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Social Media Use in Patients with Alopecia Areata

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ABSTRACT

Background: Alopecia areata (AA) is an autoimmune disease that significantly affects people's quality of life. Today, the use of social media (SM) is a factor that substantially affects patients' knowledge and adherence to treatment, and clinicians' awareness of this issue is essential. In this study we aimed to investigate the relationship between the use of SM to obtain information about the disease and the patient's clinic and quality of life in patients with AA.

Materials and Methods: A total of 118 patients with AA were evaluated by filling in the questionnaires prepared by the authors and containing their Dermatologic Life Quality Index.

Results: It was observed that 72.6% of the patients used SM for information about the disease. 58.5% of the patients preferred Google. 31.4% of the patients chose Instagram. 30.5% of the patients preferred YouTube, and the rest picked other SM tools. It was observed that 9.3% of the patients were group members, and 66.9% made group comments. The patients said they would trust the doctor with 96.5% in case of conflict between the SM and the doctor. It has been shown that 18.2% of patients attempt to reach the doctor via SM. They frequently preferred doctor's websites for this. They most commonly asked questions about drugs.

Conclusion: Our study has shown that AA patients use SM extensively to obtain information about their disease, emphasizing the importance of clinicians' presence on these platforms to provide accurate patient information.

Keywords: Alopecia areata, Social media, Internet

Introduction

Alopecia areata (AA) is an autoimmune disease characterized by non-scarring alopecia in which the hair follicles are affected but not usually destroyed. It occurs in 2% of the population at some point in their life. Although the disease can start at any age, it often begins under 40. The fact that the disease is seen in identical twins, siblings, and many family members indicates a genetic component [1].

People think of AA as a cosmetic disorder rather than a medical problem. As a result, stigmatization and social, economic, and psychological problems occur in patients [2]. It has been determined that half of the patients with AA have impaired quality of life, and

66-74% have psychiatric diseases at any stage of their lives [3]. One study showed that 72% of internet users use the internet to obtain health-related information [4].

Social media (SM) is an internet-based communication platform that allows more than 3 billion users to interact with video, picture, and audio content [5]. The SM platforms patients use most frequently for information are Facebook, Twitter, Instagram, and YouTube [4]. SM has been used in every field and has attracted significant attention in dermatology [5]. The fact that dermatology is a visual field substantially impacts this interest [6]. In a study, it was seen that 82.4% of dermatology patients used the internet to obtain



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information, and 65.4% used SM [7]. When we look at the most searched hashtags about skin diseases on Instagram, alopecia is in the second place, showing that AA patients use SM intensively [8].

Objectives

In the literature, there are no studies on the use of SM in AA patients so far. In our study, we aimed to investigate the use of SM to obtain information about their disease and to explore the expectations of the patients in AA patients who applied to our clinic.

Materials and Method

Patients

Patients followed in the Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty Skin and Venereal Diseases Hair Diseases outpatient clinic between November 15, 2020, and May 15, 2021, were included in our study. Written informed consent was obtained from themselves in adult patients and from the participants' parent/legal guardian/next to kin to participate in the study for every minor patient. The patients were divided into two groups according to age (4-16, 17≤).

Procedure

This study protocol was reviewed and approved by the Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty Clinical Research Ethics Committee (decision number: 14429, date: 22.01.2021). The patients were filled with questionnaires prepared by the researchers who planned to study. Parents' help was received for the 4-16 age group. Demographic characteristics of patients, Severity of Alopecia Tool (SALT) scores, clinical characteristics, comorbidities, SM use and participation in patient groups, reputation for information on SM, and Dermatologic Life Quality Index (DLQI)/child Dermatologic Life Quality Index (CDLQI) scores were noted by their physicians. Written informed consent was obtained from themselves in adult patients and from the participants' parent/legal guardian/next to kin to participate in the study for every minor patient.

Statistical Analysis

The study gives descriptive statistics as mean, standard deviation, percentage, and frequency. In the survey, Mann-Whitney U and Kruskal-Wallis tests were used to examine the difference in DLQI levels in patient groups according to patient characteristics and SM use. The all-pairwise method was used to determine the different groups. In the study, a chi-square analysis was performed to examine the rates of patients' SM use status according to age groups. In the analysis, the critical decision value was taken as 0.05. Analyzes were finalized with the SPSS 25.00 package program.

Results

Sociodemographic and Clinical Characteristics of the Patients

One hundred eighteen patients (67 males, 51 females) were included in the study, and it was determined that 58.5% of the patients were 17 years and older, and 41.5% were in the 4-16 age group. The SALT scores of the patients were determined as follows; 17.8% (S1), 16.9% (S2), 13.6% (S3), 15.3% (S4), 36.4% (S5). In Table 1, demographic and clinical characteristics of the patients are summarized.

Using SM to Get Information about the Disease, Search Topics, Group Membership

It was determined that 72.6% of the patients used SM for information about the disease. No significant correlation was found between the use of SM and gender, age, education, SALT score, site of involvement, disease duration, another disease, and family history. Although not significant, the rate of people with university and higher education levels in the group with SM use related to the disease was 3 times that of the other group. Again, although not significant, the rate of those with a SALT score of 100 in the group using SM was 41.2%, while this rate remained at 25% in those who did not use SM (Table 2).

Patients using SM are distributed as follows; 58.5% Google, 31.4% Instagram, 30.5% YouTube, 19.5% patient blocks, 14.4% Facebook, 6.8% other SM channels, 5.1% Twitter. No significant relationship

Table 1. Demographic and clinical characteristics of the patients

Features		n	%
Gender	Male	67	56.8%
	Female	51	43.2%
Group	17≤ age	69	58.5%
	4-16	49	41.5%
SALT score	S1	21	17.8%
	S2	20	16.9%
	S3	16	13.6%
	S4	18	15.3%
	S5	43	36.4%
Location	Scalp	116	98.3%
	Eyebrow	93	78.8%
	Eyelash	53	44.9%
	Beard	25	21.2%
	Trunk	37	31.4%
Comorbidities	No	98	83.1%
	Vitiligo	6	5.1%
	Thyroid disease	14	11.9%
Family history	Yes	17	14.4%

SALT: Severity of Alopecia Tool

Table 2. Relationship between SM use and other variables

Patient characteristics		Using SM to learn about the disease				p-value
		Yes		No		
		n	%	n	%	
Gender	Male	48	56.5%	19	59.4%	0.21
	Female	37	43.5%	13	40.6%	
Age (X + SD)		21.06	10.58	18.75	12.03	0.09
Education	No	4	4.7%	4	12.5%	0.13
	PE	25	29.4%	11	34.4%	
	HS	25	29.4%	13	40.6%	
	U	27	31.8%	4	12.5%	
	PG	4	4.7%	0	0.0%	
SALT score	S1	12	14.1%	8	25.0%	0.06
	S2	14	16.5%	6	18.8%	
	S3	13	15.3%	3	9.4%	
	S4	11	12.9%	7	21.9%	
	S5	35	41.2%	8	25.0%	
Scalp involvement	No	2	2.4%	0	0.0%	0.16
	Yes	83	97.6%	32	100.0%	
DD (months) (X + SD)		66.21	58.07	79.56	82.72	0.26
Comorbidities	No	72	84.7%	25	78.1%	0.53
	Vitiligo	5	5.9%	1	3.1%	
	Thyroid disease	8	9.4%	6	18.8%	
Family history	Yes	14	16.5%	2	6.3%	0.10
	No	71	83.5%	30	93.8%	

SALT: Severity of Alopecia Tool, SM: Social media, PE: Primary education, HS: High school, U: University, PG: Postgraduate, DD: Disease duration, SD: Standard deviation

was found between the types of SM used and gender, age, education, SALT score, site of involvement, disease duration, another disease, and family history. The topics the patients searched for on SM were 61% disease, 46.6% drugs, 39% patient comments, and 47.5% doctors. It was observed that 9.3% of the patients were group members, and 66.9% made group comments. It was observed that 34.7% of the patients searched for what was mentioned in the group, 28% only read, 14.4% thought that doctors and products were advertised, and 8.5% were happy to be together with those with the same disease.

Trust in Doctors and Expectations of Patients

We asked patients a few different questions about trust. Other results were obtained in response to these questions. Patients stated that they would trust the doctor with a rate of 96.5% (82/85) in case of conflict between the SM and the doctor.

The patients stated that they would trust the answers 37.1% (13/35) if they had the chance to ask a question with a photograph. According to 60.6% (20/33) of the patients, the doctor does not have to answer the patients via SM.

Using SM to Reach Doctors

18.2% of the patients made attempts to reach the doctor via SM. Patients trying to get the doctor preferred 40% doctor sites, 20% telephone, 20% Instagram, 10% search engines, and 10% health sites.

Patients who reach the doctor ask questions about AA 28.6% and questions about drugs 71.4%. It was observed that all patients (6/6) trusted the answers, and 83.3% (5/6) acted per these answers. Since this last data were obtained from six patients, it cannot draw safe conclusions.

SM-DLQI/CDLQI Relationship

Investigation of Variables Affecting DLQI Levels of Patients 17 Years and Older

SALT scores and involvement sites (p>0.05) and the presence of another disease (p=0.11, p>0.05) did not significantly affect the DLQI scores of the patients (Table 3).

It was determined that patients with a family history of the disease had significantly higher DLQI scores (p=0.01, p<0.05) (Table 3).

It was determined that the SM usage status of the patients (p=0.12, p>0.05) and searching for the disease in the SM (p=0.09, p>0.05) did not significantly affect the DLQI scores. It was determined that the patient’s use of SM channels such as Facebook, Instagram, YouTube, Google, Patient blocks, and other media did not significantly affect their DLQI scores (p>0.05). It was determined that the patients using Twitter had significantly higher DLQI scores (p=0.01, p<0.05) (Table 3).

It was determined that the topics searched on SM, group memberships, comments in groups, and patients’ opinions about groups did not affect DLQI scores (p>0.05). If the SM contradicts the doctor, it was observed that the DLQI levels of the patients who preferred the doctor were higher (p=0.01).

It has been determined that DLQI levels do not differ according to whether they have the chance to ask a question with a photograph, trust the answers, think that doctors are obliged to answer, and try to reach doctors through SM (p>0.05).

Examination of Variables Affecting the CDLQI Levels of Patients Aged 4-16

CDLQI levels of the patients did not differ according to the SALT scores, the sites of involvement (p>0.05), and the presence of other diseases (p=0.23, p>0.05) (Table 3).

Patients with a family history did not significantly affect their DLQI scores (p=0.11, p>0.05). It was determined that the patient’s use of SM (p=0.32, p>0.05) and searching about the disease on SM (p=0.42, p>0.05) did not significantly affect CDLQI scores (Table 3).

The patient’s use of SM channels such as YouTube, Twitter, Patient blogs, and other media did not significantly affect their CDLQI scores (p>0.05). CDLQI scores of patients using Facebook,

Table 3. Examination of variables affecting the DLQI levels of patients								
Patient characteristic		17≤		p-value	4-16			p-value
		DLQI			CDLQI			
		X	SD		X	SD		
SALT score	S1	5.91	7.70	0.13	S1	5.00	5.50	0.17
	S2	4.77	5.02		S2	6.86	9.70	
	S3	4.38	7.31		S3	5.86	5.46	
	S4	4.31	2.87		S4	7.20	4.71	
	S5	4.91	5.03		S5	7.25	5.50	
Scalp	No	4.00	5.66	0.22	No	5.49	5.88	0.43
	Yes	4.89	5.43		Yes	6.53	5.98	
Eyebrow	No	4.45	5.30	0.24	No	6.85	4.75	0.49
	Yes	5.41	5.56		Yes	6.43	6.73	
Eyelash	No	5.02	5.89	0.16	No	6.30	5.94	0.13
	Yes	4.44	3.81		Yes	8.60	6.62	
Beard	No	4.50	4.96	0.26				
	Yes	5.48	6.10					
Trunk	No	4.50	4.96	0.26	No	7.66	5.79	0.43
	Yes	5.48	6.10		Yes	7.55	5.91	
Comorbidities	No	4.87	5.15	0.11	No	6.68	6.29	0.23
	Vitiligo	3.80	3.42		Vitiligo	6.00	0.02	
	Thyroid	5.40	7.55		Thyroid	5.00	1.41	
Family history	Yes	10.83	9.26	0.01*	Yes	8.60	5.50	0.11
	No	4.28	4.57		No	6.00	6.05	
SM usage	Yes	5.07	5.73	0.12	Yes	6.24	5.27	0.32
	No	3.82	3.09		No	7.20	7.52	
SM usage for information about the disease	Yes	5.35	5.53	0.09	Yes	6.19	6.25	0.42
	No	3.40	4.88		No	7.18	5.57	
Facebook	No	4.91	5.56	0.36	No	5.74	4.98	0.01*
	Yes	4.56	4.42		Yes	11.29	9.29	
Instagram	No	4.43	4.72	0.39	No	5.50	4.68	0.01*
	Yes	5.60	6.40		Yes	10.09	8.53	
Twitter	No	4.73	5.43	0.01*	No	6.53	6.11	0.41
	Yes	7.67	4.04		Yes	6.50	0.71	
Youtube	No	4.02	5.16	0.18	No	6.56	6.11	0.43
	Yes	6.19	5.59		Yes	6.38	5.68	
Google	No	3.96	4.77	0.06	No	5.09	6.89	0.01*
	Yes	5.44	5.73		Yes	9.26	4.90	
Patient blogs	No	4.86	5.78	0.52	No	6.90	6.06	0.09
	Yes	4.88	4.08		Yes	4.29	5.31	
Other sites	No	4.85	5.56	0.33	No	6.65	6.13	0.11
	Yes	5.00	2.92		Yes	4.67	3.06	

SALT: Severity of Alopecia Tool, DLQI: Dermatologic Life Quality Index, CDLQI: Child Dermatologic Life Quality Index, SD: Standard deviation, *p<0.05

Instagram, and Google were found to be considerably higher ($p=0.01$, $p<0.05$) (Table 3).

DLQI scores of the patients who searched the SM about the disease, drugs, patient comments, and doctor were at similar levels ($p>0.05$).

DLQI scores of the patients were similar according to group membership, making comments within the group, and opinions about the group ($p>0.05$). It was determined that trusting the answers if there is a chance to ask a question with a photo, thinking that doctors have to answer, and trying to reach the doctor via SM did not significantly affect DLQI levels ($p>0.05$).

Discussion

Clinical Features

AA is a disease that is frequently seen together with vitiligo and thyroiditis because it originates from autoimmunity [1]. In a meta-analysis, vitiligo was found in 2.3% of AA patients, and autoimmune thyroid disease was found in 13.9% [9]. Similarly, our study found that 5.1% of the patients had vitiligo, and 11.9% had thyroiditis.

It has been shown that 20% of AA patients have a family history [10]. In our study, it was observed that 14.4% of the patients had a family history. Having a family history is considered a poor prognostic factor [10]. In our research, DLQI scores were significantly higher in those over 17 years of age than those with a family history, but no significant increase was found in the 4-16 age group.

Using SM to Obtain Information about the Disease

In a study by Gantenbein et al. [7], it was seen that 82.4% of dermatology patients used the internet to obtain information, and 65.4% used SM. Similarly, our study found that 78% of the patients used SM, and 72.6% used SM for information about the disease.

In a recent SM study on acne vulgaris patients, patients most frequently preferred Google, Instagram, and YouTube to obtain information [11]. Similarly, most SM patients chose Google, Instagram, and YouTube in our research. A study conducted with acne patients found that the use of SM related to the disease was higher in women with shorter disease duration and more advanced disease [11]. In our study, no significant relationship was found between the use of SM, the selected SM platforms, personal characteristics, and the patients' clinics. This data may be due to the larger patient population in the acne study, but 118 patients in our study.

Information Searched by Patients

In a previous study the most frequently searched information by patients online was the treatments (24.1%), followed by doctor's recommendations (11.5%), information about the disease, and information about diet. Another study on Facebook, the most frequently searched information was found to be side effects,

treatment options, and drug interactions [12]. In the survey conducted with acne vulgaris patients, the patients most commonly searched for information about the disease, followed by drugs, treatment options, and cosmetics [11]. Similarly, our study found that patients most frequently searched for information about the disease, followed by doctors, medications, and patient comments. These results show that the most commonly searched information includes similar topics, although it varies.

Patient Support Group Membership

There are many hidden and open patient support groups on SM. With over 1 billion users, most patient groups seem to be on Facebook [13]. A study conducted in the USA showed that 5% of internet users are members of patient support groups [14]. Again, in a survey conducted with acne vulgaris patients, 4.3% were members of support groups [11]. In our study, it was determined that 9.3% of the patients were group members, and the majority of these groups were on Facebook. It was observed that the vast majority of patients made comments in groups. A study conducted with acne patients showed that 47% of the patients read the words in the groups [11]. In our research, it was observed that 62.7% of the patients read or searched the information in the groups, and this result shows that the patients give importance to SM information. However, here, doctors should not advertise their clinics while providing information [13]. In our study, 14.4% of the patients think that doctors and products are advertised in patient groups, emphasizing that doctors should pay attention to this issue.

Trust in Doctors

A study conducted with acne vulgaris patients showed that 84.4% of the patients preferred doctors in case of conflict between the SM and the doctor [11]. Similarly, in our study, 96.5% of the patients stated that they would trust the doctor in case of disagreement between the SM and the doctor. In addition, it was determined that 36.6% of the patients who preferred the doctor had a university or higher education level, and 41.5% had a SALT score of 100 (Table 4). These results suggest that patients with more severe diseases and high sociocultural levels prefer doctors. While these high preference rates show that we still have a strong hand as doctors, it shows the importance of the presence of doctors in SM to avoid conflicts between patients.

In a study conducted with acne vulgaris patients, it was determined that 41.1% of patients would not trust the answers if they had the chance to ask questions with photographs [11]. In our study, 62.9% of the patients stated that they would not trust the answers if they had the opportunity to ask a question with a photograph, and they were found to be insecure at a higher rate. These rates show that patients still find clinics and face-to-face examinations more reliable than online.

Table 4. Characteristics of the doctor-preferred group in the SM-doctor conflict

Patient characteristics		The group that chooses the doctor if SM contradicts the doctor	
		n	%
Gender	Male	47	57.3%
	Female	35	42.7%
Age (X + SD)		20.59	10.47
Education	No	4	4.9%
	PE	25	30.5%
	HS	23	28.0%
	U	26	31.7%
	PG	4	4.9%
SALT score	S1	11	13.4%
	S2	14	17.1%
	S3	12	14.6%
	S4	11	13.4%
	S5	34	41.5%
Scalp involvement	No	2	2.4%
	Yes	80	97.6%
DD (X + SD)		65.41	57.44
Comorbidities	No	69	84.1%
	Vitiligo	5	6.1%
	Thyroid	8	9.8%
	DM type I	0	0.0%
Family history	Yes	13	15.9%
	No	69	84.1%

SALT: Severity of Alopecia Tool, SM: Social media, PE: Primary education, HS: High school, U: University, PG: Postgraduate, DD: Disease duration, SD: Standard deviation
 *no p-value because there is only one group (who chose the doctor)

In a previous study, more than 40% of patients discontinued their treatment based on the recommendations in SM [15]. In our research, it was seen that 83.3% of the patients who reached doctors from SM followed the advice here. Interestingly, although the patients express that they do not trust the answers to the questions they ask from the SM, they follow the recommendations here at a high rate.

Reaching a Doctor via SM

Since patients see online consultations as more convenient and time-independent than face-to-face consultations, they ask doctors various questions in this way. Although it is possible to ignore these messages, it is evident that doctors have an ethical responsibility towards a person who asks for help [16]. In the study conducted with acne vulgaris patients, 40.7% of the patients stated that the doctors did not have to answer the patients via SM [11]. In our study, 60.6% of patients said doctors do not have to answer patients via SM. These results indicate that the patient’s expectations differ, and some want to see their doctors as always available.

SM Choice to Reach the Doctor

In a study, 41% of the patients stated that they were affected by SM in choosing a doctor or health institution [17]. In the study by Albeshri et al. [18], 21% of dermatology patients found doctors from SM and received information most frequently from Twitter and Instagram. Similarly, in our study, 18.2% of the patients reached the doctors via SM. They most preferred doctor sites and then Instagram. These results show that SM is an effective platform in health research.

Relationship Between SM and DLQI/CDLQI

It was observed that the DLQI levels of the patients who preferred the doctor if the SM conflicted with the doctor in the over 17 age group were higher. To our knowledge, this has not been shown in the literature before; it can be explained by the fact that patients with high DLQI, whose disease has a significant impact on their lives, are more conscious about their diseases and trust the professionals of the job.

Usually, the increase in SALT should be related to the rise in DLQI but did not occur. The reason for this may be the uneven distribution

of SALT score groups in the patient population included in the study and the differences in education levels and genders of the patients in these groups. A study showed a positive correlation between education level and disease compliance, and men were stronger in personal control than women [19].

Study Limitations

The small number of patients in some parameters (ex. trust) is not capable of drawing safe conclusions.

Conclusion

SM is being used more and more in health research in every field. It is crucial in branches such as dermatology, where visuality is at the forefront. AA patients are affected both physically and mentally due to the loss of hair, which has a vital role in the person's appearance. The data in our study show that dermatologists and dermatology associations should keep up with this change and exist on the Internet and SM, along with changing conditions. This way, disinformation will be prevented by ensuring that patients get the correct information from the right source.

Ethics

Ethics Committee Approval: This study protocol was reviewed and approved by the Istanbul University-Cerrahpasa, Cerrahpasa Medical Faculty Clinical Research Ethics Committee (decision number: 14429, date: 22.01.2021).

Informed Consent: Written informed consent was obtained from the patients.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: S.G., Concept: T.K.U., Ö.A., Design: S.G., Ö.A., Data Collection or Processing: S.G., Analysis or Interpretation: S.G., T.K.U., Ö.A., Literature Search: S.G., Writing: S.G.

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