

The Unintended Consequences of Social Media in Healthcare: New Problems and New Solutions

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Summary

Objectives: Social media is increasingly being used in conjunction with health information technology (health IT). The objective of this paper is to identify some of the undesirable outcomes that arise from this integration and to suggest solutions to these problems.

Methodology: After a discussion with experts to elicit the topics that should be included in the survey, we performed a narrative review based on recent literature and interviewed multidisciplinary experts from different areas. In each case, we identified and analyzed the unintended effects of social media in health IT.

Results: Each analyzed topic provided a different set of unintended consequences. Most relevant consequences include lack of privacy with ethical and legal issues, patient confusion in disease management, poor information accuracy in crowdsourcing, unclear responsibilities, misleading and biased information in the prevention and detection of epidemics, and demotivation in gamified health solutions with social components.

Conclusions: Using social media in healthcare offers several benefits, but it is not exempt of potential problems, and not all of these problems have clear solutions. We recommend careful design of digital systems in order to minimize patient's feelings of demotivation and frustration and we recommend following specific guidelines that should be created by all stakeholders in the healthcare ecosystem.

Keywords

Social media, gamification, epidemics, chronic disease, outcomes, ethics, legal, crowdsourcing

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1 Introduction

At the end of 2015, the average social network penetration rate worldwide was estimated to be 29% [1]. Approximately 2 billion Internet users from around the world are using social media (SM), and although the use of social networks varies among countries, people worldwide are engaged in these technologies and actively use them [2].

The latest developments in health information technology (IT) and the increased acceptability of SM in health are leading to IT solutions that combine both tools. This integration of SM with IT-based health solutions provides several benefits to society. In chronic disease management, SM offers advantages such as increased psychological well-being, social health, and cognitive health [3]. SM data itself may be used in protecting citizens from public health threats or as a means of communication during epidemics [4-5]. This may help improving notification times and make firsthand information available to the public. When SM is combined with gamification techniques to help patients have a healthier lifestyle, their engagement and motivation is potentially increased [6]. SM is also one of the main pillars of crowdsourcing. It allows patients to seek multiple opinions from an online crowd, which could help inform them about their treatment or diagnosis options. Previous studies have shown that crowds can offer better advice than single individuals and, at

times, can provide more accurate opinions than educated professionals [7-9].

Nevertheless, despite these potential benefits, the challenges of these new opportunities may result in negative outcomes if not addressed properly. For instance, YouTube can be used to spread anorexia-related misinformation, tobacco promotion, and public exhibitions of unhealthy behavior [10-11]. In this study, we do not intend to provide a comprehensive analysis of the issue, but the aim is to provide an overview of some of the potential unintended consequences of SM and health IT.

2 Methods

Over the course of five days, all members of the IMIA Social Media Working Group (SMWG), who agreed to participate in this study, discussed their own experience in order to elicit the topics to be explored. The authors agreed to include ethical and legal considerations, the prevention and detection of epidemics, chronic disease management, crowdsourcing, and gamified health solutions. These topics were divided into two groups: "Healthcare professionals and other stakeholders" included the first two topics and "Patients as stakeholders" the later three.

Since this study was intended to be exploratory rather than comprehensive, the authors chose different approaches and

sources for each topic. Three of the topics were analyzed using a literature review, as summarized in Table 1.

The topic of the prevention and detection of epidemics was explored by collecting experiences of the authors in the development and testing phase of the M-Eco system [5], a surveillance system that analyses Twitter and other SM data for the purpose of detecting public health threats. Further, we summarized the relevant ethical, legal, and social implications discussed at the DELSI (Digital Epidemiology and its ethical, Legal and Social Implications) International Symposium [12], where epidemiologists, sociologists, lawyers, and computer scientists discussed the implications of digital epidemiology.

With regard to the topic of patient use of health crowdsourcing platforms, the authors combined their own experiences with literature from PubMed and Forbes Magazine online.

3 Results

3.1 Healthcare Professionals and Other Stakeholders

Ethical and Legal Considerations when Using Social Media for Health Purposes

The incorporation of SM in daily health care activities should be accompanied by the development of measures to ensure their safe use guaranteeing medical professionalism and ethical and legal requirements, especially when using open and massive online services [13]. Several guidelines and recommendations for good practices were developed to highlight the most important aspects for the use of SM for health purposes as well as descriptions of their advantages and drawbacks [14-18].

The use of SM tools has led to innovations in health care that have generated issues and left unanswered legal and ethical questions.

The use of SM has led to unexpected drawbacks and challenges regarding the protection of personal data, particularly in the case of sensitive data such as health information.

Taking into account that connections with other users result in making content accessible to anyone connected to the Internet, risks related to misinformation, privacy, and confidentiality, and the right to be forgotten are the main concerns when posting and participating in SM. In addition, the use of sophisticated and automatic tools for collecting and monitoring personal data and behavior has become increasingly common and less detectable. Studies have suggested that unprofessional uses of SM are frequent among health professionals and various improper behaviors, such as violations of patient privacy, posting sexually suggestive photos, defamation and criticism of others, and racist content online are among the most common problems detected on these platforms [17, 20-25].

SM tools are in the process of being widely adopted in health care services, and it is common for laws and ethical guidelines to lag behind new technical developments. Thus, it is essential to urgently fill the gap among policy makers and healthcare professionals. It is also important that the relevant authorities and governments apply ethical and legal guidelines related to the use of SM tools for health communication [26]. This should be done in collaboration with patient associations and professional institutions to establish specific policies that benefit to healthcare professional-patient relationship and the general public.

Social Media Use for the Prevention and Detection of Epidemics

Scientific assessments of the utility of SM web mining in the domain of public health have shown that such use could help in overcoming time delays in reacting to health threats, e.g. by providing additional information about outbreaks [27]. However, while beneficial, the use of SM to detect epidemics can lead to some undesirable or unintended consequences with regard to technical, functional, and formal issues. Although it is still unclear how reliable the content collected from SM is to detect public health threats, it is technically possible to do it as multiple

Table 1 Summary of the literature reviews conducted for the topics "Ethical and legal considerations", "Chronic disease management", and "Gamified health solutions with social components".

| | Keywords | Databases | Unfiltered hits | Final results (non-duplicated, and relevant) |
|---|---|--|---|--|
| Ethical and legal considerations | "SM," "web 2.0," "ethics," "ethical," "legal," "legislation," "professionalism," "medical doctors," "guidelines," "recommendations" | PubMed, Google | 588 returns (we took the first 150 from Google, and the rest from PubMed) | 28 papers |
| Chronic disease management* | "social media," "chronic disease," "chronic illness," combined with: "fear," "misrepresent," "mislead," "misinform," "dangerous," "disreputable," "withdrawal," "frustration," "confusion," "uncertainty," "distress," "dejection," "isolation," "alienation," "catastrophism," "desperation" | PubMed, Web of Science, Scopus, Computers and Applied Sciences | 14 returns | 4 papers |
| Gamified health solutions with social components | "gamification," "social," "health." | PubMed, PsycNet, IEEE and ACM. | 100 returns (we took the first 43 — sorted by higher relevance — from ACM, and the rest from the other databases) | 7 papers |

* keywords used for unintended negative consequences in the literature search were adopted from a global online survey of SM use in managing chronic disease (i.e., chronic pain) [10].

projects have shown [4] [5] [9]. Legal issues include the responsibilities of public health officials when using SM for epidemiological purposes since through social media, personal data from individuals that usually remains unknown to health officials at a national level becomes available. We were unable to identify any guidelines for health organizations using SM to detect public health threats. It is unclear how they should react when they identify a group of sick persons based on their SM discussions: are these organizations allowed to react to or act on this information?

Technical and functional challenges exist related to data volume and there is an increased risk of generating false alarms. Although SM data provides a new source of information regarding public health threats, its analysis and interpretation are challenging. The ambiguity of language makes automatic interpretation difficult: for example, symptoms can be used in other contexts than expected (e.g., “football fever” could produce an alert since the keyword “fever” is used). Such ambiguity could create an additional undesirable workload for epidemiologists due to the a priori large numbers of such false alarms.

Another issue is the quality and reliability of the data as well as the localization of outbreaks. As reported by Goff et al. [7], misinformation regarding infectious diseases is sometimes disseminated through Twitter. The majority of SM users are young people originating from the more developed countries making SM-based information biased and open to the spread of misleading information, as reported by Paul et al. [9]. Dyar et al. [8] found out that Twitter leads to the promotion of some searches and the sharing of information about outbreaks globally rather than locally. This can become misleading as an outbreak can occur in a certain part of the world while information about it is being shared in other parts (e.g. Zika virus).

3.2 Patients as Stakeholders

SM Use May Lead to Negative Patient Emotions

Some of the positive health outcomes reported from SM use include improvements on psychological well-being, social health, and

cognitive health [28-31]. However, despite the observed largely positive patient-reported outcomes (PROs), unintended consequences can sometimes arise from SM-based self-managed support, such as apprehension, frustration, confusion, or dejection.

Apprehension surrounding personal identity disclosure in online environments can manifest from fear of the unknown to concerns of inadvertent interactions with people masquerading as an illness peer [32]. Regarding personal identification, Nordfeldt et al. [33] suggested that the use of SM can not only increase sensations of stigmatization, but it may also create an identity centered on a patient’s disease. This was echoed by Pousti and Burstein [34], who suggested that the use of SM might have a role in self-esteem lowering.

Feelings of frustration have been suggested by Nordfeldt et al. [33]. They reported that when a search fails to retrieve up-to-date relevant information in a timely manner, it can be extremely frustrating to SM users. However, the primary negative consequence attributed to SM use is quite possibly confusion. The studies examined by the authors indicated that SM users may be left feeling confused when an online search returns conflicting information [33] [35]. According to Zebrack and Isaacson [35], this may have a negative impact on an individual’s ability to successfully evaluate information and distinguish potentially useful and helpful information from irrelevant and misleading information. According to Nordfeldt et al. [33], confusion is also one of the main reasons for health-related SM use attrition.

The positive impact of sharing one’s experiences through SM has been reported in the light of the emotionally cathartic effect it has on SM users [32]. However, it has also been observed that certain negative outcomes can arise in conjunction with the generally positive perception of the narrative effect that SM enables. Findings by Merolli et al. [32] highlighted instances of patient comments that include distress, dejection, isolation, alienation, catastrophizing, and desperation related to sharing experiences with others. This suggests that communicating about one’s experiences with illness may have a potentially negatively impact. Pousti and Burstein [34] proposed the term “emo-

tional discomfort” to label this sensation. However, there were few such reports in the articles in our analysis, and the emotional impact of sharing experiences was described as largely positive.

Patient Use of Crowdsourcing Platforms: the Power and Limitation of Crowds

Crowdsourcing allows patients to seek opinions from an online crowd, which can help inform their diagnosis or treatment options. Although concerns arise with fraudulent patients seeking out financial and emotional support from the online community, previous studies have shown that crowds may offer more informed advice than single individuals can, and at times, crowds can provide more accurate opinions than can educated professionals [36-38]. Crowdsourcing can also help uninsured patients in the United States raise funds to pay their medical bills. For instance, one patient raised \$41,032 to cover the expenses of cancer treatment; this patient’s friends shared the campaign information using Facebook and e-mail. Another patient’s campaign was shared on both Facebook and Twitter, and resulted in the raising of more than \$50,000 [39]. However, there are some unintended consequences of crowdsourcing for healthcare, e.g. the accuracy of crowd’s diagnoses, the use of trusted health crowdsourcing platforms, and the privacy and confidentiality related to the sharing of health information online.

Crowdsourcing proponents state that crowdsourcing leads to knowledge discovery and can help solve real problems. The process is collaborative and involves people from different disciplines, which allows for innovation [40]. Despite these promises, our search of the evidence did not find research claims justifying the accuracy of the diagnoses and treatments established when using online crowdsourcing systems. Patients currently use health crowdsourcing platforms as an alternative to professional medical advice, which may cause them more harm than benefits. Without proper evidence, more research is needed to test health crowdsourcing platforms for this use.

Specific to crowdsourcing, there are privacy and confidentiality issues that arise when patients begin to use these kinds of platforms. One of the issues noted by De-

necke et al. is the inability for any legislation to regulate the online sharing of personal health information by patients. The current legislation in European and North American countries only prevents patients' healthcare information from being shared by providers and institutions. Patients themselves are free to share their personal information [41].

Gamified Health Solutions with Social Components: Lessons Learned for their Design

Most gamified health and fitness apps may either have pre-set goals or they let users set their own. For people with special needs, it may be risky to let them follow an app's instructions on their own. If such users receive incorrect training from an app, this may cause injuries or lead to poor performance [42]. To mitigate this risk, healthcare professionals should first approve the goals of gamified health apps according to each person's special health needs.

The social component in competitive gamified health systems may be a strong motivator. This differs from games because games are designed to be played, while gamified systems are meant to be used. When a gamified system is going to be implemented, it is crucial to set limits for those who want to "play the system". It is indeed necessary to establish barriers in order to avoid that people forget for what the system was designed. Otherwise, people may lose track of their initial goal of getting healthier, as was reported by Yeoreum Lee et al. [43]. To solve this issue, we should introduce safeguards that stop people from playing the system. Other types of non-social incentives could be introduced to contribute to these types of personal improvements.

In some gamified systems, patients have to input or track their health data, which may be emotionally charged. If they think their health is trivialized in a game, or if they do not manage to reach their game goals and feel judged by others in the social game, they are likely to abandon it. Ancker suggested [44] that to avoid this, it is beneficial to have fewer game elements and simply retrieve the necessary health data. Pure data tracking will not trigger negative emotions. Another option is to set variable privacy settings, so that each person decides how much and what part of their personal health data they want

to share [45]. Comparison is also an important issue when competing in teams. In two gamified family-focused collaborative health app studies [46] [47], parents complained about the possibility that their children may become demotivated if other families ranked better than theirs did. The extensive usage of gamification creates a tolerance to it. This may negatively impact other non-gamified systems because users will need gamification to become engaged with the system, as Walthouwer reported [48].

Table 3 displays the summary of the unintended consequences of SM and health IT for patients as stakeholders.

4 Conclusions

4.1 Healthcare Professionals and Other Stakeholders

The use of SM tools for health purposes generates several problems and unanswered legal and ethical questions. Although SM can provide many benefits and opportunities, as previously mentioned, its main legal and ethical concerns rely on the risks related to misinformation and maintaining privacy, confidentiality, and the right to be forgotten. Thus, it is necessary that authorities and

governments establish, in collaboration with patients associations and professional institutions, specific guidelines and policies to assist health professionals and help Internet users benefit from the use of SM for health.

The use of SM data has also proven to be useful in monitoring public health and in detecting health threats, such as epidemics. To effectively introduce it in health systems, IT professionals need to create the conditions to sufficiently filter the data, and authorities and epidemiologists need to create the rules and guidelines describing how to react to the signals generated to avoid unintended consequences.

4.2 Patients as Stakeholders

Regarding PROs from SM use within a chronic disease management context, one worthwhile discussion focuses on the relatively small number of studies on the potential negative consequences of SM use (four in total in our analysis). Future SM use in chronic disease research is necessary to address patient-reported issues such as confusion and frustration regarding online information and the need to find up-to-date information in a timely manner. This could have a positive impact on improving the eHealth literacy of the online health consum-

Table 3 Summary of the unintended consequences of health social media for patients as stakeholders.

| | Patients as stakeholders | | |
|--------------------------------|---|--|--|
| | Chronic disease management | Crowdsourcing | Gamified health solutions with SM components |
| Unintended consequences | <ul style="list-style-type: none"> - Being deceived by someone claiming to be someone else. - Creation of an identity around the disease. - Confusion in distinguishing useful from harmful or irrelevant information. - Insecurity about how to introduce oneself online and in trusting others. - Distress, dejection, isolation, alienation, catastrophizing, and desperation when sharing experiences with illness online. | <ul style="list-style-type: none"> - Limitation regarding accuracy of crowd diagnoses. - Privacy and sharing confidential health information online. - Manipulation of vulnerable patients. - Use of trusted health crowdsourcing platforms. | <ul style="list-style-type: none"> - Gamified preset goals do not meet patients' health needs. - Lack of barriers to prevent cheating. - Patients' tolerance to gamification affecting non-gamified systems. - Patients forget the health aim of the system and "play it" instead. - Patient demotivation and low adherence if they do not win, do not reach their own goals, feel judged, or feel their health is trivialized. |

ing public. The consequences of patients' narcissism derived from SM use are worthy of consideration for future research.

Crowdsourcing in healthcare provides patients with the power to harness the knowledge of crowds, and it can result in diagnosis and treatment options, but there remains a multitude of challenges, as previously described. To solve these, we propose the use of trusted health crowdsourcing platforms to provide medical advice to patients, especially vulnerable patients with rare diseases. Vulnerable patients are at risk of being manipulated by unscrupulous health crowdsourcing platforms promising to help them find diagnoses or treatments for medical conditions. Trusted platforms are needed to allow patients to seek medical advice from real patients and healthcare professionals. Mechanisms are needed, such as the HON Code Foundation, to verify trusted health crowdsourcing platforms.

As we saw in section 3, most of the problems concerning gamification and SM may be overcome through proper design. Having healthcare professionals tailor the gamified goals for each patient is highly recommended. Unfortunately, there currently exist no health-specific gamification frameworks, and we encourage future research on this issue.

5 Limitations

The topics discussed were selected by the members of the IMIA SMWG, and their selection may have been biased by members' areas of expertise. Therefore, other relevant topics may have been overlooked in this study. In addition, the aim of this paper was not to conduct an exhaustive review of each topic, but rather the aim was to present an exploratory synthesis of the existing studies and reviews. Thus, deeper research using a homogeneous and systematic methodology is recommended for each topic.

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