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ANALYSIS

Social networks, social media, and social diseases

Use of social media in healthcare is increasing. **Enrico Coiera** argues that it has the potential to change not only the way we deliver care but also the way we treat some diseases

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Social processes underpin everything from our lifestyle choices, our health decisions, to the way healthcare is conceived and delivered. Social media—information tools that both exploit and celebrate our social nature—are beginning to be used across healthcare, and proponents see this technology reshaping everything from disease management to biomedical research. However, social media could have an even stronger role, enabling us to treat socially shaped diseases such as obesity, depression, diabetes, and heart disease. In this article I outline the growth of social network thinking and describe several current uses of social media in healthcare before describing how our understanding of social networks and media could be harnessed for this stronger role of treating socially shaped diseases. I also end with a caveat about the dangers of social media.

Social networks and social media

Social networks are a way of representing the ties that bind us as individuals into families, groups, organisations, and societies.[1] With the realisation that even weak social ties have the power to influence,[2] social network research has grown dramatically (box 1). The past decade has seen a growth of over 50% in the literature on social networks in healthcare.[3] Social networks underpin the way physicians seek advice from each other[4] and adopt new drugs,[5] the way that evidence propagates,[6] and the diffusion of safety and quality practices.[3]

Social media differ from traditional broadcast media because they directly support or create social networks using information and communication technologies.[11] Social media (which include familiar ones such as Facebook and Twitter) are a diverse and rapidly evolving cluster of technologies that create online communal spaces where groups of people can interact, discuss, coordinate, or coproduce. The social structures and networks of these online communities are as diverse as human social structures and can be anything from loose, open, and opportunistic through to closed, tight, and secretive. It is this capacity for social media to create loosely aggregated coalitions of individuals who share a short term common purpose that often captures attention. The role of social media in the Occupy movement, whose protests against inequality spread rapidly around the world, and the civil unrest in the Arab Spring are two recent examples. Crowdsourcing, which seeks contributions from online groups to solve particular problems or elicit information,[12] is another powerful tool of social media that has potential in healthcare (box 2).

Using social media in healthcare

Social media are already being used in many different ways across the health sector, allowing old things to be done in new ways and creating entirely new models of delivering care (see examples below). However, the ways in which health professionals use social media in daily practice remain underexamined.[15] One study of the Twitter accounts of US physicians reports that although clinicians shared medical information with the public in a potentially beneficial way, there were also breaches of privacy and ethics.[16] Concerns about public social media not conforming to the security and privacy rules for health information have led professional organisations to develop policies on appropriate use.[17] Nevertheless, recent experience indicates that the application of social media in supporting health services is bearing fruit.

Measuring the quality and safety of clinical care—Patients and their families are a potent source of "signal" about the quality of healthcare,[18] and social media can be used to tap into this information.[19] For example, crowdsourced public ratings of health service safety and quality found on the internet correlate with more traditional quality measures,[20] as well as hospital mortality and infection rates.[21]

Emergency services—Social media are being used both to broadcast emergency information and to track unfolding events using the first hand accounts of citizens in disaster areas, which are often enriched with video, audio, and GPS location data.[22] Sites such as Facebook can help establish emergency communication cascades and buddy networks or communicate emergency room locations and current waiting times to citizens. Twitter was heavily used by US government agencies during the Deepwater Horizon 2010 oil spill[23] and was an important source of information about the unfolding Fukushima disaster after the 2011.[24] The Red Cross has developed smartphone apps

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Box 1: Social contagion

People tend to have friends who are similar to themselves—in interests,[7], beliefs, and behaviour—a phenomenon known as homophily.[8] The big debate in social network research has been whether homophily is simply the result of similar individuals clustering ("birds of a feather") or whether it is the result of individuals altering their behaviours to match those of their peers—social contagion.[9] Recent controlled experiments suggest that both forces are at work and reinforce each other. For example, diffusion of the use of a simple diet diary was strongest in more homophilous networks,[10] suggesting that the friends who are most similar to us have most influence on our behaviour.

Box 2: Crowdsourced healthcare

Salvatore Iaconesi is an academic who teaches digital design. His response to his diagnosis of brain cancer was to put every medical record and every scan on his blog.[13] He published his medical history to seek the collective wisdom of the online crowd, in search for an "open source cure" for his glioma. There was a deep, immediate, and very human response. Hundreds of thousands of people visited his site, leaving videos, poems, and their own stories.[14] Among them were more than 90 doctors and scientists who offered him their expertise, including a geneticist who offered to sequence the genome of his tumour. Salvatore's story seems brave today but heralds new forms of engagement between patients and the health system.

that help people create an emergency plan and share it with others.[25] During the 2010 Haiti earthquake social media facilitated interactions between the multiple agencies that responded. Wikis (collaborative workspaces that allow many people to contribute content) facilitated knowledge sharing, bypassing traditional formal liaison structures that previously blocked such interaction.[26]

Public health and health promotion—So far, public health services seem to use social media mainly for one way broadcasting of public messages.[27] Social media have the potential, however, to reach a broader, more diverse audience and provide new mechanisms to foster engagement and partnerships with consumers around health promotion.[28] As we will see below, online communities can help with behaviour change, such as in smoking cessation.[29]

Disease management—Social media can directly support disease management by creating online spaces where patients can interact with clinicians and share experiences with other patients. Cancer patients use Twitter to discuss treatments and provide psychological support,[30] and online engagement seems to correlate with lower levels of self reported stress and depression.[31] Personally controlled health management systems integrate personal health records with consumer care pathways, booking services, communication channels such as email that link consumer with provider, and social forums where consumers can ask questions and share experiences. They have been applied in diverse settings such as in vitro fertilisation[32] and mental health and wellbeing support.[33] Early evidence suggests that they can shift consumer behaviour. For example, in a randomised trial where consumers were provided with vaccination information, social feedback, and tools for online booking, influenza vaccination rates were significantly higher than in the control group (11.6% *v* 4.9%), as was the rate of health service visits (29.5% *v*. 17.9%).[34] Research is ongoing to understand what the right bundle of components might be in different settings and tasks.[33]

Social media and research

Social media are also beginning to transform the way we conduct and translate research. Social media can help identify members of the public who are interested in participating in clinical trials[35] and, more interestingly, bring them in as collaborators.[36] Patients have a vested interest in the outcomes of research and are displaying a clear appetite to share medical records and data they collect with the research community. Sites such as curetogether.com and patientslikeme.com are designed to support the collection, aggregation, and analysis of patient outcome data to inform both treatment decisions and more basic research.

Large scale social media sites such as Facebook and Twitter also have a role in crowdsourcing patient level data—for example, contributing to disease surveillance and epidemiology.[37] Tweets are a valuable channel for disseminating health messages during pandemics, and analysis of tweets can track pandemics in real time.[38] Similarly, analyses of search terms in Google have been used to predict flu outbreaks, although the predictions require recalibration as search behaviours change. Increased awareness of the disease among the US public during the recent flu season triggered higher than expected web searches and an overshoot in the prediction of the number of likely cases.[39]

As calls for data from clinical trials to be made public grow,[40] the online social collaborative model will also change the way researchers engage with each other and with the public. Today researchers gather their data, analyse them, and publish results, but the data remain behind academic or commercial walls. In the social collaborative model, research data are placed in open, perhaps publicly funded, databases, where others can access and reanalyse them or pool datasets to answer new questions.[41] The community can formulate research questions, suggesting analyses and interpreting findings. In one recent example, the task of aligning multiple gene sequences was turned into a computer game that ordinary web users could play with minimal knowledge of the biological context. This approach reportedly led to a 70% improvement in the accuracy of sequence alignment.[42]

Network therapy

As promising as it all is, the current use of social media in healthcare services may not be exploiting its true potential. For those diseases that are socially shaped, social media could be used to directly intervene in their primary pathological pathway, hastening the arrival of what some are calling network medicine.[43] For this strong social media hypothesis to hold, several conditions must be satisfied:

- The pathogenesis or spread of a disease must be mediated by social networks
- These "offline" social networks can be manipulated to treat the disease
- Online social networks can mirror the offline networks and then substitute for them
- The online networks can be manipulated to change the behaviours that cause disease.

Social diseases—A growing body of research shows that a substantial proportion of the burden of disease is directly mediated by social networks. Many major "non-communicable" conditions are nothing of the sort. Obesity, smoking, alcohol

consumption, and depression have all been shown to "spread" along social networks,[44-46] as have patterns of health screening, sleep, and drug use.[9] Our rate of becoming obese, for example, is estimated to increase by 0.5 percentage points for each obese social contact we have.[44] It is not that obesity or depression are literally spread by social contact, but the norms and behaviours that lead to them. Our individual lifestyle choices are shaped by the behaviours of those with whom we have close social ties, and these behaviours propagate along the networks created by these ties.

Network therapy—Network interventions are the purposeful use of social networks to influence behaviour. They seek to harness network properties such as social contagion to target individuals, organisations, communities, or indeed whole populations.[47] Network therapy has long been used to help manage alcohol and substance misuse—for example, using members of an individual's network to provide social support.[48 49] The design of network intervention depends on its goals (box 3). During an epidemic, interventions designed to increase infection control would be different from those aimed at identifying and isolating infected individuals.

Online social networks—Online ties are real. Just as in offline relationships, those close to each other in online networks share common interests.[7] Although the choice of social media used differs by tie strength (different groups have their preferred ways of interacting online), what is communicated between them does not vary with the medium chosen—for example, work-only pairs talk about work.[54] Social media also allow new relationships to develop by facilitating previously unavailable interactions. Experiments with "matched health buddies" show that participation in online health forums is more likely when individuals receive social reinforcement from multiple buddies in their social network.[55]

Network substitution—For social media to work as a network intervention when existing social structures are the problem, we need evidence that they can step in as a substitute. Young adult cancer survivors seem to use social media in just this way, to fulfil needs that are not being met in their offline lives.[56] Use of social media was higher among those whose pre-existing social support was low, with little social support from friends and family, lower family interaction, and weaker social bonds. More generally, Facebook provides a mechanism for maintaining existing ties as people move on from social settings such as college. And there is good evidence that network substitutability goes both ways. When relationships formed online reach a certain strength, they often translate into offline ones.[57]

Online network therapy—There are now multiple lines of evidence that online networks can change offline behaviour. Early evidence suggests engagement with online communities is associated with a reduction in anxiety and depression among patients with cancer through increased social interaction.[31 58] We also know that consumer opinions about the meaning of health information they read on the web can be shaped by the views of others on the web.[59] A huge randomised controlled trial involving 61 million Facebook users over the 2010 US congressional elections showed that online political messages directly influenced voting behaviour. Messages shared through social media were significantly more effective than targeted messages and most sharing occurred between close friends with a face to face relationship.[60]

Caveats

Any new technology brings potential risks. One analysis of online social networks in diabetes found wide variation in the quality and scientific validity of discussions and in auditing, moderation of discussions, and governance.[61] A review of the video content and online discussions found on YouTube found many risks for consumers, including tobacco marketing and direct to consumer drug advertising, public displays of risky behaviour (such as pro-anorexia groups), and the "tainting" of public health messages by negative opinions.

As exciting as the prospect is of designing network interventions that will benefit individuals, today vested interest groups and industry are free to intervene online for their own ends. We will need to think through whether social network interventions in healthcare take place in these ungoverned public commons or in more controlled information spaces where consenting patients agree to freely engage in social networks that they know are there to help.

Conclusion

At present the focus in healthcare is to use social media to support clinical practice and consumer engagement. But we have a much bigger opportunity to use social media to tackle some of the most costly, damaging, and intransigent disease challenges faced by society. Social shaping of human behaviours exploits a human need to conform and to imitate those in our close social group. Online social media provide a powerful vehicle to redefine social ties and reshape individual views of conformity and normality.

McLuhan famously contended that "the medium is the message"—that is, the way a medium structures human interactions is at least as important as the things we say over it.[62] Technical systems have social consequences, just as social systems have technical consequences.[63] When it comes to online social media, the technical and the social are becoming one. If we can directly harness social media to change the behaviours that lead to disease, then the medium becomes the medicine.

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Box 3: Network interventions

Social networks can be manipulated in various ways, depending on the state of the existing network and the goal of the intervention[47]:

Individuals—Influencing "champions" who are central to a network can lead to an increase in the diffusion of evidence based practices.[6] When the desired change requires diffusion across networks then the target may shift to bridging individuals who span them[50]

Groups—Some behaviours result from group norms, and the only way to change the behaviour of individuals is to target the whole group—for example, communities of practice, such as a multiprofessional team assembled to improve safety and quality at a hospital[51]

Network induction—Word of mouth, snowballing, and "viral" interventions seek to propagate information widely by stimulating communication among social network members. HIV prevention messages, for example, seem to be distributed more effectively when a peer network is used rather than traditional public health messaging methods[52]

Network alteration—When existing networks are unable to support the desired change, they can be manipulated, adding or removing individuals or changing the nature of connections. Changing the social network of alcohol dependent patients from one supportive of drinking to one supportive of abstinence seems to be both effective and sustainable over the long term[53]

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