Sharing Health Information on Facebook: Practices, Preferences, and Risk Perceptions of North American Users

Sadegh Torabi
University of British Columbia
Department of Electrical and Computer
Engineering
sadeq@ece.ubc.ca

Konstantin Beznozov
University of British Columbia
Department of Electrical and Computer
Engineering
beznosov@ece.ubc.ca

ABSTRACT

Motivated by the benefits, people have used a variety of web-based services to share health information (HI) online. Among these services, Facebook, which enjoys the largest population of active subscribers, has become a common place for sharing various types of HI. At the same time, Facebook was shown to be vulnerable to various attacks, resulting in unintended information disclosure, privacy invasion, and information misuse. As such, Facebook users face the dilemma of benefiting from HI sharing and risking their privacy.

In this work, we investigate HI sharing practices, preferences, and risk perceptions among Facebook users. We interviewed 21 participants with chronic health conditions to identify the key factors that influence users' motivation to share HI on Facebook. We then conducted an online survey with 492 Facebook users in order to validate, refine, and extend our findings.

While some factors related to sharing HI were found in literature, we provide a deeper understanding of the main factors that influenced users' motivation to share HI on Facebook. The results suggest that the gained benefits from prior HI sharing experiences, and users' overall attitudes toward privacy, correlate with their motivation to disclose HI. Furthermore, we identify other factors, specifically users' perceived health and the audience of the shared HI, that appear to be linked with users' motivation to share HI. Finally, we suggest design improvements—such as anonymous identity as well as search and recommendation features—for facilitating HI sharing on Facebook and similar sites.

1. INTRODUCTION

Individuals with health condition(s) can benefit from sharing their health information (HI)[1] in different ways: seeking or providing social support, learning from the shared experiences, and

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[1]Any type of information related to the health of an individual including personal health information (PHI), electronic health records (EHRs), and personal health records (PHRs)

self-management education [34, 39, 47]. Furthermore, sharing HI was shown to be beneficial not only to the individuals themselves, but also to their social peers. Motivated by the two-way benefits, people have used different online services to exchange their HI and experiences (e.g., blogs, emails). Among these services, social networking sites (SNSs), which have attracted the largest number of active online users, have emerged as a common place for sharing different types of personal information, including HI [15, 38].

Recent studies suggest that various user groups with health conditions (e.g., breast cancer patients) may benefit from sharing HI on SNSs [34, 39]. On the other hand, revealing HI to other people has been always associated with privacy concerns. Not only have researchers identified an implicit consensus among people that their HI should be considered as "personal" and "private" [33, 39], but also Facebook and SNSs were shown to be vulnerable to various attacks that could result in unintended information disclosure, privacy invasion, and medical data misuse [18, 46].

One can argue that the users' attitude toward disclosing HI might be influenced by their perception of privacy and the expectation of benefits (privacy calculus) [31]. Although a number of studies brought to the attention of the research community the benefits and the privacy concerns related to HI sharing on Facebook, we need to do more work to understand the interplay among various factors (including privacy concerns) and the users' motivation to engage in HI sharing [30, 34, 35]. In order to increase the benefit of sharing HI by SNS users, it is important to investigate socio-technical features that motivate and enable users to share their HI effectively and safely. This, however, demands building a better understanding of users' HI sharing practices and risk perceptions.

To this end, we studied why, how, and with whom users share their HI on Facebook. Following a grounded theory approach [7], we interviewed 21 individuals who had chronic health conditions. We focused on exploring participants' practices, preferences, and risk perceptions when sharing HI on Facebook. The interviews enabled us to develop a better understanding of the key factors linked to users' motivation to share HI on Facebook. We then conducted an online survey with 492 active Facebook users, in order to confirm and extend upon our findings.

All studies were reviewed and approved by our university's ethics committee. We minimized risks to participants by excluding any personally identifiable information from the collected data, generated results, and published reports. Participation in all studies were completely voluntary, and participants were able to withdraw from the study at any time.

The results of our investigation suggest that participants who previously shared their HI on Facebook, especially those who gained some benefits, were more willing to share their HI on SNS in the future. Yet, despite the perceived benefits, participants who had strong privacy concerns were always unlikely to share their HI, as compared to participants with medium or low privacy concerns, who showed more flexibility in the presence of different motivating factors (e.g., perceived benefits). Furthermore, we found that participants' perceived health status correlates with their motivation to share HI with different Facebook users, even strangers. It also matters for all types of users who the intended recipients are. Based on the findings, we suggest a number of features (e.g., anonymous identity, specialized search and recommendations, trusted SNS provider) that could motivate users toward engaging in effective HI sharing on Facebook.

In summary, this work makes the following contributions:

- We provide a better understanding of Facebook users' HI sharing practices, preferences, and risk perceptions.

- We identify factors linked to users' perceived privacy and motivation to share HI on Facebook.

- We suggest design features that could facilitate effective HI sharing among Facebook users.

In what follows, we present background and related work (Section 2). In Sections 3 and 4, we present details of the exploratory and confirmatory studies. In Section 5, we discuss the main findings along with study limitations and implications for design. We conclude by presenting conclusions in Section 6.

2. BACKGROUND AND RELATED WORK

Several studies have indicated that HI sharing is becoming a common behavior among a considerable number of SNSs users [15, 32, 40]. The results of the Pew Internet survey suggest that a considerable number of internet users in the U.S. went online to follow their friends' personal health experience, with a noticeable increase when compared to previous years [14]. Meanwhile, 16% of the surveyed participants reported going online to find others who had similar health concerns [15]. Moreover, people with health concerns have been shown to visit their SNSs (e.g., Facebook) to seek support from other online peers [38].

The benefits of using SNSs for HI sharing have been investigated by a number of studies [33, 34, 47]. Lederman et al. [29] discussed the benefits of addressing socio-technical needs by utilizing SNSs and developing engaging therapeutic solutions for mentally ill patients. Following a user-centered design approach, Skeels [39] captured breast cancer patients' HI sharing requirements and designed an online interactive technology to facilitate HI sharing and management. Kamal [22] also used a similar approach to design a SNS prototype for promoting healthy behavior changes.

Despite the reported benefits for people with chronic health conditions, only a small number of studies explored the effects of using SNSs on health management. For instance, Newman et al. [37] interviewed 14 participants who joined health-focused online communities in order to investigate the way people think about sharing HI as they pursue social goals related to their personal health. The methodological limitations (data collection/analysis) and the focus on the niche demographics in their study render the findings non-generalizable to the user (or even patient) population at large. In addition, Newman et al. explore

the mixture of online and offline user experiences, unlike our research of users' HI sharing behaviors on Facebook. In another relevant investigation, Merolli et al. [34] reviewed the literature and found that among all the examined studies (N=19), only five focused on SNSs (referred to as web 2.0 sites). Moorhead et al. [35] surveyed primary research and identified the lack of information about the uses, benefits, and limitations of social media for health communication among the general public, patients, and health professionals. Similar conclusions were drawn by Lefebvre and Bornkessel [30], where they suggest further investigations, in order to better understand how SNSs can be effectively and efficiently used to improve health across the population.

People's motivation to engage in protective health behaviors was shown to be influenced by the severity and the likelihood of their health conditions [43]. In the context of HI sharing on SNSs, a number of studies have shown that people who suffered from chronic health conditions were likely to visit SNSs to seek or share their HI with social peers [14, 38]. For instance, Lederman et al. [29] highlighted the motivation of mentally ill patients toward engaging in online therapeutic procedures on their proposed SNSs. Skeels [39] on the other hand studied breast cancer patients' engagement in HI sharing on an online SNS that was built to help them manage their health issues. Both studies were conducted with participants who suffered from chronic health conditions (mental illness and breast cancer). Therefore, while the likelihood of having a health condition for their participants was at its maximum value (100%), the severity of their health conditions was assumed to play a major role in motivating them toward discussing their HI on SNSs.

There are different ways to assess one's overall health status and the severity of his health conditions. A number of studies used the self-reported perceived health status as a reliable measurement of individuals' overall health status [20, 45]. Also, they found a correlation between the perceived health status and the number of health conditions, with those who had "poor" health to have more health conditions. On the other hand, the self-reported assessment of health conditions might not always accurately describe the overall health status. For instance, one might suffer from a number of severe health conditions and yet consider his health to be stable or good, while another person might have a minor health issue and feels completely devastated by his health issue.

Discussing overly personal information on SNSs have been associated with privacy concerns [10, 36]. The nature of SNSs can lead to the diffusion of personal information beyond its intended targets, while resulting in the lack of subsequent control over its exposure [5, 19, 35]. In general, information revelation on SNSs was shown to be influenced by the raised privacy concerns due to both the personal experiences and the negative reports in the media [46]. In the context of SNSs, privacy concerns have been always associated with sharing HI among users [10, 42]. A survey of 1060 U.S. adults found that 63% raised concerns related to publicly sharing their HI on SNSs, while 57% were concerned that their HI might be hacked or leaked from the SNSs [1]. Morris et al. [36] surveyed different types of questions that SNSs users asked their social peers about and found that "health" was a type of topic that people tend to consider too personal.

It has been shown that internet users' privacy concerns and their attitudes toward privacy could highly influence their motivation to disclose personal information to online sites [6, 10, 40]. The Westin privacy index was introduced as a way to meaningfully classify internet users based on their overall attitudes to-

ward privacy and motivations to disclose personal information on the internet [6, 9, 25, 26]. Although being commonly used in literature, the Westin based categorization was criticized for its flaws [25]. Researchers have also raised concerns with respect to the predictive value of the Westin privacy index categorization and its correlation to online information disclosure in specific contexts [12, 44]. They showed that in specific scenarios, users' behavioral intention might not be accurately represented using the Westin categories, while suggesting more fine-grained classifications considering other factors (e.g., consequences). In general, despite the flaws with the Westin privacy based categorization, we believe that the literature provides reasonable evidence to reflect on the "overall" correlations between people's privacy attitudes, as classified by Westin, and their motivation to disclose personal information online.

3. EXPLORATORY STUDY: INTERVIEWS

In an effort to develop a better understanding of users' motivation to share HI on SNSs, 21 chronically ill patients were interviewed about their HI sharing experiences. Following a grounded theory approach [7], we explored participants' HI sharing practices, perceptions, and preferences. We identified the main factors that influenced participants' perceived privacy and motivation to share HI on SNSs. We aimed at answering the general research questions: *Why, how, and with whom patients share their HI on SNSs?*

3.1 Sampling and Participants Recruitment

Following a theoretical sampling approach [7], 21 individuals with chronic health condition(s) were recruited through media advertisements (e.g., craigslist). Potential participants were invited to visit the study webpage, where they viewed details of the study, along with the consent form. To be eligible for the study, participants must be: 19 years of age or older, living in Metro Vancouver, Canada, maintaining at least one active account on an SNS that they visited regularly, and having at least one chronic health condition. Participants were compensated with $25 (CAD) for taking part in the study.

A total of 21 participants were interviewed throughout the study. The purposive sampling of participants who had chronic health condition(s) assured their involvement in HI sharing practices. The sample included 7 women and 14 men, between 21 and 68 years old. Participants came from diverse ethnic backgrounds but all were speaking English fluently. A summary of participant demographics is given in Table 1. Participants had different health conditions, including physical, mental, or a combination of both. Details about participants' health conditions are presented in Appendix A.2.

3.2 Data Collection

Data collection was done by means of audio recorded interviews during the months of February-May, 2014. The semi-structured interviews lasted approximately one hour each. Interviews were conducted in different locations to meet participants' needs and requirements (e.g., at participant's home due to his disability and limited mobility). An interview guide was developed to help in managing the interview flow and assuring purposeful data collection (Appendix A.1). Participants were always invited to tell their stories according to their style and conventions. Data collection was directed by a theoretical sampling approach, where new data was collected and analyzed to elaborate and refine the identified themes respectively [7]. After analyzing 16 interviews, the total number of identified unique codes

Table 1: Participants demographics.

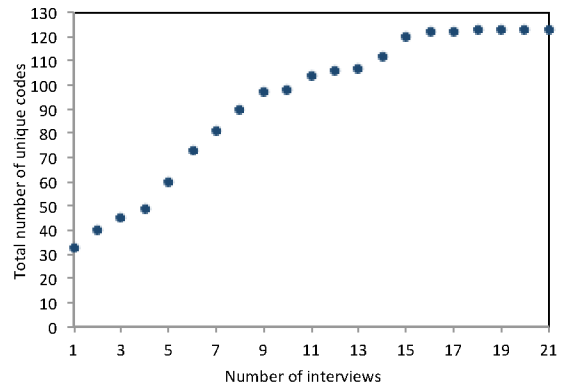| Demographic	Category	Count (N=21)
Gender	Male	14
	Female	7
Age range (21-68)	19-30	2
	31-40	9
	41-50	5
	50+	5
Completed Education	High School	3
	Some college/university	6
	Post secondary diploma	7
	University (BSc., MSc.)	5
Health Conditions	Physical (e.g., heart disease)	14
	Mental (e.g., post-traumatic stress disorder)	3
	Physical and Mental	4

Figure 1: Data analysis and theoretical saturation (21 interviews and 123 unique codes).

reached a plateau where analyzing further interviews did not result in new findings (Figure 1). Data collection was stopped after conducting 21 interviews, when "theoretical saturation" was achieved in the analysis.

3.3 Analysis

The analysis process started immediately after transcribing the first interview and continued concurrently with the data collection process. The recorded interviews were transcribed verbatim by professional transcriptionists. Interview transcripts were anonymized by removing identifiable information (e.g., names). NVivo (Version 10.1) was used as the main qualitative data analysis tool for coding and analyzing the transcripts.

Constant comparison of coding and analyzing data through several iterative stages of *open, axial,* and *selective* coding were applied [7]. Open coding was initially used to identify, describe, and categorize interesting phenomena that were found in the data. The first set of transcripts were read line by line and coded accordingly, resulting in 90 unique codes after analyzing 8 interviews. At that point, we also started to look at interrelated codes that formed meaningful categories (axial coding). The identified categories were as following: *perceived privacy, perceived benefits, the recipients of the shared HI, used technologies, prior HI sharing experiences, HI sharing motivation, trusted entities, anonymous communication, HI sharing preferences, and health status.* Then, we identified participants' *Motivation to*

share HI on SNSs as the core category (selective coding). We also identified the following sub-categories: *perceived privacy, perceived health status, the recipients of the shared HI, prior HI sharing experiences, and health status*. The transcripts were further analyzed by selectively coding new data that was related to the core category until theoretical saturation was reached. Finally, memoing was used frequently to describe coded events, as well as explain observed concepts and their relations.

The analysis resulted in a total of 2,521 coded excerpts, with an average of 120 coded excerpts per interview. The quality and consistency of the analysis was checked by a second researcher, who reviewed and coded a total of 100 randomly selected excerpts using our generated codes. The two coders reached about 90% agreement.

3.4   Results

3.4.1   HI Sharing Practices on SNSs

While participants used a variety of SNSs, all participants were active users on Facebook. Considering the fact that more than 71% of North American internet users are on Facebook,[2] it is not an anomaly to have all participants to be Facebook users. Participants indicated going on their SNSs on regular basis. Moreover, participants indicated using a variety of sites to share or seek HI online (e.g., SNSs, blogs). Despite the fact that the identified sites were not designed to support HI sharing among social peers, the majority of participants recalled sharing HI instances on them in the past:

"I've got a lot of pictures on Facebook of when I was in hospital. I had pictures of myself, my scar, and everything else. All of those are on my Facebook."–P2 (M, 59, fractured back/defective knee)

3.4.2   Perceived Benefits

From simply sharing how a person feels at a specific moment, to sharing detailed information about treatments, participants experienced sharing HI with select individuals or groups in the past. Participants shared their HI with others for the sake of getting benefits. The benefits of sharing HI include but not limited to: learning from the shared experience, initiating conversations with online peers, justifying specific behaviors, reaching out to others who had similar health conditions, and engaging in social support. Moreover, participants showed interest in helping others by providing social support, empathy, and experience-related feedback. It was also interesting to see that regardless of the expected reactions and responses, some participants felt relieved simply by talking about their problems with others:

"I feel better letting them know. Whether they understand or not, I feel relieved telling them."–P15 (M, 37, bipolar depression/anxiety)

3.4.3   The Recipients of the Shared HI

A number of participants (5/21) shared detailed HI with select family members and/or close friends via online services (e.g., email, SNSs). For instance, P21 (F, 35, herniated disks at L4-L5) used Facebook occasionally to communicate her health issues with her friend, who happened to be an experienced therapists, and tried to ask for her opinion and advice. Generally speaking, while participants preferred to have in-person discussions of their health issues with other friends and family members, the online services have provided them with a con-

venient way of communication, especially when physically distanced from friends and/or family members:

"I do [talk about health on Facebook], and especially with my wife [who lives in a different region]. Because my wife is a nurse so, rather than going to a doctor, she would be somebody that I would talk to first."–P12 (M, 59, degenerative disc disease/brain injury)

In addition to close friends and family members, participants shared their HI with others who had been through similar health experiences. In fact, they believed that the mutual health experiences had helped them in understanding each others and communicate with less effort:

"I talk about all kinds of things I'd never talk to my able-bodied friends about, because these people know what our lives are like. Our lives are all different but they have a commonality that doesn't exist with able-bodied people."–P4 (F, 68, C4-C5 quadriplegic)

3.4.4   Perceived Health Status

Participants developed an overall perception of their health status based on their knowledge of their health conditions and their perceived control over its outcomes. For instance, P19, who suffered from HIV, considered his health condition as yet another manageable disease that required only few tweaks to his life style:

"Totally manageable. You got to watch your cholesterol, watch your liver, take two pills in the morning, one at night, and that's it."–P19 (M, 50, HIV)

This was mainly because he was completely aware of his condition, its complications, and the necessary ways to control it. Interestingly, participants who perceived their health status to be "manageable" were found to be less motivated to engage in sharing their HI on SNSs. Moreover, participants who suffered from chronic pain due to physical injuries and/or arthritis (9/21), considered their health status to be stable and "manageable." As such, they showed less interest in using SNSs for sharing their HI with other people.

On the other hand, P9 (F, 42), who suffered from a rare disease called Neuromyelitis optica (NMO), was heavily engaged in sharing her HI on blogs and SNSs (e.g., MS society, Twitter, Facebook). She described a number of reasons for her enthusiasm toward sharing her HI online: helping newly diagnosed patients, finding new information about the disease, and participating in research. Moreover, the insufficient scientific knowledge about the health condition, and the relatively small population of diagnosed patients with similar health condition, were also motivating her to actively engage in online HI sharing activities.

3.4.5   Perceived Privacy

Despite the perceived benefits, users' attitude toward disclosing HI on SNSs is also influenced by their perception of privacy (privacy calculus) [24, 31]. By exploring users' HI sharing practices and preferences, we tried to develop a better understanding of the factors that shaped chronically ill patients' perception of privacy when sharing HI on SNSs. In what follows, we highlight some factors that contribute to users' perception of privacy.

The Shared HI.

To minimize the privacy concerns related to sharing HI on SNSs, the majority of participants tried to keep their shared information very general, with the least details about their personal health. Moreover, participants altered their HI sharing behaviors with respect to the audience in different SNSs. For instance, while P11 (M, 40, L3-L4 fusion) shared information

about his back injury with a group of people who suffered from similar injuries on LinkedIn, he tried to maintain his professional image by not posting irrelevant and unprofessional details on LinkedIn (e.g., feelings and emotions, certain drug usage). Some participants on the other hand, avoided talking about their health issues on their SNSs because their social peers had not experienced similar health issues. They felt that their social peers might misread their situation and make judgments:

"I'm not the kind of guy that is just going to throw it out there [on Facebook] and get responses from anyone on a medical issue. I think it's just common sense like, people judge. People rumour. You don't want to throw out a bunch of stuff that's going to be misconstrued."–P1 (M, 38, chronic sciatica).

It was interesting to see that some participants considered the shared HI instances to be mostly of abstract nature. For instance, P2 (M, 59, chronic back/knee pain) shared pictures of himself and his scar on Facebook while staying at the hospital. Some participants believed that the shared HI contained no important details about them, and therefore, they did not mind sharing it with their social peers:

"I posted pictures of the brace that I had on Facebook. There's no story behind it, it's just like a picture, like "oh, this is gross", you know?"–P10 (M, 37, osteoarthritis)

Health Conditions and Associated Stigma.

Participants shared general aspects of their health on different SNSs. Moreover, they were likely to share information related to their physical health conditions (e.g., injuries, chronic pain, arthritis), as compared to other types of HI. Participants showed more discomfort when sharing information related to their mental health. In fact, the stigma associated with such health issues stopped them from sharing their HI with specific audiences, especially with people whom they knew. Furthermore, we noticed that some male participants were less motivated to talk about their health issues with friends and family members on SNSs. They believed that there is a stigma of men talking about their health, especially mental health issues:

"It's just a stigma of men not talking about stuff like that. With you, you're a complete stranger and I'll never see you again probably. So, it's not that hard for me to be candid and open about. But with friends, I'm always worried about bumping into people I've known."–P20 (M, 50, depression/chronic neck pain)

Few female participants also raised concerns about sharing information related to their mental health issues on their SNSs. For instance, P5 used an online website (reddit)[3] to anonymously ask questions related to her depression. She also tried to maintain her privacy by hiding her reddit name from her friends. Another way of avoiding the stigma associated with sharing information regarding mental health was to engage in online discussions and express feelings and health issues in an indirect manner. For instance, P15, who suffered from chronic depression, talked about his mental health issues by posting philosophical questions on his blog and Facebook page. He used these questions as a way to indicate his willingness to talk about his feelings and mental health issues with others.

Anonymity and Online Identity.

Despite the existing concerns of sharing HI with known people, P20 (M, 50, depression/chronic neck pain), for instance, shared his health issues with a couple of friends on Facebook. Those friends were not living in the same city where he lived

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[3]http://www.reddit.com/

in and therefore, there was a very little chance of running into them on a typical day. Interestingly, few participants indicated that the physical distance had provided them with some level of privacy, and therefore, they felt more comfortable to communicate their health issues with physically distanced people through Facebook:

"Even if I'm using my real name, it still feels kind of anonymous because they're not right there beside me. I'm not looking at them while I'm talking to them. They could be in Sydney, Australia."–P16 (M, 48, post-traumatic stress disorder)

As described by P16, his anonymity was maintained by keeping himself physically unreachable. The importance of the physical proximity in defining privacy in the online space was clearly present in participants' responses during the interviews. Participants also raised serious concerns with regards to revealing their physical location in online environments. Regardless of their healths status, participants wanted their current and/or future location to be kept strictly confidential. Moreover, even though participants did not mind being in the same virtual space with several other people (e.g., friends, acquaintance, possible strangers), they were concerned with the unexpected presence of their social peers in their physical proximity. As a result, some participants tried to hide their location information from different recipients while posting information on the SNSs:

"You just don't know who's reading it [online posts]. So, I don't want to say: "Oh, I'm going to Location today," and I get there and then there's somebody there. It would just be creepy. So, for things like that, I will post later: "Hey, went to Location today." So, it's done and I'm back home now."–P9 (F, 42, NMO).

SNSs Vulnerabilities and HI Misuse.

A number of participants perceived existing SNSs to be vulnerable to privacy and security exploits and therefore, risking the confidentiality of their information and increasing the chances of undesirable information disclosure. On top of that, some participants were also concerned about the probability of having their HI being misused by insurance companies and some governmental agencies. Participants recited several stories about themselves and other individuals in their social networks that became victims of shared information misuse. For instance, P7 (M, 54, quadriplegic) was overwhelmed by the attempts made by insurance companies towards cutting disability benefits by misusing patients' shared information on their SNSs. Moreover, both P1 (M, 38, chronic sciatica) and P5 (F, 30, chronic depression) raised concerns with respect to sharing specific "risky" information regarding their health on their SNSs, especially if their behavior was classified as illegal in a different jurisdiction (e.g., licensed drug consumptions). Furthermore, P5 was worried about being denied access to the U.S. if she shared information about being hospitalized for depression or bi-polar disorders. She mentioned knowing over a dozen of stories about people who were turned away from the U.S. borders just because they shared similar HI on Facebook.

3.4.6   HI Sharing Preferences

Preferred User Groups.

Participants identified three main user groups, with whom they were willing to share their HI on SNSs:

1. Doctors and Health Professionals. Almost all participants preferred to have their doctors involved in their SNSs. They are the source of information, advice and medical care. Also, they

have the knowledge, experience, and the authority to initiate health management decisions [4]. As a result, having them in any SNS that will be used for sharing HI might be preferable.

2. *Select Friends and Family Members.* Participants preferred to keep their family members and friends updated about their overall health status. More importantly, participants indicated their interest in sharing further details of their HI with select friends and family members. However, the nature and the level of details of the shared HI was dependent on the mutual health experiences and the closeness of their relationships. Participants were also open to discuss details of their health issues with those friends and family members who had expertise in the medical field.

3. *Others with Similar Health Condition(s) and Experience(s).* All participants identified the importance of having access to a pool of people who had gone through similar health issues. Due to the mutual experiences, the perceived benefits were higher when communicating HI with others who had gone through similar health experiences. It was also important for participants to consider other mutual factors (e.g., age, ethnicity, treatments) when deciding to share their HI with other people.

The SNS Environment.

For the majority of participants, it was important to know who owns/operates the SNS. Most of the participants (20/21) considered the government and/or their doctors' offices to be the most reliable and trusted entities with their HI. Moreover, participants did not necessarily trust private companies with their health records, unless recommended by their doctors. The ability to maintain an online version of their health records in the SNS was essential to all participants. Nevertheless, participants required to have their health records fully contained in the SNS environment. Participants preferred to keep their health records private and not shared with other users. Participants also required adequate security measures for protecting their stored data (e.g., using proper encryption).

Communication and HI Presentation.

To maintain their boundaries while communicating with strangers, participants required having anonymous communication capabilities in the SNS. Anonymity does not necessarily mean hiding all personal information. In fact, the majority of participants did not mind revealing their first name and their city of residence. However, the anonymity was necessary to maintain privacy by managing the identity and hiding some HI from other social peers. In general, participants preferred to perform one-to-one communications whenever they wanted to discuss details about their health with other social peers. Participants also indicated their need to maintain the way their HI was viewed by others. For instance, while participants did not want others to view every detail of their HI, they did not mind sharing an aggregate view of their HI with others who had similar health conditions (e.g., viewing progress updates during a course of treatment).

3.4.7   Results Summary

We interviewed 21 SNS users who had chronic health conditions about their HI sharing practices and risk perceptions. We explored their prior experiences with sharing HI on SNSs while inquiring about their preferences for the ideal HI sharing environment. We highlighted the main factors that related to users' motivation to share HI on SNSs (perceived benefits, perceived privacy risks, and perceived health status). We also showed that the recipients of the shared HI can influence users' perceived benefits and perceived privacy risks. Furthermore, we characterized the preferred recipients of the shared HI (people with medical expertise, mutual health experiences, and/or strong social ties). Finally, we discussed requirements for creating a trusted SNS environment that facilitate HI sharing among social peers (e.g., anonymity, trusted owner/operator, HI communication/presentation).

4.   CONFIRMATORY STUDY: ONLINE SURVEY

We conducted an online survey to confirm our findings from the exploratory study. The online survey consisted of a mixture of close- and open-ended questions. The survey gave us the opportunity to reach a larger sample of SNSs users, which in return helped in achieving more generalizable findings.

4.1   Why Facebook?

Results of our previous interview study indicated that the majority of participants were Facebook users (Section 3.4). Facebook is one of the few SNSs that have been extensively studied by social and computer scientists. This has resulted in a good understanding of how it is generally used and for what purposes [13, 27, 28]. Facebook is also the most popular SNS today, consisting of more than a billion users, with a large user population that goes on Facebook on daily basis.[4] As of August 2015, Facebook remains by far the most popular SNS in the U.S., with 72% of online adults to use Facebook (62% of all adults in the U.S.) [11].

4.2   Participants Recruitment

Participants were recruited via Amazon Mechanical Turk (MTurk),[5] which is a crowdsourcing website that provides a reliable source of high-quality data for research involving human-subjects [41]. A respondent was expected to finish the survey in less than 30 minutes. To ensure quality data collection and analysis, we used MTurk's features to recruit participants who had successfully completed 100 tasks or more on MTurk while having a minimum approval rate of 95%. Participants were limited to a single submission only. Participants were compensated with $1 (U.S.) through MTurk for successfully completing the survey. To ensure successful compensation on MTurk, participants were required to submit a unique code, which was assigned to them after completing the survey.

4.3   Data Collection

A total of 537 participants responded to the online survey between October 16–23, 2015. As shown in Appendix B.1, the online survey consisted of the following items: (1) demographics and background; (2) health conditions and perceived health status; (3) previous HI sharing experiences; (4) motivation to share HI on Facebook; (5) preferred recipients of the shared HI; (6) anonymous online identity; (7) trusted SNS providers; and (8) attitudes toward privacy. The average completion time was approximately 10 minutes, with an overall survey completion rate of 96.5%. Responses were closely examined based on completion time. Submissions that lasted less than 4 minutes were fully examined to ensure quality of the provided responses. Finally, to insure consistency of the sample, and avoid the effects of cultural differences, submissions made from people residing

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[4]http://newsroom.fb.com/company-info/
[5]www.mturk.com

outside of the U.S were excluded. The remaining 492 submissions were included in further analysis through the study.

4.4 Data Analysis

The survey was employed using our university's online survey tool. We used MS Excel and SPSS (Version 23.0) to perform statistical analysis on the data. We also used NVivo (Version 10.1) for coding and analyzing qualitative text responses. Descriptive statistics were used to explain the underlying properties of the collected data (e.g., mean, SD), while a number of inferential statistic analysis tests were used to highlight correlations and significant differences among groups (e.g., person's correlation). A series of between-subjects tests were used to explore participants' motivations and perceptions. Non-parametric statistics were used when the normality of the data was not assumed, especially with ordinal data (e.g., Likert-Scale). We used Kruskal-Wallis test for comparing $k-$independent samples, with post-hoc pair-wise comparisons using Mann-Whitney U tests (if necessary). We also employed Friedman's test and/or Wilcoxon signed-rank tests to check for statistically significant differences in participants' responses when repeated measurements were collected from the same participants (within-subjects).

4.4.1 Privacy Attitudes

Westin explored people's attitudes and concerns toward a number of privacy-related topics by conducting several surveys since 1978 (e.g., confidence in organizations that handle personal information). In order to summarize results and highlight trends in privacy, Westin created "privacy indices" for most of his surveys (e.g., General Privacy Concern Index, Computer Fear Index). Despite its flaws [12, 25, 44], the Westin privacy index has been used as an indicator of internet users' general attitudes toward privacy and their motivation to disclose personal information online [6, 9, 26]. According to Westin, people could be categorized based on their overall privacy attitudes, as follows: (1) privacy *Fundamentalists*, who highly value privacy and feel very strongly about it; (2) privacy *Pragmatists*, who have strong feelings about privacy but can also see the benefits from surrendering some privacy in situations where they believe they can prevent the misuse of their information; and (3) privacy *Unconcerned*, who have no real concerns about privacy or about how other people and organizations use their information [25].

In this study, we modified the statements typically associated with the Westin privacy index in order to fit them into the context of HI sharing on SNSs. We replaced the words "consumers" and "companies" with "internet users" and "social networking sites" respectively (as shown in Appendix B.1.8). Inspired by the Westin categorization procedure, we used participants' responses to the modified statements to group them into people with high, medium, or low privacy concerns, as corresponding to privacy *Fundamentalists*, *Pragmatists*, and *Unconcerned* categories. About 54% of participants were categorized to have high privacy concerns, while approximately 34% and 12% of participants were categorized to have medium and low privacy concerns respectively.

Contextualizing the Westin privacy index (e.g., by using brand names) can have a significant effect on the categorization outcomes [44]. Therefore, although we used a categorization procedure similar to Westin, we do not know how the modifications to the original Westin privacy index have impacted our analysis, as compared to using the original Westin statements. Nevertheless, we believe that our categorization could be of interest to the community. In fact, our categorization proportions were

very close to those presented in Woodruff et al. [44], where they implemented the Westin privacy index to categorize MTurk workers (49% *Fundamentalists*, 40% *Pragmatists*, and 10% *Unconcerned*). In general, our sample included a larger number of participants with high or medium privacy concerns, as compared to the general population [23, 44].

To corroborate our categorization outcomes, we asked participants to indicate the privacy-preserving actions that they had performed on Facebook (e.g., changing profile visibility). Participants selected all that applies from a list of 10 common privacy-preserving actions (Q34 in Appendix B.2). On average, participants performed 7.16 privacy-preserving actions in the past ($\sigma = 2.63$). About 26% of participants performed all 10 privacy-preserving actions on Facebook. The correlation analysis using Spearman's test showed a negative correlation between the number of performed privacy-preserving actions and participants' attitudes toward privacy ($r(490) = -0.176, p < 0.001$). This supports our analysis of the Westin inspired categorizations, which relates participants with higher privacy concerns to performing more privacy-preserving actions, as compared to those with lower privacy concerns.

4.5 Results

4.5.1 Demographics

We analyzed responses from 492 participants residing in the U.S. with ages ranging between 19 and 74 years ($mean = 34.7$ and $\sigma = 10.8$). A summary of participant demographics is presented in Table 2. The sample consisted of almost equal number of male and female participants, with a wide range of employment categories including Students (32/492) and Unemployed (72/492). While about 75% of participants were younger than 40 years old, almost half of all participants were between 19 and 30 years of age (46.1%). About 60% of participants completed a post-secondary degree (e.g., Diploma, Bachelor's, Master's, or PhD). Approximately 20% of participants indicated having a degree and/or work experience in fields related to Computer/IT. Furthermore, the vast majority of participants (91.1%) spent more than two hours on the Internet on daily basis ($mean = 6.5$ and $\sigma = 3.4$). These demographics reflect the nature of MTurk workers, who were shown to be highly active internet users with higher education levels and younger ages than the general population [41].

We also asked participants about their Facebook usage. About 97% of participants have been on Facebook for at least 4 years ($mean = 7.7$ and $\sigma = 2.3$). On average, participants had approximately 289 Facebook friends ($min = 0, max = 3165$). The majority of participants (98.8%) were checking their Facebook account at least once a week, while 84.6% of all participants checked their Facebook on daily basis. Participants were asked to describe their Facebook friends by selecting all that applies from a list of categories. Family members and relatives, offline friends, colleagues/co-workers, and friends' friends represented the top four friends' categories. A comparison of participants' Facebook usage frequency and friends' demographics with Pew research centre's recent report shows that our sample is in fact representative of U.S. Facebook users with slightly more active participants, which is typical for MTurk workers [11].

4.5.2 Perceived Health Status

We asked participants about their overall health status and existing health conditions. Only 73 participants (14.8%) did not have any chronic health conditions while the remaining 419 par-

Table 2: Participants demographics ($N = 492$).

Demographic	Category	Count	(%)
Gender	Male	**246**	**50.0**
	Female	245	49.8
	Unspecified	1	0.20
Age range	19–30	**227**	**46.1**
(19–74)	31–40	145	29.5
	41–50	62	12.6
	51+	58	11.8
Completed	Undergraduate University (Bachelor's)	**208**	**42.3**
Education	Some college/university courses	136	27.6
	Graduate University (Masters's/PhD)	58	11.8
	High School	51	10.4
	Diploma (post-secondary courses)	33	6.70
	Less than High School	3	0.60
	Other	3	0.60
Employment	Business, management, or financial	**65**	**13.2**
Categories	Services (e.g., retail)	62	12.6
(Top 5)	Computer engineer, IT professional	41	8.30
	Administrative support	34	6.90
	Education (e.g., teacher)	33	6.70

ticipants (85.2%) reported 55 different health conditions. Allergies, anxiety, depression, stress, arthritis/chronic pain, asthma, obesity, diabetes, heart disease, and cancer represent the most frequent health conditions reported by participants (Figure 6 in Appendix B). About one third of all participants (33.9%) suffered from one chronic health condition, while slightly over half of all participants (51.2%) reported two or more chronic health conditions. Among participants who had chronic health conditions ($n = 419$), the majority (96.9%) reported having the chronic health condition(s) for at least two years.

Participants were asked to identify their perceived health status on a 4-point Likert scale ("poor", "fair", "good", and "excellent"). A number of studies showed that the self-reported health status could be considered as a reasonable indicators of one's overall health [20, 45]. Despite that, in Section 3.4.1 of the exploratory study, we discussed that patients' perceived health status could be influenced by their perceived control over their health conditions. In line with our previous findings, we noticed that 253 of the online survey participants (about 51%), had one or more health conditions and yet perceived their health status to be "good" or "excellent." Furthermore, 13 participants reported "fair" health status without having any health conditions. Therefore, we used a combination of the self-reported health status and the number of health conditions in order to group participants into three meaningful categories: (1) *Healthy* (14.8%), individuals who had no chronic health conditions; (2) *Manageable* (51.4%), individuals who had at least one chronic health condition and perceived "good/excellent" health status; and (3) *Unhealthy* (33.7%), individuals who had at least one chronic health condition and perceived "fair/poor" health status. We believe that these categories provide a better representation of participants' overall health, and therefore, we used them for further comparison of participants' behaviors according to their health status.

We also explored the relationship between participants' privacy attitudes and their perceived health status. While the correlation analysis was marginally significant (p=0.035), the resulted correlation coefficient was very small (r=-0.095). Therefore, we did not include this relationship in further analysis.

4.5.3 HI Sharing Experiences

We asked participants to indicate if they ever shared details of their health information with different people on Facebook. About half of participants (48.6%) never shared their HI on Facebook. Among the remaining participants, 71.1% indicated sharing their HI with "some close friends or family members," while 37.9% shared their HI details with "select friends who had medical expertise and/or mutual health experiences." Furthermore, we asked participants to evaluate their prior HI sharing experiences on Facebook (*Positive*, *Negative*, *Both* positive and negative, or *Neither* positive nor negative). Three participants were not able to provide an evaluation for their prior HI sharing experiences on Facebook. Among the remaining 250 participants, more than half of them (57.7%) evaluated their prior HI sharing experience to be *Positive*, while about 18.2% had *Both* positive and negative experiences. It is interesting to see that only 8 participants (3.2%) indicated having only *Negative* experiences, while the remaining participants (19.8%) indicated *Neither* positive nor negative experiences. We also asked participants to explain in their own words why they thought that their experiences were *Positive* or *Negative*. In general, *Positive* experiences were related to gaining benefits (e.g., positive social support), while *Negative* experiences resulted mainly from the lack of benefits (e.g., impractical advice) or privacy concerns (e.g., over-sharing one's HI, judgments). Detailed analysis of participants' responses is presented in Appendix B.3.1.

4.5.4 Motivation to Share HI

Participants were asked to indicate the reasons that might motivate them to share their HI on Facebook by selecting all that applies from a list of common reasons. About 41.7% of participants considered Facebook as a place for seeking social support from friends and family whenever necessary. About one third of participants (33.5%) were motivated to share their HI on Facebook in an exchange for other people's expertise and experiences. Furthermore, 32.3% of participants were motivated by their previous positive experiences. It is also interesting to see that 28.9% of participants were passionate to help others by sharing their own health-related experiences on Facebook. This highlights the two-way nature of information sharing on SNSs, where some people tend to generate and disseminate content for the rest of the population. Finally, it seems that the lack of knowledge about the health issues, and the fact that Facebook could help in connecting to other people with similar health issues, were also motivating about 20% of participants to share their HI on Facebook.

Prior HI Sharing Experiences.

A series of Mann-Whitney U tests resulted a statistically significant difference among participants' willingness to share HI on Facebook when compared based on their prior HI sharing experiences, with mean ranks of 328.3 and 160.0 for the two groups respectively ($p < 0.001$ and large effect size $r = 0.61$). This indicates that those who had previously shared their HI on Facebook are more willing to share their HI on Facebook in the future. To investigate further, we used participants' evaluation of their prior HI sharing experiences to group them into the following categories: (1) *Positive*, those with only positive experiences; (2) *Negative*, those with only negative experiences; (3) *Both*, those with both positive and negative experiences; and (4) *Neither*, those with neither positive nor negative. A Kruskal-Wallis test followed by a series of pair-wise comparisons using Mann-Whitney U tests showed statistically significant differences for all pair-wise comparisons except when comparing *Both* and *Neither*

groups. The results showed that having only positive experiences in the past can highly influence the motivation to share HI in the future. Moreover, participants who had only negative experiences were also shown to be less motivated to share their HI details on Facebook, as compared to other groups.

Privacy Attitudes and Motivation to Share HI.

Participants were grouped based on their privacy attitudes (high, medium, or low privacy concerns). A Kruskal-Wallis test showed a statistically significant difference in willingness to share HI on Facebook ($\chi^2(2) = 33.42, p < 0.001$), with mean ranks of 218.4, 263.5, and 325.1 for participants who had high, medium, and low privacy concerns respectively. The pair-wise comparisons using Mann-Whitney U tests showed significant differences between all three groups, with $p \leq 0.001$ for all pair-wise comparisons ($r_{1-2} = 0.168$, $r_{1-3} = 0.287$, and $r_{2-3} = 0.226$). This confirms that people with higher privacy concerns are less willing to share their HI on Facebook, as compared to those with lower privacy concerns.

Health Status and Motivation to Share HI.

To investigate the effect of health status (*Healthy, Manageable,* and *Unhealthy*) on the motivation to share HI on Facebook, we conducted a of Kruskal-Wallis test. The test showed a statistically significant difference in the motivation to share HI details on Facebook among the three groups ($\chi^2(2) = 8.11, p < 0.017$), with mean ranks of 241.4, 242, and 267.4 respectively. Furthermore, the pair-wise comparisons using Mann-Whitney U tests showed a significant difference in the motivation to share HI on Facebook between *Healthy* and *Unhealthy* groups only ($p = 0.007$ and $r_{1-3} = 0.176$). This conforms with prior findings that associated online HI seeking/sharing activities with the overall health status and the number of health conditions [11, 16, 45]. A closer look at the participants shows that about 91% of those who were motivated to share their HI on Facebook were categorized as *Unhealthy* or *Manageable*. This might also be a good indication on the influence of health status on users' overall motivation to share HI on Facebook.

4.5.5 Preferred Recipients of the Shared HI

We asked participants to indicate their willingness to share their HI with different recipients on Facebook. As shown in Figure 2, about 67% of participants considered sharing their HI with "some close friends and/or family members," while about 65% considered sharing their HI with "friends and/or family members who had medical expertise and/or mutual health experiences." On the other hand, about 73% of all participants did not consider sharing their HI publicly with "all their Facebook friends." Furthermore, about 53% of participants did not consider sharing their HI with strangers through Facebook, even if they had "expertise in the medical field or mutual health experiences." Within-subjects comparison of the repeated measures showed that participants were significantly more willing to share their HI with "close friends and/or family members" and "friends/family who had medical expertise and/or mutual health experiences," as compared to other recipients. Moreover, while the "closeness" of the relationships among friends and family members was shown to influence their motivation to share HI with each other, the "medical expertise and/or mutual health experiences" were also considered as important motivating factors that encouraged people to share their HI.

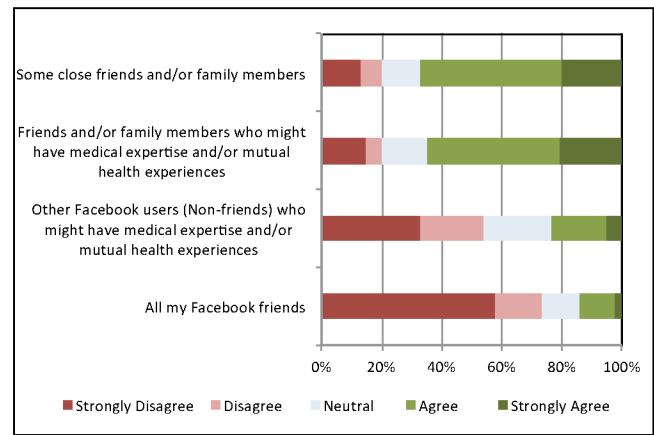To extend our investigation, we compared participants' will-

Figure 2: **Willingness to disclose HI to different recipients on Facebook.**

ingness to share HI with different recipients on Facebook.[6] We found statistically significant differences in participants' willingness to share HI with all recipient groups when compared based on their prior HI sharing experiences and privacy attitudes. However, when comparing participants based on their health status, we only found a statistically significant difference in their willingness to disclose HI with "non-friends Facebook users who had medical expertise and/or mutual health experiences" ($\chi^2(2) = 7.43, p = 0.024$), with mean ranks of 208.6, 247.9, and 261 for *Healthy, Manageable,* and *Unhealthy* groups respectively. We found that *Unhealthy* participants were significantly more willing to share their HI with non-friends Facebook users as compared to *Healthy* participants ($p = 0.007$ and $r = 0.18$). The results suggest that while participants' health status was not a determining factor when sharing HI with friends and family members, it might have influenced participants' motivation to share HI with non-friends Facebook users.

4.5.6 Willingness to Search for Specific Users

In a hypothetical situation, participants were asked to identify their willingness to use customized search features that could help in finding other Facebook users who had "mutual health experiences" or "expertise in the medical field." Between 32-29% of all participants were "(Very) Likely" to use the search features to find other Facebook users who had "mutual health experiences" or "medical expertise" respectively. On the other hand, about half of all participants were "(Very) Unlikely" to do the same. Within-subjects comparison of participants' willingness to use the search features for finding different users showed that participants were significantly more willing to search for other Facebook users who had mutual health experiences, as compared to users with expertise in the medical field ($p < 0.001$ and $r = 0.2$).

We compared participants' willingness to use the search features to find other users on Facebook by performing a series of between-subjects tests. We found that participants' who had *Positive* experiences to be more likely to use the search feature as compared to those who had neither positive nor negative experiences. When comparing participants' willingness to use the

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[6]The "All Facebook friends" group was excluded from the pairwise comparisons since it was not representing specific recipients.

search features based on their privacy attitudes, we found statistically significant differences among all groups, with participants who had high privacy concerns to be significantly less likely to use the search features as compared to those who had medium or low privacy concerns.

4.5.7 Anonymous Identity

We asked participants to indicate their willingness to use an anonymous online identity for sharing their HI on Facebook. About 47% of participants were "(Very) Unlikely" to use an anonymous identity when sharing their HI. On the other hand, about 36% of participants were "(Very) Likely" to do so. A between-subjects comparison of participants' willingness to use anonymous identities for sharing HI on Facebook showed that participants who had IT/Computer knowledge were significantly more willing to use anonymous identities on Facebook, as compared to those who had no IT/Computer knowledge ($p = 0.036$ and small effect size $r = 0.1$). Furthermore, our comparisons showed that participants with medium privacy concerns were significantly more willing to use anonymous identities for sharing their HI on Facebook than people who had high or low privacy concerns ($p = 0.016$ and $p = 0.015$). This however might be due to the pragmatic nature of people with medium privacy concerns, who might be more willing to mitigate risks in exchange for the expected benefits.

Moreover, we were unable to find statistically significant difference in the willingness to use anonymous identities for sharing HI on Facebook, when comparing participants based on their health status. This means that regardless of participants' health status, their motivation to use an anonymous online identity for sharing HI on Facebook is mainly influenced by their privacy attitudes and their IT/Computer knowledge and experience.

Participants were asked to indicate their willingness to "hide" different personal information when creating their anonymous identity that would be used for sharing HI with strangers. As shown in Figure 3, about 95% of participants were "(Very) Likely" to hide their residential address and phone number, while approximately 90% preferred to hide their current/future location information, identifiable profile picture, email address, and last name. On the other hand, slightly over 60% of participants were "(Very) Unlikely" to hide their gender. Also, it is interesting to see that while 29% of participants were "(Very) Likely" to hide their health condition(s), about 50% of all participants were "(Very) Unlikely" to do so.

We performed Principle Component Analysis (PCA) in order to reduce the correlated personal information items presented in Figure 3 into fewer meaningful components.[7] The analysis showed that about 66% of the cumulative variance was described by selecting three components, as shown in Table 3. We considered an information item to be a part of a component if it had a factor loading of at least 0.6 for the particular component and a factor loading under 0.4 for the other components. Moreover, KMO and Bartlett's tests showed adequate sampling and statistically significant correlations that were appropriate for using PCA ($KMO = 0.87$, $p < 0.001$, $df = 91$).[8]

As shown in Table 3, twelve information items were grouped into three components, while the remaining two items did not conform to any particular component (occupation and employment, and city of residence). We named the identified components as following: (1) *Contact and location* information, which consisted of information that could be used to directly reach an

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[7]PCA with Varimax rotation method was used.

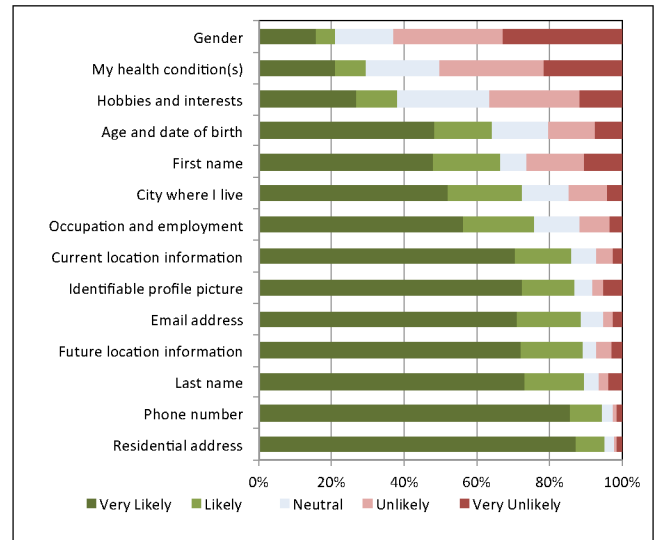[8]A KMO test result >0.8 is considered as "meritorious".

Figure 3: Willingness to hide different information items when creating an "anonymous" online identity.

Table 3: PCA results for different personal information items. The last column represents the percentage of participants who were likely to hide each information item.

Component	Factor loading	Agreement (%)
Contact and location information	—	**91**
Phone number	0.87	94
Residential address	0.80	95
Email address	0.74	89
Future location information	0.73	89
Current location information	0.72	86
Demographic information	—	**38**
Gender	0.83	21
My health condition(s)	0.80	30
Hobbies and interests	0.69	38
Age and date of birth	0.62	64
Identity information	—	**81**
Identifiable profile picture	0.79	87
Last name	0.75	89
First name	0.72	66
Information items that did not conform to any component	—	—
Occupation and employment	NA	76
City where I live	NA	72

individual (e.g., phone number, residential address); (2) *Demographic* information, which consisted of information that were not considered to be identifiable by themselves but could be used to describe properties of an individual in real life (e.g., age, gender, hobbies); and (3) *Identity* information, which represented information that could lead to revealing one's real identity (e.g., picture, first/last name). We created an index variable for each component by averaging participants' rating for each information item within the component.

Considerably more participants were "(Very) Likely" to hide information related to *Contact and location* information and *Identity* information, with average scores of 91% and 81% respectively. *Demographic information* on the other hand had the least score among all components (average score of 38%), with sta-

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tistically significantly fewer participants who were likely to hide their demographic information on Facebook, as compared to identity, contact, or location information. It was also interesting to see that "health conditions" were categorized as *Demographic* information, with about 30% of participants who were likely to hide their health conditions.

By comparing participants' motivation to hide different information based on their privacy attitudes, we found statistically significant differences among all groups with the following two exceptions: (1) motivation to hide *Contact and location* information, when comparing participants who were classified as having medium privacy concerns to those with low concerns. This confirms the relatively higher level of concerns raised by most participants toward revealing their *Contact and location* information, and (2) motivation to hide *Demographic* information, when comparing participants who were classified as having high privacy concerns to those with medium concerns. This might indicate the overall lower concerns with regards to revealing demographic information.

Finally, comparing participants' motivation to hide different information based on their prior HI sharing experiences resulted in a statistically significant difference for hiding *Demographic* information ($p = 0.003$), with mean ranks of 113.8, 182.8, 127.2, and 149, for those who had different experiences (*Positive, Negative, Both* positive and negative, and *Neither* positive nor negative). Furthermore, the pair-wise comparisons showed that participants who had *Positive* experiences in the past were less likely to hide their *Demographic* information, as compared to other participants.

4.5.8   Willingness to Trust SNSs with HI

We asked participants to indicate their willingness to trust an SNS with their HI, based on its provider. About 27% of all participants trusted an SNS with their HI if it were provided by a governmental health authority, while slightly less than 20% of participants trusted a governmental agency (non-health related) and a recognized private company. On the other hand, about 58% of participants did not trust an SNS if it were provided by a non-health related governmental agency, which was relatively more than the percentage of participants who did not trust a recognized private company and a government health authority (about 52% and 48% respectively). Within-subjects comparisons showed that significantly more participants were willing to trust an SNS with their HI if it were provided by a governmental health authority, as compared to other providers.

We also asked participants to indicate their willingness to trust an SNS with their HI if it were recommended by different people (doctors, friends with mutual health experiences, friends with medical expertise, and close friends/family members). The results of a Friedman's test and the post-hoc comparison using Wilcoxon signed-rank test showed statistically significant differences in participants' willingness to trust an SNS with their HI if it were recommended to them by their doctors, as compared to other people. We imagine that the higher level of trust might also influence participants' willingness to use an SNS for sharing/seeking HI if it were recommended to them by their doctors.

5.   DISCUSSION

The results of the online survey showed that participants' overall willingness to share HI on Facebook was linked to the following factors: (1) prior HI sharing experience; (2) privacy attitude; (3) perceived health status; and (4) the intended recipient(s) of the shared HI.

We found that participants' prior HI sharing experiences had a significant correlation with their willingness to share HI on Facebook, with participants who previously shared their HI on Facebook to be more willing to do the same in the future. Furthermore, participants who described their prior HI sharing experience to be *Positive*, were significantly more likely to disclose their HI on Facebook, as compared to participants who had *Negative* experience. By analyzing participants qualitative responses, we found that *Positive* HI sharing experiences were described as online communications with other social peers that benefited the participants (e.g., positive support). It appears that sharing HI on SNS might be a way for some people to initiate conversations and discussions with other social peers, while creating the opportunity toward finding other people that might had similar health experiences. *Negative* experience was mainly due to the lack of gained benefits. Participants were also intimidated by the loss of control over their shared HI in the semi-public SNS environments, and by the fear of oversharing their HI, which might lead to unforeseen consequences such as gossips, rumours, and judgments.

Inspired by the Westin privacy index [25], participants' attitudes toward privacy were used to group them into people with high, medium, or low privacy concerns. In general, we found that higher privacy concern was associated with performing more privacy-preserving actions on Facebook. This indicates that participants who were classified as having higher privacy concerns were willing to put more effort into protecting their online privacy in the context of SNSs. Furthermore, when sharing their HI on Facebook, participants with high privacy concerns were significantly less likely to disclose their HI than the other groups (medium or low concerns). This is inline with findings from previous studies of the influence of users' privacy attitudes on their overall willingness to disclose sensitive personal information on websites [6, 31]. Also, it indicates that HI might be treated as sensitive/personal information by users and therefore, should be handled with extra care in the context of SNSs.

We used participants' health conditions along with their self-reported health status to categorize participants into *Healthy*, *Manageable*, and *Unhealthy* groups. We discovered that *Unhealthy* participants (who had one or more health conditions and perceived their health to be *poor* or *fair*) were significantly more likely to disclose their HI on Facebook than *Healthy* ones (with no health conditions). This is in line with previous findings, which showed that those who perceived their health poor, were more willing to share and/or seek HI online, as compared to people in good health [16, 20, 45]. Furthermore, our participants with *Manageable* health status (i.e., had at least one chronic health condition yet perceived their health to be good or excellent) were somewhere in between *Healthy* and *Unhealthy* in terms of their motivation to share HI on SNSs. We conclude that patients' motivation to share HI on SNSs is linked to their confidence in the level of control over their health conditions, with those who had higher control to be less motivated to discuss their HI issues with other online users.

We explored participants' willingness to disclose their HI with different audiences on Facebook. The results suggest that regardless of participants' health status, they were more willing to disclose their HI to friends and family members than other Facebook users (e.g., non-friends). Moreover, while the "closeness" of the relationship among friends and family members was likely to increase their willingness to share HI with each other, "medical expertise" or "mutual health experiences" appear to be contributing factors that encourage friends and fam-

ily members toward exchanging their HI with each other. On the other hand, participants were less likely to share their HI with non-friends Facebook users, even if those users had expertise in the medical field or had mutual health experiences. At the same time, *Unhealthy* participants were significantly more willing to share their HI with those non-friends who had medical expertise or mutual health experiences, as compared to *Healthy* participants. This indicates that those users who have poor health might be more willing to discuss their health issues with strangers on Facebook, especially if those strangers have expertise in the medical field or mutual health experience.

5.1 Limitations

Individual interviews have few limitations: First, the interview results are limited by participants' experiences with existing HI sharing services. Therefore, we restricted the participation to patients who were also active SNSs users, with at least one SNS account that they used regularly. Second, it is possible that participants indicate some behavioral preferences during the interviews that they are not necessarily practicing in their real lives [3]. To address that, we tried to infer privacy preferences from participants' previous HI sharing practices rather than directly asking them. Third, to address generalizability of our findings, we conducted a followup online survey in order to test our findings with a more representative sample. Finally, to minimize interviewer's biases on both the data collection and analysis processes [21], we asked open-ended questions and tried to probe the participants to tell their story from their own perspectives. Furthermore, we tried to validate our coding scheme by comparing our results to the results of a second researcher who analyzed 100 randomly selected excerpts from the interview transcripts. Ideally, we believe that involving more than two researchers throughout the data collection and analysis will always help in minimizing existing biases.

The main limitation of the online survey was in the self-reported nature of the data, which was difficult to verify in practice. For instance, participants reported a number of health conditions that were difficult to confirm without violating participants' privacy. Furthermore, we used a contextualized version of the Westin privacy index in order to categorize participants according to their privacy attitudes. While our findings might be of interest to the community, a formal validation of our Westin inspired categorization would be necessary before comparing our categories to the Westin based categories.

5.2 Implications for Design

By exploring participants' motivation to use a hypothetical search feature for finding different Facebook users, we found that participants were more willing to search for Facebook users who had mutual health experiences, as compared to users who had expertise in the medical field. Furthermore, while our results showed that *Unhealthy* participants were more willing to share their HI with different user groups, we did not find statistically significant difference in their willingness to use the search features, when compared to participants with *Healthy* or *Manageable* health status. Aside from the reasons behind participants' motivation to use the search features, we believe that SNSs can utilize users' shared HI in order to provide automatic recommendations that could facilitate finding the preferred user groups on behalf of users. For instance, while we showed that patients were less sensitive toward revealing their health conditions when creating their online anonymous identity, we believe that current recommendation systems on Facebook can utilize this information to automatically search and suggest other users who might have mutual health experiences or medical expertise.

Using an anonymous online identity to share HI with strangers was considered to be a preferable option for overcoming the privacy concerns [2, 34]. Similarly in our exploratory study (Section 3), participants considered using anonymous identities to protect their privacy when discussing their health issues with online users, especially strangers. We believe that providing the ability to anonymously share HI on SNS can encourage users, especially people with medium privacy concerns (i.e. pragmatists), to engage in more active HI sharing by regaining some of the privacy surrendered when users disclosed their HI online. In order to maintain anonymity, it is important for users to have the ability to hide *contact and location information* and *identity information* from other users. Furthermore, we imagine that SNSs can also benefit from users' low sensitivity towards revealing their health conditions, in order to facilitate HI sharing among users and increase their interactions by offering them an option to use anonymous online identities whenever needed.

Internet users' trust in web-based services was shown to influence their motivation to provide personal information to these services [8, 17, 45]. In the context of sharing HI on SNSs, we identified a number of trusted SNS providers, among which a "governmental health authority" appeared to be the most trusted SNS provider by the participants. Furthermore, we found that regardless of the SNS provider, participants were more likely to trust an SNS with their HI if it were recommended by their doctor(s), as compared to others (e.g., friends with mutual health conditions). We believe that SNS providers, especially those specialized in HI sharing and management, can benefit from patients' trust towards their doctors and utilize them as intermediate channels for attracting new users. This however will require incentivizing, educating, and motivating doctors, which might be a challenging process by itself.

6. CONCLUSION

We employed qualitative and quantitative instruments to investigate users' motivation to share HI on Facebook. Our results indicate that users' prior HI sharing experiences, attitudes toward privacy, and perceived health status, are linked to their motivation to share HI. In addition, we identified the key characteristics of the recipients that users preferred to share their HI with. Armed with such an understanding, we discussed the opportunities of utilizing existing features in order to optimize the gained benefits, while improving users' privacy when sharing HI. Also, our results indicate that users' health conditions could be used to facilitate HI sharing on Facebook without compromising their online privacy. Finally, by hiding *Contact and location* information, Facebook users' can maintain some level of anonymity and privacy when sharing HI with strangers.

Through this study, we (1) provide a better understanding of Facebook users' HI sharing practices, preferences, and risk perceptions, (2) identify factors linked to users' perceived privacy and motivation to share HI on Facebook, and (3) suggest design features that could facilitate effective HI sharing among Facebook users.

7. ACKNOWLEDGMENTS

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APPENDIX

A. SUPPLEMENTARY MATERIALS FOR THE EXPLORATORY STUDY (INTERVIEWS)

A.1 Interview Guide and Questions

Will collect qualitative data by means of semi-structured interviews. The interview lasted between 60-90 minutes, and were audio-recorded and transcribed. The interviews started by reviewing the consent form and the collection of demographic information (age, gender, education, etc.). Then, a number of research-related questions were asked, as shown in the following subsections. A follow-up telephone call or email communication was made when necessary to clarify issues arising from the discussion. The interview questions are presented as following:

A.1.1 Health Condition Background

- What is the health condition you have?
- How/When did the health condition appeared or started the first time?
- How does the health condition affect your daily life?
- What are the challenges that you face due to the health condition you have?
- How does the health condition you have affect your social life?
- Is there anything specific about your health condition that is of your concern?

A.1.2 Health Management

- How do you manage your health condition?
- How others (if any) are involved in your health management process?
- What is your relationship with doctors, physicians, and nurses?
- Do you have any concerns regarding your health management?

A.1.3 SNS Usage and Background

- How many SNS accounts do you maintain?
- How often do you log into your SNS accounts and what do you usually do there?
- Who do you connect to using the SNSs? Who are your online friends?
- What do the SNS environments mean to you (e.g., Facebook)?

A.1.4 HI Sharing on SNSs

- Have you ever shared HI in your SNSs? Why?
- Whom do you usually share your HI with?
- How do you think sharing HI could be helpful/beneficial to you or others in your social network?
- When it comes to sharing HI, do you have specific preferences about the type of the SNS where you share your HI in? Why?
- How do you think about existing privacy settings in SNSs?

A.1.5 A Specialized SNSs for Managing Health Conditions

- Have you ever considered using an SNS to manage, share, and seek HI?
- What do you expect from a specialized SNS that is used to help you manage your health conditions and get connected to others?
- How do you define your privacy?

A.1.6 Study Related Feedback

Do you have any comments, suggestions or concerns related to this study? We appreciate your constructive feedback?

A.2 Supplementary Results

Participants came with different health issues. Nine participants suffered from chronic pain and arthritis in different parts of their body. We interviewed two quadriplegic participants with limited physical mobility, among whom one had also suffered from chronic lung and heart diseases. We also interviewed an HIV positive patient, who was infected as a results of an accidental needle poke while doing his job as a paramedic. Finally, one participant had Neuromyelitis Optica (NMO), which is a rare disease that attacks the central nerve system and causes blindness, paralysis, and other health issues. The remaining participants suffered from a combination of mental and/or physical illnesses (e.g., eating disorder and depression, arthritis and lung disease). More details about participants' health conditions are presented in Table 4.

Table 4: **Participants demographics and health conditions. The first column represents participants' ID.**

ID	Gender	Age	Health condition(s)
P1	M	38	chronic sciatica due to an accident
P2	M	59	back fracture and defective left knee
P3	M	31	severe arthritis in right hand due to a car accident
P4	F	68	C4-C5 incomplete quadriplegic due to damaged neck in a sport accident
P5	F	30	chronic depression
P6	F	21	curved spine and chronic back pain
P7	M	54	C5-C6 quadriplegic due to a motor accident, and chronic heart/lung disease
P8	M	38	chronic back pain
P9	F	42	Neuromyelitis optica (NMO), episodes of blindness, headaches, and fatigue
P10	M	37	osteoarthritis (deformed leg) and defective knee
P11	M	40	L3-L4 fusion due to a work-related accident and COPD (lung problem)
P12	M	59	degenerative disk and brain injury (lost senses of balance, taste, and smell)
P13	M	51	osteoarthritis in all joints
P14	F	39	eating disorder and post-traumatic stress disorder
P15	M	37	bipolar depression and anxiety
P16	M	48	post-traumatic stress disorder
P17	M	48	arthritis in hands and knees
P18	F	38	degenerative arthritis in foot and ankle, anemia, and depression
P19	M	50	HIV due to an accidental needle poke
P20	M	50	depression and chronic pain from broken neck
P21	F	35	herniated disks (L4-L5) with chronic pain

B. SUPPLEMENTARY MATERIALS FOR THE CONFIRMATORY STUDY (ONLINE SURVEY)

B.1 Survey Items

Our survey questionnaire is presented in Appendix B.2. The survey consists of the following parts:

B.1.1 Demographics and Background

As presented in Appendix B.2, we collected general demographic information that were used to characterize different groups of participants (Q.1–Q.5). We also asked participants to identify their IT background and computer experiences (Q.6). Finally, we collected information about participants' Facebook usage (Q.7–Q.11), and asked them to describe their Facebook friends (Q.11).

B.1.2 Health Conditions and Perceived Health Status

We asked participants' to report their health conditions background (Q.12–Q.13). We also asked participants to indicate their perceived health status (Q.14). The demographic characteristics of SNS users and their health status might be highly predictive of their attitudes. For instance, younger SNS users, who did not have health problems, were assumed to have different HI sharing preferences and perceptions than older SNS users who suffered from a number of chronic health conditions.

B.1.3 Previous HI Sharing Experiences

We asked participants to indicate their HI sharing experiences with health-related SNSs (Q.15–Q.18). We also surveyed participants' previous HI sharing experiences on Facebook (Q.19–Q.20). Furthermore, we asked participants to evaluate their previous HI sharing experiences on Facebook (Q.21–Q.22). We aimed at comparing the attitudes and behaviors of participants who experienced sharing their HI on Facebook with others who did not have any experiences. It was assumed that prior experiences might affect participants' future HI sharing behaviors, especially if they had gone through good/bad experiences (e.g., gained benefits, privacy breaches, information misuse).

B.1.4 Motivation to Share HI on Facebook

Participants were asked to indicate their overall willingness to share their HI on Facebook by rating their choice on a 5-points Likert scale (Q.23). We also asked participants to identify the factors that might motivate or stop them from sharing their HI on Facebook (Q.24–Q.25).

B.1.5 Preferred Recipient(s) of the Shared HI

Participants were asked to indicate their motivation to share their HI with different user groups by rating their level of agreement on a 5-points Likert scale (Q.26). We also asked participants to indicate their willingness to use a search feature to find certain online social peers through Facebook (Q.27).

B.1.6 Anonymous Online Identity

We asked participants to consider an option for creating anonymous online identities and indicate their willingness to use it whenever sharing their HI with other Facebook users (Q.28–Q.29). Participants were also asked to identify the personal information that they were likely to hide from other online social peers if they were to create an anonymous online identity for HI sharing purposes (Q.30).

B.1.7 Trusted SNSs Provider(s)

We identified possible SNS providers and asked participants to identify their level of trust in each SNS providers (Q.31). We also ask participants to indicate their level of trust in an SNS if it was recommended to them by either a close friends/family member, friends who had medical expertise, friends who had mutual health experiences, or their doctors (Q.32).

B.1.8 Attitudes Toward Privacy

The following are the statements used in the Westin privacy index: (1) (Consumers) have lost all control over how personal information is collected and used by (companies); (2) Most (companies) handle the personal information they collect about consumers in a proper and confidential way; and (3) Existing laws and organizational practices provide a reasonable level of protection for (consumers) privacy today.

We modified the above statements by replacing the words in the parentheses with context specific words. Inspired by Westin, we asked participants to rate their level of agreement on a 4-points Likert scale for the modified statements, as shown in Q.33 (Appendix B.2). Participants who agreed (strongly or somewhat) with the first statement and disagreed (strongly or somewhat) with the second and third statements were classified as to have high privacy concerns. Participants with low privacy concerns were those who disagreed with the first statement and agreed with the second and third statements. The remaining participants were considered to have medium privacy concerns.

B.2   Survey Questionnaire

By volunteering to take part in this study, participants declare that they are at least 19 years old and that they maintain an active Facebook profile that they visit regularly. To complete the survey, participants were required to answer the following questions:

1. What is your gender?
   - Male
   - Female
   - Decline to answer
2. How old are you: [Select from list between 19 and 99]
3. What is your highest level of completed education?
   - Less than High School
   - High school (secondary school)
   - Some college/university courses
   - Diploma (post secondary courses)
   - Undergraduate University degree (Bachelor's)
   - Graduate University degree (Masters's or PhD)
   - Other (Please specify)
4. What is your employment category?
   - Administrative support (e.g., secretary, assistant)
   - Art, writing, or journalism (e.g., author, reporter)
   - Business, management, or financial (e.g., manager, accountant, banker)
   - Computer engineer or IT professional (e.g., systems administrator, programmer, IT consultant)
   - Education (e.g., teacher)
   - Engineer in other fields (e.g., civil engineer, bio-engineer)
   - Legal (e.g., lawyer, law clerk)
   - Medical (e.g., doctor, nurse, dentist)

- Scientist (e.g., researcher, professor)
- Service (e.g., retail clerks, server)
- Skilled labor (e.g., electrician, plumber, carpenter)
- Student
- Unemployed
- Other (Please specify)

5. What is your current country of residence? [Select from the list]
   - United States of America
   - Canada
   - Afghanistan
   - ... Additional choices hidden ...
   - Zimbabwe
   - Other
6. Do you have a college degree or work experience in computer science, software development, web development or similar computer/IT related fields?
   - Yes
   - No
   - I don't know
7. Approximately how many hours do you spend on the Internet each day? [Select between 0 and 24 hours]
8. When did you start using Facebook? [Select between 2004 and 2016]
9. How often do you check your Facebook?
   - At least once a day
   - At least once a week
   - Every month
   - Less often than every month
   - Don't use it at all
10. Please check your Facebook profile and tell us how many friends you have on Facebook?
11. How do you describe your Facebook friends? [Select all that applies]
    - Family members and relatives
    - Offline friends (e.g., childhood friends, school friends)
    - My friends' friends (online and offline)
    - Colleagues and co-workers
    - People whom I met online for the first time (e.g., people with common interests)
    - Celebrities and public figures
    - People with specific expertise/profession (e.g., lawyers, doctors, engineers)
    - Others (please specify)
12. Do you currently suffer from any chronic health conditions? [Please select all that applies]
    - Allergies
    - AIDS/ HIV
    - Asthma
    - Heart disease
    - Stroke
    - Cancer
    - Diabetes

- Arthritis and chronic pain
- Eating disorder
- Obesity
- Stress
- Depression
- Anxiety
- None
- Others (please specify)

13. How long have you had the above mentioned health conditions (if any)?
    - I don't have any chronic health conditions
    - Less than a year
    - About two years
    - About three years
    - About four years
    - More than four years

14. In general, would you say your health is:
    - Poor
    - Fair
    - Good
    - Excellent

15. Have you ever joined health-related social networking sites?
    - Yes
    - No
    - I don't know

16. Why did you join the health-related social networking sites?

17. Are you still using the health-related social networking sites?
    - Yes
    - No
    - I don't know

18. If you are not using the health-related social networking site anymore, then why did you decide to do so? [Type "NA" if you are still using the health-related social networking sites]

19. Have you ever shared details of your health information with anyone of the following people on Facebook? [Select all that applies]
    - Everyone on my Facebook friends list
    - Some close friends or family members
    - Select friends who had medical expertise and/or mutual health experiences
    - Other Facebook users (Non-friends) who had medical expertise and/or mutual health experiences
    - No one (Never shared my health information with others on Facebook)
    - Other people (Please specify)

20. Why did you share (or didn't share) your health information on Facebook?

21. How do you evaluate your prior experience with sharing your health information on Facebook?
    - Positive
    - Negative
    - Both positive and negative

- Neither positive nor negative
- I don't know or does not apply to me

22. What was positive and/or negative about your prior experience of sharing your health information on Facebook? [Leave blank if does not apply to you]

23. How likely would you share details of your health information with other people on Facebook? [Participants are asked to rate their response on a 5-points likert scale with responses varying from "Very Unlikely" to "Very Likely"]

24. What might motivate you to use Facebook for sharing your health information details with other people? [Please select all that applies]
    - My previous positive experiences
    - Lack of knowledge about my health issues (if any)
    - My passion to help others by sharing my health-related experiences with them
    - The need to learn from other people's expertise and experiences
    - Facebook provides me with the ability to hide my personal information and real identity from others
    - Seeking social support
    - Facebook can help me find other people with similar health issues
    - Facebook helps me to communicate with other people without having to meet them in real life
    - Nothing motivates me to share my health information on Facebook
    - Other (Please specify)

25. What might stop you from using Facebook to share your health information details with other people? [Please select all that applies]
    - My previous negative experiences
    - I don't see any benefits of sharing my health information with others
    - I am a healthy person and I do not have anything to say about my health
    - My health issues are personal and I do not want to share them with other people on Facebook
    - Others don't understand my health conditions
    - I don't have any Facebook friends that have expertise and/or experiences in the medical field
    - I don't want others to worry about my health
    - I have different people on my Facebook and I prefer not to talk about my health to all of them
    - My health condition(s) are completely manageable
    - I don't like to cry for help or feel week, my friends might misunderstand me
    - I don't feel protected online, my shared information might be misused against me
    - Other (Please specify)

26. I would consider sharing my health information details with the following Facebook users: [For each user group, participants must rate their response on a 5-points likert scale with responses varying from "Strongly disagree" to "Strongly agree"]
    - All my Facebook friends
    - Some close friends and/or family members

- Friends and/or family members who might have medical expertise and/or mutual health experiences
- Other Facebook users (Non-friends) who might have medical expertise and/or mutual health experiences

27. Facebook provides a "search" feature that can help you in finding people with specific interests, expertise, and/or experiences. Suppose that you have a chronic health condition, how likely would you use the "search" feature to find people with: [For each user group, participants must rate their response on a 5-points likert scale with responses varying from "Very Unlikely" to "Very Likely"]

- Expertise in the medical field (e.g., Doctors, nurses, health professionals)
- Mutual health experiences (e.g., people with similar health conditions)

28. Suppose that Facebook allows you to create an anonymous online identity. How likely would you use an anonymous online identity if you want to share your health information with other people on Facebook? [Participants are asked to rate their response on a 5-points likert scale with responses varying from "Very Unlikely" to "Very Likely"]

29. Why would you use (or not use) an anonymous online identity when sharing your health information on Facebook?

30. Suppose you want to create an anonymous identity in order to share your health information with strangers on Facebook. How likely would you "hide" each of the following personal information? [For each item, participants must rate their response on a 5-points likert scale with responses varying from "Very Unlikely" to "Very Likely"]

- First name
- Last name
- Identifiable profile picture
- Residential address
- City where I live
- Occupation and employment information
- Hobbies and interests
- Current location information (e.g., I am in "restaurant name" now)
- Future location information (e.g., I will be in "restaurant name" at 6 PM)
- My health condition(s)
- Email address
- Phone number
- Age and date of birth
- Gender

31. In general, I would trust a social networking site with my health information if it is operated/owned by: [For each provider, participants must rate their response on a 5-points likert scale with responses varying from "Strongly disagree" to "Strongly agree"]

- A governmental agency (non-health related)
- A governmental health authority (e.g., city, state/province, federal/national)
- A recognized private company

32. In general, I would trust a social networking site with my health information if it is recommended by: [For each group, participants must rate their response on a 5-points likert scale with responses varying from "Strongly disagree" to "Strongly agree"]

- My close friends and/or family members
- Friends who might have medical expertise
- Friends who might have mutual health experiences
- My doctor(s)

33. Please rate your level of agreement with each given statement below [4-points likert scale with the given responses: "Strongly disagree", "Somewhat disagree", "Somewhat agree", and "Strongly agree"]

- Internet users have lost all control over how personal information is collected and used by social networking sites
- Most social networking sites handle the personal information they collect about consumers in a proper and confidential way
- Existing laws and organizational practices provide a reasonable level of protection for internet users' privacy today

34. Have you ever performed any of the following actions on Facebook? [For each action, participants must answer with "Yes", "No", or "I don't know"]

- Modified the privacy settings to specify the people who can see your photos, likes, comments, and other posts
- Deleted some shared photos, comments, and/or other posts
- Changed profile visibility (profile information that others can see)
- Hid your friends' list from other Facebook friends
- Modified the privacy settings to specify the people who can post on your Timeline
- Deleted and/or blocked friends
- Refused to provide some profile information or used fake information because it was too personal or unnecessary
- Modified the way people can search your information on Facebook
- Hid a specific post from others and shared it only with select friends
- Modified the privacy settings to specify the people who can comment on and/or like your posts

B.3 Supplementary Results: Online Survey

Participants' age distribution and employment categories are presented in Figures 4 and 5. Also, Table 5 presents a list of health-related sites that were used by participants (note that these sites were not considered to be SNSs).

B.3.1 Positive and Negative Experiences

We also asked participants to explain in their words why they think their experiences were *Positive*. As presented in Table 6, a total of 272 text responses were analyzed and coded to represent participants' positive experiences. Positive emotional and social support in the form of sympathy, empathy, and prayers, were identified as the most common positive experiences among participants. Useful recommendations and advice came second
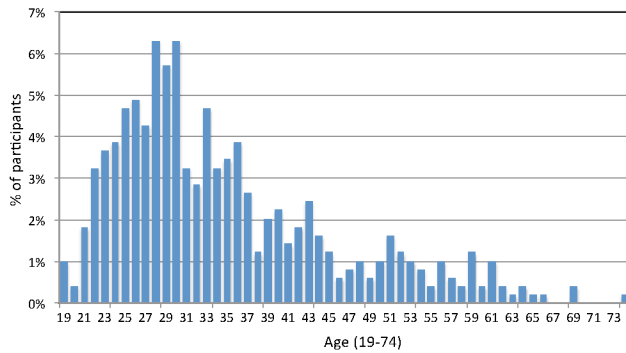
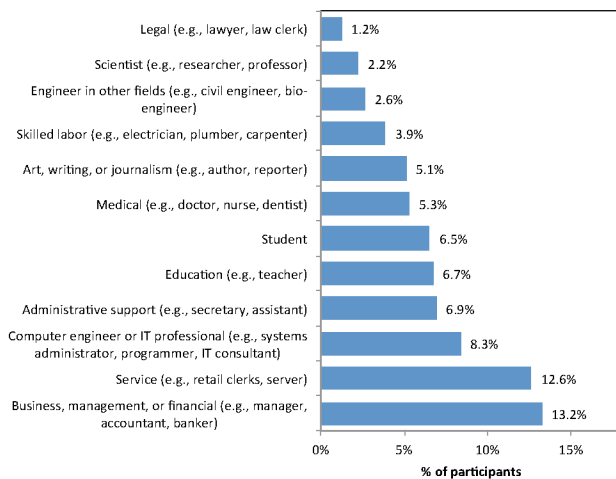Figure 4: Participants' age distribution.

Figure 5: Participants' employment categories distribution.

Table 5: Health-related sites used by participants that are not considered as SNSs.

| Name/Description	Name/Description
Insulin Pump forum (www.insulinpumpforums.com)	PBC Group
Lymphomation.org	Hypothyroid Mom
www.community.breastcancer.org	Post traumatic stress self help group
JDRF (T1 Diabetes)	Understood.org (Kids learning)
Wrongplanet	Inspire (www.inspirehealth.ca)
Achalasia support group	Reddit communities
Weight Watchers	Healthy Brain Network
IBS Groups (ibsgroup.org)	MS Society (beta.mssociety.ca)
MS World (www.msworld.org/)	mdjunction (www.mdjunction.com/)
Mitoaction (www.mitoaction.org/)	Myelomabeacon (www.myelomabeacon.com/)
fibromyalgia of Ireland lupus and me (Facebook group)	enotalone (www.enotalone.com/)
Parenting/Breastfeeding	MedHelp (www.medhelp.org/)
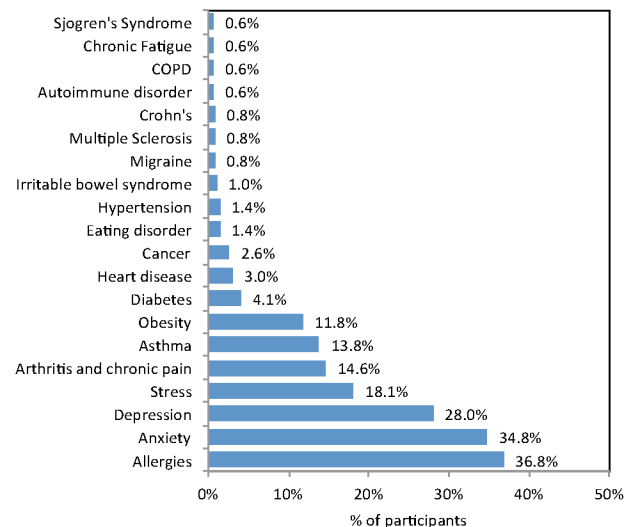
Figure 6: Reported health conditions frequencies (cumulative percentage frequency=95%).

in the list, with participants receiving feedback that positively helped them toward managing their health conditions. Participants also described their positive experiences by indicating that Facebook was used as an effective communication channel for broadcasting information related to their health, while receiving timely feedback from other social peers. Furthermore, participants benefitted from their conversations with others in order to bring awareness to their health issues and justify their behaviors whenever necessary. By sharing their HI on Facebook, participants were able to find other social peers who had mutual health experiences. Communicating with these social peers provided participants with valuable information/experiences while making them feel that they belong to a group of understandable and easy to communicate people. Finally, the two-way benefits of sharing HI on SNSs was easy to identify by going through participants' positive experiences in trying to help other people whenever possible.

As shown in Table 7, participants identified a number of reasons for describing their prior HI sharing experiences to be *Negative*. Participants were frustrated by the responses they received from their social peers who overreacted to their health problems and showed overwhelming and unnecessary concerns. Participants were also agitated by the social peers who used their shared HI in order to make judgments, spread rumours, gossip,

or participated in insulting discussions. Furthermore, participants raised some privacy concerns with respect to discussing their health issues in a semi-public environment lie Facebook, which occasionally led to oversharing their health information without their permissions. Finally, while participants did not appreciate the impractical recommendations and advice given to them by some social peers, they felt lonely and unimportant when they received no support/replies from other social peers.

Table 6: Positive HI sharing experience. The first two columns represent the coded category and related sub-categories. The last two columns represent the total number/percentage of positive coded events under each category (272 total references).

Category	Sub-categories	Coded events	(%)
Positive support	sympathy, empathy, prayers, emotional and social support	107	39
Useful recommendation and advice	new medication, alternative medicine, health condition management tips, shared experiences and information resources	74	27
Communication with other peers	start conversations, quick/practical way to broadcast health information, bring attention to health conditions, receive quick feedback, justify behaviors	49	18
Mutual experiences	finding others with similar health issues, easy communication, mutual understanding, useful feedback and advice, sense of belonging	27	10
Two-way benefits	others helped me, I tried helping others	15	6

Table 7: Negative HI sharing experience. The first two columns represent the coded category and related sub-categories. The last two columns represent the total number/percentage of negative coded events under each category (86 total references).

Category	Sub-categories	Coded events	(%)
People don't understand	people overreact on health issues, feel pity, create unnecessary worry, provide responses that may increase anxiety	27	31
Negative social impact	gossips, rumours, insulting discussions and trolls, judgements, condescending responses	22	26
Privacy concerns	public/open environment, people get too involved/nosy, over sharing one's health information, receive spam/junk	17	20
Impractical advice	impractical recommendations, advice, and information	12	14
Ignored post	no replies to posts, no social support/interactions, feel lonely/unimportant	8	9