

The Role of Social Media for Patients and Consumer Health

Contribution of the IMIA Consumer Health Informatics Working Group

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Summary

Objectives: To provide an overview on social media for consumers and patients in areas of health behaviours and outcomes.

Methods: A directed review of recent literature.

Results: We discuss the limitations and challenges of social media, ranging from social network sites (SNSs), computer games, mobile applications, to online videos. An overview of current users of social media (Generation Y), and potential users (such as low socioeconomic status and the chronically ill populations) is also presented. Future directions in social media research are also discussed.

Conclusions: We encourage the health informatics community to consider the socioeconomic class, age, culture, and literacy level of their populations, and select an appropriate medium and platform when designing social networked interventions for health. Little is known about the impact of second-hand experiences facilitated by social media, nor the quality and safety of social networks on health. Methodologies and theories from human computer interaction, human factors engineering and psychology may help guide the challenges in designing and evaluating social networked interventions for health. Further, by analysing how people search and navigate social media for health purposes, infodemiology and infoveillance are promising areas of research that should provide valuable insights on present and emerging health behaviours on a population scale.

Keywords

Social media, healthcare consumers, patients, health behaviour, social network

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Introduction

The emergence of online social network services such as Facebook and Twitter has enabled consumers to share and exchange information and to communicate with each other. Many of these interactions are not only limited to online social network sites (SNSs) but are emerging on a variety of media and delivery platforms, such as videos, games, mobile and pervasive technologies. These interactions, whether they are intentional or not, have the potential to influence patient outcomes and consumer health behaviours. It has been suggested that these technologies can transform healthcare systems, empowering healthcare consumers to manage their own well-being and management of chronic diseases [1].

We provide an overview of the current and potential use of social media in three populations that span the Diffusion of Innovations [2]. Selected studies are presented to illustrate social network influences on individual health behaviours, facilitated by 1) different types of social media (such

as SNSs, games, mobile applications, and online videos), 2) across different populations (such as Generation Y born between 1977 and 1990 [3], low socioeconomic status populations, patients suffering from and consumers at risk of developing chronic diseases), and 3) from different discipline perspectives (e.g. human computer interaction, human factors engineering, psychology, infodemiology and info-surveillance).

In this directed literature review, we provide the medical informatics community an illustrative overview on social media through snapshots of recent research – from the types of social media, to current and potential users, and to future directions for social media. First, we provide an overview of social media use by Generation Y, an established early adopter and early majority of social media. Then, we look into late majorities and laggards as we discuss the use of social media to address the needs of low socioeconomic status (SES) and chronically ill populations. This review concludes with a call for further research.

Methods

Due to space constraints, we do not provide a systematic review, instead we identify the most influential papers in each area of social media (SNSs, computer games, mobile applications, online videos), and then follow backward and forward citations to identify relevant literature. We aim to inspire the community to: 1) consider types of social media they would not otherwise consider; 2) design for populations in various stages of the Diffusion of Innovation adoption [2]; and finally, 3) to dream about the future possibilities of social media.

We focused on three population groups: Generation Y, low socioeconomic status, and chronically ill populations. Generation Y is recognised as the group that has grown as the technology develops, their use of social media has driven innovative uses that were not thought of when the media first became mainstream. Social media is also seen as a means of crossing the divide that currently exists for low SES populations. For those suffering from chronic conditions social media has enabled them to communicate with others suffering from similar conditions across the globe.

These populations may suffer from (or are at risk) of developing long-term health issues due to 1) lack of physical activity, 2) lack of self-management knowledge and skills, and/or 3) financial and environmental circumstances that do not allow them to practice a healthy lifestyle. They may benefit from use of high-tech and/or low-tech social networked interventions, facilitated by different social media types, supporting existing (or opening) new channels of influence, engagement, and support from a range of social resources for health.

Importance of Social Networks and Impact on Health

Studies reported that peers are one of the most important sources of infor-

mation that influences one's actions and decisions when facing a health matter [4-9]. According to Berkman and Glass [10], five processes facilitated by social networks and relationships have been identified to affect health behaviours and outcomes:

- *Social influence*: how the presence, actions or expectations of others influence the way one behaves [11].
- *Social engagement and attachment*: how social network ties increase engagement and contact with other people [12].
- *Social recommendations*: how social network structure affects one's sources of knowledge and access to resources and recommendations [13].
- *Social contagion*: pioneered by Fowler and Christakis, describes how health behaviours and non-infectious conditions (such as happiness, obesity, depression) may be 'transmitted' by 'person-to-person spread' across social networks [14].
- *Social support*, such as emotional, functional, and informational assistance, are well-documented to influence one's health significantly [10].

Social network studies in health have examined the health impact of *offline* social ties, the web of social relations around an individual, and the nature of ties that connect them [15]. There are few if any studies which have systematically 1) assessed the *online* social processes that can affect health behaviours [16-18], 2) examined elements of social networked interventions that effectively encourage positive behaviour change or reduce impact of negative influences on health, and 3) evaluated the health impact of social processes that is possible through other social media types such as games, mobile applications, and online videos.

Types of Social Media

Social Network Sites (SNS) for Health

There has been an increasing interest in utilising SNSs in the area of health. For instance, Yang and Tang [19] in-

vestigated the "MedHelp" social network, by identifying influential users in the social network according to their messaging patterns on health matters. Jones and Salathe [20] reported attitudes and risk perception of swine flu during the first few days of widespread media coverage in the 2009 outbreak, and found that people's anxiety about swine flu and the preventative actions taken to avoid infection declined as the perceived gravity of the outbreak decreased. Studies from large-scale SNSs for health, such as patientslikeme [21], describe new ways of patients using online social tools (e.g., accessing similar patients' health data to conduct social comparison [22] to learn about treatment experiences and symptom management; [23]). Other studies have proposed new approaches to evaluate the safety and efficacy of drugs using patient-reported outcomes in online patient repositories [24]).

Computer Games for Health

While the mainstream of computer games is meant for entertainment, health games are mainly divided into three types:

1. *Educational health games* emerged in the 1990s, aimed to educate patients and consumers about health. Examples include increased children's knowledge in diseases [25, 26], enhance leukemia patients' understanding of drugs and cancer cells [27], and promote self-efficacy among diabetic patients [28].
2. *Games for self-management* aim to increase one's ability to take care of their health, which are increasingly focused on self-management, where many of the essential ingredients are also present in computer games. For example, i) players seek to fulfill "personal missions" (i.e., goal setting [29]); ii) personalisation techniques such as skills leveling are used to meet the player's needs and wishes (i.e., tailoring [30]); and iii) social features embedded in popular

multiplayer games and virtual worlds such as World of Warcraft [21] and Second Life [31] to encourage social support, cooperation, competition, and peer encouragement [32-34].

3. *Activity games* focus on increasing one's physical activity. Depending on the level of exertion, they are classified as fun games, lifestyle games, or exercise games. Fun games merely serve entertainment purposes and have not yet demonstrated significant contribution to an active lifestyle. Lifestyle games are more demanding and have demonstrated a significant benefit over sedentary activities like TV watching and hand-held games [35-37]. Exercise games approximate the exertion of real-life sports activities and are used for training and rehabilitation. Most activity games for health are based on popular entertainment platforms such as Dance Dance Revolution (DDR) and Nintendo Wii. Studies show that these games enhance the energy expenditure of children [35, 36], where a study with DDR-games used by US primary schools showed promising results in reducing risk factors in overweight children [37].

Unfortunately, most activity games are not easily accessible by the ageing generation, where the prevalence of chronic patients and the need for lifestyle change are increasingly high. Surprisingly, commercial vendors hesitate to invest in this target population. Although there is an established annual conference in games for health which is gaining a lot of interest [38], much research needs to be conducted to ensure activity games are accessible by elderly people and chronic patients with special conditions.

Mobile Applications and Social Health Impact

Mobile technology is getting increasingly powerful and intelligent. Con-

sumer mobile phones are now equipped with a plethora of sensors which can be used to track users' physical behaviour and social networks. Studies on the impact of social networks facilitated by mobile applications on health behaviours are emerging. A study conducted by Madan et al [39] on social influence using mobile phones found that individual weight changes could be affected by the influence and proximity of social ties.

To fully utilise mobile technologies in health behavioural change, we identify three main challenges. Firstly, techniques need to be developed to present massive data to users in a meaningful way. For example one could use graphical charts to present individuals' health status/history, or use virtual worlds to show their health process [40]. Secondly, it is crucial to build into the user interface a mechanism to keep users motivated. Several options appear promising, such as i) enable consumers or patients to see positive improvements of their health, ii) receive social feedback support from family, friends and peers, iii) utilise the concept of social competition [41, 42] to keep consumers motivated, and iv) incorporate computer game-like interfaces to engage attention and maintain motivation [43]. Further, ensuring data privacy and security is particularly challenging on a mobile platform, especially for health. If we are able to overcome these challenges, social networking, coupled with mobile technology, should provide a promising intervention to achieve positive health outcomes [44].

Finally, a key issue in recent studies focusing on the use of smart phones with high quality active sensors (such as camera, GPS, Wi-Fi), particularly for data collection and health information, is the gaps in implementation and assessment of mobile health systems between high-income and low/middle-income countries [45]. Addressing this problem will require a multidisciplinary approach, bringing together health experts and computer scientists to inno-

vate mobile solutions that are acceptable to its users, and inform and influence keystone holders to invest appropriate resources in large scale mobile health solutions.

Importance of Health Videos

Watching online videos is one of the main activities of Internet users [46]. Studies show that videos can be effective tools for health education [47, 48], and online videos are becoming a powerful tool for health communication. Online health videos have become popular with many hospitals, health authorities and patients sharing videos online. For example, the Centers for Disease Control and Prevention (CDC) maintains a YouTube's channel with over 100 videos viewed by more than 3 million times [49]. Further, CDC has recently published a guideline on health promotion using online videos [50].

The most important characteristic of online video watchers is that they share videos with their peers [46]. Thus, facilitating the sharing of videos (e.g., with sharing buttons) is crucial to increase the impact of health videos. Video providers must be aware that the viral dissemination on the Internet also implies that funny and polemic videos may acquire high popularity and receive high rankings. In fact, misleading health information is common on platforms such as YouTube [51, 52]. Unfortunately, providing evidence-based recommendations on ways to use online videos for health promotion is difficult due to the lack of published studies in the field. Most research focuses on analysing top-ranked videos on YouTube [51, 52, 53]. So far, only one research paper addressing videos from patient perspective has been published [54].

Online videos break down literacy and contextual barriers, which are lost with text or graphics only communication, by providing community mem-

bers with a medium to richly convey information. In addition, online videos extend social media because they can be shared in social networks, such as via viewer comments [55] and video responses created by other members of the video sharing community. To our knowledge, there are no published studies on the evaluation of online social videos used for health promotion and education. Consequently, understanding online videos for health promotion is likely to be an important area of research within the field of health social media.

Current and Potential Users

Similar to the findings about online video and game use, it is not surprising that Generation Y are the most active users of SNSs, particularly in health information. We summarise Generation Y use of SNSs, and highlight potential users for future SNSs (such as low socioeconomic groups, patients suffering from and consumers at risk of developing chronic diseases).

Generation Y and Health Information Sharing

Since their introduction, social network sites (SNSs) have attracted millions of users globally. Their use has become so pervasive that millions of people have integrated access to these sites as part of their daily practice. The most visible use of these sites is within the Generation Y group (e.g., those born between 1977 and 1990 [3]). In a recent Pew Internet Report, a telephone survey of 1650 people in the US found that one in five will use an SNS to follow a “friend’s” health experiences, and that among the 39% participants who used an SNS ([56], p24):

- 22% have followed their friends’ personal health experiences or updates on the site.
- 15% have posted comments, queries,

or information about health or medical matters.

- 6% have started or joined a health-related group on a social network site.

Although a majority of these participants are in the Generation Y group, an increasing number of the older population are joining SNSs and benefiting from the friendship and fellowship found online. Yet, few to no studies have reported how different age groups utilise SNSs for health, nor the expectations that different age groups have on SNSs for health purposes (e.g., indifference vs. expressing concerns over matters of privacy in sharing).

Low Socioeconomic Status Populations in Developed Countries

Low Socioeconomic Status (SES) populations stand to benefit the most from advances in low-cost social media technologies designed to promote health-related behavioural change because of their high risk of chronic diseases [57] – a recognised global burden [58]. There has been some work by the human computer interaction community to create guidelines on how to develop applications for low SES populations [59-62], however apart from the work done by Grimes et al. [63, 64], there has been limited research in health related social networked interventions.

We encourage the health informatics community to address the health needs of low SES people and consider the technology available to this population when designing social networked interventions for their health. For example, Grimes et al. [63, 64], used mobile phones where participants called in to leave messages and listen to other participants’ messages, i.e., creating a *low-tech social network*. We also challenge the community to better understand their target population – understanding not only the community

dynamics, but the internal family and cultural dynamics. If digital barriers can be overcome, social media should help low SES populations because these technologies provide the anonymity, asynchronous communication, portability, and convenience desired by low SES people [60].

Chronic Disease Patients and At-Risk Consumers

Due to the combination of an ageing population and the sedentary lifestyle of many young people, the prevalence and risks of developing chronic diseases are increasing. In an attempt to slow down this increase, much effort has been put into physical-activity programs for a healthier lifestyle, both in public health and in healthcare. Behavioral change, however, requires much discipline and persistence. Most physical-activity programs suffer from a lack of compliance. A meta-analysis of 127 physical-activity interventions for older people shows that half (40-65%) of the participants dropped out within three to six months [65].

To increase patient and consumer compliance, activity programs are increasingly focused on self-management rather than behavioural directives. Self-management requires psychological adjustment to one’s illness or risk profile, and one’s sense of confidence to perform that behaviour (i.e., self-efficacy). There is evidence that *cooperation* and *competition* lead to greater self-efficacy. Peers that cooperate, actively encourage, and can see each other’s achievements promote social learning and self-efficacy [32]. Competition with peers has also been demonstrated to improve self-performance on activity tests [33]. The combination of cooperation and competition, delivered on an appropriate social medium, may lead to higher levels of intrinsic motivation and enduring changes to lifestyle management [34].

Future Directions

So far, we have argued for the importance of social networks in health and have identified the major types of technologies that have been used as social media. We have also recognised specific population groups that would benefit most from using such health social media. In this section, we discuss a number of future directions to further social media research in health.

When designing and evaluating social networked interventions for health behavioural change, researchers may benefit from methodologies and theories in human computer interaction, human factors engineering and psychology, to ensure their interventions meet safety and quality standards and that their findings are theoretically-based. Further, the amount of user-generated data on social media and other Internet-based venues opens up a new exciting area of research and development to study the health of populations, known as infodemiology and infoveillance.

Usability of Social Media

Human factors engineering is the field which deals with the interface between systems and sociotechnical influences that affect the usefulness and acceptability of systems [66]. Many specialised patient and consumer populations bring specific challenges to our ability to provide usable interfaces for community engagement and information delivery. This points to the need for customised interfaces and workflows designed to reach individuals with different needs, where each profile of individuals would have the need for an independent validation *usability* study. A usability study evaluates how a particular process (or product) works for individuals [67]. Optimally one would test a population of individuals who are a sample of typical users of the type of process being tested.

When designing social networked interventions for patients and consum-

ers, the usefulness and acceptability of the intervention should be measured from all user perspectives regardless of whether the use case is for consumers and patients to network with their healthcare providers, to network with their carers and family, or to network with similar others. Further, each type of social media presents its unique technological challenges and may require customisation when designing and executing usability studies. Overall, social media that seek to assist with patient care and provide consumer support should be usability tested so that errors related to human factors are minimised, leading to greater patient safety.

Safety and Quality of Social Network

Little is known about the quality and safety of social networked interventions for health [68], both in the hands of users and machine-related errors. Although initiatives such as Health On the Net Foundation are formed to govern the quality of health and medical websites (such as its role in certification of websites with collaborative and Web 2.0 elements) [69], measuring the safety and quality of a social network is complex because the extent of influence of a social network may not be easily captured, tracked or recognised due to the ‘viral’ nature of the network.

To our knowledge, not much is known about ways to assess the safety and quality of a social network, facilitated by social media. A recent study proposed a safety and quality index for SNSs with 28 indicators across four areas: 1) alignment of content with clinical practice recommendations, 2) safety practices for content, transparency and moderation; 3) policies and communication of privacy risks, and 4) sharing of member data and member control over sharing [70]. Overall, ways to measure the ‘viral’ nature of a social network and metrics to assess network influence on patient and consumer safety are still relatively unknown.

Role of Experience and ‘Apomediation’

A current hot topic in the psychology of decision making is the role of experience [71-73] and its usefulness has been discussed recently in the context of making medical decisions with possible rare events (e.g., small chance of side effects) [74]. When making decisions about a treatment associated with risks of rare side effects, one source of experience that healthcare consumers can draw upon is whether they know of someone who has undertaken the same treatment and had experienced the rare side effects. We term this knowledge as *second-hand experience*, as the rare event is experienced by someone else.

We suggest that the notion of second-hand experience may be closely related to Berkman and Glass’s proposed social processes such as social engagement and attachment, social recommendation, and social support [10]. The concept of second-hand experience is also closely related to the notion of “apomediation”, which is the process of replacing or complementing a solitary information gatekeeper (intermediary) with peers and collaborative filtering processes, and “stand by” to provide second-hand experiences and steer consumers to relevant information [75]. This opens up new research questions such as “would a close friend’s experience of a rare side effect influence your decision to get a vaccination despite large volumes of credible evidence describing the benefits and the rare risks of its side effects?” and “what if the experience comes from an anonymous post made on an online forum?”. As social media facilitate consumers and patients with easy access to a variety of second-hand experiences, often read without the aid of a healthcare professional, many questions on the subsequent impact on health decisions, behaviours and outcomes are awaiting to be explored.

Infodemiology and Infoveillance

The possibility to systematically mine, aggregate, and analyse user-generated data to inform public health and public policy is an area which Eysenbach terms as “infodemiology” [76-78] (and “infoveillance” if used for surveillance purposes [78]). The underlying idea is to measure the “pulse” of public opinion, attention, behaviour, knowledge, and attitudes, by tracking what people do and write on the Internet.

A more formal definition of infodemiology is the “science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy” [78]. This information can include for example search or navigation data (“information demand”), or postings (“information supply”) on websites, blogs, microblogs (Twitter), discussion boards, or other social media. It can also include data on what people buy, read, and shop on the Internet, or social networking data (who people are “friends” with) harvested from sites such as Facebook. One example of an infodemiology study classified and monitored tweets during the H1N1 pandemic, illustrating that they contain a wealth of information relevant for public health [79]. By analysing how people search and navigate the Internet for health purposes, and how they communicate and share this information, infodemiology and infoveillance are promising areas of research that should provide valuable insights on current and upcoming health behaviours on a population scale. However, metrics of identifying timely and reliable outcomes, privacy of individuals, and clear governance of data are fundamental issues that need to be addressed to ensure individual identities and personal data are not compromised and that findings drawn about the population are timely, accurate and reliable.

Conclusion

The popularity and growth of social network services among consumers, across different social media types (such as SNSs, games, mobile applications, and videos), provides a great opportunity to utilise the power of social processes to induce behavioural change. As increasing number of people engage in using social media, social networks are likely to change in structure, size and shape, affecting the types of people and resources we are connected with, and the relationships we develop with others. Hypothetically, we can expect one’s health behaviour to change and adapt as social media alter our social networks in the following manner:

1. The crowd around us (or the collective presence, actions, or expectations of people proximal to us) (i.e., social influence);
2. The contacts we develop and the subsequent changes in activities, experiences and relationships we engage in, e.g., via friends of friends, people with similar goals or are in similar health conditions (i.e., social engagement and attachment);
3. The recommendations we receive from those we know, as well as others we do not know, delivered via different forms of social media in different contexts (i.e., social recommendation);
4. The awareness of individuals around us, close to us, or similarity to us, and the impact of their activities, opinions, experiences and beliefs upon our circumstances (i.e., social contagion);
5. The types of informational, functional and emotional support we receive due to changes in our social network (i.e., social support).

We encourage the health informatics community to 1) not miss the opportunity of using social media to promote and influence health behaviours; 2) consider the socioeconomic class, age, culture, and literacy level of their respective populations; and 3) select ap-

propriate technological media and platforms when designing social networked interventions for health behavioural change. More importantly, social media and social networked interventions that seek to provide diagnostic and therapeutic advice have the ability to bring benefits as well as inflict harm onto patients. Human computer interaction errors can unintentionally cause harm (as seen with computerised physician order entry (CPOE) systems) [80], and therefore interventions that influence health behaviours and decisions should be usability tested to minimise errors resulted from human factors. In addition, one needs to be aware of the “viral” nature of a social network, as its extent of influence is not easily captured, presenting methodological challenges to measure and assess the safety and quality of social networked interventions on health.

When designing and evaluating social networked interventions for health, methodologies and theories from human computer interaction, human factors engineering and psychology may help guide the challenge of 1) meeting and respecting individual health circumstances, 2) supporting and monitoring social interaction, and 3) governing the safety and privacy of personal identities and data across different platforms and contexts. We anticipate social media to be natural fits for designing social networked interventions that would influence health outcomes for Generation Y, low socioeconomic populations [81], consumers at risk of chronic diseases, and patients currently dealing with chronic diseases. Yet, without further empirical studies on how (or whether) social media alter our social networks, and the subsequent impact on health behaviours and decision making across different populations, these prospects remain hypotheses awaiting to be investigated.

As massive amounts of data across different social media types can be gathered with relative ease, infodemiology and infoveillance are exciting fields of research that promise to

offer fresh insights about our health on a population scale. However, issues of data quality, metrics to identify timely behaviours and infer accurate outcomes, and protection of individual privacy are important issues awaiting to be clarified and cannot be overlooked.

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