



The impact of social media and online communities of practice in rheumatology

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Abstract

The COVID-19 pandemic changed healthcare practices and social media played a significant role in those changes. While social media and online practice communities allow collaboration and engagement, education and knowledge dissemination, research and publication, promotion, and the potential for improved clinical care, their use also involves perils and pitfalls. The literature suggests that rheumatologists use innovative social media platforms for both professional and social purposes. Similarly, many patients with rheumatic disease use social media for education and communication. This review outlined the background of social media platforms, the reasons for their use, and associated risks. This review further discussed the need to better understand the benefits of social media and online communities as well as the potential negative effects that could impact the practice of rheumatology.

Keywords

Social media, virtual communities of practice, rheumatology, COVID-19, ethico-legal, free open-access medical education

Introduction

Social media usage has grown rapidly, with over five billion users worldwide as of 2024 [1]. Social media allows content to be rapidly disseminated, making it a vital tool for both keeping the scholarly environment up-to-date and enhancing professional development [2]. Social media and online communities may also improve health-related communication [3], with virtual communities of practice creating a forum for both knowledge exchange and professional interaction among healthcare providers [3, 4]. In fact, specialists in several disciplines use social media for these reasons [2].

In rheumatology, regarding professional purposes, social media is often used for continuing professional development, networking, publicity around rheumatology societies, and patient education [5]. The number of studies with the keywords “social media” and “rheumatology” is increasing; in 2012, two



studies were published with these keywords, but that rose to 10 in 2019 [2]. Among rheumatology fellows attending the 2014 American College of Rheumatology annual meeting, one survey showed that 40.9% of respondents had used social media for professional purposes [6]. Nikiphorou et al. [7] examined the perceptions of, barriers to, and patterns of social media usage for rheumatology fellows and basic scientists. In their study ($n = 233$), 83% of the participants stated that they used at least one form of social media for six hours per week on average.

During the COVID-19 pandemic, while social distancing measures were in place, social media platforms also provided a means for clinicians to connect and establish virtual communities [8]. Moreover, during the pandemic, social media emerged as both a mode of remote patient monitoring and a tool for conducting research [9]. We conducted a survey of 33 currently utilized social media or virtual communities of practice as they related to the practice of rheumatology ($n = 33$). In the same survey, 21.21% of respondents stated that COVID-19 had affected their use of social media and online communities of practice. Moreover, 72.73% of them agreed on finding benefits when using social media and virtual communities of practice (Figure 1).

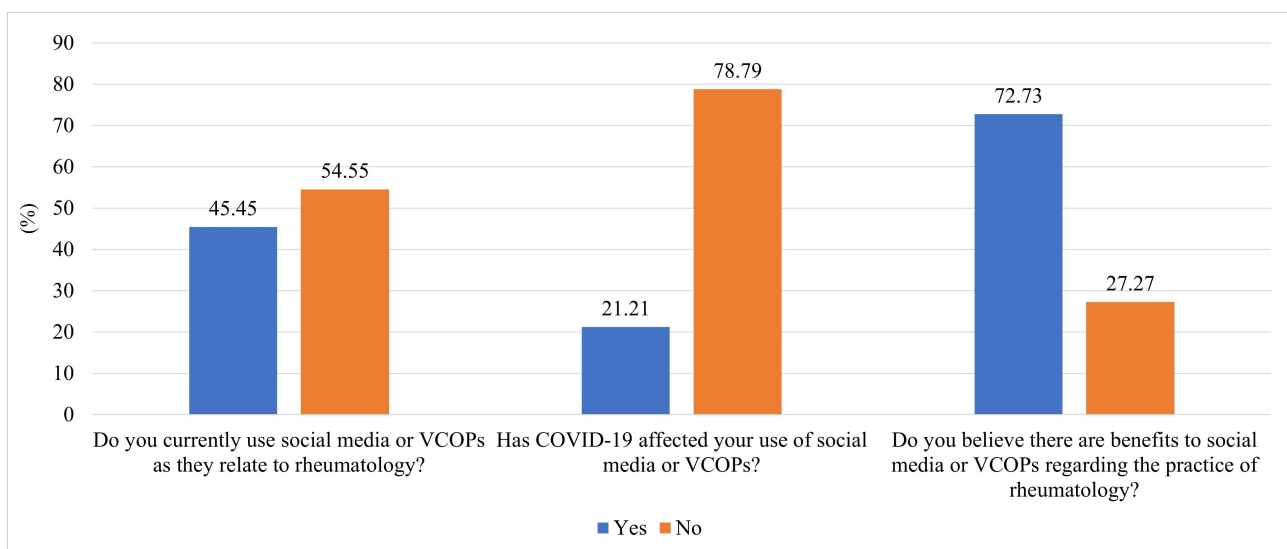


Figure 1. Social media and rheumatology. VCOPs: virtual communities of practice

In the post-pandemic world, social media retains its importance to educators, scientists, government organizations, and the public. However, it is not clear whether the usefulness of these communication platforms will persist [10]. Many healthcare providers in rheumatology clearly engage in some form of social media use, and the overall usage pattern changed during the COVID-19 pandemic [9].

How do healthcare providers define social media?

The definition of social media is constantly evolving and there is not yet an agreed-upon academic definition. Some definitions suggest that social media involves digital technologies that are based on user content or interaction [11, 12]. Certain social media can also be defined by channel characteristics, that is, looking at the directionality of the message. Others have defined social media in terms of the mode of interaction, such as Facebook and Twitter [11]. Carr and Hayes [11] aimed to develop a definition of social media based on current technology, hoping that the definition would remain valid in 2035. They proposed the following: social media are internet-based channels that allow users to opportunistically interact and selectively self-present, either in real-time or asynchronously, with both broad and narrow audiences who derive value from user-generated content and the perception of interaction with others [11].

This uncertainty regarding the definition of social media persists among healthcare professionals [13]. Additionally, many healthcare providers do not recognize the differences between online communities and social networking sites. It is important to note that online communities are typically established (and maintained) by individuals who share similar goals; however, these individuals may not know each other

outside of the online community. In contrast, social media sites are built around existing connections, relationships, and referrals [14].

For example, a 2020 study of USA rheumatologists used semi-structured interviews to demonstrate that each of the 13 participants defined or described social media and virtual communities of practice differently. Interaction was the most common feature mentioned during the interviews. In total, 8 of the 13 participants defined social media as a platform—that is, a medium for communication and connectivity. The participants described their interactions and usage in terms of social, educational, and professional purposes [3]. Given this, the lack of a clear definition has several implications for healthcare practitioners.

Social media use in healthcare and rheumatology

We conducted a 2023 survey of USA rheumatologists and found that 25% of the respondents stated that social media and virtual communities have changed the way in which they practice. Over a period of 36 months in 2018, observational data from the Rheumatology Journal Club on Twitter (#RheumJC) showed that 646 individuals from 36 countries participated in 23 online journal club sessions. In total, 86% of the individuals reported they were either “satisfied” or “very satisfied” with their overall experience [15]. Twitter is one of the most common social media platforms used by healthcare providers for educational purposes. Over 18,000 tweets have been shared over the last several years using the hashtag “#Rheumtwitter” to discuss various topics in the field of rheumatology. Since Twitter is international, practitioners can access vast amounts of content and learning, as well as varying perspectives on healthcare. Additionally, the medical education derived from Twitter allows rheumatologists who practice in rural areas or developing countries to access the most current information [5].

Healthcare providers are also engaged in clinician-focused social media sites such as Doximity and Sermo [16]. Furthermore, other social media platforms have also been used to exchange clinical information. These include, but are not limited to, Facebook, LinkedIn, WhatsApp, Instagram, and YouTube [8, 16]. Facebook is often used to teach medical students in closed groups. WhatsApp allows for group chats to facilitate educational discussions. Instagram provides a means to educate clinicians (or medical students) through shared images. Finally, videos on YouTube can improve understanding of physical examinations and complex medical procedures [8].

Amon et al. [17] conducted a systematic review of publications examining clinicians’ use of Instagram, an image-based platform. This study yielded 51 articles that demonstrate how Instagram was used among healthcare providers, showing that healthcare professionals may use Instagram to learn about healthcare topics that do not necessarily fall within their area of expertise. Six types of image content were identified: (a) educational, (b) promotional, (c) patient experience, (d) personal, (e) emotion-based, and (f) other. To measure post engagement, the researchers looked at (a) likes and comments, (b) the use of hashtags, and (c) the number of followers. In addition, the researchers identified certain risks associated with this platform, including (a) a lack of reported credentials, (b) edited images, (c) content quality, and (d) patient and client confidentiality issues. Healthcare providers clearly use Instagram for several reasons [17].

Currently, healthcare providers use social media platforms to share information, connect with peers, provide patient education, and receive up-to-date clinical information [2]. A 2021 survey conducted by the e-Communication Committee and Scientific Initiatives Committee examined the use of social media among the healthcare community in a professional setting. The 19-question survey garnered 285 participants across 35 countries. Specifically, the majority (42.7%) stated that they used social media passively, whereas 38.3% and 19.0% used social media to share information on a non-daily and daily basis, respectively. Of note, LinkedIn was the most commonly used platform (60.8%). One survey found several advantages in the use of social media: updates on recent publications (66.0%), networking (48.5%), and access to rare and interesting cases (47.9%) [18].

Reasons for the use of social media and online communities of practice among rheumatologists and other healthcare providers

The following section reviews several key reasons why rheumatologists (and other healthcare professionals) use social media. Although there are many factors that contribute to usage, the literature most frequently mentions collaboration, education, knowledge dissemination, research, and clinical practice [19–21].

Collaboration and engagement

Social media is often used in healthcare as a means of collaboration [2, 19]. Digital crowdsourcing was already a common practice prior to the COVID-19 pandemic; during the pandemic, it allowed for collaboration among researchers and the ability to produce scientific research at a more rapid pace. Crowdsourcing allows practitioners to share and discuss information and collaborate on projects with colleagues around the world [21]. One of the most significant collaborative efforts that utilized social media was the establishment of the COVID-19 Global Rheumatology Alliance (GRA). During the COVID-19 pandemic, the organization collected, analyzed, and disseminated data regarding how COVID-19 affected patients with rheumatic diseases. This crowdsourcing began with a single tweet asking the registry to collect data on patient outcomes during the pandemic. Within a few days, over 300 rheumatologists and scientists began to exchange information to establish a registry for collecting and reporting data. As of 2020, more than 30,500 cases had been submitted to the GRA registry. This process resulted in more than 30 original publications [20, 22].

Online communities of practice have also proven to be a means of collaborating and engaging with other rheumatologists who share similar concerns or interests. For example, news stories, journal articles, case studies, and specific topics are shared and discussed in several online rheumatology communities on platforms such as Facebook, Instagram, and YouTube. Moreover, rheumatology journal clubs have been established via social media to discuss trending articles and create interactive experiences [5].

Education and knowledge dissemination

Technology-based learning provides opportunities to distribute high-quality medical education [19]. There has been a shift in learning styles among clinicians and students from traditional didactic learning to interactive online educational content. Formal medical education, such as Grand Rounds, medical conferences, and educational lectures, was disrupted by the COVID-19 pandemic; thus, social media platforms have become an important means of disseminating information and providing continuing medical education for healthcare providers [8].

Katz and Nandi [8] conducted a literature review to better understand the reasons, applications, challenges, and disadvantages of social media-based medical education following the COVID-19 pandemic. They found that Facebook, Twitter, Instagram, YouTube, WhatsApp, and podcasts were the most frequently used social media platforms. As previously stated, each platform offers different tools; thus, these specific parameters allow each site to be used on an individualized basis depending on the specific type of medical education needed.

Free open-access medical education (FOAMed) refers to online medical education tools and resources [23]. FOAMed uses social media for information sharing and online discussions [24], and these resources are widely used among medical students [25]. The FOAMed movement was conceived in 2010 and has continued to evolve; individuals are able to publish blogs and podcasts and receive instant feedback via social media platforms. One such educational activity, “Rheums with a New View,” was developed by My Virtual Clinical Community of Practice and Med Mentors, LLC. The activity took place online as a virtual community in 2021 and 2022 to educate rheumatologists and other healthcare providers caring for patients with rheumatic diseases. This activity was sponsored by the University of Louisville CME & CPD and supported by educational grants from Bristol-Myers Squibb, Gilead, Lilly, Myriad Genetics, and Sanofi. “Rheums with a New View” consisted of four educational modules as well as an opportunity for discussion

with faculty and colleagues. The content focused on measuring disease activity, telereumatology, patient-reported outcomes, and the utilization of a multidisciplinary approach to managing patients. A total of 508 global learners participated in the activity, of which the qualitative outcomes, as stated by the participants, are presented in the following:

- (1) The importance of evaluating the whole patient.
- (2) An increased interest in offering more telehealth.
- (3) The significance of implementing evidence-based care and clinical guidelines.
- (4) Improvement in understanding of assessments when caring for patients with rheumatoid arthritis (RA).

Social media platforms for education also offer patients access to educational content as well as the ability to host online communities to share resources. In the USA, many patients with rheumatic diseases engage with social media to share stories, education, and new information. Further, clinicians can also create platforms for patient education and promote connectivity [21]. In summary, social media has become a vital part of interactive education and knowledge dissemination [26].

Research and publication promotion

Social media platforms play a significant role in rheumatological research. Social media allows for collaboration, data collection, circulation of findings, and interactive discussions. For example, organic tweets allow for ever-evolving topics of interest, thereby providing discussions that can publicize and circulate rheumatology research. As another example, “live tweeting” rheumatology conferences were popular before the pandemic; it is a way to promote research and generate discussion [21].

In March 2020, the COVID-19 GRA sought to address issues concerning outcomes for rheumatology patients and potential patients regarding COVID-19. For example, the questions raised were whether COVID-19 could worsen rheumatic diseases and since some of the therapies used to treat COVID-19 were also used for rheumatic diseases, whether those treatments would become difficult for current patients to access. To address these concerns, the COVID-19 GRA collaborated with other patient organizations to develop the Patient Experience Survey. The survey collected individual data from patients and caregivers to examine how COVID-19 affected their ability to manage rheumatic diseases. In April 2020, the Patient Experience Survey received 9,541 responses, with the most common diagnoses being rheumatoid arthritis (25%) and systemic lupus erythematosus (20%) [27]. In total, 4.9% of patients ($n = 465$) had been diagnosed with COVID-19 (based on symptoms or positive laboratory tests). This survey shows how social media can support collaboration and data collection when difficult issues must be addressed quickly [27].

One study examined the acceptance, perception, and willingness to participate in the development of social media-based education. The researchers found that 74% of the participants ($n = 102$) supported the use of social media platforms for article promotion, with the use of visual abstracts ranking the highest (81%) [28]. Visual abstracts present the key points of research articles in an accessible way [29]. Research suggests that graphical and visual abstracts tend to reach a larger audience than text-based ones (or links to the original article), thereby increasing the number of impressions, retweets, and article views [30].

The concept of omnichannel planning, an individualized and integrated means of accessing information among a wide array of interconnected channels, can also be seen within the medical community. For research content, communication must be coordinated beyond traditional print publications. The literature suggested that many researchers discuss publications using their personal social media accounts [16].

Social media has also become an avenue for enrolling patients in research studies. For example, social media can be extremely useful when studying rare diseases as obtaining a considerable sample size may be challenging in a clinical setting [6]. In summary, social media platforms have affected academic healthcare research through collaboration, data collection, patient recruitment, and the dissemination of research findings [16].

An international study conducted by Hmamouchi et al. [31] examined best practices when recruiting patients with rheumatic and musculoskeletal diseases for online surveys. This study yielded 1,595 patients from 19 Arab countries. A total of 711 (44.7%) patients were recruited through anonymous social media platforms (Facebook, Instagram, Twitter, and Snapchat); 647 (40.7%) through their doctor, either directly or via WhatsApp messages from the doctor's office; and 233 (14.6%) through patient associations; only 15 patients (less than 1%) were recruited through email. The researchers found that the most effective e-recruitment method was personalized WhatsApp reminders. This study also underscored the effectiveness of social media as a means of patient recruitment among younger patients. These findings are in line with those of the current research, suggesting the important role of social media in recruiting patients for research [31].

Clinical practice

Social media has emerged as a technological platform that can affect patient care and care delivery. Using the Technology Acceptance Model (TAM), one study sought to better understand how rheumatologists described the impact of social media on care delivery. The TAM assesses perceived usefulness, ease of use, intent to use, and actual use. In one study that used semi-structured interviews ($n = 13$), participants indicated that social media and online communities of practice had benefits in terms of patient care and staying up-to-date with new information [3]. This study also utilized the TAM2 scale developed by Venkatesh and Davis [32] to examine the perceived usefulness and intent to use related to social influence and cognitive instrumental processes on a seven-point Likert scale (Table 1) [3]. A total of 23 participants were surveyed, and 86.26% were men. Participants' ages range from 25 to over 65 years. The majority of the participants are in a private practice setting (63.64%), 27.27% are in an academic setting, and 9.09% are in a hospital setting.

Table 1. TAM2 scale survey results ($n = 23$)

Domain	Mean (standard deviation)
Intention to use	4.22 (2.22)
Perceived usefulness	4.09 (1.63)
Perceived ease of use	4.55 (1.52)
Subjective norm	4.30 (1.50)
Voluntariness	5.71 (1.88)
Image	3.69 (1.79)
Job relevance	4.08 (1.99)
Output quality	3.95 (1.67)
Result demonstrability	4.67 (1.57)

TAM2: Technology Acceptance Model 2

In summary, this study found that social media enables connectivity with colleagues, thus facilitating knowledge exchange and professional interactions. Several participants believed that "ease of use" was a major determinant when considering how social media could affect care delivery [3].

According to Garcia Vivar et al. [33], many rheumatologists were not confident in the use of telemedicine before the COVID-19 pandemic, because they did not have access to technology or there was no reimbursement or training. The researchers conducted a study on biologic therapy among a controlled group of patients with axial spondylarthritis to assess the acceptance of asynchronous telehealth follow-up using the WhatsApp platform. This study included 60 patients (83.3% male). Researchers found that there was a preference for telehealth among those with higher education levels and those who were working (86% vs. 70%), but the difference was not statistically significant. Researchers did not find any correlation with gender, age, or disease characteristics. In summary, although some patients were hesitant, this study demonstrated that asynchronous telehealth appears encouraging. However, further research is warranted [33].

Another study by Venuturupalli et al. [34] examined patient-reported health data from Twitter to identify diverse patients with lupus and examined their views regarding their symptoms and treatment. Between September 1, 2017 and October 31, 2018, the authors located 47,715 public lupus-related tweets from 8,446 users. After analyzing the findings, the authors noted that patients with lupus on Twitter were diverse in both race and gender; thus, disease symptoms and treatment varied significantly. This study demonstrated the role of social media surveillance in providing clinically relevant data from the perspective of patients. Clinicians should use this opportunity to apply these data to a patient-centered care approach, particularly when managing underrepresented patient groups [34].

Barahona-Correa et al. [35] explored the reliability, patient engagement, comprehensiveness, and information quality of videos uploaded to YouTube for Spanish-speaking patients with rheumatoid arthritis. Of the 200 videos examined, the authors deemed 67% to be useful. This was based on the number of views, time spent online, and duration. Notably, engagement was similar for both useful and misleading videos. The authors concluded that while most YouTube videos for Spanish-speaking patients were useful, the development of high-quality multimedia with academic involvement would be beneficial [35].

The quality of YouTube videos on autoinflammatory diseases (AID) was examined in an analysis conducted by Sasse et al. [36]. The YouTube search assessed AID-related videos for quality and usefulness from both clinician and patient perspectives. The examination criteria included video duration, number of views, likes and dislikes, comments, and upload sources. Of the 140 videos screened, 105 met the inclusion criteria for further analysis. Based on the Global Quality Scale, the researchers found that most patient videos were low quality (64.8%), and 27.6% and 7.6% were intermediate and high quality, respectively. These findings were somewhat similar to the clinician videos, with 54.3%, 23.8%, and 21.9% being low, intermediate, and high quality, respectively. The authors concluded that only a small fraction of AID-related patient videos were considered useful; thus, high-quality educational videos are needed for this patient population [37].

Flurie et al. [37] conducted a study looking at patient-reported outcomes from communication via social media among patients with gout. This study explored the impact of different management strategies on the emotional state of these patients. Management was classified as either reactive or proactive. Negative words were more predominant among reactive management statements (59%) than proactive ones (44%). The word “fear” occurred more frequently in reactive statements, while “trust” prevailed among proactive statements. The authors concluded that exploring gout-related conversations on social media might provide a better understanding of the clinical management and emotional states of patients suffering from gout [37].

Patients use social media to search for medical information and connect with like-minded people to share their experiences and stories. Patients can form their own social media groups, which can unfortunately lead to misinformation and non-evidence-based treatment options [38]. Clinicians should recognize the positive and negative aspects of patients’ social media use to develop a shared decision-making approach to care.

Challenges and barriers to the use of social media

Research suggests that healthcare providers’ adoption of social media presents certain challenges. Kwan et al. [39] surveyed members of the Assessment of Spondyloarthritis International Society to examine their use of social media. The 24-question survey was sent to all 198 members. In total, 53 members stated that they did not use social media for work-related matters for several reasons, including concerns about privacy, not suited to their needs, lack of knowledge about how to use social media, lack of interest, concerns regarding the validity of the content posted, time constraints, safety concerns, and potentially negative effects on reputation [39].

We conducted a 2023 survey of USA rheumatologists, and found that 68.75% of respondents ($n = 32$) indicated that they experienced challenges with using social media, including volume overload, validity of

content or misinformation, privacy, time, legal issues, and professionalism. While social media has many benefits, healthcare providers must recognize the challenges and barriers that can arise from its use. Social media use's harmful effects are described in the following subsections.

Misinformation, disinformation, and the “echo chamber effect”

In the context of social media, misinformation refers to the sharing of information without knowing it is “fake” [5]. Content on social media is often posted hastily, without proper validation. Additionally, plagiarism occurs in many circumstances. Fact-checking plays an important role in determining the validity of social media content and identifying misinformation. However, because posts on social media occur rapidly, it is almost impossible to attend to every piece of health misinformation posted [26]. In a systematic review conducted by Gabarron et al. [40], the researchers found that social media had a substantial effect on the dissemination of both accurate information and misinformation on COVID-19 (misinformation accounted for 0.2–28.8% of posts). The studies included in the review examined the overall effects of misinformation and found that it led to fear and panic. According to the literature, false statements posted on social media during the pandemic led to avoidable hospitalizations and deaths around the world [40]. Misinformation refers to posting content on social media while knowing that the information is not factual, which could, in turn, lead to fear and mistrust [41].

The “echo chamber effect” concerns the idea of biased information and relates to users' social media content being personalized to match their viewpoints and eliminate opposing perspectives [5]. Individuals often look for information congruent with their beliefs; therefore, seeking like-minded individuals can lead to a confirmation bias [35]. The echo chamber effect was prevalent during the pandemic among anti-vaccine activists who shared emotional distress and conspiracy theories [5].

Privacy and confidentiality

Rheumatologists must recognize issues concerning privacy and confidentiality regarding social media use. Further, identifiable patient information must not be disclosed on social media [5]. This is essential for vulnerable populations, such as pediatric patients and members of marginalized groups. In fact, the release of identifying information can lead to discrimination and/or stigmatization [6]. Privacy is also important when recruiting patients for research through social media. Most social media platforms require individuals to provide personal information to register and participate. This could lead to unforeseen research challenges. Although research ethics boards mandate the removal of identifiable patient information, anonymization of these data may not be satisfactory when attempting to safeguard the privacy of social media networks [42, 43].

Ethico-legal matters

Ethical considerations are crucial in the use of social media. An ethical framework, informed consent practices, and appropriate data management strategies are necessary [44]. While overseeing media and proposing recommendations for social media could conflict with the USA's free speech laws, several large social media sites have established policies to regulate confusing and/or incorrect information [40].

Social media has created a forum through which clinicians and patients can connect online. It is imperative that both parties recognize the clinician-patient partnership as a professional rather than a social relationship [5]. In the USA, for example, the General Medical Council and the British Medical Association have set forth guidelines for standard expectations for physicians when communicating via social media [45]. That study examined perceptions of doctors' Twitter activities from doctors, patients, the public, and other healthcare professionals. The researchers examined issues surrounding mistrust using univariate and multivariate analyses. The survey was conducted with 726 participants. In the univariate analysis, a greater number of non-doctors conveyed that they had observed unprofessional behavior and potential violations of patient confidentiality compared to doctors. Moreover, the non-doctor cohort believed that employers and regulators should oversee physicians' Twitter accounts [45].

Reputation

Around the world, social media affords patients the opportunity to search for and review healthcare providers' and facilities' reputations. Providers must recognize the impact of "bad reviews" on social media, as these reviews relate to their overall status [46]. Further, cyberbullying can lead to defamation. Clinicians must understand that offensive posts made previously (even while in school) can always re-emerge, and the resulting conflict can lead to an overall mistrust in the medical profession. Therefore, healthcare providers should respect their colleagues and avoid online harassment [5].

Conclusions

Social media clearly plays a significant role in the current healthcare landscape. Although there are many benefits to its use, such as collaboration, medical education, knowledge dissemination, research, and clinical practice, healthcare providers must be aware of the challenges and pitfalls associated with social media. These challenges include, but are not limited to, misinformation, disinformation, privacy, and ethico-legal matters. If social media policies exist in their practices or institutions, providers should be aware of them [47]. Moreover, clinicians should recognize how patients' social media use can affect their medical decision-making [38]. The literature suggested that more research on the benefits and risks of social media is warranted. During this post-pandemic era, it is important to recognize the role of telehealth, patient-reported outcomes, and the potential for patient education and care as it relates to social media [48].

Abbreviations

AID: autoinflammatory diseases

FOAMed: free open-access medical education

GRA: Global Rheumatology Alliance

TAM: Technology Acceptance Model

Declarations

Author contributions

JLS: Conceptualization, Investigation, Writing—original draft, Writing—review & editing. AFW: Conceptualization, Investigation, Writing—original draft, Writing—review & editing, Validation. Both authors read and approved the submitted version.

Conflicts of interest

Both authors declare that they have no conflicts of interest.

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Consent to participate

Not applicable.

Consent to publication

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Availability of data and materials

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