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Sharing Sensitive Personal Health Information through Facebook: the Unintended Consequences

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Abstract. The purpose of this paper was to explore the types of sensitive health information posted by individuals through social network media sites such as Facebook. The researcher found several instances in which individuals, who could be identified by their user profiles, posted personal and sensitive health information related to mental and genetic disorders and sexually transmitted diseases. The data suggest that Facebook users should be made aware of the potential harm that may occur when sharing sensitive health information publicly through Facebook. Ethical considerations in undertaking such research are also examined.

Keywords. Social networking, Privacy, Health information, Facebook

1. Introduction

In 2011, the Markle Survey of Health reported that privacy around the exchange and use of health information was a top concern for physicians and patients [1]. Although the concerns voiced by patients and physicians in the survey are legitimate, they have been a focal point of the healthcare informatics agenda for many years. One of the earliest papers on the subject of privacy and confidentiality regarding health information was published by the *New England Journal of Medicine* in 1968 [2]. In the paper, the authors advocate for state laws, ethical and clearly defined regulations regarding the protection of health information. It was not until 30 years later that the United States passed the Health Insurance Portability and Accountability Act (HIPPA) to protect the privacy and confidentiality of health information [3]. In addition, with recent advancements made in the collection and analysis of genetic data within the field of bioinformatics, the United States Congress has passed the Genetic Information Nondiscrimination Act of 2008 to protect the improper use of genetically identifiable data collected by health insurers and employers. Similar health information privacy legislation has been introduced in Europe through the Personal Data Directive introduced in 1995. As science makes new discoveries and advances to collect an array

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of new health information, new legislation will be needed to ensure that the privacy and confidentiality of health information is maintained.

Historically, HIPPA and other acts to protect the privacy and confidentiality of health information were designed to protect the patient from privacy violations that could impact their employment, relationships, or public perceptions of them. Such violations did occur, as reported in 2003 by the Health Privacy Project [3], and they included privacy violations such as

- A woman's medical records being posted on the internet after she was treated for complications that were a result of an abortion
- A man being fired after an insurance company informed his employer that he received treatment for alcohol abuse
- A clerk working in a hospital stole social security numbers and applied for credit cards and opened bank accounts
- Files of persons living with sexually transmitted diseases being sold by a U.S. state

These examples are enough for legislators to propose and pass laws that protect the personal privacy and confidentiality of the patient's health information from improper use by clinicians, staff, hospitals, and government. With the advent of social networking and the promotion of individualized healthcare, however, there is a growing trend of patients sharing their own personal health information to the world through social networking sites such as Facebook. Within this context, the purpose of this paper was to explore the various types of groups and information shared by various Facebook pages and to make recommendations for concerns surrounding privacy and confidentiality for patients with regard to sharing their health information via social networking sites. The focus of this paper was not the health information people may be sharing about others, but rather the health information they may be sharing about themselves. Ethical considerations while conducting this type of research were also examined.

2. Methodology

The research focused on reviewing sensitive health information related to mental disorders (anxiety, depression, eating disorders, and drug addiction), sexually transmitted diseases (HIV, chlamydia, and gonorrhea), and sexual and genetic disorders (cystic fibrosis, hemophilia, and sickle cell) shared through Facebook groups. To limit the scope of the study, the researcher investigated only anxiety, HIV, and cystic fibrosis.

Briefly, Facebook is a social networking site that allows users to network with other individuals or groups registered on the Facebook site. Registration is free, and each user sets up their own network of friends and groups. Each user can upload videos, pictures, and hyperlinks as well as engage in live chatting and many other features. In addition, users can set up their own privacy settings, which can range from simple issues such as making their profile public or visible only to the friends they invite.

For the purpose of this study, Facebook group pages regarding anxiety, HIV, and cystic fibrosis were searched. Only groups that were publicly made available to all Facebook users were reviewed in this study. The researcher logged in with his own personal account, and the search was carried out on February 3, 2011. The search was filtered to include only anxiety, HIV, and cystic fibrosis groups and to excluded pages

(e.g., pages with information on the subject) and people with names similar to the search terms. The researcher only selected one group with the most registered users for anxiety, HIV, and cystic fibrosis. Once in the group, the researcher observed discussions of group members and various types of information shared. Data from the Facebook Wall and Facebook Discussion forums were the only data included. According to Facebook, the Wall feature allows users to share text, pictures, videos, and hyperlinks. People can comment on the Wall, which is for all Facebook users to view. The discussion forums are more focused on specific issues and are more detailed in their content. See Figure 1 for an illustration.

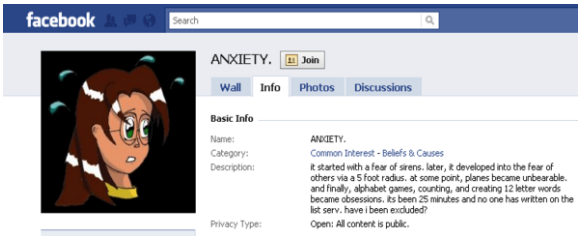

Figure 1. *Facebook Anxiety Group Page*

3. Results

For the top group site regarding anxiety, there were 266 registered users as of February 3, 2011. The data showed that there were a total of 15 Wall postings by a total of 12 users between July 1, 2010 and January 31, 2011. Two of the Wall postings were commented on by group members. In general, of the 12 users, 7 generally discussed their struggles with anxiety, 1 posting was an herbal advertisement, 1 was advertising a course on anxiety, and 3 were links to non-relevant websites and advertisements. Much of the wall discussions centered on the individual's struggles with anxiety. For example, one person was seeking help because their anxiety was leading them to contemplate suicide. Another Facebook user was asking for advice about prescription drugs and strategies to cope with anxiety. In the discussion tab, there were no group discussions surrounding the issue from July 1, 2010 to January 31, 2011. Several posts, however, were found before this time period, with the highest number of discussions focusing on panic attacks.

For HIV, the top group on the subject had 926 registered users as of February 3, 2011. There were only two Wall comments made in this group, both of which were from two different users regarding disease-related information. As for the discussion forum, there were two postings for the specified time period. One posting was demeaning, whereas another was about a man sharing his struggles with HIV. This particular Facebook user listed his picture, name, location, and work in his public profile. Although it appeared to be genuine, it was not confirmed given the scope and ethics of the study.

For the Sickle Cell group, the top group had 3786 members as of February 3, 2011. On the Facebook Wall, there were 32 wall postings made by 24 members of the Sickle Cell group between July 1, 2010 and January 31, 2011. Most of the postings (a total of 8) shared on the wall were related to general information sharing regarding education, new treatments for the disease, and experiences with physicians or hospitals. There

were seven postings in which the Facebook user was seeking information or help about a problem they were having related to the disease. There were about 6 postings related to advertisements for fundraising events or links to products and articles. Finally, members posted stories about their life struggles in living with the disease. With regard to the discussion threads, there were only two discussion threads posted between July 1, 2010 and January 31, 2011. The first discussion thread was about a Facebook user suffering from the disease where they expressed their frustration with trying to find adequate care and a job. Two respondents provided the Facebook user with support and advice on what to do. The other thread was about a Facebook user contemplating graduate school who was afraid of not obtaining acceptance because of his/her disease. A Facebook user responded by encouraging the individual and letting them know of another individual they knew who was working while living with the disease.

4. Discussion

In this study, it was found that there are Facebook users sharing their personal details along with their health information without realizing the potential ramifications of doing so. According to HIPPA regulations, there are no laws that stop the individual from sharing their personal health information [4]. Trying to interpret the results behind this behavior is difficult to ascertain, given the limitations of this study. One conclusion may be that the individuals sharing their health information on Facebook are unaware that such information could potentially be used against them by unscrupulous organizations or individuals. There have been several recorded instances in the news media where employers have fired Facebook users as a result of their public postings. A recent study on Facebook patient privacy violations showed that numerous privacy violations were carried out by medical residents and students [5]. Therefore, there is a growing need for Facebook to make its users aware of potential abuses that may result from sharing health information online. To remedy this issue, Facebook should provide policies and guidelines and create an awareness campaign for its users regarding the sharing of health information via its social networking site.

Another possible interpretation to the nonchalant behavior in sharing health information on Facebook could be a result of the cultural change surrounding patient engagement and empowerment in taking control of their own health. For example, Sunnybrook Hospital in Canada has recently provided its patients full access to their personal healthcare records [6]. Google Health and similar technologies are empowering patients to manage their own health. Facebook provides a platform for individuals to connect with other individuals suffering from the same disease or disorder. With over 500 million users on Facebook [7], the potential to connect with people suffering from the same disease or disorder is higher than on any other alternative social media networking sites known to date. The only drawback to Facebook is the ability to identify individuals sharing personal health information and the potential misuse of this information by organizations and individuals, which may cause harm to the individual.

5. Limitations and Future Research

Based on the results of this study, future research should examine the perceptions of individuals regarding the sharing of personal health information through social media networks such as Facebook, Twitter, and YouTube. Future studies should also examine other diseases and disorders shared through Facebook to explore the potential threats that may arise as a result of sharing sensitive health information.

There are several limitations worth noting in this study. The manual data analysis was conducted by the researcher and was not verified by another researcher. As a result, this may have caused bias in interpretation of the results. Furthermore, because of time constraints, the data were limited to the period between July 1, 2010 and January 31, 2011. Finally, there was no way to prove the authenticity of the Facebook users who posted their health information on the Facebook group pages.

6. Ethical Considerations

When conducting the research study, various ethical considerations were considered. All of the data used in this study were publicly available data that could be accessed by any Facebook user with a Facebook account. The researcher did not solicit information nor did the researcher ask to join a particular group to gain access to data. While conducting the analysis, the confidentiality of the individuals included in the study was strictly enforced; however, anonymity is not guaranteed given that the information is publicly available to any Facebook user. Consent of the groups to use the data was not solicited. With the pervasive use of social networking sites such as Facebook and YouTube, the issues regarding confidentiality, anonymity, and consent are pushed to the limits, and the ethical considerations within the context of such research studies should be reexamined.

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