gender		
		Women	Men	*p*-value
Has AD impacted on how many children you planned to or have had?				
Yes, *n* (%)	19 (15.7)	13 (68.4)	6 (31.6)	0.310
No, *n* (%)	102 (84.3)	57 (81.4)	45 (88.2)	
Reason (Option to select multiple answers)	Total $n = 19$			
Difficulty taking care of child due to AD, *n* (%)	5 (26.3)	3 (60)	2 (40)	1.000
Fear of stopping AD treatment, *n* (%)	7 (36.8)	6 (85.7)	1 (14.3)	0.237
Fear that my treatment is harmful to a foetus/child, *n* (%)	6 (31.6)	5 (83.3)	1 (16.7)	0.399
Fear that my child will inherit AD, *n* (%)	15 (79)	9 (60)	6 (40)	0.857
Lack of information concerning disease and treatment management while trying to conceive, *n* (%)	4 (21.1)	4 (100)	0 (0)	0.137
Fear of AD getting worse during pregnancy, *n* (%). Women only ($n = 13$)	6 (46.2)	6 (100)	–	–

The lack of sufficient FPP information may contribute to unnecessary concerns and impact family planning decisions. Our findings indicates that 15.7% of patients with AD chose to have fewer biological children than desired due to their skin disease. Common reasons included concerns about the hereditary nature of AD, apprehensions about discontinuing treatment, and fears of disease exacerbation during pregnancy. Similarly, 18% of patients with psoriasis reported that their condition influenced their number of children (15). Another study highlighted childlessness as a frequent issue among patients with IBD, associating it with insufficient disease-related knowledge (16). However, even among patients with factual knowledge, concerns over parenthood persisted, emphasizing the importance of consultations with experienced physicians (14). Future research should explore the impact of factual knowledge in family planning decisions among patients with AD. Meanwhile, ensuring comprehensive information for patients remains critical.

Our study also identified an association between lower educational level and not having biological children. Given that the average age of first-time mothers in 2023 was 29.9 years (17), our findings suggest that age may play a more significant role in family planning decisions than educational level, as patients with lower educational attainment were also the youngest.

Consistent with findings from other chronic autoimmune and inflammatory diseases, this study underscores the insufficiency of FPP information provided to patients with AD (13–16,18). Addressing these concerns could involve mandating consultations regarding FPP between patients and dermatologists. A potential approach is implementing a standardized questionnaire for patients to complete before consultations, facilitating thorough and consistent discussions of FPP. Such a questionnaire, validated in Spain in 2022 (19), could be adapted for broader applicability, including customization for male patients and validation in additional languages.

Limitations

This study has several limitations that should be considered when interpreting the findings. Most participants were recruited from highly specialized dermatology clinics, which may limit the generalizability of the results to the broader population of patients with AD. This recruitment setting may have led to a study sample with more severe or complex cases compared with the general AD population.

Subgroup analyses were restricted due to the limited sample size. While we initially aimed to analyse data by age, gender, treatment type, and disease severity, many subgroups were too small for reliable statistical interpretation. Additionally, disease severity data based on EASI scores at the time of questionnaire completion were available for only about 70% of patients. These scores were probably underestimated for patients already receiving systemic treatment at that time, as treatment may have reduced the severity of their symptoms prior to assessment.

The anonymous design of the questionnaire prevented us from linking responses to clinical records, limiting our ability to assess disease severity prior to treatment initiation and restricting our ability to incorporate this information in our analysis.

We did not adjust for potential confounders such as psychological factors, comorbidities, or socioeconomic status due to the limited data available and small sample sizes in key subgroups. Future research with a larger, more diverse cohort could explore these potential confounding variables in greater detail.

Finally, the cross-sectional design of the study limits the ability to establish causality or track changes in patient concerns or information needs over time. Prospective studies could provide more comprehensive insights into the evolving needs of patients with AD regarding family planning and pregnancy.

Summary/conclusion

Our study highlights that the information provided by dermatologists to patients with AD regarding FPP is often inadequate. This lack of comprehensive guidance may lead to concerns and potentially influence patients to have fewer children than they might otherwise desire because of their condition. To address these issues, it is

crucial to prioritize the provision of thorough and balanced information about managing AD in the context of family planning. Ensuring that both men and women with AD receive comprehensive FPP information should be a key focus to support better-informed family planning decisions.

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