

Social media as a tool against eye cancer

Mídias sociais no combate ao câncer ocular

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The constant evolution of technology is changing the way we live. With the advent of highly developed and robust telecommunication networks, we can instantly communicate and send high-definition images and videos across the globe. According to the International Telecommunication Union (ITU), almost 85% of the world's population is covered by a 4G network,⁽¹⁾ and phones have become considerably more affordable. These information and communication technologies can play a significant role in providing cost-effective and high-quality dissemination of health information and medical care. Moreover, the way people search for health information has also changed. Nowadays, three out of four Americans are estimated to have turned to internet sources for medical information, with similar rates among Europeans.⁽²⁻⁴⁾

This environment is particularly fertile for the advance of telemedicine, defined by the World Health Organization (WHO) as “the delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for the diagnosis, treatment, and prevention of disease and injuries, research and evaluation.”⁽⁵⁾ The development of these technologies and their application in telemedicine were already on their way, but the coronavirus disease 2019 (Covid-19) pandemic accelerated the process.

Social media, a form of electronic communication through which users create internet-based communities to share information, is particularly important due to its astounding reach. Facebook, for example, has 2.85 billion active monthly users.⁽⁴⁾ When other platforms such as YouTube, Twitter, Instagram, and TikTok are considered, the number of active users of social media is estimated at 4.2 billion.⁽⁶⁾ These platforms allow health professionals, organizations, and patients to interact easily despite geographical barriers, and are already used as valuable medical education tools. Already in 2012, 60% of the State Health Departments in the United States reported using at least one social media channel: 86.7% had Twitter accounts, 56% had Facebook profiles, and 43% had YouTube channels.⁽⁷⁾ Health institutions mainly use social media for infoveillance, disseminating health information, and combating misinformation, health intervention, and social mobilization. Social media use by health researchers includes facilitating health-related research, professional development, doctor-patient communication, and offline services. Lastly, the public uses social media to seek and share health-related information, exchange social support in online communities, and track and share health status or activities.⁽⁸⁾

Ophthalmology is a primarily visual medical specialty, and it is intrinsically related to technology. That makes it especially suitable for social media, particularly image-based platforms such as Instagram, which 40% of the adult US population uses.⁽⁹⁾ Even large organizations such as the American Academy of Ophthalmology (AAO) have

a presence on the platform (@aaooeye), with 38.1K followers as of May 2022. A study conducted by Huang et al.⁽⁶⁾ analyzed a list of 36 ophthalmology-related hashtags on Instagram. For top-performing posts, the most frequent content format was a photo (82.2%), followed by video (8.8%) and infographic (8.4%). Ophthalmologists (35.8%) were the most common source of ophthalmology-related content, followed by patients (27.1%), optometrists (20.1%), and other organizations (12.7%).

Several other ophthalmology organizations, such as the AAO Ophthalmic News & Education Network (ONE Network®), the Pan-American Association of Ophthalmology (PAAO), and the European Society of Cataract and Refractive Surgery (ESCRS), also adopted e-learning platforms. Ophthalmologists can use available video platforms such as YouTube as a training resource to develop surgical skills. One study showed that self-learning surgical techniques such as descemet membrane endothelial keratoplasty (DMEK) surgery are feasible using YouTube.^(9,10)

Social media has also impacted the industry of scientific publishing, as a tool to disseminate published manuscripts and increase their reach. Journals use their own social media channels to promote articles and authors also share their publications on their own personal profiles. To gauge the online activity surrounding a research article beyond typical metrics, such as impact factor or citation counts, a new score has been created, which is called the Altmetric Attention Score (AAS). In ophthalmology, studies have demonstrated a weak to moderate correlation between the AAS and conventional metrics such as the number of citations and H-index.⁽¹¹⁻¹³⁾ A recent study showed that publications that are promoted on Twitter end up having a higher number of citations than the ones with no tweets.⁽¹⁴⁾ In a study looking into publications from a different specialty (cardiology), Twitter promotion was linked with a 1.12 higher citation rate.⁽¹⁵⁾

Due to the Covid-19 pandemic, educational courses and meetings that were previously in-person transitioned to an online environment using platforms such as Zoom. Between 14th March and 30th, June 2020, 1,030 webinars with links to YouTube or Facebook have taken place.⁽⁹⁾ Congresses and conferences have been hosted virtually due to the pandemic's mandatory social isolation and travel restrictions. Ophthalmologists also use social media messaging apps such as WhatsApp or Facebook Messenger to help communicate with patients after cataract surgery and as a tool to gather data for performing large epidemiological studies.

Until today, few reports have been published on the patterns of social media use by ophthalmologists in a professional context. In 2020, Al-Khersan et al. analyzed the use of social media for professional purposes among Bascom Palmer Eye Institute Alumni.⁽¹⁶⁾ In a sample of 160 subjects, more than 70% used social media for personal use and nearly 40% for professional use. Employment in private practice was positively correlated with the use of social media, and age >40 years old was negatively correlated. Reasons for not using social media were concerns regarding privacy laws, the time commitment needed to maintain a social media profile, or some professionals did not believe that it would positively impact their practice.

Our group pioneered social media initiatives to spread information on ocular diseases, especially eye cancers. The main objective is to provide early diagnosis and proper treatment for every patient with eye cancer in Brazil, the 5th largest country per area. In 2019, there were an estimated 20,445 ophthalmologists for a population of 208,494,900, a ratio of 1 ophthalmologist per 9,224 inhabitants, which is more than the WHO recommendation of 1/17,000. However, roughly 50% of these professionals are concentrated in only 14 cities, leaving a considerable portion of the country's population underserved.⁽¹⁷⁾ Since most ocular cancers are rare, it is our view that it is inefficient and possibly impossible to train and teach all general ophthalmologists in the country the knowledge and surgical skills to diagnose and treat each specific cancer. A referral network to tertiary centers is ideal, but travel from remote locations is often complicated. Therefore ideally, only more complex cases would be referred, minimizing the burden of unnecessary travel. Thus, we can help and share our expertise with any general ophthalmologist who has access to a smartphone connected to the internet. Our goal is to empower them to diagnose and treat less complex ocular tumors and help identify the cases that need specialized medical care. To accomplish such a goal, we provide free peer-to-peer consultation with our team of ocular oncologists, free educational videos for ophthalmologists and patients on the most common eye malignancies, and on-line educational courses to increase awareness about ocular cancers using social media.

Our flagship service is called Oncophone,⁽¹⁸⁾ in which we provide free consultation exclusive to general ophthalmologists and other medical professionals but not direct to patients. Typically, the doctor sends clinical information, supporting clinical pictures, and ancillary exams of patients with a suspicion of ocular cancer through the WhatsApp messaging service. Our group of specialists provides a prompt response helping to establish an early diagnosis and treatment recommendation if appropriate. Our colleagues have widely accepted Oncophone, and we receive hundreds of consultations every year from Brazil and other Latin American countries. WhatsApp was our choice as a telemedicine tool because it is

already widely used by 2 billion people worldwide,⁽¹⁹⁾ and it is the primary channel for instant communication in Brazil. Second, it is free, quick, reliable, user-friendly, and encrypted. Third, WhatsApp allows the transfer of text, images, videos, audio, and documents in high quality. Several studies have shown the usefulness of WhatsApp as a tool for exchanging medical information between physicians.⁽²⁰⁻²²⁾

Another service from our group is publishing educational videos on the YouTube platform (www.cancerocular.com.br/videos). We have two types of videos for each topic, one with information for doctors and health professionals and another one for the lay audience of patients and families. Our channel already had over 163,782 views and has been added to the ONE Network® by the AAO. We also have an Instagram account (@centro_oncologia_ocular) with more than 6,000 followers, where we share ocular oncology case reports and unique clinical photos weekly, targeting ophthalmologists, ocular oncologists, medical students, and residents.

Another way we use social media channels is to recruit patients with rare diseases, such as phacomatosis and xeroderma pigmentosum (XP). As an example, in our outpatient clinic, we had a small number of XP patients being followed – only seven. Upon investigation, we realized that none of these patients had access to ocular oncologists before coming to our institution. That inspired us to perform a proactive search for patients with XP using social media posts on Facebook and Instagram. The results were excellent, and we now have 47 patients with this disease being followed up in our service.

Finally, during the pandemic, our habitual in-person ocular oncology courses were transferred to a virtual setting using the Zoom platform. One of our projects was the OncoSundays, where we hosted weekly online teleconference meetings on Sundays for three months. The courses were presented in Portuguese with instant translation to English. We hosted specialists in ocular oncology from Brazil and all over the world. The meetings were successful and well-received by ophthalmologists, with each session having between 500 and 750 viewers.

In summary, social media can be an essential tool for exchanging and spreading medical information among professionals and the general population. However, besides all the benefits it can bring, caution should be taken when sharing medical content. When preparing content for the public, the source of information should always be checked for accuracy to avoid misinformation and disinformation. For example, during the Covid-19 outbreak, social media channels were used to spread disinformation about the disease and vaccines. Translating medical and scientific jargon so that a patient can understand it is no easy feat. Even with good intentions, such content could have unintended consequences due to poor interpretation. Specific to peer-to-peer exchanges, doctors should follow standard guidelines to anonymize clinical data and protect patients' privacy. As a resource, the AAO has an advisory opinion to guide the appropriate use of social media by ophthalmologists.⁽²³⁾

Our experience is that social media can be a fantastic tool for general ophthalmologists to connect with ocular oncologists and discuss cases with a suspicion of ocular cancer. Avoiding delays in diagnosing and treating those patients can potentially avoid ominous outcomes.

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