Habits of Using Social Media and the Internet in Psoriasis Patients

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Key words: psoriasis, social media, internet, habit

Citation: Aslan Kayıran M, Karadağ AS, Oğuz Topal I, et al. Habits of using social media and the internet in psoriasis patients. Dermatol Pract Concept. 2022;12(3):e2022143. DOI: https://doi.org/10.5826/dpc.1203a143

Accepted: December 9, 2021; Published: July 2022

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Funding: None.

Competing interests: None.

Authorship: All authors have contributed significantly to this publication.

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ABSTRACT Introduction: Psoriasis significantly affects the patients quality of life, which often leads patients to seek online information about this disease.

> **Objectives:** To explore the habits of patients with psoriasis related to their use of social media (SM) and the internet to obtain information about their disease.

> Methods: 1,520 patients completed the survey and the Dermatology Life Quality Index (DLQI) questionnaire. The Psoriasis Area Severity Index scores (PASI) and clinical data of the patients were recorded by their physicians.

> Results: Of the 1,114 patients that reported using SM and internet, 48.38% regularly and 31.14% sometimes resorted to obtain information about psoriasis. The use of SM and internet for psoriasis was statistically significantly higher among young people (P = 0.000), those with university or higher education (P = 0.009), higher DLQI (P = 0.000) and PASI (P = 0.011) scores, facial (P = 0.050), scalp (P = 0.032), hand (P = 0.048), genital (P = 0.001) and inverse (P = 0.000) involvement, and arthralgia/arthritis (P = 0.006). The participants mostly used the Google (86%) and Facebook (41%). More than half of the participants (62.8%) expected dermatologists to inform society that psoriasis is not contagious.

> Conclusions: Internet and SM being widely available and offering substantial information to be easily accessed make it very attractive for patients to use these platforms to investigate diseases, including psoriasis. If what is presented on SM conflicts with what the physician says, patients mostly trust the latter, but at the same time, they tend not to share the results of their online inquiries with their physicians.

Introduction

Psoriasis is a chronic systemic inflammatory disease seen at a rate of 1-3% across the world [1]. Sufferers may experience itching, burning and pain sensation, and restrictions in social life, which reduce their quality of life [2]. Social media (SM) comprises internet-based communication tools that have entered people lives very quickly [3]. It is utilized for many different purposes, such as accessing educational tools and creating educational resources, creating campaigns to reach the public, and even inviting patients to participate in clinical trials or online surveys [3]. Today, access to information through technology tools has become extremely easy and fast. As in every subject, the internet has become almost the first source of reference for health problems.

Although there are a few studies related to the use of SM and the internet conducted with patients presenting to dermatology outpatient clinics, there is no research specifically focusing on psoriasis patients [4,5]. Psoriasis affects the quality of life of patients due to recurrent nature of the disease, long-term and sometimes laborious treatment processes, accompanying symptoms including pain, itching, and xerosis, and involvement of visible areas such as the face or intimate parts of the body such as the genitals [6]. This prompts patients to explore different treatment options, seek different physicians and hospitals, and reach other patients and various medical organizations. In this respect, the internet and SM provide patients with a wide range of sources and fast access to information.

Objectives

This study aimed to explore the habits of patients with psoriasis related to their use of SM and the internet to obtain information about their disease, methods they used, whether they followed programs concerning the disease available on media outlets, whether they read related brochures, and their recommendations to dermatologists and dermatological associations concerning the use of SM related to psoriasis.

Methods

Patients

The study included voluntary literate psoriasis patients over the age of 18 years and who were followed in the psoriasis-specialized outpatient clinics of 18 different dermatology departments located in seven regions of Turkey between January 1, 2020, and July 1, 2020. Each researcher had to enroll at least 75 patients in the study [7]. Although part of the study coincided with the pandemic period, dermatology outpatient clinics were actively working in hospitals due to the regulations of the health authority.

Procedure

This is a non-interventional, cross-sectional multicenter study. Approval for the study was obtained from the ethics committee of the university (ID 25.12.2019/0527). The survey questions were prepared by the researchers. Information on the patients clinical findings and the Psoriasis Area Severity Index (PASI) scores were noted by their physicians. The patients were asked to complete the survey (Supplementary Table 1) and the Dermatology Life Quality Index (DLQI) questionnaire without any time limitation [8,9].

Statistical Analysis

Data obtained were analyzed using SPSS IBM software package at the 95% confidence level, ie, 5% margin of error. Descriptive statistics concerning the survey results were given as frequencies and percentages. In continuous measurements showing a normal distribution, paired-group comparisons were undertaken with the independent-samples t-test while three groups were compared using analysis of variance (ANOVA). In cases where there was a significant difference in ANOVA, the groups that caused the significant difference were examined using the least significant difference test as a post-hoc method. In continuous measurements that did not show a normal distribution, two groups were compared using the Mann-Whitney U test and three-group comparisons were undertaken with the Kruskal-Wallis H test. The test statistics for the comparison of two or more groups were obtained using the chi-squared test.

Results

A total of 1,520 participants (709 women and 811 men) were included in the study and all of them agreed to participate. Of the participants, 51.40% stated that they used SM and the internet regularly, 21.90% sometimes used them, and 26.70% never used them. In addition, of the participants

who stated that they used SM and the internet, 48.38% regularly and 32.14% sometimes made inquiries about psoriasis on these platforms while 19.48% did not consult online platforms for this purpose.

The use of SM and the internet for psoriasis was significantly higher in young people, those with university or higher education levels. Although there was no significant difference between smokers and non-smokers, the smoking pack years were significantly higher in SM users than non-SM users (11 ± 23 pack years, 9 ± 14 pack years; P=0.027, respectively). Social media and internet use in psoriasis patients were found not significantly associated with gender, marital status, alcohol use, and monthly family income (Table 1). The use of the internet and SM for psoriasis-related inquiries was higher in Marmara region where the education level and the rate of working population are high, as well as in Central Anatolia where the capital of Turkey is located.

Social media and internet use was significantly higher in those with higher DLQI and PASI scores, those with facial, scalp, hand, genital and inverse involvement, and those with arthralgia/arthritis. Nail involvement, family history of psoriasis, and disease duration were not found associated with SM and internet use (Table 2). There was no difference between psoriasis subtypes in terms of SM and internet usage.

SM tools used by the participants to investigate psoriasis are shown in Figure 1. Most participants (86%) reported using Google for this purpose. The participants most frequently (76%) sought information about the disease itself, followed

Table 1. Social media and internet use according to demographic characteristics.

Frequency of social			Yes		No		Sometimes		Overall	
media use		N	%	N	%	N	%	N	%	
Gender	Female	238	45.9%	122	23.5%	159	30.6%	519	46.6%	0.136
	Male	274	46.1%	165	27.8%	155	26.1%	594	53.4%	
Marital status	Married	356	45.6%	211	27.0%	214	27.4%	781	70.1%	0.336
	Single	144	48.5%	67	22.6%	86	29.0%	297	26.7%	
	Divorced	13	36.1%	9	25.0%	14	38.9%	36	3.2%	
Smoking status	Non-smoker	277	44.2%	161	25.7%	188	30.0%	626	56.3%	0.193
	Smoker	236	48.7%	126	26.0%	123	25.4%	485	43.7%	
Ex-smoker	No	473	46.6%	253	24.9%	290	28.5%	1016	91.4%	0.173
	Yes	39	41.1%	32	33.7%	24	25.3%	95	8.6%	
Alcohol	No	404	45.7%	228	25.8%	252	28.5%	884	79.4%	0.918
	Regularly	13	54.2%	6	25.0%	5	20.8%	24	2.2%	
	Social drinker	96	46.8%	53	25.9%	56	27.3%	205	18.4%	
Monthly income level*	300\$ and below	96	41.4%	69	29.7%	67	28.9%	232	20.8%	0.376
	300-650\$	277	47.7%	135	23.2%	169	29.1%	581	52.2%	
	650-1,300\$	110	45.1%	70	28.7%	64	26.2%	244	21.9%	
	above 1,300\$	29	51.8%	13	23.2%	14	25.0%	56	5.0%	

Table1 continues

Table 1. Social media and internet use according to demographic characteristics. (continued)

Frequency of social		Yes		No		Sometimes		Overall		Р
media use		N	%	N	%	N	%	N	%	
Education level	Literate**	2	11.1%	10	55.6%	6	33.3%	18	1.6%	
	Primary-middle school	156	43.8%	99	27.8%	101	28.4%	356	32.0%	
	High school-college	208	46.3%	102	22.7%	139	31.0%	449	40.4%	0.009
	University	129	50.0%	66	25.6%	63	24.4%	258	23.2%	0.007
	Post-graduate (Masters-PhD)	17	56.7%	9	30.0%	4	13.3%	30	2.7%	
Age, years, mean ± standard deviation		39 ± 13		43 ± 15		40 ± 13		41 ± 14		0.000

^{*}Calculated based on the exchange rate at the time of the study.

Table 2. Social media and the internet use according to disease involvement.

Frequency of social		Yes		ı	lo	Some	times	Overall		Р
media use		N	%	N	%	N	%	N	%	
Joint pain/involvement	Arthralgia	120	45.1%	55	20.7%	91	34.2%	266	25.0%	
	Arthritis	73	52.9%	27	19.6%	38	27.5%	138	12.9%	0.006
	Absent	287	43.4%	197	29.8%	178	26.9%	662	62.1%	
Nail involvement	Absent	310	47.9%	167	25.8%	170	26.3%	647	58.1%	0.20.5
	Present	203	43.5%	120	25.7%	144	30.8%	467	41.9%	0.205
Scalp involvement	Absent	217	43.3%	148	29.5%	136	27.1%	501	45.0%	0.022
	Present	296	48.3%	139	22.7%	178	29.0%	613	55.0%	0.032
Facial involvement	Absent	402	44.4%	244	26.9%	260	28.7%	906	81.3%	0.050
	Present	111	53.4%	43	20.7%	54	26.0%	208	18.7%	0.050
Hand involvement	Absent	324	46.0%	196	27.8%	184	26.1%	704	63.2%	0.049
	Present	189	46.1%	91	22.2%	130	31.7%	410	36.8%	0.048
Genital involvement	Absent	382	44.2%	246	28.4%	237	27.4%	865	77.6%	0.001
	Present	131	52.6%	41	16.5%	77	30.9%	249	22.4%	
Inverse involvement	Absent	375	43.5%	249	28.9%	239	27.7%	863	77.5%	0.000
	Present	138	55.0%	38	15.1%	75	29.9%	251	22.5%	
PASI		6.8 ± 9		5.7 ± 9.7		6.8 ± 9.5		6.5 ± 9.4		0.011
DLQI		10.3 ± 8.7		6.6 ± 7.1		9.7 ± 8.4		9.1 ± 8.4		0.000
Disease duration		14 ± 10		15 ± 11		15 ± 11		14 ± 10		0.217
Family history of psoriasis	Absent	188	44.0%	111	26.0%	128	30.0%	427	38.8%	0.560
	Present	315	46.7%	176	26.1%	183	27.2%	674	61.2%	

DLQI = Dermatology Life Quality Index scores; PASI = The Psoriasis Area Severity Index scores.

by medication and treatment options (62%), physicians (40%), and other patients posts (43%). Of the respondents, 9.9% were members of SM groups related to psoriasis, 3.1% were former members, and 87% stated that they had never joined such a group. The platforms used for patient groups were Facebook for 80.3% of the participants, Instagram for 21.4%, WhatsApp for 10.3%, Twitter for 2.6%, and other platforms for 12%. When asked about their views on what was discussed in these groups, 35.7% of the respondents

reported that they read the posts if they caught their attention, 23.6% looked for further information on what was discussed, 20.7% just read the posts, 22.2% felt relieved to see others with similar problems, and 8.4% thought that a physician or product was advertised in these online groups. We determined that 78.7% of the participants did not ask their physician about the accuracy of information obtained from SM and the internet (Figure 2A). In case of contradiction between their findings in internet search and their physicians'

^{**}Refers to participants that have no formal education but know how to read and write.

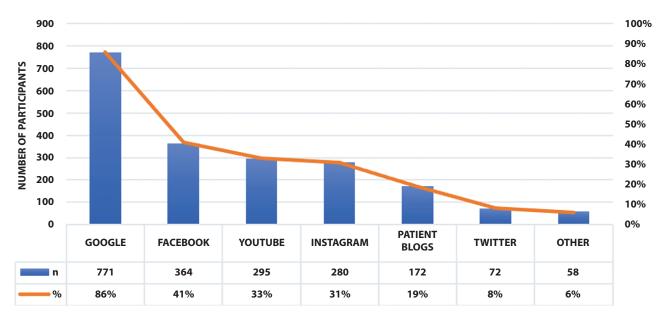


Figure 1. Social media and internet platforms on which the participants sought information about psoriasis.

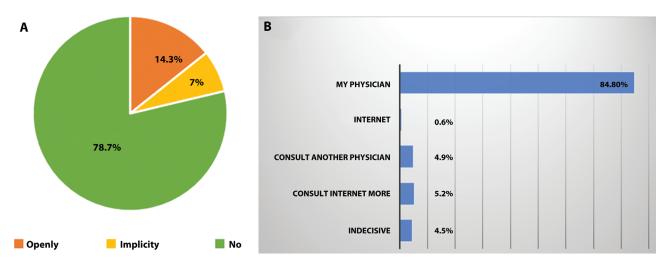


Figure 2. (A) The answers to the question "Do you ask your physician about the accuracy of information obtained from social media?". (B) The answers to the question "In case of contradiction between the SM and your physician, who would you trust?".

recommendations, 84.6% of the participants stated that they would trust their physicians (Figure 2B).

Of the participants, 19.4% stated that they used SM to try to contact dermatologists to ask questions about their disease. When online platforms were used for this purpose, 14.2% of the participants considered that physicians should answer patients' questions, 13.6% stated that only physicians working in private hospitals should answer such questions, 32.8% thought that physicians should respond politely even if they were not obliged to answer, and 43.6% believed that physicians did not have to answer. The participants stated that they most frequently (66.7%) tried to contact physicians by personal or clinic phone (Figure 3A). Of those that tried to contact via SM, they mostly used Facebook (49.3%) (Figure 3B). When they reached physicians, they mostly asked questions about their treatment

(41.4%) and disease (31.1%). Furthermore, 8.7% stated that they sent physicians photographs of their symptoms in order to ask for their advice, 12% asked for help to get hospital appointments, and the remainder asked for advice on other skin diseases or the health problems of relatives. The majority of the participants that tried to contact physicians on SM (77.9%) added that they did not receive a response, while most of those that obtained a response (61.8%) mentioned that they followed physicians' recommendations, 21.2% sometimes followed these recommendations, and 17% did not do what was recommended. When the participants were asked whether they would trust a physician's answer if they directed him/her a question accompanied by a photograph, 56.6% responded as no, 11.4% as yes, and 32% as yes but they would still visit a physician for an examination.

Of the participants, 36.9% did not like the television and radio programs on psoriasis, 29% considered that such programs only aimed to promote physicians or advertise products, 31.7% wanted to be given information, and 22.8% stated that it was a relief to see other psoriasis patients. While 52.5% of the participants did not follow such programs, 14.5% followed them regularly and 33% sometimes watched them. Most of the respondents (83.9%) reported that they did not apply what they saw on television, and 9.1% always and 7% sometimes tried them. In addition, the participants made further inquiries about what they saw on television by consulting the internet (27.4%), a physician (18.4%), a pharmacist (7%), and other patients (8.2%). Among these participants, 13.6% sought further information if what was presented on television appeared logical while 46.3% did not make any further inquiries. Only 0.2% of the respondents contacted the television or radio program to ask questions. Of the participants, 75.2% stated that they never asked their physicians about what they saw on television programs while 10.6% asked such questions implicitly and 14.2% openly.

When asked whether they had read a book/brochure about psoriasis, 5.8% of the participants stated that they had, 71.7% had not, and 22.5% were not aware of such publications. Furthermore, 62.7% of the respondents wanted seminars on psoriasis to be given by physicians and 30.3% by official institutions, and 21.9% stated that they would attend such events if they were free, 9% would be willing to pay a fee, and 19.3% were not interested. More than half the participants (56.5%) reported that hospitals or physicians did not give them educational brochures while 26.9% were provided such publications and read them, and 16.6% were presented such materials but did not read them.

Table 3 summarizes the participants responses concerning their recommendations for dermatologists and dermatological associations. The respondents most frequently (62.8%) wanted the public to be informed that psoriasis was not contagious. Secondly (62%), the patients wanted the dermatologists and the dermatology associations to prepare the publications and information shown in SM and the

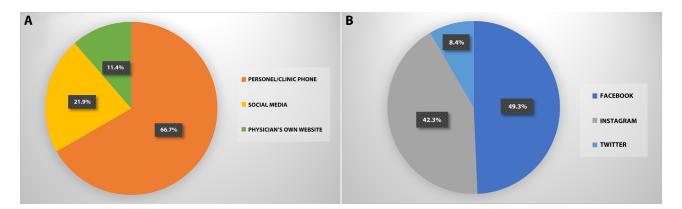


Figure 3. (A) The patients answers to the question "How do you try to contact your physician?". (B) The social media platforms which they use to communicate their physician.

Table 3. Recommendations of the participants to dermatologists and dermatological associations concerning the use of social media and internet related to psoriasis

Recommendation	N	%		
Society should be made aware that the disease is not contagious.				
These publications should be prepared by the authorities in this area.				
Sharing false information should not be allowed.				
Society should be made aware that treatment is available for the disease.	752	49.5%		
Only dermatologists should discuss the disease.				
Seminars should be organized in places easily accessible to the public.				
Associations should file a criminal complaint if inaccurate information is present.	494	32.5%		
Books-booklets should be prepared and distributed.	449	29.5%		
More media programs should be made available to present introductory information about the disease.	402	26.4%		
Patient schools should be organized in hospitals.	353	23.2%		
More information should be shared on the internet.	302	19.9%		

Total percentage exceeds 100 since the participants were allowed to choose more than one option

internet. They (54.7%) also did not want to see false information about psoriasis on SM and the internet.

Conclusions

Our study showed that 80.5% of the patients with psoriasis had the habit of regularly or sometimes using SM and the internet to seek information about their disease. This behavior was more common in young people, those with university or higher education levels, those with higher DLQI and PASI scores, those with facial, scalp, hand, genital and inverse involvement, and those with arthralgia/arthritis. The most commonly used search engine was Google (86%) and the most commonly used SM platform was Facebook (41%).

While it is known that globally, 4.5% of online inquiries was related to health in the 2000s, this rate has gradually increased, reaching 79% today [4,10,11]. Patients resort to SM and the internet to obtain information about their diseases and treatments, communicate with other patients and physicians, and look for organizations related to their diseases [12].

A previous study conducted in the United States of America (USA) reported that 80% of internet users consulted the internet to access information about at least one disease throughout their lifetimes [13]. However among the studies conducted for this purpose, especially those related to internet use on a disease basis have not yet become widespread, and research on the general use of the internet about diseases has only accelerated in the last few years. Our study is the first to investigate the internet and SM use of patients with psoriasis and includes data obtained from 1,520 patients participating from different regions of Turkey.

In a study conducted with 460 patients who presented to a general dermatology outpatient clinic, the rate of those consulting SM was found to be 80% [14]. In another study conducted with patients who presented to the dermatology outpatient clinic in Saudi Arabia, this rate was found to be 47% [4]. In a general surgery study, the rate of patients referring to online research before hernia surgery was reported to be 67% [15]. In our study, 80.5% of the patients with psoriasis stated that they resorted to the internet or SM to obtain information about their disease. The difference in this rate seems to be due to our research focusing on a specific chronic disease. The rate of online medical inquires is also reported to be higher among women, people with higher income, those with higher education levels, and those more affected by the disease [5,14-16]. Similarly, in our study, we observed that the use of SM and the internet for psoriasis was statistically significantly higher in young people and highly educated individuals. In dietetic studies, the use of SM was found to be higher in women and in young adults aged 18 to 35 years [17]. In the current study, there was no gender

difference, but internet and SM users had a mean lower age and higher education level. This can be explained by the higher internet and SM usage among young adults and those with a higher education level [18]. Furthermore, the more people quality of life was, the more likely they would look for a solution to their disease. In addition, it has been shown that the involvement of the visible parts of the body such as the face and hands and intimate parts such as the genitals and skin folds, as well as the presence of accompanying painful conditions, including arthralgia/arthritis are more likely to have negative psychosocial effects on patients and result in higher DLQI scores [6]. Unsurprisingly, in the presence of such involvements, patients tend to make more online inquiries concerning their disease.

In the USA, the rate of individuals referring to Facebook to obtain information about health was found to be 38% [19]. In a study conducted with dermatology patients, it was shown that the patients obtained information about their physicians through SM 9.7 times more frequently compared to traditional media sources [11]. The source of this information was mostly Twitter (44.5%), followed by Instagram (27.9%), and Facebook (2.8%). However, the authors did not include search engines such as Google in their study [11]. In another study, the patients most frequently used Google (42.3%), followed by YouTube (34.6%) and Facebook (22.3%) for their medical searches[5]. In our study, 86% of the patients used Google for this purpose, while 41% used Facebook, 33% YouTube, 31% Instagram, and 8% Twitter. Since Google is globally the most used search engine as in our country, it is natural for patients to seek information about their diseases using this engine. Facebook is the most frequently used SM tool for adults using the internet [20]. However, SM habits can change over time. Some websites/ applications may lose popularity while others may become more popular or their popularity may fluctuate. In addition, SM applications can be expected to vary according to geographical regions [21].

One of the interesting findings of our study is that 19% of the participants used patient blogs to obtain information. In addition, 22.8% stated that it was a relief seeing patients with psoriasis like themselves on traditional media programs such as television. In general, patients express that they feel comfortable and less embarrassed when they meet people with the same disease and exchange views about their disease [22]. The findings from our study indicate that patients are interested in what other patients with the same disease experience and they may even compare their experiences to others, and it is comforting for them to realize that there are others that suffer from the same problems.

Our participants reported that they mostly consulted the internet to seek information about their disease, followed by treatment options and physicians. Patients motivations to

resort to SM and the internet to obtain information about their diseases can be listed as understanding the disease, exploring personal diagnosis-treatment methods and alternative treatments, and obtaining information about doctors and hospitals. However, they still consider physicians as the most trustworthy source [14]. In our study, 84.6% of the participants stated that even if they conducted online searches, they would trust the physician in the presence of conflicting information. As a more interesting finding, 56.6% of the participants stated that even if they had been given the opportunity to obtain information about their disease by sending photographs to their physician, they would have not trusted the physician response and 32% would still go to a physician for an examination. This shows that although the patients trusted physicians' knowledge, they would still prefer to be personally examined by a physician and exchange ideas.

In this study, 78.7% of the respondents stated that they did not share with their physicians what they inquired about on the internet related to their disease, which is in agreement with previous studies. ¹⁴ This can be interpreted as patients not being willing to disclose to their physicians that they consult online sources and they may even be concerned about their physicians reaction.

When asked about their recommendations to dermatologists and dermatological associations regarding the use of SM, internet and traditional media, most of the participants (62.8%) stated that society should be informed that psoriasis is not contagious. In addition, they stated that informative publications and broadcasts should be prepared by the authorities in the field, such as dermatologists (62%) and that false information about the disease should not be allowed to spread (54.7%). It is now widely known that psoriasis is not contagious, but even today patients with lesions, especially in visible areas still express that other people refrain from touching them or shaking hands [23,24]. In this respect, it is very important that three out of every five participants in the current study recommended that the public should be informed about the non-contagious nature of the disease. It is clear that this situation affects the social relationships of patients.

The main limitations of our study are that the data were collected through a survey, and therefore they were based on the self-reported statements of the patients and a part of the study period coincided with the ongoing pandemic. During the first months of the pandemic, working from home may make the patients access SM frequently. A comparison with another chronic skin disease or with a control group may be done for further studies. However, this study is important due to being the first in this area, multicenter design involving the whole country, and inclusion of a large patient series.

Although SM comprises many favorable characteristics, such as allowing for the mutual exchange of information

and comments, it is inevitable that some of the shared information is false. Our study showed that a high rate of patients with psoriasis consulted online sources to seek information about their disease. They most frequently used Google, Facebook, and YouTube channels to obtain information about the disease, treatment options, and doctors. However, although they consulted the internet and SM to seek information, most stated that they had greater trust in the information given by physicians. They also followed patient blogs and were relieved to see the presence of other patients suffering from psoriasis. They expressed their discomfort with the misbelief of a section of society without the disease that psoriasis is contagious, and they recommended dermatologists and dermatological associations to educate the public in this regard. As dermatologists, we have great responsibility in sharing accurate information about psoriasis on SM and the internet, as well as raising the awareness of society.

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Supplementary Table 1. Survey questions directed to the participants

Are you actively using social media and the internet?

Are you using social media and the internet to obtain information about psoriasis?

If yes, Which social media/internet platforms are you using?

What subjects are you inquiring about concerning your disease?

Are you a member of any online patient groups? If yes, which social media groups?

Are you following/writing posts in these groups? What do you think about these groups?

Would you share with your physician what you have seen on online about your disease?

If the information on social media conflicts what your physician says, which would you trust?

If you consult a dermatologist with a photograph of your disease on social media, would you trust his/her answer? Are you trying to contact physicians using social media? If yes, on which platforms?

When you contact a physician online, do you think he/she is obliged to answer your questions about your disease? What do you ask physicians that you contact online?

Do you trust their answers? Do you follow their recommendations?

What do you think about the health programs on television/radio concerning your disease?

Do you follow these programs? Do you further investigate what you see in these programs?

Would you consult your physician about the information presented in these programs?

Have you ever applied the recommendations you have seen in these programs to relieve your disease?

Do you read books/brochures on psoriasis? Do you read information booklets provided by physicians?

Would you like educational seminars to be organized on psoriasis?

Do you have any recommendations to dermatologists and dermatological associations concerning the use of social media/media related to psoriasis?