Jiang Bian · Yi Guo · Zhe He · Xia Hu
Editors

Social Web and Health Research

Benefits, Limitations, and Best Practices

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Preface

In the last decade, we have witnessed a rapid growth of social media, social networks, or more widely interactive websites and online tools. These combined formed the broader social web that has changed the communication landscape in recent years. In 2018, 89% of US adults have access to the Internet, raised from 52% in early 2000, according to the Pew Research Center. Just 5% of US adults used some sort of social media platforms when Pew Research Center started tracking social media adoption in 2005; by 2018, that number had risen to 69%. Use of social media and presence on the social web is a daily routine for many people nowadays. And the usage pattern has changed from initial interpersonal communications to more expansive use of the social web for many different purposes such as supplementing traditional news media, organizing massive social events, and so on. These changes are stimulated by a rapid diffusion of Internet penetration, online communities, mobile technologies, and a host of different types of participative channels.

These changes have also shaped the health communication landscape. In 2013, the latest national survey from Pew Research Center found that 72% adult Internet users have searched online for health information about a range of issues, but mostly about specific diseases and treatments to facilitate self-diagnoses and self-treatments. Furthermore, 26% (one-in-four) adult Internet users have read or watched someone else's health experience; and 16% of adult Internet users have gone online to find others who share the same health concerns. On the other hand, people want their voices to be heard, and they voluntarily share a critical mass of data about their health status and health history, perceived value of care, experience interacting with health care systems, opinions and thoughts on public health programs, among many other user-generated health data on social web platforms. As shown in many studies, these user-generated contents can be unique data sources to understand individuals' health behavior. Many health behaviors, despite being an individual choice, are often influenced by social and cultural context. Social web platforms such as Twitter, Facebook, Youtube, and online discussion forums afford us enormous opportunities to understand the intersections of individual behaviors, social-environmental factors, and social interactions on these platforms. Over the

past several years, our research has shown that we can mine the social web for invaluable insights into public and consumer health. Nevertheless, we have few tools to "judge" the utility and quality of the abundant social media analysis studies. Significant questions and concerns have been raised such as the representativeness of social media populations, the presence of bots and fake accounts, the sample units, the difference between active (e.g., survey) and passive (e.g., social media) data collections, the unstructured and noisy nature of colloquial text, and sparsity of the topic coverage.

On the other hand, social web is not just a "new" data source, but also an emerging tool for health promotion and other public health efforts. Various types of social web platforms, from traditional digital platforms such as blogs and online forums, to modern mainstream tools including Facebook and Twitter, have great potential in delivering and upscaling health promotion programs in cost-effective ways to quickly reach a large number of diverse audiences across geographic distances. Over the past decade, a wide range of social web-based interventions have been implemented and evaluated to address different health areas, such as weight management, smoking cessation, and cancer prevention and control. Nevertheless, social web is not a silver bullet that can magically solve all issues in health promotion programs. More work is needed to answer questions such as their effectiveness, participant engagement and retention, and participant self-efficacy.

This book is a collection of contributions from leading scientists in the intersection of social web and health research. The goal of the book is to present diverse types of health-related social web research projects, introduce state-of-the-art methods and best practices, and discuss the benefits and limitations.

We will start with a chapter from Ru and Yao on a literature review of social media-based data mining methods for health outcomes research. The most studied health outcome in social media data was adverse reactions to medications. While the most common text analysis methods are named-entity recognition and text mining-based feature construction, most of these studies adopted content analysis and machine learning models. In Chap. 2, Guo and Bian described the state-of-the-art for health interventions that use social media through reviewing relevant systematic literature review papers on the topic. In addition, this chapter aims to evaluate how social media is being used in these interventions and to provide an update on the effectiveness of these interventions. Chen and Hao, in Chap. 3, presented a bibliometric study analyzing social media and health research publications to acquire the predominant subjects, journals, and countries, collaboration relationships, as well as major topics using social network analysis and topic modeling approaches. In Chap. 4, Huo and Turner provided a comprehensive introduction to various concepts and definitions of social media applications in health communication. They further discussed a number of examples of social media usage across the spectrum of health care and reviewed current guidelines for health care professionals' use of social media. Zhang, in Chap. 5, discussed sources of health information for consumers in a way to understand individuals' health information seeking behavior, where social media environment is a critical component. Health information seekers' source selection behavior merits systematic and thorough research as it is the starting point

of an information seeking process and important for the fulfillment of information needs. In Chap. 6, He explored the issue of lay information consumers' health literacy with a specific focus on bridging the language and terminology gap between health professionals and consumers using social media data. In Chap. 7, Hou and Park presented their study on documenting what contents surrounding risky and stigmatized health issues are shared on social media as well as the characteristics of those messages. In Chap. 8, Akbari, Hu, and Chua presented another case study learning wellness profiles of social media users in terms of diabetes with extension to obesity and depression. Chapter 9, Ismail, Du and Hu discussed the possibility of training machine learning models to identify mental health issues using social media data with promising results. In Chap. 10, Mercadier et al. leveraged state-of-the-art deep learning models and conducted a content analysis of tweets related to cervical cancer screening from the #SmearForSmear Twitter campaign launched in 2015 for the European Cervical Cancer Prevention week. In Chap. 11, Zhang et al. discussed how to improve public health via mining social media data and presented a case study of human papillomavirus (HPV). More importantly, their case study assessed the validity of social media-based measures comparing to similar measures derived from traditional survey data guided by a well-established health behavior theory (i.e., the Integrated Behavior Model). In Chap. 12, Yin et al. studied hormonal therapy medication adherence using data from an online breast cancer forum. Finally, the book is concluded with a chapter from Valdez and Keim-Malpass discussing the ethical concerns in health research using social media.

We hope you enjoy the book and find the diverse content helpful in navigating the new and exciting social web-based research field.

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Chapter 1
A Literature Review of Social Media-Based Data Mining for Health Outcomes Research

Boshu Ru and Lixia Yao

Abstract Patient-generated health outcomes data are health outcomes created, recorded, gathered, or inferred by or from patients or their caregivers to address a health concern. A critical mass of patient-generated health outcome data has been accumulated on social media websites, which can offer a new potential data source for health outcomes research, in addition to electronic medical records (EMR), claims databases, the FDA Adverse Event Reporting System (FAERS), and survey data. Using the PubMed search engine, we systematically reviewed emerging research on mining patient-generated health outcomes in social media data to understand how this data and state-of-the-art text analysis techniques are utilized, as well as their related opportunities and challenges. We identified 19 full-text articles as the typical examples on this topic since 2011, indicating its novelty. The most analyzed health outcome was side effects due to medication (in 15 studies), while the most common methods to preprocess unstructured social media data were named entity recognition, normalization, and text mining-based feature construction. For analysis, researchers adopted content analysis, hypothesis testing, and machine learning models. When compared to EMR, claims, FAERS, and survey data, social media data comprise a large volume of information voluntarily contributed by patients not limited to one geographic location. Despite possible limitations, patient-generated health outcomes data from social media might promote further research on treatment effectiveness, adverse drug events, perceived value of treatment, and health-related quality of life. The challenge lies in the further improvement and customization of text mining methods.

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1.1 Introduction

Patient-generated health outcomes data refer to information on health outcomes created, recorded, gathered, or inferred by or from patients or their caregivers to address a specific health concern. They are distinct from the outcomes data generated in clinical settings by healthcare providers. Because healthcare is increasingly focusing on the patient, patient-generated health outcomes data have drawn growing attention from various healthcare stakeholders.

Today, in addition to posting travel pictures, people share their health experiences on popular social media websites (e.g., Facebook, Twitter) or primarily health focused patient forums and online communities to seek collective knowledge for health-related decision-making, connect with others suffering from the same disease, or voice their opinions on certain treatments and healthcare providers [1]. These personal stories often mention a broad collection of health outcome topics. For example, how the drug has impacted his or her quality of life, what side effects he or she has suffered from, and how difficult adherence to the therapy is. The information has attracted some clinicians and researchers to mine social media data for patterns and trends that could lead to new biomedical hypotheses and discoveries. To name a few, Yang et al. identified adverse drug reaction (ADR) signals in the MedHelp forum, using an ADR lexicon created for the Consumer Health Vocabulary [2]. Furthermore, Yates et al. extracted ADR signals from breast cancer drug reviews on askpatient.com, drugs.com, and drugratingz.com, using an ADR synonym list generated from the United Medical Language System (UMLS) [3].

In this study, using PubMed (the search engine for the MEDLINE bibliographic database of biomedical science), we systematically reviewed and analyzed original research work on patient-generated health outcomes data in social media. The purpose was to summarize the key points of this emerging research area, particularly in terms of data accessibility, textual data preprocessing methods, analysis methods, and opportunities and challenges.

1.2 Methods

1.2.1 Automated Search

As noted above, we used the PubMed search engine—specifically the PubMed advanced search builder (see Fig. 1.1a)—to identify pertinent studies. PubMed provides access to millions of biomedical publications in the MEDLINE biblio-

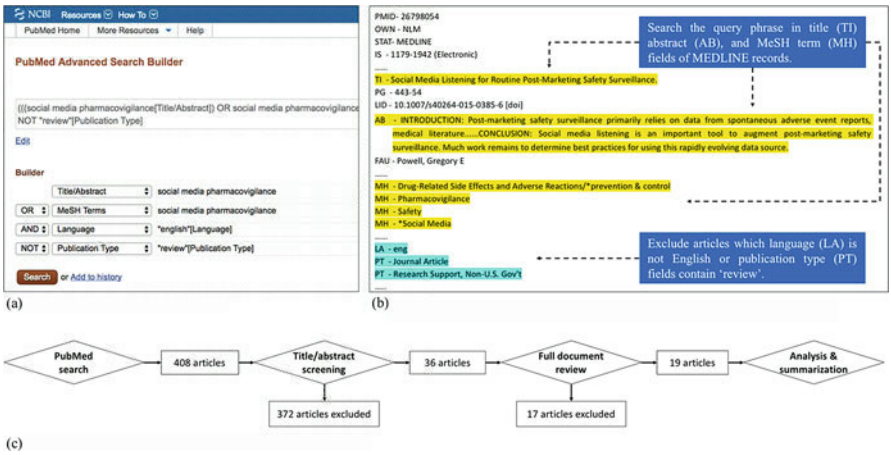

Fig. 1.1 Literature review workflow. (**a**) PubMed advanced search builder. (**b**) An abstract in MEDLINE format with different bibliographic elements. (**c**) The flow diagram of the search and selection process

graphic database and enables users to specify their search fields and build queries via keywords and logic operators. We employed two sets of keywords to form the query phrases. The first set covers a range of interchangeable terms for social media (scientists use different terms, depending on the specific field), such as *social media*, *online health community*, and *patient forum*. The second set focuses on the different concepts related to health outcomes, such as *patient outcome assessment*, *treatment outcomes*, *health outcomes*, *side effect*, *effectiveness*, *medication adherence*, *financial distress*, and *pharmacovigilance*. We chose one keyword from each set to create each query phrase (e.g., *social media health outcomes*, *online health community medication adherence*, and *patient forum treatment outcomes*). We entered these query phrases into the PubMed advanced search builder, retrieving original research articles in English that contained the searched query phrase in the title, abstract, or Medical Subject Heading (MeSH) [4] fields of the publication record, which are all in MEDLINE format (see Fig. 1.1b). After removing duplicated articles, we retrieved a total of 408 unique articles.

1.2.2 Manual Article Review

We manually reviewed all 408 articles in two rounds. In the first round, we screened the titles and abstracts to determine which articles would receive a full-article review. Through this process, we excluded 372 articles that utilized social media for purposes other than analyzing health outcomes reported by patients, such as treating diseases or supplementing other treatments [5, 6], improving

communication between patients and clinicians [7, 8], or recruiting participants for research studies [9]. In the second round, we reviewed the full text of the remaining articles, ultimately removing 17 based on the same selection criteria as in the first round. Therefore, a total of 19 articles were included in our analysis. The entire workflow is illustrated in Fig. 1.1c.

1.3 Results

Of the 19 reviewed articles, the oldest was published in 2011 and 14 have been published since 2015. This suggests that mining social media data for health outcomes remains an emerging research topic in the biomedical research community. Table 1.1 summarizes the reviewed articles according to social media source, data type, data volume, data preprocessing method, and analysis method. Specifically, nine studies collected data from popular social network websites such as Twitter and Facebook, 11 from online patient forums such as WebMD and MedHelp, and three from other websites such as Amazon (e.g., user reviews of health products) and Google (e.g., side effects-related discussions indexed by the search engine). All 19 studies analyzed patients' (or user) comments in an unstructured free-text format [10–28], with four studies also obtaining demographic information such as age, gender, and race [11, 16, 24, 27]. The number of social media posts collected ranged from 639 to 2,737,067, with a median of 100,000. As for data preprocessing method, 11 studies identified various medical concepts (e.g., diseases, symptoms, drugs) in social media data and mapped them to standard medical ontologies via automated named entity recognition and normalization techniques [10, 13, 15, 18–20, 22, 24, 25, 28] or human annotators [26]. Five studies utilized text mining techniques such as n-gram, word embedding, sentence dependency-based parse tree, and Latent Dirichlet Allocation (LDA) topic modeling to extract features from the free-text for further analysis [14, 18–21]. Finally, regarding the analysis methods, 12 studies performed content analysis [10–12, 15–17, 22, 24–28], 11 studies conducted hypothesis testing [10–12, 14, 16, 20–24, 28], eight studies used supervised machine

Table 1.1 Characteristics of the reviewed studies

Social media source	Social network website: 9 Online patient forum: 11 Other: 3
Data type	Unstructured text: 19 Unstructured text + Demographic info: 4
Data volume (number of patient posts)	Min—25%—50%—75%—Max 639—3,243—100,000—1,024,041—2,737,067
Data preprocessing method	Named entity recognition and normalization: 10 (automated), 1 (manual) Text mining-based feature construction: 5
Analysis method	Content analysis: 12 Hypothesis testing: 11 Supervised learning: 8 Unsupervised learning: 4

learning methods [10, 13, 15, 18–21, 25], and four explored unsupervised machine learning methods [13, 14, 23, 25].

1.3.1 Patient-Generated Health Outcomes

In the 19 reviewed studies, side effects due to medication was the most examined type of patient-generated health outcome (15 studies; Table 1.2), followed by treatment effectiveness (three studies), treatment adherence (two studies), perceived value of treatment (one study), and health-related quality of life (one study). These results echoed the findings of our previous study [29]. The fact that patients wrote more often about side effects is probably due to the psychological phenomenon known as the negativity bias [30], according to which negative events or ideas have a stronger impact on a person's impressions and evaluations than do positive events or ideas of equal intensity. None of the reviewed studies focused on financial distress, which suggests that researchers have not yet utilized social media data to analyze the cost and burden of medication, or financial distress might be less frequently discussed on social media, as many patients were covered by health insurance plans and might not be sensitive to the cost. It would seem that a massive amount of social media data are essential to understand the full spectrum of patient-generated health outcomes, provided that they be systematically collected and analyzed.

1.3.2 Data Accessibility

Social media websites have different data sharing policies. For instance, Twitter offers free application programming interfaces (APIs) for users to download tweets, and researchers can search tweets that match specified keywords [19] or download tweets in real time [13]. However, this free API grants researchers access to only 1% of all tweets in the search result or the first 500 tweets in the stream [13]. To address this limitation, two studies purchased data from data vendors with access to all Twitter data archives under a commercial use license [15, 17]. By contrast, Facebook does not provide free API tools to search user posts by keywords and

Table 1.2 Types of patient-generated health outcomes

Patient-generated health outcome type	# articles	References
Side effects	15	[10, 11, 13–22, 25, 26, 28]
Effectiveness	3	[10, 12, 26]
Adherence	2	[27, 28]
Perceived value of treatment	1	[23]
Health-related quality of life	1	[24]

prohibits unauthorized computer programs from accessing user data. Of the two studies utilizing Facebook data, Egan et al. searched for Facebook groups relevant to *migraine surgery* and *occipital neuralgia*, and then downloaded all user discussions posted in these groups [12], while Powell et al. obtained Facebook posts from an authorized data vendor [15]. As for the online patient forums, they often organize their (static) html pages by disease, treatment, or medical event, which enables researchers to easily crawl the data [11, 16, 18–21, 24–28]. In particular, we found three studies that crawled patient-generated content from hundreds to thousands of patient forums [10, 17, 27].

It is worth mentioning that only six studies provided the Institutional Review Board (IRB) information in the articles [10–12, 17, 27, 28]. The remaining 13 studies (nine of which were performed in US institutions) did not provide any such information, including two that analyzed demographic information [16, 24]. Despite the prevailing myth that publicly visible data on the Internet are not considered as human subjects so long as the individual users are not re-identified, social media data can contain private patient information protected under the Health Insurance Portability and Accountability Act (HIPPA). For example, the real identity of a user with a rare disease might be revealed when combining other information such as age, gender, race, and location. Therefore, it is advisable that future research articles provide detailed information on human subjects ethical procedures, even if the studies are exempted from IRB approval.

1.3.3 Named Entity Recognition and Normalization

Numerous social media analyses depend on accurate named entity recognition and normalization. Here, recognition refers to the identification of entities, such as drugs, diseases, and medical events, that were mentioned in the social media text, while normalization involves mapping them to predefined categories or standard medical ontologies. Of the reviewed studies, ten automatically identified and mapped named medical entities using medical lexicons and software tools [10, 13, 15, 18–20, 22, 24, 25, 28]. The specific lexicon resources adopted in these studies were UMLS [31], medical terms in the FAERS [32], SIDER side effect resource database [33], and Canada Drug Adverse Reaction Database (MedEffect) [20]. The software tools included MetaMap [13, 18, 20], BioNER [22], Treato [10], IBM SPSS Text Analytics Platform [24], and self-developed programs [15, 19, 25, 28].

Dictionary lookup and machine learning are two major approaches commonly adopted by current tools. The dictionary lookup method typically matches strings from social media text to certain medical lexicons. Studies based on this method [13, 15, 18, 20, 22, 25, 28] often applied text standardization (e.g., morphological normalization and stemming) and partial string match to improve the matching performance. It does not require annotated data and can be applied to different

research topics by changing the lexicon resource. However, the normalizing and mapping the colloquial language of patients on social media remains a challenge. By contrast, the machine learning approach utilizes algorithms such as continuous random field and SVM [19] to predict the semantic type (e.g., adverse drug effect and disease) of given terms or to rank candidate standard medical terms in the normalization step. However, training these models requires large amount of annotated data, which can be labor intensive. We also found one study that manually conducted named entity recognition and normalization [26].

1.3.4 Text Mining-Based Feature Construction

Feature construction involves creating a new representation of free-text data to enable various analysis or modeling methods. Several of the reviewed studies translated free-text user posts on social media into a format that computers can process, using text mining techniques such as n-gram, word embedding, sentence dependency-based parse tree, and LDA topic modeling analysis [14, 18–21]. An n-gram refers to a contiguous sequence of n words from a given text, which captures the pattern of how people use this combination of words in their communication. Sarker et al. employed unigrams, bigrams, and tri-grams ($n = 1$, 2, and 3, respectively) to represent user posts on social media in a matrix [20].

Word embedding involves semantically mapping words onto high-dimensional spaces using a transformation function in which the parameters are learned from an unlabeled text corpus [34]. It has been recently widely adopted for research, applications, and competitions [35, 36]. Nikfarjam et al. used word2vec, a word embedding implementation, to map words from social media onto a vector space of 150 dimensions [19]. Subsequently, they employed the k-means algorithm to group these words into 150 semantic clusters according to their distances in the high-dimensional space. Finally, each word in the corpus was represented using the identifier of the cluster to which it belonged.

A sentence dependency-based parse tree represents a narrative sentence in a hierarchically structured tree of words, using the structure to show syntactic relations and the direction of links to demonstrate semantic dependencies. It can be generated by grammatical rules and statistical learning methods [37] and was adopted by Liu et al. to construct syntactic and semantic features to analyze drug discussion posts in patient forums [18].

LDA topic modeling utilizes a generative statistical model to associate each document with a probability distribution over a set of topics learned from a corpus of documents [38]. Compared to the term-matrix generated via an n-gram model, the features constructed from an LDA topic model can maintain the semantic structure of a text with a significantly lower dimensionality. This advantage was leveraged by two of the studies in this review [20, 21].

1.3.5 Analysis Methods

In total, 12 studies conducted content analyses [10–12, 15–17, 22, 24–28]. Six of them manually annotated social media data to summarize patient-generated health outcomes [11, 12, 16, 17, 26, 27]. The annotation process included the creation of a codebook of target entities to look up, parallel or sequential rounds of annotation by multiple annotators, and evaluations of agreement between annotators. In the remaining six studies, researchers summarized social media contents using the results from the automated named entity recognition and normalization step [10, 15, 22, 24, 25, 28].

Eleven of the studies conducted hypothesis testing to quantify the associations between medical entities or agreement between annotators [10–12, 14, 16, 20–24, 28]. Specifically, chi-square tests were used to quantify the association between types of antidepressant and the adverse effects of these drugs reported in social media [11], or to evaluate the relationship between type of migraine surgery and the degree of resolution of symptoms [12]. Correlations between time series was calculated to examine the association between drug pairs frequently mentioned on Twitter and drug pairs with known interactions [22].

Eight studies utilized supervised machine learning models, such as the random forest [13], support vector machine [18–20], Bayesian classifiers [15, 21], logistic regression analysis [21], and a discriminative model based on distances to labeled instances [25]. These studies focused on predicting specific health outcomes such as ADR. The models they used were often considered the baseline in recent research on machine learning methods. Four studies also adopted unsupervised machine learning approaches. They explored the distribution and underlying structure of social media data for generating research hypotheses or learning associations between health outcomes and events. Specifically, Sullivan et al. developed a modified LDA model by adding a second per-document topic Dirichlet distribution to "generate topics that are semantically similar to the adverse reactions" [14]. Eshleman et al. utilized the topological feature of common neighbor size in a network of drugs and effects to identify potential adverse drug events [13]. To evaluate how the distribution of reported outcomes influenced overall product ratings, de Barra et al. designed a formula that divided the distribution of reported outcomes by a constant factor that was proportional to the reporting rate [23]. Finally, Wu et al. proposed a generative model to evaluate the likelihood that a side effect is related to a given drug [25].

1.3.6 Evaluation Methods

The evaluation methods of the 19 reviewed studies can be placed into two categories. In the first category, authors cited existing studies to validate their findings or demonstrate the novelty [11–13, 18]. For example, Egan et al. found that the distribution of improvement levels among Facebook group members who received

migraine surgery was close to past results in the literature, and accordingly suggested that social media is a valid data source for research on this surgical outcome [12]. Hughes et al. claimed that the impact of emotional and behavioral factors on treatment decision-making was underestimated after comparing their findings based on social media data to that of previous studies [11]. Liu et al. compared the top 20 reported adverse events for beta-blockers on social media with the FAERS and concluded that social media offers additional insights into traditional adverse event data [18]. The second category of evaluation methods is built on quantitative metrics, such as precision, recall, specificity, and f-measures, which quantify the performance of analysis methods with model outputs and human annotated ground truth data [10, 13–15, 18–20, 25]. Articles adopted quantitative metrics for evaluation typically concentrate on developing analytics methods and often use existing gold standard data that is either annotated by themselves or by others. Between these two evaluation methods, citing existing studies can validate the novelty of some findings, but it cannot assess findings that have not been covered in other studies, neither can it identify false-negative cases. Machine learning metrics can comprehensively assess the sensitivity and specificity of models and tools. However, curating ground truth data is often expensive and can be suboptimal due to the subjectivity and random factors of annotators. A more rigorous design of experiment is to combine both approaches, as two studies did [13, 18].

1.4 Discussion

In this study, we searched PubMed to retrieve 408 original research articles written in English and manually selected 19 relevant articles for full examination. In these 19 studies, popular social network websites and online patient forums were the two most utilized types of social media. Side effects due to medication was the most examined type of patient-generated health outcome. Method wise, conducting biomedical named entity recognition and normalization on social media data is a nontrivial task, given that many existing tools, such as MetaMap and BioNER, are specifically designed for analyzing scientific literature. In particular, the informal, colloquial language used by patients and Internet users differs substantially from the formal language of scientific articles. Therefore, future studies might seek to customize named entity recognition and normalization tools for social media data.

1.4.1 Social Media as a New Data Source for Patient-Generated Health Outcomes

Social media is an emerging data source for healthcare with rich information on patient-generated health outcomes. In Table 1.3, we compare social media data with EMR, claims, FAERS, and survey data in terms of their advantages and limitations.

Table 1.3 Summary of patient-generated health outcome data sources

	Social media	EMR	Claims	FAERS	Survey
Pros	• Large volume • Presumably patients not limited to one geographical location • Voluntarily contributed by patients • Reflecting real opinions of patients	• Clinically most rigorous data • Large volume • Complete patient information (e.g., diagnosis, lab tests) • Easily support controlled study	• Information recorded by standardized codes • Huge volume • Capture complete information of patients • Support controlled study	• Dedicated for adverse drug events • Large volume	• Directly reported by patients • Clinical conditions and treatments are specified clearly • Patient demographic information is often included
Cons	• Noisy. Patient self-reported outcomes can be inaccurate • Patient use informal and colloquial language online • No context information (e.g., demographic, disease comorbidity) • No population information and no control	• Challenges to integrate patient medical records from multiple providers • Only information collected during clinical encounter • Difficult to access for research purpose outside the clinical facility	• Data primarily captured for billing • Diagnosis codes can be inaccurate • Only for patients with the insurance	• Limited to adverse drug events and medical error reports • Low reporting ratio in many cases • No population information and no control	• Small volume • Small sample size; results and conclusions are difficult to generalize • The question design can introduce bias

First, social media data contain a large volume of health outcomes information that was voluntarily contributed by patients. These reported outcomes reflect the real, unmoderated opinions of patients. EMR and claims data are also large in volume, but they are recorded by clinical professionals [39, 40], who might interpret outcomes differently from patients. FAERS data have been criticized for low patient reporting rates in many cases [41]. Survey data were directly collected from patients, but were relatively low in volume because of their high costs. Additionally, survey responses are often subject to biases because (1) researchers might choose questions and outcomes that they believe are important to patients based on their training and orientation, while avoiding outcomes considered difficult, expensive, or time-consuming to assess under realistic constraints and (2) patients can be hesitant or reluctant to openly express their real opinions (which might be extreme). Second, social media data are presumably not limited to a single geographic location or caregiver, whereas EMR and survey data usually cover only patients from a few locations and caregivers. Third, social media data might contain additional health outcomes information not available in other data sources. For example, a patient's recovery progress after an outpatient visit might not appear in an EMR or claims data until a follow-up visit or additional insurance benefits are claimed; in contrast, many patients discuss their progress on social media. The FAERS and similar systems were designed to collect adverse effects and do not cover other aspects of health outcomes. While surveys can be specifically designed to collect various outcomes information and often include detailed patient demographic information, the results are often difficult to generalize or adapt (e.g., translate to new cultures or languages, introduce new interventions or comparators).

Of course, the limitations of social media data must also be acknowledged. First, there is a significant amount of noise in social media data, such as commercial advertisements, spam, casual chat, and rhetorical mentions of medical terms for sarcasm or entertainment. In fact, using current data collection tools, over 90% of data retrieved from social media were reported to be noise [17, 29]. Second, many patients who write drug reviews online lack basic medical knowledge, and their descriptions of health outcomes can be ambiguous, hyperbolic, or inaccurate. In contrast, EMR and claims data, being entered by well-trained clinical professionals, tend to be more consistent and accurate. Third, social media language often contains informal writing conventions, typos, improper punctuation, and other such problems, making it difficult for computers to process, whereas most of the data in EMR, claims, and the FAERS are recorded in structured formats. Moreover, important contextual information such as co-prescribed drugs, diagnoses, treatment history, and chronic disease conditions might be missed in social media posts, but are usually available in EMR, claims, and surveys. Finally, population information (e.g., the total number of social media users who took a drug) is not available in social media data (or the FAERS), making it difficult to apply commonly used inferential statistics such as the proportional reporting ratio or odds ratios.

1.4.2 Limitations of This Review

This review concentrated on original research articles indexed in the MEDLINE bibliographic database of biomedical science. However, researchers in the computing and engineering fields have also analyzed social media data for patient-generated health outcomes. Their research has focused on building technical methods and has been published in computer science conferences and journals that cannot be retrieved by PubMed. We encourage audience with further interest to follow relevant research works on additional venues such as IEEE Xplore Digital Library [42]. Additionally, extracting and analyzing patient-generated health outcomes in social media is a relatively new research topic, and currently it has not been specifically indexed in MEDLINE. While we tried our best to use as many keywords relevant to this topic as possible, our search queries can miss some relevant articles on PubMed. Moreover, negative results are conventionally less likely to be published, thus contributing to publication bias; however, we did not account for this in our study.

1.5 Conclusion

Mining patient-generated health outcomes data in social media is a novel research topic. Emerging research on this topic has primarily examined side effects due to medication and has primarily used named entity recognition and normalization as well as text mining-based feature construction as data preprocessing methods. In the data analysis, content analysis, hypothesis testing, and machine learning methods have been widely used. Compared to EMR, claims, FAERS, and survey data—all of which were traditionally used in health outcomes research—social media data contain a large volume of information voluntarily contributed by patients not limited to one geographic location. However, the limitations of social media data include inaccuracy in patient self-reported outcomes, colloquial language usage, missing contexts, and difficulty in estimating population sizes for causal inference. To facilitate further health outcomes research on treatment effectiveness, adverse drug events, perceived value of treatment, and health-related quality of life using this promising data source, we need to improve and customize text mining methods and tools.

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Chapter 2
Social Media-Based Health Interventions: Where Are We Now?

Yi Guo and Jiang Bian

Abstract The unprecedented growth in the use of modern technology and social media has revolutionized how health information is disseminated and shared among people. Social media sites such as Facebook and Twitter have been increasingly used for health promotion and other public health efforts. In this chapter, we aim to describe the state-of-the-art for health interventions that use social media by reviewing relevant systematic literature review papers. The chapter has three objectives: (1) to identify health interventions that included social media as an intervention component, (2) to evaluate how social media is being used in these interventions, and (3) to provide an update on the effectiveness of these interventions.

Keywords Social media · Intervention · Education · Social support · Health behavior · Mental health · Chronic disease

2.1 Introduction

The unprecedented growth in the use of modern technology and social media has revolutionized how health information is disseminated and shared among people. Social media sites such as Facebook and Twitter have been increasingly used for health promotion and other public health efforts. Social media encompasses a range of Internet-based communication tools, from traditional digital platforms such as blogs and online forums, to modern mainstream tools including Facebook, Twitter, YouTube, and other interactive web and mobile applications. These social media tools have great potential in delivering and upscaling health interventions in cost-effective ways since they can quickly reach a large number of audiences

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across geographic distances and potentially sustain high levels of user engagement and retention, compared to traditional Internet-based interventions. Over the past decade, there has been a growing interest in the use of social media to deliver health information and education programs. Social media-based interventions have been implemented and evaluated in many health areas including weight management, smoking cessation, cancer prevention and control, and diabetes self-management.

This chapter aims to describe the state-of-the-art for health interventions using social media. More specifically, the chapter has three objectives: (1) to identify health interventions that included social media as an intervention component, (2) to evaluate how social media is being used in these interventions, and (3) to provide an update on the effectiveness of these interventions. The remainder of the chapter is organized as follows. First, we present the methodology used to identify systematic reviews of social media-based interventions. Second, we detail the characteristics of the identified interventions by health areas and subareas. We summarize the ways by which social media is used in these interventions and the effectiveness of these interventions. Third, we discuss our results and the implications for future studies.

2.2 A Review of Reviews

In this chapter, the methodological approach that has been taken is a review of systematic literature review papers that summarize social media-based health-related interventions. We searched electronic databases, PubMed and Web of Science, for original review papers published through October 2018. Our search covered papers that contain terms "intervention," "intervene," or "intervening," in combination with "social networks," "social media," "social network," "social networking," "Twitter," "Facebook," "Instagram," "Tumblr," "LinkedIn," "Snapchat," "Pinterest," "YouTube," "Google Plus," "Reddit," "Flickr," "Vine," or "WhatsApp" in the title or abstract. The search was limited to review papers published in English. We manually reviewed all titles and abstracts to exclude papers that (1) were not systematic reviews and (2) did not review any interventional studies. The literature search resulted in 18 systematic review papers for further analysis. We grouped the papers into the following health areas: modifiable health behaviors (11 reviews), mental health (two reviews), and chronic diseases (five reviews). Reviews by health areas and subareas were summarized in Table 2.1.