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Corey Allen Heidelberger
Dakota State University

Omar F. El-Gayar
Dakota State University

Surendra Sarnikar
Dakota State University

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Online Health Social Networks and Patient Health Decision Behavior: A Research Agenda

Cory Allen Heidelberger
Dakota State University
caheidelberger@pluto.dsu.edu

Omar El-Gayar
Dakota State University
Omar.El-Gayar@dsu.edu

Surendra Sarnikar
Dakota State University
Surendra.Sarnikar@dsu.edu

Abstract

Patients and health care practitioners alike are using the Internet and specifically online health social networks to gain access to knowledge and social support that they could not obtain as quickly or efficiently from their traditional face-to-face social networks. Given concerns about the quality of information available on the Internet and the differences between social interaction online and offline, it is important to determine whether this new phenomenon influences health decision behavior. We propose a framework for investigating the influence online health social networks may have on the health decisions that patients and their physicians make. We also propose a number of research questions that flow from this framework.

1. Background

Online social networks have quickly become an important part of many Internet users' lives. The phenomenon is sufficiently new that research remains to be done on how this form of interaction may affect individuals' social relationships and behavior.

Among questions worth exploring is the potential influence of online social networks dedicated to health issues on the health decision behavior of their users. Health social networks are those websites providing users the opportunity to access, share, and contribute to health resources at a number of different levels [adapted from 35]. Health social networks form around shared interest in a specific health condition like obesity or cancer, a specific area of health care like children's medicine or hospice, or health information in general. The key characteristic of an online health social network is interaction that can support sharing knowledge and/or providing emotional support for individuals dealing with health-related questions and problems affecting themselves or other people they care about. Health social networks like PatientsLikeMe (www.patientslikeme.com), CureTogether (www.curetogether.com), and CarePages (www.carepages.com) increase by at least an order of magnitude the amount of health-related information and avenues for social support that patients can access compared to what most traditional, offline social networks provide [35]. Whether individuals can and do marshal these expanded cognitive and emotional resources in ways that impact their health-related decisions, as well as the extent to which any such impact is positive, would be useful for patients and health care practitioners alike, not to mention the designers and entrepreneurs behind health social networks.

To investigate this problem area, we propose a framework for understanding how online health social networks may influence patient health decisions. We first review findings in the study of traditional and online social networks, with particular attention to health decisions and outcomes. We develop the proposed framework, then sketch a corresponding research agenda. As researchers with a particular interest in rural issues, we include a brief discussion of this research framework and agenda in the context of rural communities.

2. Literature review

The positive relationship between strong and supportive social relationships and health outcomes—and conversely, the negative relationship of isolation and limited social networks with health—is well attested [3, 19, 23]. In a detailed longitudinal study, Christakis and Fowler [8] found clear network effects on obesity; however, their analysis did not identify specific decision-making behavior that might be shaped by social networks. Loss of a significant member of one's social network has negative relationship with health [7]. Strong social networks have shown strong correlation with decreased risk or mortality from diabetes among elderly patients [38]. Significantly, while the correlation between social support and health is strongly established, research still has not determined the causal relationship between social networks and health or the mechanisms by which social networks influence a number of psychological processes, including decision-making [9].

Traditionally, health care professionals are the primary source of medical information for patients.

However, patients do turn to their social networks to seek information. As one might expect, the quality of information from a circle of friends and family may be uneven [10]. Nonetheless, research has found social networks have a significant effect on health decision making [14, 27].

Online social networks are a technological extension of social networks. While there are reasonable concerns about the quality of health-related data available on the Internet, 61% of American adults look online for health information; 42% of all adults report being helped or knowing someone who has been helped by medical advice or health information found online, while only 3% report having been harmed or knowing someone who has been harmed by such information [17]. This result suggests that, at least in the perception of users, online health information is mostly either useful or harmless. 13% of users of online health information report their most recent online health inquiry had a "major impact" on the way they care for themselves or someone else; 44% report a minor impact; 41% report no impact [17]. This result suggests online content can indeed influence decision-making, although it does not (and arguably cannot) ascertain the extent to which those decisions differ from decisions the actors might have made without online input. Only a small minority of individuals who seek health information online use social networking websites for that purpose; nonetheless, individuals who seek health information online are more likely to engage with social media [17]. Among questions not answered by the preceding research is the extent to which social networking websites differ in the quality and impact of their information on user decision-making compared to online information in general (which comes from the broader, much more diffuse social network that the Internet as a whole constitutes) and information obtained from traditional offline social networks.

Research on the online health community PatientsLikeMe has shown such a community can serve as a platform for members to share personal health information and use that shared information to seek and offer advice and foster relationships [18]. This research demonstrates apparently positive information-seeking behavior by patients, though as in the case of social networks overall, such relationships are still not fully understood [35]. Eysenbach [16] speculates that online social networking may mitigate attrition in e-health self-monitoring and health improvement programs. However, the preceding literature fails to establish whether and the extent to which information seeking and sharing in online health communities influence health decision-making behavior.

In studying relationships between online social network engagement and health care decision behavior, it is worth noting concerns that online social networking may replace traditional social network activity and weaken the social support that correlates with various desirable health outcomes [25]. The idea that increased online social networking might increase loneliness and lead to unhealthy behavior as users engage more with pale computer-screen shadows of their former face-to-face interactions fits with conventional conceptions of Internet use as a mere extension of previous forms of passive electronic media consumption (e.g., television). However, that conception (advanced in papers such as the popularly cited [32] is not strongly supported by contemporary research that recognizes the increasingly interactive nature of online activity (a point [32] misses: see [2]. Any negative social or psychological effects of online social networking uncovered during the early stages of Internet adoption appeared to dissipate in follow-up research [22]. Loneliness does not appear to predict a preference for online social activity or total time spent online [5, 33]. Among older people, greater use of the Internet to find new people has demonstrated a relationship with greater emotional loneliness, but greater use of Internet communication has demonstrated a relationship with less social loneliness [34]. Among college students, online social networking is positively associated with social capital and psychological well-being [13]. Valkenburg and Peter [37] review a decade of research and find that, while early Internet use may have reduced social interaction, increased adoption among adolescents has made it easier for their online social network engagement to support their offline social activity. None of this research establishes clear relationships between online social network engagement and decision behavior (health-related or otherwise), but this stream of research does suggest that online social networking does not reduce social connectedness and weaken previously demonstrated relationships with positive health outcomes in a way that would confound efforts to determine relationships with health decision behavior.

3. Research framework

Figure 1 depicts a conceptual framework investigating influence of online health social networks on health decision behavior. In the absence of online health social networks, patients make their health decisions in the context of two major influences: their traditional (usually face-to-face) social networks and their physicians. Traditional social networks provide social support that influences decisions and patient attitudes about them. Traditional social networks can

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also contribute to the knowledge patients can bring to bear on health decisions; however, physicians usually occupy a much greater role, often a unique authoritative role, in providing relevant health information about patient conditions and treatments.
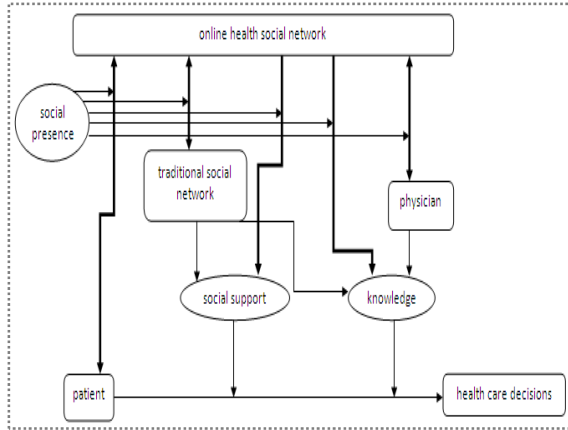

Figure 1: Framework for investigating influence of online health social networks on health decision behavior

Online health social networks are an extension, not a replacement, of patients' existing social networks. Patients and members of their traditional social networks may interact in online health social networks as well. Patients' immediate friends and family may use online health social networks as a supplemental channel through which to communicate with patients and provide additional knowledge and support. Online health social networks may provide patients with social support from individuals who are geographically distant but emotionally and experientially close to the patients. New acquaintances made through online health social networks may become part of traditional social networks as they choose to enhance their relationships by meeting face to face.

Physicians are not excluded from online health social networks, either. Within appropriate professional boundaries, physicians may find constructive ways to engage with their patients in the online context as well as in the traditional contexts of office visits and face-to-face treatment in health care facilities. Through online health social networks, physicians may learn sooner about patient conditions, complaints, or behaviors; this knowledge may more fully inform diagnoses and prescriptions.

The ability of online social networks to provide social support and trustworthy knowledge depends in part on their ability to support social presence, the awareness users get that they really are interacting with other members of a social network [31], not just reading or typing words on a screen. The absence of face-to-face interaction suggests that online social

networks will always be deficient in positive outcomes related to social network engagement in general; however, the increasing integration of online social networks into our daily social and knowledge-seeking activities may reduce any such gap [28]. Such compensating behavior is seen in social networks employed in such critical fields as battlefield intelligence: stateside Air Force officers communicate observations and warnings from spy planes and drones to Marines in combat in Afghanistan. They use perhaps the least socially present social networking tool, a bare-bones text-only chatroom, but the soldiers build rapport with personal conversations and supplementary channels like Facebook and the telephone [12].

Online social network users can produce social presence via self-presentation [1]. The resulting social presence and concomitant trust are central to effective, satisfying social interaction and deeper relationships among community members [6, 26].

In some settings, traditional social networks may not be able to develop sufficiently to support health care decision behavior. For example, in a remote rural community, a patient with a particular form of cancer or undergoing a particular treatment may not have regular face-to-face contact with people in his small and geographically isolated community who can share knowledge and experiences about those specific health issues. A rural doctor may not have regular face-to-face social interaction with fellow professionals to discuss medical issues, new research, or the practical implications of new health insurance regulations. Where traditional social networks fall short, online social networks may provide vital knowledge and social support. Even if online social networks lack some level of social presence, it is important to determine whether online social networks can provide "just enough" social presence to bring the apparent benefits of social networks to rural areas and other places where geography and other factors may hinder the formation of traditional social networks [36].

Our objective is thus to explore whether online social networks can complement existing social networks in providing support for healthcare decision making, and whether they can exhibit relationships to positive outcomes that are not achieved by traditional social networks.

Health decision behavior in the context of social networks makes sense when we recognize the social dimension of decision-making. Working from the example of health care decision-making for children, Buetow [4] offers a framework for distributed decision-making that recognizes the dual nature of decision-making as both individual and social. Buetow's model assumes a relatively strong network, where a "family" is relatively deeply invested in the health outcomes of fellow members and will exhibit

some level shared authority and collaboration in making decisions. In health social networks, online community members can indeed develop close relationships and possibly even refer to each other as "family." They can derive emotional and social support and empowerment from sharing their health experiences with other community participants [35]. But those connections are unlikely to translate into any sort of group decision-making in the context of the online social network itself, at least not immediately. The online social network currently extends an individual's social network, which is granted influence but not authority in individual health care decisions. Those decisions will still take place in the combined individual-social context of the individual's most immediate family or social network, in coordination with health care providers, whose role in the decision-making process may range from paternalism to partnership [35].

This model is not static; Swan [35] can see health social networks following the same stages of social network activity outlined by Shirky [30]: first sharing (where health social networks clearly are now), then collaborating, then organizing for collective action, perhaps in issuing calls for research or negotiating group health insurance plans. Such collective agency could profoundly change the nature of health care delivery and policy, but it also lies in the realm of group decision making, beyond the realm of the discussion here of influence of social networks on individual health decision behavior.

Swan [35] identifies four key dynamics in the evolution of the health care delivery model in response to expanding health social networks:

1. Health social networks facilitate more patient engagement and more collaborative decision-making. The role of doctors and other health care professionals is shifting from "sole custodian of medical data" [15] to "one of many input sources" [35].
2. Health social networks require institutions to change: providers must learn about and adapt to the new information tools patients have available.
3. Health social networks can aid patients in managing the information explosion. Done right, health social networks can respond to the need for "value-chain participants to help consumers navigate and interpret" the wide variety of sources online. Health social networks also give users the opportunity to process this information themselves, discussing it with other interested individuals and constructing their own practical understanding.
4. Health social networks manifest a "patient-driven relaxation of privacy." Ungoverned by privacy regulations, patients can and do inject their personal medical information into online discourse, allowing them and fellow discussants to put medical information into very personal contexts.

The second point above highlights the fact that this evolution in health care and any influence on decision-making from health social networks will depend on physician willingness to adapt to this model. One limited study finds patients who publish health information online report generally neutral (55%) or positive (33%) reactions from physicians when the patients share patient-generated online content with the physicians [24]. Some evidence shows physicians adapting to and engaging with online social networking tools [35]. Engaging with online social networks may not necessarily translate into an embrace of the content there; physicians may do well to engage with social networks to identify prominent yet inaccurate content and prepare effective strategies to neutralize the ability of bad advice propagated through a network to influence health decisions [20]. Any investigation of the influence of social networks on health decision behavior by patients must also account for physician acceptance, "veto" power, and sometimes well-advised counterprogramming.

These observations lead us to propose the following framework for investigating the possible influence of online health social networks on health decision behavior. Pre-Internet, patients made health decisions in the context of social support and knowledge from their traditional, face-to-face social networks. Patient knowledge is influenced even more strongly by physicians, who are the primary if not sole source of health information specific to patient conditions.

5. Research agenda

We know there is some connection between social networks and health outcomes. We don't know what that connection is or which way it runs causally. Exploring and explaining that connection is a complicated task, given the multitude of individual and environmental factors shaping health outcomes. One step toward this understanding is the analysis of the influence of online health social network engagement on decision behavior. Both patients and doctors can be users of health social networks; the influence on both groups' decision behavior is of interest. The above framework thus serves as a basis for investigating the following questions:

1. Does greater social presence in online health social networks translate into greater influence on users' health decision behavior?

2. If there health social networks influence health decision behavior, to what extent does that influence flow through social support and/or knowledge from the network?
3. What online and offline strategies do users of health social networks use to enhance social presence?
4. Do online health social networks influence patients differently from physicians?
5. Does social presence mediate the decision-making influence of online social networks differently for patients than for doctors?
6. Do patients who more actively engage health social networks perceive less paternalistic, more partner-like relationships with physicians in their health decision-making process?

One subfield of inquiry pursuable under this framework is the use of health social networks in rural settings. Rural areas appear to rank lower on various measures of health than suburban and urban areas [11, 21]. If online health social networks extend traditional social networks and influence health decision-making, rural residents and especially rural health care providers may derive greater benefit from such networks than their urban counterparts. Rural social networks may be every bit as strong and supportive as urban networks. But in the area of health decisions, rural residents may find it more difficult to find people within and via their traditional social networks who have useful specific knowledge. Patients may find only one or two other people in their small town or county who have experienced a similar medical condition or undergone a similar treatment. Physicians, especially small-town practitioners who may be the only doctors in their communities, may lack fellow professionals with whom they can consult (or just commiserate) face-to-face. Online health social networks give rural patients and practitioners an easy avenue by which to seek knowledge and make new social connections that would not be available within their more isolated geographical contexts.

The researchers note that their own rural state may be fertile ground for investigations of the use of online social networks in health care decision-making. One much quoted analysis of social media engagement finds South Dakota has the highest statewide rate of adoption of Facebook in the United States, 31.1% [29]. On the one hand, this figure reminds us that seven in ten South Dakotans do not participate in the most popular online social network, which suggests that an online social network developed to support decision-making would face significant effort in getting a large majority of South Dakotans to even be aware of, let alone log into, such a system. On the other hand, if online social networks do have potential for helping

individuals make health care decisions, South Dakota has an unusually large number of users who are already familiar with online social networking technology.

The above framework suggests various questions of interest to researchers in information systems, health care, and rural affairs:
1. Do rural residents take advantage of online health social networks at the same rate as urban residents?
2. Do health social networks influence health decision behavior differently between rural and urban settings? Can differences be identified between rural and urban residents within a predominantly rural region?
3. Does rural isolation drive increased reliance on online social networks for health information?
4. Do rural patients and rural physicians engage with health social networks differently and experience different levels of influence from those networks on their health decision behavior?

6. Issues for further consideration

Knowing why patients and physicians make decisions matters primarily in the context of understanding whether they make good decisions. Ultimately, we want to know whether online health social networks influence users toward decisions that produce desirable health outcomes. Connecting the dots among a set of patients, a set of decision inputs, a set of decisions, and a set of health outcomes is a devilishly complicated research challenge that the above framework alone cannot answer.

Even before reaching the stage of measuring and correlating health outcomes, simply measuring the influence of health social networks on health decision behavior poses difficulties. Identifying factors within the above framework requires identifying changes in decisions that users make that they would not have made without the inputs of an online health social network. Changes in decisions may not be so clear cut as choosing Treatment B over Treatment A. The influence on user decisions may lie in factors like the content and duration of deliberation, perceptions of patient involvement, and patient confidence in and satisfaction with their decisions. Attention to these complications will permit us to better understand online social networking can have on health decision behavior and inform the design of better online communities to meet the health care needs of patients and practitioners.

Conclusion

The proposed research framework addresses the impact of one specific subset of online social networks,

those dedicated to health issues, and their impact in one specific area of patient life, their decision behavior. It is our hope that investigating how individuals seek and use knowledge and social interaction to inform their decisions will form a basis for understanding more broadly how online social networks in general may extend and enhance social interaction and influence individuals' decisions, behavior, and overall quality of life.

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