Social Media and Health

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Abstract:
Social media creates online places where groups of people can interact, share, discuss, or collaborate. Facebook and Twitter is now part of everyday life. We investigated the effects of social media on the belief and behavior of its users. We also explored how the NHS, Healthcare trusts, public health services and individuals employ social media to improve health and wellbeing including possible areas for future development. Risks to health are researched and listed. One form is a generic risk related to the general use, this includes addiction potential, cyber bullying, and the spread of risky behavior e.g. Nek Nominating. The other form is related to misuse and misinformation. Finally we studied how to maximize social networks benefits for health and minimize risks. The responsibility is a collective one on both providers and users to root out the bad and allow the good to thrive.

Introduction:
The Internet can be seen as an abstract idea that the majority of us just accept is there without fully understanding its composition. In fairness, the invention of the Internet was not a ‘eureka type’ moment with one inventor, but instead evolved throughout time. The evolution carried on into the late 20\textsuperscript{th} century with the introduction of “packet switching” and “node-to-node” communication. However it was in 1991 when Tim Berners-Lee enhanced the Internet into a “web” of information rather than a file transmitter\textsuperscript{1}. This is known today as the World Wide Web. Since then, the web has become a staple in people’s everyday lives and has advanced technologically from Web 1.0 up to Web 4.0.

In 1998 Tim Berners’ Lee said, “The dream behind the Web is of a common information space in which we communicate by sharing information”\textsuperscript{2}. This dream was not exercised in Web 1.0 and it is web 2.0, which ultimately gets it right and resulted in the birth of social media.

While social media has generally been recognized as an advantageous part of our lives, what impact does it have on our health? We decided to look first at how social media influence its users then how different health organizations and individuals use social media in health. Finally we look at the inherent risks and how to minimize it.

Social Media influence on its users:

The powerful influence of social media has been shown recently in the “Occupy movement” and the “Arab spring”. The homogeneity of an online community is likely to be a product of both “homophily” (tendency for people with similar interest, belief and behavior to cluster together) and “social contagion” (individuals altering their behavior to match their peers)\textsuperscript{3}. Large networking sites such as Facebook or Twitter can have a significant psychological impact on our behavior. This happens by its encouragement of “herd” mentality. Our opinions tend to be swayed by what our online peers think. A recent study has shown that this opinion change is much more likely to happen over a positive online comment\textsuperscript{4}. Other studies however have found trends of negative impact on individuals’ views as a result of an increase in online interaction. By looking at opinion dynamics models in social networks, we can compare people’s intrinsic beliefs before social influence and then after. This showed an increase in error percentage and therefore suggests that people’s views are changing for the worse\textsuperscript{5}. With the above in mind health information, therefore has to be displayed with delicacy and utmost professionalism.
Use of social media by governments, health services and related organizations:

The NHS Choices is a comprehensive web-based resource that covers a wide area, ranging from lifestyle decisions to finding, comparing and using NHS services. It was launched in a preliminary version in late 2013. The website offers information on 840 conditions and treatments. The interactive section permits individuals to check their symptoms against a wide range of conditions and get advice. Performance data for consultants and trusts are published and regularly updated. 

NHS Choices has established a large following on most popular social networking platforms with more than 125 thousand followers on Twitter alone. Its Facebook page keeps the public updated on the latest health news and posts regularly about getting fit, losing weight and improving mental health. It also provides a place for the public to share their own experiences and discuss health topics with others.

Measuring the quality and safety of clinical care through patient's feedback by using social media is one aspect that is currently applied by some organizations. This Internet based patients' rating has been shown to correlate with the conventional survey methods. However the NHS has to be cautious in using such method since the unsolicited web is potentially prone to biases. The news that some NHS trusts' staff pretended to be patients and gave 5 stars rating to their own hospitals have sent shock waves. Despite that patients’ experience acquired on line appear to be distend to become of major value to the public, to the healthcare organizations and possibly to the regulatory bodies. They are likely to compliment rather than replace traditional patients' surveys.

Clinical Commissioning Groups (CCG) manage general practice and allocate resources for its community. One of the NHS smart guides advises on the use of social media as a part of CCG’s strategy to engage, listen and learn from its service users.

Personally controlled health management systems integrate personal health records with care pathways, booking services, communication channels and social forums. They have been applied in diverse diseases like diabetes and inflammatory bowel diseases.

Patient Reported Outcomes (PRO) means self-reporting on medicine safety. By having PRO enabled website, benefits and risks of medicinal products can be communicated through the voice of patients and is one way to realize the full potential of social media in pharmaco-vigilance. The current system of reporting by health professionals results sometimes in under reporting or discordant reporting with the patients.

Public Health Services’ use of social media:

Unfortunately, so far public health services use social media mainly for one way broadcasting of public messages. This is however an underuse as social media has the potential to reach a broader, more diverse audience and can therefore revolutionize the way in which health information is gathered and communicated. Public health workers might talk to mothers’ groups about vaccinations. A Facebook specially created group encouraged gay men to reach out for information about home HIV testing. Public health agencies therefore have
to develop a strategic plan that incorporates best practices for expanding reach and encouraging interactivity.

In 2010, the informal reports from Twitter enabled researchers to track the Cholera outbreak in Haiti more quickly than official sources. The researchers used a public health Internet tool called health map to capture references to cholera in news media and discussion groups between October 2010 and January 2011. The data gathered matched that collected by the Haitian ministry of health however was available 2 weeks earlier. This use of social media therefore can be employed around the world to provide a faster response to an epidemic.

The concept of “network therapy” promises to open a new frontier for use of social media in healthcare. This refers to the purposeful use of social networks to influence behavior as friends who are most similar to us have the most influence on our behavior (social contagion). Potential uses are in treating people with alcohol abuse, help smokers to stop and support obese people with weight loss.

Cancer awareness:
Cancer awareness is key in early detection and prevention. Collaboration through social media can be used to promote it. Support, education, raising funds, sharing testimonies and advocating are the essential elements that shape this collaboration.

Cancer Research UK has invested heavily in social media. A dedicated team manages the charity Facebook page, Twitter account and specialized forum called Cancer Chat. The three platforms work in different but complimentary ways. The cancer chat is a moderated forum that allows people to contact a nurse in confidence over phone or post a message. Cancer Research UK also uses the patients' feedback to inform and influence its policies and campaigns.

Organ donation promotion:
On the first of May 2012, Facebook in USA altered its platform to allow members to specify organ donor status as part of their profile (the Facebook organ donor initiative). A link to complete an official registration and educational links were offered to those considering organ donation. As a result 13054 new online registrations were recorded in the first day alone representing a 21-fold increase over the baseline average. The massive increase on the first day remained high in the following 12 days with no correspondent increase in the usual panels of registration. This novel application of social media may prove effective in other refractory public health problems in which communication and education are essential.

Use of social media to support and help research:
Social media can help identify members of the public who are interested in participating in clinical trials and also bring them in as collaborators. Patients have vested interest in the outcome of research. Sites such as curedtogether.com and patientslikeme.com are designed to support the collection and analysis of patient outcome data to inform both treatment decisions and basic research. Large-scale social media have a role in crowd sourcing, which can be used in epidemiological studies for disease surveillance.
Crowd sourcing and use of social media by individuals:

Individuals have used the web for health related purposes. Crowd sourcing employs the endless capability of the social media to spread a message and collect data. A mother from South Wales posted a video of her baby having a fit on Facebook hoping to get some insight into the child illness. After this created a lot of attention, one seizure specialist suggested the diagnosis that has eluded the boy’s doctor.

Engagement between individuals and healthcare trusts has been shown in Brighton and Hove Maternity Services Liaison Committee. This is a group run by parents for parents and parents to be and use the power of social media to influence hard to reach groups. Through sponsorship from the primary care trust, it has a web site, Facebook page, Twitter account and a blog which are used to inform its users about available services, get them in touch with appropriate healthcare professionals and also answer their queries. Birth at home is being promoted. The Facebook page advertises the availability of midwife services 24 hours a day, allowing hundreds of women to give birth at home each year.

Risks and possible misuse:

Online gaming

While Online gaming might have a positive health benefits such as promoting social interaction and enhancing skills, it can also impair real-world interaction. This in turn can lead to failure in school, family and relationship problems. Furthermore prolonged use leads to Internet addiction and lack of exercise, which adds to the growing obesity burden. Between 1993 and 2012, the proportion of men in UK that were obese increased from 13.2% to 24.4% and from 16.4% to 25.1% among women. Other reported medical problems linked to the excessive use of the Internet includes dry eyes, headaches, sleep disturbance, backaches and Carpal Tunnel Syndrome.

Nek Nominating

In early 2014, an online drinking game called 'Nek Nominating' had taken over the social media. The game requires the participants to upload a video showing them drinking a pint of an alcoholic beverage in one go, and then nominate two other people to participate. It became very popular to post videos in extreme activities such as sitting on the edge of an open window in order to impress their friends. This online peer pressure and the widespread phenomenon have lead to the death of 5 people in UK.

Others have used the Nek Nominating phenomenon to a positive effect such as nominating girls to upload a make-up-less photo on Facebook and to donate £3 to Cancer Research UK. £8 million were raised in six days. This shows how it is possible to turn negative effects of social media into positive ones.

Anorexia and bulimia

Anorexia nervosa is an eating disorder and mental health condition. Anorexia sufferers have a distorted body image. They feel overweight despite they are in fact underweight. Bulimia is another eating disorder where affected people try to control their weight after eating excessively by forcing themselves to be sick or use laxatives. The highest mortality rate of any mental illness is from eating disorders at around 20%. Two thirds of adolescent girls seek health information online with...
a half of them looking for methods to lose weight and a quarter researching information about eating disorders. Pro-anorexia and pro-bulimia websites encourage and motivate users to lose weight by sharing tips, often in an unhealthy manner and to share pictures of emaciated girls as “thinspiration”. These websites provide a sense of community, where support is provided and are portrayed as nurturing and caring, which overshadows the dangers that they entail. A study has shown a correlation between the use of pro-anorexia and pro-bulimia websites and a longer disease duration and hospitalization.

Cyber bullying

Bullying through modern forms of communication such as social media, or text is an easy path to bully, where anonymity is an option. Being a victim of cyber bullying can have an impact on one’s health. Those being targeted put strains on mental health services and suffer from emotional and psychological problems. Victims may feel threatened, helpless or humiliated with consequences such as, attempted suicide, refusal to go to school, running away or becoming chronically ill.

Misuse of health information

Companies are using the social network cleverly for their benefit by utilizing users’ endorsements of their products to evade the limited power of the regulators. Ionic balance is a company that produces ion-emitting wristbands. The manufacturer claimed on Facebook that these wristbands boosted Metabolism and increased stamina. When the UK advertising standard authority ordered the company to stop making such claim because of lack of evidence, the company removed the list of assertions but left and allowed the consumers to post their own messages on its Facebook page. These messages simply continued to propagate the same claim, in the face of which the regulators were powerless due to lack of previous precedence to follow. Moreover some companies hire people to write glowing reviews of their products without being identified or disclosing the relation to the company. As Smith and Jones put it, “Are the social media environment and online platforms becoming the international waters of the web where jurisdictional boundaries are confused and lawlessness prevails?”

Wrong or inaccurate health messages are also common. A review of YouTube video contents and online discussions discovered many risks for consumers including tobacco marketing, direct to consumer drug advertising and publicically displays of risky behavior such as pro-anorexia groups. One study found that the information about alcohol-associated risk for people with type I diabetes on social networks contained inaccurate information. Using web based disease surveillance can get the trends wrong as, for example, Google flu which overestimated the number of Americans stricken with flu in 2013.

Minimizing the risk of misleading health information:

Moderation of comments posted on social media of government’s websites is one example of protecting the consumers. Despite the NHS Choices allows lively debates, the publication of comments are pre-moderated i.e. not published instantly. The moderation policy states that comments will be normally approved for publication as long as they are on the topic, respect other people’s comments, do not insight hatred, reveal personal details or advertise commercial products.

Nuffield council report in 2010 suggested the possible intervention to stop misleading or poor quality information. This included; state provision of good quality
information, voluntary adoption of good practice, third party accreditation, litigation of allegedly false or misleading claims and state imposed standards.

Healthcare professionals are advised on their use of social media by their professional bodies. Doctors are asked to identify themselves as doctors and using their names when advising about professional matters and declare any conflict of interest.

Several guidelines to the public exist on how to assess health information on the web. One report found that the public are discerning in terms of their willingness to trust health information. Following the aftermath of the 2011 Great East Japan Earthquake, rumors spread through social media that consuming large quantities of salt water would reduce potential adverse effects from radiation leak. The WHO however was able to successfully counter these rumors through similar means i.e. using twitter to dismiss the rumors and provide more accurate scientific information. The results were a decrease in the number of messages being circulated advising people to buy salt.

Conclusion:
The second incarnation of the Web (Web 2.0) has been called the “social Web” because its content can be more easily generated and published by users, in contrast to Web 1.0. This announced the birth of social media networks, which create online places where groups of people can interact, share, discuss, or collaborate. These social networks have the power to influence and or change attitudes. Web 2.0 also allowed a more interactive platform between its users, healthcare professionals and health organizations. This has opened a new frontier with endless capabilities to promote health and wellbeing. Currently the main focus is to use social media for distributing information and the collection of consumers’ opinions. However the NHS is heavily investing in the web and online social networks. NHS Choices is the UK’s largest health website. The ambitious project led by NHS England aims to create a new digital, world leading, multichannel service that allows everyone to engage with the NHS and social care. Through the NHS Choices and its Facebook and Twitter, patients are able to look up information on health and diseases, check their symptoms and rate or comment on any service. This helps the public to make informed decisions and encourages healthcare providers to improve services. In Public health, social media is already being used to track disease spread and mobilize responses. This use can be employed around the world to provide a faster response to an epidemic. Cancer awareness, organ donation and support to research are all gaining grounds on social networks. Individuals employ Facebook and Twitter for crowd sourcing and in search for answers to their health problems. Network therapy can be used in the future to tackle some of the most costly and damaging diseases we face in the society. This new frontier created by social media, however is not a without risks and opportunists. There are two different types of risks to health. One is a generic risk related to the general use of the Internet and social media. This includes addiction potential, cyber bullying, and the spread of risky behavior e.g. Nek Nominating and anorexia promoting groups. The other is related to wrong, misleading or false health messages. Quality and scientific validity of discussions on social networks are of an extremely wide variety. Interest groups and industries are free to intervene online for their own ends with claims of cure, magic bullet treatment or false promises. Users generated contents and endorsements are not regulated and only if the company uses them in its marketing strategy, they remain
on the Internet propagating the false message. Lack of oversight of information on
the Internet and the limited powers of regulators raises a collective responsibility on
both providers and users to ensure that health information and health related
discussions are true and reliable. Responsibilities to root out the bad and allow the
good to thrive. Pre-moderation of comments on NHS choices aim not to sensor
views but to ensure comments are relevant and that the website is not being
spammed or used for commercial or political reasons. Voluntary adoption of good
practice, third party accreditation, litigation of allegedly false or misleading claims
and state imposed standards are some suggestion by the Nuffield council. Finally
there is also a very important role on the public to weigh the information and check
its validity before they believe it, spread it or act on it.
References:


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