

Research Letter

Outreach Through Facebook: Do Patients With Atopic Dermatitis Provide Clinically Relevant Information When Recruited for Surveys on Social Media?

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KEYWORDS

social media; atopic dermatitis; digital survey; recruit; patient perspectives; patient-reported outcomes; real-world data

Introduction

Atopic dermatitis (AD) is a common chronic skin disease with a prevalence of up to 20% in children and up to 10% in adults [1]. There has been an increasing focus on the impact on the quality of life of the patients, family members, and caregivers [2], yet performing surveys to elucidate this is often laborious, time-consuming, and expensive. Social media has been used as a new platform for gaining insights into diseases through surveys, but for AD this has not been adequately tested. We have investigated the results obtained from a web-based survey recruiting respondents from a Facebook group hosted by the Danish Atopic Eczema Patients' Organization (DAEPO) concerning whether it was representative of the population and if it returned relevant information on their disease.

Methods

The survey consisted of 35 close-ended questions with checkboxes and was designed together with DAEPO. The inclusion criteria (self-reported) were being 18 years or older, previously or currently using a topical corticosteroid, and having been diagnosed with AD. No incentives were offered to

participants. Data were collected anonymously between November 11 and December 22, 2021. Data collection and storage were compliant with European Union regulations on General Data Protection Regulation (GDPR). For the analysis, respondents were stratified into three groups according to severity as defined by the Patient Oriented Eczema Measure (POEM) instrument.

Results

In total, 140 participants of 182 respondents met the inclusion criteria (recruitment rate 76.9%). [Table 1](#) presents demographics, symptoms, and comorbidities. [Table 2](#) shows health care use and disease management. Representativeness of survey responders (age, gender, and educational level) was investigated using chi-square test for goodness of fit, which confirmed the overrepresentation of younger female respondents with a higher educational level compared to the general Danish population. The limited participation of older adults has likewise been observed in previous studies using social media platforms [3]. Our data also indicated that the severity of AD correlated inversely with educational level in line with previous registry-based results, showing severe AD decreases the chance of completing higher education [4].

Table 1. Demographics and symptoms of respondents with atopic dermatitis (AD), stratified by disease severity.

	Mild (n=37)	Moderate (n=48)	Severe (n=55)	All (N=140)	P value (between AD severity group comparison) ^a
Age (years; N=140), n (%)^b					
18-29	5 (14)	21 (44)	18 (33)	44 (32)	.01
30-39	9 (24)	8 (17)	17 (32)	34 (24)	.24
40-49	12 (32)	10 (21)	11 (20)	33 (24)	.33
≥50	11 (30)	9 (19)	9 (16)	29 (21)	.28
Female (n=138), n (%) ^b	30 (83)	44 (92)	51 (94)	125 (91)	.20
Educational level (n=139), n (%)^b					
Basic compulsory education ^c	0 (0)	1 (2)	7 (13)	8 (6)	.17
Youth education ^d	13 (35)	20 (42)	24 (44)	57 (41)	
Higher education ^{e,f}	23 (60)	25 (52)	22 (40)	69 (50)	
Education not completed	1 (3)	0 (0)	0 (0)	1 (1)	
Other	1 (3)	2 (4)	1 (2)	4 (3)	
Age at diagnosis (years; n=139), n (%)					
0-2	14 (38)	19 (40)	31 (56)	64 (46)	.11
3-12	14 (38)	10 (21)	8 (15)	32 (23)	.04
Older than 12 years^g					
13-19	3 (8)	4 (9)	6 (11)	13 (9)	.33
20-40	4 (11)	9 (19)	7 (13)	20 (14)	
>40	2 (5)	5 (11)	2 (4)	9 (7)	
Do not know	0 (0)	0 (0)	1 (2)	1 (1)	N/A ^h
Comorbidities (N=140), n (%)					
Asthma	18 (49)	16 (33)	24 (44)	58 (41)	.33
Allergic rhinitis	24 (65)	27 (56)	34 (62)	85 (61)	.71
Food allergies	12 (32)	15 (31)	24 (44)	51 (36)	.36
No asthma nor allergy	15 (41)	21 (44)	24 (44)	60 (43)	.67
Other types of allergies	5 (14)	9 (19)	7 (13)	21 (15)	.95
Bothersome symptoms (N=140), n (%)					
Itch	29 (78)	47 (98)	55 (100)	131 (94)	<.001
Dry skin	32 (87)	45 (94)	54 (98)	131 (94)	.08
Red rash	27 (73)	36 (75)	52 (95)	115 (82)	.008
Exudation	7 (19)	15 (31)	28 (51)	50 (36)	.005
Swelling	9 (24)	15 (31)	26 (47)	50 (36)	.06
Poor night's sleep	6 (16)	15 (31)	39 (71)	60 (43)	<.001
Skin pain	16 (43)	22 (46)	41 (75)	79 (56)	.002
Other	0 (0)	6 (13)	5 (9)	11 (8)	.10
No symptoms	2 (5)	0 (0)	0 (0)	2 (1)	.06

^aPearson chi-square test for AD severity group comparison. Significance level 5%.

^bChi-square goodness-of-fit test for responders' representativeness with the Danish general population—age: χ^2 goodness of fit=47.8, df=3, $P<.001$; gender: goodness of fit $\chi^2_1=87.9$, $P<.001$; education: goodness of fit $\chi^2_1=13.8$, $P<.001$).

^cBasic compulsory education includes 9th and 10th grade.

^dYouth education includes high school and vocational school.

^eHigher education includes bachelor's, master's, or PhD programs.

^fPearson chi-square test for AD severity group comparison split between higher education or not.

^gPearson chi-square test performed for the AD severity group whose age at diagnosis was older than 12 years.

^hN/A: not applicable.

Table 2. Management of disease, stratified by disease severity.

	Mild (n=37)	Moderate (n=48)	Severe (n=55)	All (N=140)	P value (between AD ^a severity group comparison) ^b
Time since last AD consultation by dermatologist (n=139), n (%)					.10
Within last 6 months	13 (36)	16 (33)	32 (58)	61 (44)	
Within last 6-12 months	4 (11)	7 (15)	3 (6)	14 (10)	
Within last 1-2 years	9 (25)	9 (19)	6 (11)	24 (17)	
More than 2 years ago	9 (25)	14 (29)	14 (26)	37 (27)	
Never	0 (0)	2 (4)	0 (0)	2 (1)	
Do not know	1 (3)	0 (0)	0 (0)	1 (1)	
Use of moisturizers (n=137), n (%)					.45
Daily	31 (89)	40 (83)	50 (93)	121 (88)	
At least once a week	2 (6)	3 (6)	3 (6)	8 (6)	
Less than once a week	0 (0)	1 (2)	0 (0)	1 (1)	
When needed	2 (6)	4 (8)	0 (0)	6 (4)	
Never	0 (0)	0 (0)	1 (2)	1 (1)	
Moisturizers are recommended by the treating physician (n=137), n (%)	31 (89)	42 (89)	49 (89)	122 (89)	N/A ^c
TCS^d group, current or ever used (N=140), n (%)^e					
Group I	17 (46)	22 (45)	22 (40)	61 (44)	.79
Group II	23 (62)	38 (79)	34 (62)	95 (68)	.12
Group III or IV	30 (81)	37 (77)	54 (98)	121 (86)	.004
Do not know which group	1 (3)	2 (4)	0 (0)	3 (2)	.33
Frequency of current TCS use (n=136), n (%)					<.001
Daily	3 (9)	8 (17)	22 (40)	33 (24)	
3-5 times a week	5 (14)	16 (35)	18 (33)	39 (29)	
1-2 times a week	9 (26)	11 (24)	6 (11)	26 (19)	
1-3 times a month	5 (14)	6 (13)	3 (6)	14 (10)	
Less than once a month	13 (37)	5 (11)	6 (11)	24 (18)	
Periods of proactive use of TCS the last year (n=134), n (%)					.05
Less than 1 month	5 (15)	11 (24)	9 (17)	25 (19)	
1-6 months	5 (15)	7 (15)	6 (11)	18 (14)	
More than 6 months	5 (15)	12 (26)	24 (44)	41 (31)	
No	19 (56)	16 (35)	15 (28)	50 (37)	
Reactive use of TCS within the last month (n=131), n (%)					<.001
1 week	8 (25)	16 (36)	9 (16)	33 (25)	
2 weeks	2 (6)	9 (21)	2 (4)	13 (10)	
3 weeks	0 (0)	4 (9)	4 (7)	8 (6)	
All last month	7 (22)	10 (23)	31 (56)	48 (37)	
I have not used reactive treatment	15 (47)	5 (11)	9 (16)	29 (22)	

^aAD: atopic dermatitis.^bPearson chi-square test for atopic dermatitis severity group comparison. Significance level 5%.^cN/A: not applicable.^dTCS: topical corticosteroid.^ePearson chi-square tests for AD severity group comparison for each of the TCS groups.

The majority of respondents had their AD diagnosis in childhood. Many across the three AD severity groups had asthma and allergy comorbidities. Symptoms such as itch, red rash, exudation, poor night's sleep, and skin pain were significantly more frequent among patients with severe AD (Table 1). The frequency of dermatology visits did surprisingly not differ significantly between severity groups, whereas reactive treatment use patterns in the last month were observed significantly more in those with severe AD (Table 2). This indicates that many patients with AD are not adequately treated and should have closer contact with the health care system to receive timely and optimal treatment.

Discussion

In conclusion, we found that social media may be used for disease surveys, although with a risk of lack of representativeness of the general population (ie, favoring those who are female, younger, and well educated). With this in mind, however, outreach through social media is an easy cost-effective way of acquiring a large amount of information and may be a useful platform to obtain relevant disease information on patient-reported outcomes for patients with AD, and female patients in particular.

Conflicts of Interest

STG, AGF, and PBP are employees at Pfizer Denmark. AGF and PBP own shares in Pfizer Inc. CV has received honoraria for lectures and add boards from Sanofi Genzyme, Eli Lilly, Pfizer, LEO Pharma, Novartis, and AbbVie. He has received research grants from Sanofi Genzyme, LEO Pharma, Novartis, and Pfizer.

References

1. Brunner PM. Early immunologic changes during the onset of atopic dermatitis. *Ann Allergy Asthma Immunol* 2019 Aug;123(2):152-157 [doi: [10.1016/j.anai.2019.03.033](https://doi.org/10.1016/j.anai.2019.03.033)] [Medline: [30953783](https://pubmed.ncbi.nlm.nih.gov/30953783/)]
2. Ali F, Vyas J, Finlay AY. Counting the burden: atopic dermatitis and health-related quality of life. *Acta Derm Venereol* 2020 Jun 09;100(12):330-340 [doi: [10.2340/00015555-3511](https://doi.org/10.2340/00015555-3511)] [Medline: [32412644](https://pubmed.ncbi.nlm.nih.gov/32412644/)]
3. Darko EM, Kleib M, Olson J. Social media use for research participant recruitment: integrative literature review. *J Med Internet Res* 2022 Aug 04;24(8):e38015 [FREE Full text] [doi: [10.2196/38015](https://doi.org/10.2196/38015)] [Medline: [35925655](https://pubmed.ncbi.nlm.nih.gov/35925655/)]
4. Pálsson K, Slagor RM, Flachs EM, Nørreslet LB, Agner T, Ebbelhøj NE. Childhood atopic dermatitis is associated with a decreased chance of completing education later in life: a register-based cohort study. *J Eur Acad Dermatol Venereol* 2021 Sep;35(9):1849-1858 [doi: [10.1111/jdv.17346](https://doi.org/10.1111/jdv.17346)] [Medline: [33988855](https://pubmed.ncbi.nlm.nih.gov/33988855/)]

Abbreviations

AD: atopic dermatitis

DAEPO: Danish Atopic Eczema Patients' Organization

GDPR: General Data Protection Regulation

POEM: Patient Oriented Eczema Measure

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