

## ORIGINAL ARTICLE

# Navigating through the healthcare system with atopic dermatitis: Analysing patient journeys in Germany

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## Abstract

**Background:** Atopic dermatitis (AD), which can significantly impact quality of life, is a complex, heterogeneous skin disease affecting all ages and therefore can lead to very different patient journeys. Understanding the patient journey within the healthcare system is essential for improving care outcomes.

**Objectives:** To explore the patient journey of individuals with AD in Germany, with a specific focus on the utilization of Internet resources throughout this process.

**Methods:** A cross-sectional study using a self-administered questionnaire was conducted from June 2021 to February 2022. Participants were recruited from dermatology private practices, a university hospital and online platforms.

**Results:** The study included 276 participants (62.3% female; mean age: 46.3 ± 18.4 years; mean disease duration: 26.9 ± 17.5 years; mean DLQ Index: 10.0 ± 5.6). Around 191 participants were currently receiving medical treatment, with 9.1% receiving biologic therapy. Most of the people initially contacted a GP (42.4%) and were diagnosed by a dermatologist first (57.6%). Around 47.1% were currently in treatment by a dermatologist, seeking dermatological care on average 4.5 times a year. Almost all individuals (86.2%) have already consulted more than one physician during their patient journey. Overall, participants consulted a median of five physicians, while those with severe AD consulted a median of six physicians. Initial symptoms to diagnosis and between consulting two different physicians both had a median duration of 6 months. Dissatisfaction with treatment outcomes emerged as a common reason for changing physicians. Approximately 76.4% of participants used the Internet for disease-related information, primarily relying on Google. Overall, 63% found the information quality unsatisfactory.

**Conclusions:** The study underlines the widespread utilization of medical treatment and the proactive healthcare-seeking behaviour during a long patient journey. Dissatisfaction with treatment outcomes, alternative medicine and the quality of the Internet sources emphasize the potential for improving the comprehensive disease management to improve care outcomes.

## BACKGROUND

Through symptoms such as itching and painful skin, atopic dermatitis (AD) is the skin disease with the highest disease burden measured by disability-adjusted life-years (DALYs) worldwide.<sup>1</sup> In 2019, approximately 3.6 million

people in Germany were affected by AD, with women (4.7%) having a higher prevalence than men (3.6%).<sup>2</sup> Worldwide, the prevalence in adults is up to 11.6% and in children up to 25%.<sup>2–6</sup> However, studies indicated that the prevalence might be even higher as not all people with AD were seen by physicians.<sup>2,4–6</sup>

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AD is a complex, heterogeneous disease with substantial individual suffering and economic impact.<sup>6,7</sup> It follows a relapsing course, with severe itching and dry skin on different skin areas.<sup>6</sup> A variety of medical specialists are consulted for symptoms such as dermatologists, general practitioners (GP), pulmonologists and paediatricians.<sup>8,9</sup>

The term 'patient journey' refers to the various stages and experiences a patient goes through when seeking and receiving healthcare services. It encompasses the entire process from the initial recognition of symptoms, seeking medical advice, being diagnosed and treated.<sup>10,11</sup> Understanding the patient journey is essential for healthcare professionals and organizations to improve the overall patient experience, enhance their quality of care, and identify opportunities for better communication and support throughout the healthcare process.<sup>12</sup> In recent years, the Internet has grown in importance for medical information, including AD.<sup>13,14</sup>

In 2017, roughly 50% had Internet access, with 80% using it for medical topics. In Germany, the Google search volume for AD-associated keywords was about 15 million between January 2017 and December 2020.<sup>14</sup> For some people, the Internet is the preferred source of information, shifting information sharing from professionals to the layperson.<sup>15,16</sup> For social media users, accessing health information is vital, 95.2% of dermatological patients have sought or shared disease-related information on social media.<sup>17</sup>

The aim of the study was to investigate the patient journey including contacts within the healthcare system and used Internet resources for medical advice to identify which interfaces can be utilized to prevent potential shortcomings in care.

## MATERIALS AND METHODS

### Study population

The study was conducted as an anonymous non-interventional cross-sectional study between June 2021 and February 2022. During that time, people who were undergoing outpatient or inpatient treatment for AD at the Department of Dermatology and Allergy of the Technical University in Munich, Germany, were asked to participate in the study. Furthermore, 914 patients who had been treated at the clinic within the past 2 years were contacted by mail. In addition to the paper-based questionnaire, these patients received a cover letter, the study information and a prepaid return envelope to send back the questionnaire. Furthermore, dermatologists working in private practice in Bavaria who were listed in the Bavarian Association of Panel Doctors were sent paper-based questionnaires and a QR-code for the online questionnaire and asked whether they could share it with their patients. To include people who are not necessarily undergoing medical care, people were also recruited online. The online questionnaire was shared in Facebook groups on the topic of skin diseases and on the websites of online self-help groups (Bundesverband-Neurodermitis e.V. Umwelt,

### Key points

#### Why was the study undertaken?

- The study was undertaken to explore the patient journey of individuals with atopic dermatitis (AD) in Germany, focusing on their use of Internet resources, number of medical consultations and identifying factors and stages that influence their healthcare experience to improve care outcomes.

#### What does the study add?

- This study provides new insights into the patient journey of individuals with AD in Germany. It shows that patients frequently consult multiple doctors and often use the Internet for information, though they often find the quality of this information inadequate. A significant portion of patients change doctors due to dissatisfaction with treatment outcomes.

#### What are the implications of this study for disease understanding and/or clinical care?

- The study highlights the need for improved comprehensive disease management for AD. Enhancing online information quality and addressing treatment dissatisfaction can improve patient experiences and outcomes. Better understanding the patient journey enables healthcare providers to tailor approaches, leading to more effective and satisfactory treatments.

Deutscher-Allergie-Asthmabund e.V.). Inclusion criteria for study participation were physician-diagnosed AD, a minimum age of 18 years and written informed consent for voluntary participation in the study. Patients who were unable to complete a German questionnaire were excluded. Questionnaires for which less than 80% were completed were not included in the analysis. The study was reviewed and accepted by the Ethics Committee of the Medical Faculty of the Technical University of Munich (reference 238/21S-EB).

### Questionnaire

The questionnaire consisted of 40 items that asked for demographic data such as gender or age. To assess AD history, individuals were asked about disease duration, initial AD diagnosis, current consulting doctors and total number of doctors consulted. In this context, the therapies carried out up to this point were also asked about the number of medications prescribed, whether and how many systemic therapies they had already received, or to what extent they were

aware of these therapeutic measures at all. Additionally, participants were asked about therapy satisfaction, reasons for changing doctors and trying alternative treatments. The questionnaire also inquired about the Internet's role in their illness (e.g. frequency of use). AD severity was assessed using the Dermatology Life Quality Index (DLQI) and the Patient-Oriented Eczema Measure (POEM).<sup>18,19</sup> The DLQI includes 10 questions that revolve around the topic of quality of life and the extent to which affected individuals feel limited by their disease in daily lives. The responses are assigned point values between zero and three points. The score can therefore vary between 0 and 30 points and is divided into five levels (21–30).<sup>6</sup> In this study, three groups mild (0–5), moderate (6–20), and severe (21–30) were used in order to have groups of approximately equal size. The POEM measures the severity of AD by asking the frequency of seven typical AD symptoms within the last 7 days; the responses can achieve a score between 0 and 4. Accordingly, the total score ranges between 0 and 28 points. A score between 0 and 7 corresponds to mild AD, between 8 and 19 to moderate AD and a score between 20 and 28 to severe AD.<sup>20</sup>

The tool SoSci Survey (Version 3.1.06, SoSci-Survey-GmbH, Munich, Germany) was used for the online questionnaire. Paper-based questionnaires were digitized twice

using the same tool, with discrepancies corrected using the original questionnaires.

## Statistical analysis

All variables were analysed descriptively, using total and relative frequency for categorical variables, mean and standard deviation ( $\pm$ SD), median and interquartile range [IQR] for continuous variables. To examine differences within the study population, individuals were divided into several groups. Firstly, people were divided into receive current medical treatment or not (Table 1). Secondly, people were grouped into having mild, moderate or severe AD based on the results of POEM (Table 2). Thirdly, a group of people using the Internet and one not using it was built (Table SI). To test for differences between these groups, Pearson's chi-square test was used to examine categorical variables and Student's *t*-test for continuous normally distributed variables. For non-normally distributed variables, differences were tested with the Mann–Whitney *U*-test or Kruskal–Wallis test for multiple groups. IBM Statistics (version 28, IBM-Corporation, Armonk, NY) was used for data analysis.

**TABLE 1** Comparison of demographic and patient journey characteristics between people with AD who are currently receiving and not receiving medical care.

	Overall ( <i>n</i> = 276)	Currently in medical care ( <i>n</i> = 191; 69.2%)	Currently not in medical care ( <i>n</i> = 85; 30.8%)	<i>p</i> -Value
Age in years, mean $\pm$ SD	46.3 $\pm$ 18.4	47.8 $\pm$ 18.7	43.0 $\pm$ 17.3	<b>0.047</b>
Missing, <i>n</i> (%)	3 (1.1)			
Gender, <i>n</i> (%)				0.247
Female	172 (62.3)	115 (60.2)	57 (67.1)	
Male	102 (37.0)	75 (39.3)	27 (31.8)	
Missing, <i>n</i> (%)	2 (0.7)			
Disease duration, mean $\pm$ SD	26.9 $\pm$ 17.5	28.0 $\pm$ 18.7	24.6 $\pm$ 13.9	0.425
Missing, <i>n</i> (%)	9 (3.2)			
Number of dermatologists consulted due to AD, median [IQR]	3 [2–5]	4 [2–6]	3 [1–4]	0.060
Missing, <i>n</i> (%)	7 (2.5)			
Number of GP consulted due to AD, median [IQR]	1 [0–2]	1 [0–2]	1 [0–2]	0.219
Missing, <i>n</i> (%)	8 (2.9)	2 (1.3)	6 (7.1)	
Number of drugs received <i>n</i> (%)				<b>0.010</b>
≤5	92 (33.3)	57 (29.9)	35 (41.2)	
>5	162 (58.7)	125 (65.4)	37 (43.5)	
Missing, <i>n</i> (%)	22 (8.0)			
DLQI, mean $\pm$ SD	10.0 $\pm$ 5.6	10.6 $\pm$ 5.6	8.7 $\pm$ 5.7	<b>0.012</b>
Mild, <i>n</i> (%)	58 (21.0)	33 (17.3)	25 (29.4)	
Moderate, <i>n</i> (%)	106 (38.4)	74 (38.7)	32 (37.6)	
Severe, <i>n</i> (%)	107 (38.7)	84 (44.0)	23 (27.1)	
Missing, <i>n</i> (%)	5 (1.8)			

Abbreviations: AD, atopic dermatitis; DLQI, dermatology life quality index; GP, general practitioner; IQR, interquartile range; SD, standard deviation. The italicized values represent missing data for which no significance can be provided.

**TABLE 2** Comparison of demographic and patient journey characteristics between people having mild, moderate or severe AD according to the POEM.

	Overall (n = 276)	Mild AD (n = 83; 30.1%)	Moderate AD (n = 117; 42.4%)	Severe AD (n = 66; 23.9%)	p-Value
Age, mean ± SD	46.3 ± 18.4	47.8 ± 18.5	45.4 ± 18.2	46.3 ± 18.9	0.624
Missing, n (%)	10 (3.6)				
Gender, n (%)					
Male	100 (36.2)	42 (50.6)	40 (34.1)	18 (27.3)	0.063
Female	164 (59.42)	39 (46.9)	77 (65.8)	48 (72.7)	
Missing, n (%)	12 (4.3)				
Disease duration, mean ± SD	26.9 ± 17.5	25.5 ± 16.9	26.7 ± 17.3	29.4 ± 19.1	0.516
Missing, n (%)	17 (6.2)				
Currently in medical care, n (%)					
Yes	191 (69.2)	57 (68.7)	80 (68.4)	50 (75.8)	0.532
No	85 (30.8)	26 (31.3)	37 (31.6)	16 (24.2)	
Missing, n (%)	0				
Currently in therapy by a GP, n (%)					
Yes	52 (18.8)	15 (18.1)	17 (14.5)	19 (28.8)	0.065
No	224 (82.2)	68 (81.9)	100 (85.5)	47 (71.2)	
Missing, n (%)	0				
Currently in therapy by a dermatologist, n (%)					
Yes	171 (62.0)	53 (63.9)	73 (62.4)	44 (66.7)	0.846
No	105 (38.0)	30 (36.1)	44 (37.6)	22 (32.3)	
Missing, n (%)	0				
Number of physicians consulted due to AD, median [IQR]	5 [3–7]	4 [2–6]	5 [3–7]	6 [4–8]	<b>0.007</b>
Missing, n (%)	13 (4.7)				
Number of medical consultations in the last 12 months	5.3 ± 4.5	5.5 ± 4.8	4.3 ± 3.4	6.5 ± 5.7	<b>0.042</b>
Missing, n (%)	1 (0.4)				
DLQI, mean ± SD	10.0 ± 5.6	6.2 ± 3.5	10.3 ± 4.2	14.5 ± 6.4	<b>&lt;0.001</b>
Missing, n (%)	10 (3.6)				
Number of drugs received, n (%)					
≤5	92 (33.3)	41 (53.2)	39 (34.5)	12 (19.4)	<b>&lt;0.001</b>
>5	160 (57.9)	36 (46.8)	74 (65.5)	50 (80.6)	
Missing, n (%)	24 (8.7)				
Previous hospitalization for AD, n (%)					
Yes	177 (64.1)	53 (64.6)	72 (62.1)	52 (78.8)	0.060
No	87 (35.2)	29 (35.4)	44 (37.9)	14 (21.2)	
Missing, n (%)	12 (4.3)				
Using the Internet for information on AD, n (%)					
Yes	211 (76.4)	60 (72.3)	93 (79.5)	58 (87.9)	<b>0.047</b>
No	58 (21.0)	23 (27.7)	24 (20.5)	7 (10.6)	
Missing, n (%)	7 (2.5)				

Abbreviations: AD, atopic dermatitis; IQR, interquartile range; POEM, Patient-Oriented Eczema Measure; SD, standard deviation.

The italicized values represent missing data for which no significance can be provided.

## RESULTS

### Study population

Overall, 276 people with AD (62.3% female, mean age 46.3 ± 18.4 years) participated in the study of which 210 (76.1%) individuals completed the paper-based questionnaire (response rate 23.0%). The mean disease duration was

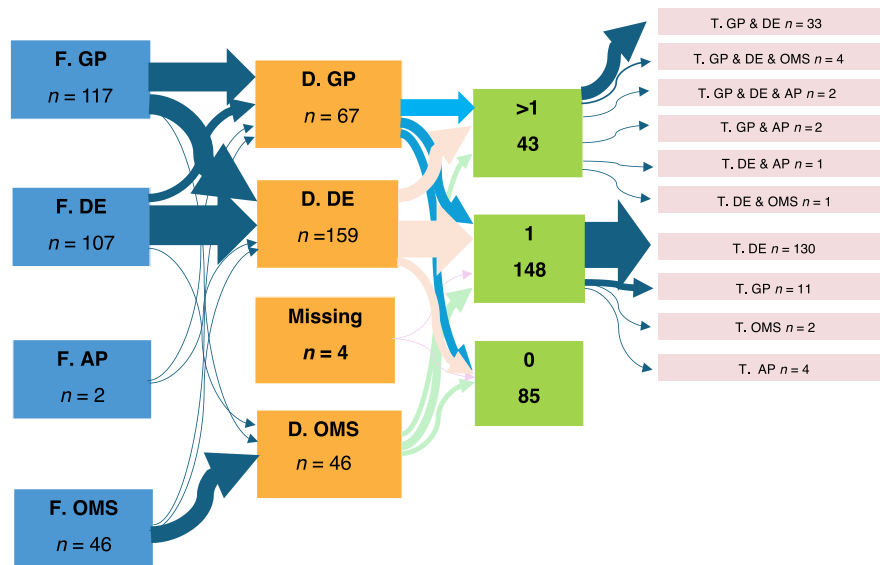
26.9 ± 17.5 years and the mean DLQI was 10.0 ± 5.6, corresponding to a 'moderate impact' on quality of life (Table 1).

### Contact with medical care

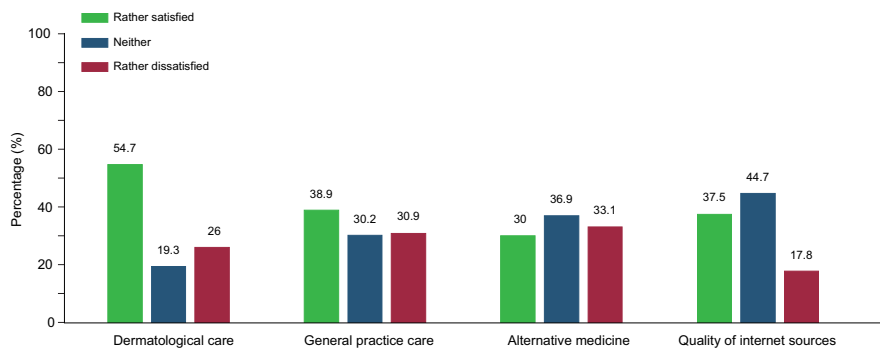
While nearly the same number of participants contacted a paediatrician first (n = 42; 15.2%) and receive their initial

diagnosis from him ( $n=44$ ; 15.9%), there was a considerable difference in the number of people who contacted a GP first ( $n=117$ ; 42.4%) and received their initial diagnosis from him ( $n=67$ ; 24.3%). More than half of the participants were initially diagnosed by a dermatologist ( $n=159$ ; 57.6%) and were treated by only one physician within the last 12 months ( $n=148$ ; 53.6%). The time between the initial symptoms and diagnosis can vary widely, ranging from a few days to several years. The median duration is 6 months [IQR: 1–24]. Of the 43 (15.6%) individuals who reported to be treated by more than one physician within the last 12 months, the vast majority were treated by a GP and a dermatologist ( $n=33$ ; 76.7%); however, 4 (9.3%) people said they were treated by a GP, a dermatologist and other medical specialists (Figure 1). The median number of the visited dermatologists was 3 [IQR: 2–5] and that of GP was 1 [IQR: 0–2] (Table 1). The time between changing doctors can vary significantly, ranging from a few days to several years. In the median, it is 6 months [IQR: 2–12]. An AD-related GP consultation occurred on average  $3.6 (\pm 3.3$ ;

$n=52$ ) times a year and a dermatological presentation  $4.5 (\pm 3.6$ ;  $n=171$ ) times. The vast majority ( $n=238$ , 86.2%) of people have already consulted more than one physician for AD. Main reason for changing physicians was dissatisfaction with the therapy results ( $n=166$ ; 69.6%). Most had already received over five different medications ( $n=162$ ; 58.7%). More than half of the participants were rather satisfied with dermatological care ( $n=93$ ; 54.7%), while 26.0% ( $n=44$ ) were rather dissatisfied with it. In comparison with that, 38.0% reported to be rather satisfied with the treatment by a GP and 30.9% were rather dissatisfied with it (Figure 2). Overall, 65.2% ( $n=180$ ) had already received inpatient treatment. Systemic therapy had already been heard of by 55.8% ( $n=154$ ), with 23.9% ( $n=66$ ) of these individuals had also heard of biologics. Around 71.7% ( $n=198$ ) of the study population have already tried alternative treatment options, with changes in diet being the most common one ( $n=165$ ; 83.3%), followed by homeopathy ( $n=132$ ; 66.7%). However, less than one-third ( $n=59$ ; 30.0%) were satisfied with it (Figure 2).



**FIGURE 1** Sankey diagram that shows the progression from initial contact to current therapy. First contacted therapist group. Diagnosing physician. Number of therapist groups currently visited. Associated specialization of therapists (from left to right).



**FIGURE 2** Proportion of AD affected participants that were rather satisfied, neither, or rather dissatisfied with treatment by a dermatologist ( $n=254$ ), treatment by a GP ( $n=149$ ), alternative medicine ( $n=187$ ) and quality of Internet sources ( $n=208$ ).

## Comparison between people being in medical care and not

Overall, 191 (69.2%) individuals reported currently receiving medical treatment for AD, whereas 85 (30.8%) people did not. People in medical care were significantly older ( $47.8 \pm 18.7$  vs.  $43.0 \pm 17.3$  years;  $p=0.047$ ); no gender differences were observed ( $p=0.247$ ). The DLQI was higher among people undergoing treatment ( $10.6 \pm 5.6$  vs.  $8.7 \pm 5.7$ ;  $p=0.012$ ), indicating a higher impairment in quality of life. The analysis further revealed that the proportion of people already receiving more than five drugs was higher in the treatment group (65.4% vs. 43.5%;  $p=0.001$ ). The main reasons why people were not in medical care were 'symptom free' ( $n=25$ ; 25.8%) and 'dissatisfied treatment outcomes' ( $n=30$ ; 30.9%), followed by 'alternative healing methods' ( $n=12$ ; 12.4%; [Table 1](#)).

## Comparison between disease severity levels

According to POEM, most of the participants had moderate AD ( $n=117$ ; 42.4%), followed by mild ( $n=83$ ; 30.1%) and severe AD ( $n=66$ ; 23.9%). Patients with a mild AD reported an average disease duration of 25.5 ( $\pm 16.9$ ) years, whereas those with a severe reported an average of 29.4 ( $\pm 19.1$ ) years ( $p=0.516$ ). People with mild AD reported having consulted a median of 4 [IQR: 2–6] physicians, while those with severe consulted 6 [IQR: 4–8] ( $p=0.007$ ). With increasing POEM scores, the DLQI also rose ( $6.2 \pm 3.5$  vs.  $10.3 \pm 4.2$  vs.  $14.5 \pm 6.4$ ;  $p < 0.001$ ). Patients with severe conditions received more than five medications significantly frequently ( $p < 0.001$ ). In total, 180 (65.2%) individuals had been previously treated in hospitals, of whom 78.8% ( $n=52$ ) were classified as severely affected. Among those with mild, it was 64.6% ( $n=53$ ), and for those with moderate severity, it was 62.1% ( $n=72$ ) ( $p=0.060$ ). Severely affected patients had the highest average visits to GP and dermatologists in the last 12 months, at 6.5 ( $\pm 5.7$ ;  $p=0.042$ ). In generally, severely affected people were most likely to be treated by dermatologists ( $p=0.846$ ) and GP ( $p=0.065$ ), to use the Internet ( $p=0.047$ ) and to try alternative treatment options ( $p=0.254$ ; [Table 2](#)).

## Internet and AD

Around 76.4% ( $n=211$ ) of the participants stated that they use the Internet to receive information on AD ([Table S1](#)). Of those, 42 (19.9%) people used it before their first contact with a physician. The main reasons for usage were to obtain general information ( $n=159$ ; 75.4%) or to learn about further treatment approaches ( $n=144$ ; 68.2%). Mean disease duration in the group of non-users was higher in comparison with users ( $32.4 \pm 20.5$  vs.  $25.3 \pm 16.1$  years;  $p=0.036$ ), which is probably due to the higher average age ( $59.3 \pm 18.4$  vs.  $42.8 \pm 16.7$ ;  $p < 0.001$ ). In contrast to

that, the median number of visited physicians was lower among non-users (3 [IQR 2–7] vs. 5 [IQR 3–7];  $p=0.047$ ). The mean DLQI among users was higher ( $10.5 \pm 5.7$  vs.  $8.3 \pm 5.1$ ;  $p=0.004$ ). About three-quarters of the users ( $n=156$ , 74.0%) said they hardly used the Internet for AD in the past 3 months, while only five people used it daily. Majority of people reported using Google to search for information, both in general ( $n=195$ ; 92.3%) and in preparation for a doctor's visit ( $n=206$ ; 97.6%). Only 11.9% ( $n=25$ ) of the respondents used websites of self-help groups before seeing a doctor, whereas 31.6% ( $n=67$ ) used them in general ([Figures S1](#) and [S2](#)). The statement 'Information found has prompted me to see a doctor' was agreed by 40 (19.2%) people, whereas 108 (51.7%) disagreed with this statement. About 63% ( $n=133$ ) of individuals rated the quality of Internet sources as rather dissatisfactory or neither satisfactory nor dissatisfactory. Despite Internet use, there was no information advantage about the range of therapies. In both groups, one in four had heard of biologics ( $p=0.825$ ). Overall, 25 (9.1%) people already received a biological, without differences in the groups ( $p=0.450$ ).

## DISCUSSION

The aim of the study was to assess the patient journey of individuals with AD within the healthcare system including contacted physicians for initial contact, diagnosis and treatment as well as the usage of the Internet for disease-related information. The results indicated that a considerable number of different physicians were contacted during the long patient journey, with GPs often being the first point of contact, but diagnosis and further treatment were provided by dermatologists. Patients with severe AD required even more extensive medical care in terms of number of consultations and therapies. Additionally, they were more inclined to search the Internet for information related to AD. Despite concerns about the quality of online information, the Internet serves as a common platform for accessing AD-related information, covering both general and therapeutic aspects. However, most people appeared not to utilize this source regularly.

In 2019, people went to the doctor an average of 9.8 times in Germany, a relatively high frequency by European standards.<sup>21,22</sup> Interestingly, chronic conditions accounted for just 22% of outpatient visits, and dermatological diseases were not in the top 10 diagnoses for medical presentations. According to the study results, patients with AD visit their dermatologist on average 4.5 times a year. For AD patients, this means that every other doctor's visit in a year is due to AD. Dermatological treatment was higher (62%) compared with literature (39.1%), while fewer received treatment from a general practitioner (18.8% vs. 36.74%), likely due to participant selection.<sup>2</sup> The mean DLQI was 10 points which was higher than in other studies.<sup>20,23</sup> Conversely, the detected POEM was slightly lower.<sup>23,24</sup> However, both numerical values correspond to a moderately severe disease. Around 24%

people had a POEM score corresponding to severe disease, which is in the range of reported prevalence (10%–34%).<sup>25–27</sup> Remarkably, 65.2% of patients had already received inpatient treatment, which is notably higher than the 8% hospitalization rate reported in the literature for patients in dermatology outpatient clinics.<sup>28</sup> This discrepancy is most likely due to recruitment in the clinic.

The time from symptoms to diagnosis can vary from a few days to years. In our case, the median is 6 months, but for others, it is lower, averaging 2–4 weeks.<sup>26</sup> Visible skin changes and a high level of suffering were main reasons for consulting a doctor.<sup>28</sup> For many, the GP is the first point of contact with healthcare system for questions, but satisfied with its treatment is one in three. Before this, however, people from the personal environment are often already questioned.<sup>29</sup> Previous studies showed that medical tips from laymen leads to dissatisfaction and a search for alternative treatment options.<sup>29,30</sup>

About half of those treated by dermatologists stated that they were satisfied with their treatment; however, those who are severely affected are less satisfied.<sup>31</sup> Gaps in care caused by dissatisfaction could be closed by new therapy options.

Hurdles for the therapy arise, for example, due to high therapy costs, low reimbursements and fear of regress claims.<sup>32–34</sup> Also, the efficacy of topical steroids is rated highest by dermatologists in moderate AD.<sup>12</sup> One way to counteract this would be to increase the awareness of treating physicians. With sufficient documentation of indications, patient claims would be nearly impossible.<sup>35</sup>

The Internet plays a growing role as an additional source of information, but it does not necessarily lead to comprehensive knowledge about the full range of therapies. In Germany, 62% of Internet users stated that they obtain information digitally in preparation for a doctor's appointment. After the appointment, 67% use it.<sup>36</sup> In our case, only 19.9% of the individuals reported using the Internet before visiting a doctor. Every second user discusses diagnoses and therapies in forums and blocks, which carries the risk of unfiltered information.<sup>37,38</sup> More people said they did not visit a doctor because of the information they found than visited him or her because of it (43.0% vs. 19.2%).<sup>36</sup> Despite concerns regarding information quality, the Internet is highly valued as an information source. Nevertheless, evaluating the reliability of the information remains a challenge for most users.<sup>39</sup> This presents an opportunity to tailor information campaigns more effectively.<sup>14</sup> Dermatologists acknowledge the benefits of online resources in patient education about the disease but caution that well-informed and engaged patients may raise more demanding questions.<sup>13</sup>

A major limitation of the study is selection bias. The majority of participants were selected from dermatological practices and departments, resulting in a highly selected patient population. Accordingly, the generalizability of the results is limited. Additionally, comorbidity related to atopic conditions was not assessed. The results show that online

participants tended to be younger and severely affected people were mainly recruited in the clinic. Furthermore, response, recall or desirability biases are to be assumed, which could lead to distorted results. Another limitation is that participants were not asked about other diseases associated with AD, and not about specific medications that were already receiving.

In conclusion, this study offers valuable insights into the patient journey of individuals with AD in Germany. It highlights the substantial disease burden, the widespread utilization of medical treatment and the proactive healthcare-seeking behaviour, particularly among those with severe AD. Treatment satisfaction remains a challenge, often leading patients to switch physicians in search of improved care. The study also underscores the role of digital resources in patient education and support, though there is room for improvement in the quality of online information. Accordingly, comprehensive approaches for AD management are needed, which should encompass effective medical treatments, enhanced patient education and improved digital resources. Further research and collaboration are essential to enhance care outcomes and improve the well-being of individuals living with AD in Germany.

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#### CONFLICT OF INTEREST STATEMENT

LuT has no conflict of interest. LiT received speaker's honoraria and/or received from Novartis Pharma and Janssen Cilag and currently works for ViiV Healthcare. SS has no conflict of interest. HW received unrestricted research grants by Novartis Pharma. TB has been an advisor and/or received speaker's honoraria and/or received grants and/or participated in clinical trials of the following companies: Almirall, Celgene-BMS, Lilly, Novartis, SanofiGenzyme, Regeneron, Viatrix, AbbVie, Alk-Abello, BoehringerIngelheim, Leo Pharma, Novartis, GSK and Regeneron. JW has been an advisor and/or received speaker's honoraria and/or received grants and/or participated in clinical trials of the following companies: Almirall, Janssen, Abbvie, Novartis, BMS, Boehringer, Ingelheim, Leo and Lilly. AZ has been an advisor and/or received speaker's honoraria and/or received grants and/or participated in clinical trials of the following

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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.

## ETHICAL APPROVAL

The study was reviewed and approved by the local ethics committee of the Medical Faculty of the Technical University of Munich.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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