



# Patients with rheumatic diseases are ready to use social media in clinical practice; what about rheumatologists? A cross-sectional survey

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#### Abstract

Social media can be an innovative communication method between patients and physicians that help to overcome time limitation in outpatient clinics. In this study, we investigated how patients with rheumatic diseases (RD) and physicians use and are willing to use social media platforms to communicate with each other. We used a face-to-face survey that provides information on current social media habits and communication methods of rheumatology patients and physicians. We studied 399 (135 M/262 F) patients with RD with a median age of 45 (IQR: 34) years. We also studied 55 (30 M/25F) rheumatologists with a median age of 37 (IQR:34–44) years. Among patients with RD, 288 (72%) used at least one social media site within the previous month. Facebook was the most preferred social media platform, whereas Twitter and Instagram were favored by males and higher educated patients. While 17% of the patients with RD could communicate with their physicians outside of the hospital, 94% expressed that they would like to. Most patients (74%) defined social media as a reliable source for health-related information, yet 90% declared that they would like to obtain information about their disease using face-to-face communication. Forty-two (83%) rheumatologists were using social media and reported that they already communicate or would like to communicate with their patients outside of the hospital. Internet-based mobile applications and social media platforms are promising communication and educational tools for rheumatology patients.

Keywords Health communication  $\cdot$  Health education  $\cdot$  Internet  $\cdot$  Internet use  $\cdot$  Rheumatologists  $\cdot$  Rheumatology  $\cdot$  Social media  $\cdot$  Social networking

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## Introduction

Social media has been popular among patients for exchanging information, sharing feelings, and supporting each other [1-3]. Preferred social medial platforms and the extent of its use are determined by social, economic, religious, political, cultural and ethnic factors [4]. Medical professionals, organizations, and companies are increasingly using social media for education, communication, recruiting patients to studies, acquiring information about pharmacovigilance or other patients' experiences. For instance, although only 5% of treatment-related adverse events can be documented by traditional methods, up to 62% of all treatment-related social media posts have information about adverse events [1]. Physician-patient communication has a crucial role in disease management, as it affects patient's adherence to the treatment [2]. Social media has the potential to be a beneficial method for improving physician-patient communication, since a face-to-face daily practice has time constraints.

There is limited information about the social media habits and communication methods of patients with rheumatic diseases (RD) and their physicians for medical aspects. We performed a survey to investigate how rheumatology patients and physicians use and are willing to use social media to communicate with each other in a tertiary hospital in Istanbul, Turkey.

# Methods

We studied consecutive patients with diverse diagnoses attending the rheumatology outpatient clinic of Cerrahpasa Medical Faculty at University of Istanbul-Cerrahpasa, Istanbul between January 2018 and June 2019. We used a survey that is composed of multiple-choice questions, which was used Hausmann JS et al. for an adolescent population [3]. The questionnaire was slightly modified and administered randomly to outpatients by a physician (O.Y.) and in-person survey method. The survey included multiple type of questions including, multiple choice, checkbox, close-ended followed by open-ended and non-response answer options on information on demographic, educational status, patients' diagnosis, and the type of internet connectable electronic device they use. Participants were also asked whether they were using social media platforms, how often and for what purposes they were using. Furthermore, they were asked whether they would like to use social media as a communication tool with their rheumatologists and other healthcare providers if such opportunity was possible, and how much they rely on websites/social media platforms to obtain medical information (Likert-scale was used in this question). No standardized validation or reliability testing method was used.

A similar but modified survey for physicians was administered to rheumatologists during a Turkish National Rheumatology Meeting in 2018. Rheumatologists from different centers and academic levels were asked about their social media habits, preferences for physician–patient communication regarding social media usage, and academic and demographic information.

#### Statistics

The categorical variables were compared by the chi-square test or the Fisher exact test. All tests were performed using SPSS for Windows, v. 20.0, software (SPSS Inc, Chicago, IL, USA). Patients were compared according to gender, age, and education level. No imputation was performed for missing values, analyses were done for the reported number of patients for each variable. We did not do a sample size calculation.

# Results

A total of 399 patients with RD with a female predominance (n = 263, 66%) completed the survey. The median age of the patients was 45 years (IQR: 21). Patients' demographic features and diagnoses were shown in Table 1. A total of 150 patients (40%) were primary school graduates or received lower level of education.

Of 399 patients, 329 (83%) owned at least one device to connect to the internet and 306 (77%) had a smartphone. Those who did not own these devices (n = 70, 18%) were significantly older and more likely to be female, and had a lower educational status compared to those who owned (p = 0.001, p < 0.001, and p = 0.009, respectively).

Among patients who owned a device to connect to the internet, 288 (87%) used at least one social media site within the previous month (Table 2). When we asked patients if they agree that social media allows them to obtain useful health information; 240 (74%) strongly or partially agreed, 48 (15%) disagreed while the remaining 35 (11%) did not respond to the question.

Table 1 Socio-demographic characteristics of the patients

Age median, years (IQR)	45 (34–55)
Female $n$ (%)	263 (66)
Rheumatologic condition, n (%)	
Rheumatoid arthritis	99 (25)
Behcet's syndrome	74 (19)
Spondyloarthropathies	68 (17)
Connective tissue disease	58 (14)
Familial Mediterranean fever	57 (14)
Others	43 (11)
Undefined	21 (5)
Working status, <i>n</i> (%)	
Housewife	127 (32)
Government or private sector official	103 (26)
Retired	54 (14)
Unemployed	47 (12)
Unknown	25 (6)
Student	21 (5)
Laborer	11 (3)
Tradesmen	11 (3)
Patients with device to connect to the internet, $n$ (%)	
None	70 (18)
At least one device	329 (82)
Smartphone	306 (77)
Laptop computer	105 (26)
Personal computer	72 (18)
Tablet computer	68 (17)

 Table 2
 How often patients

 and rheumatologists use social
 media

	Never	Once a month	Once a week	Most days	Once a day	Few times a day
Facebook, n (%)						
Patients	93 (28.5)	6 (1.8)	14 (4.3)	41 (12.6)	40 (12.3)	132 (40.5)
Rheumatologists	25 (45)	2 (4)	5 (9)	3 (5)	6 (11)	14 (25)
Twitter, $n$ (%)						
Patients	233 (71.3)	6 (1.8)	6 (1.8)	14 (4.3)	14 (4.3)	53 (16.2)
Rheumatologists	37 (67)	4 (7)	5 (9)	0	1 (2)	8 (15)
Instagram, n (%)						
Patients	125 (32.2)	3 (0.9)	11 (3.4)	32 (9.8)	20 (6.1)	135 (41.3)
Rheumatologists	26 (47)	0	3 (5)	1 (2)	5 (9)	20 (36)
Pinterest, n (%)						
Patients	287 (87.8)	6 (1.8)	7 (2.1)	5 (1.5)	4 (1.2)	15 (4.6)
Rheumatologists	44 (80)	5 (9)	2 (4)	5 (5)	0	1 (2)
Forums, <i>n</i> (%)						
Patients	280 (85.6)	9 (2.8)	9 (2.8)	9 (2.8)	2 (0.6)	15 (4.6)
Rheumatologists	45 (82)	6 (11)	1 (2)	2 (4)	0	1 (2)

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Facebook (71%) and Instagram (62%) were the most preferred social media platforms with a daily usage rate of 53 and 47%, respectively (Table 2). Higher educated patients preferred Instagram and Twitter. Those who use Facebook were similar to those who do not regarding age (age < 50 vs  $\geq$  50 years), gender, or educational status (lower vs higher educational status) (Fig. 1).

#### Posting on social media about health

In the last six months, 41 patients (13%) posted about their health status, 51 (16%) posted about their mood, and 57 (18%) posted about their wellness habits. For these posts, 56% used Facebook, 33% used Instagram, 11% used Twitter and only 1 patient used Pinterest. Twenty-eight percent of the patients used social media for connecting with other rheumatology patients, 27% for obtaining information about

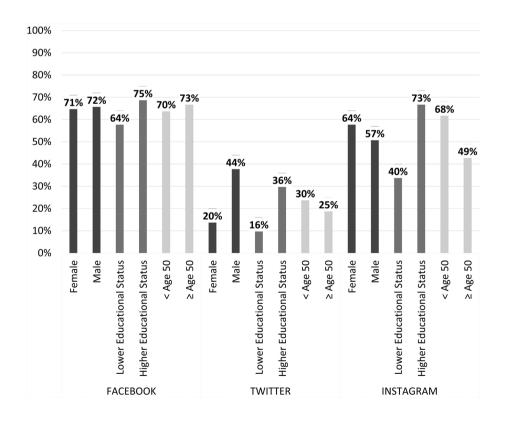


Fig. 1 Frequency of social media users among patients with rheumatic diseases: comparison by gender, educational status, and age treatment options, 27% for receiving advice on their disease, and 11% for receiving emotional support.

#### Connecting with rheumatologists via social media

Among social media users, 8% were following their rheumatologist and 4% were following other healthcare givers and/ or rheumatology patients on Facebook or Twitter. A total of 77% declared that that they were willing to follow their physicians while 16% were willing to follow other healthcare givers and/or rheumatology patients. While 83% of the patients were not communicating with their physicians out of the hospital, while the remaining reported that they were in touch with their rheumatologists (through phone call: 11%, text-messages: 3%, mail: 2%, and social media: 1%). Only 6% would not prefer to communicate with their physicians out of the clinic. A majority (64%) of the patients declared that they would prefer to communicate through WhatsApp (Table 3).

Most of the patients (90%) declared that they would like to obtain information about their disease face-to-face, while a small portion preferred other sources such as online connection with a physician (13%), patient's meetings (14%), another patient's advice (6%), internet websites (7%) or television (4%). The reasons for the willingness to connect out of the clinic can be seen in Table 3.

# The effects of age, gender, and educational level on types of social media platforms

There were significantly more Instagram users among patients aged < 50 years (n = 65) compared to those aged  $\geq 50$  years (n = 25) (68 vs 49%, p = 0.001). Twitter

**Table 3** Why and how patients with rheumatic diseases and rheumatologist wish to communicate with each other?

	Patients	Rheumatologists
Why, <i>n</i> (%)		
I feel more connected	109 (30)	2 (5)
Make the physician more responsible	82 (22)	12 (29)
Easier to communicate	135 (37)	9 (22)
My disease would get better/Positive effect on prognosis	77 (21)	23 (56)
Other people can attend our conver- sation	33 (9)	0
Positive effect on personal popularity	-	1 (2.4)
How, <i>n</i> (%)		
WhatsApp	243 (64.3)	20 (36)
Text-messages	145 (38.4)	15 (27)
Facebook	66 (17.5)	1 (2)
Website of the clinic	79 (20.9)	14 (25)
Twitter	20 (5.3)	0

was more likely to be preferred by male patients (n = 52) compared to females (n = 41) (44 vs 20%, p < 0.01) Patients who received a higher level of education (n = 226) were more likely to use all three types of social platforms more frequently than those who had a lower level of education (n = 102) (Facebook: 75 vs 64%, p = 0.06; Twitter: 36 vs 16%, p < 0.01 and Instagram: 73 vs 40%, p < 0.01) (Fig. 1).

# Rheumatologist' opinion towards connection with patients via social media

Fifty-five rheumatologists (30 M/25F), including trainees, academic and non-academic physicians completed the survey. Their mean age was 37 years (IQR: 10) and the median duration in profession was 15 years (IQR: 12). The median daily number of patients was 40 (IQR: 40). Among the attendees, 65% were working in a university hospital, 21% in a government hospital, 14% in a special hospital or clinic. Forty-two (83%) of the rheumatologist used one of the social media with varying frequency in the previous month. Most of the respondents (n = 40, 80%) defined social media as a useful source for gaining health information. Forty-one (75%) rheumatologists reported that they already communicate or would like to communicate with their patients outside of the clinic (through phone calls: 68%, text-messages: 56%, e-mails: 59%, and social media: 10%). The remaining 25% reported that they would not like to make connection outside of the hospital. When we asked, "Would you like to communicate with your patients by one of the methods below?" 36% preferred WhatsApp, 27% Facebook and 25% web site/forum of the Rheumatology clinic whereas none preferred Twitter.

There was no significant difference for all questions, when compared according to age ( $<40 \text{ vs} \ge 40 \text{ years}$ ), gender, the daily number of patients seen ( $<30 \text{ vs} \ge 30$ ), academic title or type of clinic (university, government or private).

#### Discussion

This cross-sectional survey done in a tertiary hospital in Turkey revealed that a great majority of the patients with RD owned at least one device to connect to the internet or smartphone and was using at least one social media platform regularly. Facebook and Instagram were the most preferred social media platforms. Despite high numbers of social media use, only less than one-fifth used social media for health-related purposes. While a 3/4th thought that social media was a reliable source of health information, still 90% of the study participants would have preferred to obtain information regarding their disease via face-to-face communication. A vast majority of the patients declared their wish to communicate with their physician outside of the hospital. Similarly, most of the rheumatologists reported that they would like to communicate with their patients outside of the hospital, however, with a lesser percentage compared to patients (75 vs 94%).

Our results were considerably different than what was found in the study by Hausmann JS et al. [3]. In their study in which only adolescents and young adults (AYA) were included, almost all participants had owned one or more devices to connect to the Internet, including smartphones and had used at least one social media site within the prior month [3]. Facebook, Twitter, and blog use were similarly prevalent among both genders, while females intended towards Instagram and Pinterest. Privacy was the most important factor determining which platform to use among AYA. While about half of the AYA had posted about their health on social media [3], only a quarter among AYA considered social media as a source of useful health information. Moreover, about a third among AYA was not interested in communicating with their primary care providers with phone, email or any of the social media platforms [3]. This was significantly higher when compared to our study, in which only 6% would not prefer to be in touch with their physicians outside of the clinic. It seems rather apparent that compared to adults most AYA would like to maintain their privacy on social media regarding their health as was previously shown in several studies [3-6].

In our study, Facebook was the most preferred social media followed by Instagram and Twitter among patients with RD similar to that seen in the general population [7–9]. Facebook users were distributed well according to the age, gender, and educational level, whereas Instagram and Twitter were more popular among higher educated patients. Female patients seemed less likely to use Twitter. WhatsApp seemed to be the most preferred communication method for both patients and physicians.

As mentioned earlier, preferred social medial platforms and the extent of their use are determined by social, economic, religious, political, cultural and ethnic factors [4]. A comprehensive review unveiled significant disparities around the world with regard to communication means [10]. The authors observed that the use of social media platforms in Central Asia and neighboring regions is limited [10]. The social media platforms that are commonly used all over the world are barely recognized in this region [10]. Hence, the global connectivity and contribution to the scientific field are significantly hampered [10].

Despite many online and innovative options, still, many patients in our study favored face-to-face communication for obtaining health related information when compared with alternative methods including telemedicine [11, 12]. It has to be noted that our study was done before the pandemic. One systematic review, published in 2000, found little evidence of clinical benefit in patient care using telecommunication technologies [12]. Moreover, the systematic review provided variable and inconclusive results for psychological outcomes of these technologies [12]. With the outbreak of the COVID-19 pandemic, telemedicine was demonstrated to be feasible, acceptable, and effective [13]. Additionally, it allowed significant reduction in health care costs [13]. Telemedicine services have been also used effectively in the evaluation and management of rheumatic diseases in the pandemic [14–18]. Findings of a conjoint survey assessing both patients' and physicians' perspectives on digitalization in rheumatology during the pandemic indicated that both parties believed that digital health applications were useful in the management of RD and felt confident in their own usage [18]. The study suggested that the pandemic introduced a permanent paradigm shift in the management of patients with RD [18]. In line with that, a recent study revealed that 61% patients would prefer to be examined by a doctor in tele-medicine even after the pandemic [16]. Therefore, whether our results still hold true after the pandemic should be re-evaluated with further studies.

Considerable portion of the rheumatologists in the current study defined social media as a useful source of information for patients. However, they were not so keen to use social media as a communication method as one fourth did not wish to communicate with their patients outside of the clinic. Surveys revealed that most of the young rheumatologists (ages between 30 and 39) from several countries were active social media users and were using social media for professional purposes [19, 20]. However, we could not find any study that reports rheumatologists' preferences about patient-physician communication on social media. The relatively high rate of unwillingness for communication observed among the rheumatologists in our study may be associated with the high daily burden of patient care in Turkey.

WhatsApp seemed to be preferred online application method for both patients and physicians for communication. This can be due to the widespread use of WhatsApp, which is the most common mobile application in Turkey [21]. Moreover, it has an advantage of better preserving privacy compared to other social media platforms.

Patients' knowledge about their disease and better patient-physician communication can improve patient's treatment adherence and eventually the clinical outcome [22, 23]. Social media and mobile communication applications can be important instruments for effective education and communications for patients as well as physicians [24, 25]. Combining social media platforms and digital health technologies may have added benefit on communication between patients and health providers, monitoring disease activity, disease management and education [26]. These tools can be also used to make public announcements or to recruit patients for clinical studies. It has to be noted that patients' preferences should be well recognized because of the variability of social media use regarding age, gender, or education [27]. Furthermore, for quite a while, social media has become a vigorous tool in guiding recognition and credibility in the medical publishing fields [28–30]. This has especially accelerated with the pandemic [30]. It has been observed that various social media channels are increasingly used by scholars to comment on articles [28–30]. All these comments are followed and listed by Altmetrics which is basically a metric system [28–30]. The Altmetrics, together with conventional citations, promote publications thus may have a role in improving academic development [28–30].

Our study has some strengths. We performed a face-toface questionnaire method, which provides better and reliable information about patients who don't use social media. By performing a similar survey at the same time interval to rheumatologists, we could analyze the gaps of communication between the two interdependent populations.

Our study has limitations. Geography limited nature of our survey was the major limitation because there can be important variability due to economic, religious, political, cultural, and ethnic factor differences between countries [7]. Our study was done before the Covid-19 pandemic era, and we could not re-assess our survey during the pandemic. Habits, opinions, and preferences are subject to change with time and especially during pandemics, disasters, and war times. There are other limitations. We included only patients who could be able to come to the clinic and our patient population included mostly females and residents of Istanbul. Patients with more severe illness could have been omitted. All these factors may affect the generalization of the results. We did not include Snapchat and YouTube in the questionnaire, which are common platforms worldwide. We did not validate and test reliability of the questionnaire. A sample size calculation was not performed either. The number of rheumatologists studied was smaller compared to that of the patients. Finally, this was a pilot survey; it can be followed by larger and properly validated online surveys.

# Conclusions

The majority of the patients seem to use a social media platform regularly, however, health-related posts were scarce. We found that most patients were in need of communication with their care providers outside of the hospital. The use of social media and mobile communication applications are important instruments for effective education and communication; thus, their access should be promoted. Accordingly, patient management strategies may need to be reviewed and tailored. **Acknowledgements** Thanks to all patients and rheumatologists who attended the study.

Author contributions ME, substantially contributed to the conception, design of the work; the acquisition, analysis, and interpretation of data for the work drafting the work; approved the version to be published, agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. OA, substantially contributed to the acquisition of data for the work; approved the version to be published, agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. ES, substantially contributed to the conception, design of the work; drafting the work; approved the version to be published, agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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#### Declarations

**Conflict of interest** Mustafa Erdogan, Okan Aydin, and Emire Seyahi declare that they have no conflict of interest.

Ethical approval The questionnaire and methodology for this study was approved by the Human Research Ethics committee of Cerrahpasa School of Medicine of University Istanbul-Cerrahpasa (Date-No:03/05/2017 -166578). The survey was voluntary. Participants were not obliged to respond all questions and they were free to leave it any time they wanted. We certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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