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DE GRUYTER

Social media and the patient – on education and empowerment

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Abstract

Social media has unprecedentedly impacted the world, and this includes patients and physicians alike. This article provides a glimpse of the pros and cons of social media to both parties, and how, despite its pitfalls, rheumatologists can put its use in daily practice to help bridge the gap between, and among, rheumatologists and patients to ultimately improve patient outcomes.

Keywords

social media • patient education • patient empowerment

As a rheumatologist from the Philippines, dubbed the "social media capital of the world,"[1] I found writing this piece both timely and relevant. With our roughly 112 million population[2] and merely 200 actively practicing rheumatologists in the country, how can we help reach our patients better to bridge the geographic and manpower gap? Everyone, let us all welcome social media with a round of likes and emoticons. What follows include both personal takes and published literature on the impact and importance of social media for patients, especially during this time of pandemic and beyond, as well as the drawbacks and challenges to both patient and health-care provider.

Let me share the results from an informal survey I posted on my Instagram stories (where posts only last for 24 h). My first question was, "Do you check your phone first thing in the morning upon waking up?" And within 24 h, over 6000 people answered, and 94% of them said "yes." Then I asked, "Aside from checking the time, what do you check on your phone first?" More than half (54%) ticked "messages," 39% said "social media," and the rest checked other things.

Next, I asked my followers how many social media platforms they had. Only 4% said they had only one social media platform, while the rest had two or more, with 25% of the responders having four or more platforms. This shows us the many avenues we can use to reach patients and the likelihood to find one we are most comfortable with. To my question "How many hours do you browse through social media on a regular day, on the average?," only 8% answered less than an hour, while up to a third spent more than 5 h of their day on social media. To most, this is already a third of their waking hours.

Lastly, I asked, "Do you like seeing patient education or patient empowerment posts on social media?" A whopping 96% said, "yes." And if this overwhelming affirmative is not yet enough to convince you to start reaching out to people regarding rheumatology, this might – according to Statista, by the year 2025, there would be around 4.4 billion people using social media around the globe.[3]

The Good

There are numerous studies that elaborate on the impact of social media in patient education across different specialties in medicine. Patients have improved outcomes if their knowledge about their diseases is better, due to enhanced self-care and compliance to their treatments. Self-management programs that are able to integrate social media help reduce the necessity of the face-to-face encounters for patients to learn about their conditions from their health-care providers.[4] Patients are able to empower themselves, and therefore become more engaged in their journey to better health.[5]

Specifically, in rheumatology, social media is now considered not just by patients, but also by new generations of students and physicians as both learning and communication tools. An

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article about digital health as a new dimension in rheumatology patient care discussed use of technology to facilitate care for patients by using mobile applications (Apps), videos, social media, or messenger platforms, or a combination of these, which enable easier health-care delivery and help overcome barriers including time and distance.[6] For example, there are online chronic pain management programs, which significantly improve pain severity and perceived disability when complemented with standard management. There are also digital tools that help encourage increase in physical activity monitoring, for example, the number of steps per day, and these support the advice given by rheumatologists to remain physically active as a means of improving inflammatory rheumatic diseases.

Social media can also offer online social support, which removes barriers of space. Face-to-face support groups have been found to be positively correlated with improved health outcomes, and online social support is also as good as them. Doctors can facilitate these social media platforms for their own patients and even for their own countries.[7]

With this in mind, and as we continue to progress into a more technologically advanced millennium, patients are increasingly seeking out health information online. Hosting a social media page gives physicians the power to control and manage the information that their patients access.[8] Essentially, we can curate what patients will read online. I send my own patients links to certain social media posts from institutions and doctors because I trust these sources to be helpful for making them understand their condition more.

The Bad

Drawbacks are expected. One study evaluated the content, reliability, and quality of the most viewed English-language YouTube videos on spondyloarthritis (SpA) and found that majority of these have useful information on SpA and are important educational sources to patients when these are uploaded by health-care professionals. However, majority of the misleading videos were from nonphysicians, usually containing wrong clinical features and unproven alternative treatments.[9]

Aside from being a vehicle for inaccurate information and promotion of unhealthy, and even dangerous, methods by self-serving individuals or companies, social media makes way for influencers trusted by many to be exploited by marketers, who then use consumer-created content to influence public perceptions.[10] "I use this and so should you." Intertwined with this are the online platforms for social media, or social networking sites, wherein big data analytic techniques are commonly exploited.[11] From pursual of personal data using geofencing or browser fingerprinting to influencing decisions to purchase or to simply believe inaccurate information, social media platforms have given way to complications including exposure of private data and an infodemic. In fact, Cuan-Baltazar *et al*.'s[10] analysis showed that official advisories about the current pandemic have been drowned out by inaccurate and potentially harmful information from rampant poor-quality online sources that platform algorithms only heighten. We are living in a time when "fear of missing out" (FOMO) is at its peak, the pandemic has stuck many, and health and wellness is a booming industry that is being capitalized well.

For physicians with social media that allows direct messaging, it is inevitable that some members of the general public will "direct message" (DM) serious medical questions to doctors. A single reply to a follower's medical question may be taken out of context and disseminated to many other individuals for whom the advice is not appropriate. Therefore, it is important for physicians to avoid offering individualized medical advice on public fora.[9]

Doctors on social media are uniquely positioned because of the perceived knowledge. Hence, vulnerable individuals may be exploited unintentionally if doctors recommend specific brands of products or are marketing their own brand. Deliberate conflicts of interest, self-promotion, and financial gain are potential defects in the system, and doctors' posts may be used without permission to falsely endorse products which either do not work or produce outright harm. These false and unverified claims can influence our daily decisions and can have negative effects on the health of the public.

The Not-So-Ugly: Challenges

What makes social media so successful? Aside from the volume of users, important elements inevitably engrained with the rampant include networking and perceived truth. Patients look online for information; but more so, they believe and trust this information to be accurate and true, regardless of the source. Inasmuch as there are only 24 h in a day, there is usually no time nor the desire to fact-check data that people read online. Hashtag #fakenews.

For patients, there is the ever-present digital divide, a measure of disparity in the level of access to technology, depending on the socioeconomic levels or other demographic categories. People who are living in poverty, technologically challenged individuals, or less-advanced communities may have little or no access to computers and the internet.[5] "Cyberchondria,"[12] or exacerbated anxiety over knowing about the experiences of patients who have the same disease, is a rising concern and leads to stress and an increase in anxiety. The adage "What you don't know won't hurt you" is becoming more and more questionable. It is, therefore, imperative for doctors to direct patients to specific and curated online resources to keep them from being victimized by the algorithm of social media platforms pushing for selective data capitalizing on financial gains. It has also become our responsibility to help put out accurate online information for layman consumption and diversify methods for health education.

For physicians, professionalism may be questioned. Our digital reputation now precedes us, our patients may have already looked us up online before seeing us in the clinic. One's online identity is the result of a sustained accumulation of self-produced content, which can be challenging to change overnight. It is important for physicians to protect their own privacy as the pervasive nature of social media is discordant with our boundaries, both personal and professional.

As social media is here to stay, a crucial step into creating and maintaining a safer internet experience for patients and physicians alike is the establishment of regulatory bodies to monitor and gatekeep health-related information and private details readily available online. Alongside is the regular examination and review of the code of ethics by different stakeholders – bloggers, health-care workers, hospitals, and even pharmaceuticals.

Should I Now Leave My Comforts of Privacy and Enter this Daunting World for My Patients?

It depends. People have different comfort levels in the online world, technological quotient, and priorities. If being constantly proactive online leads to a deterioration of one's mental health, then logically, care for self should precede taking care of others.

I started teaching on my Facebook page since September 2017, although I did not create my page; rather, it was created by an exceptionally online-present physician saying there was a need for more rheumatism health content in the Filipino language. After my initial resistance, he turned over the account to me when I was ready to start posting health content. But for my sanity, I disabled direct messaging, I rarely read the comments, and I do not engage when I do read something that is incorrect or outright offensive. I knew my priority, which is to disseminate information, and not to increase my "followers" just for the sake of "growing."

If you think you are ready to start this journey, recommendations for doctors from Wong and Liu[8] include posting your formal qualifications to assert authority and a disclaimer for serious medical issues, should your audience need further attention; use of succinct, educational, original content; citation of sources; and being proactive online and posting regularly. I may not concur with the last because I believe in tuning out and disconnecting regularly to maintain soundness of mind and body, but again, our priorities will dictate our actions. Make sure there is a signed consent form and be mindful of institutional rules in the use of clinical images and patient information before publishing online, whereby its very nature will most likely have infinite presence, even if the post is deleted.

Social media can help bridge the gap between, and among, rheumatologists and patients. Despite its pitfalls, patients are empowered by the information and social support, and physicians can be one step ahead by curating and creating these for them, ultimately improving overall patient outcomes.

Conflict of Interest

The author declares no conflict of interest in this article.

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