

Commentary

“I’m Home(screen)!”: Social Media in Health Care Has Arrived



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ABSTRACT

In more than a decade, the adoption and use of some type of social media among American adults has risen from 5% in 2005 to nearly 70% in 2016. The reigning social media platform by usage, Facebook, has 142% more American adult users than the second most utilized social media platform, Instagram, which was purchased by Facebook in March 2012. Of the 68% of American adult Facebook users, more than three quarters visit the site daily. Although social media applications (apps) such as Facebook and Instagram are the clear draw among users, health care apps are beginning to gain traction as well. In 2017, 32% of consumers now have at least 1 health app on their smartphones or tablets, doubling over the past 4 years. Although having an app should not be confused with using an app, having an app downloaded and available for use is a step closer to ongoing adoption. Mobile apps in health care are being used for ordering and scheduling health care services, as well as tracking and managing aspects of health and wellness. An incredible opportunity now exists to connect and leverage social media to enhance the impact of health care, particularly in the areas of drug development, clinical trial recruitment, and therapy administration and adherence, in which dose reminders, sharing of side effects and response, and the accessibility of patients to one another has both a context and a platform. This commentary serves as an introduction to the ways that social media and mobile health care apps are being used in real-world settings as tools to advance the development and effectiveness of clinical therapeutics. (*Clin Ther.* 2017;39:2189–2195) © 2017 Elsevier HS Journals, Inc. All rights reserved.

Key words: Social media, digital health, drug development, clinical trials, online communities, smartphone applications.

INTRODUCTION

With the near-universal ownership of smartphones and tablets in advanced countries, the rising availability in emerging economies and almost ubiquitous usage of social media applications (apps) on those technologies, the ability to continuously and readily measure, influence, and change health care is within reach more now than ever before. Social media usage among American adults has risen from 5% in 2005 to nearly 70% in 2016, with the application Facebook having more than 142% more American adult users than Instagram. With more than 75% of American adult users of Facebook visiting daily, there is a clear draw among users. Moreover, in 2017 32% of consumers have at least 1 health app on their smartphones or tablets. Those reporting Internet usage or smartphone ownership in a 2015 Pew Research Center survey was a median of 87% across 11 advanced economies, including the United States and Canada, major Western European nations, developed Pacific nations (Australia, Japan, and South Korea), and Israel. A median usage or ownership of 54% was reported for developing countries such as Malaysia, Brazil, and China.¹ In 2017, ~70% of Americans use social media in an effort to connect with one another; to share thoughts, information, and news; and to learn, explore new topics, and entertain themselves.²

Although social media apps, such as Facebook, Twitter, and Instagram, are the clear draw among users, mobile health care apps are beginning to gain traction as well. Mobile apps in health care are

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seeking to address a number of categories of health management, either discretely or across multiple areas within 1 app. These apps can be geared toward physicians and clinicians, to patients, or to both groups as a way to enhance communications and engagement. There are apps that support self-directed health education and research into a particular condition, such as WebMD; measuring, monitoring, and tracking of physiology, such as Azumio, maker of Cardio Buddy and Sleep Time; medication dosage reminders and management, such as MediSafe and PillPack; and connecting physicians and nurses with patients, such as Pager and Patient IO. Although there is a range of app categories, the majority of mobile health care apps are currently associated with wellness, such as tracking calories, steps taken, and sleep rates via smartphone and wristband devices.³

SOCIAL MEDIA AND MOBILE HEALTH CARE APP INNOVATIONS FOR DISEASE TREATMENT AND MONITORING

Disease and treatment apps with a singular focus on a particular therapeutic area, despite comprising a relatively small proportion of health apps in the marketplace, have been at the center of innovative medication treatment and monitoring programs over the past several years. Such apps may aid patients with chronic illnesses such as diabetes and cardiovascular disease, for which self-management is impactful on healthy eating, being physically active, monitoring vital signs, taking medications, and generally adhering to good disease management techniques.

The Trulicity App is 1 example of patient engagement through an innovative treatment online app. In September 2016, Eli Lilly and Company introduced a multifaceted mobile app with call/instant message support to engage patients with type 2 diabetes who use Trulicity (dulaglutide), the company's once-weekly injectable diabetes medication. The 2 main goals of the app and instant message support functionality are to ensure correct usage of the Trulicity Pen and to improve adherence. To achieve these goals, Lilly incorporated a virtual demonstration of the Trulicity Pen in its app that walks patients through every aspect of the device, including sound. Weekly reminders for dosing and tracking of time between doses help keep patients engaged and adherent, while assistance is a tap or call away via the Lilly Answer Center.⁴

The Lilly Trulicity app can also serve as a basis of commonality for discussion and engagement among the broader Trulicity patient community via social media forums. These forums are created by patients, are separate from the company-sponsored app, and can serve as a support to patients who are also accustomed to using mobile technology, such as the Trulicity smartphone app. An example of this type of engagement can be found on the American Diabetes Association Support Community website (community.diabetes.org), where one can find a number of online communities started by patients. Some of these online communities discuss user experiences with Trulicity, such as the community forum "Introduction and Trulicity Thoughts" (community.diabetes.org; search term "Introduction and Trulicity Thoughts").

This type of social media and mobile engagement is expected to benefit both Trulicity-treated patients and Lilly. Beyond the expected improvements in adherence and device usability, sharing experiences with one another via the app can be a powerful way to encourage authentic insight gathering among patients. Such community engagement may result in greater usage of the app and, ultimately, a better treatment experience for patients who use Trulicity. Although pharmaceutical companies continue to incorporate mobile health app components into their drug adherence programs, the need remains to study and publish the impact on adherence, and ultimately health outcomes, from their usage.

TEXT AND TELL: SHARING HEALTH CARE EXPERIENCES THROUGH ONLINE COMMUNITIES

"Online community" is the updated social media term for what was previously known from sociology as "reference groups." In a definition >60 years old, "reference groups are commonly defined as individuals or collectives that serve as a point of comparison (or reference) to a given individual in the constitution of its values, attitudes, or behaviors, thus influencing the individual's choices, behaviors, and attitudes."⁵ A unique aspect of the online community, as explored by Scaraboto et al,⁶ is that all communication is via text. Nuances of tone, intent, and meaning, detectable in speech, are missing in text-only communication. In addition, it would be useful to further research and explore whether individuals posting to online

communities are aware of the permanence of their self-disclosure in these forums.

With the rise of usage, what type of impact do social media and online communities have on influence and engagement for a particular disease or treatment? One measure of impact is through permanence, in which text entries within an online health care community become a searchable, historical reference for visitors and contributors. Finding relevant disease or treatment experiences, by reading the entries that either validate one's own experience or illustrate what might be an experience to come, is a powerful way for patients to gain knowledge and power over their disease.

Although the research of Scaraboto et al⁶ focused on pregnancy-related online communities, my own Internet review, using a Google search of a number of online communities associated with therapies treating oncology and diabetes, yielded similar findings. Both in the article by Scaraboto et al and my online review, a consistent pattern of communication was observed. Most online community threads began with the patient (as poster) setting expectations of the post to the community, where "the first message is phrased as a question or a request for personal opinions about a specific product, brand, or service."⁷ This expectation setting is an important component of derived impact from usage of an online community because it facilitates search within the community postings. Being able to search a thread of interest within an online community helps guide the patient, either for a specific question or as an entry point into the community, for further engagement and relationship building.

More broadly, one of the most impactful areas of influence and engagement via social media usage has been with rare diseases.⁸ The advent of these outlets has opened access to and decreased isolation across every rare disease community. Organizations such as the National Organization for Rare Disorders, the Rare Disease Foundation, and the Rare Disease United Foundation are just 3 of many groups that have a dedicated page on Facebook as well as active online communities. In addition, there is an annual Rare Disease Day that gathers participants globally for a daylong session of action, awareness, and information with in-person and simultaneous online activities via Facebook, YouTube, Twitter, Flickr, and Google+.

CLINICAL TRIALS BECOME SOCIAL AFFAIRS

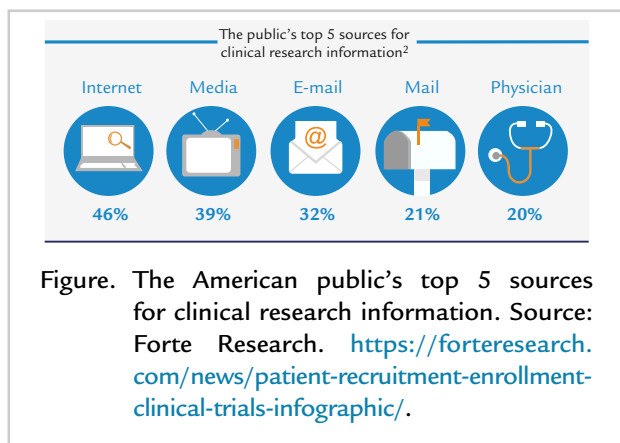
Online patient communities, particularly for rare diseases, are now a way of daily interaction for participants. However, these communities pose both challenges and opportunities for pharmaceutical companies that have clinical trial enrollees who are both reliant on and savvy users of social media.

Transparency and information sharing are the currency of trade within online patient communities. As a blogger noted on raredr.com, "Rare disease clinical trial participants will share information with one another and their disease community. In many cases, they will unblind trials, especially if their lives or the lives of their children hang in the balance of a drug development program. To expect otherwise is either paternalistic, naïve, or both."⁹ Moreover, this information sharing is not just of interest to online community participants. Online communities are open forums, as are social media channels such as Facebook, Twitter, and blogs, and can be mined for information by investors, analysts, competitors, and regulators.

At a MassBio forum I attended several years ago ("Harness the Power of Social Media Part II: Clinical Trials in the Age of Social Media—Strategies for Increasing Trial Awareness and Patient Recruitment"), I recall 1 of the attendees, the General Counsel for an orphan drug biotechnology company with a compound in a Phase II clinical trial, was soliciting advice on how to manage a pair of trial participants who were very active social media users. These trial participants became such prolific information sharers that they were followed and contacted on a near-daily basis by analysts and investors who were tracking their posts across a broad spectrum of social media. Complicating this issue further was the company's status as a publicly traded firm, and with each day's social media content, the stock was fluctuating wildly.

LEVERAGING SOCIAL MEDIA FOR CLINICAL TRIAL RECRUITMENT

A considerable upside of a pharmaceutical company's usage of social media is in the area of clinical trial recruitment. With only one third of randomized clinical trials meeting their enrollment targets in a timely manner,¹⁰ there is an opportunity to leverage social media to augment, or potentially replace, traditional recruitment methods, such as a trial



website, print advertising, television, e-mail, or telephone call targeted outreach (Figure).

Using social media for clinical trial recruitment is a beckoning vista ripe for exploration; however, it is an area in which thoughtful campaign development is essential. Although there have been some useful guidelines provided by the National Institutes of Health for clinical trial recruitment via social media, categorized as “new technologies,”¹⁰ there remains a lack of finalized regulatory guidance by the US Food and Drug Administration (FDA) addressing the main concerns of pharmaceutical companies in this area. These main concerns, identified from input across 20 pharmaceutical companies via a white paper by the Tufts Center for the Study of Drug Development,¹¹ were as follows: how to directly engage with patients; how to develop methods to capture and report adverse drug events shared via social media channels; and how to avoid introducing potential biases within a study. Even with these significant concerns, there is a developing body of evidence^{12,13} that social media has a substantial positive impact on the rate and reach of clinical trial recruitment. With many campaigns being free or at minimal cost, social media is also a very cost-effective way to engage for recruitment. A study by Khatri et al,¹⁴ examining social media and Internet-driven study recruitment, found that these channels “substantially assisted study dissemination in a cost-effective manner... and resulted in a substantially higher click-through rate... to recruit collaborators when compared to other studies recruiting members of the general public.”

AN APP A DAY FOR HEALTH

Once undergoing therapy, patients are increasingly using their health care apps for ongoing engagement

with their providers, and themselves, around their treatments. As of 2013, Walgreens saw >40% of its online refill requests come from the Walgreens app, with presumably more now that the app is the third most downloaded retail health care app. As a Walgreens executive explained, “You have your pill bottle, you take your smartphone, you scan the barcode, you select your store, and you're done. You get a text that your prescription is ready. And our customers have voted with their downloads.”¹⁵

Getting a prescription easily filled is the first step in treatment. However, with ~50% of patients not taking their medications as prescribed,¹⁶ there is an expanding category of health care apps dedicated to providing treatment reminders, dosage trackers, side effect insights, and management of polymedications across comorbidities. One such app, MediSafe, has been downloaded >1 million times¹⁷ and has demonstrated a self-reported medication adherence rate among users of 81%, considerably greater than the World Health Organization's estimated average of 50%.¹⁸ MediSafe uses a virtual pillbox, created by scanning the bar code on each of a patient's prescriptions, as a visual reminder presented throughout the day to remind the patient of which prescriptions have been taken and which remain in the pillbox to be taken. MediSafe has gone a step further with the introduction of a buddy system in which a reminder is sent both to the patient as well as to his or her designated recipient who will provide an extra push, if needed, to take the prescription.¹⁹

MANY APPLICATION CHOICES FOSTER VARIABILITY OF USAGE AND IMPACT, YET OBSTACLES REMAIN

Although there are many health care app options to explore in either the Google Play or iTunes stores, there is inconsistency across both functionality and usability in keeping the apps updated with new features. A review of 272 medication adherence apps in Australia found that more than one half had not been updated by the developer within several years' postlaunch.²⁰

There are many benefits to patients using social media and online communities to engage with one another, as well as to gain education and insight into a condition or treatment. There is also the potential to cause harm by relying on these channels for self-

diagnosis or treatment plan management. It is an issue that needs to be further understood and managed given the number of patients tapping into social media for just this use.

In a 2012 PwC health care social media report and Health Research Institute survey, 24% of consumers were found to have used social media to access health-related consumer reviews, such as wait time in the physician office and ability to understand and relate to the physician. One in four had posted on a social media platform regarding their health experience, and 20% of responders said they had joined a health forum or community. “More than 40% of respondents reported that information found via social media would affect the way they coped with a chronic condition, their approach to diet and exercise, and even their choice of doctor.”²¹

An interesting study undertaken by Lupton and Jutel²² sought to measure the impact of this phenomenon, labeling it “digitized diagnosis.” The combination of a significant amount of disease and treatment information online, coupled with the proliferation of online communities and forums, has affected the dynamic between patient and physician. As Lupton and Jutel note, historically a patient would schedule a physician appointment to determine a diagnosis. Now, using their online research as a discussion tool, patients are morphing their physician visit into an endorsement of a diagnosis they have researched and identified.

One such app fueling the digitized diagnosis trend is WebMD. WebMD has been downloaded >5 million times on Google Play while another app, iTriage Health (itriagehealth.com), has been downloaded >1 million times on Google Play and similarly on iTunes.²² iTriage Health has an anatomic avatar that allows a user to select the site of concern on the body and then get a list of symptoms and potential treatments. WebMD serves as a source of insight into illness and diagnosis, represented in understandable terms to a layperson. iTriage Health, WebMD, and other sites provide a general overview based on a patient’s self-assessed issue or condition without a clinical validation. These can be printed and brought to a physician visit for discussion (or debate, as the case may be).

POSTMARKETING AND REGULATORY CONSIDERATIONS

The acceleration of in-home and smartphone-enabled health-monitoring devices offered and in use, such as

heart rate monitors and vital signs detectors, will further transition the role of patients to first-line data collector for themselves and their caregivers. However, this transition requires medical grade monitoring devices, such as the one introduced by Philips in 2016. As Philips announced at the time, “unlike fitness trackers and consumer focused wearables, the new medical-grade, connected biosensor automatically and continuously measures clinically relevant vital signs including heart rate, respiratory rate, skin temperature and more. The biosensor then transmits the data it collects to a connected clinical decision support software application, where the software can be configured to promptly notify the appropriate caregiver or clinician when preset limits are exceeded.”²³ Medical grade health monitoring devices are a newly evolving category, with Philips claiming their biosensor is an industry first. However, the consumer market is still at the stage of wearable health tracker devices, with International Data Corporation’s Worldwide Quarterly Wearable Device Tracker reporting that wearable device shipments will reach 173.4 million units in 2019.²⁴

Although consumer wearable products are considered “general wellness products not intended to cure or treat a specific illness or condition” by the FDA,²⁵ and currently do not require registration, a new Digital Health Innovation Plan from the FDA is looking at ways to create “a novel, post-market approach to how we intend to regulate these digital medical devices.”²⁶ One proposal within the plan is certification of trackers, health monitoring devices, and software apps. This certification “could be used to assess, for example, whether a company consistently and reliably engages in high quality software design and testing (validation) and ongoing maintenance of its software products.”²⁵ A standard certification framework would address the issue of inconsistent updates and release schedules for downloaded apps that can leave patients with a potentially unusable app over time.

The National Evaluation System for Health Technologies attempts to address an unmet need in harnessing in 1 place the collected data from medical devices for outcomes measurement and postmarketing surveillance of medicines via “a federated virtual system for evidence generation composed of strategic alliances among data sources including registries, electronic health records, payer claims, and other sources.”²⁴ This system, managed via a 501(c)(3) public-private partnership, can play a critical role as

a central, albeit voluntary, repository in combining the application of real-world evidence data collection and ongoing outcomes measurement for a range of apps classified as medical devices.

KEEPING PACE IS SOCIALLY ACCEPTABLE

A broad suite of social media and Internet-based connective tissue is fueling the continued impact of health care innovation. Consumer and patient-driven usage of technology in daily living, such as smartphones, social media channels, and apps, is outpacing the traditional ways medicine and health care have been managed. It is heartening to see the recognition and awareness across both industry and regulators that a proactive, collaborative approach with patients is the way to drive better outcomes and broader access to impactful care. It is also comforting to see that taking a considered, thoughtful approach to the benefits, as well as the pitfalls, of social media in medicine—for patients and with patients—will be the guiding principle as we navigate our way across the evolving health care app landscape.

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CONFLICTS OF INTEREST

The author has indicated that she has no conflicts of interest regarding the content of this article.

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