Patient Education and Engagement through Social Media

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Abstract: This review addresses the demographics of social media users and their relative health literacy. Means of overcoming health inequities via social media and the role of social media in patient education and engagement are explored. This review discusses forms of appropriate patient engagement, including the pitfalls of social media use.

Keywords: Patient education, social media, consumer health information, online health information, health information needs, health literacy.

1. INTRODUCTION

The advent and proliferation of personal electronic devices and access to the Internet have given rise to novel communication platforms [1]. These venues are a means for sharing information that can be sought after by patients: from chat rooms to Facebook feeds to blogging and microblogging sites, all may be accessed by patients seeking information relevant to their medications, treatment options, and healthcare expertise. While there has been an influx of medical information available to the public, health literacy has remained low, resulting in poorer health outcomes with disproportionately high rates of disease [2, 3]. There is a significant gap in health literacy based on socioeconomic and generational differences, leading to further health inequities [4, 5]. For the past two decades, there has been a push for personal communications and community-based outreach, which social media has the potential to achieve [6]. The role of social media in patient education and engagement and how social media can be a tool in research dissemination, patient education, and engagement have been explored in this review.

2. SOCIAL MEDIA PARTICIPANTS

Over the past two decades, people across the world have increased social media use with the objective to become more informed [7]. More Americans are turning to social media to obtain information, often citing social media’s convenience [8]. The Pew Research Center has found that since 2005, social media use has increased from 5% of the general American population to approximately 69% of the population now utilizing Facebook and 73% utilizing YouTube. Microblogging sites, like Twitter and Reddit, capture the attention of approximately 22% and 11% of the population, respectively.

There are generational, income, and racial differences in the platforms used. While Snapchat and Instagram are popular with people under the age of 24 years, they are used by only 3% and 8% of the population over the age of 65 years, respectively [9].

Pew Research finds that approximately half of higher-income people (49%) and college graduates (51%) utilize LinkedIn, while fewer than 10% of the population that is rural, lower-income, or has not attended any college, uses this service.

Racial demographics also factor into which social media is used: while 42% of Hispanics utilize WhatsApp, a messaging application, only 13% of Caucasians do. Rural populations across the board utilize social media less often than their urban counterparts.

Social media has some limitations to reach target audiences – namely, Internet access [10]. The advent of smartphones, with 87% of adults now owning one, has changed access to social media sites. While Internet users previously were reliant on broadband, they are no longer bound by expensive plans - 27% of Americans are no longer subscribed to home broadband. This is especially seen in poor (26%), rural (20%), less educated (26%), and racial minorities (Hispanic 25%), who in general had more difficulties to obtain the broadband Internet. Currently, when utilizing the Inter-
4. EXPANDING REACH TO PATIENTS VIA MOBILE AND SOCIAL MEDIA

Social media has the scope of reaching a wide audience to fill in the gaps in patient education. In fact, clinicians often encourage patients’ use of social media to further research their conditions [19]. As overall literacy increases, younger patients may be able to adopt more readily to employ social media to gain information.

Older patients are also becoming more adept at social media use to increase their health literacy. In one study, patients who discussed cardiovascular disease on Twitter were older than the average Twitter user [20]. Hence, social media has allowed older demographics, who were previously less willing to participate in their care, to bridge the communication gap [18,21].

While there has been an overall increase in literacy in all races, White and Asian/Pacific Islander adults had a higher average literacy than Black and Hispanic adults [22]. Access to the internet was an issue; however, with the increase in the use of smartphones, this disparity is decreasing with 72% and 75% of black and Hispanic adults utilizing smartphones. Social media is uniquely situated to bridge the literacy gap as it is readily available in the nearly ubiquitous smartphones [23]. Nonetheless, the information must be presented in a culturally competent way, in addition to being at a literacy level that can be understood by most individuals.

Rural populations have persistently had the lowest life expectancies, especially those with the lowest socioeconomic status, where the average lifespan is less than 77.9 years. Urban populations within the same income quintile have an average lifespan of 80.6 years [24]. While rural populations were previously reliant on broadband, they have seen an increase in internet use with the expansion of smartphones use from 21% in 2011 to 71% in 2019 [25].

Given the increased access to social media, people of lower socioeconomic status and those with cultural barriers have a greater opportunity to become more health literate. Such examples of patient education of health conditions include platforms like CardioSmart.org and their infographics and patient education information. (Fig. 1) Social Media platforms also offer a means to advance change, advocacy, and point out barriers and obstacles to care. Patients are able to utilize social media to lobby for decreases in disparities of care, such as inequities in cardiovascular care for women. Patients and their health care team often utilize social media platforms to advocate for increased access to high-priced medications, using Twitter platforms to reach insurers when medications are not approved (as has been seen for PCSK9 inhibitors) or when testing ordered for a patient is necessary but denied (Fig. 2).

5. PEER GROUPS AND HEALTH LITERACY

Unmoderated peer to peer groups have not shown an effect in health literacy, but there has been no evidence of these virtual communities causing any harm [26]. The Health Information National Trends Studies reveal that 5% of internet users participated in online support groups in 2007 with mostly younger, subjectively poorer health patients most likely to participate [27]. The 2012 study found that those who were younger, female, with higher socioeconomic status were the most likely to participate in eHealth platforms [28].

Sites that help patients connect with each other, such as “PatientLikeMe” and “WomenHeart”, help foster a peer community for a wide range of conditions [29]. Blogging communities such as Nightscout, DiaTribeLearn, DiabesMine, established in the early 2000s, have been a means for patients to network and gain valuable knowledge and support. Patient-designed sites have led to patient-powered research networks to help advance patient care [30]. While vulnerable populations were not early adopters for these resources, they have since seen an increase in participation as access improves [31].

Along with peer support, social media has been a venue for emotional and social support for patients. This has led to the mobilization of people’s energy towards improving health [32]. Platforms such as Facebook and Twitter have been shown to aide patients to quit smoking. Abstinence was especially prevalent in those patients who were engaged with tailored content. They also had fewer relapses, and if they did relapse, they were more likely to have an increased number of quit attempts [33].

Educational sites that are patient-centered and created by the medical community, such as CardioSmart.org (the patient educational initiative from the American College of Cardiology), have created educational content by healthcare
Fig. (1). Patient Education and Advocacy Through Social Media: CardioSmart.org
Platforms such as the American College of Cardiology’s CardioSmart.org offer engaging and accessible patient education tools, such as this graphic available for download regarding women’s heart disease.
Ref: https://www.cardiosmart.org/Heart-Conditions/Women-and-Coronary-Artery-Disease
(A higher resolution / colour version of this figure is available in the electronic copy of the article).

Fig. (2). Social media for patients.
Patients can utilize social media platforms to become empowered, by engaging with experts in the field, becoming educated, gaining support with peer groups, and advocating for care. (A higher resolution / colour version of this figure is available in the electronic copy of the article).
professions, providing patients with an online source of relevant information regarding the prevention and treatment of cardiovascular disease. It was created to release practical information in a variety of social media forms, with continual updates of relevant information. Through infographics, social media interaction, and freely accessible information, it has become part of a cardiologist’s office in the virtual space. To help with patient literacy, the content is reviewed to try to ensure an adequate comprehension level and cultural competency. Additionally, to target an increasingly diverse country, the information is being translated into other languages [34].

6. PATIENT ENGAGEMENT

At the start of the millennium, many recognized that the use of the internet would rise and that the world was on the brink of a technological revolution that could and would disrupt healthcare [35]. This has mostly come to fruition in terms of both electronic medical records and telemedicine. Older studies of interactions between patients and physicians, such as the DECISIONS study, did not show a robust shared decision-making process [36]. Access to electronic health platforms may enhance this process – especially in patients interested in lifestyle and preventative medicine [37]. Early adopters of patient portals are similar in demographics to those who adopt other social media and internet platforms. The role of health care systems is paramount in engaging the patients and has shown success with clear and thoughtful communication targeting diverse audiences [38].

Factors in the patient portal – such as ease of access, usability, and provider endorsement – drive the success of these platforms [39]. The Centers for Medicare and Medicaid Services (CMS) for the calendar year 2019 issued Healthcare Common Procedure Coding System (HCPCS) codes for engagement via these portals, which may prompt more health systems to initiate and interact with these portals [40].

While the use of social media varied among hospitals and clinics – with the greatest use in large, private, nonprofit, urban, and teaching facilities – nearly all had at least one social media site with a majority using multiple platforms such as Facebook (94.41%), Twitter (50.82%), and Yelp (99.14%) [41]. Hospitals that engaged with patients on Facebook or had a social media presence tended to have better than national average 30-day readmission rates [42]. Though only 11% of tweets were directed at hospitals regarding care quality, nearly 77% of these tweets were positive. The other content was related to health information, fundraising events, and messages of support [43]. Studies of physician reviews, on sites such as RateMD, have shown geographical differences in perceptions of care, and that patient’s satisfaction correlates with higher costs of care [44]. These interactions can further drive public health and reform the health care system.

Social media offers a means to provide real-time communication about public health emergencies. As public health crises occurred from seasonal Influenza, researchers employed social media data to identify and alert patients about impending outbreaks [45]. Data from social media sites are harnessed to study a range of disease processes. Social media was deployed to address the under-representation of women in cardiovascular disease studies, such as the REPRIEVE study that address cardiovascular disease prevention in HIV patients. This study created a Follow YOUR Heart campaign to recruit and educate women [46]. Social media platforms are also instrumental in increasing collaborations and physician network building, especially in terms of research [47].

Social media also provides a stage for physician organizations such as the American Heart Association (AHA) and the American College of Cardiology (ACC) to relay relevant information to patients [48]. They can promote educational resources for patients and physicians via their chosen medium, such as Facebook, Instagram, Twitter, and WhatsApp [49]. The promotion of evidence-based medicine by these organizations has resulted in an increase in educated health professionals willing to share their experiences and research [50]. These platforms have also allowed for nonacademic clinicians to join the conversation, reducing the ivory tower effects of limiting communication to a select few in choice academic centers. It has also allowed the engagement of physicians-in-training, again with equal footing on a more level field, of interacting, sharing, and educating, both patients and physicians. These networks provide organizations with a wide audience to advertise activities and initiatives [51]. This is well evidenced by the millions of interactions that occur during cardiovascular diseases scientific and advocacy conferences [52].

7. APPROPRIATE ENGAGEMENT

Patients assess the credibility of a media based on the source, design, scientific language, and ease of use; however, they often fail to remember from where information is retrieved [53]. The onus is on healthcare professionals to find media that best fits their and their patients’ needs.

Hospital systems are well served to invest in a social media presence, as it is a relatively inexpensive but effective advertisement. Additionally, physicians and the healthcare team remain the most reliable source online to patients for medical advice. Allowing reliable information to counter inaccurate information will always serve patients well. Hospitals may similarly benefit from establishing efficient patient portal systems, which with new payment models, may be in the financial interest of hospitals and medical groups, in addition to the benefit of the patient for easy access and communication with their healthcare team.

Physician organizations and some medical journals, in efforts to disseminate research and educational material, have a robust social media presence, with some tapping on influential social media savvy physicians to promote their work. Academic and nonacademic clinicians can use social media to further their own education, to promote new research or their medical practice, in addition, to retain and build a professional network and to educate patients.

There are limitations for engagement, namely: privacy concerns, reliability of content, inappropriate content, information onslaught, and barriers of access. Care must be taken to engage in a respectful and effective manner. As with any professional interaction, it is imperative that a civil tone is maintained. Patient privacy and confidentiality must always
be preserved. While social media offers a means to disseminate health information, physicians should refrain from offering diagnosis or treatment plans for patients not in their direct care. When physicians are approached by patients online in any social media network, it is recommended that healthcare professionals refrain from providing patient-specific advice. Many physicians currently note in their profile that their messages (retweets or comments) are not to be construed as medical advice or endorsement.

Hospital systems should have a social media policy in place and should ensure that the staff is well-versed in it. They must also ensure that physicians-in-training know and abide by the social media policy, as they are most likely to share information [54].

In the landscape of disinformation, it is important to disseminate reliable material from reliable sources. One of the benefits of increasing accessibility must be balanced with quality metrics to ensure the validity of the content [55]. By consistently providing trustworthy content, a solid reputation will build, which can dissipate distrust [56]. Care should be taken to trust the patients’ intellect and not to curtail their curiosity. In Belgium, for example, there were some attempts to curb patients researching their symptoms. While this was to decrease the overload of information that could lead to anxiety about an unlikely diagnosis, it was deemed to undermine the patients’ autonomy [57].

Besides maintaining the confidentiality and providing evidence-based information, clinicians should take care to avoid the spread of inappropriate content. Patients, especially those with chronic illnesses, are targeted for their illnesses by bullying. The open platform allows for derogative and negative stereotypes; a hazard that, unfortunately, can be harmful [58]. Healthcare professionals have an opportunity to decrease this bullying by providing evidence-based research in a nonjudgmental manner.

Given the vast choices of media, it is becoming evident that the sheer volume of content available to patients can make them feel overwhelmed. Healthcare professionals can act as guides to traverse the landscape to provide suitable material (Fig. 3) [59].

**CONCLUSION**

Given the relative lack of health literacy, new means of reaching patients to engage and educate them must be undertaken. The near-ubiquity of smartphones, and in turn, social media platforms offer a distinct means of engagement. Social media has allowed patients to engage in peer groups, research studies, and advocacy. Healthcare providers should utilize these resources to share accurate information and be a reliable, trusted source of medical information. This will ultimately help patients, guiding them to accurate sources of information in an easy and accessible way, with the goal of improving patients’ health literacy and ultimately improving health outcomes.

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