

Social media in health – what are the safety concerns for health consumers?

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Abstract

Recent literature has discussed the unintended consequences of clinical information technologies (IT) on patient safety, yet there has been little discussion about the safety concerns in the area of consumer health IT. This paper presents a range of safety concerns for consumers in social media, with a case study on YouTube. We conducted a scan of abstracts on 'quality criteria' related to YouTube. Five areas regarding the safety of YouTube for consumers were identified: (a) harmful health material targeted at consumers (such as inappropriate marketing of tobacco or direct-to-consumer drug advertising); (b) public display of unhealthy behaviour (such as people displaying self-injury behaviours or hurting others); (c) tainted public health messages (i.e. the rise of negative voices against public health messages); (d) psychological impact from accessing inappropriate, offensive or biased social media content; and (e) using social media to distort policy and research funding agendas. The examples presented should contribute to a better understanding about how to promote a safe consumption and production of social media for consumers, and an evidence-based approach to designing social media interventions for health. The potential harm associated with the use of unsafe social media content on the Internet is a major concern. More empirical and theoretical studies are needed to examine how social media influences consumer health decisions, behaviours and outcomes, and devise ways to deter the dissemination of harmful influences in social media.

Keywords (MeSH): *Public Access to Information; Social Media; Safety; Consumer Health Information; Misinformation; Internet*

Introduction

Health information technology (IT) is becoming increasingly important in patient care and consumer decision-making (Hordern et al. 2011). Recent literature has analysed the unintended consequences of clinical IT on patient safety (Black et al. 2011; Institute of Medicine [IOM] 2011; Coiera, Aarts & Kulikowski 2012), but so far there has been little discussion about the safety concerns in the area of *consumer* health IT. The last five years have seen social computing sites like Facebook, YouTube and Twitter gain unprecedented community acceptance, and many similar commercial sites for health are now in operation. However, little is known about the impact of social media on consumer health decisions, behaviours and outcomes, or the quality and safety of these sites.

Social media (e.g. videos, games, blogs, mobile applications, and social networking sites) may overcome many of the reading and writing barriers people experience due to limitations in their health literacy. However, consumers are likely to experience harmful effects when accessing social media that is unsafe, especially when the content is salient. This paper presents a range of safety concerns that health consumers are already experiencing in the social media world, with a case study presented on YouTube.

A case study of safety concerns on YouTube

A recent scan of abstracts on 'quality criteria' related to YouTube conducted in November 2011 across PubMed, ISI Web of Knowledge, PsychINFO and Scopus returned

456 abstracts. Among these were numerous examples of safety concerns on the popular video sharing platform YouTube. We have grouped them into five areas:

Harmful health material targeted at consumers

Pro-tobacco videos hold a significant presence on YouTube, and consist primarily of indirect marketing activity conducted by tobacco companies or their proxies (Elkin, Thomson & Wilson 2010). Although authorities worldwide have joined forces to prohibit tobacco advertising, a review of 163 YouTube videos containing cigarette brands found that 71.2% of these videos had pro-tobacco content (Elkin, Thomson & Wilson 2010). A positive portrayal of smoking is predominant on YouTube (Forsyth & Malone 2010), and tobacco is often presented along with themes of interest that are popular among young people, such as celebrities, movies, sports and music (Elkin, Thomson & Wilson 2010). In particular, smoking fetish videos are prevalent and easily accessed by adolescents (Kim, Paek & Lynn 2010).

Another example of inappropriate activity targeted at consumers in the social media world is the marketing of drugs. While direct-to-consumer pharmaceutical marketing is only legal in the US and New Zealand (Liang & Mackey 2011), all of the top 10 top global pharmaceutical corporations and some illegal online drug sellers have presence in the social media world, such as Facebook, Twitter/Friendster, sponsored blogs, and really simple syndication (RSS) (Liang & Mackey 2011). They use these outlets to market themselves and their top-selling drugs. Furthermore, illicit online sellers

of drugs, herbs, roots, mushrooms, and leaves are active in the social media world, where substances with highly potent qualities and those that may become lethal can be purchased online (Spring 2009).

These are just two examples illustrating the presence of organisations pursuing commercially motivated objectives using social media. It is foreseeable that many other products and services will utilise social media and online social networks in a similar manner to target consumers and influence their purchasing beliefs without adequate control or regulation.

Public display of unhealthy behaviours

Other harmful and pernicious images can be seen on social video platforms, such as people displaying self-injury behaviours, hurting others, or taking drugs voluntarily. Over the last decade, the presence of non-suicidal self-injury on the Internet has grown considerably (Whitlock, Lader & Conterio 2007), especially among young people, with recent research suggesting that adolescents are avid consumers of these videos (Duggan et al. 2011). Lewis and colleagues analysed the top 100 YouTube videos on 'self-injury' and 'self-harm' and found that these videos were viewed over two million times. Viewers rated this explicit, self-harm imagery positively, and many of these videos had been selected as favourites over 12,000 times (Lewis et al. 2011).

Another dangerous behaviour, conducted for a few seconds to achieve the state of euphoria, is the 'choking game'. In this 'game' individuals strangle themselves, either alone or in a group. Obviously this 'game' can cause immediate death or lead to irreparable damage of the brain or other vital organs through lack of oxygen. Despite the risks, millions of young people watch these videos on YouTube, normalising this behaviour and potentially promoting self-harm behaviours among themselves and others (Linkletter, Gordon & Dooley 2010).

In addition to these unhealthy behaviours, there are countless YouTube videos showing people using drugs: injecting themselves with heroin, sniffing cocaine or glue, and using other emerging drugs such as *salvia divinorum* (Lange et al. 2010).

Tainted public health messages

Another phenomenon is that social media have become outlets for organisations, news sources, and consumers alike for channelling and expressing their opinions and points of view on controversial topics (Briones et al. 2011). In the health domain, this often consists of trashing public health messages, thereby reducing the effectiveness of major public health campaigns.

Researchers have interpreted these opposition movements using Conspiracy Theory and Civil Liberties (Briones et al. 2011), concluding that social media outlets such as YouTube have the potential to significantly shift public attitudes and beliefs about a controversial topic in a short period of time. This was illustrated in a

recent publication on the content analysis of videos on the Human Papilloma virus (HPV) vaccine, which found that the majority of videos were expressed in a negative tone, disapproving of the HPV vaccine (Briones et al. 2011), and that most of these opposing videos were consumer-generated content or news clips (Briones et al. 2011). This phenomenon is also apparent across different languages, where another study involving a content analysis of 74 websites in Italian and 114 in English found that 16.2% and 6.0% of the websites, respectively, were opposed to the HPV vaccine (Tozzi et al. 2010).

It is interesting that the first review paper on this subject, conducted in 2008, found that most of the videos on the HPV vaccination were positive (Ache & Wallace 2008). It appears that the negative user comments and posts about the HPV vaccine emerged after a period of time. Health authorities considering the use of social media to promote public health messages need to consider carefully the balance between engaging their target audience, and moderating comments on promotional material. Unsolicited comments, even from a small number of individuals, can have detrimental effects on the effectiveness of public health campaigns, which are often expensive to run and costly to repair.

Psychological impact from accessing inappropriate social media content

Accessing social media content that is salient, with no warnings about disturbing or offensive material, can cause unintended psychological impact on its viewers, especially when accessed by minors without adult supervision. An example of this was published in *The Lancet*, where a six-year old boy about to undergo surgery viewed the full surgical procedure on YouTube without editing or warning, with the result that his parents cancelled the operation the following day (Maskell, Cross & Gluckman 2010).

Other examples of inappropriate social media content include treatment options on prostate cancer, such as prostate-specific antigen testing, radiotherapy and surgery. A recent review of YouTube videos on prostate cancer found that YouTube is an inadequate source of prostate cancer information for patients. At the time of writing, the authors concluded that healthcare professionals should not recommend YouTube to their patients to learn about their condition and treatment options on prostate cancer (Steinberg et al. 2010). In addition, YouTube contains many examples that stigmatise patient illnesses or symptoms, such as epilepsy (Lo, Esser & Gordon 2010) and obesity (Hussin, Frazier & Thomson 2011; Yoo & Kim 2012), causing unnecessary psychological pain to its sufferers and spreading misconceptions about these conditions.

Overall, health professionals need to be aware that patients access social media sites for information about their health, and most of these sites are not regulated (O'Keeffe et al. 2011). Clinicians need to anticipate the psychological impact and misconceptions patients may

already have about their condition, prognosis, treatment plans, and procedures due to accessing inappropriate and incorrect content online. This is especially important with younger patients (Maskell, Cross & Gluckman 2010).

Social media and public policy distortions

In 2008, researchers in Italy found a correlation between a venous insufficiency and Multiple Sclerosis (MS), where an abnormality called 'Chronic Cerebro-Spinal Venous Insufficiency' (CCSVI) was described as the possible cause of MS (Zamboni et al. 2009). These so-called 'ground-breaking' findings immediately attracted the attention of the mass media as this could have meant the first step towards the 'cure' of MS with simple endovascular treatment in the jugular. However, these results have been seriously disputed as the evidence does not support such treatments outside clinical research settings.

However, there is a community of people affected by MS who are major supporters of the CCSVI liberation theory (where liberation refers to the insertion of a stent in the jugular vein to 'cure' MS). These communities are active in the social media world (YouTube, Facebook, blogs), advocating a surgical treatment that has not yet been proven effective. Videos with recoveries post-surgery became popular on YouTube. This movement was particularly active in Canada, where social media lobby groups managed to influence and modify national research agendas in MS, pushing for more research funding into CCSVI in detriment to other more evidence-based research (Chafe et al. 2011). In addition, Chafe et al. alerted the scientific community that research agendas can be manipulated by online communities, and that researchers need to consider spending more effort communicating evidence-based science to the public, such as using social media outlets. Overall, this case highlights the problems faced by researchers when significant research funding decisions are influenced by movements in social media without adequate support of scientific evidence.

Social Media has also been used to facilitate communication between healthcare professionals and policy makers. In Taiwan, Syed-Abdul et al. reported a case where a Facebook group was created to protest about the inadequate staffing situation of medical doctors in emergency departments. Remarkably, the ministry of health joined the Facebook group and interacted with the doctors as part of his effort to reform the staffing situation in the healthcare system (Abdul et al. 2011).

Discussion

Can we learn from regulatory bodies on ways to use social media in a safe and effective manner?

In Australia, there are limited policies to guide and regulate the safety of health consumers in the social media world. One example is the Cybersmart program, which is a national cyber safety and cyber security education program managed by the Australian

Communications and Media Authority (ACMA) (ACMA 2012). This program is designed to meet the needs of children, young people, parents, teachers and library staff, to address cyber safety issues such as e-bullying. However, the initiative is not dedicated to health concerns nor designed for health consumers. Another example is the joint initiative of the Australian and New Zealand Medical Associations (AMA and NZMA) and the Australian Medical Students' Association (AMSA). Together they produced a guide on social media for the medical profession, which presents case studies and advice on ways for medical practitioners and medical students to maintain online professionalism in the social media world (AMSA 2010). However, no guidelines were provided on how to safeguard consumers from experiencing harm in the social media world.

Centers for Disease Control and Prevention (CDC)

In the US, a major public health agency, the CDC, is actively engaging the use of social media to educate and communicate with its targeted health consumer audience. The CDC has recently published social media guidelines outlining ways of engaging consumers in different outlets such as YouTube, blogs and Facebook (CDC 2012). These guidelines are based on their experience to '*reach target audiences with strategic, effective and user-centric health interventions*'. For example, the CDC reported their experience of hosting public health promotion material on YouTube, which they found was more effective in attracting visitors than hosting it on their website (CDC 2011a).

Social media is not just about designing and publishing content; it is also crucial to consider the way content is disseminated because it has the potential to 'become viral' in the online community. The CDC once experienced a significant viral impact with its citizen outreach blog, where its servers collapsed as a result of the volume of visitor traffic. The blog described ways of preparing for a Zombie invasion, with lessons at the end teaching citizens about catastrophe preparedness (CDC 2011b). Although officials have not yet evaluated the impact of these viral campaigns, the CDC has published guidelines on how to address risks in these viral situations and offered advice to mitigate them (CDC 2009). For example, how to address open comments (e.g. defamatory remarks), which may be disseminated; and how to identify malicious 'friends' who want to extract private information from other users (i.e. trolls).

US Food and Drug Administration (FDA)

The open nature of social media also presents limitless opportunities for stakeholders to misuse the online community to promote their products and services. In 2007, the Wikipedia community identified a pharmaceutical company that was editing articles on Wikipedia and deleting side effects of certain medications (Friday 2007). Evidence is also emerging that pharmaceutical companies are sponsoring e-patients

to blog about their diseases, which involves writing about certain classes of pharmacologic treatments and devices in their blog entries without disclosing their conflict of financial interest (Sparling 2011). In response, the FDA has established guidelines on the marketing of medical products using social media (FDA 2011a).

Policy makers face additional challenges with social media. Mobile applications are emerging and being promoted as diagnostic tools and critical data collection instruments for clinicians and patients. However, the efficacy and safety of these mobile applications have not been properly verified through rigorous testing. In response the FDA has recently released a guideline outlining the classes of mobile medical applications requiring approval by the FDA in clinical trials before being made available to users in the market (FDA 2011b). These include: (a) mobile applications that are used as an accessory to a regulated medical device (e.g. viewing medical images on a mobile platform and performing an analysis or process for diagnosis); and (b) mobile application that transforms a mobile platform into a regulated medical device (such as connecting the mobile platform to vital sign monitors, bedside monitors, cardiac monitors, or other similar devices) (FDA 2011a).

Can we improve consumers' skills, motivations and attitudes to make their consumption and production of social media material safer?

The examples presented so far have focused on establishing regulatory frameworks, monitoring standards compliance, regulating software quality, and improving communication flows from public authorities (Coiera, Aarts & Kulikowski 2012). Yet, consumers remain untapped sources who are likely to have a more significant role in detecting potential mistakes, harm, and problems related to health software and misuses of social media.

e-Health literacy refers to the '*ability of individuals to seek, find, understand, and appraise health information from electronic resources and apply such knowledge to addressing or solving a health problem*' (Norman & Skinner 2006; Stellefson et al. 2011). Although social media (such as videos, games, mobile applications) may break down many of the *traditional* reading and writing barriers in health literacy, navigating safely in the social media world requires a new set of e-health literacy skills. In practical terms, not only should consumers be informed of social media channels that are credible for health purposes, they should also be aware of their responsibilities to (a) avoid potentially harmful material, (b) report incidents of discerning content, (c) consider the consequences before commenting and disseminating harmful and disrespectful content, (d) be cautious of commercially motivated objectives, and (e) be aware of undue social influences from other users in the online community.

When producing content, consumers need to be aware of their (a) obligation to be responsible content producers, and (b) consider the broader consequences

when they disseminate content. Encouraging producers to place warnings to advise users of potentially offensive material should become norms of practice to deter the spread of undue harmful effects. In addition, authorities should consider developing versions of standardised media product rating systems for laypersons to classify and rate social media videos, such as the Australian Classification Board (ACB 2012), and the Motion Picture Association of America (MPAA) film rating system (MPAA 2012). Like other areas in public health, *preventing* access and production of unhealthy material is likely to be a more cost-effective approach than providing *treatment* to those who have already accessed unhealthy content.

Can we learn from the Institute of Medicine to develop a scientific approach in designing and monitoring the safety of social media interventions for health?

When designing and developing e-health interventions intended for public consumption, one assumption is often overlooked: consumers may not have the skills or resources to use these interventions (Norman and Skinner 2006). Many social media websites are not designed for people with disabilities (e.g. cognitive impairment, visual problems), preventing parts of the population from benefitting from these interventions. Privacy is also an issue since many online platforms change their privacy policies on a regular basis and users can end up with problems when attempting to delete private information that they published unintentionally. For example, Fernandez-Luque et al. found that many comments on YouTube health videos contained private health information, and in a number of cases, these comments remained after users had deleted their accounts (Fernandez-Luque, Elahi & Grajales 2009).

The recent IOM report outlines 10 recommendations relating to the design, implementation, usability, and safe use of health IT for all users, including patients (IOM 2011). Its recommendations call for cross-disciplinary research towards the design and use of health IT, with a focus on: (a) user-centred design and human factors; (b) socio-technical systems approach; (c) post-deployment safety testing; and (d) policies to govern the use of health IT. Although there is little reference to the safety of social media, these principles are relevant when designing and developing social media interventions for health consumers and professionals.

The IOM also endorses the need for vendors and users to report health IT related deaths, serious injuries, or unsafe conditions (IOM 2011). This is reminiscent of an incident-reporting system initiated by Eysenbach and his team about a decade ago. Named the 'Database of Adverse Events Related to the Internet' (DAERI), its objective was to solicit cases submitted by healthcare providers and patients, and collect reports in lay publications to understand adverse events on the Internet (Eysenbach & Köhler 2002; Köhler & Eysenbach 2002). Although the project is no longer active, the examples

collected are still relevant today, and are likely to be exacerbated in the social media world. These examples include misdiagnosis or wrong treatments due to online prescription of drugs or medical consulting via the Internet, and discontinuation of life-saving treatments due to misinterpretation of Internet information by patients (Eysenbach & Köhler 2002).

Conclusion

This review presents a glimpse of the possible harm that social media can inflict on consumers when it is misused. Social media has the potential to overcome many of the reading and writing barriers in health literacy. However, due to the salient nature of social media and the social influences surrounding its use, consumers and patients are likely to be subjected to greater risks when unsafe content is consumed than in the pre-social media world.

The potential harm associated with the use of poor quality health information on the Internet has been a concern since the rise of the Internet (Bessell et al. 2002; Eysenbach & Köhler 2002; Eysenbach & Kummervold 2005). However, this does not mean that we should not engage in the use of new technologies to improve the way we communicate and learn about health. What is needed is a better understanding of how consumers digest online content, and how potential harm operates and disseminates (Eysenbach & Köhler 2002), especially in the social media world.

More experimental and observational studies are needed to investigate the prevalence and mechanisms of potential harm related to the use of social media (Eysenbach & Köhler 2002). Given the recent progress in scale development for measuring patient activation and empowerment, such as the e-Health Literacy Scale (eHEALS) (Norman & Skinner 2006), Patient Empowerment Scale (Bulsara et al. 2006), and the Patient Activation Measure (PAM) (Hibbard et al. 2004), researchers can use these scales to systematically measure consumers' level of influence (or activation) from accessing social media, and subsequently evaluate the impact on their health behaviours and outcomes (Greene & Hibbard 2011).

From the consumer perspective, incorporating new skill-sets in e-health literacy, such as (a) promoting online etiquette to become responsible consumers and producers of online content, and (b) encouraging the reporting of adverse events on the Internet, should deter the spread of harmful influences in social media. Further, researchers should consider using social media to disseminate their findings, improve the scientific literacy of the public, and ensure research findings and funding decisions are not misdirected (Chafe et al. 2011).

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