



Sharing Personal Health Information on Social Media: Balancing Self-presentation and Privacy

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ABSTRACT

Sharing personal health information (PHI) on social media can be highly rewarding, but it also contains a range of potential risks. While previous research has identified many of these benefits and risks, there is less work examining the nuances of health-related self-presentation online and questions about preserving the privacy of this sensitive content. This paper presents quantitative and qualitative findings from an online survey study with Mechanical Turkers (N=553). We investigate motivators and barriers related to PHI sharing online, with an emphasis on privacy-related factors. We identify distinct motivations for PHI disclosures. We find PHI sharing is related to experiential and contextual factors, including negative online experiences, perceived gratifications, and privacy attitudes and practices. Additionally, we highlight the role of self-stigma in shaping individual decisions regarding online health disclosure strategies.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)** → **Empirical studies in HCI**

KEYWORDS

Disclosure; Privacy; Self-stigma; Health social network; Personal health information; Self-presentation;

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1 INTRODUCTION

People are increasingly open to sharing their personal health information (PHI) on social media. For instance, on PatientsLikeMe, a patient social network site, more than 600,000 users have shared their data regarding 2,700 diseases, encompassing experiential, behavioral, and genomic information about themselves [43,51].

Previous research has linked online sharing of PHI with various intrinsic rewards for individuals, such as increased optimism and control [13], self-esteem and social wellbeing [44], and improvements in health [39]. However, the practice of PHI sharing can also invoke privacy concerns. For instance, the majority of members of PatientsLikeMe feared that data they shared on the platform might be used without their knowledge and in detrimental ways, such as to deny them future job opportunities or health care coverage [21]. Privacy concerns further translate into reluctance to share—privacy is a key reason people merely consume information (i.e., lurk) rather than actively participate online [5,10,33].

Scholars have examined how people's willingness to share their health data is related to type of information [50], type of recipient [53,54], level of anonymity [47], health condition [6,53], and the perceived value of health information sharing [29]. Although useful to identify the factors that influence people's attitudes toward PHI sharing, this line of research has several constraints. First, the *actual* behaviors of health data sharing have not been comprehensively investigated. Most studies only examined people's attitudes or intentions (i.e., willingness) regarding PHI sharing, focusing solely on participants who have not directly engaged in sharing activities themselves. Second, the majority of studies (e.g., [2]) focus on organizational use of patient health data in a centralized electronic health records system, rather than peer-to-peer sharing platforms in which individuals have the agency to decide how and what to share about their personal health data. Additionally, PHI examined in these study contexts tends to be narrowly defined, such as data shared within online cancer

communities [18], data of healthy individuals [8] electronic health data [30], or data collected by fitness trackers [38]. Yet in real life, people might share a wide range of health-related information and experiences [28] that are not homogeneous.

This study takes a different approach. Looking beyond one specific social media, or one type of personal health data, we conceptualize personal health information sharing as a subset of self-presentation—a way to convey some information about oneself or some image of oneself to other people [7]. In this study, we distinguish and examine two forms of online self-presentation behaviors involving personal health:

- **Health disclosure** is defined as one-time information disclosure pertaining to *a specific health condition*, such as diabetes diagnosis, symptoms, and treatment.
- **PHI sharing** encompasses *any body-related data*, ranging from body measurement to fitness tracking data, and any medical information related to a disease, self-reported mental wellness, genetic testing results, etc.

A given health disclosure could be the beginning of PHI sharing, while PHI sharing goes beyond a specific disease or one-shot revelations, and it often involves continued self-disclosures over time, contributing to potentially more in-depth knowledge of one's physical and mental wellbeing. For instance, sharing data using fitness trackers (e.g., Apple Watch and Fitbit) is PHI sharing, but not a health disclosure since it's not about a disease or health condition.

In this paper, we present both qualitative and quantitative findings from an online survey of Mechanical Turkers (N=553). This paper first explores the motivations for self-presentation involving PHI. We then examine how self-stigma along with privacy-related considerations shapes individual decision regarding online health disclosure strategies. Finally, we investigate how the breadth of PHI sharing is related to various contextual factors (such as use gratification, negative online experiences, and self-protection behaviors). This paper contributes to the study of Social Media and Society through characterizing motivations for self-presentation involving personal health data and identifying privacy-related factors that influence health disclosure and PHI sharing. Additionally, this study illustrates the need for integrating privacy-enhancing technology on health data sharing platforms in order to help patients balance the risks and benefits of sharing their personal health information online.

2 RELATED WORK

2.1 Self-presentation and Self-disclosure Goals

Self-presentation refers to the ways in which individuals convey some information about themselves or some image of themselves to others [7]. Sociologist Goffman theorized

that individuals develop a “line” and present various versions of themselves [19], as they are often quite aware of the perceived appropriateness of specific forms of self-presentation in different situations [14]. Self-disclosure was firstly defined as any message about the self that an individual communicates to another [48,49]. Previous research has examined both the intrinsic (e.g., stress relief) and social (e.g., relationship development, intimacy, and social validation) goals of self-disclosure [4,20,33,45]. The overlapping between these two terms has enlarged as scholars started to consider self-disclosure as an interaction [3,23,25] that undergoes a decision-making process.

From the self-presentation perspective, identity is constructed through the information that people choose to disclose about themselves. A growing body of research shows that group identification has a profound impact on mental and physical health [31,52]; accordingly, information about one's health status, beliefs and behaviors could be linked with one's social networks and identity. As such, individuals might strategically select what and how to share about their health. Understanding people's motives and goals regarding health-related self-presentation online helps to contextualize individual decisions on how and what to share about one's health. Therefore, we investigate the following research question:

RQ1. What are the motivations for people to engage in health-related self-presentation online?

2.2 Health Disclosure and Stigma

Specifically focusing on self-disclosure regarding one's health condition, Greene's health disclosure decision-making model [23] posits that individuals go through these stages before revealing their disease-related information: (1) assessing the risks/benefits of revealing their disease; (2) anticipating the audience's response to the news; (3) evaluating the confidence in one's own ability to share and control their health information. Additionally, Greene and other researchers have demonstrated that an individual's prior expectations [2], relationships with the targeted audience [22,24] and perceptions of stigma [7,16], all contribute to their decisions. Several studies [3,9,22,25] have empirically tested this model in contexts of mental illness, diabetes, and sexual health.

In this process, stigma is an important predictor, as it influences both perceived risks and perceived benefits of sharing one's personal health information. Goffman describes “differences in physical body” as one origination of stigma [15]. Researchers have come to distinguish public stigma from self-stigma [11,40]. According to Corrigan et al. [12], public stigma refers to the negative attitudes held by members of the public about people with devalued characteristics. Self-stigma occurs when people internalize these public attitudes and suffer numerous negative consequences as a result. Although well-investigated within

the offline contexts, the effects of self-stigma on health disclosure decision-making are not yet fully understood in relation to online self-presentation. Therefore, the current study also seeks to investigate:

RQ2: What differences—if any—exist in the level of self-stigma and other individual characteristics among people who chose different online health disclosure strategies?

2.3 The Role of Privacy

An abundance of studies focuses on privacy-related attitudes towards organization-initiated health information exchange, specifically, sharing electronic health records among information systems. For instance, [37] indicates that consumers' support of these initiatives are influenced by two main variables: (1) potential benefits and (2) privacy and security concerns. Recent studies find that individual characteristics, such as demographic factors and prior experience using the internet for managing one's healthcare, can affect people's perceptions regarding the issues of privacy and security [17]. One study [35] suggests that females report more computer anxiety and concern about a potential data breach. Another [36] found that racial and ethnic minorities are more concerned about privacy and security of their digital health records. McGraw and colleagues [34] found that patients with a chronic illness are also more concerned about their privacy and the security of their digital health records; however, Willison found the opposite—if a person has a progressive or chronic illness, he or she tends to be more willing to share [53].

The role of privacy in peer-to-peer sharing of health information activities is less commonly investigated, with just a few exceptions. For example, Wicks et al. [51] surveyed PatientsLikeMe.com users and found they may have fears about the potential risks of sharing their personal health data, such as discrimination by employers, insurance companies, or friends and family members. This fear was heightened particularly in regard to stigmatized illnesses, such as HIV or mental disorders. Researchers also demonstrated that when people believed they had control over their disclosures and adopted privacy protection strategies, they shared more of their own personal health data [1,32]. Additionally, undergoing an informed consent process correlated with users' likelihood of holding pro-sharing beliefs (e.g., sharing health data can benefit myself and help other patients) [32]. Our study seeks to provide a more complete view of PHI sharing by investigating the actual behavior of sharing. Specifically, we ask:

RQ3: To what extent is *PHI sharing* influenced by people's privacy attitudes and behaviors (e.g., use privacy settings) on a platform?

3 METHODS

We used Qualtrics to create an online survey consisting of three sections of questions regarding: (1) Demographic and background; (2) Condition-specific health disclosure decision; and (3) Personal health information sharing platform use. While the first two sections were displayed to all respondents, only respondents who indicated they use an online social platform for PHI sharing were eligible to complete the last section.

After the study was approved by IRB, we employed Amazon Mechanical Turk to recruit survey respondents. Each participant was paid \$1.75 for their time; the average response time is 8.73 minutes. In order to collect a sufficiently large sample of people who actually use health information sharing platforms and/or share their personal health data online, we stated in the MTurk recruitment advertisement that, in order to be qualified for participation in this study, one needs to have used information technology (e.g., internet, smartphone) for health-related purposes at some point in the past three months. This criterion helped to narrow down the sample to people who considered health as a somewhat salient issue for their online activities, while also serving to include respondents whose experiences with online health-related self-presentation was diversified.

A total of 631 MTurkers participated in the survey. Several strategies were used to assure data quality. First, recruitment was limited to Turkers whose average task acceptance rate was 90% or higher. Second, each worker could only take part in the study once. Any duplicate submissions from the same MTurk account would be rejected. Third, the response patterns were reviewed on a daily basis so that a case could be removed if one or more of the following red flags were raised: (1) Speeders' response, where respondents finished survey in less than 5 minutes, (2) Careless response, where respondent rushed through the survey by clicking randomly that showed the same patterns (e.g., a straight line or a Z pattern), and (3) Gibberish response or random typing in the entry box provided for the open-ended questions. As a result of data cleaning, 78 cases were removed and a total of 553 observations were used for the final analysis.

3.1 Participants

Our survey respondents were 51.4 percent female, 47.7 percent male, and 0.7 percent gender non-conforming. Their average household income fell between \$50,000 to \$59,999. Participants were generally young, with an average age of 36 ($SD=11.51$); however, they ranged in age from 18 to 79 years. The majority (57.6%) held at least a bachelor's degree. Most participants (81.4%) reported that they have good or excellent health, with just 18.7 percent describing their health as just fair or poor. Additionally, we

asked whether participants have ever had a severe health condition²; a total of 86 (15.5%) respondents indicated that they were currently affected, 74 (13.9 %) had recovered, and a majority (357; 66.9%) had never had such a severe health condition.

As mentioned, the second section of the survey focused on how respondents (n=553) made decisions related to online disclosure of a particular health condition. If they never had a severe condition, respondents were asked to consider the most recent illness that compelled them to seek medical assistance. Their selection of online health disclosure strategies are shown in Table 1 (row 1). The third section of our survey pertained to those respondents (n=347; 62.7%) who actually used an online platform regularly to share their personal health information. Respondents were asked to specify a site or platform that they used most frequently for sharing their personal health information. These platforms for PHI sharing were categorized into five types, as shown in Table 1 (row 2) below.

Online Health Disclosure Strategies	1. Online Secrecy <i>Non-disclosure online: 335, 64.6%</i> 2. Selective Disclosure <i>- Under pseudonym/screen name: 54, 10.5%</i> <i>- Anonymously: 51, 9.7%</i> <i>- Only to close friends or family: 50, 9.5%</i> 3. Indiscriminant Disclosure <i>Public online disclosure using real identity: 63, 13.0%</i>
PHI Sharing Platform Types	1. General social media sites (e.g., Facebook, Twitter, Instagram, Youtube): 176, 34.2 % 2. Fitness-tracking platforms (e.g., MyFitnessPal, Fitbit): 62, 12.1% 3. Special subgroups created for health purposes on social media (e.g., a Facebook sub-community for cancer patients, r/diabetes on Reddit): 53, 10.3% 4. Health-specific social network sites (e.g., PatientsLikeMe.com): 47; 9.1% 5. Blogs: 9, 2%

Table 1. Distribution of Respondents by Online Health Disclosure Strategies and PHI Sharing Platform Types

3.2 Measures

Self-stigma ($M=2.80$, $SD=1.33$, $\alpha=.94$). We adapted seven items from the Stigma Scale for Chronic Illness (SSCI) [11] for this study; Example statements were: “I felt embarrassed about my illness,” “Some people might think my health condition is my fault.” Participants rated their level of agreements with these statements using a 6-point Likert scale ranging from 1 (Strongly disagree) to 6 (Strongly agree).

² A health condition refers to a physical or mental issue that has kept one from participating fully in work, school, or other daily activities.

Offline Social Support ($M=3.52$, $SD=1.08$, $\alpha=.95$). We assessed perceptions of social support with the scale developed in the Medical Outcomes Study Social Support Survey [42]. Our survey asked participants to rate how often a certain type of social support was available if they needed it. Twelve items encompass three dimensions (i.e., emotional, informational, and tangible) of functional support. Example items are: “Someone who understands your problems,” and “Someone to help you if you were confined to bed.” Statements were rated using a 5-point Likert-type scale, ranging from 1 (Never) to 5 (Always).

General Privacy Concerns ($M=3.23$, $SD=.97$, $\alpha=.93$). We used Vitak’s 11-item scale measuring the general privacy concerns a respondent might have when using communication technologies (e.g., social media, email and messaging apps) [43]. Respondents were asked to identify their level of concerns regarding scenarios, such as: “Being tagged in a photo you don’t want linked to our profile,” and “Private messages becoming publicly visible.” Responses were recorded on a 5-point scale, ranging from 1 (Not concerned at all) to 5 (Extremely concerned).

Digital Privacy Literacy ($M=25.25$, $SD=9.9$, $\alpha=.88$). This original measure evaluated people’s existing technical literacy around online privacy and security. Eight tasks that aim to protect online privacy were listed, such as: “Choosing strong passwords to protect your online accounts,” and “Using the internet without having your online behavior tracked.” Respondents first checked task(s) that they had ever performed. For each task selected, respondents then ranked how successful they felt about their performance on the task, using a scale of 1 (Never successful) to 5 (Always successful). We calculated the final value for this measure by aggregating scores for all eight items, resulting in final scores ranging from 2 to 40.

Negative Online Experiences ($M=3.15$, $SD=2.35$, range: 0-9). We included a list of 10 yes/no questions in the survey to assess people’s negative experiences using the internet. For example, we asked, “Has your social media account been compromised?”; “Have any of your devices been compromised by viruses, malware or ransomware?”; and “Have you experienced persistent and unwanted contact from someone online?” The final score on this measure is the sum of negative incidents that occurred.

Online Health Disclosure Strategies. Participants reported different methods that they used for online health disclosure of their most severe health condition (if they have any) or the most recent time that they needed medical help. Based on varying risks of social disapproval, we categorize these methods to three types of strategies: (1) Online secrecy (did not disclose online); (2) Selective disclosure (disclosed using a pseudonym/screen name, anonymously, and/or only to close friends or family); and (3) Indiscriminant Disclosure (disclosed in public using real identity, e.g., on Facebook). This variable was used as

a dependent variable in the analyses for RQ2, which focuses on people's selection of online disclosure strategies.

Attitudes towards Online Health Disclosure ($M=-.46$, $SD=11.29$, range: $-27-30$). We asked participants to rate their level of agreement with 13 statements that presented both favorable and unfavorable attitudes towards online health disclosure. Example statements include: "I believe that talking about my health condition online benefits me emotionally" and "I might regret sharing my personal health information in the future." Responses were recorded on 5-point Likert scale, ranging from 1 (Strongly disagree) to 5 (Strongly agree); items indicating an unfavorable attitudes were recoded as negative numbers. The final scores were aggregated across all 13 statements.

The following variables and measures were associated with the third section of survey questions that only presented to participants ($n=347$) who had used a site or platform to share their personal health data.

Perceived Costs of PHI Sharing ($M=56.93$, $SD=18.83$, $\alpha=.76$). To measure the perceived cost of PHI sharing, respondents were asked to think about various types of personal health data they shared online and respond to the following questions using a 0-100 slider scale. These questions includes: 1) Data Sensitivity: "How sensitive would you rate the health information and data you've shared with the site/platform?" 2) Data Security Breach Concerns: "How concerned would you be if your health information and data shared on this platform was compromised, such as through a security breach?"

Self-Protection Behaviors on the Platform ($M=2.86$, $SD=0.84$, $\alpha=.89$). We used an 11-item scale to measure the behaviors people may engage in to obtain their desired level of privacy and security on a specific site for health information sharing. Some examples of privacy-enhancing behaviors include: "Configure privacy settings to restrict the audience of your personal health information" and "Report, unfriend or block someone because they have sent you unsolicited messages." Participants indicated how often they engaged in each of these behaviors on a 5-point Likert-type scale, ranging from 1 (Never) to 5 (Always).

Gratification from Platform Use ($M=55.59$, $SD=17.46$, $\alpha=.79$). We asked six questions to gauge the level of gratification people derived from the use of a platform focusing on the following aspects: General User Satisfaction, Obtainment of Emotional Support, Obtainment of Information Support, Obtainment of General Advice, Social Connectedness on the Site, and Trust in the Site. Responses were recorded on a 0-100 scale.

Breadth of PHI Sharing. ($M=4.23$, $SD=3.11$, range: 1-16). We asked respondents to identify the specific types of PHI they had shared on the platforms that they had used most frequently; we then measured the breadth of PHI sharing by counting the total types of health data shared. Health habits and behaviors (e.g., diet, exercise, smoking)

were shared most widely (73%), followed by emotional experience and well-being (50%); race/ethnicity (50%); body measurement (48%); current or past health condition (45%); condition-related symptoms (38%); treatment and medication (35%); self-tracking data, such as step count and time spent sleeping (34%); contact information (33%); sex orientation (32%); clinical diagnosis and/or prognosis (28%); results of physical exams and tests (22%); and other information. This variable was used as a dependent variable in the analyses for RQ3.

Control Variables. Participants provided demographics as their background information. We also asked them questions about their perceived internet skills [27], social media use, frequency of platform use for personal health information sharing, and types of information they shared online. In responses to open-ended questions, participants provided their primary reason for disclosing their health condition online and explain why they share personal health information.

3.3 Data Analysis

To explore **RQ1** on the motives to engage in health-related self-presentation online, we undertook multiple iterations of structural coding and thematic analysis [41] to categorize and interpret responses to two open-ended questions focusing on (1) Health Disclosure: "What is your primary motivation to share your experience dealing with this condition online?"; and (2) PHI Sharing: "What is your primary motivation to share your health information on this site/platform? First, all the open-ended responses were closely read through; we came up with a preliminary set of codes that described respondents' main motivations for sharing their personal health information. We then used this initial codebook to analyze 50 responses that were randomly selected, leading the codes to be revised, expanded or grouped into a hierarchy. The updated codes were then applied to another 50 responses, while we iteratively amended the list of codes. Next, we conducted a thematic analysis in the coded data and summarized them into themes that account for fundamental aspects of motivation for health sharing behaviors.

To answer **RQ2**, which focuses on differences in self-stigma and other individual characteristics among people who choose different health disclosure strategies, we conducted a multinomial logistic regression analysis—an extension of binomial logistic regression to allow for a dependent variable (DV) with more than two categories. For this model, the choice of online health disclosure strategy is the DV with three categories, including online secrecy, selective disclosure, and indiscriminant disclosure. Independent variables (IVs) in the model include background factors, internet and privacy-related factors, and health disclosure attitudes.

To answer **RQ3**, we employed general linear regression models to predict the breadth of PHI sharing (DV). The final models included background factors, internet and privacy-related factors, and platform-specific factors.

4 RESULTS

4.1 RQ1: Identifying Motivations to Engage in Health Sharing Behaviors Online

To answer RQ1, we identified four themes emerged from the thematic analysis: (1) facilitation of social support, (2) normalizing stigma by raising awareness, (3) establishing self-accountability, and (4) managing impression online. We discuss each of these in more detail below.

4.1.1. Facilitating Social Support. Two recurrent themes—seeking and providing social support—were often intertwined and motivated people to share PHI online. P353, a 27-year-old male who used Instagram to share his experience dealing with skull fractures over the past six years expressed:

“I was just lonely and in a rough place at the time. I had just got off heroin and had a terrible traumatic brain injury. I just wanted to share. I like to show my progress to friends to motivate them.”

Compared to other forms of social support, emotional support was most mentioned. For example, P476, a 32-year-old female who use Reddit expressed: *“My primary motivation is to connect with others and hope I am not alone in this. I hope to get answers and feel less lonely.”* By revealing their struggle with a disease to others, participants benefited from “venting” “catharsis” and “emotional relief”. For example, P239, a 54-year-old female who used Facebook for health disclosure, wrote:

“I shared because someone else had the same disease and I wanted to give them support. Also, sometimes I am frustrated with it and it helps to vent.”

Informational support was also a key component, particularly when people sought to obtain advice related to diagnosis, treatment, or medication. For example, P165, a 69-year-old male who used Facebook considered “faster access to give some sort of health analysis” as his primary motivation to share PHI. A few participants also indicated that tangible support (such as financial assistance) incentivized them to share PHI. For instance, P131, a 29-year-old male, identified “employer health benefits” as his primary reason to share on Virgin Pulse, which is a platform specifically used for employee wellness programs.

For people affected by a disease, the desire to share their experiences and to connect with other patients was

particularly strong. P183, who participated in a Reddit subgroup expressed:

“Sharing lessens the emotional burden I have to carry— it’s the “you’re not alone” factor. I want others to know they’re not the only ones with crappy health stuff going on.”

Likewise, P476, a 32-year-old female who shared PHI on Reddit, mentioned: “My primary motivation is to connect with others and hope I am not alone in this.”

4.1.2 Normalizing stigma by raising awareness. When people sought to combat the stigma around their conditions, they considered PHI sharing as a means to raise public awareness. For example, P141, a 39-year-old female who used Twitter to share her experience dealing with anxiety disorder expressed: *“I feel like sharing helps normalize the idea of mental healthcare. It helps remove some of the stigmas.”* Similarly, P491, an 18-year-old female who used Instagram wrote:

“I track my healing from anorexia and raise awareness about mental health and fight the stigma – encourage others suffering to seek help.”

4.1.3 Establishing Self-accountability. Some people shared their PHI to facilitate the process of self-tracking to achieve accountability for better health outcome. As P123, a 34-year-old male who used Facebook indicated: *“[My primary motivation is] to be held accountable for trying to lose weight due to type 2 diabetes.”* This motivation was particularly prominent among participants who shared their PHI on platforms primarily designed for fitness tracking. For instance, P200, a 28-year-old male who used Samsung Health expressed: *“Based on the information I’ve shared, Samsung Health sets specific goals for me and motivates me to be more active.”* Further, sharing self-tracking results was also associated with a desire to compare oneself with peers; Several participants pointed out the reasons to share were “to compete virtually against others”; “to measure progress in a sport or activity”; and “to keep track of progress and compare with friends.”

4.1.4 Managing Impressions. People in good health sometimes shared their PHI on social media in order to create a positive image. P205, a 32-year-old female who used Facebook, expressed: *“Being honest, [my motivation is] boasting about how far I’ve run or biked, and how many calories I burned.”* On the other hand, some people who were not in perfect health shared their experiences dealing with a disease through social media; they hoped to keep their family and friends informed while avoiding the “awkwardness” of doing so in person. As P258 mentioned,

“When I was diagnosed with phimosis [a condition in which tight foreskin can’t be pulled back over the head of the penis], I was definitely embarrassed. I was out of school for almost two

weeks and my friends were wondering what was wrong and I wanted to tell them without having to do it in person and feel embarrassed. Therefore, I thought the best way to inform them was online so that they knew what was going on without having to say it face-to-face.”

4.2 RQ2: Modeling Decisions on Health Disclosure Strategies

Online Health Disclosure Strategies ^a		
	Selective Disclosure	Indiscriminant Disclosure
	Parameter Estimates:Beta (Odds Ratio)	
<i>Background factors</i>		
Income	-.12 (.89)*	-.04 (.96)
Age	-.01 (.99)	-.02 (.98)
Social support offline	.11 (1.11)	-.12 (.89)
Severe condition (Never)	_{-b}	_{-b}
Severe condition (Current)	1.09 (2.96)*	2.12 (8.32)***
Severe condition (Past)	1.76 (5.82)***	1.67 (5.32)**
Condition knowledge	.04 (1.04)***	.03 (1.03)*
Self-stigma	.57 (1.77)***	.36 (1.43)*
<i>General privacy factors</i>		
General Privacy concerns	-.24 (.79)	.16 (1.17)
Negative online experience	.19 (1.21)*	.34 (1.40)***
Digital privacy literacy	-.06 (.94)**	-.07 (.93)**
<i>Health disclosure attitudes</i>		
Health disclosure intention	.14 (1.15)***	.20 (1.22)***
Disclosure w/o real identity	.08 (1.08)	-.55 (.58)**
Disclosure w/ real identity	.10 (1.10)	.46 (1.59)**

Model fit: $\chi^2 = 269.96$, $df=26$, $p<0.001$

Nagelkerke Pseudo- $R^2=.58$

* $p<.05$, ** $p<.01$, *** $p<.001$

Note: a. The reference category is: Online secrecy.

b. This parameter set to zero because it is the reference level

Table 2: Multinomial regression model explaining people's choice of online health disclosure strategies

To answer RQ2, which focuses on self-stigma and other individual characteristics among people who choose different health disclosure strategies, we conducted a multinomial logistic regression analysis with Online Health Disclosure Strategies as the DV. Since this DV has three levels, we used *online secrecy* as the reference category in the model (see Table 2), which indicates that any statistically significant differences is between people who maintained *online secrecy* and those who chose to make health disclosure online (i.e., those in the *selective disclosure* and *indiscriminant disclosure* categories).

The model is a good fit to the data, with Nagelkerke pseudo- $R^2=.58$, $\chi^2(26,486)=269.96$, $p<.001$. Participants who chose to make health disclosure online showed similar patterns regarding background and health-related factors—they were more likely to have a severe health condition

(either currently or in the past) and have a higher level of knowledge about their condition.

Surprisingly, respondents who engaged in online disclosure were more likely to report a higher degree of self-stigma associated with their disease/health condition, even though people with higher self-stigma seemed to have a higher level of privacy concerns (Pearson's $r=.21$, $p<0.001$). We conducted ANCOVA to compare the level of self-stigma across different disclosure strategies and found a significant difference, with $F(2,527)=23.50$, $p<.0001$. Further pair-wise comparison of the adjusted means showed that the highest self-stigma was reported by people who engaged in selective disclosure ($M=3.41$, $SD=.12$), followed by people that chose indiscriminant disclosure ($M=3.12$, $SD=.15$), while people who maintained online secrecy had the lowest self-stigma ($M=2.51$, $SD=.07$).

Comparing privacy factors, respondents who disclosed their disease online were more likely to have a lower digital privacy literacy, and these same groups of people were more likely to report having encountered negative online experiences.

To summarize, people who chose to make health disclosure online tended to have a severe health condition/disease; they perceived a higher level of self-stigma associated with their disease. On the other hand, this group of people reported more negative online experiences and lower digital privacy literacy.

4.3 RQ3: Modeling the Breadth of PHI Sharing

Our RQ3 explores how PHI sharing is shaped by

Breadth of Personal Health Information Sharing		
	Model 1	Model 2 ^a
<i>Background factors</i>		
Severe condition(Never)	— ^b	— ^b
Severe condition(Current)	2.07***	1.92***
Severe condition (Past)	1.10*	.95*
Condition-specific self-stigma	.01	.02
<i>General privacy factors</i>		
Digital privacy literacy	.07***	-.03
Negative online experiences	.23***	.23***
Privacy concerns	-.13	-.11
<i>Site-specific factors</i>		
Self-protection behaviors	-.31*	-.31*
Data sensitivity	.04***	.03***
Data security concerns	-.02*	-.01*
Gratification	.04**	-.03
<i>Interaction term</i>		
Digital Privacy literacy x Gratification	—	.02*
Adjusted R-square	.24	.27

* $p<.05$, ** $p<.01$, *** $p<.001$

Note: a. Model 2 included the interaction term

b. This parameter is set to zero because it is the reference level

Table 3. Regression models predicting PHI sharing. Values represent standardized beta coefficients.

individuals' privacy attitudes and behaviors on a platform. Of 347 participants who indeed have engaged in PHI sharing on a platform, we built two regression models (see Table 3) to predict the breadth of PHI sharing (i.e., how many types of PHI people shared) on the site.

Model 1 (without the interaction term) explained 24% of the variances (adjusted $R^2 = .24$), $F(11, 329) = 15.74$, $p < .001$. Compared to those who had never had a severe health condition, people who had one—either currently or in the past—shared more PHI on a platform they used most often for health data sharing. Digital privacy literacy was positively related to the breadth of PHI shared on the site. But more PHI sharing was also associated with respondents reporting a greater number of negative online experiences.

Regarding site-specific factors, people who reported more self-protection behaviors and a higher degree of data security concerns tended to share less PHI. Gratification was positively related to the amount of PHI sharing. Meanwhile, people who shared more PHI also reported having perceived a higher degree of data sensitivity.

As the next step in our analysis, we built Model 2 to test the interaction effect between *digital privacy literacy* and *gratification* on PHI sharing. The resulting model explained slightly more (27%) of the variance (adjusted R square = .27), $F(12, 328) = 26.53$, $p < .001$. While the interaction term was statistically significant, the two main effects fell short of significance. This evidence of cross-over interaction [26] showed that the effect of gratification on PHI sharing is contingent upon the level of digital privacy literacy. Recall that Model 1 indicated gratification positively associates with PHI sharing; however, this effect of gratification was mitigated by the factor of privacy literacy. In fact, as Figure 1 below shows, respondents with high privacy literacy did not share more PHI even though the degree of gratification increases.

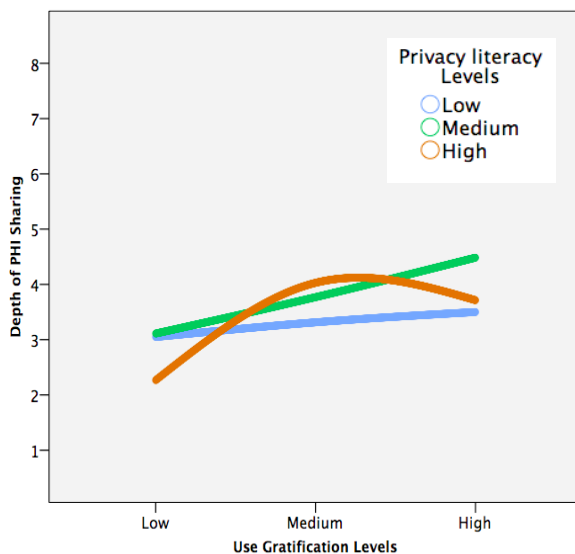


Figure 1. The interaction effect of Digital Privacy Literacy x User Gratification on the breadth of PHI

In summary, people's gratification from their use of a social platform might compel them to share more PHI. Given their more active engagement with the platform, they considered the health data they shared to be more sensitive and expressed higher data security concerns. However, they reported more negative online experiences and were less likely to adopt self-protection behaviors on that platform.

5 DISCUSSION

This study investigated two types of online self-presentation: condition-specific health disclosures and general PHI sharing practices. Below, we highlight how self-stigma along with other health- and privacy-related factors have shaped different health disclosure strategies. Further, we emphasize the role of privacy considerations (such as data security concerns and data sensitivity) in the process of PHI sharing.

In the online world, self-presentation is "more selective, malleable, and subject to self-censorship" than in face-to-face interaction (p. 20) [46]. On the other hand, differentiated affordances of platforms allow for specialized selection of how and what one wishes to share about one's health. For example, a person who just posted his outstanding bodybuilding results on Facebook might later turn to Reddit, a pseudonymized forum, for a discussion around how to manage depression. Our findings suggest that self-stigma might compel people to seek information and emotional support through online health disclosure, contradicting the results of previous research (e.g., [9]) applying Greene's health disclosure decision model in the offline context. Originally, according to Greene, the perception of stigma reduced the likelihood of health disclosure because individuals might fear a social disapproval or dissolution of one or more relationships.

When it comes to the online environment, we found a different tendency toward health disclosure: people seemed to be more open about their experiences coping with a stigmatized disease. It is important to note that self-stigma increases the chance of both selective disclosure and indiscriminate disclosure, but the underlying decision-making mechanism might be different. For people who chose selective disclosure without revealing their real identity, they might feel less pressure from potential social disapproval, and disclosing their disease anonymously or with a pseudonym will not risk that their existing social networks could find out about their condition. They might join a health-specific social network to seek out a community made up of peer patients. But people who chose indiscriminate disclosure using their real identity might want to seek validation from their existing network rather than avoid it. This finding adds evidence to recent studies (e.g., [28]) about the online self-disclosure of a stigmatized disease, such as mental illness and HIV.

Our findings indicate that people who engaged in online health disclosure reported lower digital privacy literacy but more occurrence of negative online experiences. This alarming trend might preface a violation of privacy expectations when people shared their sensitive health information online. Additionally, people with higher self-stigma reported higher privacy concerns. This suggests that people with stigmatized diseases might face a conundrum: they can potentially yield the benefits of social support and public awareness through online disclosure, but the perceived cost of such behavior becomes greater due to the high sensitivity of their health data.

The priority for social media service providers like Facebook is to increase user engagement on the platform. Likewise, health-specific social network platforms such as PatientsLikeMe are driven to maintain an active patient community by incentivizing data sharing. Our study suggests that online self-presentation involving personal health data could often be a result of a complex, nuanced decision-making process. It's important to consider the contextual factors that motivate or inhibit people's health data sharing behaviors. Our analysis shows that perceived data security concerns negatively correlated with PHI sharing. In order to ensure users' continued engagement and health data sharing, service providers should consider increasing transparency and sense of control for users in terms of how their health data will be used.

6 LIMITATIONS

Based on a one-time survey, this study presents a snapshot of people who engaged in health-related self-presentation online; as a result, we can only identify correlations between variables and cannot establish causation. Future work should consider the possibility of changes in attitudes and behaviors related to online PHI sharing over time, specifically, how privacy attitudes influence personal health data sharing behaviors.

Our online survey only collected responses from MTurkers who reside in the United States, and the majority of the respondents were Caucasian. Thus, findings from this study might not be generalized to other cultural or ethnic contexts. Our participants also tended to be young and well-versed in technology and the internet; future studies could focus on recruiting participants that are marginalized, such as older adults who are less readily engaging with online platforms in a private and safe manner, but who, at the same time, might be able to reap greater benefits due to their need for social support.

7 CONCLUSION

People driven by individual health-related circumstances turn to online platforms to share their personal health information. Their motivations to engage in health-related self-presentation are diverse. They demonstrate the sense of

agency by adopting various health disclosure strategies to balance self-presentation needs and concerns regarding privacy risks online. People's decisions regarding online health disclosure strategies and the breadth of PHI sharing are influenced both by their privacy attitudes and self-protection behaviors, as well as the perceived benefits associated with the use of health data. Designing usable privacy enhancing features will be critical to help patients remain safe and secure while satisfying their self-presentation needs.

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