In sickness and in health: Clinical research and social media

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INTRODUCTION

Many of us have grown up hearing the proverb “An apple a day keeps the doctor away,” but today’s youngsters have coined a different one, “A tweet a day keeps the doctor away.” This signifies the huge impact that social media is having on our life in this “digital age,” globally. To define “social media,” it includes websites and applications which allow the users to create and also share content, empowering individuals for social networking. Currently, social media is omnipresent in most of the turfs. It has changed our perception right from politics to patient care, even altering the inter-industry relationships. A survey of more than 4000 physicians, conducted by the social media site QuantiaMD, found that more than 90% of physicians use some form of social media for personal reasons while 65% use these sites for professional reasons.[1] In another survey conducted by the Institute of Medicine, in the US; the report says that 94% agree with sharing their health data to help doctors to improve care; 92% agree to do so to help research work; 78% patients wish to help drug companies learn more about their disease; and 92% wish to help other patients.[2] Clinical research marking a big territory in the world’s healthcare map is also dealing with this changing scenario due to increasing awareness and accessibility to social media. Being a highly regulated sector and where confidentiality of the patients’ data has prime focus, these changing situations, with respect to social media, are bound to create a resounding impact, primarily in the way it is practiced and interpreted. In this article, we have focused on the meeting points where the leading social media portals are impacting different areas of healthcare functionalities including clinical trials. The gap between the existing regulations and the requirements should meet to make the best use of social media for better healthcare outcomes, which would also help to create awareness in this rapidly evolving era of patient centricity.

Keywords: Big data, communication, healthcare, mobile applications, patient centricity, social media

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THE MEETING POINTS

There is a myriad of social media platforms built with different features, which attract different users based on their needs and interests. The social media platforms can be categorized broadly on their differences in the primary functionality. If each of these sites and applications (apps) are carefully analyzed, a very complex web of communication can be observed among people from varied background.

- Social networking (Facebook, Pinterest, Google Plus, Twitter, etc.)
- Health portals (patientlikeme.com, sermo.com, etc.)
- Media sharing (YouTube, Flickr, etc.)
- Content production (blogs [Tumblr, Blogger] and microblogs [Twitter])
- Knowledge/information aggregation (e.g., Wikipedia, RxWiki, Medpedia).

The origin of the term “blog” is from the word “Web log,” which is the oldest form of social media and has been used in medicine since 2004. To mention a few more, the professional site, Sermo is a “physician-only” social networking community that verifies the credentials of new members during registration as a unique policy. Physicians representing 68 specialties in all fifty states of the United States of America make a virtual presence on this site for multiple reasons like networking, to discuss multiple treatment options, and to consult peers for expert advice. Shifting our focus from healthcare professionals (HCPs) to the care seekers, in the third quarter of 2015, more than 1 billion of active users visited the social networking site Facebook on a daily basis, where one can find profiles of physicians, patients, nurses, pharmacists primarily. Although this use is most often for personal communications, interestingly more than ninety pages on Facebook are related only to the pharmacy profession where the discussions are certainly not limited only to a personal level. The “Healthcare Hashtag” project, which aims to make the use of Twitter more accessible to the healthcare community as a whole, has recorded over 134 million healthcare-related tweets till date.

Other than Facebook and Twitter, Pinterest is unique as it inspires and educates users with its attractive visual formats. YouTube is another popular platform where two billion videos are viewed every day. Many healthcare and pharma companies are using YouTube to promote or describe their products online. For gathering quick knowledge, surprisingly, Wikipedia is the most commonly used wiki in the medical community. It is often used as a reference by clinicians, despite its known shortcomings, such as errors and narrow breadth of information.

In a nutshell, published as in Mashable, a digital media website which is also referred as a “one stop shop” for social media; the most accessed online resources for health-related information [Figure 1].

This figure portrays a change in mindset of the patients and consumers and the way the information seeking and sharing has changed in the past few years under the influence of the social media.

CLINICAL RESEARCH AND SOCIAL MEDIA: THE NEW BOND IN MAKING

Clinical research with its rising number of participants is also observing the change in the dynamics in sharing and gaining health-related information online. According to data from health consumer insights firm Treato, over half of the 300,000 patients posts available online today about clinical trials, were published in the last 6 months. The empowered patient of today is more “health-literate” and connected with other patients with similar health conditions across the globe. The healthcare industry should join in a productive conversation with them to strike the poise. The communication webs between the stakeholders are not evenly woven. Communication through social media between the regulatory agencies and pharmaceutical companies to doctors and patients is in a very early stage; patients have established the most active gateway of communication among them. However, between doctors and patients, the communication channel is slowly establishing as briefed in the figure below communication through social media between different stakeholders [Figure 2].

CLINICAL RESEARCH, SOCIAL MEDIA, AND THE REGULATIONS

Revisions or amendments of healthcare industry regulations regarding social media usage have not been able to match...
the pace with which social media usage has increased in different areas of clinical research. One of the renowned healthcare authorities, European Medicines Agency (EMA) is one of their recent press release (September 2016), on EMA's increasing engagement through social media concluded expressing the need for developing a social media strategy to broaden EMA's engagement, as a solution to people's comments regarding their absence in portals such as Facebook and Pinterest. From the house of Food and Drug Administration, there are three draft guidance had been launched in 2011 and one in 2014, which addressed issues such as, responding to unsolicited requests for off-label information about prescription drugs and medical devices; Internet/social media platforms and correcting independent third-party misinformation about prescription drugs and medical devices; Internet/social media platforms with character space limitations presenting risk and benefit information for prescription drugs and medical devices, but none of the guidelines has been finalized yet.

Apart from the regulatory authorities, social media usage guidelines for HCPs have also been issued by few professional organizations. In 2010, the American Medical Association released official guidelines for the ethical use of social media by physicians. In 2012, the American Society of Health-System Pharmacists released a statement regarding the use of social media by pharmacists. Unfortunately, none of these guidelines is definitive or tailor-made for platform-specific recommendations. To date, research sponsors and contract research organizations have neither established specific company policies nor formalized coordinated processes. Instead, most of them are using social and digital media communities on selected programs and moreover giving an experimental try. The existing guidelines of the sponsors to address employee use of social media also has a very generalized approach, for example, guidelines for posting videos online, rules for discussing company business on personal sites, social media advisory board specified practices, which needs to be extended so that it addresses the practical and modern issues churning from the use of social media.

MEETING THE GAP

Although healthcare is the fastest growing content category for mobile device users, there is a lack of awareness across the industry and also lack of definitive guidelines, primarily related to content regulation, which is preventing maximum utilization of it. In fact, among the fifty largest drug makers worldwide, only half even dabble in social media. Giving it a further closer look, a new study by the IMS Health, Institute for Healthcare Informatics stated only ten drug makers are using all three of the most popular sites - Facebook, Twitter, and YouTube. Within that small group, even fewer are actually interacting with patients and the public.

The key focus areas which are monitored by communication service leaders to review the social media performances based on six categories:

1. Social presence - How many social networks were the company on?
2. Social network - How simple and intuitive was the connection between social networks?
3. Community size - How big was the community?
4. Activity - Was the content kept fresh with regular updates?
5. Engagement - Were the companies engaging their users and generating interest?
6. Virality - Was the content spread around the social sphere?
There are different ways, in which social media could add speed and new dimensions to clinical trials when used in a structured and ethical manner.

- Social media can boost study recruitment\(^{[19]}\) for example, Novartis used a Twitter feed to boost awareness of a phase 2 trial involving stomatitis and breast cancer, and others have used text messaging.
- Strategizing a speedy recruitment by engaging key opinion leaders as bloggers, trafficking a trial website to the recruitment page could save a lot of time for the sponsors. Clubbing similar type of content, for example, an advertisement of an arthritis trial, right beside an article like “how to stay fit at the age of 60”, in a web page may decrease the probability of delay in kick-starting a trial\(^{[16]}\).
- Social media engagements fosters interaction and further satisfaction by allowing them to communicate with patients with similar health conditions (e.g., various long-term diseases).\(^{[20]}\)

The above-mentioned ones are the most popular uses of social media in modern-day trials, but the risk that comes with various irresponsible behaviors of many users of social media restricts from its further positive contribution. As social media allows communications at various levels, a proper “risk calculation” is advisable for the sponsors as well as there is a huge need to educate the healthcare seekers when it comes to making comments in different social media portals. Clinical trial sponsors must work closely with regulators to define pathways to monitor social media used by trial participants to understand if conversations on the internet will affect their interpretation of study results by patients’ sharing confidential trial information or conversations involving an early indication of whether a drug will be a success or not, to name a few.\(^{[21]}\)

**PATIENT CENTRICITY AND SOCIAL MEDIA**

The National Institutes of Health defines patient-centered care as “Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and patients’ input on the education and support they need to make decisions and participate in their own care.”\(^{[22]}\) In simple words “patient centricity” has empowered today’s patients to be a part of the healthcare decision-making system more than ever. First, the internet and then the social media have heavily fueled the easy exchange of health-related information in today’s patient-centric healthcare system as briefed below:

**Healthcare mobility**

It includes exchange of data and very active communications among the payers, service providers, and patients through various mobile apps and enterprise platforms. Use of these latest technologies has resulted in lesser rehospitalizations and better clinical outcomes.\(^{[23]}\)

**Enterprise application solutions**

Different healthcare setups have restructured their work-model as mobile technologies, and enterprise application solutions have positively influenced handling collaborations and workforce management. Now, we have a big force of virtual caregivers (doctors, nurses, etc.) who can extend their consultation on real-time basis building more on the personalized care and simultaneously minimize the whole turnaround time.\(^{[24]}\)

| Table 1: Summary of the survey of top healthcare applications |
|-------------------------------------------------------------|
| The most supported health condition for apps was cancer, which 11% of apps addressed, followed by coronary heart disease and diabetes, each the subject of 7% of apps. 38% are specific to a particular drug. 30% of Pharma app have never been updated. 295 have only been updated once. 21% had 2-3 updates and 20% had 4 or more. 50% of the apps in question were found to be patient-facing, and 36% were made to be used by physicians. 14% had another user in mind. |

**HEALTHCARE APPS AND PHARMACEUTICAL COMPANIES**

Different mobile applications related to healthcare launched by different big and small pharma companies are available in different operating systems such as Android, iOS, and Windows. They are important as there is a need to understand the digital transformation that is taking place in the Pharma world and how the end users are reacting to this transformation. Few apps mentioned below created a positive impact in the recent past.

- GlaxoSmithKline’s Diabetes Health Mate app not only track patient’s blood sugar readings but also shows how physical exercise, medications, mental wellbeing, and diet interact with physiological outcome measures\(^{[25]}\).
- Quantified self app - recently launched by Janssen collect health data from other tracking apps and turns the whole process into a game.\(^{[26]}\)

Meanwhile, in a Digital IQ survey done by PriceWaterHouseCooper, it was found that, 29% of drug and device executives consider mobile as the most potential device for advancement in digital technology for their companies in coming 3–5 years, substantiating it further by stating that, 60% of them are investing in mobile technologies to make a stronger connect to the
consumer base. To get an idea about the current pharma app market, in the US, UK, and Germany an analysis done by a Munich-based app company, Smart Patient found that the top ten apps accounted for 66% of all downloads. The survey has covered 359 apps from twenty of the world’s largest pharmaccompanies, including AstraZeneca, Bayer, Sanofi, Janssen, Novartis, and Pfizer. Some highlights of their findings are summarized in Table 1.

Along with usefulness and rising popularity, these apps come with shortcomings, such as having very basic user interface, and geographical restriction (e.g., Pfizer’s Meds app). In another study, it was stated that, over the next 5 years, 86% of clinicians believe that mobile apps will play a major role in a physician’s practice which is popularly known to be a part of today’s “do-it yourself healthcare.” However, unfortunately, this flowing stream of digital health remains highly unregulated.

**THE BIG DATA ADVANTAGE**

The word of the hour “big data” is surfacing as a term that describes large volumes of structured, semi-structured, and unstructured data with the possibility of being mined for information. The development of social media has a major contribution toward this mega trend of big data. As estimated by McKinsey Global Institute, application of big-data strategies for well-informed decision-making could generate an annual value sum of up to $100 billion across the US healthcare system. It can optimize innovation, maximize the efficiency of research and clinical trials, and facilitate the innovation of tools for major stakeholders and give rise to individualized approaches. Big data can be a game changer in the healthcare industry as it is capable of supporting multiple future possibilities such as predictive modeling of biological procedures and drugs, bonding with the patient to offer successful recruitment in trials, and monitoring trials in real time to manage the flow of data exchange between parent companies and research organizations.

To briefly a few, “sentiment analysis” helps to measure, analyze, and ultimately influence the customer’s sentiment, which helps in the generation of customer loyalty and revenue. On the other hand, maturity models are established mechanisms that help organizations assess their capabilities along with a particular domain of interest, and determine the need to grow further to reach the desired end-state. There are five levels such as motivated, organized, aware, informed, and assertive, where assertive being most conscious about their companies’ reputation and connect in the social media arena.

**CONCLUSION**

The current role of social media in the spread of clinical research globally, is demanding a close analysis, weighing its benefits against its risks if we imply it with its full availability and scope. Like we do for a drug before it hits the market, we should follow the same approach in this situation so that we do not miss any opportunity for leveraging more advantage for the patient. At the same time, safeguarding the integrity and safety of the patient is a concern. When used wisely and prudently, social media sites and platforms offer the potential to promote individual and public health, along with professional development and advancement. However, when used carelessly, the dangers of these technologies posed to HCPs are formidable. Having said that, historically, any new wave of change with a huge potential has essentially followed the same pattern of glowing opportunities intermingled with risks. The call of the hour is to work faster to build up governance, which can give a global platform for better understanding and usage of social media without challenging the ethical and legal boundaries. The primary aim while creating guidelines for the usage of social media should remain patients’ “right to safety and well-being.”

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