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Peer-to-peer communication, cancer prevention, and the internet:

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Abstract

Online communication among patients and consumers through support groups, discussion boards, and knowledge resources is becoming more common. In this paper, we discuss key methods through which such web-based peer-to-peer communication may affect health promotion and disease prevention behavior (exchanges of information, emotional and instrumental support, and establishment of group norms and models). We also discuss several theoretical models for studying online peer communication, including social theory, health communication models, and health behavior models. Although online peer communication about health and disease is very common, research evaluating effects on health behaviors, mediators, and outcomes is still relatively sparse. We suggest that future research in this field should include formative evaluation and studies of effects on mediators of behavior change, behaviors, and outcomes. It will also be important to examine spontaneously emerging peer communication efforts to see how they can be integrated with theory-based efforts initiated by researchers.

INTRODUCTION

People are getting together online to discuss their health and illnesses, share personal stories, and search for health-related information in unprecedented numbers. The proportion of American adults with internet access has been increasing steadily and is at about 70% (1). Up to 80% of internet users search for health information online (2–4). More and more people – especially adolescents and young adults (5) – use the internet to communicate with peers and friends individually and in groups through social networking, creating blogs, sharing photos, and participating in public discussion boards.

Two examples show how such online peer-to-peer communication is intersecting with health promotion and cancer prevention behavior. One site is www.FacingOurRisk.org, which supplements its traditional read-only resources about the risks of hereditary breast and ovarian cancer with active online discussions, support groups, and advocacy (6, 7). Another site, www.Stickk.com, capitalizes on peer pressure in the service of health goals; users can publicize a goal such as quitting smoking and then recruit peers to monitor their progress both online and in person. However, overall, it is not clear whether (or under what circumstances) peer-to-peer communication makes a positive contribution to health and well-being.

In this paper, we will discuss key ways in which web-based peer-to-peer communication may influence primary and secondary cancer prevention, and present theoretical models that can inform the development and evaluation of communication strategies and systems. Examples of recent research will be used to illustrate emerging areas of investigation and recommendations for further study.

SCOPE AND TECHNOLOGIES

To keep the scope manageable, we focus on online communication on the internet. The so-called Web 2.0 revolution (3, 8) is transforming internet communication from one-way (publication by a relatively small number of experts and advertisers) to multi-way (with millions of consumers and small organizations using easy-to-use software to create, share, aggregate, and edit content, from text blogs to videos to collections of news stories to software).

One Web 2.0 activity of special interest in preventive behavior is the use of the internet to form or support *social groups and networks* including patient support groups and health-related interest groups such as fitness clubs or weight-loss groups (3). Such virtual communities may use a variety of web resources, including static informational text, listservs, or online discussions. The discussions can be synchronous through chat rooms or email, or asynchronous in bulletin boards or forums. Unlike in-person discussions, on-line discussions are often read by non-participants. The resulting threads may be available years afterwards, broadening dissemination but also increasing the possibility of perpetrating old or out-of-context information. Another activity relevant to health communication is the personal weblog or *blog*, an individual's online journal. These journals turn into interactive discussions as readers subscribe to receive notifications of updates, add comments, or follow links to others' blogs and resources. Another relevant activity is the creation of *knowledge resources* such as Wikipedia, the online encyclopedia created by volunteers from the public rather than only by experts.

KEY AVENUES INVOLVED IN ONLINE PEER COMMUNICATION

Peer-to-peer communication can influence health behavior and health through several key avenues discussed in this section: information sharing, emotional and instrumental social

support, and peer modeling. To be clear, the impact of virtual communication technologies on these methods is not always known. It is possible that web-based technology could enhance the effects of communication, attenuate them, or alter them in other ways.

Information

First, people share health information, including advice, interpretation of medical language or events, and personal experience. Such patient-generated information is likely to be written in common terms, rather than medical jargon, and may be easier to understand by those with lower health literacy or numeracy (9, 10). Patients may also share their own medical data with each other when asking questions or offering answers (11). Also, patients and consumers frequently share useful health-related information that is outside the purely medical domain, such as personal perspectives on how a treatment will feel (12) or how to integrate some healthy behavior into their life. It is important to consider sociodemographic differences in the use of information on the internet; individuals seek information from social networks and peers they trust, and sociodemographic factors influence trust in information source. The Health Information National Trends survey found blacks more likely than whites to place “a lot” of trust in health information from family or the internet, while whites were more likely than blacks to place “a lot” of trust in information from doctors (13).

Pragmatically, it is important to recognize that although online health information from peers can be extremely helpful, it can also be inaccurate, biased, or incomplete. In medicine, few cases of injury directly linked to online health information have ever been reported (14). Organizers of resources such as Wikipedia argue that postings tend to be self-correcting over time (3). A comparison of Wikipedia with *Encyclopedia Britannica* found the two compared fairly well in accuracy (a mean of four versus three errors per article) (15). A content analysis of an unmoderated breast cancer email list found very few instances in which participants posted false or misleading information; almost all were corrected by other participants within hours (16). However, whether this finding is applicable to rarer conditions or less active online communities has been challenged (17). In addition, a patient community may be more highly motivated to correct information about a disease than the general public is to correct information about prevention. Nonetheless, the impact of even occasional misinformation could be extremely harmful. For health sites, the use of an expert moderator might be appropriate. In the model used by Citizendium (www.en.citizendium.org), anyone can contribute, but experts oversee and edit the material for accuracy. Additional content analyses of online discussion forums and knowledge resources in the field of cancer prevention would be useful to establish the prevalence of misinformation and of self-correction, as would research assessing reader and posting characteristics that affect perceived accuracy and credibility of information.

Emotional support

People use online communication for emotional support by sharing their feelings and receiving supportive comments (11). Posting to online communities is a form of expressive writing, which is known to improve many subjective and objective measures of health and well-being in both short- and long-term studies (18–20). Unfortunately, sharing some negative feelings is in some instances associated with poor outcomes (21). In some situations, emotional support may simply fail to make a difference to physical or mental health (22).

Instrumental support

People use communication to seek and offer practical help and material such as money, transportation, or meals, or partners with whom to exercise or diet (12). The “Buddy Check”

systems promoted by several local news organizations are groups of friends who remind each other to perform breast self-exams every month (see, for example, <http://www.wbir.com/life/community/health/buddycheck/default.aspx>). However, communication systems can also be used for reasons harmful to health, such as buying drugs.

Peer modeling

Communication within peer networks also establishes social norms and role models. Group norms have a strong influence on health-related behavior such as condom use (23). Anecdotal stories about other patients' experiences tend to have stronger effects on patient decision-making than aggregate or statistical information (24). Even passive communications about peer and celebrity role models affect preventive health behaviors. For example, Katie Couric's coverage of her colorectal cancer screening in 2000 was followed by 20% boost in colonoscopies performed by gastroenterologists in a large national sample (25). However, unhealthy behaviors can also be maintained as social norms, as was shown in a recent analysis of Framingham data, which found strong effects of friendship and family networks (but not neighbors) on the spread of obesity (26).

THEORETICAL APPROACHES

Theories that focus on information processing in health, communication, and social networks are all likely to be applicable to the study of online peer communication. Broadly interdisciplinary collaborations may be needed to integrate these perspectives.

One particularly relevant concept from sociology, *social capital*, describes the value provided by connections and networks, such as informational and instrumental exchanges (27, 28). Putnam describes two forms of social capital: bonding (socializing with people with similar characteristics) and bridging (socializing across groups) (28). Bridging brings new information and resources into one's bonding group. Patient support groups can be seen as sources of bonding capital, whereas use of the internet to find experts is a form of bridging capital. Network analysis is an analytic tool to trace social connections and analyze them mathematically (26). A socially based research method is *community-based participatory research*, which builds partnerships between communities and researchers to create research agendas that serve community concerns (29). This method could be particularly helpful for formative research to ensure that communication approaches are relevant and culturally appropriate. A sociocultural approach is particularly important in light of concerns that underserved populations tend to have less access to and familiarity with electronic resources, and that electronic information revolution could widen disparities instead of narrowing them (30).

Another perspective on communication comes from examining message characteristics through persuasion and communication theories. An example is the *extended parallel process model* of health risk communication developed to predict the impact of messages about health risks (31). Response to a message about a risk such as smoking is determined by the relative weight of the information about the threat's severity, perceived susceptibility to that threat, efficacy of the recommended response (such as quitting smoking), and self-efficacy for adopting this response. The *elaboration likelihood model* also addresses individual responses to health messages (32). People who do not think deeply about a persuasive message may display temporary attitude change, but those who think more deeply about the message (e.g., scrutinizing the message and its source, reflecting on its implications, and mentally rehearsing arguments), are likely to show more stable attitude change. The likelihood of this deep thinking or "elaboration" can be influenced by factors such as the personal relevance of the message. Information on peer-to-peer communication sites resonates strongly for some participants.

A psychosocial perspective on health communications comes from the cognitive-social health information processing (C-SHIP) model, which integrates a variety of behavioral factors established in previous work, including the individual's encoding of information, his or her outcome expectancies, self-efficacy beliefs, health values, previous knowledge, and self-regulatory skills (33). Online peer communication has the potential to influence virtually all of these factors.

RESEARCH ISSUES AND EXAMPLES

The limited literature in this field provides ample opportunity for exploration. Critical research topics include: 1) formative evaluation to design and test theory-based interventions; 2) studies examining effects on key theoretical constructs expected to mediate behavior change (such as knowledge); 3) outcomes studies of effects on cancer risk behaviors, biomedical outcomes, or surrogate outcomes such as use of the healthcare system; 4) examination of the effect of communication technology and format (in-person, chat room, blog, etc.) on mediators and outcomes; 5) strategies for incorporating spontaneously emerging peer communication efforts with theory-based efforts initiated by researchers, and 6) effects with and usefulness for digital divide populations.

Much of the research into online peer communication has focused on disease rather than on prevention. An example is an analysis of an online breast cancer support group in the long running CHES system (Comprehensive Health Enhancement Support System) (34, 35). However, prevention is the focus of Facing Our Risk of Cancer Empowered (www.force.org), a national group for women at risk of hereditary breast and ovarian cancers. Its discussion boards focus on topics such as lowering cancer risk through hormone replacement therapy or prophylactic mastectomy. Women use the community to seek information about both personal experiences and medical data, as well as instrumental help and emotional support with issues such as self-image and stigma (6, 7). Such efforts might be expected to improve mental and physical health, but no such studies have yet been conducted. A limitation to generalizability is that most participants have been diagnosed with a BRCA mutation and are well-educated (6, 7).

An example that focuses on health promotion in a minority community is www.GetHealthyHarlem.org, an online space for residents of Harlem to connect and share locally relevant health information (36). Some content is being created by experts, but other material is to be created by residents through articles, blogs, and discussions. Formative development is proceeding under the direction of a community advisory board using the community-based participatory research model. A randomized trial is planned to assess effects on knowledge, social support, and other mediators of health behavior.

The difficulty of following such efforts to measurable health outcomes is demonstrated by a recent systematic review (37). Eysenbach et al found 38 studies that included some element of peer-to-peer communication, but only 6 evaluated the contribution of the peer communication component itself. Results were difficult to interpret. For example, with depression, peer-to-peer communication was associated with significant improvements in 2 studies and was not in 2 others; for social support, 1 study produced a significant improvement and 1 did not (37). Few studies focused on prevention.

TECHNOLOGICAL FUTURE

The whirlwind of change in technologies means that future evaluation and intervention research into communication must be both nimble and cautious in incorporating new peer-to-peer communication modalities. Researchers must also examine ongoing technological changes in other realms that affect communication. For example, electronic personal health

records, under development for patients to use in managing their own care, might provide a platform for peer communication if people use them to communicate with friends and family about personal health matters. Some unique and potentially problematic issues in online peer communication stem from data collection and aggregation (8). For example, www.Patientslikeme.com encourages patients to input their own medical data and examine the aggregated data, raising the issue of fair use. Who owns such data? Can it be sold? A second, critical methodological concern is that of validity and reliability of information. Even assuming that people post correct data about themselves (or correct explanatory information about health conditions), the self-selection of the participants reduces the generalizability of the information. Researchers analyzing the data are likely to take this limitation into account, but lay people may not. A third concern is confidentiality. Participants in online discussions (particularly if they use names or identifiable emails) may not realize that they are revealing personal information not just to members of a particular online community, but to an unlimited number of potential readers with greatly varying agendas. Even if sites require consent before posting, is consent truly informed?

CONCLUSION

Additional research into peer communication in disease prevention is needed, and future studies will have to be increasingly interdisciplinary to integrate theoretical models from multiple areas. Social scientists and health professionals will have to partner with ethicists, lawyers, economists, and specialists in health informatics to answer the kinds of questions raised in this summary. In addition, researchers will have to recognize that consumers are not motivated to wait for research results to find out how online communication will benefit their health or well-being. Internet users, not healthcare professionals, are leading the way on peer-to-peer communication, and researchers will have to follow their lead.

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