Seeking and Sharing Health Information Online: Comparing Search Engines and Social Media

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ABSTRACT
Search engines and social media are two of the most commonly used online services; in this paper, we examine how users appropriate these platforms for online health activities via both large-scale log analysis and a survey of 210 people. While users often turn to search engines to learn about serious or highly stigmatic conditions, a surprising amount of sensitive health information is also sought and shared via social media, in our case the public social platform Twitter. We contrast *what* health content people seek via search engines vs. share on social media, as well as *why* they choose a particular platform for online health activities. We reflect on the implications of our results for designing search engines, social media, and social search tools that better support people's health information seeking and sharing needs.

Author Keywords
Health; social search; search engine; social media; Twitter

ACM Classification Keywords
H.5.3. Group and Organization Interfaces; Web interaction.

INTRODUCTION
The Internet is a popular place to learn about health matters. According to a January 2013 Pew survey [10], 59% of U.S. adults reported using online resources to obtain health information in the past year. The Web is used for a range of purposes, including seeking advice [17,32], connecting with experts and individuals with similar experiences [9,24], sharing questions and concerns around treatment options [27], or understanding professional diagnoses [4]. Online health content can enhance coping and self-efficacy [8], affect health-related decisions and behavior of users and their friends and family [11], enable better management of chronic health conditions [1], and fuel discussions with healthcare providers [15]. Besides electronic mail, the use of search engines and social media are the most common online activities of adult U.S. Internet users [27]; in this work, we compare and contrast the use of these platforms for health activities.

People often use general purpose search engines (e.g., Bing, Google, or Yahoo!) to find online health information [29].

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Recently, social media (e.g., Twitter, Facebook) has emerged as an alternative platform for sharing, and even seeking, health information. A recent survey [11] indicated that as many as 39% of online health information seekers used social media, and a fraction of them had also followed their contacts' health experiences or updates, posted their own health-related comments, gathered health information, or joined a health-related group. Other research has shown that Twitter is used for health-oriented question-and-answer tasks [26]. Disease-specific exchanges on social sites can provide new sources of knowledge, support, and engagement, particularly important for patients with chronic conditions [12].

Such emergent practices around seeking and sharing health information online indicate a shifting landscape. Search engines and social media platforms form an important continuum in terms of how people (privately) seek health-related information, as well as (publicly) share such information, respectively. As these mechanisms for seeking and sharing health information continue to grow in accessibility and popularity, and individuals utilize them to take a more active role in managing their health, it is imperative to understand the nature of health information sought or shared via the two platforms, as well as individuals' motivations and intentions. We address this challenge in the research described in this paper, focusing on the following three research questions:

RQ1: What is the relative prevalence of health activity on a search engine vs. social media? (We focus on Twitter here given its public nature). What motivates people to seek and share health information via each platform?

RQ2: What are the characteristics of health activities on search engines and on Twitter? Are there differences in the *severity* of health conditions on which information is sought or shared, or in terms of the *social stigma* associated with the health condition? What topical contexts typically distinguish (private) health information seeking on search engines from (public) health information sharing on Twitter?

RQ3: How do people evaluate both: (1) the information that they seek or share via search engines and Twitter, and (2) the risks associated with health activities on these platforms?

We adopt a mixed-methods approach, combining data from a survey with 210 respondents, with 15 months of log data from a major Web search engine (anonymized for blind review) and from Twitter. Our findings indicate that there are considerable differences in health activity between the platforms. We show that people prefer search engines when seeking information on serious medical conditions, disabilities, and conditions known to bear social stigma, while Twitter is used more often to share information around symptoms of different health issues, and on conditions with benign explanations. Regardless, our finding that people use Twitter to seek or share information on *some* health concerns shows that they may underestimate the privacy implications of pursuing health content in such public channels. The differences in how people use search engines and social media suggest that they tailor their healthcare needs to the accepted norms and characteristics of the two platforms, and has implications for the design of next-generation search and social systems.

RELATED WORK

Searching the Web for health-related information is a common pursuit [10]. Studies have examined how people find and appraise health information online [8], and its connection to healthcare utilization and health-related behaviors [1,31]. Sillence et al. [31] showed that examining online content influences health-related decision making and improves patient-physician communication. Ayers and Kronenfeld [1] found a positive correlation between online health information seeking and changes in health behavior.

A common goal in health searches is self-diagnosis. One recent study estimated that 35% of online health seekers performed this activity in particular [10]. Studies have shown that during diagnostic searches people pursue both evidence-based search (focused on symptoms) and hypothesis-based search (focused on conditions and treatments) [4]. Recent research indicated a positive correlation between the frequency and placement of serious illnesses on result pages and negative emotions, e.g., feeling overwhelmed and frightened [18].

People afflicted by medical conditions also find support via online health communities (OHCs) [9,30]. One study suggests that 30% of U.S. Web users have participated in medical or health-related groups [17]. In this light, approaches to community building have been proposed, e.g., [13,34]. In this work, we focus on how search engines and social media (two of the most heavily used online platforms [27]) are used for health activities, rather than dedicated forums and OHCs.

Recent research has demonstrated that social media provides a way for people to communicate with their contacts regarding health concerns [7,10,25]. Newman et al. [23] interviewed people with significant health concerns who participated in both OHCs and Facebook. They showed that people consider the target and the means of sharing information as they pursue social goals related to their personal health, including emotional support, motivation, accountability, and advice. Oh et al. [24] examined people's use of Facebook for health purposes and showed that the level of emotional support was a significant predictor of health self-efficacy.

New practices raise concerns about matters such as privacy. The implications of sharing health information in open fora such as social media have been examined in general [21], and specifically in the context of health [14,35]. Young et al. [35] studied factors influencing the disclosure of health information on Facebook and steps that people took to protect their privacy. Hartzler et al. [14] showed that people often made errors in determining what health information was shared with whom in their social network.

Closely related to information disclosure on online social platforms is the inherent stigma ascribed to many health conditions [5]. Social stigma describes negative feelings towards an individual or group on socially-characteristic grounds that distinguish them from others [6,20]. Berger et al. [3] showed that compared with those with non-stigmatized conditions, those with stigmatized illness were more likely to find health information online. Liu et al. [19] showed that video logs (to help people share stories, experiences, and knowledge) could support the disclosure of serious illnesses such as HIV, helping those afflicted overcome aspects of social stigma.

Our research extends prior work in several ways. We are the first to directly compare and contrast health activities on search engines and social media, two of the most-used online tools. Second, we describe how people assess the health information they encounter, including motivations for selecting a particular platform. Third, we examine the characteristics of the information sought, including social stigma and topical context. Fourth, we examine in detail the nature of health information sharing on Twitter. Finally, we complement a survey with large-scale data captured in naturalistic settings; the aforementioned prior studies mainly used only one method (e.g., surveys, focus groups, interviews), or have small sample sizes, limiting their generalizability.

DATA AND METHODS

Data on Health Conditions

A key challenge of this research was to identify the different health conditions on which people seek and share information via search engines and Twitter, respectively. We identified four broad categories of conditions based on their severity and types: (1) symptoms of major diseases, (2) benign explanations (non-life-threatening illnesses), (3) serious illnesses, and (4) disabilities. We also characterized each condition by the degree of perceived social stigma provided by third-party judges. Our final list contained 165 conditions.

Health Condition Severity and Types

Symptoms: We filtered logs based on a symptom list from the online version of the Merck medical dictionary. Starting with the Merck list, we removed duplicates (e.g., multiple references to the same condition with different cohorts), and split symptom pairs into singletons (e.g., "*Nausea and Vomiting in Adults*" and "*Nausea and Vomiting in Infants and Children*" became "nausea" and "vomiting"). The list has 58 symptoms (e.g., chest pain, headache, twitching), and has been used in prior work on health search analysis [4].

Benign explanations: We used a list of 43 non-life-threatening conditions, defined in a prior log-based analysis of search behavior [33]. The list comprised a range of commonly-occurring conditions selected from across the *International Classification of Diseases 10th Edition* (ICD-10: *www.who.int/classifications/icd/en/*) published by the World Health Organization. Examples of the conditions chosen include caffeine withdrawal, common cold, and pregnancy.

Serious illnesses: We utilized a list of 58 serious conditions defined in [33], again based on the ICD-10. Note that these are well-known conditions that were likely to appear in our data. Examples of serious illnesses chosen included "heart failure", "multiple sclerosis", and "hepatitis".

Disabilities: In addition to the acquired health conditions listed above, we also included six common disabilities ("autism", "attention deficit hyperactivity disorder", "deafness", "blindness", "cerebral palsy", "dyslexia"), to provide insight on the use of search and social media for seeking and sharing information related to this class of chronic health disorders.

Stigma of Health Conditions

To understand how stigma impacts people's health activities on search engines and social media, we characterized each condition in terms of its level of social stigma.

We used Amazon Mechanical Turk (*www.mturk.com*) to obtain ratings on the degree of social stigma for each condition on a three-point scale: 1 = low stigma, 2 = moderate stigma, and 3 = high stigma. For each condition we obtained 10 ratings from crowdworkers and three ratings from three human factors researchers. For conditions with agreement exceeding 50% (seven or more raters agreed on a single rating), we used the majority rating as the final measure of condition stigma. 126 out of the 165 conditions (76%) met this criterion. For the other conditions, with no clear consensus, we set stigma to moderate. This resulted in 81 conditions with low stigma (e.g., headache), 72 with moderate stigma (e.g., malaria), and 12 conditions with high stigma (e.g., AIDS).

Log Data Collection

Twitter. We focus on the social media platform Twitter, a popular microblogging service used by 18% of U.S. Internet users, and whose popularity continues to increase [28]. Twitter is particularly interesting to study since nearly all posts are public; the public nature of tweets provides an interesting counterpoint to the private nature of search engine activity.

We gathered a 15-month sample of Twitter's Firehose stream (which includes all public tweets) between November 1, 2011 and March 31, 2013, made available to us under contract, focusing on English-language tweets. Twitter post count and unique user count were computed for each condition, and aggregated over the full time period. Specifically, we considered a post to belong to a certain health condition if there was a regular expression match of the condition to the text of the post (this would not permit substring matches within terms). To reduce noise, we excluded posts that were retweets or contained hyperlinks, since they were likely related to general news and not a user's personal health.

Using this method, we obtained 125,166,549 tweets on the 165 health conditions from 62,269,225 users in the time period of interest. The median number of posts was 51,687 per condition, from a median of 40,152 users per condition.

Search Engine. We mined the logs of a popular search engine over the same 15-month period used in the Twitter analysis, focusing on English-language queries. We processed billions of queries from which the queries for the health conditions of interest were extracted. We searched for queries that were either an exact match with one of the symptoms or conditions, or those where the condition was some subset of the query terms. As with Twitter, substring matches within query terms were not permitted to reduce noise.

We also used synonyms of symptoms and conditions to increase coverage. Synonyms were identified via a two-step walk on the search engine click-graph using an approach similar to [2]. Example synonyms for "abdominal pain" included "sore stomach" and "belly ache." We applied this procedure to all of the conditions. Note that, synonyms were not used in the data collection process from Twitter to ensure efficiency by limiting the size of the substring match space (Twitter posts are considerably longer than search queries).

We observed 174,605,024 searches on health conditions from 38,676,368 users. The median number of searches was 293,505, from a median of 85,848 users, per condition.

Health Information Seeking and Sharing Survey

To gain qualitative insight into people's health information seeking and sharing practices, we conducted an online survey during June 2013, using a recruiting service (Cint) that offers "Census representative sampling" in terms of gender and age throughout regions of the U.S. Respondents were paid approximately 4 USD to complete the survey, and were required to have a Twitter account to qualify to participate.

The survey comprised 37 questions, and took approximately 10 minutes to complete. Participants were asked if they had ever sought health information on a search engine such as Google or Bing, or on Twitter, and whether they had ever shared health information on Twitter. If they answered affirmatively, they were asked to describe the most recent occasion on which they did so, including the health condition that motivated them to search or share, and their objective in performing the activity. The survey included questions about how often participants used search engines and Twitter for various types of information seeking or sharing, views about risks associated with each platform, and basic demographics.

In total, 237 respondents completed the survey. After discarding low quality responses (as determined by nonsensical or sarcastic responses to open questions), 210 valid survey responses were analyzed. Of these respondents, 53% were female, they resided in 38 U.S. states and the District of Columbia, and 43% had a college degree or higher. Ages ranged from 18 to 70 years (median = 35 years). Respondents reported using search engines frequently (76% at least once per day, with only 7% using them less than once per week). 71% of respondents had public Twitter accounts, while the remaining 29% had "protected" accounts (i.e., only approved followers could view their postings).

RESULTS: PREVALENCE, INTENT & MOTIVATIONS

To answer RQ1, we turn to our survey data to examine the relative prevalence of search engine and Twitter use for health activity, and users' motivations and intents in using these platforms. Note that the health activities we focus on are *seeking* health information and *sharing* health information. The *seeking* activity is relevant to both search engines (i.e., issuing health-related queries) and Twitter (i.e., asking health questions), whereas the *sharing* activity is relevant only to Twitter (i.e., posting health-related tweets). Accurately determining seeking vs. sharing distinctions from Twitter data is challenging: while presence of a question mark may provide some indication, it still captures many non-information-seeking tweets [26], requiring human labeling to accurately determine intent [16]; an approach that does not scale to our large dataset. Consequently, our log analyses considered all health-related Twitter posts to be incidents of *sharing* (since even seeking information on Twitter is a type of sharing due to the public nature of posts); however, our survey allowed us to ask users for insight on the distinction between their Twitter seeking and sharing activities.

Prevalence

The survey is useful for understanding prevalence, because it allows us to include those who did not search or tweet (who would not be visible in the log data). Recall, however, that all survey respondents had Twitter accounts, so the perspectives of non-Twitter users are not represented in survey data.

Overall, 94% of respondents (n=197) reported having used a search engine to seek health-related information. 11% sought health information for themselves on search engines at least once per day, rising to 40% doing so at least once per week. 13% sought health information on behalf of family or friends at least once per day, with 34% doing so at least once a week. Many fewer respondents, 19%, reported having sought personal health information on Twitter. 23% reported having used Twitter to share information related to their health.

Intent of Health Activities

Intent of Search Engine Use

The 197 survey respondents who reported seeking health information using a search engine were asked to recall the most recent instance, and to answer questions related to that specific incident. Respondents also described their search objective. These responses were classified using an iterative open coding process. A second rater used this scheme to rate a random sample of 30 responses; inter-rater reliability (Cohen's κ) indicated substantial agreement (κ = .72). The same verification strategy is used in the rest of this section. We coded the intent for 183 respondents (the others had unclear intent). Some searches had multiple intents and received multiple categorizations, so the percentages sum to more than 100%.

The most common motivation for using a search engine was to identify *treatment* options (53.0%), e.g., "stretches to cure or ease [tight hamstring]." Alternative and holistic treatment was a popular sub-category, comprising 13.5% of treatment searches, e.g., "alternative treatment [hypothyroidism]."

The next most common motivation was *diagnosis of a health condition* (26.8%) (e.g., "whether or not the symptoms matched my behavior [depression]") or interpreting the symptoms that they experienced (e.g., "what may be a cause of this and if it may mean something more may be wrong [very heavy menstrual cycle]").

A third motivation was *general understanding of a health condition or procedure* (20.8%), including understanding what a medical procedure might entail (e.g., "more about the surgery process, healing time [umbilical hernia]"), understanding the causes of an illness (e.g., "the caused [sic] of it… [infertility]"), or other general learning about a condition (e.g., "prognosis [congestive heart failure]").

7.1% of recalled searches were motivated by *understanding medications*, such as understanding side effects (e.g., "to be able to learn the side effects [cholesterol medications]"), comparing and contrasting medications (e.g., "effectiveness [of cancer treatments]"), or seeking information on available medications, such as whether non-prescription options are available or learning more about how a medication worked.

6.0% sought *lifestyle information for chronic concerns*, particularly nutrition information for managing diabetes, cholesterol, or weight loss ("special diet [cholesterol]").

Beyond these broad categories, participants also described other intents behind their search activity. 2.2% sought *recent medical research findings* on conditions or their treatments, and 1.1% sought *social support* such as online support groups for people with their diagnosis.

Intent of Twitter Use for Health Information Seeking

In a similar way to engine use, the 40 respondents who indicated they had sought health information on Twitter were asked to recall the most recent event. They explained their objectives in free-text. Open coding was used to categorize responses; the same categories were used for why people used search engines, with additional categories added as needed. Once again, substantial agreement was observed with the second coder (30 ratings, κ=.77). Three responses were unclassifiable; percentages are of the remaining 37.

As with search engines, the most common objective was locating *treatment* information (56.8%), e.g., "how to help relieve the pain [numbness in the legs]". 8.1% specifically sought natural or alternative treatments, e.g., "natural remedies to headaches." 16.2% of respondents sought information about *healthy lifestyles*, such as nutrition, dieting, or fitness (e.g., "different ways to lose weight"), and 13.5% sought to gain a *general understanding of a health condition,* e.g., causes (e.g., "why it happens…" [enlarged prostate]), consequences, or general knowledge. 5.4% sought *new research* about conditions or treatments, and 5.4% looked to find others with a similar situation to offer *support or advice* (e.g., "if anyone else hsd [sic] allergy problems"). Only 2.7% reported seeking *diagnostic* information on Twitter.

Intent of Sharing Health Information on Twitter

The 48 respondents who recalled *sharing* information related to their health on Twitter were asked to consider the most recent incident, and to answer a series of questions with that specific occurrence in mind. Participants explained in free-text what their intent was behind sharing health information on Twitter (substantial agreement with second coder, κ=.65). 10 were not coded due to vagueness or missing responses.

Of the remaining 38 responses, 63.2% reported that they intended to share information about their *immediate health status or symptoms* (e.g., "I was having a few teeth removed and I may not be online for a few days"). 34.2% wanted to share information or news about a condition (e.g., “treatments that work for me [fibromyalgia and neuropathy]”).

Motivations for Health Activities

Motivations for Search Engine Use

Respondents also explained why they chose to use a search engine, rather than alternatives such as asking a family member, consulting a health professional, or using a Q&A or social networking site. Free-text responses were classified into themes using an iterative open coding method (substantial second-coder agreement, κ=.63). Percentages are reported of the 151 responses that were classifiable, and the sum may exceed 100% since respondents provided several rationales.

Convenience (speed, ease, availability) was the most commonly cited motivator for using a search engine to find health info (e.g., “easy to access”); routine comfort with using search engines was another factor for 6.6% (e.g., “I use google very often, and I trust it”). The next largest motivator, for 15.2%, was the *plurality of results* returned for any given inquiry (e.g., “The internet has way more answers than just 1 person, or even 10”). *Privacy of the information seeking experience* was also cited as a benefit of using a search engine to find health information by 9.9% (e.g., “because its [sic] awkward to ask someone else”).

Overall, 11.9% of respondents indicated that they had consulted a health care provider and needed *more detailed info or were dissatisfied with what a health care professional had previously told them* about the issue, and turned to search in response (e.g., “I have consulted my physician and was not satisfied”). Another 9.3% indicated that they were *performing research that they intended to later share with a health care provider* (e.g., “wanted to know what kinds of questions to ask the doctor at my appointment”). Sometimes (3.3%) a search was also used when *medical care was not available* (e.g. “it was after-hours for my doctor”). For 3.3% *monetary costs* determined whether to use search versus talk to a professional (e.g., “too expensive to go to a doctor”).

Motivations for Twitter Use for Seeking Health Information

Like with search, participants were asked to explain in free-text why they used Twitter rather than alternatives such as health professionals and search engines). As previously, open coding was used to categorize responses (substantial agreement was attained with the second coder, κ=.72). 14 of the 40 responses were unclassifiable due to vagueness; reported percentages are of the remaining 26 responses.

As with search engines, *convenience* (ease of use, speed) was the most common reason for seeking health information via Twitter (46.2%) (e.g., “I [already] had it opened”). The next reason, specific to Twitter but perhaps analogous to the perception that search engines return a large variety of relevant results, was the *perceived large audience* of Twitter (23.1%) (e.g., “lot of people there”). 15.4% indicated using Twitter because they were *trying something different* – they had exhausted more conventional options or were trying to corroborate information found elsewhere (e.g., “second source”).

11.5% sought other people’s *recommendations, advice, or opinions* on treatments or managing health conditions (e.g., “just to see what advice i could get…”), and 7.7% sought social support (e.g., “find other people who can relate”).

Motivations for Twitter Use for Sharing Health Information

Participants were also asked to explain in free-text why they chose to use Twitter to share information. A total of 38 participants had codable responses. Most commonly, respondents wanted to *reach a large audience* (e.g., “because I wanted my friends to know”; “just to inform the regular crowd of a hashtag”) (22%). Some specifically wanted other people to *benefit from health information* they personally had found useful (e.g., “there are other mothers out there that are looking for the same option…”) (8%). A few (4%) found Twitter to be a useful platform for *complaining* (e.g., “place to vent”); some (4%) noted Twitter had some privacy benefits (e.g., “Facebook has too many of my family members”).

Summary

The findings presented in this section indicate that search engines are more extensively used for health activities than social media like Twitter. While learning about the treatment and the diagnosis process of a health condition was a common purpose of health searches, gathering knowledge about the impact of health conditions on lifestyle and deriving general understanding of a medical procedure were popular goals behind using Twitter for health activities. Respondents indicated the plurality of search engine results, perceived large social media audience for feedback, and the diversity of the information available via search engines and social media to be primary motivating factors behind these practices, beyond the obvious convenience of the two platforms.

RESULTS: COMPARING HEALTH INFORMATION

To answer RQ2, we use log data to study the aspects of health that people engage with on search engines versus on Twitter.

Definitions

We first introduce several measures used in our analysis.

Relative use – For a given health condition, its relative use on Twitter or the search engine is given by the ratio of its volume of use in that medium, to the volume of the health term that is most used in that medium. For example, the most searched condition on the search engine was “cancer” appearing in 31,443,735 queries, and the second-most queried was “pregnancy” found in 25,721,056 queries; the relative use for “cancer” on the engine=1, it was .82 for “pregnancy.”

Rank – A relative ranking based on normalized relative mention of a health condition (on Twitter or the search engine)—lower ranks mean greater use. For example, on Twitter, the most-used term from our list is “headache”, that appeared in 24,607,507 posts; it would receive a rank=1.

Rank difference – We compute rank difference between the search engine and Twitter for each health term – large negative values indicate that a term is searched *relatively* more than tweeted, whereas large positive values mean the reverse. For example, “cough” has rank 4 on Twitter and rank 26 on the search engine – its rank difference is 22, reflecting its relative prominence on Twitter as compared to search.

Top rank (Twitter)	Top rank (search)	Largest pos. rank difference	Largest neg. rank difference
(1) headache	(1) **cancer**	(124) tiredness	(-98) multiple sclerosis
(2) stress	(2) pregnancy	(97) jet lag	(-70) pelvic pain
(3) **cancer**	(3) multiple sclerosis	(74) insomnia	(-68) **vaginitis**
(4) cough	(4) diabetes	(73) irritation	(-65) **vaginal bleeding**
(5) *heart attack*	(5) stress	(69) *wheezing*	(-63) liver disease
(6) fever	(6) *anxiety*	(68) toothache	(-62) dermatitis
(7) *anxiety*	(7) *acne*	(66) tonsillitis	(-61) *irritable bowel syndrome*
(8) insomnia	(8) arthritis	(65) *panic attack*	(-60) influenza
(9) **AIDS**	(9) *allergy*	(64) *twitching*	(-58) cyst
(10) stroke	(10) cyst	(63) sore throat	(-57) *hematuria*
(11) pregnancy	(11) stroke	(61) motion sickness	(-54) kidney disease
(12) diabetes	(12) **autism**	(58) food poisoning	(-55) balance disorder
(13) asthma	(13) **AIDS**	(51) indigestion	(-51) **myopathy**
(14) mole	(14) tumor	(48) *dysmenorrhea*	(-50) *bipolar disorder*
(15) tension	(15) *heart attack*	(45) laryngitis	(-48) anemia
(16) *diarrhea*	(16) *rash*	(45) bruise	(-46) *lymphoma*
(17) migraine	(17) *heart disease*	(45) amnesia	(-45) **sexually transmitted disease**
(18) sore throat	(18) fever	(43) narcolepsy	(-42) alopecia
(19) bruise	(19) influenza	(41) nasal congestion	(-41) *tuberculosis*
(20) *rash*	(20) constipation	(40) *heartburn*	(-39) *hepatitis*

Table 1. Use of health conditions on Twitter and search engine, in the light of their severity/type and social stigma rating. We show the 20 conditions of top rank (highest relative use) on Twitter and the search engine respectively, as well as top 20 conditions in terms of their most positive (more tweeted than searched) and most negative (more searched than tweeted) rank differences. Numbers in parentheses indicate ranks or rank differences. Color codes assigned to conditions indicate their severity/types: blue = benign, red = serious, green = symptom, and grey = disability. The font format indicates stigma level: bold = high stigma (level 3), italics = moderate stigma (level 2), and normal/unformatted = low stigma (level 1).

Based on these definitions, in Table 1 we report the top 20 most searched and most shared health conditions in terms of their rank and relative use on each platform. The table also shows the top 20 most positive rank difference (relatively more tweeted than searched) and most negative rank difference (relatively more searched than tweeted) conditions, along with severity/type and stigma level of each conditions.

Comparison: Severity and Type of Conditions

We first report on a comparison of the nature of health conditions appearing in search engine queries and Twitter posts, in the light of their severity and type. From Figure 1 we observe that search engines are used more frequently to seek information on serious conditions, compared to Twitter (per a Wilcoxon test, this difference is statistically significant: z=4.98, p<.001). Examples can be found in Table 1: in the 20 top-ranked conditions shared on Twitter and sought on the search engine respectively, there are six serious conditions in the former (e.g., "diabetes"), while nine in the latter. Benign conditions show relatively similar use on both search engines and Twitter (in Table 1, seven of 20 are benign conditions in the 20 top rank conditions for search as well as Twitter, e.g., "pregnancy", "anxiety" appear in both)—a Wilcoxon test reveals only marginal significant differences (z=1.42, p=.02).

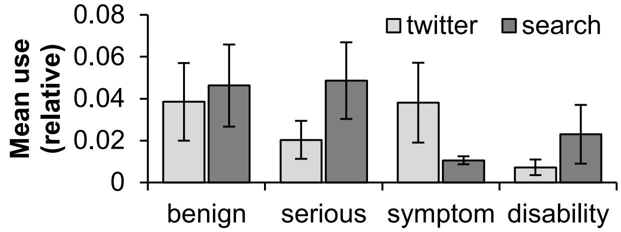

Figure 1. Relative use of health terms on Twitter and the search engine, for each condition studied (± standard error of mean).

Next, per Figure 1, relative use of symptoms suggests symptoms to be shared more on Twitter than searched (per Wilcoxon test, this is a statistically significant difference: z=-2.95, p<.01). Taking examples from Table 1, seven of 20 top ranked conditions for Twitter are symptoms while it is only three in the case of the search engine. Finally, disabilities are searched more than they are shared on Twitter (per Wilcoxon test, z=1.76, p<0.01). In Table 1, *none* of the disabilities appear in the 20 top rank conditions for Twitter; in the case of search, "autism" is found to be ranked 12. The sensitive nature of many of the disabilities studied (mean stigma rating of the six disabilities=1.83, leaning toward the higher-stigma end of the scale) means that people may be more comfortable privately searching about their treatments, diagnosis, or coping mechanisms, than discussing them publicly on Twitter.

We elaborate on these observations by analyzing rank differences (Table 1). We first observe those terms that are shared more on Twitter than searched. For the 20 most positive rank difference values, 11 are benign (e.g., "insomnia", "toothache", "sore throat", "food poisoning") and only one is serious and eight are symptoms. Supporting the observations from Figure 1, social media may be preferred for sharing benign conditions and symptoms, rather than serious illnesses.

Next, we examine which terms that are searched relatively more than shared on Twitter. For the top 20 most negative rank difference values, 12 are found to be serious conditions (e.g., "kidney disease", "bipolar disorder'", "sexually transmitted disease"), three are benign, and five are symptoms. This suggests a tendency to prefer search engines to Twitter for online activities related to serious health conditions.

Comparison: Social Stigma of Conditions

We now focus on understanding usage of health conditions on search engines and social media, and their levels of social stigma. Comparing across the platforms, from Table 1 (columns one and two), we observe notable differences between Twitter and the search engine, e.g., conditions perceived to have higher stigma are searched more (nine of the 20 top rank conditions for search have moderate or high stigma; three of them are extremely stigmatic, e.g., "autism", "AIDS") than they are shared on Twitter (six of the 20 for Twitter have moderate or high stigma; two extremely stigmatic).

Examination of the rank differences (Table 1) reveals the same pattern more prominently. Among the top conditions searched more than tweeted, four are highly stigmatic (e.g., "vaginitis", "myopathy"), whereas there are no highly stigmatic conditions tweeted more than searched (although there are moderately stigmatic ones such as "wheezing", "dysmenorrhea"). These considerable differences regarding stigma span all 165 health conditions (not just the top 20 shown in Table 1). Wilcoxon tests reveal that the relative use of moderate or highly stigmatic conditions is higher on search engines than on Twitter (for moderate stigma: z=4.57, p<.001; for high stigma: z=1.89, p<.01). Not surprisingly, but important to show, people prefer search engines over Twitter for online activity related to health conditions that may be associated with social taboo. This is reasonable given the nature of the platforms, but it is interesting that people do use Twitter to share *some* information on stigmatic conditions.

Comparison: Context of Use

From our log data, we examined the set of all non-stop-word unigrams that co-occur (≥10 times) with each of the health conditions in Twitter posts and search queries. We cluster the unigrams based on LIWC's (Linguistic Inquiry and Word Count: *www.liwc.net*) categories (style categories, e.g., pronoun use, are excluded), to obtain a general sense of the *context* of use of each term. For comparison across Twitter and search, we use a relative measure of use of each linguistic category to account for different usages in the two sources—defined in the same way as the relative use of a condition.

Across Condition Severity

We first compute the Jensen-Shannon divergences between the unigram category distributions of the condition severities/types (Table 2). Next we show differences between unigram distributions on Twitter and search (Table 3).

From Table 2 we observe that for both Twitter and the search engine, there are significant differences in the context of use of different conditions. For example, the top unigram categories for benign conditions on Twitter and the search engine are: *past* and *future* tense words, *social, work, anxiety, negative emotion*, and *anger* (example unigrams include "hate", "relieve", "tomorrow", "now", "cry", "worries", "school"). This suggests that people are referring to their benign conditions with negativity, in terms of how they are disrupting their current and future social or professional life.

On the other hand, mentions of serious conditions on Twitter and the search engine tend to include categories like: *see, hear* (perception terms), *body, family, death*, and *numbers* (e.g., "awareness", "treatment", "signs", "survival", "prognosis", "rate", "pain"). People may be seeking information

Twitter				
	Benign	*Serious*	*Symptom*	*Disability*
Benign	0	0.5324***	0.2785 *	0.4854***
Serious		0	0.4574***	0.3785 **
Symptom			0	0.5469***
Search				
Benign	0	0.6555***	0.3057 *	0.4922***
Serious		0	0.5491***	0.4218 **
Symptom			0	0.5061***

Table 2. Jensen-Shannon divergence across the unigram category distributions of the condition types. Statistical significance tests based on paired *t*-tests (* *p*≤.05; ** *p*≤.01; * *p*≤.001).**

Twitter\Search	JS divergence	*t*-stat	SD	*p*
Benign	0.3387	0.1426	0.1236	0.0389
Serious	0.4178	0.372	0.0838	0.0232
Symptom	0.5501	1.5679	0.1604	0.0124
Disability	*0.6952*	*2.2325*	*0.0729*	*0.0025*

Table 3. Jensen-Shannon divergence between unigram category distribution on Twitter and the search engine, corresponding to the four condition types. Significance (at *p*≤.01) in italics.

related to the physical ordeals associated with serious health concerns, or specific treatment information.

Next, the context of use of symptoms Twitter and the search engine spans the categories *health, insight, cognitive mechanisms* (e.g., "pain", "hard", "remedies", "medicines", "outbreak", "bad", "sleep", "woke", "feel", "ugh", "damn"). These indicate people may be seeking information to do a self-diagnosis on their symptoms, as well as expressing frustration on the inconvenience the symptoms may be causing.

Finally, examining the context of use of disability terms, we find that on Twitter categories like *present* and *future, money, religion, social,* and *friends* are common (e.g., "god", "day", "children", "support", "month", "special", "today", "please", "money"). This indicates that through their postings, people share disability related information in the context of monetary costs and challenges, and perhaps even seek comfort through sharing religious thoughts and reaching out to their social audiences. For search these span over *motion, health, space, work* (e.g., "disorder", "school", "banned", "therapy", "treatment", "walk", "speak", "children"). Disabilities can be a personal and social challenge and impact people's life activities and work; hence through search people appear to seek coping mechanisms to deal with their condition and experiences. Thus, the context of use of disabilities is distinct from that of acute conditions. In fact, comparing the unigram category usage around disabilities for Twitter and search, we find a distinctive contrast (ref. Table 3). Perhaps individuals are less inhibited in their searches on disabilities, since search engines provide a more private experience while seeking for information on a stigmatic experience (mean stigma rating of the six disabilities=1.83).

Across Stigma Levels

Next we analyze the context of use of the health conditions in the light of their level of social stigma.

We find that the context of use of high stigma conditions is considerably different from that of low stigma conditions.

Twitter			
	Stigma 1	*Stigma 2*	*Stigma 3*
Stigma 1	0	0.2238*	0.6797***
Stigma 2		0	0.2404 *
Search			
Stigma 1	0	0.1626*	0.4884 **
Stigma 2		0	0.1623 *

Table 4. Jensen-Shannon divergence for Twitter and the search engine respectively, across the unigram category distributions for the three stigma levels. Statistical significance of differences using paired *t*-tests is shown (* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$).

Twitter\Search	JS divergence	*t*-stat	SD	*p*
Stigma 1	0.3853	1.8911	0.1093	0.020
Stigma 2	0.2760	0.9701	0.1057	0.037
Stigma 3	*0.6991*	*2.1208*	*0.0784*	*0.009*

Table 5. Jensen-Shannon divergence between unigram category distribution on Twitter and the search engine, corresponding to the three stigma levels. Significance (at $p \leq .01$) in italics.

This is consistent for both Twitter and the search engine (Table 4). For instance, for low stigma terms, Twitter and search engine use spans context that includes categories such as *past, present*, and *future* tense, *insight, time*, and *work* (e.g., "life", "sleep", "week", "ugh", "now", "tomorrow", "people", "test", "effects", "work", "signs", "sick"). It appears that individuals are seeking or sharing information on these conditions in the light of their mundane day to day experiences and how they are affecting their lives and work conditions. However, for high stigma conditions, usage context on Twitter and search engines comprises categories such as *anger, sadness, anxiety*, *health, body*, and perception words like *feel* (e.g., "surgery", "HIV", "treatment", "hospital", "children", "prognosis", "die", "lost", "mad", "cure", "hate", "fight"). Highly stigmatic conditions appear to present themselves within contexts associated with mental stress and anxiety in Twitter posts and search queries; people also attempt to seek information on these high-stigma conditions for educational and treatment purposes.

However, as one would expect, Table 5 indicates that the context of use of high stigma conditions on Twitter and the search engine is statistically significantly different. For Twitter, the unigram categories for high stigma conditions span: *sadness, anxiety*, *social,* perception words like *see, feel* (e.g., "hope", "feel", "shit", "support", "please", "family", "suck", "mad", "fight"). In contrast, for search they include *health, body, feel, motion* (e.g., "signs", "treatment", "hospital", "children", "prognosis", "die", "surgery", "rate", "awareness"). This aligns with our prior observation: individuals are more cautious in the way they discuss highly stigmatic conditions on a public platform like Twitter, perhaps for fear of being judged by their audiences and contacts.

Summary

This log study comparing the nature of online health information sought and shared reveals self-censorship—serious health conditions, disabilities, and highly stigmatic conditions are generally searched considerably more than they are mentioned in Twitter postings. Symptoms of health conditions, however, were more frequently present in Twitter posts than in search queries. This perhaps indicates people's propensity to use social media as a broadcasting platform to express the ordeals and inconveniences that are caused by symptoms they face in their day to day lives.

RESULTS: PRIVACY, QUALITY, SOCIAL SUPPORT

Turning to RQ3, we investigate how people evaluate their health information seeking or sharing experiences as manifested through their use of search engines and social media. We consider three aspects: (1) any privacy risks involved, (2) the quality of information they access, and (3) the availability of social support from others through this activity.

Respondents indicated on a seven-point Likert scale (ranging from 7 = *strongly agree* to 1 = *strongly disagree*), whether they agreed that using a search engine to seek health information was a *privacy* risk. Respondents slightly agreed (mean = 3.5, median = 3), but were more concerned about the privacy risk on Twitter (mean = 4.7, median = 5; Wilcoxon signed-rank test: z=7.87, p<.001). Similarly, in terms of health information sharing through Twitter, people slightly agreed that using Twitter to share health information is a privacy risk (mean = 4.9, median = 5) and more so than seeking on Twitter (Wilcoxon test: z=3.96, p<.001).

Respondents were in slight agreement that health information available via search engines is of *high quality* (mean = 4.8, median = 5) and moderately agreed that search engines were useful for finding sources of *social support* (mean = 5.6, median = 6). Conversely, respondents were neutral in agreement that health information available via Twitter is of high quality (mean = 3.7, median = 4). Surprisingly, people were neutral about Twitter's utility for finding social support related to health issues (mean = 4.6, median = 4).

These differences in perceptions of information quality were statistically significant, with search engines being perceived as providing higher-quality information than Twitter (median 5 vs. 4), z=-8.81, p<.001. Surprisingly, search engines were also viewed as more useful for finding social support for health issues than Twitter (median 6 vs. 4), z=-8.54, p< .001, perhaps because they are useful for surfacing forums and OHCs, which prior work has shown are seen as key venues for social support for health concerns [9,17].

Note, however, that respondents who *did* report searching for information on Twitter viewed it as less of a privacy risk (median 4) than those who had not (median 5) (Mann-Whitney test, z=-2.46, p=.01). These people also viewed health information on Twitter as of higher quality, z=4.12, p<.001, and viewed Twitter as better for finding social support on health issues (median 6 vs. 4), z=4.78, p < .001. Similarly, respondents who reported having *shared* health information on Twitter viewed it as less of a privacy risk (median 4 vs. 5) than those who had not (z=-3.74, p< .001). It is unclear whether this view of Twitter as a higher-quality, lower-risk venue for health activity results from positive experiences in engaging in health activity on Twitter despite initial skepticism, or whether these users were more likely to engage in health tweeting because they held these positive views.

DISCUSSION

Our results indicate that online health activity as manifested via search engine queries and tweets provides insight into users' health information needs, as well as norms of use of these two prominent online platforms with regard to this sensitive topic. The complementary nature of the two media (public vs. private, seeking vs. sharing) help develop a more complete picture of the range of online health activities.

Analyzing health trends based on public Twitter posts is an important emerging research topic [25], but our findings suggest a need for caution if using Twitter to infer health trends for high-stigma conditions—there is evidence of self-censorship. Combining Twitter data with an alternative data source (such as search logs) could give a better understanding of health information seeking and sharing practices online than using either source alone. Differential prevalence of health term use on different platforms, or differential contexts (e.g., co-occurring unigrams) might be a useful indicator of the perceived stigma associated with a given health condition.

Design Implications

The popularity of online venues for seeking information around health issues also raises the point of developing appropriate credibility indicators. Credibility seems particularly important given the relatively high level of confidence our survey respondents reported placing in the content found online, a level of confidence health professionals consider misplaced [22]. Potentially, credibility-specific analogues of Twitter's "verified account" seal (currently used to label elite users) may be developed for health accounts (or websites, similar to healthonnet.org, but with verification of content accuracy). Systems that support easy sharing of online content with a user's healthcare provider might also be helpful.

New kinds of health information search systems maybe built that support standing queries over search and/or social media to keep users apprised of new developments related to different common health concerns, since seeking new research about conditions and diversity of health content were the goals of many respondents. Such queries might even be personalized based on a user's medical history (perhaps using data from electronic health records) to increase the likelihood that users learn about relevant health information in a timely fashion (although such personalization has serious privacy implications). Besides, users' interest in finding information about medications (e.g., drug interactions, side effects), diagnostic and treatment information for specific conditions suggest that search engines might serve users well by introducing new categories of "instant answers" that return such content directly in response to medication or illness queries.

Although our findings indicate some degree of risk-awareness (as evidenced via self-report in the survey and differential activities for high-stigma and serious conditions across the two platforms), there is need for work on educating users about the privacy risks of seeking and sharing health information online (building on some initial efforts in this area [14]). Participants' self-reporting and logged behavior suggests that they view search engines as quite private, and they may be unaware of how some search and advertising companies may collect and distribute their information. Even though less high-stigma content was shared on Twitter, the presence of any level of health information sharing in such a public venue may have serious repercussions (e.g., higher insurance rates, denial of employment, etc.). Developing interfaces to remind users of these risks (perhaps by showing an "are you sure?" dialogue upon detection of sensitive terms in a query or tweet) is an important area for further research.

Future Directions

Finally, we outline some limitations of this work. In our survey, 94% (197) reported using a search engine to seek information related to their health. This fraction is much higher than the figure reported in the Jan 2013 Pew health survey [10], which showed that 59% of U.S. adults have looked online for health information in the past year. Possible reasons for discrepancies include a slight difference in the question (we asked "have you ever" versus "past year" in Pew) and the characteristics of individuals who volunteered for our online survey: This population may be more Internet-literate than the pool in Pew where participants are recruited via telephone, and where having a Twitter account was not a prerequisite for participation. Though popular, Twitter is only one of several key social media platforms; understanding the role of other social network sites such as Facebook, in online health activity would be a valuable complement to this work.

More research is needed to understand the characteristics of online health information seekers and those who seek such information from offline sources. Although we presented a comparison of the use of health conditions in searches and Twitter posts, in the absence of demographics (age, gender, etc.) and corresponding incidence rates of each of the 165 conditions for those populations, it is difficult to infer differences in their norms of use in searches or Twitter alone or in the prevalence of a term's use online compared to its physical manifestation. Differences in the demographics of the user base between the two platforms may introduce confounds in the cross-platform comparisons. Considering the impact of these factors are interesting extensions to our research.

CONCLUSION

Search engines and social media are popular tools for seeking and sharing information about a range of health conditions. We presented an in-depth study around the prevalence of these practices, the nature of health information sought, and why people are increasingly choosing to use such tools for their health information needs. We demonstrated that the prevalence and characteristics of health information that are sought via search engines or shared via social media are considerably distinct. People modify their information seeking and sharing practices depending on condition type: whether it is a serious condition, a disability, or simply an issue with a benign explanation. Despite being aware of the privacy risks of search engine use or public social media use, people did in fact use both, though differentially, to seek and share information on conditions which are socially considered to be stigmatic. We believe, through the findings in this paper, we have been able to shed new light on understanding health seeking and sharing practices both on search engines and on social media, and how these findings might influence the design of future iterations of these platforms.

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