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

Social Web and Health Research

Benefits, Limitations, and Best Practices

Springer

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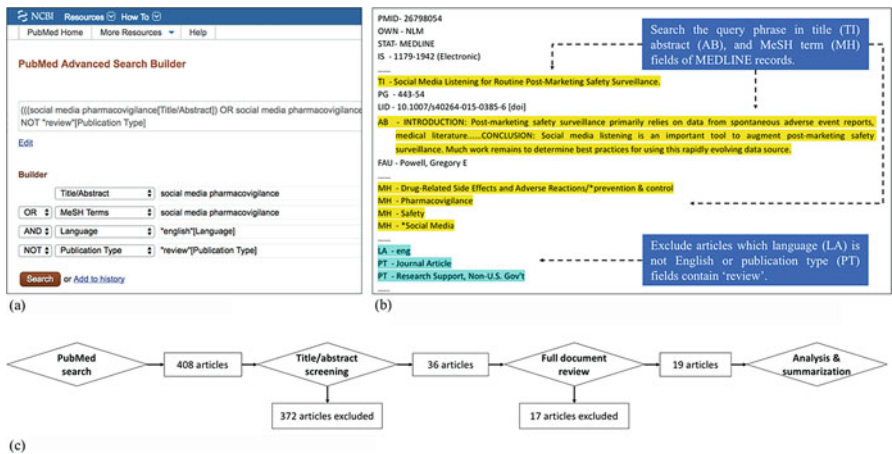
Fig. 1.1 Literature review workflow. (**a**) PubMed advanced search builder. (**b**) An abstract in MEDLINE format with different bibliographic elements. (**c**) The flow diagram of the search and selection process

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.

Table 2.1 Systematic reviews of social media-based interventions by health area

Health area	Subarea	Number of reviews	First author, year	Topic
Modifiable health behaviors	Diet/physical activity/body weight	9	Chang et al., 2013 [1]	Social media use in online weight management interventions
			Laranjo et al., 2014 [2]	Interventions using social networking sites (SNSs) to change health behaviors
			Maher et al., 2014 [3]	Review of evidence regarding the effectiveness of online social network health behavior interventions
			Williams et al., 2014 [4]	Use of social media to promote healthy diet and exercise in the general population
			Mita et al., 2016 [5]	Social media use as part of interventions to reduce risk factors for noncommunicable diseases
			Rose et al., 2017 [6]	Digital interventions for improving the diet and physical activity behaviors of adolescents
			Willis et al., 2017 [7]	Weight management interventions delivered through online social networks
			An et al., 2018 [8]	Social media-based interventions on weight-related behaviors and body weight status
			Hsu et al., 2018 [9]	Social media-based interventions in promoting positive changes in nutrition behaviors among adolescents
	Smoking	1	Naslund et al., 2017 [10]	Social media interventions for smoking cessation

(continued)

Table 2.1 (continued)

Health area	Subarea	Number of reviews	First author, year	Topic
	Vaccines and immuniza- tions	1	Odone et al., 2015 [11]	Interventions that apply new media to promote vaccination uptake and increase vaccination coverage
Mental health	Schizophrenia	2	Alvarez-Jimenez et al., 2014 [12]	Internet or mobile-based interventions for participants diagnosed with schizophrenia-spectrum disorders
			Välimäki et al., 2016 [13]	Social media interventions for supporting mental health and well-being among schizophrenic patients
Chronic disease	Cancer	1	Han et al., 2018 [14]	Interventions in cancer prevention and management
	Diabetes	2	Cotter et al., 2014 [15]	Internet interventions to support lifestyle modification for diabetes management
			Gabarron et al., 2018 [16]	Social media interventions targeting people affected with diabetes
	HIV	2	Muessig et al., 2015 [17]	Interventions to address the HIV continuum of care
			Cao et al., 2017 [18]	Interventions to promote HIV testing, linkage, adherence, and retention

2.3 The Effectiveness of Social Media-Based Health Intervention

2.3.1 Modifiable Health Behaviors

2.3.1.1 Diet, Physical Activity, and Body Weight

Obesity and overweight is a major public health problem in the United States and worldwide [19, 20]. It elevates the risks of various diseases that are leading causes of preventable death, including hypertension, heart disease, stroke, type 2 diabetes, and certain types of cancer [21]. According to the most recent data, the prevalence of obesity among US adults is worryingly high at 39.8%, affecting about 93.3 million individuals [22]. Further, obesity and overweight is a huge financial burden on the healthcare system. It is estimated that the medical expenditure attributable to obesity and overweight will reach ∼$900 billion US dollars by 2030, accounting for 16–18% of total US healthcare expenditures [23].

The key strategies for preventing obesity typically involve promoting an active, less sedentary lifestyle and a healthy diet [24]. Although these healthy behaviors have many benefits for health and well-being, a significant portion of the population are not sufficiently active or do not adhere to dietary recommendations [25–27]. Population-based interventions that target these healthy behaviors are delivered through various media, including printing media, television, the Internet, and recently, social media. In this chapter, we identified nine systematic reviews that summarized social media-based interventions aiming to promote physical activity and/or healthy diet [1–9]. Among these reviews, two focused on adolescence [6, 9] and seven did not impose any age restriction [1–5, 7, 8].

Among the seven review papers that did not impose any age restriction, six reviews conducted the database searches in or before 2015 and one review, An et al., conducted the searches in May 2017. There is an overlap of intervention studies across the six older reviews. Chang et al., Williams et al., and Mita et al. searched the major databases for diet- and exercise-related interventional studies and identified 20, 22, and 16 interventions, respectively. Among the three reviews, there are only 30 unique interventions. Lanranjo et al. and Maher et al. searched for interventions targeting modifiable health behaviors and identified an additional five unique interventions on diet and exercise. Willis et al. searched for interventions on diet and exercise that included online social networks as the main platform and identified three more unique interventions. In these 38 unique studies, the interventions typically involved components such as online diet and/or exercise programs, educational modules, and self-tracking of diet, physical activity, and/or weight, along with a social media component for providing social support. The majority of the studies used online text-based message and discussion boards as their social media component of the intervention. Few studies used a social media platform other than online discussion boards. Two studies used Facebook [28, 29] and two studies used Twitter [30, 31]. As the most recent systematic review and

the only one conducted after 2015, An et al. identified 27 social media-based diet and exercise interventions, among which many were newly conducted between 2015 and 2017. Many of these interventions used the mainstream social media sites: 17 used Facebook, four used Twitter, and one used Instagram. Findings from these systematic reviews suggest that behavioral interventions with a social media component have a moderate effect on diet and physical activity outcomes. However, the effect is not consistent across all interventions, with some studies reporting noneffective interventions. Further, most studies used social media as an integral part of the intervention. Therefore, the isolated impact from social media on diet and physical activity outcomes cannot be measured or assessed.

Two systematic reviews summarized social media-based interventions on diet and exercise targeting adolescence. Rose et al. identified a single social media-based intervention, in which Facebook was used to deliver educational content and weekly private messages to encourage exercise [32]. The investigators found the intervention had no effect on total physical activity as measured by accelerometer. In Hsu et al., the authors identified seven social media interventions for positive nutrition behavior published between 2004 and 2014. All the interventions used web-based programs, and none of the them used the mainstream social media sites. The majority of studies reported significant increases in fruit and/or vegetable intake. Overall, Hsu et al. claimed that social media intervention had a small to moderate impact on positive nutrition behaviors.

2.3.1.2   Smoking

Smoking is the leading cause of preventable death in the United States and worldwide [33]. In the US, cigarette smoking causes more than 480,000 deaths per year, responsible for roughly one in five deaths annually [34]. Worldwide, tobacco use causes about six million deaths per year [35]. Financially, smoking imposes a huge economic burden throughout the world [36]. The total economic cost of smoking is estimated to be $1436 billion worldwide in 2012 [36] and more than $300 billion a year in the United States [34, 37]. Although smoking rate has declined in the past few decades, the prevalence of smoking remains high [38]. It is estimated that 15.5% of all US adults (37.8 million individuals) are current cigarette smokers in 2016 [38]. Further, smoking prevalence differs across population subgroups. For example, smoking prevalence is significantly higher among males, American Indian/Alaska Natives, those with high school or lower education, and those living below the poverty level [38]. Therefore, it is critical to identify innovative approaches and tools to advance population level smoking cessation efforts by specifically targeting population subgroups with higher rates of smoking.

One systematic review (Naslund et al. 2017) examined the feasibility and preliminary effectiveness of social media-based interventions for smoking cessation [10]. Naslund et al. searched the major databases through July 2016 and identified seven relevant intervention studies on smoking cessation published between 2015

and 2016. Among the seven studies, three were pilot studies, four were RCTs, and the remaining study employed a quasi-experimental design. Typical intervention components included online interactive education modules, group discussions moderated by smoking cessation experts with individualized feedback, and a social media component for encouraging social support. All interventions used the mainstream social media sites, with five interventions using Facebook and another two using Twitter. In particular, two interventions used multiple social media sites: one intervention used an interactive website, Facebook, and YouTube; another intervention used WhatsApp and Facebook. In these interventions, social media were typically used to deliver educational and motivational messages, host group discussion sessions, send discussion session notifications and feedback, and host other group activities (e.g., photo-challenges). Overall, the majority of the interventions showed preliminary effectiveness in increasing interest in quitting, prompting quitting attempts, and sustaining abstinence. Although low participant retention was a potential concern, Naslund et al. concluded that social media sites were feasible and acceptable platforms for delivering smoking cessation interventions since the studies were successful in recruiting and retaining smokers online.

2.3.1.3 Vaccines and Immunizations

Vaccine-preventable diseases (VPDs) are a major cause of morbidity and mortality worldwide. Every year, 1.5 million children die from VPDs such as pneumococcal disease and Hepatitis B [39]. In adolescents and adults, VPDs include life-threatening diseases such as influenza, meningitis, and certain cancers. An extremely successful and cost-effective way of preventing VPDs is vaccination. It is estimated that vaccination prevents more than two million deaths every year worldwide [39]. However, vaccination coverage is suboptimal in certain population subgroups and for certain vaccines. One reason is the widespread misconceptions about vaccination side effects in the general population as many question the safety of vaccines, thinking vaccines can cause attention-deficit or autism [40]. The emergence of new media, including social media, has provided new ways through which people communicate and share information about vaccination for education purposes. Social media's ability to reach a large audience quickly has made it an ideal tool for delivering intervention aiming to improve vaccination coverage.

One systematic review (Odone et al. 2017) examined the effectiveness of interventions that apply new media (i.e., smartphone and internet-based mass communication tools) to improve vaccine uptake and coverage [11]. Odone et al. searched the electronic databases Medline and Embase for intervention studies, published between January 1999 and September 2013, that adopted the following new media: text messaging, smartphone applications, email communications, social networks and portals such as Facebook, Twitter, and YouTube, websites, and blogs. They considered interventions targeting vaccinations universally recommended for children, adolescents, and adults, including diphtheria, tetanus, pertus-

sis, poliomyelitis, hepatitis B, measles, mumps, rubella, Haemophilus influenzae b (Hib), varicella, pneumococcal vaccine, meningococcal vaccine, papillomavirus (HPV), and seasonal influenza vaccine. The authors identified 19 studies for review, in which 16 were published between 2010 and 2013. Seven studies were RCTs and five were nonrandomized trials.

Seven of the 19 studies reported findings on the use of internet-based, including social media-based interventions, to improve immunization coverage. These interventions typically included education modules and reminder/recall systems delivered through personalized portals, websites, and mainstream social media such as Facebook and YouTube. Only one study assessed vaccination uptake as the primary outcome. In this particular RCT, the investigators examined the efficacy of a personalized web-based portal on influenza vaccination uptake. The portal provided personal health records, social forums, and messaging tools that allowed consumers to interact with each other and with healthcare professionals. It was reported that participants with access to the portal were more likely than those with no access to receive an influenza vaccine. Other studies assessed perceived vaccine efficacy and safety, and willingness to get vaccinated as primary outcomes. These social media-based interventions in general increased individuals' willingness to get vaccinated.

2.3.2 Mental Health

2.3.2.1 Schizophrenia

Schizophrenia is a chronic and severe mental illness that has disabling symptoms, including hallucinations, delusions, thought and movement disorders, and negative symptoms [41]. Current schizophrenia treatments typically include pharmacotherapy, psychotherapy, and family psychoeducational interventions that target relapse prevention, symptom management, and functional recovery. It has been shown that psychoeducational interventions are effective in managing schizophrenia beyond pharmacotherapy alone [42]. However, traditional psychoeducational interventions have extremely low penetration rates (<10%) among schizophrenic patients that limit their use [43]. Common barriers for the low poor penetration rate include the high cost associated with intervention delivery and the stigma associated with mental health treatment. On the other hand, web-based psychoeducational interventions can overcome these barriers by lowering intervention cost and minimizing stigma. These online interventions have been shown to be effective among individuals diagnosed with schizophrenia [44]. It has become popular to use online tools, including social media, for delivering psychoeducation therapy.

Two systematic reviews (Alvarez-Jimenez et al. 2014; Välimäki et al. 2016) evaluated the effectiveness of social media-based interventions among individuals diagnosed with schizophrenia [12, 13]. Alvarez-Jimenez et al. systematically analyzed the evidence on the acceptability, feasibility, safety, and benefits of Internet and mobile-based interventions for supporting psychosis treatment among

individuals with schizophrenia. The investigators searched the major databases through August 2013 for Internet or mobile-based interventions conducted among individuals diagnosed with schizophrenia-spectrum disorders. A total of 12 studies, published between 2005 and 2013, were identified. Three out of the 12 studies included a social media component in their interventions. Välimäki et al. assessed the effects of social media-based interventions for supporting mental health and well-being among individuals diagnosed with schizophrenia-spectrum disorders. Ten major databases were searched through June 2015 for social media-based RCTs. Two trials, published in 2010 and 2011, were identified.

Between the two systematic reviews, we found four unique interventions with a social media component, including one pilot study, one quasi-experimental study, and two RCTs. The quasi-experimental study used a web-based family psychoeducation intervention that had a discussion board and real-time group chat sessions [45]. Although the participants reported high levels of satisfaction, the investigators found the intervention had little impact on the schizophrenic patients' clinical status or relatives' distress. Among the two RCTs, one employed a social media intervention using a peer support Listserv or bulletin board. Results showed that, compared to the control group, the intervention group reported improved symptoms and quality of life, but lower social support and less effective self-management at follow-up. The other RCT employed a web-based intervention with a family psychoeducation module (e.g., coping strategies, promotion of self-efficacy) and a moderated supporter and peer discussion forums. It was reported that the intervention group had improved stress level, but lowered perceived social support at follow-up, compared to the control groups. Overall, results from these interventions showed that social media use was generally less effective than the standard care (i.e., control) group among individuals diagnosed with schizophrenia.

2.3.3 Chronic Disease

2.3.3.1 Cancer

Cancer is the second leading cause of death in the United States and worldwide [46, 47]. Despite great progress in cancer prevention and management, it is estimated that approximately 18.1 million new cancer cases (1.7 million in the United States) will be diagnosed and 9.6 million individuals (0.6 million in the United States) will die from cancer in 2018 [46, 47]. In the United States, there are more than 15.5 million cancer survivors [47], many of whom experience persisting symptoms such as pain, fatigue, anxiety, and depression. To target populations at higher risk of cancer and cancer survivors for intervention, the use of innovative technology and tools, including social media, is needed to deliver cancer prevention and management interventions that are of high quality and cost-effective.

One systematic review (Han et al. 2018) summarized and evaluated intervention studies using social media for cancer prevention and control [14]. Han et al.

searched the major databases with cancer-related keywords, "cancer," "prevention," "management," and "oncology," and identified 18 studies published between 2011 and 2016. These studies included six RCTs, nine pilot studies with no control groups, and three survey studies with no interventions. Among the intervention studies, six targeted all cancer types, five targeted breast cancer, and one study each targeted pediatric, gynecological, skin, and colorectal cancers. The majority of the interventions used the mainstream social media sites. Facebook was the most frequently used social media either by itself or with other social media sites in 11 interventions. Twitter, YouTube, and blogs were used in 5, 6, and 7 interventions, respectively. Further, six interventions used more than one social media site. For example, Lauckner et al. compared the effects of Facebook, YouTube, Twitter, and blogs for delivering a cancer risk reduction message [48]. The primary goal of the social media-based interventions was to provide overall cancer-related knowledge and social support, a goal shared by 11 interventions.

Overall, evidence suggests that social media-based interventions can improve general cancer-related knowledge. Three studies delivered cancer prevention education through social media and showed a significant improvement in cancer knowledge and skills. Lauckner et al. suggested that YouTube might be the most effective in delivering educational messages. Only one study showed the intervention did not have a statistically significant impact on cancer knowledge and healthy lifestyles [49]. Among cancer survivors, a few studies showed that social media-based interventions could increase knowledge about cancer survivorship and decrease psychological distress, while others showed the interventions had no effect on these outcomes. In the studies included in Han et al., we found that social media interventions had no effect on quality of life among cancer survivors.

2.3.3.2 Diabetes Management

Diabetes affects more than 30 million individuals in the United States and over 422 million individuals worldwide [50, 51]. As the seventh leading cause of death, it is estimated that diabetes is responsible for more than 250 thousand deaths and cost $327 billion (total costs of diagnosed diabetes) per year in the United States. Diabetes can lead to complications, and thus reduce quality of life and increase the risk of premature death. To manage diabetes, especially among those with type 2 diabetes, lifestyle modification and behavior changes are needed to improve glycemic control and reduce complications. It is important to develop and implement interventions that aim to educate diabetic patients and their families about diabetes self-management and healthy lifestyle and behaviors. However, many diabetic patients have failed to manage their diabetes and achieve the goals of glycemic control and complication reduction. Designing diabetes management interventions that are effective in the real world settings is critical, and social media has become a popular platform for delivering these interventions.

Two systematic reviews (Cotter et al. 2014; Gabarron et al. 2018) described the current evidence on the use of social media in interventions for diabetes management among individuals affected with diabetes [15, 16]. Cotter et al. searched the major databases through January 2013 for Internet-based interventions. The diabetes-related search terms included "diabetes management" and "diabetes control." They identified nine interventions published between 2000 and 2012, including eight RCTs and one quasi-experimental study. Gabarron et al. searched the databases through February 2018 for interventions that included a social media component using keyword "diabetes" in combination with social media-related keywords. They identified 20 studies published between 2000 and 2017, including 16 RCTs and one quasi-experimental study. The majority of the interventions were published after 2012.

Between the two systematic reviews, 23 unique interventions included a social media component. The majority of the interventions were web-based interventions designed to promote diabetes education and healthy behaviors, such as being active, healthy eating, and glucose monitoring.

Although a few studies used social media as the main intervention platform, social media was typically used as a supporting tool for reinforcing regular visits of the main website and providing social support among patients. Cotter et al. reported that message boards and discussion forums were the most common types of social media. In contrast, Gabarron et al. included newer interventions and found that many interventions considered mainstream social media sites such as Facebook and Skype.

The primary outcomes of these social media interventions typically included diabetes knowledge and self-efficacy, behavior outcomes (physical activity, dietary behavior, medication adherence), and clinical outcomes (Hemoglobin A1C). It was shown that social media interventions were generally effective in increasing diabetes knowledge among individuals with diabetes. However, findings were mixed regarding healthy behaviors. Some studies reported improved physical activity, healthy eating, and medication adherence, while some found the interventions had no effect on these outcomes. The effect of social media intervention on Hemoglobin A1C is also mixed, with only a subset of the interventions showing decreased Hemoglobin A1C level at follow-up.

2.3.3.3   Human Immunodeficiency Virus (HIV)

Despite the global HIV control effort, it is estimated that approximately 36.9 million people live with HIV worldwide [52]. In 2017, about 1.8 million people became newly infected with HIV and 940 thousand people died from HIV-related causes. Some populations are disproportionally affected by HIV, such as men who have sex with men (MSM), those who inject drugs, sex workers, and transgenders [53]. HIV interventions targeting these high-risk populations face unique barriers, including persistent stigma, discrimination, and low-risk perception [54–56]. Therefore, innovative way of reaching these populations are needed to deliver HIV interventions

on HIV testing, linkage to care and therapy, and retention. In the past decade, social media sites have been gradually adopted to deliver HIV interventions, especially among the high-risk populations.

Two systematic reviews (Muessig et al. 2015; Cao et al. 2017) examined the effectiveness of social media-based interventions in promoting HIV testing, treatment, and care among key populations [17, 18]. Muessig et al. searched the major databases, including HIV-related conference databases, between 2013 and 2014 for smartphone-, Internet-, and social media-based interventions that address the HIV testing, treatment, and care continuum. The HIV-related conferences included Conference on Retroviruses and Opportunistic Infections (CROI); International AIDS Society (IAS2013 and AIDS2014), US Conference on AIDS (USCA), STD Prevention Conference, and Youth+Tech+Health (YTH). They identified ten social media interventions. Cao et al. searched the databases, including HIV-related conference databases, through August 2016 for HIV interventions using social media. They identified 26 studies published between 2011 and 2016, among which eight were RCTs. There were 33 unique social media interventions between these two systematic reviews.

The majority of the HIV-related interventions were designed to promote primary HIV prevention, HIV testing, and linkage. Many interventions used virtual communities that offered education modules about HIV and HIV testing, HIV counseling, referral for HIV testing, and expert and/or peer support. Social media was also used by many as a platform for identifying high-risk populations and delivering massages and HIV self-testing services. For example, some studies targeted men who have sex with men (MSM) by sending personal messages or promotional banners on social media and mailing home-based HIV self-testing kits [57, 58]. Both Muessig et al. and Cao et al. reported that Facebook was the most popular social media for HIV-related interventions. Grindr, a social networking app catering to MSM, was also used by many interventions. Other social media of choice included Twitter, YouTube, WhatsApp, and sexual networking sites and apps such as Gaydar.

Social media interventions that aimed to promote HIV testing uptake were generally shown to be effective. It was also shown that HIV testing uptake was even higher for interventions that were participatory and peer-driven. Further, social media interventions that delivered HIV self-testing services to MSM were shown to be effective in promoting HIV testing, as more than half of the participants returned the test kits. In one particular study conducted in China among MSM and transgender participants, social media was used as a crowdsourcing tool for delivering an intervention in the form of a video contest for promoting HIV testing [59]. The study showed that the intervention was as effective as a promotional video designed and delivered by social marketing experts, whereas the cost of the intervention was significantly lower than that of the social marketing intervention.

2.4   Discussion and Conclusion

Findings from our review suggest that, in health interventions, social media is mostly being used to deliver education programs that aim to increase awareness and knowledge, to send reminder messages that aim to encourage participation and healthy behaviors, and to facilitate communication among key stakeholders (e.g., participants, caregiver, healthcare providers) that aims to provide social support. Social media-based interventions have a small to moderate effect in promoting modifiable health behaviors including exercise and healthy diet, smoking cessation, and vaccination. However, social media-based psychoeducation interventions do not appear to be effective among individuals with schizophrenia. Findings are mixed for social media-based interventions aiming at cancer prevention and control and diabetes management, with some studies reporting noneffective interventions. Lastly, social media-based interventions are shown to be effective in promoting HIV testing among high-risk populations.

One limitation of these intervention studies is that most of them used social media in combination with other intervention components. As a result, almost none of them was able to examine the isolated effect of social media on outcome measures. Another limitation of these interventions is that many of them lacked a theoretical framework for behavior change and therefore did not explore the underlying behavioral mechanisms. Future social media-based interventions need to overcome both methodological and practical challenges related to participant recruitment and retention, sustaining clinically meaningful outcomes and identifying underlying behavioral mechanisms.

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Chapter 3
Quantifying and Visualizing the Research Status of Social Media and Health Research Field

Xieling Chen and Tianyong Hao

Abstract This chapter presents a quantitative and visual analysis of social media and health research publications from Web of Science database during the year 2007–2017. The analysis is conducted using a bibliometric method, a social network analysis method, and a latent dirichlet allocation method to acquire the predominant subjects, journals, and countries, the collaboration relationship, and the major topics. Some interesting results are presented. For example, *Journal of Medical Internet Research* is the most influential journal. *Public, Environmental & Occupational Health* and *Health Care Sciences & Services* are the subjects with the most publications and citations, respectively. The USA is the most influential country with 1317 publications and an H-index of 53. Twenty topics are identified with potential themes as: *Sex-related event*, *Analysis on medical-related content*, *Vaccine*, *Adverse drug reactions*, *Diet and weight control*, *Smoking cessation*, *Nursing*, etc., which have received much more attention in scientific community during 2012–2017 compared with the period 2007–2011.

Keywords Social media and health research · Bibliometrics · Social network analysis · Latent Dirichlet Allocation

3.1 Introduction

Internet is becoming immensely intertwined with electronic mail counseling and social question answering [1], especially for day-to-day information-seeking among users concerning with health [2]. Health-related information is actively searched and shared through the Web and social media. This kind of online information exchange benefits users in terms of searchable content, immediate access to useful

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information, easy tracking of health information, information sharing, emotional support, and health-related decision making [3]. Many people receive crucial psychological support by the way of online communication with others, which is often unfulfilled by doctors [4]. Also, as for those with chronic diseases, online discussion is usually one of the most active activities [5]. Social media provides opportunities for people with health concerns to participate in asynchronous written interactions with those interested in the designated topic [1].

As society is increasingly becoming more connected, researchers are beginning to explore how social media can be used to study health and healthcare issues in recent years [6]. Plenty of relevant studies have emerged. For example, with the purpose of providing baseline data for Zika virus (ZIKV)-related Twitter health communication, Fu et al. [7] reported the incidence trends of ZIKV-related Twitter data and their content analysis of a cross-sectional sample. They concluded that it was critical to reach users with messages of ZIKV prevention and control. A multi-stage stratified sampling survey was carried out by Xu et al. [8] to identify the influence of WeChat on the sleep quality among undergraduate students. With a total number of 126 retrospective postings from 58 participants, Grumme and Shirley [9] investigated the use of social media sites by transplant recipients as a potential source of supporting and healing as well as the usefulness of Internet postings as a rich qualitative dataset. Two major themes, i.e., sharing overwhelming gratitude and finding sanctuary, were identified. Based on 626 English-speaking adults with mild to moderate depression recruited through Web-based advertisements, Arean et al. [10] compared the use patterns and clinical outcomes among three different self-guided mobile apps for depression across the USA. Content analysis was applied by Huang et al. [11] to examine the relationship between Facebook messaging strategies employed by 110 HIV/AIDS nonprofit organizations and audience reactions including liking, sharing, and commenting. They reported that informational messages were often used by the organizations as one-way communication with their audience instead of dialogic interactions. Their findings had the potential to provide guidance to HIV/AIDS organizations in the development of effective social media communication strategies. With 99,693 suicide-related documents retrieved from 2.35 billion posts on 163 social media websites in South Korea, Song et al. [12] explored online search activity of suicide-related words in South Korean adolescents using data mining methods. They found that academic pressure contributed the most to Korean adolescents' suicide risk. Duh et al. [13] identified clinically important adverse events related with atorvastatin and sibutramine by comparing their patterns in social media postings with the FDA Adverse Event Reporting System (FAERS) and used Granger causality tests to assess the usefulness of social media postings in forecasting FAERS reports. They concluded that social media adverse events reporters were younger and focused more on less-serious and fewer types of the events. Consequently, the social media and health research field has attracted great interest of the scientific community in the past decade, witnessing from the increasing number of publications from Web of Science (WoS), i.e., from 5 in 2007 to 738 in 2017. The great amount of publications reporting research findings reflect the development of the field frontier to a certain extent.

Bibliometric analysis is the use of statistical methods on evaluating scholarly publications from an objective and quantitative perspective within a certain field. It has been widely applied to measure quality and productivity of academic output in various fields [14–18]. The use of bibliometric can help organize information in a specific thematic field, determine the impact of research funding, evaluate scientific developments in knowledge of a specific subject, compare research performance across different affiliations, identify emerging areas of research focus, etc. To our knowledge, there is no priori study examining the research status of this field. Thus, the aim of this chapter is to carry out a quantitative and visual analysis of publications on social media and health research. By retrieving relevant publications from WoS database from 2007 to 2017, predominant subjects, journals, and countries, collaboration relationship, as well as major research topics are discovered with the techniques of bibliometric method, social network analysis methods, and latent dirichlet allocation method. This work can potentially assist relevant researchers in terms of: (1) understanding the development status of the research field; (2) finding influential subjects, journals, and countries in the field; and (3) recognizing hot research topics or tracing a certain topic.

This chapter is organized as follows: Sect. 3.2 introduces the dataset and methodology. In Sect. 3.3, the predominant subjects and journals are presented. Section 3.4 presents the productive countries. In Sect. 3.5, the results of collaboration relationship analysis are reported. Section 3.6 shows topic distribution and evolution. Finally, some conclusions are drawn in Sect. 3.7.

3.2 Dataset and Methodology

WoS is an online subscription-based scientific citation indexing service that provides a comprehensive citation search. It gives access to multiple databases that reference cross-disciplinary research, which allows for in-depth exploration of specialized subfields within an academic or scientific discipline. It has been widely applied for bibliometric analysis with high normativity and authority. Therefore, we used the WoS Core Collection and retrieved relevant research publications with a list of elaborately designed terms including Pharmacology, Venereology, Optometry, etc., which were extended by using Medical Subject Headings 2017.[1] We further used the following search criteria: (1) "Science citation index expanded (SCI-E)" and "Social Sciences Citation Index (SSCI)" as citation indexes to ensure publication quality; (2) "2007" to "2017" as publication period; and (3) "Article" as publication type.

The citations of the publications were also obtained. Key elements including title, published year, journal, subject category, author address information, citations, funding, author keywords, keywords-plus, and abstract were extracted using a

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[1]https://meshb-prev.nlm.nih.gov/search

Table 3.1 The statistical characteristics of the retrieved publications

Characteristics	Statistics
Total/annual number of pub.	2986/271
Total/annual number of citations	22,916/7.69
Number of pub. with author address information	2278
Number of pub. with abstract	2267
Number of pub. with author keywords or keywords-plus	2904
Number of unique journals	1123
Number of unique total countries (or regions)/affiliations	87/2784
Number of unique first authors/last authors/total authors	2631/2606/10,750
Average number/standard deviation of author keywords or keywords-plus	9.41/4.55
Average number/standard deviation of words in title	13.58/4.70
Average number/standard deviation of character in title	97.49/33.39
Average number/standard deviation of words in abstract	227.69/88.45
Average number/standard deviation of character in abstract	1575.97/612.44

Python program. Due to the existence of duplicate records, manual review was conducted based on title, author, journal, and published year. Two thousand nine hundred and eighty six publication documents were finally retained for analysis. Table 3.1 presents the characteristics of the publications.

The number and annual citations of the publications by year were calculated and reported in Fig. 3.1. The results show that the research of social media and health field exhibits an overall upward trend. We then built a regression model for publication number with *year/1000* and *(year/1000)²* as two independent variables. The fitted model is expressed as: $y = 8412587x^2 - 33770670x + 33891410$ with the adjusted goodness-of-fit $\overline{R^2}$ reaching up to 0.98, indicating that the two variables explain about 98% of the variation in publication number. With this regression model, the future research output can be predicted. For example, the predicted number of publications in 2018 is about 980.

The data was then analyzed at the following aspects: (1) discovery of predominant subjects, journals, and countries using a bibliometric method; (2) collaboration relationship exploration using a social network analysis method; and (3) topic distribution and evolution using a latent dirichlet allocation model. The overall analysis procedure is described in Fig. 3.2.

3.3 Subjects and Journals Analysis

In the analysis of subject distribution, the WoS subject category was utilized. Due to the interdisciplinary nature of research, a publication might belong to multiple subjects. For the publications, 176 subjects are identified. Figure 3.3 reveals the top ten subjects by the quantity of publications and citations, respectively.
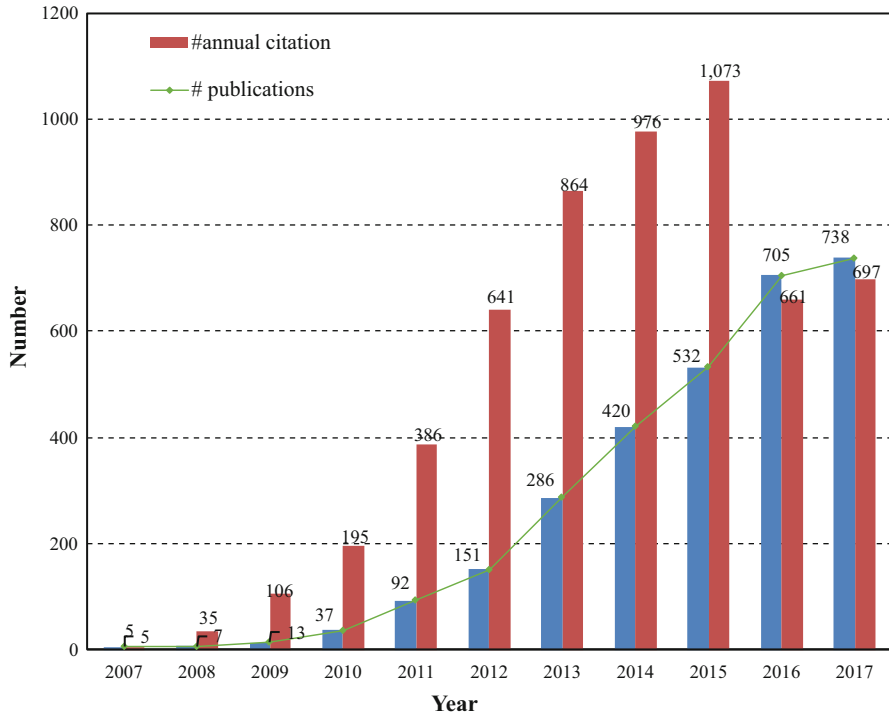
Fig. 3.1 The number and citations of publications by year (the annual citations are calculated using formula: *total citations of the publication/(2017 + 1-published year)*)
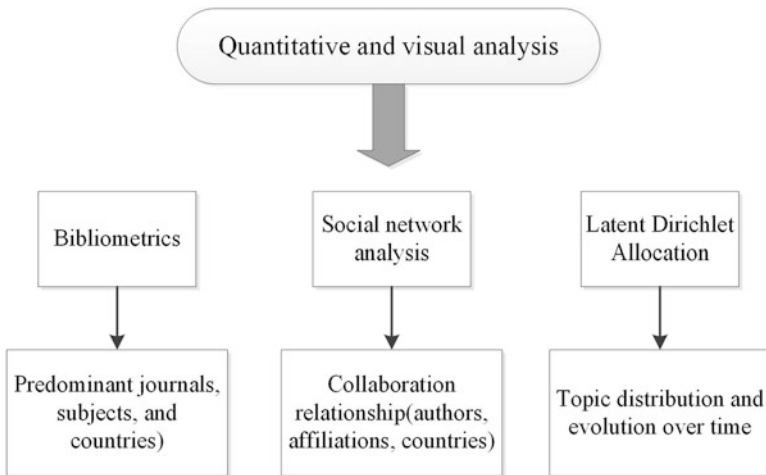
Fig. 3.2 The overall framework of the quantitative and visual analysis

Publications

Public, Environmental &
Occupational Health, 9.53%

Health Care Sciences
& Services, 9.00%

Medical Informatics,
7.18%

Nursing, 3.26%

Communication,
3.07%

Medicine, General &
Internal, 2.77%

Health Policy &
Services, 2.62%

Psychiatry, 2.62%

Psychology,
Multidisciplinary, 2.60%

Information Science &
Library Science, 2.46%

Others,
54.89%

Citations

Health Care Sciences
& Services, 12.15%

Public, Environmental &
Occupational Health, 9.24%

Medical Informatics,
9.05%

Medicine, General &
Internal, 3.71%

Communication,
3.69%

Multidisciplinary
Sciences, 3.40%

Education, Scientific
Disciplines, 2.43%

Psychiatry, 2.37%

Psychology,
Multidisciplinary, 2.28%

Health Policy & Services, 2.17%

Others
49.5%

Fig. 3.3 Top ten subjects ranked by publication and citation numbers

The result illustrates that *Public, Environmental & Occupational Health* (9.53% publications, 9.24% citations) is the subject with the most publications while *Health Care Sciences & Services* (9.00% publications, 12.15% citations) receives the most citations. *Medical informatics* is also an influential subject with 7.18%

publications and 9.05% citations. The three subjects thus contribute comparatively a lot to the development of the research field. The top ten most productive subjects account for 45.11% of the total publications, and the top ten most cited subjects contribute 50.94% of the total citations. This illustrates a diversified distribution of the publications and a broad interest from multiple research perspectives.

Research output in the field has been published on a wide range of journals. In this study, the publications are published on a total of 1123 journals. Eighteen most influential (H-index ≥6) journals are listed in Table 3.2. Of the journals, 11 are from the USA, 4 from England, 1 from Canada, 1 from Netherlands, and 1 from Switzerland. The 18 journals altogether account for 23.31% of all the publications and contribute to 33.63% of the total citations. The 18 journals account for 34.47% and 32.58% of publications with citations ≥20 and citations ≥10, respectively.

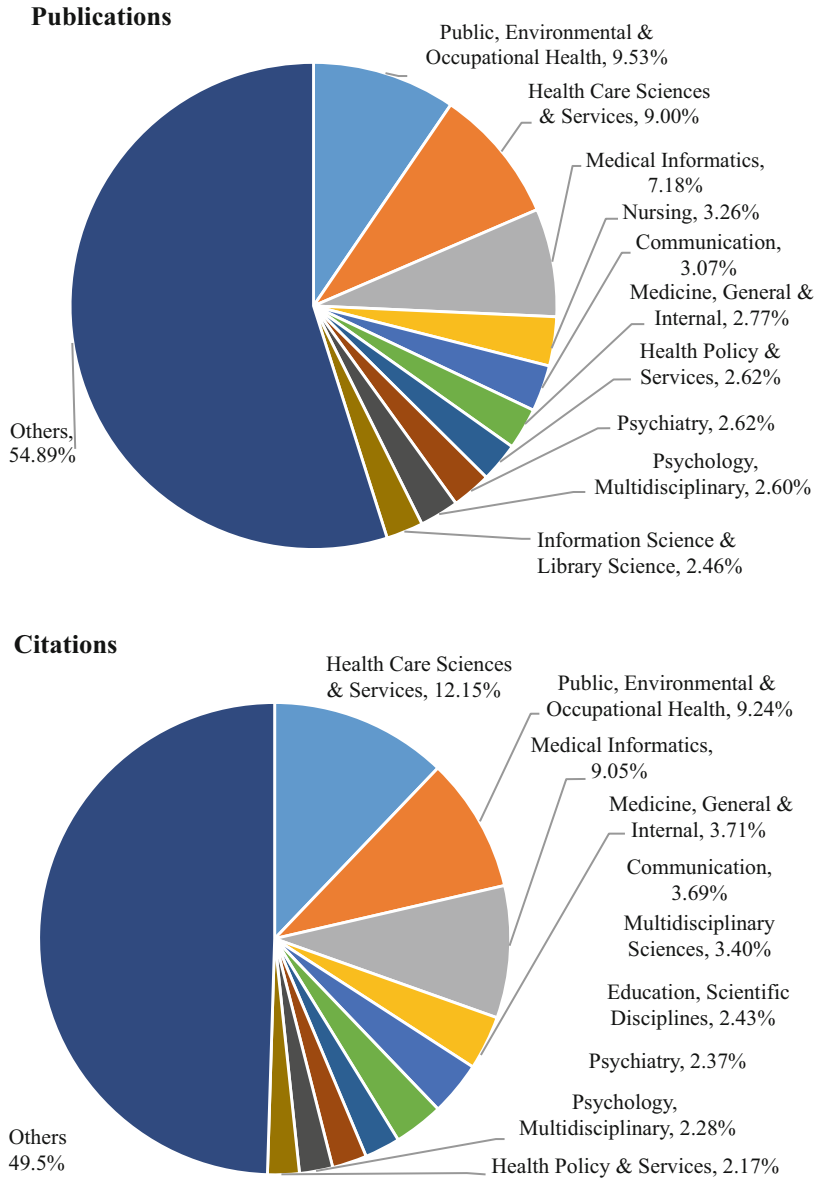According to the metrics of H-index and the percentage of publications, *Journal of Medical Internet Research* is the most influential journal of this field. This is in line with the most influential journals in the subject category of medical informatics by google scholar.[2] The other top ranked influential journals include *PLoS One*, *Computers in Human Behavior*, *BMC Public Health*, and *American Journal of Pharmaceutical Education*.

3.4   Productive Countries Analysis

Table 3.3 depicts the top 19 most productive countries with the number of publications ≥19. Among the countries, 13 of them are from Europe, 3 from Asia, 2 from North America, and 1 from Oceania. Taking five indicators including TP, TC, ACP, H, and T100 into account, the USA, Australia, and England can be regarded as the most productive and influential countries. The number of citations that the USA has received is more than six times of that received by Australia, and the USA has published more than half of the 2239 publications. It is worth mentioning that Norway has the highest ACP. With respect to international collaboration, the number of publications independently published by a single country is 1825 (81.51%). As for the 19 countries, the international collaboration rate is relatively high, most of which are around or above 50% except for the USA. The USA is the closest collaborator for 10 countries. The ACP of collaboration is much higher than that of non-collaboration for most of the countries, indicating that international collaboration could improve the quality of publications. However, the conclusion could not be supported by the USA, which might be explained by the fact that the USA possesses the strongest research strength and its collaboration with other countries could improve their publication quality, but might not for itself.

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[2]https://scholar.google.com/citations?view_op=top_venues&hl=en&vq=med_medicalinformatics

Table 3.2 The most influential journals in the social media and health research field

R	Journal	H	TC	TP (%)	ACP	≥20	≥10	IF	T100	C
1	Journal of Medical Internet Research	26	2963	240 (8.04)	12.35	38	76	4.671	14	CA
2	PLoS One	16	1178	77 (2.58)	15.30	12	20	2.766	5	USA
3	Computers in Human Behavior	11	408	69 (2.31)	5.91	2	11	3.536	2	USA
4	BMC Public Health	9	330	36 (1.21)	9.17	3	9	2.420	2	UK
5	American Journal of Pharmaceutical Education	8	207	16 (0.54)	12.94	3	7	1.495	1	USA
6	American Journal of Preventive Medicine	7	346	12 (0.40)	28.83	5	6	4.127	3	USA
6	BMJ Open	7	150	44 (1.47)	3.41	1	4	2.413	0	UK
6	Health Communication	7	128	30 (1.00)	4.27	1	5	1.710	0	USA
6	Journal of Adolescent Health	7	202	21 (0.70)	9.62	5	6	4.098	1	USA
6	Journal of Health Communication	7	235	39 (1.31)	6.03	3	6	1.648	1	USA
11	American Journal of Public Health	6	245	16 (0.54)	15.31	4	6	4.380	1	USA
11	Collegian	6	78	9 (0.30)	8.67	0	3	1.153	0	NL
11	Journal of Biomedical Informatics	6	126	19 (0.64)	6.63	2	4	2.882	0	USA
11	Journal of the American College of Radiology	6	102	16 (0.54)	6.38	1	4	3.383	0	USA
11	Journal of the American Medical Informatics Association	6	234	15 (0.50)	15.60	4	6	4.270	2	UK
11	Pediatrics	6	461	9 (0.30)	51.22	2	5	5.515	2	USA
11	Translational Behavioral Medicine	6	106	14 (0.47)	7.57	2	4	2.521	0	CH
11	Vaccine	6	210	14 (0.47)	15.00	3	6	3.285	2	UK

Abbreviations: *R* rank; *H* H-index; *TC* total citations; *TP* (%) number and percentage of publications; *ACP* average citations per publication, calculated as TC/TP; ≥20, ≥10, number of publications with citations ≥20 and ≥10; *IF* impact factor 2017 from Journal Citation Reports (JCR); *T100* number of publications in the top 100 highly cited publications; *C* country of the journal (*CA* Canada; *USA* the USA; *UK* England; *NL* Netherlands; *CH* Switzerland)

Table 3.3 The most productive countries in health and social media research field

R	C	TP	TC	ACP	H	T100	Publications with single-country			Internationally collaborated publications			
							TP (%)	TC	ACP	TP (%)	TC	ACP	TFC (n)
1	The USA	1317	15, 131	11	53	75	83.22	12, 759	11.64	16.78	2372	10.73	Australia (47)
2	Australia	236	2485	11	24	13	60.59	1260	8.81	39.41	1225	13.17	the USA (47)
3	England	229	2472	11	24	12	48.91	753	6.72	51.09	1719	14.69	the USA (39)
4	Canada	178	1653	9	19	6	58.43	958	9.21	41.57	695	9.39	the USA (41)
5	China	80	476	6	13	1	38.75	118	3.81	61.25	358	7.31	the USA (37)
6	Netherlands	70	776	11	15	5	52.86	343	9.27	47.14	433	13.12	England (15)
7	Germany	55	711	13	13	7	47.27	178	6.85	52.73	533	18.38	the USA (14)
8	Spain	45	337	7	8	3	48.89	102	4.64	51.11	235	10.22	the USA (8)
9	South Korea	40	201	5	6	1	45.00	38	2.11	55.00	163	7.41	the USA (18)
10	Italy	36	506	14	12	3	36.11	77	5.92	63.89	429	18.65	England (13)
11	Switzerland	33	247	6	7	1	12.12	11	2.75	87.88	236	8.14	England (9)
12	Sweden	32	298	9	7	2	31.25	73	7.30	68.75	225	10.23	the USA (12)
13	Scotland	31	365	12	10	2	35.48	93	8.45	64.52	272	13.60	England (13)
14	Belgium	29	344	12	10	3	27.59	32	4.00	72.41	312	14.86	England (12)
15	Ireland	29	281	10	9	1	55.17	135	8.44	44.83	146	11.23	England (8)
16	France	28	219	8	8	1	42.86	44	3.67	57.14	175	10.94	the USA (9)
17	Finland	23	214	9	6	2	43.48	29	2.90	56.52	185	14.23	England (5)
18	Israel	19	154	8	5	2	47.37	72	8.00	52.63	82	8.20	the USA (8)
19	Norway	19	371	20	10	3	10.53	32	16.00	89.47	339	19.94	Italy/England (5)

Abbreviations are the same as Table 3.2 except for: *TFC(n)* number of collaboration times with the closest collaborator

3.5 Collaboration Relationship Analysis

We explored the publication collaboration by year as shown in Table 3.4. The annual percentage of publications in three perspectives shows upward trends on the whole. As for coauthor publication, the percentage increased from 60% in 2007 to 92.55% in 2017 in slight fluctuation. A substantial increase can be observed from 2007 to 2009 with the percentage of co-affiliation publications up to 61.54% in 2009. Although decreasing from 2009 to 2011, the percentage of co-affiliation publications was still going up gradually thereafter and reached up to 66.53% in 2017. There was no co-country publication from 2007 to 2009 due to the very small number of publications available. The percentage of co-country publication was 13.51% in 2010, but decreased to 6.52% in 2011. And since 2011, it increased year by year and reached up to 24.93% in 2017. It is interesting to find that, for collaboration publications in all three perspectives, the percentage of citation is usually higher than that of publication, indicating the quality improvement brought by collaboration among authors, affiliations, and countries.

In order to visualize the collaboration relationship of authors, affiliations, and countries, we further constructed network diagrams using an easy-to-use package *networkD3* in R. Figure 3.4 is the network of 87 countries. Figure 3.5 shows the network of 50 affiliations with the number of publications ≥20. Figure 3.6 presents the network of 58 authors with the number of publications ≥6. In the networks, the nodes represent specific countries, affiliations, or authors, and the lines represent the collaboration relationship. The size of nodes represents the publication number of a specific author, affiliation, or country. The width of link indicates the collaboration frequency between the two countries, affiliations, or authors. One could simply click any node to view the collaboration relationship for specific countries, affiliations, or authors.

3.6 Topic Distribution and Evolution Analysis

Author keywords, keywords-plus, title, and abstract fields were jointly used for the topic distribution and evolution analysis. We applied different weights to them based on an empirical experience from former research [14], i.e., the weights for keywords extracted from author keywords and keywords-plus, title, and abstract were 0.4, 0.4, and 0.2, respectively. The term frequency-inverse document frequency (TF-IDF) was used to exclude terms with lowest importance by setting TF-IDF ≥ 0.1. Terms with TF-IDF ≥ 0.1 were then used for topic model construction. The top ten terms by TF-IDF are "Cancer," "Drug," "Men," "Video," "Sexual," "Food," "HIV," "Weight," "Smoking," and "Sex."

Through sampling, 14 different topic numbers were set as *c(2:10,15,20,50, 100,200)*. For each topic number, tenfold cross-validation was used to evaluate model performance. Perplexity criteria was used to select optimal topic number

Table 3.4 Collaborated publications by year

| Year	TP	TC	Collaborated publications			Collaborated publications' citations		
			Author (%)	Affiliation (%)	Country (%)	Author (%)	Affiliation (%)	Country (%)
2007	5	54	3 (60)	0 (0)	0 (0)	47 (87.04)	0 (0)	0 (0)
2008	7	353	4 (57.14)	2 (28.57)	0 (0)	282 (79.89)	39 (11.05)	0 (0)
2009	13	950	11 (84.62)	8 (61.54)	0 (0)	714 (75.16)	599 (63.05)	0 (0)
2010	37	1559	33 (89.19)	20 (54.05)	5 (13.51)	1463 (93.84)	1224 (78.51)	139 (8.92)
2011	92	2702	71 (77.17)	45 (48.91)	6 (6.52)	2233 (82.64)	1343 (49.70)	94 (3.48)
2012	151	3843	122 (80.79)	88 (58.28)	23 (15.23)	3329 (86.63)	2029 (52.80)	933 (24.28)
2013	286	4322	255 (89.16)	165 (57.69)	44 (15.38)	3693 (85.45)	2364 (54.70)	791 (18.30)
2014	420	3904	370 (88.10)	251 (59.76)	69 (16.43)	3646 (93.39)	2516 (64.45)	765 (19.60)
2015	532	3218	483 (90.79)	339 (63.72)	109 (20.49)	3066 (95.28)	2250 (69.92)	641 (19.92)
2016	705	1321	639 (90.64)	451 (63.97)	147 (20.85)	1244 (94.17)	953 (72.14)	408 (30.89)
2017	738	697	683 (92.55)	491 (66.53)	184 (24.93)	634 (90.96)	483 (69.30)	166 (23.82)
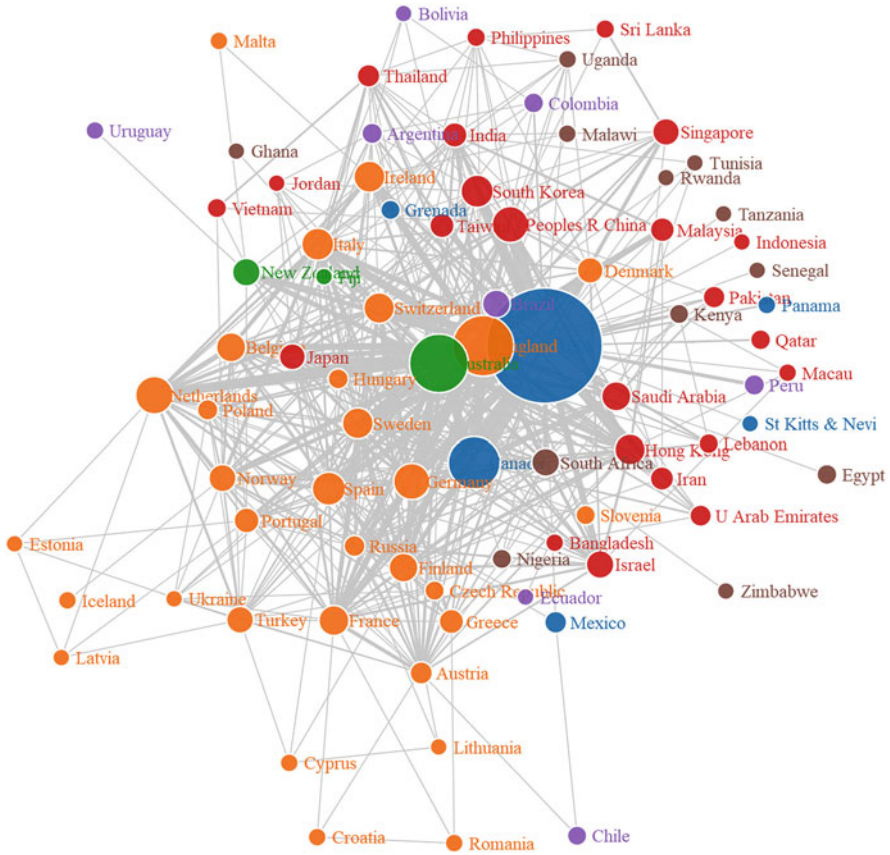
Fig. 3.4 The network of 87 countries (node colors represent different continents, i.e., orange for Europe, red for Asia, brown for Africa, blue for North America, purple for South America, and green for Oceania). The network can be accessed via the link. http://www.zhukun.org/haoty/resources.asp?id=B_SMH_country

[19]. The perplexities of the test data for the models fitted using Gibbs sampling with a burn-in of 1000 iterations are shown at the right of Fig. 3.7, which suggests that about 20 is the optimal topic number.

α for Gibbs sampling was initialized as the mean value of α values for model fitting using VEM with the optimal topic number. With the optimal topic number as 20 and the initial α value as 0.0227, we estimated the latent dirichlet allocation model using Gibbs sampling with a burn-in of 1000 iterations and recorded every100th iterations for 1000 iterations. Only the best model with respect to the log-likelihood $\log(p(w|z))$ observed during Gibbs sampling was returned. The 20 topics detected by Gibbs sampling with their ten selected most likely terms are listed in Table 3.5.
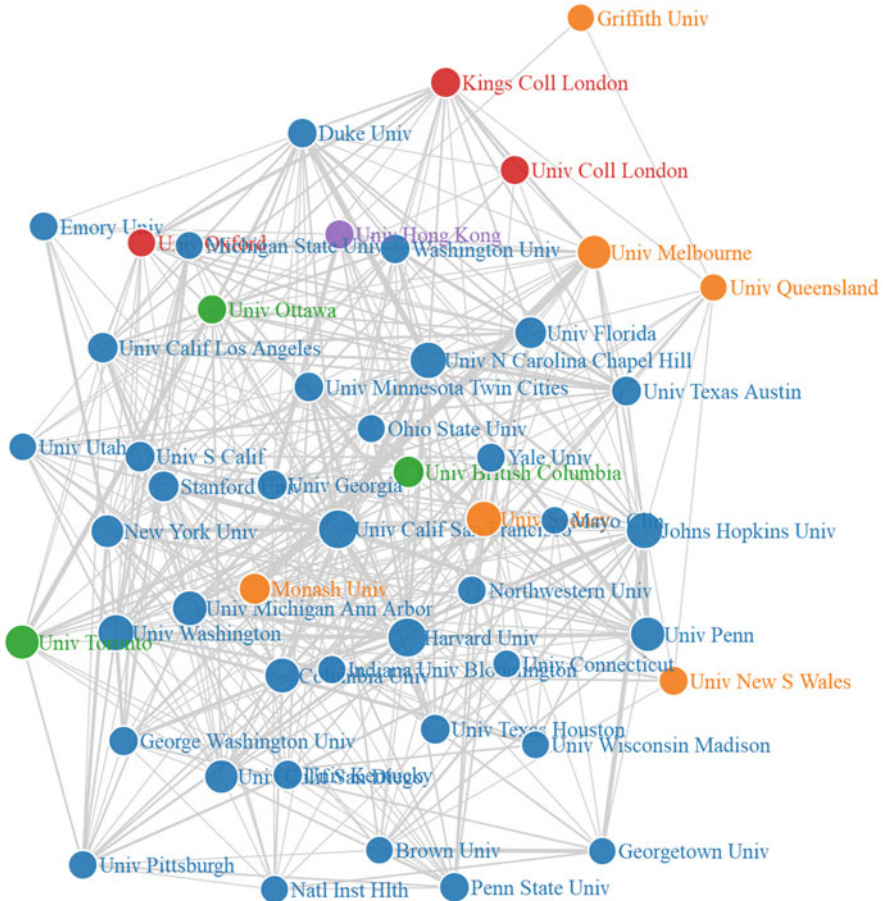
Fig. 3.5 The network of 50 affiliations with publications ≥20 (node colors represent different countries, i.e., blue for the USA, orange for Australia, green for Canada, red for England, and purple for Hong Kong). The network can be accessed via the link. http://www.zhukun.org/haoty/resources.asp?id=B_SMH_affiliation

We gave the specific meaning of each topic by analyzing the semantics of the representative terms and reviewing the relevant abstract content. The 20 potential themes are given as: *Sex-related event*, *Analysis on medical-related content*, *Vaccine*, *Adverse drug reactions*, *Diet and weight control*, *Smoking cessation*, *Nursing*, etc. These themes are easy to understand and the reprehensive terms of each theme are much related to the theme. We then explored the contribution of the identified topics through annual per-document topic distribution as shown in Fig. 3.8. Each publication was assigned to the most likely topic with the highest posterior probability. From Fig. 3.8, we find that compared with the period 2007–2011, the
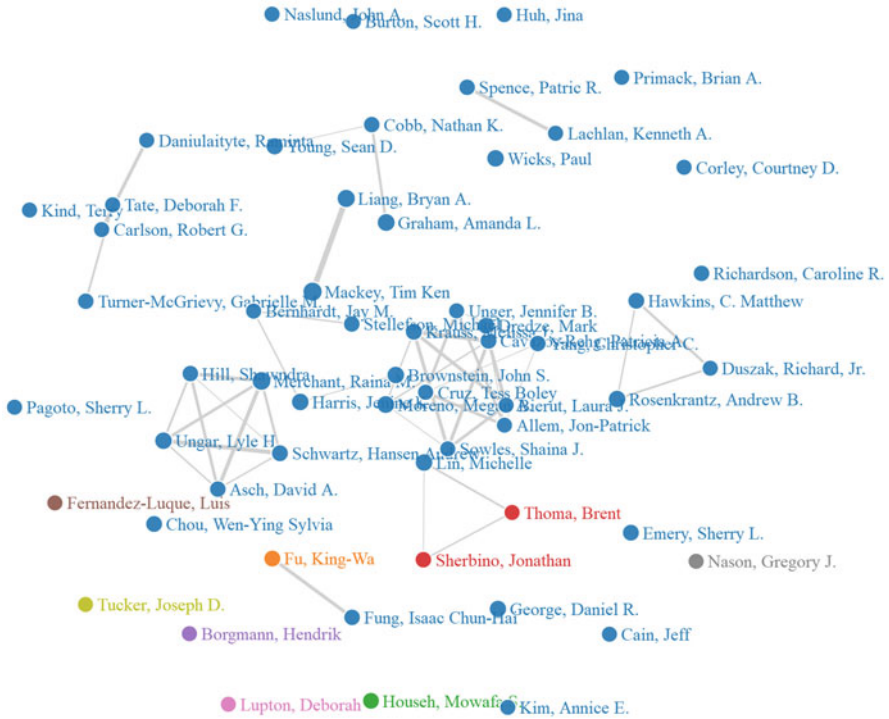
Fig. 3.6 The network of 58 authors with publications ≥6 (node colors represent different countries, e.g., blue for the USA, red for Canada, and pink for Australia). The network can be accessed via the link. http://www.zhukun.org/haoty/resources.asp?id=B_SMH_author

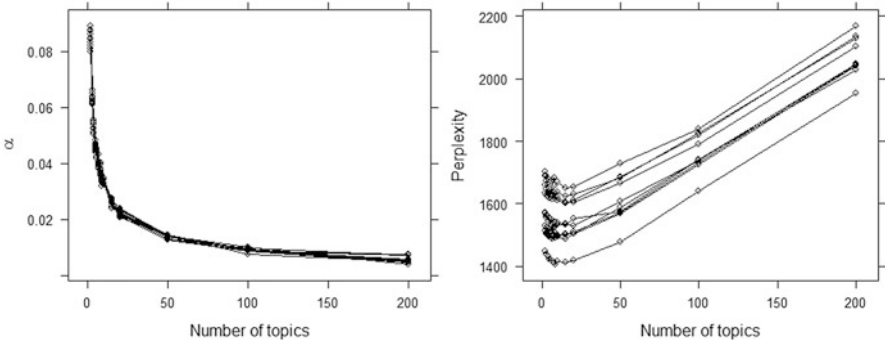

Fig. 3.7 Left: estimated α value for the models fitted using VEM. Right: perplexities of the test data for the models fitted using Gibbs sampling. Each line corresponds to one of the folds in the tenfold cross-validation

increase in volume is very significant for all the topics during 2012–2017, indicating the much attention they have received in the scientific community recently.

Table 3.5 20 topics detected by Gibbs sampling with their selected ten most likely terms

| Potential theme	Top high frequency terms
Sex event	Men; Sexual; Sex; Gay; Transmitted; Latino; Sexually; Transgender; HIV/AIDS; Condom
Medical content analysis	Cancer; Breast; Prostate; Colorectal; Spectrum; Testicular; Autism; Genetic; Ovarian; Lung;
Vaccine	Vaccine; Influenza; Vaccination; Papillomavirus; Immunization; Urology; Flu; Infectious; H1N1; Pandemic
Adverse drug reactions	Drug; Adverse; Pain; Pharmacovigilance; Cardiovascular; Asthma; Hypertension; Corpus; Acupuncture; Inhibitor
Diet and weight control	Food; Obesity; Occupational; Eating; Weight; Dietary; Foodborne; Fruit; Vegetable; Cooking
Smoking cessation	Smoking; Tobacco; Cessation; Smoker; E-cigarette; Seizure; Nicotine; Waterpipe; Supervision; Hookah
Nursing	Nurse; Nursing; Dialysis; Leadership; Interprofessional; Abortion; Midwife; Graduate; Faculty; Workplace
Surgery	Professionalism; Surgery; Faculty; Surgeon; Pediatric; Director; Graduate; Surgical; Trainee; Plastic
Parturition event	Pregnancy; Mother; Infant; Birth; Movement; Feeding; Breastfeeding; Postpartum; Milk; Childbirth
Crisis	Emergency; Crisis; Outbreak; Ebola; Disaster; Preparedness; Infectious; Disability; Resilience; Injury
Telemedicine	App; Mhealth; Addiction; Fitness; Veteran; Sensor; Stem; Podcast; Pedometer; Telemedicine
Heart disease	Video; Heart; Cardiac; Congenital; Anatomy; Resuscitation; Fitspiration; Defibrillator; Rehabilitation; Cardiopulmonary
Diabetes	Diabetes; Similarity; Mellitus; Resistance; Competency; Antibiotic; Respiratory; Ehnic; Self-efficacy; E-technology
Alcohol	Drug; Alcohol; Drinking; Sleep; Prescription; Abuse; Direct-to-consumer; Sale; Illicit; Binge
Psychosis	Suicide; Marijuana; Stigma; Recovery; Schizophrenia; Inflammatory; Cannabis; Injury; Psychosis; Self-harm
Drug	Pharmacy; Syndrome; Pharmacist; Telehealth; Acquired; Deficiency; Immune; Wikipedia; Preceptor
Organ donation	China; Donation; Microblog; Organ; Donor; Recipient; Transplantation; Transplant; Registration; Retrieval
Disease	Sclerosis; Stroke; Violence; Amyotrophic; Impairment; Venous; Cerebrospinal; Patientslikeme; Recovery; Disability
Psychology	Emotion; Personality; Temporal; Bullying; Victimization; Burn; Mood; Loneliness; Sentiment; Compulsive
Sports injuries	Radiology; Radiologist; Sport; Concussion; Injury; Brain; Traumatic; Mobility; Imaging; Athlete
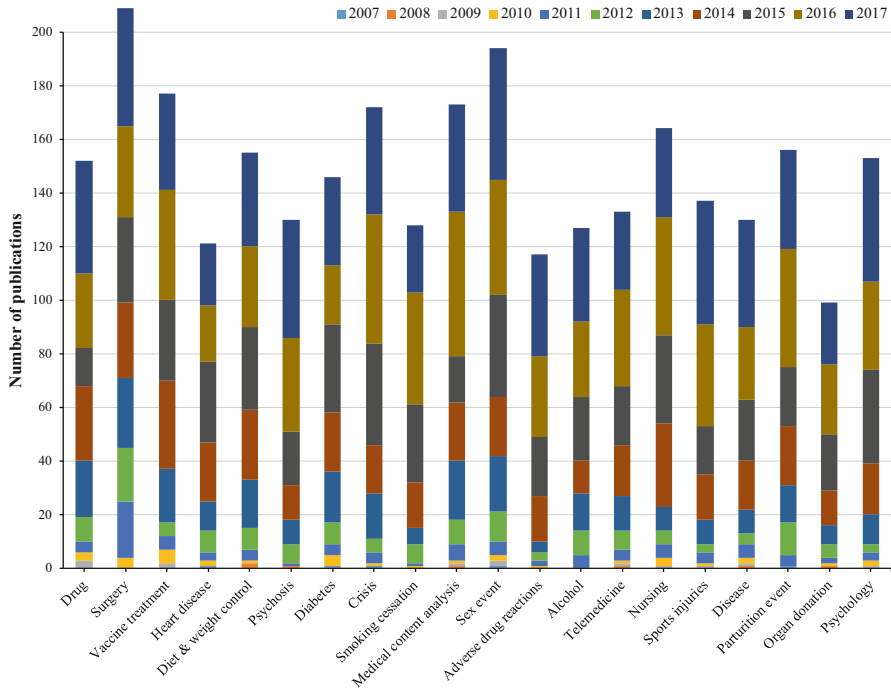
Fig. 3.8 Annual per-document topic distribution for the 20 topics

We give interpretation for some of the topics as follows:

Ten publications published during 2007–2011 are distributed to Topic *Sex-related event*. For example, based on a recruitment of 500 adolescents who engaged in voluntary sex for most recent sex, Wong et al. [20] conducted a case-control study to access personal and environmental factors with premarital sex among adolescents. During 2012–2017, the number of sex event-related publications increased to 184, indicating a growing interest it has attracted in the scientific community. Most studies focused on HIV prevention among men who have sex with men [21], social media-based health intervention [22], and health communication [23]. Ireland et al. [21] used regression analysis to examine the correlation between county-level HIV rates and aggregate usage of future-oriented language, as well as HIV rates and individual words and phrases. They found that there were fewer HIV cases in counties with higher rates of future tense on Twitter, and HIV cases were independent of strong structural predictors of HIV such as population density in those countries.

As for Topic *Analysis on medical-related content*, there are only nine publications in the first period, but the number reaches to 164 during the second period. Most studies were conducted on social media-related content, e.g., videos [24], publicly available user profile [25], twitter messages [26], online health communities or groups [27], and literature or publications [28], for certain disease,

e.g., breast cancer [29], prostate cancer [30], and testicular cancer [28]. The work of Stellefson et al. [24] suggested that it was potential for chronic obstructive pulmonary education via YouTube to reach and inform patients, but the existing video content and quality varied significantly. Lyles et al. [26] confirmed Twitter's potential of serving as a rich source of information and being used to design new health-related interventions. A systematic review conducted by Cartledge et al. [31] showed that there existed no problem of professionalism in social-networking sites for educational purposes, and no solid evidence revealing social-networking as equally or more effective than other media available for educational purposes could be found.

The number of publications for Topic *Vaccine* during 2007–2011 was 12, while it increased to 165 during 2012–2017. Some were related with human papillomavirus vaccine (HPV). For example, Massey et al. [32] adopted a codebook to characterize sentiment and content of the HPV-related tweets and tested for significant differences in tweet characteristic by sentiment. Some were about vaccination. For example, through the analysis of the articles posted on five national and 82 local Canadian online news sites, Lei et al. [33] revealed several popular topics.

Only three publications published during 2007–2011 were distributed to Topic *Adverse drug reactions*, and the number reached to 114 during the second period. Liu et al. [34] adopted a feature-based approach to utilize different lexical, syntactic, and semantic features for the construction of a relation extraction system. With an aim of exploring natural language processing for automatic classification of ADR assertive text segments, Sarker and Gonzalez [35] designed a feature-rich classification approach. Taewijit et al. [36] proposed a key phrasal pattern-based bootstrapping method for characterizing ADR relation.

As for Topic *Diet and weight control*, the number of publications during the second period was 21 times of that during the first period. Relevant studies mainly centered on food and diet [37], obesity [38], weight loss [39], and fitness or physical activity [40]. Based on five focus group discussions, Deliens et al. [41] explored determinants of the eating behavior of Belgian university students. Vidal et al. [37] took into consideration eating/drinking to conduct a case study on the theme "what people say when they tweet about different eating situations." They concluded that it was worthwhile to include Twitter data in the toolbox for research purpose, but it was no panacea. So et al. [42] conducted a content analysis of obesity-related tweets that were frequently retweeted. By measuring some outcome measures in overweight and obese individuals in a weight management program delivered via social media, Jane et al. [43] aimed to determine the usefulness of social media.

As for Topic *Smoking cessation*, the number of publications was only two during the first period, and the number increased to 126 during 2012–2017. Most publications in the Topic were related to *Smoking cessation*, e.g., intervention for smoking cessation through Internet [44] especially Facebook [45], content analysis of smoking cessation-related tweets [46], and exploration of social media advertising as a recruitment intermediary for smoking cessation clinical trials [47]. Some studies were e-cigarette-related, e.g., e-cigarette-related YouTube videos [48], analysis on e-cigarettes-related tweeter content [49], and e-cigarette advertisements on Twitter

[50]. In addition, there were a few researches concentrating on depression, e.g., major depressive disorder screening [51], the relationship between depression and media usage [52], and perceived social support [53].

Nine publications published during 2007–2011 were distributed to Topic *Nursing*. During 2012–2017, the number of Nursing-related publications increased to 155. Most of the nursing-related studies centered around the use of social media in enhancing nurse education. For example, Green et al. [54] discussed about the potential and implications of using social-networking sites such as Facebook in nurse education. Richardson et al. [55] conducted a thematic analysis of a Twitter chat to explore the concept of sustainability in nurse education. Some studies focused on family nurse. For example, Isaacson and Looman [56] explored strategies for the development of family nursing communities of practice with the use of social media. Some other studies with concern for nurse-patient relationship [57, 58] and comprehensive nursing care service [59] can also be found.

3.7   Conclusions

Social media and health research area has attracted the interest of the scientific community throughout years, which is witnessed from the annual growth of publications. To our knowledge, there is no study examining the research status of this field. In this chapter, we develop a quantitative and visual analysis of social media and health research publications from WoS database from 2007 to 2017. Our aim is to present detail understanding of the current research status in terms of predominant subjects, journals, and countries, the collaboration relationship, as well as the major topic distribution and evolution with the methods of bibliometrics, social network analysis, and latent dirichlet allocation. Some important findings are as follows:

- *Journal of Medical Internet Research*, *PLoS One*, *Computers in Human Behavior*, and *BMC Public Health* are the top four most influential journals in terms of H-index.
- Three subjects including *Health Care Sciences & Services*, *Public*, *Environmental & Occupational Health*, and *Medical Informatics* contribute 25.71% of total publications and 30.47% of total citations to the development of the research field.
- The USA is the most influential country with 1317 publications and an H-index of 53.
- The number of publications in co-author, co-affiliation, and co-country perspectives shows increasing trends on the whole. The collaboration among authors, affiliations, and countries may potentially improve the quality of publications.
- The top 20 research themes are discovered as: *Sex-related event*, *Analysis on medical-related content*, *Vaccine*, *Adverse drug reactions*, *Diet and weight control*, *Smoking cessation*, *Nursing*, etc.

- Compared with the period 2007–2011, all the 20 research topics have received much more attention in the scientific community during 2012–2017.

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Chapter 4
Social Media in Health Communication

Jinhai Huo and Kea Turner

Abstract In the past 10 years, social media usage and the development of new social media platforms have grown rapidly in the United States. This new technology enables users to socialize and exchange knowledge with other users in a virtual community. Social media also has a number of advantages over other modes of communication including the ability to track and analyze communication, tailor information for individual users, and reach a broad audience in a short amount of time. Many health care providers have already started piloting social media-based interventions to improve patient care and population health. This chapter describes the current application of social media in health communication, beginning with a definition of social media and health communication, and then focusing on examples of social media usage across the spectrum of health care. The chapter also reviews current guidelines for health care professionals' use of social media and limitations of social media use, such as privacy and quality concerns. The chapter concludes with implications for future research and practice.

Keywords Health communication · Social media · Patient · Health care provider

4.1 Introduction

Worldwide, nearly three billion people were active social media users in 2018 [1], and this number is predicted to exceed 3.02 billion by 2021 [2]. The countries with the highest number of social media users are China, India, and the US [3]. The total number of social media users in the US alone has reached 210 million in 2018 [4], a fourfold increase compared to 10 years ago in 2009 [5]. People in the US are also spending more time on social media. Over the past 7 years, the daily average number of minutes spent on social media has also grown from 90 to 135 min [6].

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There is wide variation in usage, however. Research has shown that the time spent by users visiting their social media pages can range from 10 min to 3 h [7–9].

Because of increased usage, social media has become a routine part of life for many people. Social media serves as a way to maintain daily personal communication, socialize with friends and family members, and expand social networks by building new connections with strangers regardless of where they live. In addition, social media has become a tool for health care delivery and public health. In recent years, the improved access to internet services and relative low-cost of developing internet-based health applications have led to increased interest in implementing social media-based health interventions [10–14]. Social media-based interventions can facilitate provider-provider, patient-provider, or patient-patient communication [15, 16]. It can also be used to disseminate health information [16–19]; monitor epidemics, pandemics, and outbreaks of disease [20, 21]; facilitate health awareness campaigns [10, 11]; recruit clinical trial participants [22–24]; and reduce stigma associated with certain health conditions [25, 26].

Social media interventions can overcome many of the barriers associated with traditional, in-person health care interventions, such as limited access among underserved and underrepresented populations and the long length of time it takes to deliver in-person interventions. For example, social media has the potential to overcome disparities in access to information and reach underserved and underrepresented populations frequently missed in the traditional delivery of health care [27, 28]. Social media can also reach a large number of people in a short amount of time through viral marketing. Viral marketing occurs when the texts and images posted by a single social media user are reposted, retweeted, and re-blogged quickly by followers and subscribers of that user, and then, the process is repeated, exponentially expanding information access [29]. Additionally, social media can be used to track and analyze communication—such as patient concerns or quality of patient-physician communication—whereas tracking communication between patients and providers in a traditional, in-person office visit may be more challenging.

Users of social media also receive many benefits. Users can receive social support in online communities with peers who have similar health issues and concerns. This is particularly important for patients with rare health conditions or patients from rural communities that may not have access to anyone with the same condition. Social media also offers interactive tools that allow individuals to get feedback from multiple individuals rather than just one person (e.g., discussion boards). Additionally, social media offers anonymity. Patients can conceal their identity, which may protect against discrimination that they may incur offline. For example, patients with stigmatizing conditions, such as HIV/AIDS or mental health conditions, may find it easier to disclose concerns about their health condition anonymously [25, 30]. Users can also receive health information and support tailored to their individual needs; for example, individuals that need informational support can seek out informational support instead of emotional support and vice versa [31]. Finally, social media usage can bolster self-esteem and protect against

feelings of loneliness and social isolation, especially among users interacting with peers who share a similar health care condition [32, 33].

Social media also provides patients with a flexible platform for receiving and communicating health information. For example, some patients, such as patients with severe mental illness, may struggle with face-to-face communication due to social functioning impairments [34]. Social media may reduce the need for face-to-face communication and allow patients to decide what level of engagement they prefer to have with other individuals [25]. Additionally, patients can use social media to receive health information without having to commit to sharing any information about themselves. Social media also allows patients to access information at a time when the information will be most useful—such as after diagnosis with a condition or following a negative health care event. There is also the issue of convenience. Social media platforms offer 24/7 access and opportunities for asynchronous communication; social media users can visit these sites, seek health information, or leave messages for peers or health care professionals at any time.

There are also some downsides to social media interventions. While there is some evidence to suggest that social media interventions can be effective at facilitating positive behavior change [35, 36], there are also instances where social media interventions have had no effect [13, 37, 38]. For example, a randomized controlled trial comparing social media-based versus print-based health promotion materials for cancer patients reported no significant effect of the social media-based intervention compared with the control arm [38]. There are also concerns about whether social media can help spread information that is incorrect (i.e., misinformation) and whether patients can discern correct information from incorrect information [39, 40]. For example, one study conducted a content analysis of social media resources offering information on prostate cancer screening guidelines and found that less than half of sites (43.8%) had information on the most recent guidelines and only 30.7% of websites discussed the prostate-specific antigen test [41]. On the other hand, researchers have argued that social media could be used to identify common misunderstandings and allow researchers to clarify misunderstandings (e.g., appropriate use of antibiotics) [18].

Besides the benefits and potential downsides of using social media for health care, it is also important to understand which individuals are most likely to use social media in health communication. The first factor to consider is access including how many individuals have access to the internet (through either a computer or smart device). Research has shown that, in the US, about 76% of the population has accessed the internet [42]. Internet usage is similar across gender, race, and ethnicity [43], but varies across age groups. Individuals 65 years of age and older have a lower usage rate (66%) than other age groups [43]. Internet access also varies considerably based on geography. There is considerable variation in access across countries for example. Some countries, such as the Falkland Islands and Iceland, report almost 100% internet penetration, and other countries, such as Eritrea and Somalia, report less than 2% internet penetration [42, 44]. Within the US, there is also variation in penetration rates and internet speed. For example, some states like

Washington have a low percentage of individuals with no internet access (20%), whereas some states like Mississippi have a higher percentage of individuals with no internet access (41%) [45]. Some states, such as Iowa and North Dakota, have better broadband and ultra-fast Internet access, compared to stats such as Montana or New Mexico [46].

Besides internet access, the other most important factor that contributes to the use of social media in health communication are personality traits. Most of the population can be classified into five personality traits: extraversion, neuroticism, openness to new experiences, agreeableness, and conscientiousness [47, 48]. Among these five personality traits, extraversion and neuroticism are strongly associated with frequent social media use [49–51]. However, the association between social media use and personality traits may change in the context of health communication. People with extraversion and neuroticism traits are more likely to use social media to make new friends and socialize with other users [8]. In contrast, the same personality traits may not predict which individuals use social media for communicating and seeking information about health. The increased usage of social media for health care information seeking, such as communication with a health care professional, may attract more users who do not have these two personality traits [8].

Given how much social media usage has increased in recent years, social media will soon become an important mode of health communication for patients, family caregivers, providers, and health policy makers [16]. Therefore, it is critical to understand what social media is and how it has been used in health communication.

4.2 Social Media in Health Communication: Understanding Keywords

4.2.1 Social Media

There are several ways to define social media. In 2010, Kaplan and Haenlein defined social media based on two concepts: (1) Web 2.0 represents the shift from Web 1.0—where content is static—to a dynamic environment where web content and applications are constantly being modified by users, and (2) User-Generated Content (UGC) which represents publicly available media content generated by web users [52]. In other words, the Web 2.0 represents the platform for social media (e.g., RSS feeds, Asynchronous Java Script) and UGC represents all of the ways in which social media is used (e.g., sharing of pictures on Facebook, text-based communication shared through Twitter). Specifically, Kapan and Haenlein described social media as:

Social Media is a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of UserGenerated Content.

More recently, Obar and Wildman (2015) defined social media based on four common components of social media defined in previous literature [53]:

1) *Social media services are (currently) Web 2.0 Internet-based applications*
2) *User-generated content is the lifeblood of social media*
3) *Individuals and groups create user-specific profiles for a site or app designed and maintained by a social media service*
4) *Social media services facilitate the development of social networks online by connecting a profile with those of other individuals and/or groups.*

The definition of social media from Merriam-Webster has a focus more on the function of social media and discards the technical terms [54]:

Social Media (are) forms of electronic communication (such as websites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (such as videos).

In addition to defining social media, researchers have developed categorizations of the types of internet-based services that encompass social media. Social media ranges from the blog, the oldest format of social media developed in the late 1990s, to the social networking site, the most commonly used type in the recent decade. Currently, the two largest social media platforms, Facebook and Twitter, have more than 2.20 billion and 336 million monthly active users, respectively [1]. Grajales III and colleagues have developed the following categorization of commonly used social media platforms (Table 4.1) [55].

Different types of social media have different rates of usage among users. For example, Facebook has a high rate of usage across all adult age groups, with the highest usage among 30–44 year olds (89%) and the lowest usage among individuals over 65 (77%). Twitter is less commonly used among adults [56]. The highest group of adult users are ages 18–29 (52%) and the lowest group of adult users are over 65 (20%). Interestingly, among adolescents, social media sites such as YouTube (85%) and Instagram (72%) are used more frequently than Facebook (51%) and Twitter (32%) [57].

One theory that is likely to be useful in predicting which users will participate in a social media-based intervention is the Diffusion of Innovation theory [58]. The Diffusion of Innovation theory maintains that characteristics of an intervention—such as how easy it is to use or whether it offers a relative advantage compared to other interventions—predicts the likelihood that an individual will adopt that intervention. Other factors affecting adoption rates include individual characteristics—such as education level—and characteristics of the social system—how many other individuals does that person know. Some studies have already applied the Diffusion of Innovation theory to social media applications, such as Twitter hashtag use [59]. Future exploration of social media-based health interventions should explore adoption rates using the tenets of Diffusion of Innovation Theory.

Table 4.1 Social media: types, definition, and examples

Service type	Definition	Example
Blog	Short for "web log": a blog is an easy-to-publish website where bloggers (authors of blogs) post information and essays in sequential order	WordPress, Blogger
Microblog	A tiny blog service that allows networks of users to send short updates to each other in less than 140 characters. Microblogs are considered a platform for information dissemination, social networking, and real-time communication	Twitter, Identi
Social networking site	A social networking site is an online service, platform, or site that focuses on building and visualizing social networks or social relations among people, who, for example, share interests and/or activities. A social network service essentially consists of a representation of each user (often a profile), their social links, and a variety of additional services	Facebook, MySpace
Professional networking site	A professional networking site is a type of social network service that is focused solely on interactions and relationships related to business or a person's professional career	LinkedIn, Sermo, Asklepios, Ozmosis, Drs Hangout, Doc2Doc
Thematic networking sites	Social networking sites centered on a particular theme, such as disaster response. These share many aspects of, and operate as a community of, practice	Telehelp, Innocentive, 23andMe, PatientsLikeMeCureTogether
Wiki	Wikis are used to denote communal websites where content can be quickly and easily edited. Wikis support collaboration and information sharing; feature multimedia, such as video, slides, photographs; and allow anyone to edit or are password protected	Wikipedia, Fluwiki
Mashups	A website that combines data and functionality from two or more services to create a new, value-added, service	HealthMap, Google FluTrends
Collaborative filtering sites	A website where information is filtered or collected according to patterns. Techniques involving collaboration among multiple agents, viewpoints, and data sources are often used. These agents engage through a variety of sites, through a process called crowdsourcing, where the crowds join forces for a common purpose	Digg, Delicious
Media sharing sites	A hosting service that allows individuals to upload and create galleries of photos, videos, and other digital media (e.g., slide presentations). The host will then store them on a server and make them either publicly or privately available	SlideShare, YouTube, Flickr, Pinterest
Social Q&A sites	A website where individuals ask questions and share knowledge by answering the other's questions	Yahoo Answers, Quora
Other	Multi-User Virtual Environments, also known as Virtual Worlds	Second Life

Adapted from Grajales III, Francisco Jose, et al. "Social media: a review and tutorial of applications in medicine and health care." Journal of medical Internet research 16.2 (2014) [55]

4.2.2 *Health Communication*

In addition to defining social media, it is important to define health communication. The Community Preventive Services Task Force (CPSTF) established by the U.S. Department of Health and Human Services (DHHS) defined health communication as [60]:

Health communication is the study and use of communication strategies to inform and influence individual and community decisions that enhance health. Health communication considers a variety of channels to deliver its targeted or tailored messages to specific segments among varied audiences, including individuals, communities, health professionals, special groups, and decision makers.

A concise definition of health communication from the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute is [61]:

The study and use of communication strategies to inform and influence individual decisions that enhance health.

The United States of America (USA)'s Healthy People 2010 also define health communication as [62]:

The art and technique of informing, influencing, and motivating an individual, institutional, and public audiences about important health issues.

There are several elements of health communication that are identified in these definitions—who is delivering the communication and who is receiving the communication, what channel is used to deliver the information, the content of the message, and what effect the communication has on health-related decision-making and behavior. We have developed a definition of each of these components based on prior health communication theories [58, 63–65] (Table 4.2).

To ensure that health communications have the desired impact on health behavior, health communication interventions are often guided by a strategy that includes selecting the right sender, audience, and communication channel and choosing a message strategy (e.g., framing the message in a certain way, tailoring the message to a specific individual) [58, 63, 64]. Additionally, health communication interventions are often guided by a health behavior theory and are targeted to a particular level of analysis (e.g., individual versus community) [64]. For example, if you were to design a health communication strategy targeting vaccination behavior, you might develop messages using the Health Belief Model, which assumes individuals engage in health behaviors to avoid risks [66]. Studies have found that constructs of the health belief model—such as perceived risk—are important predictors of vaccination behavior [67]. Another theory that is likely to be useful is social support theory or the idea that certain forms of social support may help to buffer the effects of stress related to a health care condition [68, 69]. For example, social support can include emotional support, such as showing empathy or concern, tangible support, such as offering financial assistance or transportation, or informational support, such as offering guidance or advice. The form of online social support that an individual needs may vary depending on their health care condition and access to in-person

Table 4.2 Definition of key components of health communication

Key component	Definition
Sender	The individual or group of individuals that develop content for and distribute the message (i.e., encode)
Audience	The individual or group of individuals that receive and derive meaning from the message (i.e., decode)
Segment	A subgroup of individuals that have similar characteristics or needs and may be targeted audience for a message
Channel	The medium used to disseminate the message
Message	The content shared during communication
Framing	Deciding on what content to emphasize within a message to maximize effect on health behavior
Tailoring	Adapting the message content to individual characteristics, needs, and preferences
Targeting	Adapting the message content for a subgroup based on their characteristics, needs, and preferences
Effect	The impact of the message on determinants of health behavior (e.g., knowledge, attitude) and health-related decision-making and behavior

social support. Therefore, social media-based health communication interventions may be used to develop a tailored social support intervention that matches the type of social support with the users' needs.

Health communication can flow several ways. It can occur between health care providers and patients or caregivers, across patients, or between health care providers. We will discuss the various forms of health communication in the following section.

4.3 Social Media for Health Communications

4.3.1 Cancer Care Communication

A diagnosis of cancer brings patients and their family members a wide range of emotions, such as sadness, fear, or helplessness. These emotions affect patients and their families for a long time and may be heightened at certain times. Health communication can help cancer patients and caregivers to deal with the emotions that stem from a cancer diagnosis by lessening anxiety or providing comfort [70]. For example, while a patient is in active treatment (e.g., undergoing chemotherapy), patients and their family members may seek out emotional support or information support (e.g., what side effects to expect). Having information on what side effects to expect can then help reduce anxiety associated with the cancer diagnosis. Social media has emerged as a new venue for social support for cancer patients, survivors, and their caregivers. Cancer patients can interact with peers who have been diagnosed with cancer through social media and share their experiences. Studies

have reported that cancer patients may be more willing to accept health education and information when it is obtained from cancer survivors' narratives [71–73]. This phenomenon is often referred to as emphatic support or when emotional support may have more relevance when it is provided by someone with a similar experience [74]. Besides communication with peers, social media platforms also have many active health care providers and medical societies that generate health information and educate the public on accurate cancer-related knowledge. One study found that cancer patients who searched for cancer-related information online had more confidence in the validity of the information than those cancer patients who sought this information offline [75]. However, concerns remain about whether these cancer patients visited web sources with accurate information. Studies have found inaccuracies and inconsistencies across web sources with prostate cancer care information, such as incorrect definition of Gleason sum and PSA screening [76].

4.3.2   Diabetes Care Communication

Diabetes can be a challenging chronic condition to manage since many factors affect blood sugar control. As a result, patients can experience diabetes-related complications due to disease management. For these patients, continuous support from health care professionals and problem-based learning strategies are important for disease management and quality of life [77]. Additionally, diabetes patients benefit from social support from their friends, families, and peers since health behavior reinforcements—such as medication reminders—may not be available from health care professionals [78]. Social media-based programs are being increasingly used for diabetes management and have been successful in increasing health care utilization, modifying patients' behaviors and attitudes, and educating patients on proper diabetes management [79, 80]. Health care professionals are also receptive to using social media as a tool to educate diabetes patients [81]. There are also a number of peer support programs that have been created through social media platforms. These programs have enrolled a large number of relevant users, such as family members, researchers, pharmacists, and physicians [82].

4.3.3   Mental Health Care Communication

Although mental illness is preventable and/or treatable, many patients with mental health conditions remain undiagnosed and untreated due to the stigma associated with seeking mental health care. Access to timely treatment can be critical in reducing the burden associated with mental health illness and improving quality of life. Social media can reduce some of these barriers to mental health care, such as reducing stigma, promoting treatment engagement, and identifying undiagnosed individuals. One of the main benefits of social media is providing peer support from

social media connections, such as mutual counseling and information exchange with peers, which may help to reduce the stigma associated with mental illness [83, 84]. Social media usage can also reduce feelings of loneliness and social isolation among patients with mental illness, which may prevent worsening of psychiatric symptoms. Social media can also be used to identify individuals with mental illness. For example, studies have found that some individuals express depressive symptoms in posted texts and images shared through social media [85, 86]. Future interventions could leverage social media data to identify individuals at risk for mental health issues and develop a social media-based information campaign to disseminate information about treatment resources.

4.3.4   Public Health Communication

Social media can be used to promote public health in a variety of ways, such as increasing knowledge and awareness, prompting healthy behaviors, or predicting disease activity. For example, social media can transmit health information during public health emergencies, supplementing traditional information venues, such as TV, radio, newspaper, and internet news sites. With the current high penetration of social media in the general population, social media can be used to spread information on urgent public health issues to a large audience in a short amount of time. For example, during the Ebola outbreak of September and October 2014, over 26 million tweets were shared containing the word Ebola [87]. Public health agencies are also using social media to increase awareness about smoking and to prompt individuals to seek out smoking cessation resources, such as quit lines. The CDC, for example, launched the Tips from Former Smokers campaign, which has used traditional information venues, such as TV, and social media platforms, such as Twitter and Facebook, to disseminate anti-tobacco ads [88]. An evaluation of the Tips campaign found that calls to smoking quit lines increased by 132% during the campaign. State and local health departments in the US are also increasing their presence on social media—about 60% of state health departments and 24% of local health departments are using some form of social media (e.g., Twitter, Facebook, Youtube) [89–91]. Social media also offers an opportunity for public health researchers and policy makers to understand public response to emerging health issues [11]. In the past H1N1 influenza pandemic, researchers found that the Twitter traffic can describe social media users' concerns about H1N1 influenza [11] and can be used to predict disease activity in real time [92]. In countries where the penetration of social media is high, social media-based surveillance may become an important supplemental system to the traditional disease-surveillance systems [92].

4.3.5   Youth Health Communication

Many adolescents now use social media making it an ideal tool for disseminating health information, prompting healthy behaviors, and for reducing risk behaviors. Adolescents have heightened risks for unhealthy behaviors due to factors such as peer pressure; peer effects, for example, have a greater influence in adolescence than adulthood [93]. Therefore, adolescence is an ideal time to prevent risk behaviors that could have long-term consequences (e.g., substance use disorder). Given how much adolescents use social media, many interventions have been targeted to this group to reduce risk behaviors, such as substance use and sexual risk behavior [94–97]. Social media interventions, for example, have been used to disseminate information about smoking cessation to youth. One study found that smoking cessation social media interventions with more interactive components, such as discussion groups or ask an expert tools, were used more frequently by youth than social media interventions without these components [95]. The need for anti-tobacco social media interventions for adolescents may increase due to increases in adolescent use of e-cigarettes and e-cigarette advertising aimed at youth [98, 99]. Social media can also be used to reduce risk behaviors. For example, adolescents who share personal information online or talk about sex online are 1.7 times more likely to receive unwanted sexual solicitations online [100]. To reduce this risk, one intervention used tailored messages from a pediatrician to explain the risks associated with publicly referencing sex on social media sites [94]. The intervention significantly reduced adolescents referencing of sex on social media and significantly increased the number of adolescents who set their social media profiles from public to private.

4.4   Disparities in Use of Social Media for Health Communication

The persistent disparities in health care access and utilization have been widely reported in the past decades [101–104]. Therefore, adoption of any new technology in health care—such as social media—brings about concerns over whether existing disparities in access will be exacerbated. In the US, and in other countries, there has historically been a digital divide where internet access varies by race/ethnicity, socioeconomic status, age, and geography. For example, households with an annual income of less than $30,000 have lower rates of home broadband access and home computer and smartphone ownership [105]. Across race and ethnicity, ownership rates of smartphones are similar; however, Black and Hispanic Americans have lower rates of home broadband access and home computer ownership [106].

There have been several initiatives that have helped reduce these disparities. For example, access to high-speed internet has significantly improved in the past 10 years in the US after a $1.7 billion appropriation from the Federal Communications Commission's (FCC) Universal Service program, which lowered the cost of

high-speed internet and improved access [107]. Several other national initiatives, including the FCC's low-income support program, the U.S. Agriculture Department's Rural Utilities Service, and the U.S. Commerce Department's National Telecommunications and Information Administration, also aimed to improve internet access [108].

There are several studies that have examined racial disparities in use of social media for health information that have found inconsistent results. In 2006, a nationwide cross-sectional study reported significant racial disparities in access to online health information [109]. The white population was 20% more likely to use the internet to search for health information than the Hispanic population [109]. A similar cross-sectional study conducted in 2007 and 2012 did not find evidence of racial disparities, but the 2012 study found disparities in online health information seeking based on income and education [27, 28, 110]. A more recent study using 2017 national survey data further supported that there may no longer be a digital divide among racial and ethnic groups in social media use in the US [111].

Some studies have also explored whether the type of health information that is being searched for affects racial and ethnic disparities. For example, one study found that Black and Hispanic women were less likely to use the internet to seek health information about contraception, but more likely to search for health information about pregnancy tests and sexually transmitted infections compared to white women [112]. The same study found that Hispanic women had similar odds of seeking health information about smoking cessation, weight control, alcohol/drug use, mood disorders, and skin disorders, compared to white women, but both groups (White and Hispanic) had higher odds of searching for these topics than Black women [112].

There have also been several studies examining disparities in access to health information through social media across countries. For example, one study found that Twitter traffic regarding Ebola was higher in the US than in countries where the Ebola outbreak occurred including Sierra Leone, Liberia, and Guinea [113]. Studies have reported that it was easier to disseminate information about Ebola in countries such as Nigeria that have a higher internet penetration (46%) than countries such as Sierra Leone, which have a much lower internet penetration (2%) [114].

4.5 Health Care Professionals' Use of Social Media for Health Communication

Increasingly, health care professionals are becoming engaged in the social media community. In a 2011 survey of 4000 physicians, 87% of physicians used social media sites for a personal reason, and 67% of physicians used social media for a professional reason [115]. As health care professionals become more engaged in social media, there is greater opportunity for interactions between health care professionals and patients through social media. One study found that 35% of health

care professionals had received a friend request from their patients or patients' family members, and about 16% of health care professionals have visited the social media profile of their patients—rates that are projected to increase [116, 117]. Health care professionals are also creating blogs to share information with the public. A recent study exploring the content of health-related blogs found that about half of the blogs were created by health care professionals, such as physicians and nurses, and were used to disseminate general health information as well as disease-specific information [118]. By sharing this information through social media, there is the potential for health care professionals to share health information with a much broader audience than their patient population.

Health care professionals can also use social media to communicate with other health care professionals and researchers. For example, a cross-sectional survey of physicians in 2011 ($n = 1695$) found that about 46% of physicians share health information through social media for the purpose of sharing information with other physicians [119]. Similarly, health care professionals participating in medical conferences also use social media to share information. A study estimating the information dissemination during the 2013 American Urological Association Annual Conference found that there were more than 5000 tweets from 644 contributors for a 5-day conference [120]. It is possible that the impact of this social media-based information dissemination could be even larger since some Twitter users, such as passive followers and users who read Twitter feed on boards, were not captured in the study.

Many individual-level factors influence health care professionals' adoption of social media for the purpose of health communication. For example, a recent study found that 57.5% of physicians perceive social media to be beneficial for obtaining high-quality information and 57.9% perceived social media to be beneficial for improving patient care [119]. The same study found that perceived benefits of social media were associated with higher social media usage [119]. The purpose for using social media may vary across health care professions however. For example, one study found that specialists use social media to acquire cutting-edge knowledge in disease management and treatment, while primary care physicians are more likely to use social media to communicate with peers to identify strategies for improving practice efficiency and clinical outcomes [121]. The same study found that individual-level factors, such as perception and attitude towards social media, are more predictive of social media usage than practice-related factor [121]. Studies also suggest that age may affect social media usage among health care professionals. One medical education study found that younger health care professionals were more likely to use interactive functionalities in a social media-based e-learning module to enhance their collaborative learning and engagement compared to older professionals [122].

There are concerns, however, regarding health care professionals' use of social media. For example, there are concerns about protecting patients' privacy and confidentiality. One study found that many patients could be identified by viewing physicians' public posts on social media platforms [123]. Besides privacy and

confidentiality concerns, many other issues have also been observed in health care professionals' use of social media in health communication that bring about concerns with professionalism, such as inappropriate contact with patients, inappropriate prescribing, and misrepresentation of credentials or clinical outcome [124]. Health care professionals may also find it difficult to maintain a professional identity in their social media presence that is consistent with their professional identity in clinical practice. Therefore, it is important for health care professionals to exhibit professionalism while using social media.

4.6   Guidelines on Health Care Professional's Use of Social Media

In response to growing social media usage, many health care professional societies and organizations have issued guidelines to direct the use of social media in the health care professional community.

At the 2012 annual meeting, American Medical Association (AMA) published guidelines for social media usage entitled, "Professionalism in the Use of Social Media" [125]. In this document, AMA gave ten suggestions for health care professionals using social media: (1) take responsibility and use good judgment; (2) think before you post; (3) protect patient privacy; (4) protect your own privacy; (5) respect work commitments; (6) identify yourself; (7) use a disclaimer; (8) respect copyright and fair use laws; (9) protect proprietary information; and (10) seek expert guidance. Additionally, AMA suggested that health care professionals establish boundaries that protect patients' and physicians' privacy, maintain the patient-physician relationship, and separate personal and professional information posted online. The guidelines also provide several scenarios of social media use in medical practice along with the guidelines that explain the best option to choose in these scenarios. For example, when a patient sends a 'friend' request to the medical student after a clinical encounter, the guideline indicates that it is inappropriate to accept this request unless the doctor-patient relationship has ended.

There are also other organizations that have created guidelines for social media usage for health care professionals. The Federation of State Medical Boards published "Model Guidelines for the Appropriate Use of Social Media and Social Networking in Medical Practice" in 2012 [126]. This guideline recommends the application of three ethical standards for health professionals using social media: candor, privacy, and integrity. The Federation of State Medical Boards also advises against health professionals using personal social media platforms, such as Facebook, for health communication or treatment within the physician-patient relationship. Instead, the Federation of State Medical Boards recommends the use of the professional network site, Doximity, to communicate with patients via a secure portal that only verified and registered users can access. This guideline also explains that medical boards have the authority to discipline physicians for unprofessional

use of social media for health communication. For example, any inappropriate use, such as misrepresentation of credentials, violations of patient confidentiality, concealed conflicts of interest, or discriminatory language or practices, may lead to various actions from a letter of reprimand to the revocation of a medical license.

The American Society of Health-System Pharmacists (ASHP) has also developed guidance about social media usage entitled, "ASHP Statement on Use of Social Media by Pharmacy Professionals" [127]. The guidance encourages the use of social media among pharmacy professionals, particularly for medication optimization. In this statement, three recommendations are given to pharmacy professionals regarding social media usage: (1) advance the well-being and dignity of patients; (2) act with integrity and conscience; and (3) collaborate respectfully with health care colleagues. The statement also suggests that any advice given to patients via social media should be consistent with the professional standards of pharmacy practice. Additionally, pharmacy professionals are encouraged to recognize both the benefits and limitations of social media, to ensure that social media usage promotes accurate medication information, and to reduce outdated or inaccurate medication information. Similar to the AMA guideline, the ASHP statement reminds pharmacy professionals of their ethical obligation to disclose potential conflicts of interest and follow laws and regulations regarding patient privacy and confidentiality.

4.7   Limitations of Using Social Media for Health Communication

Even though we have observed remarkable potential of the use of social media in health communication, there are several limitations that need to be highlighted.

4.7.1   Quality and Reliability

When using social media platforms to acquire knowledge, the reliability and quality of the information being circulated is always a concern [128, 129]. The user-to-user information exchange by retweet and repost makes it difficult to trace the original source of the information, especially if the information was modified purposely or accidentally during the sharing process. Prior to online access of information, health information was controlled by expert gatekeepers (i.e., command-and-control model), but with online information, there is no medical authority to monitor most of the health information circulated via social media [130]. While it is beneficial to expand access to information, the quality of widespread patient-modified or generated-health information has become a topic of concern [39, 131].

4.7.2   Lack of Privacy

Protecting the privacy of social media users' information, especially health information, is also a key concern. Data breaches have occurred in the past and are now a daily concern of major social media platforms. For example, more than three billion Yahoo accounts were impacted in a 2013 data breach [132]. There was another massive data breach in 2013 where approximately two million passwords were stolen from Facebook, Twitter, and Gmail [133]. A recent nationally representative study on social media usage found that sharing health information via social media has reduced by 36% from 2009 to 2013 [111]. This may reflect the fact that more social media users are becoming aware of privacy issues in the use of social media for health communication.

4.7.3   Risks of Oversharing Personal Information

As discussed in the previous example of sexual harassment among adolescent social media users, many social media users are not cautious enough about the information they post in the social media community. Additionally, some users may not be aware of or know how to restrict the viewers who can read their posts on social media platforms since privacy settings can be difficult-to-use. In response, some users may reduce the amount of health information shared on social media platforms in the future, unless the better privacy safeguards are developed.

4.7.4   Digital Divide Among Older Adults

Adolescents and younger adults account for most of the growth in social media usage in the past decade. The proportion of social media users in the population aged 18–29 years old is 88%, and this number reduced to 78% among 30–49 years old, 64% among 50–64 years old, and 37% among 65 years or older [134]. Age has become a significant barrier to the use of social media in health communication. One study qualitatively explored barriers to internet access among home-bound older adults and cited concerns such as visual deficits and inability to read small font sizes and pain and dexterity issues associated with certain health care conditions (e.g., arthritis and joint pain [135]). Another cross-sectional study of older adults ($n = 1410$) found that lower income, lower education, and worse health status were negatively associated with computer usage among older adults [136]. Other studies have shown that the cause of low use of social media for older adults was not due to technology difficulties, but due to lower levels of extraversion, a personality trait [8, 137].

4.7.5 Information Overload

In recent years, there has been an exponential increase in the amount of information being shared online, which can create information overload among users. Studies among executives have found that information overload can cause unhappiness, anxiety, and may reduce productivity [138]. Information overload can be particularly problematic when searching for health information online. One study found that individuals seeking information about cancer online experienced frustration and were overwhelmed by the large amount of information available and finding contradictory information [139]. Similarly, another study found that individuals searching for health information online became frustrated or overwhelmed by duplicative information (e.g., same answers or suggestions for the same question) [140]. Social media users may have difficulty making health-related decisions because of information overload, especially when the health information is contradictory.

4.7.6 Deterrent from Visiting Health Care Professionals

Before booking an appointment with physicians, many people who have a health concern will search online for the possible diagnosis and treatment using the key words that describe their symptoms or discuss these symptoms with friends and connections on social media platforms [141, 142]. A nationally representative study found that patients are more likely to search on the internet for an answer to their health concerns (59%) than to communicate with a physician about their health concerns (55%) [143]. As usage of social media for health information grows, some patients may pursue self-guided approaches to alleviate symptoms and delay visiting a physician.

4.7.7 Adverse Health Consequences

Communication on social media platforms can adversely impact health. Several studies have found that increased personal usage of social media among adolescents and adults (not usage for health communication) is associated with increased risk of depression and suicidealthough the evidence is mixed [144–148]. Adolescents may also experience cyberbullying through social media platforms, putting them at increased risk for depression [149]. Social media platforms can also be used to share harmful information. For example, although the direct tobacco advertisement and promotion has been banned, tobacco companies and other groups may have been indirectly advertising these tobacco products using entertainment or consumer-generated media in social media platforms [150, 151]. Concerns have been raised

that these tactics to use consumer-generated media in social platforms are targeting youth in particular [152]. Many other risk behaviors, such as sexual behavior, substance use, and violence, are also displayed in various ways on social media platforms. If the online activity is not being closely monitored or the third-party security software is lacking, social media users can expose themselves to many harms in social media platform [100, 153, 154].

4.8 Future Directions

The usage of social media for health communication is still in the early stages of development and will likely expand in the future due to demand from both the public and health care providers. Social media platforms have become a daily communication tool for many people, with many users spending a lot of time on these sites not only to socialize with their connections, but also to seek out and share health information. Social media users will want to have access to accurate and timely health information posted in social media platforms. On the other side, health care providers have seen the potential of social media to become a powerful tool in health promotion and health intervention. Numerous pilot studies have been conducted to determine the feasibility of social media-based health interventions. The needs from both patients and providers, along with the rapid advancements in social media technology, will dramatically change the field of health communication. There remains a need to develop theory-informed, social media-based health interventions, develop guidelines for social media platforms that ensure high-quality content and protect user privacy, identify user perspectives and incorporate those perspectives into intervention design, and develop more rigorous evaluation of social media interventions.

Many existing social media interventions were not created using a health behavior theory, making it difficult to understand how social media interventions lead to behavior change or how to evaluate them. One theory that might prove useful for the future advancement of social media-based health communication is the Common-Sense Model of Illness Self-Regulation. This model delineates the association between the social media users' behavior in seeking health information in social media platform [155–159]. The model suggests that the individual is always trying to build a mental representation of an illness that will direct the subsequent efforts in illness management and emotion control. There are five major attributes of this representation of illness, including identity, cause, timeline, consequences, and control. The strong perception on some of these attributes of illness representation has strongly predicted the individual's behavior in caring for the illness and emotion during the treatment process: A strong perception of the control can improve the patients' adherence in illness treatment, and a strong perception of the timeline and consequences of disease are linked with high risk of depression [160–162]. The health information circulated in the social media platform has a broad focus that covers all five attributes of illness representation. It
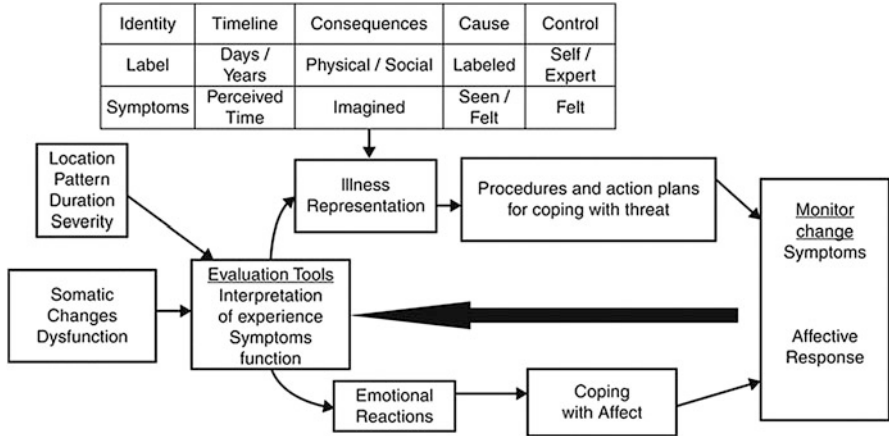
Identity	Timeline	Consequences	Cause	Control
Label	Days / Years	Physical / Social	Labeled	Self / Expert
Symptoms	Perceived Time	Imagined	Seen / Felt	Felt

Fig. 4.1 The common-sense model of illness self-regulation (Adapted from Mora P.A., McAndrew L.M. (2013) Common-Sense Model of Self-regulation. In: Gellman M.D., Turner J.R. (eds) Encyclopedia of Behavioral Medicine. Springer, New York, NY [159])

will be compelling to utilize the Common-Sense Model of Illness Self-Regulation to promote the appropriate health information to the specific target population (Fig. 4.1).

Other theories that might be useful include staged behavior change models, such as the Transtheoretical Model and the Precaution Adoption Process Model [163, 164]. Staged behavior change models are typically difficult to implement because they require health information to be tailored based on a patients' readiness to change. Although difficult to implement, staged behavior change interventions are highly effective for behaviors that are particularly difficult to change, such as substance use [165]. With social media, however, it is much easier to disseminate tailored health information than in a traditional, face-to-face intervention. An example of this is text messaging interventions, which can be used to distribute individualized text messages to patients. Text messaging interventions that have tailored text message content based on patients' readiness to change have been effective at changing health behaviors, such as reduction in cigarette consumption and smoking cessation [166, 167]. Future studies should test social media health interventions that are based on staged behavior change models, particularly for behaviors that are difficult to change including substance use and weight loss.

Another theory that might be useful for developing social media-based interventions is the Social Cognitive Theory. The Social Cognitive Theory maintains that an individual's health behavior is driven by their self-efficacy or belief that they have the ability to complete a specific behavior [168]. Self-efficacy is influenced by knowledge and by reinforcement—the factors within an individual's environment that help them to maintain a behavior, such as social support. Health communication interventions that not only increase knowledge but also provide reinforcement from an individual's environment (e.g., social support from family,

reinforcements for health behavior) tend to be more effective at eliciting behavior change [169]. For example, the Tips from Former Smokers campaign mentioned previously not only delivered health communication about the negative effects of tobacco, but it also provided the audience with a national quit line to call to receive emotional and informational support. Future studies should test whether social media-based interventions that are based on Social Cognitive Theory (e.g., include information and reinforcement) are more effective than interventions that only provide information.

There are existing guidance documents for health communication that can be applied to social media usage for health communication so that patients, health care professionals, and health care organizations have some guidance for how to use social media effectively. For example, the European Centre for Disease Prevention and Control listed out the major principles to conduct effective health communication (Table 4.3) [170]. To improve the quality and reliability of health information circulated through social media, adherence to set of guidelines may be helpful. Further research is needed on how existing guidelines for health communication need to be adapted for communication via social media. Once guidelines are established, social media sites may need to adopt a set of standards and develop

Table 4.3 The effective health communication practice

Attributes	Description
Accuracy	The content is valid and without errors of fact, interpretation, or judgment
Availability	The content (whether targeted message or other information) is delivered or placed where the audience can access it
Balance	Where appropriate, the content presents the benefits and risks of potential actions or recognizes different and valid perspectives on the issue
Consistency	The content remains internally consistent over time and also is consistent with information from other sources
Cultural competence	The design, implementation, and evaluation process that accounts for special issues for select population groups and also educational levels and disability
Evidence base	Relevant scientific evidence that has undergone comprehensive review and rigorous analysis to formulate practice guidelines, performance measure, review criteria, and technology assessments
Reach	The content gets to or is available to the largest possible number of people in the target population
Reliability	The source of the content is credible, and the content itself is kept up to date
Repetition	The delivery of/access to the content is continued or repeated over time, both to reinforce the impact with a given audience and to reach new generations
Timeliness	The content is provided or available when the audience is most receptive to, or in need of, the specific information
Understandability	The reading or language level and format (including multimedia) are appropriate for the specific audience

Adapted from European Centre for Disease Prevention and Control: Health communication [170]

strategies for enforcing or encouraging adherence to the standards among users. Future studies could examine whether implementation of the guidelines on certain social media sites improves outcomes, such as the readability and accuracy of the health information shared.

In addition to implementation guidance for high-quality communication, additional guidance and regulation is needed around privacy. Because of current privacy issues related to social media use, we may observe a shift from users publicly posting health information to using secured small group conversation with friends to share health information. A reduction in publicly shared health information will make it difficult for health care researchers to use this data for public health purposes (e.g., to track the spread of illnesses, identify health concerns among the public) or examine the validity of health information circulated via social media. There remains a need for more guidance and safeguards (e.g., making privacy settings easier-to-use and more transparent) for both users and health care professionals. While the HIPAA privacy rule does not specifically discuss social media, social media postings can violate HIPAA rules, which could result in fines and potential charges [171]. We will see more guidelines issued from health care professional societies to guide health care professional's online behavior and to protect patient privacy in patient-physician communication through social media platforms [172–175]. Increasing awareness about privacy in social media platforms and protecting patients' privacy will be critical for the success in the adoption of social media in health care.

Finally, there are many challenges and opportunities in the use of social media in health communication, that range from understanding social media users' behavior, disseminating accurate and high-quality health information via social media, designing and implementing social media-based interventions, and evaluating the effectiveness and cost-effectiveness of these interventions. To date, many social media users have been passive recipients of health communication and social media-based interventions. Additional studies are needed that gather user perspectives prior to the design of health-related social media interventions and then use those perspectives to inform the design of the intervention. Studies suggest that customer-generated social media interventions may be more effective than supplier-generated interventions [19]. There also remains a need to design more rigorous evaluations of social media interventions than compare effectiveness with alternate interventions (e.g., print materials) and examine the effects on health behavior over a longer time period. Future advancement in this field will need efforts from a transdisciplinary team, including health care providers, biomedical informatics researchers, behavior scientists, IT engineers, health services researchers, and most important one, the lay social media users. Health care providers and researchers also have the responsibility to become more visible in the social media community and to facilitate the circulation of accurate and beneficial health information in social media platforms.

4.9 Conclusions

This chapter illustrated the wide spectrum of applying social media in the health communication. This spectrum emphasizes the effectiveness of communication between social media users and health care professions, in the field of disease prevention, public health surveillance, health promotion, disease management, and quality-of-care after treatment. The public's increased usage of social media for health communication, coupled with the rapid development of technology to support social media platforms, creates an opportunity to leverage social media to improve the health of the population. The discipline of applying social media in health communication, including social media-based intervention, will continue to grow and develop at a fast pace over the coming decade. Future research on methodological issues related to how to improve the effectiveness of the use of social media in health communication and how to engage these users in social media-based health promotion and intervention program is crucial for the success of adopting this new medium in health care.

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Chapter 5
Consumers' Selection and Use of Sources for Health Information

Yan Zhang

Abstract Health information sources for consumers become increasingly diverse, ranging from traditional interpersonal and mass media sources to internet-based websites and a wide variety of user-generated social media-based sources. The quality of information in different sources varies widely and the overall quality is worrisome. As the first step in information seeking, selecting proper sources is critical for successful health information seeking and subsequently, health decision-making. Thus, it is important to understand how consumers select and use different sources to access health information. This chapter begins with an overview of various health information sources available for consumers and explanation of why we should study consumer source selection behavior. Then, popular theoretical perspectives to understand source selection are introduced, followed by a review of consumers' source preferences, actual behavior of selecting and using a particular source or combinations of multiple sources, and source selection criteria. Finally, several future research directions are outlined.

5.1 Health Information Sources

Information sources are entities that generate or carry content [1]. Sources can be individuals, institutions, and materialized intellectual products (e.g., books, pamphlets, and websites). As information carriers, sources have been differentiated from channels and messages. Channels refer to media through which information is delivered from sources to recipients (e.g., face-to-face, phone call, traditional

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publication, and digital networks) and messages refer to specific content hosted in sources [2, 3].

Human beings have a long history of seeking health information. Traditional sources include interpersonal sources (e.g., doctors, family, and friends), mass media (e.g., TV and radio programs, magazines, and newspapers), printed materials (e.g., books and pamphlets), and telephone advice lines [4–7]. The emergence of the internet in the 1990s provided a new conduit for the transfer of information and enabled a number of new forms of sources, including emails, live chat services, online databases, and websites [8, 9]. These sources made health information more accessible to general health consumers. Nevertheless, technological barriers limited content publishers to those who have capabilities to own and use the technologies, and subsequently the communication mode remained primarily one-way communication.

The appearance of Web 2.0 technologies, characterized by social networking, collaboration, participation, apomediation, and openness, significantly lowered the technological barriers and changed the way in which information is created and distributed [10]. Anyone who has access to the internet can publish content. They can share personal stories, participate in discussions, and collaborate with remote others with similar health concerns to construct personally relevant knowledge [11, 12]. Typical Web 2.0 sources, as carriers of collectively generated information, include wikis, blogs, social question and answer (Q&A) sites, online health communities, social networking sites (SNSs), and crowdsourcing sites. These interactive and collaborative Web 2.0 technologies significantly expand health consumers' reach to health information, allowing them to access not only expert knowledge accumulated from years of medical research and practice, but also experiential knowledge gleaned from patients' day-to-day combats with diseases [13]. While significantly enriching the internet as a source for health information (the internet here refers to a source carrier rather than an infrastructure/channel that transmits information), these social media sources have simultaneously made the online health information environment unprecedentedly diverse and complex.

Consumers' health information environment becomes even more diverse and complex with the recent development of mobile technologies, including smartphones and wearable devices. Smartphones not only enable consumers to access existing online health information sources wherever and whenever they need it, but also give rise to a new kind of information source, mobile apps, making the access to health information even more convenient. Further, smartphones and wearable devices allow individuals to track personal health indicators (e.g., exercise, diet, weight, sleep, and mood), manage conditions (e.g., Glooko for diabetes management), and change behaviors (e.g., quit smoking). These tracking activities create detailed and longitudinal personal records of chosen health indicators, constituting another new and highly personally relevant kind of information source that can inform health consumers.

5.2   Why Studying People's Selection and Use of Health Information Sources?

Selecting a source is usually the first step in information seeking [14]. People gain knowledge and form opinions based on their interactions with sources. Inevitably, the nature and quality of sources have a direct impact on the success of an information-seeking attempt, and subsequently the quality of people's health beliefs, decision-making, and health behaviors. Studies have found that well-informed people experience less anxiety and have more psychological independence in health crises [15–17], can better manage diseases, and are more able to actively participate in medical decision-making [18–22]. The impact of consulting information sources may become broader as patients are encouraged to actively participate in decision-makings concerning their own health.

However, selecting proper sources may not be an easy task. Health information sources are abundant and the quantity continues to grow. Sources also differ in many aspects. They deliver information through different channels (e.g., face-to-face, mass media, and the internet). They differ in format (e.g., text, image, and video) and interactivity, with some being static supporting only the viewing of information and some being interactive supporting collaboration and participation. They differ in the nature of information delivered, with some offering information backed up by rigorous medical research and clinical trials, some documenting individuals' accounts of their idiosyncratic experiences, and some providing simply subjective and biased opinions. Sources also differ in their relationship with content, with some being the creator of content and some only aggregators of information from other sources.

The volume and the diversity of health information sources may cause information overload. As a matter of fact, many consumers reported feeling overwhelmed, particularly by online health information and mobile apps [23, 24]. What exacerbates the situation is that sources differ in quality. In an early review, Eysenbach and colleagues [25] reviewed 79 studies that systematically searched health information for consumers on the Web and assessed the quality of the information. They found that 70% of the studies concluded that information quality is a problem, 22% were neutral, and 9% came to a positive conclusion. Nevertheless, positive studies were scored significantly lower in search and evaluation methods, signifying potential biases in the results. In a recent review, Zhang and colleagues [26] reviewed 165 articles published since 2002 that evaluated the quality of online health information for consumers. They found that 55.2% of the articles reported negative conclusions, 37% reported varying quality, 1.8% reported neutral, and only 6.1% reported positive results.

The complexity of the landscape of health information sources imposes great cognitive load on general consumers, making the navigation and selection of proper sources an increasingly challenging task [27]. Given the impact that sources have on people's health decision-making and the negative consequences of accessing low-quality health information, it is important to study how people approach, select,

and use sources to meet their specific health information needs. Such knowledge is necessary for any effort that intends to promote the general public's access to relevant and high-quality health information. I begin the discussion of consumer health information source selection behavior by outlining major theoretical perspectives to view this phenomenon in the next section.

5.3 Theoretical Perspectives for Understanding Source Selection

A general underlying assumption of studies on source selection is that people are active seekers of information and they decide what sources to choose. This is consistent with the assumptions that underscore the uses and gratifications (U&G) theory, which suggests that individuals are not passive receivers of media and that they actively select differing media and content to fulfill their needs and achieve their goals [28].

Built upon the assumptions of the U&G theory, Johnson [29] developed a Comprehensive Model of Information Seeking (CMIS). The model posits that individuals' information-seeking actions, including selection of sources, are affected by individual characteristics and information carrier factors. Individual characteristics include demographics (e.g., one's age, gender, ethnicity, and socioeconomic status), one's direct experience with the health condition of interest, perceived salience of the information (i.e., personal significance of health information to an individual), and the individual's health beliefs concerning whether a disease is preventable and controllable. Information carrier factors include the characteristics and utility of the information channels selected and used [30]. Some researchers pointed out that the carrier factors may have lower predictive power of information-seeking behavior than the model suggests, as "in many cases one channel may substitute for another" ([31], p. 154).

In information science and organizational studies, two models rooted in economics - the least effort principle and the cost-benefit model - are commonly used to guide research on people's selection of both material and human sources [32, 33]. The least effort principle advocates that people choose sources that require the least effort, suggesting that people do not act to maximize gains but rather to minimize costs or losses associated with accessing a particular source [34, 35]. The costs could be physical efforts (e.g., travel), cognitive difficulties (e.g., difficult to comprehend, usability issues), negative psychological reactions (e.g., loss of self-esteem), or monetary costs [32, 34, 36]. Cost/loss undermines source accessibility. Thus, the least effort principle prescribes that source accessibility is a dominant determinant of source selection, whereas quality plays a minor role in the decision process.

The cost-benefit model, on the contrary, proposes that individuals select information sources based on both expected benefits and expected costs of accessing

and using a source. Cost, similar to efforts/costs in the least effort principle, is often conceptualized as the accessibility of a source, whereas benefit is often conceptualized as the quality of information that the source offers. This model prescribes that quality, compared to accessibility, is more important in determining source selection.

In studying people's everyday life information-seeking (ELIS) behavior, several concepts were proposed to conceptualize the information environment in which individuals are situated to facilitate the understanding of people's source selection behaviors while performing ELIS tasks. One such concept is information field. An individual's information field represents "the typical arrangement of information stimuli to which an individual is regularly exposed" and "the information resources they routinely use" ([37], p. 570). This conceptualization is based on the idea that the physical world an individual is embedded in is comparatively stable: he/she tends to contact similar interpersonal sources (e.g., family, friends) and is routinely or regularly exposed to the same information sources (e.g., certain newspapers and websites). Thus, information field is a starting point for one's information seeking [38]. It constrains people's selection of sources and is comparatively static. Nevertheless, individuals are not all passive in shaping their information fields. They make choices about media (including both interpersonal and non-interpersonal sources) that they attend to based on their information needs and preferences [37].

A similar concept to information field is information horizons. An individual's information horizons refer to resources, such as social networks, information retrieval tools, knowledge in the mind, and personal observations, that he/she typically accesses when seeking information for different life tasks in different contexts or situations. Information horizons are determined both socially and individually [39, 40]. Building upon information horizons, Savolainen [41] argues that people may position information sources differently in their information horizons according to source selection criteria (e.g., accessibility). The most important sources are placed nearest to the information seeker (Zone 1); sources of secondary importance are placed farther away (Zone 2); and sources of marginal importance are placed even farther (Zone 3). The concept of information source horizon was proposed to represent this cognitive behavior and explain people's source preferences and selections.

Information fields, horizons, and zones tend to view individuals' information environments as socially, culturally, and historically constructed phenomena. A more action-oriented concept to contextualize the information-seeking process is information pathways. Information pathways suggest that information seeking is active and that people make mindful decisions to consult different sources (e.g., library and doctors) to meet their information needs. Source selections are situational, meaning that the selection of the subsequent sources is dependent on what people have found in previous sources and how they react to the information [37].

These concepts, namely information fields, horizons, zones, and pathways, imply that people are exposed to multiple sources. Information pathways, in particular, suggest that people use multiple sources in a sequential manner. The theory of

channel complementarity also explicitly recognizes this reality and further offers a general explanation for why people use multiple sources to acquire health information. It states that "people consuming one particular medium to gather information in one particular area are likely to consume other media that contain information in that specific area" ([42], p. 48). Later, Dutta-Bergman [43] defines complementarity in terms of content and source characteristics, explaining that people's need for content and/or source characteristics (e.g., modality, accessibility, and quality) is the driving force for the selection of multiple sources. Like the CMIS model, the theory of channel complementarity is founded on the U&G approach's basic assumption that people are active consumers of sources; but different from the CMIS model, which generally posits that characteristics of information carriers influence information-seeking behaviors, the channel complementarity theory emphasizes the potential impact of source characteristics on the selection of combinations of sources. In the next section, I review existing empirical studies on consumers' source selection and use behavior.

5.4   Consumers' Source Selection and Use Behavior

Consumers' selection and use of sources for health information are reviewed from four aspects: their source preferences, actual selection and use of sources, the use of multiple sources, and criteria that guide source selections.

5.4.1   Preferences for Health Information Sources

It is not surprising that healthcare providers are often rated as the most reliable, trusted, and preferred source of health information for their clinical expertise and experience [12, 27, 44, 45]. For example, Johnson and Meischke [46] interviewed women who had undergone mammography for specific cancer-related information from four information sources: doctors, friends/family, organizations (e.g., American Cancer Society, insurance companies, the local libraries), and media (e.g., magazines, newspapers, television, and radio), and found that although media were used the most, doctors were ranked as the most preferred source and media the least. Similarly, Hesse et al. [47], analyzing the 2002–2003 wave the Health Information National Trends Survey (HINTS), found that 49.5% of adults reported wanting to go to their physicians first, but only 10.9% actually did so, and 48.6% of these people went online first for information.

In some cases, however, people prefer to go online first. Asking respondents to rank the places that they would go for genetic testing as a way to determine their risk for cancer, Case et al. [48] found that they are most likely to first turn to the internet (46.5%), followed by a doctor (18.4%), a library (14.1%), and a family member (10.6%). Less than 1% choose friends as their first choice. The study also found

that people with higher domain knowledge are more able to name more sources and their preferences for sources. Surveying a group of seniors (aged 67–78 years) about their preferences for sources when seeking additional health information, Medlock et al. [49] found that 43.8% (46/105) of the respondents indicated that they prefer the internet followed by other non-internet sources (e.g., magazines) and healthcare professionals. This result may be explained by the timing of the searches: most respondents seek information after seeing a health care professional and fewer respondents reported seeking information to prepare for a doctor's visit or to decide if they need to see a doctor.

5.4.2 Selection and Use of Sources for Health Information

Given the diversity of consumer health information sources, I categorize them into internet sources and non-internet sources to give some level of clarity to the introduction to consumers' actual source selection and use behavior and factors that influence this behavior, but it is useful to keep in mind that many studies do not focus on consumers' selection and use of a particular source or a category of sources; rather, they include a range of sources, often including both the internet and non-internet sources.

5.4.2.1 Selection and Use of Internet Sources

Although people prefer healthcare professionals as a source for information, they often refer to the internet first and the internet is often reported as the most popular source [27, 44, 50]. Many factors shape this choice and can be roughly categorized into the following categories: individual-related factors, source factors, situation factors, and social factors [51].

With regard to individual-related factors, studies revealed that the use of the internet as a source for health information is influenced by a number of demographic factors and individuals' health status. Younger people and people who have a college education and higher income are more likely to get health information from new media, such as the internet, whereas people with less than a high school degree and lower income are more likely to refer to traditional sources such as TV and printed materials [45, 52, 53]. People who live with chronic diseases, particularly multiple conditions, are significantly less likely to use the internet for health information [52, 54]. This result is corroborated by an Annenberg National Health Communication Survey, which revealed that people with fair to poor health statuses are more likely to obtain health information from TV and healthcare providers and those with good health are more likely to use the internet [45].

In addition to demographics, the use of the internet for health information is also influenced by cognitive and psychological factors, one of which is health literacy. Surveying Latinos in Northern Manhattan, Hillyer et al. [53] found that

those with adequate health literacy are three times more likely to go online for health information compared to those with inadequate health literacy. Nevertheless, some studies found the direct impact of health literacy on the use of the internet for health information debatable. For example, analyzing data from a city-wide health literacy survey in England, Estacio and colleagues [55] found that individuals with adequate levels of health literacy are more likely to access the internet and use it to look for health information, but the significant association between adequate health literacy and using the internet for health information disappear after adjusting for demographic factors. Recent studies suggest that, to achieve a better understanding of the impact of health literacy on the use of the internet, it is necessary to study specific internet sources rather than the internet as one general source. For example, in a cross-sectional telephone survey of residents in New York State, Manganello et al. [56] found that residents' self-reported health literacy does not predict their use of the internet and smartphones, but is predictive of the selection of specific internet sources, with people with low self-reported health literacy being less likely to use search engines, but more likely to use social networking sites for health information.

With regard to source-related factors, both the CMIS model and the theory of channel complementarity suggest that source attributes and characteristics influence source selection. The internet contains a wide range of sources with varying characteristics. People's source selection decisions are inevitably influenced by the nature of these sources. For example, search engines are selected because they are a gateway to millions of sites, webpages, services, and applications [57], offer anonymity, and are easy to use [23]. Wikipedia is selected when introductory and comprehensible content is needed [51]. Social media, particularly disease-specific online health communities, are chosen because they make it possible for people to pursue answers specific to their idiosyncratic needs [58] and they offer anonymity as well as patient expertise [13, 59]. However, some people consider discussing health concerns or seeking health information on social media, particularly SNSs, inappropriate because these platforms are made for connecting with friends and disclosing health concerns could incur privacy concerns and damage one's image [51, 59].

Situation-related factors mainly refer to the nature of information needs. People are more likely to use search engines to research about serious conditions (e.g., cancer and diabetes) and stigmatized conditions (e.g., weight loss). They avoid using SNSs for sensitive and stigmatized conditions for impression management concerns [59]; instead, SNSs are more likely to be used to share and seek information on benign symptoms and conditions (e.g., flu, headache, stress, and cough) and to loath about inconveniences that these conditions incur [57, 60]. When people need personalized information, such as recommendations, advice, similar others' opinions on treatments, or social support, they often turn to online health communities, where people with similar conditions gather. In addition, the clinical subject of information needs may also have an impact. Medlock et al. [49] found that the respondents to their survey use the internet most often when seeking information about symptoms, prognosis, and treatment options, but use health professionals for

information about prescription medications, side effects, practical care information, and nutrition/exercise advice.

Source selections, like many other information behaviors, are influenced by social factors. It is common for family and friends to share news articles, blogs, or TV shows on a particular subject (e.g., vegetarian recipes). Thus, in many cases, people select a source because trusted people in their social networks use the source and/or recommend the source to them [51]. Some people would not disclose or seek health information on social networks that do not afford anonymity because of, as has briefly mentioned above, their internalized perceptions of social norms concerning privacy and social image [59]. In some cases, the use of the internet is a result of a lack of social infrastructure to support people's access to alternative sources, such as healthcare providers and social support. For example, Criss et al. [61] found that Hispanic mothers during their early motherhood use the internet due to a lack of well-established local support networks.

5.4.2.2   Selection and Use of Non-internet Sources

The selection and use of internet and non-internet sources are not entirely independent of one another; on the contrary, they are closely related. Medlock et al. [49] found that, among seniors, higher use of the internet as a source for health information is associated with higher use of non-internet sources, such as health professionals, pharmacists, leaflets, telephone information, TV, and radio. Another study found that individuals who visit their health providers more frequently pay more attention to health information on the internet [62]. These results suggest that motivations for using the internet as a source for health information may also motivate people to use non-internet sources. It is also possible that the use of the internet for health information is indicative of an individual's rich information environment or active information-seeking style, either of which is likely to have a similar impact on the use of non-internet sources.

However, not all non-internet sources are used equally; their usage across different user groups is different and is influenced and shaped by many factors. For example, the use of physicians as a source for health information differs among ethnicity groups. An analysis of the data from the 2008 Annenberg National Health Communication Survey suggested that Whites are more likely to obtain health information from healthcare providers, Hispanic persons are more likely to get health information from family and friends, and Blacks rely more on TV [45]. However, this result may not be generalized to a different sample. Based on a survey of 1503 adults living in Douglas County, Nebraska, Kelley and colleagues [63] found that Blacks, compared to non-Hispanic Whites, are more likely to report health professionals as their primary source of health information. They also found that residents who have a healthcare provider, are retried or unable to work, have no health insurance, and have less than high school education are more likely to report a health professional as the primary source for health information. Surveying patients attending two clinics in Dallas, TX, one public clinic serving primarily underserved

patients (51% Hispanic; 22.5% African American; 60% receive charity care) and the other private clinic (64% non-Hispanic white, 16% African-American, 10.5% Hispanic, 7% Asian, and 2.5% other race; 85% are privately insured), Gutierrez and colleagues (2014) found that patients in both clinics rate their healthcare providers their primary source of health information (50.6% public; 40.1% private). These results suggest that other factors, such as a lack of ability to access alternative sources (e.g., the internet) and health status (e.g., being patients), may also influence the use of healthcare providers as an information source.

It is worth noting that, although physicians are often rated as the second most popular source used [27, 44], information provided by physicians are extremely influential. Nelson et al. [64] found that, in choosing breast reconstruction treatments, patients are strongly influenced by their physicians and less so by the media and the internet.

5.4.2.3 Selection and Use of Multiple Sources

Most studies on source selections focus on factors that motivate or impact information seekers to select one particular source. The use of multiple sources has received less attention, although, in reality, people often consult several different sources in their journey of seeking information for their health concerns or problems [27, 65–67]. Using multiple sources has a positive impact on one's healthcare decision-making and health behavior. Gopie et al. [68] found that women who chose Deep inferior epigastric perforator (DIEP) flap (DiepBR), a breast reconstruction option, over implant reconstructions (ImBR) a more traditional option received by most mastectomy patients, are more likely to be independent and active decision makers; and these women reported using different information resources to be very important. Gargano and colleagues [69] reported that parents with three or more reported sources of information about influenza vaccine are twice more likely to have had their adolescents receive the influenza vaccine compared to parents with fewer sources of information.

As mentioned earlier, the theory of channel complementarity explains that seeking information from multiple sources is driven by people's need for content, as well as by source characteristics. The need for content as a driving force receives some support from the empirical evidence that the use of the internet for health information is positively correlated with the use of traditional media such as health professionals, TV, newspapers, magazines, and radio [49, 62]. Qualitative studies further reveal that the use of multiple sources not only makes people receive more information, but also helps them validate information for consistency and resolve contradictory information emerged in information seeking [61, 67]. The impact of source characteristics also receives some support. Ruppel and Rains [66] analyzed the 2007–2008 wave of the HINTS and found that people pay attention to source tailorability and anonymity in their health information search process and that they are more likely to use sources that are complementary in terms of these two attributes.

Studies also have identified other factors that influence the selection of multiple sources. One such factor is demographics. Cancer survivors who sought health information from more than five sources (e.g., doctors, internet, family, pamphlets, TV, and radio), compared to those who sought information from less than five sources, are more likely to be women, have higher levels of education, and report fewer problems with cancer information seeking [70]. The other factor is information-seeking stage. Analyzing the HINITS data, Ruppel and Rains [66] found that people seem to value medical expertise and anonymity (for privacy concerns) at the onset of a medical condition so they use sources complementarily with regard to access to medical expertise and anonymity; whereas when the illness and information search progress, they tend to use sources complementarily in regard to tailorability and convenience. In a qualitative inquiry of young people's health information-seeking behavior in response to a particular health concern, Zhang [67] found that the first or the second source that the participants referred to tend to be sources convenient to access, including search engines, friends, specific health websites, or parents. Doctors appear later in the information-seeking process as the third, fourth, or fifth source, partially due to the time required to schedule a doctoral visit. The differing results from the two studies may be explained by the health conditions of interest. Ruppel and Rains' study is based on HINTS and focuses on the use of cancer-related information by the American public [71], whereas Zhang's study concerns people's everyday life health information searches ranging from minor health and wellness concerns (e.g., lose weight and flu) to self-diagnosing certain symptoms and researching treatments for a known condition (e.g., back injuries). It seems that the nature of health conditions may moderate the kind of sources used at different stages of information seeking.

5.4.3 Source Selection Criteria

The previous sections reviewed consumers' preferences for sources and factors that influence their source selection behaviors. This section focuses on source selection criteria. Criteria are rules or filters that people apply to sources to assess their value or worth [72]. Criteria are, by nature, cognitive constructs, and they mediate source selection decisions.

Interviewing general health consumers about their selection of both internet and non-internet sources to address personal health concerns, Zhang [51] identified ten criteria that guide source selections: quality, accessibility, usability, interactivity, relevance, usefulness, familiarity, affection (whether an individual likes a source), anonymity, and social appropriateness. Among them, quality and accessibility are the most examined criteria. Quality has two dimensions, trustworthiness and authoritativeness, with the former referring to the incentive for a source to be truthful or biased, and the latter referring to whether the content is truthful or correct. These two dimensions tend to co-mingle [3]. In some studies, quality is indicated by trust.

People who have higher levels of trust in a site are more likely to use the site as a preferred source of information [73].

Quality is an abstract concept. In practice, it is perceived or constructed through a number of source attributes. When judging the quality of healthcare providers, the attributes used often are their educational background, specialties, affiliations, and experiences. When judging the quality of family and friends as a health information source, the attributes are occupation, the strength of the social tie, whether they had first-hand experience, or whether they read a lot [51]. When evaluating the quality of websites, the attributes used are brand (e.g., WebMD and the National Library of Medicine), scope (the range of information covered), look and feel, editorial process, popularity, and medium platforms (e.g., books and SNSs). Attributes of the content included in the websites are also used as quality indicators, including author/provider, publication date, advertisements, misspellings, as well as the accuracy and completeness of the content. Accuracy refers to whether the information is accurate. Completeness refers to whether information concerning an important aspect of a subject is provided, such as side effects of a particular medication (e.g., [25, 51]). Both accuracy and completeness are often judged by comparing the content from the source to one's own existing knowledge or to information from other sources (e.g., [74]).

Accessibility refers to whether a source is easy to access [36]. Sources are accessible when they are always available (e.g., the internet, Google), appear on the top of Google's search results pages, with in a reasonable physical distance (e.g., libraries), and could be reached within an acceptable time frame (e.g., scheduling an appointment with doctors takes time [51]).

Usability refers to whether a source, mostly computer-based, is easy to use or not; more specifically, whether a source offers sufficient functionality to support information-seeking and learning activities (e.g., searching by conditions, symptom checker, and supporting content comparison), and whether these functionalities are effective and intuitive to use. Usability also refers to whether a source presents information in a logical way that supports smooth navigation [51].

Interactivity refers to the ways in which people can interact with a source, which could be internet and non-internet sources. Concerning internet sources, interactivity could refer to whether a website provides multimedia content [75], how the content is delivered to users (e.g., pushing content to users through mail or email), what actions users can perform (e.g., whether they can highlight, annotate, or track data over time), as well as whether sources can effectively tailor to individuals' immediate needs [51]. Concerning non-internet sources, interactivity often refers to communication mode. For example, compared with computer-mediated communication, face-to-face communication (i.e., doctor visits) is often preferred for rich interaction cues and the immediacy of responses that it affords. Some people prefer to read books because books, as a communication channel, allow them to "have something tangible" in hand and "highlight notes and refer back to it" ([51], p. 917).

Being relevant is a necessary condition for selecting a source. In line with the extensive literature on relevance judgment in document selection in the field of information studies (e.g., [76, 77]), being relevant indicates that the content of a health information source is about the topic of concern, is of interest to the information seeker, and is pertinent to his/her situations [51]. It is worth noting that, in the social media environment (e.g., online health communities) where sources could be peer users, relevance could refer to whether a source has a shared experience with the information seeker with regard to diagnoses, treatments, or medications, share similar goals (e.g., losing weight), or whether the source is similar to the seeker on demographics (e.g., age and gender), geographic location, or disease stage [78].

Being relevant does not warrant a source to be selected. A source also has to be useful. Usefulness indicates the utility of a source. In order for a source to be useful, the content needs to be presented in preferred formats (e.g., video and image), specific (i.e., providing a sufficient level of detail concerning a topic), and readable (i.e., content is easy to understand, [51]).

Familiarity refers to whether an individual is familiar with a particular source, mostly based on previous experiences, that is, whether a source has served the individual well in the past [51]. Affection, whether an individual likes a source or not, also appears as a criterion that guides people's selection of sources. For example, one participant in Zhang ([51], p. 919) cited personal attitudes towards the government as a reason for not using government sources, and the other participant attributed nonuse of Wikipedia to "It is just not a favored source of mine."

Anonymity refers to whether a source allows individuals to remain anonymous while using the source. Some people are less likely to use interpersonal sources and SNSs that disclose personal identities, but more likely to use sources that allow anonymity, to protect privacy, avoid potential risks, and manage personal image [12, 23, 59]. Appropriateness refers to whether an individual considers using a particular source for health information is appropriate or not, based on one's internalized social norms. This criterion is particularly relevant when it comes to discussing health issues with other people. Some people would discuss health concerns only with family and friends, but some consider seeking health information, particularly serious conditions, from friends inappropriate [51].

The aforementioned topology of criteria is only a way to categorize criteria that consumers apply to reach source selection decisions. There are other ways to understand and categorize these criteria. For example, Fidel and Green [36] uncovered twelve different factors associated with accessibility, including sources that I know, have a lot of different types of information in one place, can give the right of level of detail, save time, have the right format, save time with which I feel comfortable, are physically close, can be searched with keywords or codes, are interactive, are not busy, and are accessible. According to this delineation of accessibility, numerous criteria reviewed here, such as usability, interactivity, usefulness, and familiarity, can be encapsulated under the roof of accessibility.

5.5   Future Research Directions

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. It is fair to predict that health information sources will grow in volume, variety, and complexity with the continuous development of information technologies; the difference in quality among sources may continue to grow as well. This presents many interesting questions for future research. For example, do information sources based on emerging new technologies help address the digital divide in health information access or widen it? Many existing studies point out the impact of structural differences (e.g., social economic status) on people's use of health information sources, including healthcare providers, the internet in general, and Web 2.0 health sources in particular remains (e.g., [79, 80]). A further question that merits investigation is what can be done to ensure that different user groups, particularly those underserved, have equal opportunities to access, explore, and benefit from new emerging technologies?

Another direction worth to pursue is the use of multiple sources. The majority of the current studies focus on factors (e.g., demographics, health conditions, and health information needs) influencing people's selection of one particular source. However, in reality, people use multiple sources to address health concerns. Researchers started paying attention to people's use of multiple sources. Factors (e.g., those related to source and to individual differences) influencing the selection of multiple sources have been identified, but many important questions remain, for example, how factors, such as information search stages (e.g., the onset of information search, and as search progresses) and disease characteristics (e.g., severity, whether it is stigmatized), influence the combination of sources? How different source combinations impact information seekers' search outcomes, health decision-making, and health behaviors? What are the optimal combinations of sources for diseases with different characteristics?

Selecting sources is not a random human behavior (e.g., [66]). Future efforts should also be dedicated to developing theories to explain and predict health information seekers' source selection behaviors. Existing theories and models, such as the cost and benefit theory, CMIS, and the theory of channel complementarity, provide valuable conceptual tools to guide the research in this area. However, further developments are needed. For example, major constructs, such as media characteristics in the CMIS model and complementarity in the theory of channel complementarity, could be further specified and developed to provide clearer guidance to future research questions or hypotheses. New constructs could be incorporated into these theories or models, such as people's health literacy, disease characteristics, and the nature of health information needs, as these concepts were found to be associated with source selection behaviors. Moreover, new theoretical perspectives, particularly perspectives that take into account the social and cultural-historical nature of people's exposure to sources, could be used as theoretical lens to understand source selection as a human information behavior or a health behavior.

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Chapter 6
Understanding and Bridging the Language and Terminology Gap Between Health Professionals and Consumers Using Social Media

Zhe He

Abstract The advancement of the Internet and the social media has engaged the general public in their own healthcare more than ever. People actively seek health information online, form online patient communities to share experiences, and seek social support. Nevertheless, the limited health literacy of lay people makes it difficult for them to find the relevant health information, understand and reconcile conflicting findings. To improve health literacy and reduce the language barriers for lay people, it is important to understand the language and terminology gap between health professionals and consumers. eHealth literacy, which is defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem, is an important factor of the gap. This chapter discusses eHealth literacy, its measurements, as well as methods and practice of harnessing social media to understand and bridge the terminology gap between professionals and consumers. This chapter also discusses future opportunities for developing health applications for consumers that are more adaptive to their health literacy level while preserving the accuracy of the information.

Keywords Health vocabulary · Consumer · Health literacy

6.1 Introduction

With the increasing availability of online health information and social media platform, patient engagement and participation in their healthcare become increasingly important in improving health outcomes and reducing healthcare costs [1, 2]. Patients, particularly those with chronic medical conditions, are encouraged to

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discuss health goals and factors associated with increased health risk with their providers and peers [3]. Started in 2010, the OpenNotes initiative aims to make healthcare more open and transparent by urging doctors, nurses, therapists, and other healthcare providers to share their clinical notes with patients [4, 5]. In the acute care setting, with the access to the clinical notes, patients reported improved access to information, better insight into their conditions, decreased anxiety, increased appreciation for clinicians, improvements in health behaviors, and more engagement in care [6].

Along with participatory medicine, in the past few decades, the rapidly growing social media platforms on the web such as PatientsLikeMe also allowed consumers (e.g., patients or caregivers) to seek health information about treatments, share experiences of care, express concerns, and provide/get social support on a variety of platforms over the Internet [7]. A recent Pew Research Center study reported that over 70% of adults in the United States searched online for health information, making it the third most popular online activity behind email (93%) and searching a product or service before purchase (83%) [8, 9]. Younger consumers are more likely to research health topics online than senior citizens.

Besides direct interaction with health professionals in the clinical setting, consumers also receive health consultations from online health professional moderators with clinical expertise [10]. In addition, health researchers disseminate their findings and knowledge to the public through scientific publications and consumer-facing health information portals. Health professionals exchange care information with patients through patient portals [11]. Although, generally speaking, people have easier access to health information in the social media age, patients with limited health literacy and education often find it difficult to understand and appraise health information with medical jargons and complex sentence structure [12]. There are several reasons for this. First, the health information available to consumers online varies widely in quality [13]. There is a mix of online health information based on experiences rather than scientific experiments. Even rigorously designed and conducted research studies published in peer-reviewed journals report different results under different controlled contexts. Social media allow its users to distribute eye-catching research findings widely in a short period of time. Second, a language and terminology gap exists between health consumers and healthcare professionals [14–16]. Health professionals often use complex medical jargons that are not familiar to consumers [17]. For example, ordinary consumers may use "high blood cholesterol" and "heart attack" to describe their conditions, whereas health professionals may use "hyperlipidemia" and "myocardial infarction" for these conditions. This gap may impact the effectiveness of consumers' communication with their health providers [17], understanding of their electronic health records [18], health information seeking [16, 19, 20], and subsequent decision making regarding their health issues [21].

With a deeper understanding of the language and terminology gap between health professionals and consumers, online health information and messages can be tailored for the patients with average health literacy. Health message tailoring has been shown to improve the effectiveness of health messages at an individual level by increasing its perceived relevance, drawing the attention, and encouraging

deeper comprehension of the information in the messages [22]. The vast amount of health documents written by health professionals and consumer-facing social media platforms provides rich resources for analyzing the terminology gap between health consumers and professionals. Further, methods, resources, and applications can be developed to bridge the gap between health professionals and consumers. eHealth literacy, which was originally defined by Norman and Skinner [23] as "*the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem,*" is an important factor of the gap. In this chapter, we will first discuss eHealth literacy and its measurements. Then we will discuss traditional approaches to assess eHealth literacy and the terminology gap between professionals and consumers. We will review the recent efforts and discuss future directions in understanding and bridging this gap using social media.

6.2   eHealth Literacy and Its Measurements

6.2.1   eHealth Literacy

When Norman and Skinner first defined eHealth literacy [23], they categorized the core literacies into context-specific (e.g., health, computer, and science literacies) and analytic-specific (i.e., traditional, information, and media literacies). The analytic component involves skills that are applicable to a broad range of information sources irrespective of the topic or context, while the context-specific component relies on more situation-specific skills. Computer literacy is dependent on the type of computer, its operating system, and intended applications. Scientific literacy is applied to research-related information. Health literacy is contextualized to health issues. Traditional literacy is about the basic skills such as the ability to read text, understand written messages, and speak and write a language coherently. Information literacy concerns "*how knowledge is organized, how to find information, and how to use information in such a way that others can learn from them*" [24]. Media literacy is a means of critically thinking about media content and is defined as a process to "*develop metacognitive reflective strategies by means of study*" [25]. eHealth literacy may be influenced by factors such as education level, age, hearing-impaired status, and race/ethnicity. It is multi-faceted and includes the abilities to obtain (via reading or listening), understand, and interpret within the context of one's own perspective, communicate with health professionals to confirm interpretations or correct misunderstandings, and then utilize information to make appropriate decisions regarding their health care. Complex health conditions, which require complex management regimens, significant symptoms, and/or treatment with substantial side effects, necessitate health literate communications. Recent research has found that patients with high eHealth literacy make more informed decisions about their healthcare [26].

6.2.2 Measurement of eHealth Literacy and Vocabulary Understanding

In the past, researchers have developed a number of measurements to measure eHealth literacy. Most of the existing measurements are conducted in the form of surveys [27]. In 2006, Norman and Skinner [28] developed the eHealth Literacy Scale (eHEALS), which is an 8-item scale that measures consumers' knowledge and perceived confidence in their ability to seek, understand, and evaluate health information on the Internet. The eHEALS assesses three factors, including (1) the awareness and learning about what online resources are available and where they are located, (2) skills and behaviors needed to access Internet-based health resources, and (3) the self-belief in one's ability to evaluate the accessed online health contents. The eHEALS have been applied to measure eHealth literacy in adolescents [28], college students [29], adults [29], older adults recruited on the Internet [30], and people with chronic diseases [31]. It has also been translated into many different languages including German, Italian, Chinese, etc. Quite a few studies have evaluated the validity of the eHEALS [30, 32, 33]. Some recent studies have examined the Web-based survey methods, which are becoming more popular due to recruitment efficiency and low cost [30, 34]. However, analyzing data collected purely online may pose questions on the reliability of the assessment due to the sampling bias. It is intuitive that older adults who can complete online surveys are more confident in their online health information-seeking skills. This may partly explain why some studies reported moderate to high eHealth literacy in older adults. To reduce the sampling bias in the Web-based survey, Neter and Brainin [35] conducted a nationally representative random digital dial telephone survey of Israeli adults aged 50 years and older to measure their perceived eHealth literacy measured by eHEALS. No psychometric data on eHEALS response was reported in this age-restricted sample. Stellefson et al. [27] recently examined the reliability, validity, and internal structure of eHEALS data in the telephone-based cross-sectional survey among older adults. They demonstrated that administering eHEALS to older adults via telephone is a reliable way to measure their eHealth literacy.

Medical terminology is a major cause for the elevated readability level with most online resources [36]. It impacts the self-belief in one's ability to evaluate online health content once accessed. The questions in the eHEALS about this factor are mostly on the perception level. Besides eHEALS, vocabulary assessments are often conducted in the form of surveys [37], focus groups [38], in-depth interviews [39], and Internet-based video conferences [40]. The assessment questions may be based on perception, spelling, or vocabulary testing [40]. For example, they may be multiple choice questions on analogy of terms, similar to those in the Graduate Record Examinations (GRE) administered by the Educational Testing Service (ETS).

6.3 Automaed Techniques for Analyzing the Complexity and Semantics of Text

Automated techniques to evaluate the language complexity of English text can be broadly categorized into readability assessment and natural language processing (NLP)-based assessment. Readability is usually assessed by traditional readability metrics. However, readability scores are empirical and superficial. They can measure the complexity of text, but not the complexity of vocabularies. With the advent of social web and biomedical ontologies, NLP-based methods have been developed to measure the complexity and familarity of vocabularies to consumers. NLP-based analysis can be conducted on these five levels: morphology, part-of-speech (POS) tagging, syntax analysis, semantic analysis, and discourse integration. In the following, the details of these techniques for the language complexity analysis are given.

6.3.1 Readability Assessment

Traditional readability metrics utilized some superficial text properties (e.g., average number of syllables per word, number of letters per word, number of words per sentence) to evaluate the complexity of the texts for people to comprehend [41]. Even though not designed specifically for the health domain, they have been used to measure the readability of health-related text. Major readability scores include Flesch-Kincaid Grade Level [42], the Gunning FOG index [43], and SMOG (Simple Measure of Gobbledygook) [44].

- Flesch-Kincaid Grade Level (FKGL) assigns a grade level to indicate the minimum schooling (grade) readers should have accomplished to understand the texts [42]. FKGL assumes that the more syllables per word and words per sentence, the more complex the text is. The scores of FKGL are matched to the school levels from fifth grade to college graduate. FKGL test was developed in 1975 by J. Peter Kincaid and his team.
- The Gunning FOG index takes into acount the average sentence length and the percentage of polysyllabic words (i.e., with at least three syllables) [43]. The limitation of FOG index is that not all the complex words are difficult. The short words can be difficult if it is not often used by most people. The FOG index can be also mapped to the school levels from sixth grade to college graduate. It was developed in 1952 by Robert Gunning, an American businessman.
- SMOG grades calculate the coverage of polysyllabic words per sentence [44]. Essentially, the more polysyllabic words, the higher the Gunning FOG and the SMOG score, and more difficult the texts are. It was developed by G. Harry McLaughlin. SMOG is widely used, especially for evaluating the readability of health messages [45]. It is a more accurate and easily calculated substitute for

the Gunning FOG index. It has been also recognized as the preferred measure of readability when evaluating consumer-facing healthcare material [46]. Compared to SMOG grades, FKGL significantly underestimated the reading difficulty [46].

6.3.2 Syntax Analysis

Syntax-level complexity utilized part-of-speech (POS) distribution to evaluate the complexity of health texts. In general, there are ten commonly used POS tags in English. The syntax analysis concerns about the POS tags of the words in a sentence. They can be categorized into content word (i.e., noun, adjective, verb, adverb) and functional word (i.e., pronoun, determiner, preposition, qualifier, conjunction, interjection) [47].

Content words mainly include nouns, verbs, adjectives, and adverbs [48]. A noun tells us which object. A verb tells us the action happening, or the state. Adjectives give us details about objects and people. Adverbs tell us how, when, or where something is done. Nouns, verbs, adjectives, and adverbs give us important information required for understanding a sentence. Besides the important content words like nouns, verbs, and adverbs, there are a few other words that are important for understanding the text, including negatives (e.g., no, not), demonstrative pronouns (e.g., this, that, these, and those), and question words (e.g., what, who, why, when, and how). Functional words help connect important information, including auxiliary verbs, prepositions, articles, conjunctions, determiner, qualifier, pronouns, and interjection. Auxiliary verbs are used to establish the tense. Prepositions show relationships in time and space. Articles show us something that is specific or one of many. Pronouns refer to other nouns.

The frequencies of occurrence of different POS tags (e.g., adjectives, determiner, interjection, noun) are regarded as an estimate of readability [41, 49]: a higher percentage of content words usually indicates a more complex text. Higher percentage of function words spaces out the content words, making them easier to assimilate. To conduct such a syntatic analysis, one can use standard NLP parsers such as Stanford CoreNLP toolkit or Natural Language Toolkit (NLTK) to parse the POS tags of the text and calculate the percentage of content words in the text to quantify the text complexity.

6.3.3 Semantic Analysis

Semantic analysis concerns the practical meaning of the content. The semantic analysis often involves the extraction of relevant and useful concepts from large textual corpus and discover the meaning of the concepts. In the biomedical and health domain, various medical controlled vocabularies have been developed in the past few decades. The Unified Medical Language System (UMLS) is a compendium

of more than 170 biomedical controlled terminologies and ontologies [50]. It has a two-level structure: the Metathesaurus [51, 52] and the Semantic Network [53]. The Metathesaurus contains over three million concepts and over ten million terms. The terms with the same meaning are mapped to the same concept in the UMLS. The Semantic Network consists of 127 broad semantic categories, called semantics types. One or more semantic types are assigned to each concept in the Metathesaurus, describing the semantics of the concept by identifying its broad category or categories. For example, the concept *Dental Fistula* is assigned semantic type "Anatomical Abnormality".

Semantic types can provide an indication of the diversity of topics discussed in each document. Semantic-level complexity concerns the complexity resulted from the content meaning of health texts. It is assumed that if the health textual corpus includes more diverse health topics, it is more difficult for consumers to comprehend [54]. Using the UMLS, the general process of semantic analysis of text involves extracting noun phrases in the text, mapping them to the UMLS concepts, and then analyze the semantic types of the concepts.

6.4 Using Social Media to Understand the Language Gap Between Health Professionals and Consumers

To analyze the terminology gap between health professionals and consumers, researchers have applied text mining and natural language processing techniques to consumer-generated text such as query logs of search engines and surveys [55]. Recently, various types of social media have been used for such an analysis. Some popular data sources include WebMD, Yahoo!Answers, MedLinePlus, Patients-LikeMe, Tumblr, and National Library of Medicine's Consumer Health Questions [55–59]. These studies resulted in a better understanding of the language gap between health professionals and consumers. These efforts are briefly reviewed as follows.

Roberts and Demner-Fushman [55] used NLP techniques to analyze the difference between health questions asked by consumers and health professionals by comparing consumer corpora (e.g., Yahoo! Answers, WebMD community, Doctorspring, Genetic and Rare Diseases Information Center, and NLM's Consumer Health Questions sites) and health professional's corpora (e.g., Parkhurst Exchange, Journal of Family Practice). They found that consumer questions tend to contain more misspelled medical terms, have longer background information, and resemble open-domain language more closely than texts written by professionals.

Zeng and colleagues [56] analyzed the difference of vocabulary used by consumers and health professions using the search log of Brigham and Women's Hospital (BWH). They used the IP addresses in the search logs to differentiate and construct datasets including the queries written by consumers and professionals (faculty and staff). They analyzed the common terms, misspelling rate, mapping

rate to the UMLS, semantic types, and their impact on information retrieval between these two datasets. They observed that only 10% unique terms are shared by consumers and professionals. Similar to the results reported by Roberts and Demner-Fushman [55], they also found more consumer terms are misspelt than clinician terms. A higher percentage of clinician terms can be mapped to the UMLS than the consumer terms. When searching online health information, using only consumer terms leads to poor search results. Later, Plovnick and Zeng [57] reformulated consumers' health queries with professional terminology and about 40% reformulated queries yielded better search performance.

Park et al. [58] recently assessed the UMLS terminology coverage in the Yahoo! Answers dataset and Tumblr databset. They found that 12 semantic types in the UMLS can cover more than 80% of the medical terms in the two corpora: "Amino Acid, Peptide, or Protein," "Body Part, Organ, or Organ Component," "Disease or Syndrome," "Finding," "Medical Device," "Organic Chemical," "Pharmacologic Substance," "Sign or Symptom," "Therapeutic or Preventive Procedure," "Finding," "Pharmacologic Substance," and "Disease or Syndrome." In addition, they did not find a significant difference between the questions and the answers with respect to the frequently used terms and semantic types.

Yu and He [59] recently conducted a study to compare the text and vocabulary complexity between the general public and people who are deaf or hard of hearing through the analysis of their respective online health communities. They observed that general patients did not use significantly more complex health texts and health vocabularies than deaf people.

6.5 Using Social Media to Bridge the Language Gap Between Health Professionals and Consumers

6.5.1 Identifying Consumer Terms from Social Media

New findings and new terms in the medical domain are constantly evolving in speed [60], and the usage of different keywords in searching may result in varying effectiveness [20]. To bridge the vocabulary gap between health professionals and consumers, early researchers have collected and analyzed diverse textual data generated by consumers to identify medical terms used commonly by consumers. These early work facilitated lay people's access to electronic knowledge resources and assisted the development of consumer-facing tools for linking complex clinical notes of external knowledge sources.

Smith and colleagues' paper published in AMIA 2002 Annual Symposium represents the earliest known work on identifying consumer concepts for controlled vocabularies [61]. They used MetaMap to identify the UMLS concepts used by consumers in the email messages submitted to University of Pittsburgh Cancer Institute's Cancer Information and Referral Service. These studies aimed to bridge

the vocabulary gap between health professionals and consumers by identifying frequently used consumer health terms that are relevant in developing consumer-oriented health information applications and linking free text to complex clinical knowledge resources.

In 2003, Brennan and Aronson's paper published in the Journal of Biomedical Informatics is also among one of the earliest works on identifying consumer concepts for controlled vocabularies [62]. They also used MetaMap to extract salient concepts from a sample of electronic messages sent by patients participating in a randomized field evaluation of an internet-based home care support service to the project nurse. They focused on finding concepts and terms from six standard vocabularies such as International Classification of Primary Care and National Drug Data File to enrich six nursing vocabularies such as Nursing Interventions Classification and Omaha System.

6.5.2   Building Consumer Health Vocabularies

6.5.2.1   Biomedical Ontologies and Controlled Vocabularies

In the big data era, the management and integration of large datasets provides enormous opportunities for the discovery of new knowledge. Ontologies and controlled vocabularies organize the domain knowledge in the form of relevant concepts/classes and relationships among them. They provide the necessary tools to overcome barriers when integrating data and knowledge from heterogeneous datasets, thereby facilitating knowledge discovery. In the biomedical domain, biomedical ontologies and controlled vocabularies lay a solid foundation in the healthcare information systems for encoding diagnoses, problem lists [63, 64], and laboratory tests in electronic health records [65] as well as in administrative documents such as billing statements [66] and insurance claims. Moreover, with concepts/classes linked by rich taxonomic and lateral relationships, biomedical ontologies play a vital role in knowledge representation and management, data integration, decision support, and natural language processing [67].

A controlled vocabulary is "an organized arrangement of words and phrases used to index content and/or to retrieve content through browsing or searching" [68]. To formalize the real-world knowledge, thousands of application ontologies and controlled vocabularies have been developed. In the biomedicine and health domain, two widely known repositories of controlled vocabularies and ontologies are BioPortal of the National Center for Biomedical Ontology (NCBO) and the Open Biological and Biomedical Ontology (OBO) Foundry [69].

It should be noted that there are similarities and differences between terminology, controlled vocabularies, and ontologies. Terminologies and vocabularies focus on representing the lexical terms that are used to designate knowledge. They can be as simple as a flat list of terms, but they can also provide hierarchical ordering (rendering it a taxonomy), definitions (in which case it can be called a vocabulary),

or codes (making it a coding system). Ontologies focus on the explicit representation of meaning, by defining a set of concepts (as classes) and relationships between them. This is done increasingly using logic-based representation languages such as Web Ontology Language (OWL). Classifications provide hierarchical ordering through classes, which are generally pairwise disjoint, by means of classification rules, and mutual exhaustiveness, by introduction of residual categories "not elsewhere classified." In the biomedical domain, due to the fact that most widely used controlled vocabularies such as SNOMED CT and NCIt were developed based on the Description Logic, they are often regarded as ontologies as well.

6.5.2.2 Open-Access and Collaborative Consumer Health Vocabulary

In an effort to formalize consumer vocabulary for various applications, a controlled vocabulary called Open-Access Collaborative Consumer Health Vocabulary ("OAC CHV," "CHV" for short) was developed in 2006 as a collection of expressions and concepts that are commonly used by ordinary health information users [70]. Importantly, CHV has been integrated in the UMLS, which has mapped terms from different source vocabularies with the same meaning into the same concept by the U.S. National Library of Medicine. As such, consumer terms are connected to their corresponding professional terms in professional vocabularies such as SNOMED CT. With CHV in the UMLS, one can translate a sentence with consumer terms to a sentence with professional terms in an automated fashion.

Domain coverage—the extent to which a controlled vocabulary covers the intended domain—is one of the most desired properties for a controlled vocabulary [71, 72]. The usability and the overall structure of a controlled vocabulary heavily rely upon its coverage [73]. Traditionally, controlled vocabulary development takes a top-down approach, which reflects a group of experts' knowledge in the respective subject matter [74, 75]. For the development of CHV, however, a bottom-up approach was taken, emphasizing two fundamental properties: (1) CHV should capture actual consumers' terms and expressions that reflect their health information needs, and (2) the expressions should be familiar to and used by consumers [70]. According to the development guildline of CHV [76], there are seven human review criteria to determine whether a term should be a term in CHV: (1) CHV terms should be syntactic constituents or phrases such as noun phrases or adjectival phrases; (2) CHV terms should have independent semantics and should not only occur as a part of longer valid terms or as a part of wild card searches; (3) CHV terms should be specific to the medical domain; (4) CHV terms should function as semantic components; (5) "n-grams" (n-grams are n consecutive words within a sentence) representing UMLS concepts are considered to be CHV terms, but CHV terms may represent non-UMLS concepts; (6) CHV terms may be eponymous forms; and (7) CHV terms may include spelling errors.

6.5.2.3 Other Consumer Health Vocabularies

Besides OAC CHV, other proprietary consumer health vocabularies have been developed. For example, Apelon has developed a CHV and has mapped their CHV terms to corresponding clinical concepts in SNOMED RT (an earlier version of SNOMED CT, developed by College of American Pathologists), ICD-9-CM, and Physician's Current Procedural Terminology (CPT) administrative codes. The CHV of Apelon has been used in various applications, such as consumer health data entry, patient results reporting clinical note translation, and web-based information retrieval [77]. Mayo Clinic also developed their own consumer health vocabulary, which has a rich content of disease concepts as well as genetic and nongenetic risk factors to diseases [19].

6.6 Future Directions

6.6.1 Comprehensive Evaluation of the Readability of the Online Health Resources

In the past, researchers have used the readability scores to evaluate the readability of online health resources. Wu et al. [78] compared the readability of trial descriptions in ClinicalTrials.gov, MedLinePlus health topic articles, and a random sample of clinical notes and found that the ClinicalTrials.gov trial descriptions are the most difficult corpus to read, even harder than clinical notes written by clinicians and nurses. This limits the capacity of ClinicalTrials.gov of making trial information accessible for the general public to accelarate subject recruitment. Future work is thus warranted to improve the readability of ClinicalTrials.gov. Ibrahim et al. [79] assessed the readability of ten top accessed websites for melanoma information and found that the online patient resources for melanoma uniformly exceed the recommended reading level and may be too difficult for many Americans to understand.

In the Web 2.0, online health information is broadly consumed by Internet users [8, 9]. Therefore, it should be a common practice to evaluate the readability of the online health resources to make sure that they are understandable by consumers with moderate literacy. At present, there is no systematic approach to evaluate the text complexity of health consumers' language. A health text complexity measurement framework should be developed to automatically assess the complexity of consumer health language. This will guide the adaption of online health information for different types of consumers, based on their preferred text complexity levels.

6.6.2 Collaborative Development of Consumer Health Vocabularies

To keep up with ever-changing medical knowledge, CHV needs to be continuously updated with new terms [70]. Professional vocabularies are mostly curated by professional organizations with a team of domain experts. On the other hand, the development of CHV employs an open-access and collaborative approach [80]. Existing studies have shown promising results in discovering consumer terms for CHV from texts on various platforms including social media [81–83], MedLinePlus [84], and Wikipedia [85]. Vydiswaran et al. [85] applied a pattern-based text mining approach to identify pairs of consumer and professional terms from Wikipedia. Doing-Harris and colleagues [82] developed a computer-assisted CHV update system, which can automatically identify prospective terms from social media. Identifying terms used by consumers in consumer-generated text in aggregate fashion can account for the variability of lay health language. These terms can be used to refine and enrich CHV [70].

However, these studies mostly reply on ad hoc lexical patterns and laborious human review, thereby limiting their scalability. He et al. [86] recently developed a tool called simiTerm to identify consumer terms that are syntactically and contextually similar to existing terms in CHV. The simiTerm algorithm first extracts the frequent n-grams from a text corpus, then represents the n-grams with a set of predefined features including basic statistical features (e.g., term frequency, inverse document frequency), syntactic features (patterns of part-of-speech tags), capitalization, prefix/suffix, part-of-speech of the surrounding words, and semantic features (e.g., semantic types of the surrounding words). Then the existing terms in CHV are used as the training data for the clustering-based model. The non-CHV terms that are close to the cluster centroids are ranked for subsequent human review. This method has been demonstrated to be effective in finding useful consumer terms from social media, while automatically fitting in the scope of CHV. Chen et al. [87] developed an unsupervised ensemble ranking model derived from the biased random walk algorithm to combine heterogeneous information resources for ranking candidate terms from each EHR note. This method can be used to guide the development of CHV with a focus on terms that more important to patients. This method has been recently improved by the same group as an adapted distant supervision method [88]. Adapted distant supervision uses distant supervision from Consumer Health Vocabulary and transfer learning to adapt itself to solve the problem of ranking EHR terms in the target domain.

Even though methods for identifying consumer terms from social media are being developed, there is no formal mechanism for submitting new terms to OAC CHV. As such, OAC CHV is not sufficiently maintained. The original website of OAC CHV (consumerhealthvocab.org) is no longer accessbile. The most recent version of OAC CHV (in 2017AA release of the UMLS) was developed in 2011. In the future, a new mechanism of collaborative development of Consumer Health

Vocabulary should be established to allow researchers submit the useful new consumer terms to the vocabulary. Further, a new team should be formed to take the charge of the continous development and maintainance of OAC CHV.

In ontologies, omissions, redundancies, errors, and inconsistencies are inevitable. Thus, ontology evaluation is an integral part of ontology development and maintenance because it can attest that what is being built meets the application requirements [89], increases the availability and reusability of ontologies [90, 91], and lowers the maintenance costs of collaboratively created knowledge bases [90]. Nevertheless, the nomenclature of ontology evaluation, especially in the biomedical domain, causes confusion among researchers. Even though researchers have assessed the coverage of CHV on online health communities [58], thus far, we have yet seen a comprehensive study in evaluating the quality of CHV. The gap needs to be filled in order to guide its future development.

6.6.3 Use of Consumer Health Vocabularies in Consumer-Facing Health Applications

OAC CHV has been used in various health-related applications to improve patients' access to health information. Zeng et al. developed a translator specifically to convert texts in electronic health records to consumer-friendly text in patient health records by replacing UMLS terms to their corresponding OAC CHV terms [92]. Many UMLS concepts have one to one match with OAC CHV concepts. All the OAC CHV concepts have predefined consumer-friendly display names. The familarity scores of OAC CHV terms can be used to assess the difficulty of the terms for normal patients [59].

Even though different consumer health vocabularies have been developed, they have not been widely used in text simplification. Qenam et al. [93] recently translated the radiology reports by replacing professionals terms with terms in the OAC CHV and then compared the original reports and the translated reports by measuring the content coverage, investigating lexical similarity, and finding trends in missing concepts. They found that OAC CHV can cover a majority of the terms selected in the reports, but unmapped concepts are associated with areas that are commonly found in radiology reports. They also found that CHV terms showed a high percentage of lexical similarity with terms in the reports, which contain a myriad of medical jargons. This suggests that many CHV terms might not be suitable for lay consumers who would not be facile with radiology-specific vocabulary. Therefore, for consumer-facing health apps, developers need to expand or customize CHV before it can be appropriately employed for text translation or used as an interface terminology.

6.6.4 Engaging Patients in the Development
of Consumer-Facing Health Applications

In many consumer-facing health applications, the development team consists of health information specialists, designers, and other health professionals. However, the end users—patients—although present, have not been active enough in participating in the development of such an IT project [94]. Designing without user and usability analysis often produces products that ignore accessibility requirements, fail to address the variations in roles, do not provide the right balance of usability requirements [95], and do not use proper consumer-friendly language and terminologies. In the future, in-depth user need analysis should be conducted for every consumer-facing health IT application and website. The user need analysis may include, but not limited to, the appropriateness of the content, the difficulty of the terminology, the accessibility of the information presented, and the information flow. For example, to better understand consumer needs, "patient personas" were developed to guide the design of a National Cancer Institute consumer-facing website. Personas help picture the audience for any system in a way that can drive the design process from the user perspective [96].

As Internet has become increasingly social and interactive, social media provide a readily available source for engaging consumers in the core development of the new applications. The reader-to-leader framework was designed to help researchers and designers understand human motivation to participate in social media [94, 97]. This framework can further help researchers and developers to identify major contributors and opinion leaders on social media to provide consistent feedback in the systems development life cycle (SDLC) of the application.

6.7 Conclusions

Over the past decade, social media has drastically changed how we seek health information and communicate with each other regarding our health issues. At the same time, enourmous amount of data on social media presents a valuable resource for understanding the concerns, experiences, and language of patients and their caregivers. The vocabulary, which is the cornerstone of language, plays a crucial role in oral and written communication. Compared to other domains, there are many complex words and jargons in the health domain. In this chapter, we discussed the methods and practice in harnessing social media to understand and bridge the terminology gap between professionals and consumers. We also discussed future opportunities for health application development towards better accessibility and understandability for normal patients. It is our hope that in the future, we will see health applications that can better engage consumers with consumer-friendly content.

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Chapter 7
Dissemination of Information on Stigmatized and Risky Health Behaviors on Social Media

Jinghui (Jove) Hou and Mina Park

Abstract While social media are heralded as an important space for seeking and sharing health-related information, social media use has nevertheless been shown to link to risky health behaviors, including illegal drug and substance use, excessive alcohol consumption, disordered eating, unprotected sex, and self-harm. In this chapter, we start by listing some common features of social media platforms and providing examples showing that social media use can pose risks pertaining to health information sharing and seeking. We discuss why people tend to share information regarding risky behaviors on social media by examining theories that have been used to understand the mechanisms driving such behavior. We then present recent research documenting what contents surrounding risky and stigmatized health issues are shared on social media and the characteristics of those messages. Negative consequences and outcomes associated with such behavior are discussed in light of social and psychological theories. Our chapter concludes with theoretical and practice implications.

Keywords Risky health behaviors · Social media · Information seeking and sharing · Stigmatized health issues

7.1 Introduction

Social media today has become essential platforms where users can seek information, generate content, share content with their personal networks, and disseminate content to the public; they have also functioned as an important source of health

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and medical information, where both lay everyday knowledge and biomedical knowledge are readily accessible. Patients and their caregivers, consumers of health information, and health professionals increasingly resort to social media to spread health messages, discuss health topics of interest, and seek health advice [1]. In their everyday life, people may experience uncertainty regarding health such as appropriate diets, ambiguous symptoms, or costs of medical treatments [2, 3]. Studies have shown that internet-based social media play a critical role in this uncertainty management process by providing convenient and effective tools for accessing health information [3]. According to a recent report, about 72% of Internet users have looked online for health information and 40% of Internet users have shared their personal health experiences [4]. In particular, about 34% of online health information seekers use social media to access and share health information [5]. Given that nearly 80% of online users engage themselves in social media [6], use of social media for healthcare is expected to increase even more. The specific technological features of social media for "privacy, immediacy, a wide variety of information and a variety of perspectives on this information" ([7], p. 321) may explain why many people go online for health information [8], which we will discuss in the proceeding sections of this chapter.

Past research found that people used social media to communicate about a variety of health topics, reviews of drugs and medical treatments, and care management (e.g., [9–11]). While, in this process, social media are found to improve health knowledge and enhance health status and life quality by facilitating the exchange of health information and social support [12, 13], they have also been blamed for promoting risky health behaviors [14–17]. Risky health behaviors, such as smoking, binge drinking, drug use, unprotected sex, and unhealthy eating, constitute a growing threat to global public health. Meanwhile, people who engage in risky health behaviors are likely to be stigmatized by society and possibly receive condemnation, as they are often stereotyped as dangerous, irresponsible, and weak. Stigma is "the situation of the individual who is disqualified from full social acceptance" and stigmatized individuals are often "perceived as [having] weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior" ([18], p.16). Thus, people engaged in risky health behaviors often feel being judged by members of their face-to-face social networks as well as by the general public [19]. In contrast, it is not uncommon for people to share posts or images documenting engagement in risky and stigmatized behaviors on their online profiles on various social media platforms [17, 20–22]. Some studies have documented that two-thirds to more than three-quarters of social media profiles contain alcohol-related content [23, 24]. Worryingly, some scholars contended that sharing and discussing content related to risky health behaviors, such as alcohol and drug use, seem to be on the rise on social media [25, 26].

While we embrace the great values and benefits that social media bring to health information consumers, the dark side associated with health information seeking and sharing in the context of social media deserves special attention. Why people

tend to share information about risky health behaviors on social media? What kind of content are being communicated? And what are the consequences of posting about risky behaviors? The current chapter devotes to these issues. We begin by discussing some specific features of social media platforms and its implications for seeking and sharing health information. Based on these discussions, we look into why people seek out and share information regarding risky, and typically stigmatized, health behaviors on social media, by examining theories that have been used to understand the mechanisms driving such behavior. We then present recent research documenting what content or messages surrounding stigmatized issues have been found on different social media platforms and why. Negative consequences and outcomes associated with such behavior are discussed in light of social and psychological theories. Our chapter concludes with theoretical and practice implications.

7.2   Social Media and Risky Health Behaviors

Social media are internet-based websites, applications, and tools where users connect and interact with other users through content sharing, community creation, and collaboration. Facebook, for example, is a social media site that has the largest social network of about two billion monthly active users and more than one billion that log on daily [27]. Twitter is another example of a widely used social media site that provides real-time, public microblogging networks where users can post short messages or tweets on their Twitter profiles. Instagram, as a third example, is a social media site that has enjoyed growing popularity and is best known for sharing visual content.

Most social media employ user accounts and profile pages that allow users to create and maintain connections with a list of others and exchange information with each other [28]. Such communication platforms are free of time and space limit and are relatively easy to use. User accounts on social media are typically self-identified and do not have to link to one's real identity. For some social media that incorporate social networking functions, such as Facebook, user profiles can serve as a stage on which users make public or semipublic presentations of themselves to peer audiences who they know offline, such as friends, classmates, family members, and coworkers. On the contrary, some recent social media applications have also emerged that have differing levels of anonymity [17, 29]. For instance, some platforms, such as Whisper, Yik Yak, and Snapchat, enable sharing of content between users without attaching any type of identifying information. Whispers allows users to post a few lines of text under a name of their choice plus a background image—without adding their real names. So essentially, users are able to seek and share information on these types of social media without the risk of disclosing their personal information. Thus, people can use various social media platforms to interact with both known and unknown peers to exchange information and establish and maintain social connections. Another common feature of social

media is that users can interact via like buttons or up-votes, comment sections, and share buttons, which allows users to promote messages they like. In fact, some posts on social media could receive huge popularity and spread like wildfire on the site. Moreover, social media can also provide a venue for users to meet people and make new friends with those who share common interests and would like to engage in similar activities or talk about similar issues. And users may find, join, or create a group of users organized around a common topic or activity, allowing the interactive sharing of information created and controlled by individuals and groups. In addition, some social media platforms, particularly those in the form of mobile applications (i.e., "geolocation apps" or "geosocial networking apps"), enable various location-based functions. Typical location-based functions allow users to find neighborhood information, events, and commercial messages (e.g., deal information) relevant to one's local geographic points as well as to meet new people nearby. Particularly because of the proximity between users, these app users are more likely to meet in person. As an exemplar social media that have a location-based component, Meetup let users connect with people sharing similar interests and being in the same vicinity. Some popular "meetups" include meeting with others to run marathons together or to learn foreign languages from each other.

These social media features (e.g., social networks and connections, public and semi-public self-presentation, anonymity, message sharing and liking, interest-oriented online groups and communities, and location-based functions) can have great implications for information seeking and sharing related to risky health behaviors. Similar to creating social circles for a healthier life, individuals who engage in stigmatized risky health behaviors can find social media users who share their same unhealthy behaviors. In this sense, social media platforms have contributed to an environment where these individuals can get together and share social support [30–32]. For example, on social media such as Twitter, YouTube, and Instagram, these users can anonymously share tips and information about committing suicide, getting drugs, and hiding eating disorders through texts, videos, and images. Users engaged in unhealthy behaviors also leave comments on such content, up-vote and "like" the content, and support each other by justifying, maintaining, or promoting risky behaviors [14, 16, 30, 33, 34]. Meanwhile, for some users, such as adolescents and younger adults, social media can be utilized as a public space where they are eager to manage positive self-images to peer audience and believe that displaying risky behaviors is one way to achieve this goal [21]. Furthermore, some people use meetup apps like Tinder or Grindr for meeting partners for casual and often unprotected sex. Thus, such social media use presents opportunities for sexual risk behaviors [35, 36]. In the following section, we discuss in detail some sociology and social psychology theories that can shed light on why it becomes a common practice for individuals to seek and share information related to risky and stigmatized health behaviors on social media.

7.3 Social Media Use to Communicate About Risky and Stigmatized Health Behaviors

Stigmatized individuals in an unaccepting world may search for others who bear the same stigma [37]. When those stigmatized individuals join together as a group, they provide one another with a circle of empathy and a sense of belonging. However, it is hard for stigmatized individuals to find one another in "face-to-face" social networks because they are often socially marginalized as discussed above [38].

Risky health behaviors, including smoking, self-harm, and unprotected sex, are often stigmatized and people engaged in these behaviors often receive harsh condemnation. As such, these behaviors are not promoted in public via traditional media (e.g., television, newspaper, magazine, etc.). Instead, family, friends, nonprofit organizations, official media channels, and pressure groups encourage recovery from the behavior. Thus, it is not easy for people engaging in risky health behaviors to discuss their behavior with others due to negative social reactions [39]. Overtime, people who got stigmatized may internalize the stigmatizing attitudes that others hold about them. Such internalized stigma is related to low self-esteem, less social support, and less disclosure of their health status [40]. Consequently, they are motivated to hide their risky health behaviors from others, especially from those to whom they are emotionally attached.

Due to this fact, such individuals have little chance of finding supportive peers in the offline world. Typically, individuals who share similar health interests exchange information about how to cope, share health-related perspectives, and empathize with each other's personal stories [41]. For example, marathon runners can easily obtain tips on effective running through other marathon runners in their social network. Likewise, it is not difficult for a cancer patient to find other patients through support groups. By contrast, it is difficult to find people or groups that encourage risky health behaviors. The difficulty of meeting fellow risk-takers offline may cause risky behavior advocates to remain ignorant of the seriousness of their behaviors and coping methods. It also prevents them from gaining social support including emotional support (e.g., sympathy, understanding, encouragement, and physical affection), informational support (e.g., situation appraisal, advice, and teaching), and esteem support (e.g., validation, compliment, and relief of blame) [42].

With fewer chances of finding those with whom they can discuss their risky health behaviors, individuals engaging in these behaviors may experience strong feelings of uncertainty about their identity. For example, a girl with an eating disorder may believe "attractiveness" is an important factor of being loved and may believe that having an extremely thin body makes her more attractive. At the same time, she may also know people around her think that an eating disorder is a disease and not a lifestyle choice. Thus, the conflicts between her internal belief and the negative views of others would increase her uncertainty about herself as she engages in the risky behavior.

The social identity perspective provides a useful framework to predict behavioral patterns of such individuals who engage in risky health behavior on social media.

This approach addresses the self-conception of group members and related phenomena including differentiation within groups, deviance, group culture, group decision making, and collective action [43]. According to the social identity perspective, when individuals feel uncertain about things that reflect on self or self-identity, they are motivated to reduce that uncertainty because the feeling is psychologically uncomfortable [44]. People want to know who they are, how to behave, who others are, and how others might behave and think [44]. High uncertainty about one's identity also causes low self-efficacy, which give a feeling of helplessness [45]. Thus, individuals who engage in risky health behaviors will strongly desire to reduce uncertainty and protect their self-efficacy.

The social identity perspective demonstrates that individuals reduce feelings of uncertainty by identifying themselves with groups of similar peers. Individuals who engage in risky health behaviors may desire to find similar peers and support groups in order to reduce their feelings of uncertainty about themselves and their behaviors. As discussed above, however, it is difficult for them to find supportive others offline. Thus, social media play an important role for them as it provides a place where they can easily get together and create social networks to share their experiences without feeling stigmatized. Users can reduce uncertainty about the worldviews held by others like them and learn how others cope with the effects of their risky health behaviors. Moreover, location-based features of social media would help them develop or maintain those social circles. Socially stigmatized individuals (i.e., men who have sex with men) have found to benefit from using location-based dating apps as they have high barriers to develop romantic relationships offline [46]. Social media would allow people engage in risky health behavior meet with similar others and make social circles through sharing sensitive information and their honest feelings offline.

Furthermore, due to the anonymous nature of some social media sites, users may feel more safe to discuss some topics that they would not typically communicate in face-to-face settings [9], as "the risks of self-disclosure may be greatly reduced and disclosers should be much less fearful of potential condemnation or rejection" ([47], p. 1428). Birnholtz et al. [48] found that users are more likely to post stigmatized and taboo topics, including risky health behaviors, on a discussion board of higher level of anonymity compared to a site of lower level of anonymity, such as one's Facebook page. The same idea applies to the anonymous voting system on some social media sites, which enables users to up-vote content that they would not otherwise support in other public contexts. Wombacher et al. [17] showed that risky behaviors were discussed with great frequency and received a large number of user votes on Yik Yak, a social media site that provides a high level of anonymity. Therefore, some social media with a higher level of anonymity might further encourage content sharing and propagation of stigmatized and risky health topics.

Meanwhile, it is worth noticing that much of the research on social media promoting risky health behavior has focused on the adolescent and young adult population [17]. Adolescence is a time when young people experience new events, news relationships, and new activities. It is also a critical transitional period during which young people are more likely to experiment and adopt risky health

behaviors and practices, such as alcohol and other drug use, unprotected sexual activities, smoking, and violence. And such behaviors could have lifelong health consequences. Research shows that young adults take more risks than any other age groups [49] because adolescents are believed to be poor at assessing risks. Recent fMRI studies [50] observed brain changes during puberty period and suggested that adolescents are more sensitive to rewards of peer relationship and less effective at controlling themselves during peer exclusion, thus they are more likely to do what peers want them to do rather than rationally regulate their behaviors. The lack of emotion regulation and impulse control may account for why young people tend to engage in risky behavior. From the Social Development Theory [51] perspective, a person's socialization units, including family, school, and peers, influence one's behavior. Youth are particularly susceptible to peer influence and thus they are more likely to engage in risky behaviors as peers show encouragement or positive feedback to the behaviors. Meanwhile, the young also makes up the primary users of social media and apps. Compared with the older counterpart, young people between 12 and 24 years of age are the most extensive users of new technology and are more likely to be virtually connected regardless of socioeconomic status, race, or ethnicity [52]. In particular, colleges and universities are social media hubs since they contain a high proportion of teenagers and early adults. Recent research found that college students spend up to 14.4 h of social media use a day [53]. A growing number of recent studies has demonstrated that adolescence and college students tend to post content on social media related to engaging in risky health behaviors (e.g., binge drinking, disordered eating, substance use; [17, 20–22]).

Some scholars suggest that the young population tends to use a variety of self-presentation or impression management strategies in their social media communications [21, 54]. The theoretical concepts of impression management point out that people intentionally create images of themselves when interacting with others [55, 56]. In most cases, individuals want to be perceived by others as likeable or attractive and therefore present themselves accordingly. Social media provide new opportunities for users to present themselves and manage self-image. For one thing, a user is able to edit and revise her self-presentation on social media before making it public, which motivates more proactive tactics of impression management [57]. For example, a user can carefully choose or edit a desirable picture as her Facebook profile photo. For another, the more publicly an individual makes an impression to other people, the more likely the individual is to engage in impression management [58]. Self-presentation on social media is more public than traditional face-to-face self-presentation because when a user posts something on social media, all of her "friends" on the site are able to see the post. This feature may as well motivate users to engage in impression management. Young people are prone to present themselves in an attractive way to their online peers, and they tend to link risky health behaviors with attractive attributes, such as achieving something or being social. Therefore, young people may use social media to present themselves as attractive by posting risky-behavior-related content. Loss et al. [21] found that when adolescents post risky behaviors on social media, they often position those behaviors in a favorable light (such as sociability, achievement, or reward) to gain recognition from their peer groups.

The following section examines what messages surrounding risky and stigmatized health issues are shared on social media, and the characteristics of those messages.

7.4   Content Discussed on Social Media

A growing body of research has been devoted to examine what health-related content are shared on social media, typically by content-analyzing user profiles and posts. Recent attention has also been paid to investigate risky and stigmatized health issues. For example, early research on publicly accessible MySpace profiles showed that displaying information about risky behaviors, including alcohol, drug, and tobacco, is a common practice, especially among teenagers [59]. Similar observation was made on Facebook profiles that over half of college students had posted profile photos in which they engage some extent of alcohol use [22]. Loss et al. [21] also identified alcohol to be the most frequently disclosed risky behavior on Facebook, while they found that a majority (90%) of adolescents' profiles contain risky behavior. A study content analyzed over 5000 alcohol and drinking-related tweets and found that pro-drinking tweets outnumbered anti-drinking tweets by 10 to 1 [25]. These authors also identified nearly 12 million alcohol-related Tweets posted in one month, often by celebrities. Other risky behaviors include marijuana use and risky sexual behavior. Another study on marijuana-related tweets posted by adolescents demonstrated that 65.6% of the tweets aired positive attitudes toward the substance and 42.9% indicated personal use. Again in the Twitter space, McLaughlin et al. [9] also observed a somewhat "dark side" of Tweeting content related to preexposure prophylaxis (PrEP), an oral drug for HIV prevention. These contents include messages that promote sale of the drug without a prescription and tweets that make moral judgments about user of the drug (i.e., high-risk populations for HIV infection). A content analysis study by Wombacher et al. [17] of 3776 posts on Yik Yak, an anonymous social media platform that is especially popular among college students, showed that risky behaviors were discussed more frequently than healthy behaviors.

People not only share such content on social media, but also build online communities to exchange information and to gain social support. For example, researchers found that like-minded people formed pro-smoking online communities and created virtual smoking clubs [32, 60]. In these communities and clubs, members share pro-smoking messages, pictures of celebrity smokers, vaping experiences, opinions about e-cigarette flavors, and information about various e-cigarettes brands [32, 60]. Pro-extreme dieting community members commonly share information about effective weight loss including the use of weight loss drugs [19, 39, 61–64]. They share photos of thin celebrities as motivation and obese people as warnings. They also support each other in their weight-loss targets and share tips on avoiding detection by professionals and family members when skipping meals. Researchers concluded that overweight people and people of normal weight were seen as being

weak in the pro-extreme dieting community, and community members believed that strength and beauty were obtained through thinness [16, 39, 62, 63]. Also, a pro-smoking community, called "Jenny Teen Smoking Page," provided information about smoker's rights. Many of the community members were influenced by this information and shared their stories about their initiations to smoking. Many of them kept posting as their smoking habit developed [65]. NekNominate, an online drinking game originated in New Zealand and later spread to the UK and Ireland, requires participants to film themselves drinking alcoholic beverage and upload the footage to social media, such as Facebook and Twitter, and to nominate another person to do the same. Zonfrillo and Osterhoudt [66] found that participants of NetNominate post about excessive and dangerous alcohol use, such as drinking while skateboarding, and nominate friends to drink as they do.

To sum up, information promoting risky behavior ranging from smoking to drugs are widely shared on social media.

7.5   Concerning Outcomes

In this section, we look into some potential consequences of displaying information about risky health behavior on social media. We again turn to social and psychological theories to inform our discussions.

Research on risky health behaviors has extensively discussed the role of social norms on people's attitudes and behavioral choices [17, 67, 68]. When individuals perceive that a behavior is prominent in their social group or that the behavior is socially normative, they are more likely to engage in that behavior [69]. Thus, when risky health behaviors are discussed or even liked on social media, such content could influence the perception of normativeness of the behaviors by portraying these behaviors as prominent and positive. Social media platforms have become important venues in which users can express, observe, and form various social norms [26]. Therefore, sharing information about risky behaviors on social media may affect other people by normalizing risky behavior within the cohort network [59]. As a result, users are likely to overestimate the frequency of their peers engaging in the risky behaviors and, as a result, may be more likely to take such risks themselves.

Wombacher et al. [17] showed that exposure to posts on social media displaying risky behaviors could influence receivers' perceptions of norms associated with these behaviors. As individuals share information related to risky behaviors on social media, they may be unwittingly influencing others' attitudes and perception norms for the behavior and thus proliferating the occurrence of the problematic behaviors [70]. For instance, a study [71] reported that college students who viewed sexually suggestive photo posts on Facebook believed that a larger portion of their peers engage in risky sexual behaviors than those who viewed less of such posts. Similarly, another study [72] found that teenagers who got exposed to photos of others with alcohol on social network sites were more likely to engage in drinking than those who did not get exposed to photos containing alcohol. It has been also

found that pro-smoking messages on social media tend to increase positive attitudes about smoking and users' intentions to smoke [73]. Another study has shown that pro-eating disorder content exacerbates or maintains users' eating disorder symptoms [74].

The underlying mechanism of such normalization can be well explained by social comparison theory. It suggests that individuals compare their health and coping mechanisms with those of others in their referent group in order to make assessments and decisions about their own health behavior [75]. In the context of risky health behavior, social media may facilitate social comparisons by allowing individuals to see other social media users engage in risky health behavior. In this sense, behaviors rewarded online are powerful socializing forces, shaping views of what is "cool" and "attractive" [76]. For example, in a pro-eating disorder community, a person may observe that when a member of the community shares a "selfie" showing her extremely thin body, she receives numerous "likes" and positive comments from other community members. By contrast, when another member shares a "selfie" showing her normal weight, it can be observed that she does not receive as much attention from other community members. Comparing these two cases, the observer would learn that the community values extremely thin bodies more than normal ones. This phenomenon, referred to as "outcome expectation," is the primary determinant influencing one's perception of a particular behavior in social cognitive theory. This process is also related to the formation of positive social images [77, 78]. On social media, pictures of underweight people would likely be depicted as more sexually attractive and cool compared to pictures of people of normal weight. Thus, observers would not only learn that risky health behaviors yield positive outcomes, but also associate positive social images with those behaviors.

This social learning process may increase self-efficacy of engaging in risky health behavior. Self-efficacy is "a person's beliefs about her capacity to influence the quality of functioning and the events that affect her life" ([45], p. 172). Bandura [79] emphasizes that self-efficacy, when combined with outcome expectations, can lead to actual behavior. Social media content promoting risky health behavior may contribute to enhancing one's self-efficacy for risky behavior by providing tips on initiating or maintaining such behavior [39]. Throughout this process, community members are more likely to engage in risky behavior without feeling uncomfortable.

Heavy users and light users in social media might be different in terms of normalization of risky behavior [80]. Cultivation studies propose that heavy television viewers are more likely than light viewers to perceive reality as television portrays it [81]. For example, when frequent violence is shown on television, heavy television viewers are likely to perceive that the world is more violent than it really is, to be less trusting of others, and to overestimate the number of people employed in law enforcement. In social media communities promoting risky health behavior, heavy users have more chance to be exposed to information about risky health behavior than light users. In other words, heavy users' estimates of the prevalence of individuals engaging in risky health behavior will be higher than light users' estimates. In addition to these individual processes of mainstreaming and resonance, heavy users' beliefs may collectively converge, regardless of user

sociodemographics, to a shared perception that risky health behaviors are common and not extreme. In this process, the more users participate in online conversation with others engaging in risky health behaviors, the more likely they are to normalize these behaviors.

As theories of social influence imply, social media users who engage in risky health behaviors are influenced by other users in their social network through information sharing and social support. Through the normalization process, the harmful behaviors of some users distort the health beliefs and health behaviors of others.

7.6 Conclusions

While social media has been heralded as an important space for seeking and sharing health-related information, they also present a means for users to engage in discussions of stigmatized topics such as risky health behaviors. This chapter provides discussions on this issue. Grounded in social and psychological theories, we demonstrated why people seek and share content on social media related to risky health behaviors, and how specific technological features associated with social media (i.e., anonymity, communities, voting mechanism, social networking) interact with the social-psychological mechanisms that contribute to such behaviors. We then review empirical studies looking at what contents of risky behaviors are discussed on various social media platforms. We synthesize these discussions and present the potential consequences of disseminating content related to risky health behaviors on social media.

People engaged in risky health behaviors may experience stigma in offline settings, thus are prone to go online to express their views, gain support as well as find information to reduce uncertainty. Social media provide an ideal environment where they can find other people who have similar experiences and can express themselves freely without disclosing personal information. Some people, such as adolescents and college students, may use social media sites as a public stage and intentionally manage their social media presence to peer audience in a positive light. To them, communicating risky behaviors is one way to build up a positive and attractive self-image. Social media posts containing risky behaviors cover a variety of topics. For example, postings about drinking, smoking, and eating disorder are commonplace on social media. Much of these content frames risky behaviors in a positive manner, and is positively appraised by others who engage in the same behaviors. As a result, posting about risky health behaviors seems to be associated with inflated perceptions of social norms, more positive attitudes (perceived attractiveness) toward risky behaviors, and increased actual engagement in such behaviors.

Our discussions in this chapter are not intended to negate the substantial benefits of using social media in public health programs. However, we encourage researchers, health professionals, and policymakers to be cautious about the risks of high engagement in social media and translate our knowledge about risky

behaviors on social media to prevention or intervention efforts. In particular, social media interventions designed for healthy behavior advocates such as weight loss programs were found to be very effective [82]. However, most social media interventions designed for individuals who engage in risky health behavior such as unprotected sex or binge drinking have been less effective or completely ineffective [83–86]. If risky behavior advocates show different behavioral patterns on social media compared to individuals who engage in healthy behaviors, a well-designed intervention for promoting healthy behavior may not work as effectively for preventing or dissuading risky behaviors. Recent studies have begun to incorporate advanced computational techniques into interventional strategies based on individuals' behavioral patterns on social media. For instance, ElTayeby et al. [87] used machine learning methods to detect binge drinking-related contents (texts, images, and videos) posted by college students on Facebook and Twitter. Their prediction models based on mining social media contents have been shown to identify risky drinking problems with significant accuracy (82% accuracy rate), which facilitates a more cost-effective way to target intervention recipients. Researchers at University of Rochester [88] looked into Instagram contents to investigate five risky behaviors: drug consumption, drinking, sleep disorder, depression, and eating disorder, and employed multitask machine learning techniques to predict potential future risk behaviors of the Instagram users. With recent advanced techniques, such as machine learning, natural language processing, text mining, and image mining techniques, social media can become a fertile resource to detect problematic contents, which can lead to potentially groundbreaking tools to monitor public health and deliver targeted prevention or awareness programs. Public health practitioners should be concerned with the social construction and formation of norms related to risky behavior on social media and could harness social norm-based interventions that help correct inaccurate perceptions of risky behaviors (e.g., perceived normality of problematic alcohol use). They could tap into networks where health promotion messages may diffuse more rapidly, thus scaling up of cost-effective prevention. On a final remark, with opportunities to reach specific risk groups of problematic health behaviors via social media, it is as important to deliver interventions in a manner that is respectful and take into consideration ethical challenges related to privacy and confidentiality.

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Chapter 8
Learning Wellness Profiles of Users on Social Networks: The Case of Diabetes

Mohammad Akbari, Xia Hu, and Tat-Seng Chua

Abstract The increasing popularity of social media has encouraged health consumers to share, explore, and validate health and wellness information on social networks, which provide a rich repository of Patient-Generated Wellness Data (PGWD). While data-driven healthcare has attracted a lot of attention from academia and industry for improving care delivery through personalized healthcare, limited research has been done on harvesting and utilizing PGWD available on social networks. This chapter focuses on wellness profiling of users where we demonstrate algorithms to effectively harvest social media to extract wellness information of individuals as well as construct the latent profile of users. In particular, we study the wellness profile of users in diabetes, with extension to obesity and depression.

8.1 Introduction

The past decade has recorded a rapid development and change in the Web and Internet. We are currently witnessing an explosive growth in social networking services, where users are publishing and consuming online contents.

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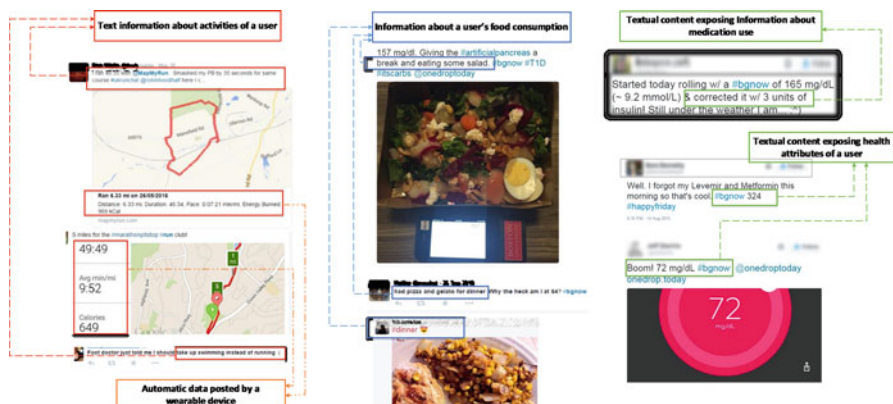e-mail: chuats@comp.nus.edu.sg

Fig. 8.1 Sample of wellness information on Twitter; (left) information about activities; (middle) information about food consumption; (right) information about wellness of users. The advent of wearable devices has resulted into device-generated contents as shown in the left column

In such a context, health consumers increasingly utilize social platforms to fulfill their health demands through seeking and sharing health information and experiences as well as providing online social support for their peers [11]. For example, it was reported that 57% of e-patients with chronic conditions constantly and actively refer to social media to acquire health information, while 20% of them have already participated in generation of online health contents.[1] The emerging of self-tracking gadgets and the enthusiasm of users in taking informed health decisions have also intensified this trend. This motivates users to disclose their health information on social platforms [19]. For example, diabetic patients frequently post about their health conditions, medications, and the outcome of medications on social media platforms like Twitter and Instagram. Figure 8.1 depicts several examples of disclosing wellness information in Twitter, where people publish detailed measurements and values about their activities, food consumption, and health attributes, e.g., blood glucose values. While Electronic Health Records (EHRs) are increasingly utilized in medical informatics as an important and distinct data source, limited research efforts have been devoted to utilizing Patient-Generated Wellness Data (PGWD) available on social networks [14, 60, 66].

Concurrently, the rates of chronic diseases, often referred to as noncommunicable diseases (NCDs), continue to drastically rise worldwide. In 2001, chronic diseases contributed to approximately 60% of the 56 million deaths in the world[2] and the burden of the diseases is expected to increase 11% by 2020, alarming the needs for controlling its increase. In health sciences, there is an inevitable consensus that chronic diseases are largely preventable diseases by lifestyle intervention [35].
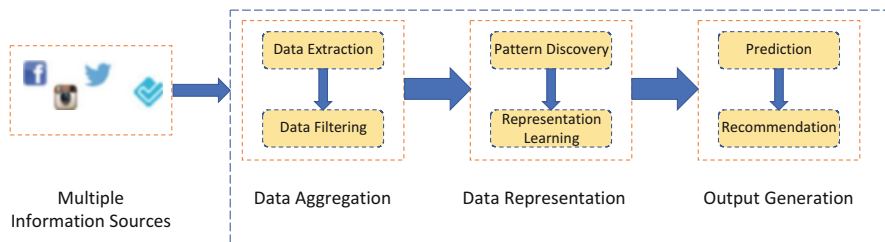
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[1]http://www.pewinternet.org/2010/03/24/social-media-and-health/

[2]http://www.cdc.gov/chronicdisease/overview/

Fig. 8.2 The proposed framework for wellness profiling of users. It includes three components of "Data Aggregation," "Data Representation," and "Output Generation"

Therefore, there is a high desire to provide computational systems that are able to assist people in managing their lifestyle and wellness. The emergence of several online services, such as "myfitnesspal" and "myfooddiary", and mobile application, such as "diet assistant" and "calorie counter", are efforts to meet this demand by assisting people in understanding and improving their lifestyle and wellness.

To mitigate this problem, we present a framework for automatic user profiling as illustrated in Fig. 8.2. The framework involves three main components: Data Aggregation, Data Representation, and Output Generation. First, we harvest users' data from different information sources. Generally, heterogeneous data sources would be available such as time-series data in wearable devices to discrete information about the user's mood entered occasionally. Thus, various information sources would be explored to extract relevant health information and filter irrelevant information. This would result into a high-dimensional feature space representing users from different aspects. Second, the framework discovers discriminative patterns in such a high-dimensional data. Here, specific models are needed to model the longitudinally and incompleteness in health data. Representation learning approaches, such as sparse low-dimensional embedding, is used to learn an optimal latent space. Finally, user wellness profiles, i.e., often the low-dimensional representation, are used to make various predictions on health and wellness of users. It is worth noting that although the framework is presented and validated for diabetes, it is a general framework and can be adopted for other health and well-being conditions.

Based on this framework, in this chapter, we focus on two efforts towards understanding users' wellness. The first is in tracking and monitoring users' wellness activities in terms of their diet, exercise, and medical measurements and tests. The second is on constructing wellness profiles of individual users and communities. In particular, we will study the wellness profiles of users with Diabetes, with extension to Obesity and Depression.

8.2 Mining Personal Wellness Events

In health sciences, it has been intensively studied and well-established that physical activities, diet planning, and taking prescribed medications are the key therapeutic treatments of many diseases [26, 55]. Further, unhealthy lifestyle behaviors such as unhealthy dietary habits, sedentary lifestyle, and the harmful consumption of alcohol are mainly related to the risk factors of noncommunicable diseases (NCDs) ranked as the leading cause of disability-adjusted life years (DALYs) [10, 41]. Therefore, the primary aim of the General Assembly of the United Nations on NCDs in 2011 was to reduce the level of exposure of individuals and population to NCDs' risk factors and strengthen the capacity of individuals to follow lifestyle patterns that foster good health.[3]

We propose to extract the wellness information and events from users' published social contents as a first step towards understanding, modeling, and predicting the wellness of users. This helps us filter out irrelevant information and content in social networks and harvest relevant information for further analysis. We term this as personal wellness events (PWEs) which cover lifestyle-related activities including what users eat, exercise, and health-related tests and measurements. The extraction of PWEs is a challenging task as they are relatively rare and often buried within streams of social media posts. To facilitate the task, we structure the wellness events into a hierarchical taxonomy as shown in Table 8.1 and propose a supervised model to extract PWEs from social media posts of a given user and categorize accordingly. In particular, we propose an optimization learning framework that utilizes the content information of microblogging messages as well as the relations among event categories. We seamlessly incorporate these two types of information into a sparse learning framework to tackle problems arising from noisy texts in microblogs.

8.2.1 Wellness Event Categorization

Before diving deep into the framework, we first formally define the problem of PWE detection from individuals' social media accounts. Suppose that there are M wellness events and let $\mathcal{C} = \{c_1, c_2, \ldots, c_M\}$ be the set of class labels. Given a corpus $\mathcal{P} = \{p_1, p_2, \ldots, p_N\}$ composed of N different training samples. Each training sample $p_i = (\mathbf{x}_i, \mathbf{y}_i)$ consists of a message content vector denoted by $\mathbf{x}_i \in \mathbb{R}^J$ and the corresponding event label vector denoted by $\mathbf{y}_i \in \mathbb{R}^M$. Let $\mathbf{X} = [\mathbf{x}_1, \mathbf{x}_2, \ldots, \mathbf{x}_N]^T \in \mathbb{R}^{N \times J}$ be the matrix representing training data and $\mathbf{Y} = [\mathbf{y}_1, \mathbf{y}_2, \ldots, \mathbf{y}_N]^T \in \mathbb{R}^{N \times M}$ be the matrix of labels. Our learning task is to find a mapping function from feature space $\mathbf{X}$ to label $\mathbf{Y}$.

We now formally define the personal wellness event detection problem as:

---

[3]https://www.un.org/en/ga/ncdmeeting2011/

Table 8.1 Taxonomy of wellness events with exemplar tweets

Event	Sub-event	Example tweet mentioning an event
Diet	Meals	Dinner just salad
	Alcoholic Beverages	Too much drink in party
	Nonalcoholic Beverages	Talking about hot chocolates, I might just go and make myself one: D
	Snacks	found Taylor's pretzels in my backpack and I'm so happy wow
	Fruit	Almost eat all the strawberries
	Others	Eat 20g carbs and go for running
Exercise	Walking	20 min walk around office . . .
	Running	After 1 h run #bgnow 130
	Biking	I just finished 1 h biking
	Swimming	BGnow 95, thanks swimming pool
	Others	Shopping and having a little dinner URL
Health	Examinations	#BGnow 100
	Symptoms	Feel too much Fatigue
	Treatment	Ate great oatmeal, toast, and eggs. Had 1 unit

Given a sequence of microblog messages $\mathcal{P}$ with their content **X***, and the corresponding event labels* **Y***, we aim to learn a model* **W** *to automatically assign events' labels for unseen messages.*

In essence, the two characteristics of personal wellness event detection are: (1) training data is sparse; and (2) event categories are deeply interrelated. Here, we first explain how to formulate the problem of PWE detection as a multi-task learning (MTL) framework, which utilizes the content information of microblogging texts as well as captures the relations between the event categories. We seamlessly integrate these two types of information into a state-of-the-art framework and turn the integrated framework into an optimization problem. We then demonstrate how to find the solution of the problem with an efficient framework.

8.2.1.1 Modeling Content Information

Compared with textual documents in traditional media, a distinct feature of texts in microblogging platforms is that they are noisy and short [16, 28], which give rise to two issues. First, text representation models, like "Bag of Words" (BoW) and n-grams, lead to a high-dimension feature space due to the variety of words. Second, the posts are too short and noisy making the representation very sparse. To mitigate these problems, we propose a sparse model to perform classification of feature space.

Assume that we have M wellness events, and view each event as one task. Formally, we have M tasks $\{T_1, T_2, \ldots, T_M\}$ in the given training set $\mathcal{P}$. The prediction for each task t is given by $f_t(\mathbf{x}; \mathbf{w}_t) = \mathbf{x}^T \mathbf{w}_t$ where $\mathbf{w}_t$ is the

coefficient for the task t. The weight matrix of all M tasks can be denoted as $\mathbf{W} = [\mathbf{w}_1, \mathbf{w}_2, \ldots, \mathbf{w}_M] \in \mathbb{R}^{J \times M}$. Matrix $\mathbf{W}$ can be inferred from the training data by solving the following optimization problem:

$$\arg \min_{\mathbf{W}} \mathcal{L}(\mathbf{X}, \mathbf{W}, \mathbf{Y}) + \Phi(\mathbf{W}), \tag{8.1}$$

where $\mathcal{L}(.)$ is the loss function, and $\Phi(\mathbf{W})$ is a regularizer which controls the complexity of the model to prevent overfitting and selects discriminant features. This formulation is a sparse supervised method, where the data instances are independent and identically distributed (*i.i.d*), and the tasks are independent. In this work, we choose logistic loss as the loss function, i.e., $\mathcal{L}(\mathbf{X}, \mathbf{W}, \mathbf{Y})$, as it has been reported to better handle the multi-label data as reported in several machine learning studies [36]. $\mathcal{L}(\mathbf{X}, \mathbf{W}, \mathbf{Y})$ is defined as:

$$\sum_{t=1}^{M} \sum_{i=1}^{N} \log\left(1 + \exp\left(-y_i^t f_t(\mathbf{x_i}, \mathbf{w_t})\right)\right), \tag{8.2}$$

where $y_i^t \in \{-1, 1\}$ is the true label indicating the relevance of i-th sample to the t-th task. Note that each sample can fall into multiple categories. For instance, the message "banana bread in the oven, mmmmm! lets just enjoy this #bgnow 70!" is related to meals and health examination categories at the same time. In this example, the user reported his blood glucose value, i.e., 70, and his decision to eat some banana bread.

To select discriminant features and control the complexity of our model, we define $\Phi(\mathbf{W})$ as,

$$\Phi(\mathbf{W}) = \alpha\|\mathbf{W}\|_F^2 + \beta\|\mathbf{W}\|_1, \tag{8.3}$$

where, α and β are positive regularizer parameters. In the defined regularizer $\Phi(\mathbf{W})$, the first term, i.e., Frobenius-norm, controls the generalization performance of the model and the second term, i.e., l_1-norm, leads to a sparse representation for the texts, performing feature selection to reduce the effects of noisy features. Thus, $\Phi(\mathbf{W})$ performs a kind of continuous feature selection as well as controls the complexity of the model [61, 65].

8.2.1.2 Modeling Events Relations

Recall that one key characteristics of PWE detection is that some events are more related to each other while differ from others, and similar events might share some features. For example, "walking" shares some features with "running" since the

context of two events are similar; however, it greatly differs from "meals." This motivates us to propose a graph-guided multi-task learning model, which is capable of capturing the relatedness among tasks to learn task-shared features as well as the task-specific features. The hope is that common information relevant to prediction can be shared among tasks and joint learning of tasks' models leads to a better generalization performance as compared to learning each task independently. A major challenge hence is how to control the sharing of information among tasks so that it leads to close models for related tasks, while unrelated tasks do not end up influencing each other. Here we assume that tasks are related to each other with different weights and the parameters of two related tasks are close to each other in l_2 norm sense.

Based on the above discussion, we used the graph structure G to model the task relationships, where each node represents one task and each edge connects two related tasks. The weight of each edge $r(t_i, t_j)$ reflects the relation strength between two tasks i and j. Given a graph G, we can formulate the task relations as minimizing the following objective function $\Omega(\mathbf{W})$,

$$
\begin{aligned}
\Omega(\mathbf{W}) &= \lambda \sum_{t_i, t_j \in \mathcal{E}} r\left(t_i, t_j\right) \left\| \mathbf{W}_{*i} - \mathbf{W}_{*j} \right\|_2^2 \\
&= \lambda \operatorname{tr}\left(\mathbf{W}\left(\mathbf{V} - \mathbf{R}\right)\mathbf{W}^T\right) = \lambda \operatorname{tr}\left(\mathbf{W}\Delta\mathbf{W}^T\right),
\end{aligned}
\tag{8.4}
$$

where $\mathcal{E}$ contains all the edges of graph G, and $\Delta = \mathbf{V} - \mathbf{R}$ is the graph Laplacian matrix [7, 49], where $\mathbf{R} \in \mathbb{R}^{M \times M}$ is the task relatedness matrix. $\mathbf{R}_{ij} = r(t_i, t_j)$ indicates the relation strength between task i and j and $\mathbf{R}_{ij} = 0$, otherwise. $\mathbf{V} = \operatorname{diag}(\mathbf{V}_{jj})$ is a diagonal matrix with $\mathbf{V}_{jj} = \sum_{i=1}^{M} r\left(t_i, t_j\right)$. The regularizer parameter λ controls the impact of relations among tasks in the learning process.

To construct the graph, we utilize a fully automated approach based on the model learnt from the relaxed multi-task problem. Following the idea discussed in [33], we first train a MTL model with Lasso regularizer to compute the model for each task ti and then compute the pairwise correlation between distinct tasks. We simply create an edge between each pair of tasks which have correlation above a defined threshold ρ. We set the threshold to $\rho = 0.7$ since it leads to the best performance in our experiments.

The optimization framework, which integrates content information and event relation information into the learning process, is defined by the integration of Eq. (8.1), through Eq. (8.4) as the following objective function, $O(\mathbf{W})$,

$$
\arg \min_{\mathbf{W}} O(\mathbf{W}) = \mathcal{L}(\mathbf{X}, \mathbf{W}, \mathbf{Y}) + \Phi(\mathbf{W}) + \Omega(\mathbf{W}),
\tag{8.5}
$$

where the first and second terms are to consider content information and perform regularization to avoid overfitting, respectively. The third term, i.e., $\Omega(.)$, captures tasks relatedness to learn task-shared features.

8.2.1.3 Optimization

The objective function $O(\mathbf{W})$ (i.e., Eq. 8.5) is nonsmooth since it is the composition of a smooth term and a nonsmooth term, i.e., l_1 penalty, and gradient descent method is not appropriate to solve the formulation. Inspired by [15, 47], we propose to solve the nonsmooth optimization problem in Eq. (8.5) by optimizing its equivalent smooth convex reformulation [4].

8.2.2 Experiments

In this section, we present the experimental details to verify the effectiveness of the proposed framework in mining wellness events of users from social networks. We conduct experiments to answer the following questions that help to validate the framework:

1. How does the proposed framework perform as compared to other state-of-the-art baselines?
2. How well the selected features discriminate PWEs?
3. How sensitive is our model to the involved parameters?

8.2.2.1 Dataset Description

Recall that one of the main problems of this research is the lack of training data. According to our statistics, the wellness-oriented tweets are only less than 5% of all the messages posted by chronic disease sufferers, and this number could be much smaller for healthy users. Therefore, we utilize a bootstrapping method to harvest the tweets corresponding to wellness events. We then manually label this tweet pool to construct our ground truth.

Wellness event categories Inspired by [62, 67], we arrive at three high-level wellness categories, namely, diet, exercise and activities (exercise for brevity), and health as shown in Table 8.1. Under each high-level event category, we further organize specific sub-events which construct a taxonomy that comprises 14 distinct wellness events. We also define a null class for messages that are not directly related to any of the defined wellness event categories.

Assigning event labels We observed that different wellness events place emphasis on different hashtags and words. For instance, "#dwalk" regularly appears in walking-related posts. Inspired by [24, 46], we adopted a bootstrapping approach to select a set of tweets related to each wellness event. To do so, we first selected some representative seed words for each wellness event by verifying top frequent keywords of each category. We then gathered tweets explicitly involving these seed words. However, the collected tweets are weakly related to events and are full of

noises. For instance, the tweet "I love music, it has a voice for every walk of life, every emotion, every bit of love"[4] even contains the word "walk", but it is not a relevant one. To filter out irrelevant tweets, we defined patterns in local context of each seed word. We applied the bootstrapping approach of [68] to extend the set of keywords and patterns and collected more positive samples pertaining to wellness events. We stopped bootstrapping after ten iterations since it often failed to find more positive candidates.

To construct the dataset, we first crawled a set of twitter users who used #BGnow hashtag, which is very popular among diabetic patients to post information about diabetes and their health states. In this way, we gathered 2500 different diabetes users. We removed accounts which had high daily traffic to avoid spammers. This filtering process resulted in 1987 diabetic users. We then crawled all historical tweets of these users using Twitter API, resulting in a set of about three million tweets. We applied the aforementioned bootstrapping procedure to find candidate tweets to construct dataset, which resulted in 11,217 tweets. We manually labeled all the tweets based on the wellness events as shown in Table 8.1. For each given event, we randomly selected negative samples from other events. Examples of the positive and negative tweets for the event "walking" are given below:

Positive "3 L of water and 4 miles of walking I am feeling super refreshed...thank god!!"
Negative "Further evidence of the benefits of exercise for people with type 2 #diabetes URL #doc (Error: It is not an event but reports general health information)."

Table 8.2 shows the statistics of our dataset. In total, our training set consists of approximately 3000 tweets corresponding to different wellness events. We also randomly selected about 3000 non-wellness tweets to be used as positive samples for the null class (non-wellness events). We intentionally selected more samples for null class due to the imbalance nature of events. We divided the dataset into two sets based on their posting times. In particular, tweets that were posted before May 2015 were utilized to train our model; while those posted from May to July 2015 were used for evaluation process.[5] We call this dataset **BG dataset** throughout this chapter as it is constructed based on the hashtag "#BGNow".

We engaged another annotator to manually examine about 3000 messages. The inter-agreement between annotator was 0.857 with the *Cohen* κ metric, which verifies a substantial agreement between annotators.

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[4]This is a real tweet from the dataset.

[5]Note that the numbers in Table 8.2 do not add up to 11; 217 since our dataset is a multi-label dataset meaning that some messages discuss about more than one PWE.

Table 8.2 Statistics of the BG dataset

	All samples	Positive samples
Posts on diet	1979	710
Posts of exercise	2771	1234
Posts on health	8802	1300
Total number of posts	11,217	3244

8.2.2.2 Feature Settings

Content and linguistic features are two major features which are used for text classification [27]. We follow them and extract the following set of features to represent each tweet from both context and linguistic aspects:

- **NGrams**: We extracted unigrams and bigrams from Twitter messages since they are commonly used to represent user-generated contents [27].
- **NE**: As shown in [39], the presence of named entities is a very useful indication of events in social media texts. We hence utilized named entities as another feature to represent tweets [59].
- **Gazetteer**: Gazetteers are commonly used as a linguistic feature in domain-specific applications [13]. We utilized two set of gazetteers: food and drink gazetteers from [2] and time gazetteers from LIWC's time-related category [56]. Hence, we used a dictionary of popular food and drink names from [2] to extract gazetteer feature for foods and drinks. We also utilized LIWC's time category which includes 68 time terms [56].
- **Modality**: In twitter, users often share general thoughts, wishes, and opinions in their accounts. Therefore, we need to filter out this irrelevant information from those which really report a wellness event. Here, we utilized modality verbs as an indicator of non-event information. We check whether the message includes some modality verbs such as "may", "could", "must", etc. [39].

8.2.2.3 On Performance Evaluation

We conducted experiments to compare the performance of our model with other state-of-the-art approaches:

- **Alan12**: Event extraction method of [59] which learns a latent model to uncover appropriate event types based on available data.
- **SVM**: We trained a binary classifier for each event to infer the label of tweets.
- **Lasso**: Logistic regression model with Lasso regularizer, i.e., l_1 term [69].
- **GL-MTL**: Group Lasso regularizer with $l_{1/2}$ norm penalty for joint feature selection [48], which only encodes group sparsity.
- **TN-MTL**: Trace Norm Regularized MTL [51], which assumes that all tasks are related in a low-dimensional subspace.
- **gMTL**: Our proposed wellness event detection model.

Table 8.3 Performance comparison among models

Method	Precision	Recall	F-1 score
Alan12	62.70	48.10	54.44
SVM	83.05	79.65	81.31
Lasso	80.45	79.21	79:82
GL-MTL	84.37	80.72	82.50
TN-MTL	83.22	78.85	80.98
gMTL	**87.15**	**82.69**	**84.86**

For each method mentioned above, the respective parameters were carefully tuned based on fivefold cross-validation on the training set and the parameters with the best performance were used to report the final comparison results. The overall performance is shown in Table 8.3 in terms of precision, recall, and F-1 score metrics.

From the table, we can observe the followings. First, all MTL methods outperform **Alan12**, **SVM**, and **Lasso** in terms of precision with a substantial improvement over **Alan12**. The main reason is that event discovery methods mostly focus on detecting general events or major personal events only [76]. These events are discussed bursty and highly connected to specific name entities such as organizations, persons, and locations. However, PWEs merely focus on individuals' local circles and may not be significantly related to any specific name entities. This hinders the learning framework to find representative latent topics from data. Second, among the multi-task approaches, **gMTL** achieves the best performance as compared to others. It verifies that there exist relationships among events and such relatedness can boost the learning performance. **GL-MTL** achieves higher performance as compared to **Lasso** and **TN-MTL** since it tries to jointly learn features which resulted in better generalization. This verifies that sharing samples among distinct task alleviates the data scarcity problem as pointed out by previous studies [61, 73]. Finally, our proposed gMTL model outperforms other methods by 2–6% since it encodes the task relatedness and group sparsity. By sharing samples between different tasks, **gMTL** simultaneously learns task-shared and task-specific features as well as mitigates the problem of data scarcity.

In addition, we performed feature analysis to verify the effectiveness of different features with regard to overall performance. The study validates that all features described in Sect. 2.2.2 are essential for optimal performance [4].

8.3 Wellness Profiling of Users

The next step after collecting wellness data of individuals is to represent information in an organized form, often called user profile. Profiling can be performed in explicit and implicit forms. Explicit user profiling focuses on inferring attributes and characteristics of users, such as the user demography, obesity level, and disease type [6, 21]. Implicit user profiling, however, learns a latent representation, often a

kind of distributed representation, for each user, which is capable of discriminating the major aspects of user behaviors and interests. Matrix factorization (MF) [34] and topic models [12] are two main techniques which have been widely used for learning a latent representation of users and items in recommendation system. The hypothesis behind latent representation learning is that users and items can be mapped into a low-dimensional space representing their relations. Recently, implicit feedback of users, such as user activities, is also utilized for inferring user preferences [23]. In this section, we introduce an approach for wellness profiling of diabetes users in a latent space. We then utilize this wellness profiles to infer users' wellness attributes as well as discover populations' subcommunities according to their wellness states.

Learning the wellness profile of users can assist individuals and communities to improve their wellness and lifestyle. At individual level, it can provide better online services which assist users in different ways. The wellness profile of a user can be used for several personalized online services to assist them in making informed health decision. Taking diabetes as an example, the system can recommend a Type II diabetes patient with content related to his specific condition and may combine with wearable sensors data comprehensively understand users' behaviors and interests, which improves the efficacy of the system. At group level, by collecting and aggregating wellness information of users, we can discover potential communities, profile the discovered communities, and study the wellness of communities which provides insights about the wellness and health of the population. It can be utilized for policy-making, trend analysis, and tracking the wellness groups. This data complements the information and insight we can obtain through traditional methods like population surveys, etc.

Despite its value and significance, PGWD in social networks has not been fully utilized due to the following challenges. (1) *Longitudinality*. Wellness data are longitudinal per se, which means multiple measurements or repeated events are available for each subject [44, 74, 77]. For example, Hemoglobin A1c (HbA1c) test might be done several times per year for diabetic patients. The longitudinal nature of the problem provides a matrix of wellness data describing patient at different time points [71, 74, 77]. This is quite different from standard machine learning representation where we have a static vector of features, as shown in Fig. 8.3. In such a context, time dimension plays an essential role. (2) *Noisiness and Incompleteness*. Social media is a highly varied and informal media; arising from various background and intention of users [70]. Moreover, missing data is an intrinsic nature of PGWD since patients do not persistently report their wellness data. In most cases, users are not keen enough to expose the event or they self-censor the content due to privacy concerns [20, 42]. (3) *Heterogeneity*. An intrinsic characteristic of the wellness domain is heterogeneity; meaning that wellness attributes and events related to each user can be highly different from the others [50]. For instance, even though diabetic users often share similar characteristics, they are still different from each other based on demographic attributes (e.g., age and gender), type of disease (e.g., Type I Diabetes, Type II Diabetes, Gestational Diabetes, etc.), and many other behavioral and genetic factors. How to share information among homogenous population while
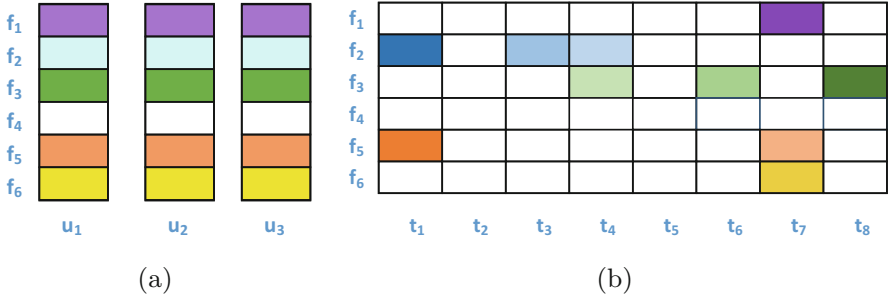
Fig. 8.3 Vector-based and Longitudinal representation, where different colors show distinct features and color intensity shows relative value of the feature. **(a)** Representation of three distinct users in vector-based approach; vector-based approach represents a single measurement for each feature; **(b)** Representation of one user in longitudinal approach with eight different time points. Longitudinal data represents each feature with a set of values pertaining to different time points
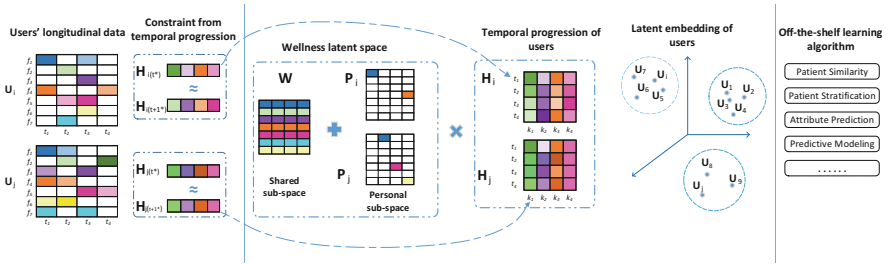

Fig. 8.4 The conceptual view of the proposed framework for representation learning of longitudinal data from social networks. The wellness latent space is comprised of two sub-spaces: shared and personal latent space. The final representation of each user, i.e., H_i, embeds the user in the latent space, while each row is his/her representation at one time point, where different colors show distinct features and color intensity shows relative weight of the feature

simultaneously avoiding interactions between heterogeneous populations is still an open problem in wellness modeling.

To deal with the challenges raised by the distinct PGWD, in this section, we investigate the learning of wellness representation of users from social media. Our framework determines the wellness latent space directly from users' longitudinal data, instead of attribute-value data. In particular, the proposed approach decomposes longitudinal data into two components: wellness latent space and temporal representation of users. To effectively handle data heterogeneity, the learned wellness latent space is comprised of two subspaces, i.e., shared and personalized latent spaces, as shown in Fig. 8.4. The learned temporal representation is constrained to model the temporal progression of wellness attributes and simultaneously tackle the problems arising from missing data values. The proposed framework has been extensively examined through several machine learning tasks to evaluate its effectiveness in user embedding.

8.3.1 Problem Statement

In this section, we first present the notations and then formally define the problem of representation learning of longitudinal data. Let $\mathcal{U} = \{\mathbf{U}_1, \mathbf{U}_2, \ldots, \mathbf{U}_n\}$ denote a set of n users' longitudinal information. Each user's longitudinal information $\mathbf{U}_i$ is denoted by $\mathbf{U}_i \in \mathbb{R}^{f \times t}$, where f is the number of different wellness events and features[6] and t is the length of observation window in which we measure the events. Note that the user's longitudinal data is a matrix where $\mathbf{U}_{i(j, k)}$ represents the measurement value of the wellness event j at time point k for the user i.

We want to learn a low-rank representation of users in $\mathcal{U}$ so that if two users u and v have similar wellness data, their representation would be closer. We assume that the longitudinal data can be factorized to two components: a latent space representing wellness concepts and the temporal progression of each user in the latent space, as shown in Fig. 8.4. The factorization process is capable of reconstructing the user data matrix on observed values. In general, a user's longitudinal representation is formally defined as a matrix $\mathbf{H}_i$, where each row of the matrix, i.e., $\mathbf{H}_{i(j*)}$, represents the user wellness state at time point j.

With the notation above, we formally define the longitudinal user representation problem as:

Given a set of users' longitudinal information $\mathcal{U}$, we aim to learn a model as follows,

$$f : \mathcal{U} \rightarrow \{\mathbf{W}_i, \mathbf{H}_i\}, \tag{8.6}$$

which can compute **wellness latent space** $\mathbf{W}_i \in \mathbb{R}^{f \times k}$ and **temporal progression** of each user in the wellness latent space, i.e., $\mathbf{H}_i \in \mathbb{R}^{t \times k}$.

The final representation of each user, i.e., $\mathbf{H}_i$, precisely embeds the user in wellness latent space, while each row is his/her representation at one time point.

8.3.2 Factorization of Longitudinal Data

8.3.2.1 Preliminaries

The key hypothesis behind the factorization of longitudinal data is that user's data matrix can be decomposed into two factors: (1) wellness latent space, and (2) the temporal onset of wellness events over observation windows, i.e., time dimension. We utilized nonnegative matrix factorization (NMF) to decompose patient data matrix into two low-rank matrices which are capable of approximately reconstructing the observed matrix. NMF is a matrix factorization algorithm that

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[6]In this text, we use wellness feature (e.g., blood glucose, hypertension) and wellness events (onset of asthma attack, hyperglycemia) interchangeably.

factorizes the nonnegative data matrix into two positive matrices [37]. Assume that $\mathbf{U}_i \in \mathbb{R}^{f \times t}$ represents the data matrix for patient i, the aim of factorization is to decompose $\mathbf{U}_i$ into nonnegative matrices $\mathbf{W}_i \in \mathbb{R}^{f \times k}$ and $\mathbf{H}_i \in \mathbb{R}^{t \times k}$, whose product provide a good approximation of $\mathbf{U}_i$, i.e., $\mathbf{U}_i \approx \mathbf{W}_i \mathbf{H}_i^T$, where k is a prespecified parameter denoting the dimension of reduced space. For instance, in topic modeling, k represents the number of topics, while it denotes the number of desired latent dimensions in feature learning. Formally, NMF aims to minimize the following objective function,

$$\min_{\mathbf{W}_i, \mathbf{H}_i} \left\| \mathbf{U}_i - \mathbf{W}_i \mathbf{H}_i^T \right\|_F^2 \text{ s. t. } \mathbf{W}_i \geq 0, \mathbf{H}_i \geq 0, \tag{8.7}$$

where $\mathbf{W}_i$ is called the *wellness basis matrix* and $\mathbf{H}_i$ is the *temporal progression matrix*. Intuitively, H_i represents how wellness dimensions evolve over time for the given user. In other words, it demonstrates how the user's wellness is going to improve, stable, or worsen as time passes. As the above objective function is not jointly convex in $\mathbf{W}_i$ and $\mathbf{H}_i$, finding the global minima is infeasible [37]. Therefore, alternating minimization is iteratively utilized to find a local minima. The iterative update rules are as follows,

$$\mathbf{W}_i \leftarrow \mathbf{W}_i \odot \frac{\mathbf{U}_i \mathbf{H}_i}{\mathbf{W}_i \mathbf{H}_i^T \mathbf{H}_i}, \quad \mathbf{H}_i \leftarrow \mathbf{H}_i \odot \frac{\mathbf{U}_i^T \mathbf{W}_i}{\mathbf{H}_i \mathbf{W}_i^T \mathbf{W}_i}. \tag{8.8}$$

where $\odot$ and the division symbol in this matrix context denote element-wise multiplication and division, respectively. Note that the above setting is different from standard matrix factorization where $\mathbf{U}_i$ represents an item-feature matrix constructed from the whole dataset.

8.3.2.2 Shared Wellness Space for Homogenous Cohort

Factorization of user's longitudinal data provides an intuitive decomposition of data matrix of a given user into wellness latent features and their temporal progression over time. However, decomposing wellness data of each user in isolation may not provide effective representation due to high sparsity of data. Besides, comparing latent spaces of different users would be a challenging task since the factorization process may extract diverse latent features fitted on each user data. Therefore, extracting a common latent space from the entire collection of data is preferred. The hypothesis behind collective latent space learning is that the wellness latent space extracted from different data instances, in our case users, should admit the same underlying structure, corresponding to higher level latent features constructed from the combination of lower level features. At the same time, the temporal progression of these wellness latent features can vary from user to user depending on user's

attributes, behaviors, and so on. Mathematically, it leads to the following objective function,

$$\min_{\mathbf{W}, \mathbf{H}_i} J_{SLS} = \frac{1}{2n} \sum_{i=1}^{n} \left\| \mathbf{U}_i - \mathbf{W} \mathbf{H}_i^T \right\|_F^2 + \frac{\lambda_1}{2} \left(\|\mathbf{W}\|_F^2 + \frac{1}{n} \sum_{i=1}^{n} \|\mathbf{H}_i\|_F^2 \right) \tag{8.9}$$
$$\text{s. t.} \quad \mathbf{W} \geq 0, \mathbf{H}_i \geq 0,$$

where the first term factorizes users' longitudinal data, while the second and third terms control the complexity of models. Here, $\mathbf{W}$ is to compute the shared wellness latent space among all patients. The above objective function assumes that all patients share the same wellness space and learns a unique mapping $\mathbf{W}$ from the original feature space to the wellness latent space. With sharing of the latent space among all patients, we indeed transfer knowledge among the patient cohorts, which is attractive especially when the available information for each patient is limited and the cohort is homogenous [53, 65]. Sharing also reduces the effect of noise since the latent space is derived from a large amount of data.

8.3.2.3 Personalized Wellness Space for Heterogeneous Cohort

Even though learning a common latent space from dataset is an intuitive and well-established tradition in machine learning, its performance is highly varied in real applications since it assumes a rigid consensus in dataset, i.e., all the data instances need to follow a specific latent space [53]. This is, however, impossible in real situations since patients can be divided into different cohorts with different characteristics. For example, diabetic users can be divided into three major patient groups: type I, type II, and gestational diabetics, and several minor groups merely based on disease type, where each group holds different characteristics [50]. This suggests that we need a personalized feature learning framework to deal with heterogeneity in data space.

Inspired by the notion of "dirty models" in machine learning for handling heterogeneous high-dimensional data [30], we assume that individual's wellness latent space can be slightly deviated from the shared space extracted from the whole population. Mathematically, we consider the following learning model,

$$\min_{\mathbf{W}, \mathbf{H}_i, \mathbf{P}_i} J_{PLS} = \frac{1}{2n} \sum_{i=1}^{n} \left\| \mathbf{U}_i - (\mathbf{W} + \mathbf{P}_i) \mathbf{H}_i^T \right\|_F^2$$
$$+ \frac{\lambda_1}{2} \left(\|\mathbf{W}\|_F^2 + \frac{1}{n} \sum_{i=1}^{n} \|\mathbf{H}_i\|_F^2 \right) + \frac{\lambda_2}{n} \sum_{i=1}^{n} \|\mathbf{P}_i\|_1 \tag{8.10}$$
$$\text{s. t.} \quad \mathbf{W} \geq 0, \mathbf{H}_i \geq 0, \mathbf{P}_i \geq 0,$$

where the latent space is estimated by the summation of two parameters $\mathbf{W}$ and $\mathbf{P}_i$. The first part of Eq. (8.10) learns three sets of parameters: (1) $\mathbf{W}$ is the shared latent space for all users inferred from the entire dataset; (2) $\mathbf{P}_i$ is to model heterogeneity in the data space, i.e., the personalized feature space; and (3) $\mathbf{H}_i$ demonstrates the temporal evolution of each individual in the latent space. By imposing different regularizations for each parameter, we can fit an effective personalized learning model. The above formulation includes two set of regularizers; the second term, i.e., ($\|\mathbf{W}\|_F^2 + \frac{1}{n}\sum_{i=1}^{n}\|\mathbf{H}\|_F^2$), controls the generalization performance of the model to avoid overfitting and the third term (l_1-norm) leads to a sparse model. It is worth noting that the aforementioned model extends the concept of dirty model to longitudinal data [30].

8.3.2.4 Modeling Temporal Information

Recall that the wellness attributes evolve smoothly over time. The temporal progression of wellness attributes suggests that these values gradually change over time [44, 74]. Thus, modeling the temporal evolution of wellness attributes can effectively reduce the noise and sparsity of the wellness data through imputation of missing values as pointed by [66, 74]. As each row of the temporal progression matrix $\mathbf{H}_{i(j*)}$ indicates the wellness representation of the user i at time point j, we can penalize the sudden changes of wellness attributes between neighboring time points as follows,

$$\mathcal{R}_{\text{temporal}} = \frac{1}{2n}\sum_{i=1}^{n}\sum_{j=1}^{t-1}\left\|\mathbf{H}_{i(j*)} - \mathbf{H}_{i(j+1*)}\right\|^2, \tag{8.11}$$

where $\mathbf{H}_{i(j*)}$ denotes the wellness representation of the user i at time point j. To facilitate the optimization of the temporal progression term, Eq. (8.11) can be restated in an equivalent form as follows,

$$\mathcal{R}_{\text{temporal}} = \frac{1}{2n}\sum_{i=1}^{n}\sum_{j=1}^{t-1}\left\|\mathbf{H}_{i(j*)} - \mathbf{H}_{i(j+1*)}\right\|^2 = \frac{1}{2n}\sum_{i=1}^{n}\|\mathbf{H}_i\mathbf{R}_i\|_F^2, \tag{8.12}$$

where $\mathbf{R}_i \in \mathbb{R}^{t \times t-1}$ is the temporal smoothness indicator and is precalculated by the following definition,

$$\mathbf{R}_{i(j,k)} = \begin{cases} 1 & \text{if } j = k; \\ -1 & \text{if } j = k + 1 \\ 0 & \text{otherwise.} \end{cases} \tag{8.13}$$

Intuitively, Eq. (8.12) imposes that the wellness representation of the given user at two consecutive time points be close to each other.

8.3.3 Algorithm Details

The optimization framework, which integrates prior information into representation, is defined as follows,

$$J_{\text{Space}} + \alpha \mathcal{R}_{\text{temporal}}, \tag{8.14}$$

where the first term, i.e., J_{Space}, denotes the objective function for learning latent space, i.e., Eqs. (8.9) and (8.10) for homogenous and heterogenous settings, respectively; while the second term incorporates temporal prior of wellness attributes into the learning model.

We adopt an alternating optimization strategy to find the optimal values for model parameters [6]. Note that the optimization problem of homogeneous setting is a special case of the heterogenous setting. Here, by substituting Eq. (8.10) into the above equation, we have the following cost function,

$$
\begin{aligned}
\min_{\mathbf{W}, \mathbf{H}_i, \mathbf{P}_i} \mathcal{O} &= \frac{1}{2n} \sum_{i=1}^{n} \left\| \mathbf{U}_i - (\mathbf{W} + \mathbf{P}_i)\, \mathbf{H}_i^T \right\|_F^2 \\
&+ \frac{\alpha}{2n} \sum_{i=1}^{n} \left\| \mathbf{H}_i \mathbf{R}_i \right\|_F^2 + \frac{\lambda_1}{2} \left(\|\mathbf{W}\|_F^2 + \frac{1}{n} \sum_{i=1}^{n} \|\mathbf{H}_i\|_F^2 \right) \\
&+ \frac{\lambda_2}{n} \sum_{i=1}^{n} \|\mathbf{P}_i\|_1 \\
&\text{s. t. } \mathbf{W} \geq 0, \mathbf{H}_i \geq 0, \mathbf{P}_i \geq 0,
\end{aligned}
\tag{8.15}
$$

where α, λ_1, and λ_2 are regularizers to control the trade-off between different components.

8.3.3.1 Computational Complexity

We now analyze the time complexity of our learning framework using big O notation. The learning algorithm includes three main steps for optimizing three set of variables, i.e., $\mathbf{W}$, $\mathbf{P}_i$, and $\mathbf{H}_i$. In update rule for $\mathbf{W}$, the time complexity is $O(nkft)$, where n is the number of users, k is the dimension of latent space, f is the dimension of original feature space, and t is the length of the observation window. The main computational time for $\mathbf{P}_i$ is to compute the derivation of smooth part of objective function, which is $O(ftk)$. As we need to update $\mathbf{P}_i$ for all samples, in our case each user, the total computational time is in order of $O(nkft)$. The computation for $\mathbf{H}_i$ is

similar to $\mathbf{P}_i$ with time complexity of $O(nkft)$. If we need q iteration for updating the values of variables, the time complexity of the final algorithm is in order of $O(qnkft)$. As t denotes the length of observation window and it is in the size of few hundred, which is a small constant, in our experiment it is a 6 months period and $t = 25$, the final complexity can be approximated by $O(qnkft) \approx O(qnkf)$, making PLS a linear representation learning algorithm. We empirically verified this in our experiments, as the actual running time of our framework was similar to running plain NMF on all longitudinal data matrices.

8.3.4 *Experiments*

In this section, we conduct extensive experiments to evaluate the effectiveness of the proposed representation learning of users from social networks in both homogenous and heterogeneous settings.

8.3.4.1 Datasets

Diabetes Dataset We evaluated our approaches on a real-world dataset containing posting of diabetic users about diabetes and their associated symptoms, medications, and activities. To construct the dataset, we first gathered a set of users who actively utilized diabetes-related hashtags like "#diabetes" and "#bgnow" and follow diabetes support groups, such as American Diabetes Association, in Twitter microblogging service. Table 8.4 shows the list of hashtags and twitter support groups that were used for collecting candidate twitter users.

We next crawled the twitter profile of these users using Twitter API and selected the users who explicitly mention diabetes as an interest in their Twitter profile, resulting into 14,108 different candidate user accounts. To construct ground truth labels, we utilized an automatic approach, inspired by similar efforts in computational social science [42], based on users who self-declared their disease information. We used expressions like "I am (Type|T) (1|2) diabetic" to extract

Table 8.4 The list of seed hashtags and twitter support group used for collecting twitter user pool

Hashtags		Support Groups	
#Diabetes	#Bgnow	@AmDiabetesAssn	@WDD
#Diabetic	#T1D	@DiabeticConnect	@DiabetesUK
#type2diabetes	#T2D	@diabetesdaily	@NDEP
#diabeteschat	#Doc	@DiabetesMine	@citiesdiabetes
#LivingwithDiabetes	#Dblog	@DiabetesHealth	@diabeteshf

Table 8.5 Statistics of the diabetes dataset

# of Users		14,108
# of Tweets		11,491,036
Disease type	Diabetes Type I	4194
	Diabetes Type II	2477
	Others	803

Table 8.6 Example of profiles from our diabetes dataset

Husband. Dad. I've diagnosed as Type 1 diabetic since DATE. On a journey …	I *diagnose* Type (1–2) diabetic	Type 1
I LOVE LIFE!! I am type 2 diabetic and take insulin ….	I * Type (1–2) diabetic	Type 2
Writer, avid reader, …; live with T1 diabetes, …	* with (T1–T2) diabetes	Type 1

disease type for each user based on his/her profile information.[7] Disease type here refers to the major types of diabetes that includes three categories: Type I diabetes, Type II diabetes, and Others. We merged all the other noncommon diabetes types as one category.[8] Table 8.5 shows the statistics of our dataset. As you can see, we could extract the health attributes of more than 50% of users (7474 Twitter accounts) based on their self-declared information in their profiles, which we will use for the evaluation of our framework. Table 8.6 shows some example profiles from our collected dataset and their associated regular expressions and ground truth labels[9].

BG Dataset This is the dataset which was constructed in Sect. 2. The dataset comprises Twitter activities of diabetes patients who actively share their wellness information on Twitter. They not only post about their lifestyle information and activities such as their diet, activities, and emotional states, but also their health information in terms of medical events and measurements like their blood glucose value, HbA1c test results, and hypoglycemia/hyperglycemia onset. We labeled all users in the dataset with "successful" and "unsuccessful" tags showing that he managed to maintain an on-target blood glucose value or failed to do so, respectively. We used this dataset to evaluate the effectiveness of our method in predicting the wellness states of users (such as the blood glucose value) based on the longitudinal wellness data of users on social media. This is important since wellness states are highly dependent on historical values, i.e., temporally dependent, showing that we need to consider longitudinal information of user's wellness instead of merely considering current state. Table 8.7 shows the statistics of this dataset.

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[7]We followed a bootstrapping approach similar to [68] to ensure the coverage and diversity of used patterns, where all extracted patterns are manually verified to ensure accuracy.

[8]In our dataset, there are three non-common diabetes types: gestational diabetes, diabetes LADA (Type 1.5), and diabetes insipidus.

[9]Due to user privacy concerns, some words/sentences may be different from original version.

Table 8.7 Statistics of the BG dataset

# of Users	1174
# of Tweets	1,060,105
# Successful Users	436
# Unsuccessful Users	738

8.3.4.2   Extraction of Longitudinal Wellness Descriptions

To comprehensively represent user's wellness, inspired by studies in clinical text mining [4], we extracted three kinds of features as follows.

1. **RxNorm description.** Medication information is one of the most important types of wellness data. Extracting medication information from free text reports is a traditional but challenging problem in clinical text processing [64]. Here, we employed a widely used approach proposed in [64] which utilizes semantic parser and domain knowledge to accurately extract medication information, i.e., medication names and signatures, from free texts.
2. **UMLS description.** We also used a widely used knowledge-based system called MetaMap to assign Unified Medical Language System (UMLS) Meta-thesaurus semantic concepts to user's social posts [9]. MetaMap is a rule-based system that assigns UMLS Meta-thesaurus semantic concepts to phrases in natural language text. MetaMap is commonly used as a complementary resource containing tremendous amount of medical knowledge, which is independent from training dataset, in contrast to other systems. We collected all MetaMap's findings in the dataset and used their gold standard medical concepts as features. We constructed a Bag-of-Concepts (BoC) in medical terminology and represent each user in the resulting space. The final BoC contains 5370 distinct concepts.
3. **Personal Wellness Events.** We next utilized the approach proposed in Sect. 2 to extract personal wellness events from users' published messages on Twitter. This will provide a high-level description of user's wellness state; containing 14 distinct dimensions.

To construct the longitudinal wellness matrices, we utilized the social media posts of users. We need to select a granularity level in time dimension to extract the information according to the selected granularity. We observed that the daily granularity is too sparse as more than 95% of users do not report their wellness information daily. We thus constructed the users' longitudinal data at weekly granularity. As we collected the data for 6 months, from May to October 2015, we constructed 25 time points for the entire period.[10]

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[10]We did not consider the first week of May and the last week of October because the data was partially crawled.

8.3.4.3 Evaluation Tasks and Metrics

To demonstrate the effectiveness of the proposed representation learning approach, we implicitly evaluated its performance in two commonly used machine learning settings: supervised and unsupervised learning. The hypothesis behind implicit evaluation is that a good representation will improve the performance of the selected tasks as compared to other baselines. We hence evaluated our problem in two supervised problems: attribute prediction and success prediction and one unsupervised problem on community detection, where communities were extracted by clustering of users in the user latent space.

Attribute detection is a critical step in many downstream applications like recommendation [72]. We hence proposed to predict the disease type of users using information from social media. To evaluate our approach, we utilized diabetes dataset with tenfold cross-validation and reported the performance in terms of precision, recall, and the area under the receiver operating characteristic curve (AUC). Due to the imbalance nature of the dataset, the latter provides a good explanation of the effectiveness of the proposed method [57].

Success prediction is the task of predicting whether a specific user can successfully maintain his/her health indicators in a suggested range. For example, a diabetic patient who can successfully control his blood glucose value in the healthy range would be categorized as a successful patient, otherwise unsuccessful. We evaluated our feature learning framework in predicting users' success in managing their blood glucose value in the healthy range. Here, we considered the success prediction as a binary classification problem and utilized **BG** dataset to evaluate our problem.

Finally, we also evaluated our representation learning approach under the clustering task, which is totally unsupervised and relies heavily on the learned features and similarity measure. We adopted the commonly used cosine similarity for clustering of users in the learned latent space. We compared the performance of different approaches in terms of accuracy and normalized mutual information (NMI) on diabetes dataset.

8.3.4.4 On Performance Comparison

To the best of our knowledge, we are the first to study feature learning of longitudinal data in social media. To demonstrate the effectiveness of representation learning approaches, we compared our learned features with those of other state-of-the-art unsupervised feature learning methods, while keeping the classification and clustering scheme fixed. We compared the following baseline methods:

- **ALL**. All original features are adopted for each user.
- **LapScore**. Laplacian score evaluates feature importance by its ability to preserve the local manifold structure of data [25].
- **Spec**. Features are selected by spectral analysis. This approach can be considered as an extension of Laplacian score method [75].

Table 8.8 Performance of attribute and success prediction

	All	LapScore	Spec	NDFS	SLS	PLS
Disease type prediction						
Prec	42.31	44.71	41.50	46.32	53.02	59.34
Recall	42.66	46.11	44.82	43.71	48.21	54.20
AUC	63.05	64.47	62.35	67.33	69.85	72.15
Success prediction						
Prec	62.21	67.34	64.08	68.82	71.33	74.12
Recall	67.45	66.72	64.31	65.01	68.20	68.75
AUC	64.10	61.20	61.40	68.95	72.21	76.80

- **NDFS**. Nonnegative discriminate unsupervised feature selection via joint non-negative spectral analysis and l2,1-norm regularization [40].
- **Shared Latent Space (SLS).** Users are embedded into shared latent space of Eq. (8.9).
- **Personal Latent Space (PLS).** Each user is represented using personalized latent space learned from Eq. (8.10) which models both temporality and heterogeneity.

We followed previous research studies to tune the parameters for all baseline methods [25, 40]. The neighborhood size has been fixed to five for LapScore and NDFS, as suggested to be the best in [25, 40]. There are some regularization parameters for NDFS, and LapScore, which were set based on the experiments from the original papers. SLS, and PLS have three different regularizer parameters α, λ_1, and λ_2. In the experiments, we empirically set $\alpha = 0.1$, $\lambda_1 = 10$, and $\lambda_2 = 0.4$ using grid search and tenfold cross-validation.

We evaluated the predictive performance of the proposed framework in supervised setting using attribute prediction and success prediction experiments.

From the learnt feature space, we derived features by averaging the latent features along the time dimension within a given observation window (25 weeks). The performance of attribute prediction and success prediction is presented in Table 8.8 in terms of precision, recall, and AUC. From the Table, we can observe the following points: (1) Feature selection is important as well as effective. The selected features can not only reduce the computational time of the algorithm [75], but more importantly can improve the final prediction performance, where all the feature learning approaches outperform the **ALL** baseline. (2) **LapScore** and **Spec** have similar performance with being slightly better LapScore which is consistent with the results reported in past research efforts [40, 75]. (3) **NDFS** often outperforms both **LapScore** and **Spec** which is attributed to the feature selection process in **NDFS**. **LapScore** and **Spec** analyze features individually which may overlook the possible correlation between distinct features, as reported in [40], while **NDFS** considers feature correlation. (4) **SLS** and **PLS** consistently outperform other baseline methods on both tasks. For example, **PLS** approximately gained up to 6% and 3% improvement in terms of precision in attribute prediction and success prediction, respectively. The reason is probably that **SLS** and **PLS** take advantages of temporal correlation between feature values to mitigate the problems

Table 8.9 Performance of users clustering

	All	LapScore	Spec	NDFS	SLS	PLS
ACC	51.32	56.10	52.84	54.88	56.11	58.01
NMI	0.0224	0.0227	0.0233	0.0240	0.0272	0.0287

arising from data sparsity and missing values. However, all baseline methods adopt the i.i.d assumption, which is not valid in the wellness domain [74]. Moreover, **PLS** outperforms **SLS** most of the time, which shows the importance of modeling heterogeneity in data space, as reported in past efforts [32, 44]. Overall, these observations support the assertion that joint learning of features and modeling of domain prior knowledge could achieve the best performance [44, 66].

We also evaluated our method under the unsupervised setting, i.e., clustering. Table 8.9 summarizes the result of clustering users in the learned latent space in terms of accuracy and NMI. The results are similar to that of supervised setting, i.e., classification. (1) **SLS** and **PLS** approaches outperform all the baseline methods in terms of accuracy and NMI, which demonstrates the importance of modeling temporal progression of wellness features as well as feature learning. The reason is probably that vector-based representation cannot capture the context around each user probably due to excessive sparsity of data, noisy information in social media, and inability to model temporal evolution of user. (2) **PLS** can effectively improve the performance with relative improvement of 2% over **SLS**, in terms of accuracy. This improvement is attributed to the effectiveness of modeling heterogeneity of the patient populations, i.e., different subpopulations in patients, which is modeled in **PLS**, while **SLS** assumes a homogeneous cohort of patients. Overall, the proposed method of *joint modeling temporality of wellness features and heterogeneity of user space* can outperform other baselines and achieve the state-of-the-art performance. This result is consistent with several past research in multi-feature machine learning where dirty models are used to model heterogeneity in samples [44, 66].

8.3.4.5   On the Effect of Temporal Information

We now conduct experiments to verify the effectiveness of different components in our proposed model. In particular, we compared the performance of incorporating temporal smoothness of wellness features in our model. i.e., r_{temporal}, by carrying out the following experimental settings:

- **PLS.** Our proposed framework which models both heterogeneity and temporality, i.e., Eq. (8.10).
- **SLS.** Our proposed framework which models temporality with homogenous assumption, i.e., Eq. (8.9).
- **PLS-noTP.** We did not consider the temporal smoothness in **PLS** by setting $\alpha = 0$.

Table 8.10 Effectiveness evaluation of each involved component in our proposed models

	Precision	Recall	P-value
PLS	74.12	68.75	–
SLS	71.33	68.20	3.1e-3
PLS-noTP	64.02	58.91	1.7e-3
SLS-noTP	62.37	56.09	2.4e-4

- **SLS-noTP.** We did not consider the temporal smoothness in **SLS** by setting $\alpha = 0$.

We only reported the results for the success prediction task since similar observations have been made for the other tasks [6]. The results of component-wise analysis are reported in Table 8.10. From the table, we can observe that: (1) **SLS** and **PLS** consistently outperform their counterparts **SLS-noTP** and **PLS-noTP**, which strongly support the importance of modeling temporality of wellness features; this result has also been reported in modeling disease progression based on patient's EHR [74, 78]; and (2) PLS is superior to **SLS**; demonstrating the importance of modeling heterogeneity along with temporal smoothness.

8.4 Related Efforts on Other Applications

In the previous sections, we demonstrate the great potential of utilizing social media data to mine and profile users' wellness, especially for diabetes patients [3, 4, 6, 8]. In this section, we briefly overview research efforts on related wellness applications. We select obesity and psychological conditions as they are closely related to diabetes and lifestyle. There is other wellness research such as smoking and alcohol drinking habits [29, 45] and human immunodeficiency virus (HIV) risk, which we will not cover here [58].

8.4.1 Wellness Profiling for Obesity

The popularity of social media platforms and the emergence of wearable sensors encourage users to share their wellness and sensor data online. The signals from various wearable sensors (such as heart rate, body acceleration or physical location) are of crucial importance for research in the wellness domain since they describe users' actual physical condition [54]. The combination of multimodal content from different social networks and sensor data for joint modeling [31] will narrow the gap between users' online representation and actual physical status.

Along this line of research, [21] proposed an approach for profiling user wellness based on data from multiple social networks and wearable sensors. The proposed wellness profile includes two personal wellness attributes—"BMI category" and

"BMI Trend." The "BMI category" is based on one out of eight predefined categories, namely "Severe Thinness", "Moderate Thinness", "Mild Thinness", "Normal", "Pre-Obese", "Obese", "Obese II", and "Obese III" [52]. The "BMI Trend" is the direction of BMI fluctuation over time (Increase/Decrease). These two attributes are closely related and correlated to one's overall health. For example, in [22], it was discovered that people whose BMI is higher than 35.0 are approximately 20 times more likely to develop diabetes.

The work of [21] addressed two main challenges of **Data Representation** and **Data Modeling** in individual physical wellness profiling. The former arises from various modalities of data available on different information sources. For instance, in Instagram[11], users share recently taken pictures and videos, while in Endomondo[12] users post information about their workouts, which is strongly dependent on the temporal and spatial aspects. Integration of such heterogeneous multimodal data sources requires the development of efficient and mutually consistent data representation approaches. Data modeling however deals with learning the significance of each information source as well as handling the incomplete data often available in social media platforms. Further, personal wellness attribute categories (classes) are often interrelated.

To address these challenges, [21] proposed a framework, called Multi-Task Multi-Source Wellness Profiling (**M2WP**), to exploit multi-task learning to address these challenges. It introduces techniques to represent data from a new sensor data source (the Endomondo workouts) and other social media sources (Twitter, Foursquare, and Instagram) from which the users' BMI category and "BMI Trend" can be infered. Mathematically, it treats individual wellness profiling as a regularized multi-task learning (MTL) problem, where different data source combinations for each inference category are represented as one task in MTL framework. Concurrently, it considers inter-category relationship by regularizing the MTL model by learning "similar" categories in a mutually consistent fashion. The effectiveness of the model has been verified on a large-scale dataset containing multi-source multimodal data and data from wearable sensors. The dataset has been released for public use [21].

8.4.2 Wellness Profiling for Psychological Health

Psychological health has also attracted much attention in social media computing to infer psychological disorders [19, 63], stress [43], and mood [18] of individuals. In this section, we overview research efforts on Depression and Stress [1, 43, 63].

Depression is a major contributor to the overall global burden of diseases. Traditionally, doctors diagnose depressed people in face to face appointments via referring to clinical depression criteria. However, people are somehow ashamed or

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[11]http://instagram.com

[12]http://endomondo.com

unaware of depression, which leads to not consulting with doctors at early stages of depression. As people are increasingly relying on social media to disclose emotions and share their daily lives, social media can be leveraged to help detect physical and mental diseases [43].

As a result, social media platforms have been studied to infer users' behavior patterns and stress through large-scale data. For example, [17] found that stressed users are more likely to be socially less active, and more recently, there have been research efforts on harnessing social media data for developing mental and physical healthcare tools. For example, [38] proposed to leverage Twitter data for real-time disease surveillance; while [5] tried to organize health data to enhance the aggregation, navigation, and access into knowledge of the crowd.

In [43], the authors presented a framework for detecting users' psychological stress states from users' weekly social media data, leveraging tweets' content as well as users' social interactions. They first defined a set of attributes for stress detection from: (1) tweet-level attributes from content of a single tweet, and (2) user-level attributes that incorporate user's weekly tweets. The tweet-level attributes are mainly composed of linguistic, visual, and social connection (i.e., being liked, retweeted, or commented) attributes extracted from a single-tweet's text, image, and social network connections. The user-level attributes, on the other hand, are composed of: (a) posting behavior attributes as summarized from a user's weekly tweet postings; and (b) social interaction attributes extracted from a user's social interactions with friends. In particular, the social interaction attributes can further be divided into: (i) social interaction content attributes extracted from the content of users' social interactions with friends; and (ii) social interaction structure attributes extracted from the structures of users' social interactions with friends. To maximally leverage the user-level information as well as tweet-level content information, they next proposed a novel hybrid model of factor graph model combined with a convolutional neural network (CNN). This is because CNN is capable of learning unified latent features from multiple modalities; the factor graph model is good at modeling the correlations. The overall model comprises: (1) a convolutional neural network (CNN) with cross autoencoders (CAE) to generate user-level content attributes from tweet-level attributes; and (2) a partially labeled factor graph (PFG) to combine user-level social interaction attributes, user-level posting behavior attributes, and the learnt user-level content attributes for stress detection.

They evaluated the proposed model as well as the contributions of different attributes on a real-world dataset from Sina Weibo. The experimental results show that, by exploiting the users' social interaction attributes, the proposed model can improve the detection performance (F1-score) by 6–9% over that of the state-of-the-art methods. This indicates that the proposed attributes can serve as good cues to tackle the data sparsity and ambiguity problems. Moreover, the proposed model can efficiently combine tweet content and social interactions to enhance the stress detection performance.

The authors [43] further conducted in-depth analysis on the result. The analysis further unveils some intriguing social phenomena. For example, they found that the

number of social structures of sparse connection (i.e., with no delta connections) of stressed users is around 14% higher than that of nonstressed users, indicating that the social structure of stressed users' friends tends to be less connected and complicated, compared to that of nonstressed users.

8.5   Conclusions and Future Work

In this chapter, we aimed to make sense of wellness of users on social networks. In particular, we focused on learning the wellness profile of diabetes patients, where we exploited their social media information to identify, understand, and estimate the wellness attributes and states of users. To accomplish this, we introduce a framework for wellness profiling of users. Although the framework is proposed and evaluated for diabetes, it can be adopted for other approaches. Following this framework, we first harvested social media posts of users to extract personal wellness events which directly expose wellness information and attributes of users. We then proposed to learn the wellness profile of users from multiple social media platforms. The proposed approaches permit us to better understand the wellness of users and communities, obtain actionable insight about the wellness of users and communities, and provide better social and information services.

This research begins a new research direction towards connecting social media and health informatics with many downstream applications. Different extensions of this work are currently being investigated. The first is to utilize the social context around users in a collaborative learning approach. As social media users are linked to each other, the incorporation of network-centric information is a promising direction. Second, from group profiling aspect, community profiling can be used to investigate the evolution of communities in a dynamic network environment, where communities can grow, merge, and dissolve. Thus, another promising direction is to complement the individual profiles based on their community affiliation and study how it can facilitate recommendation. Third, the identification of users who play crucial role in group formation and activities is another interesting promising direction.

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Chapter 9
Social Media and Psychological Disorder

Check for updates

Nur Hafieza Ismail, Mengnan Du, and Xia Hu

Abstract Globally, hundreds of millions of people are estimated living with depression reported by the World Health Organization (WHO). Even though medical technology has improved, a large proportion of sufferers are still receiving improper diagnosis and treatment. Mental illness is endured a burden interfering with emotions, feelings, and various aspects of life. It is a complex disorder that considerably affects physical health particularly severe headache, eating disorder, weakened the immune system, and sleeping disruptions on a constant basis. The traditional procedures for mental illness diagnosis typically rely solely on depression test, self-reported, and family-reported on unusual behaviors. Mental illness is considered taboo to be discussed openly hence the reluctance to seek medical attention. Thus, social media is an ideal alternative for mental illness detection by identifying the symptoms from the users' activities on social media. In this chapter, the related studies of mental illness on social media are explored and discussed. From previous work, online users with mental health problem have been spotted taking depression screening tests, participation in online forums, and often sharing about themselves on social media. The patterns of linguistic style extracted from selected techniques are used to distinguish mentally ill users from the virtual population. The trained models will assist to classify depressed users and prospective depression users through automated monitoring system on social media.

Keywords Social media · Mental health · Text processing · Feature extraction · Machine learning

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9.1 Introduction

The increase in time spent on social media sites and the rise of smartphone users might be employed to assist in reducing non-diagnostic mental health problems. A rising number of studies investigate mental health on the social media, relation of online activities with post-traumatic stress disorder (PTSD), depression, suicidal, and other psychological problems. In 2020, depression has been predicted to be the second largest cause of disability, which has caught lots of attention [1].

The futuristic analysis of social media information could potentially predict psychological problem from an early stage. The available technology nowadays has changed the way we communicate and interact with others. The convenience of smartphone and tablet has opened up the possibilities of mobile social networking to grow. Social media is one of the most popular internet activities that has a high number of user engagement rates. The report published from We Are Social, and Hootsuite in Digital in 2018 Global Overview reveals that approximately 3.2 billion people have a social media profile which equals 42% of the worldwide population.

Social media is widely used in every part of our lives. By requiring limited internet knowledge from users, social media has offered a better way of connecting with people compared to conventional approaches such as emails and letters. It has made easier for people to share life moments, send out the invitation for events, and voice out an opinion either within their contacts or public. Facebook, Twitter, Reddit, Instagram, and Snapchat are the examples of social media that offer secure connectivity and interactive presence features. These functions make users feel more natural to express themselves openly by sharing videos, photos, and texts format. Figure 9.1 shows the most popular social media sites in the world, reported by Statista.

9.1.1 Mental Illness Diagnosis via Social Media

The mental illness diagnosis rate has improved over the past years. However, there are still vast numbers of undiagnosed cases due to the cemented stigma and regarded as a taboo within our society. Physical and mental illness are different from various aspects. Physical illness tools for diagnosis and treatments have been easily accessible. It receives extensive support and recovery process rapidly. In contrast, mental illness requires various tests for diagnosis and often receives inadequate attention and support from people surrounding.

Mental illness diagnosis is contrary with physical illness diagnosis. In general hospital, mental illness diagnosis requires details and comprehensive clinical examinations. To determine the diagnosis outcome, the patients will have to undergo several tests including physical examination, lab tests, and a psychological evaluation. At first, the physical examination is conducted to rule out the physical problem that may trigger the symptoms. Then, lab tests involve a series of blood
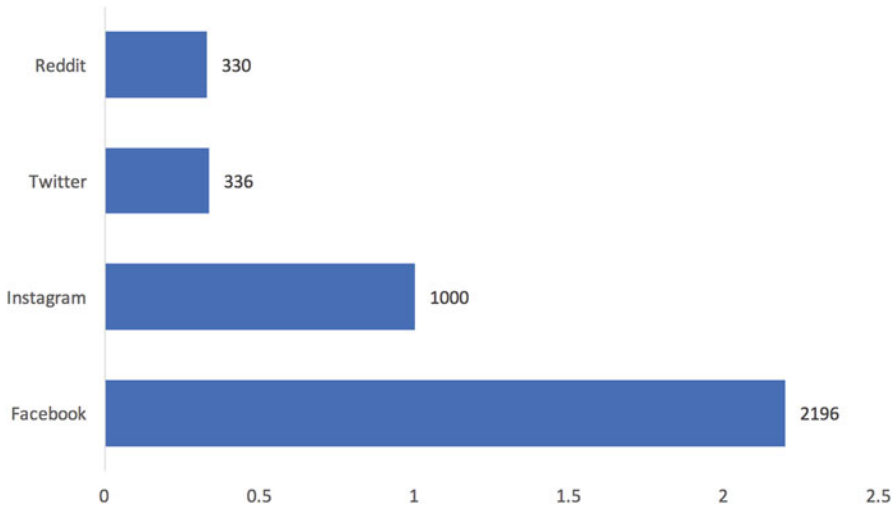
Fig. 9.1 Most famous social network sites worldwide as of July 2018, ranked by number of active users (in millions)

tests that are also usually undertaken to find out the thyroid levels. The reason is that a person with hypothyroidism may have trouble concentrating and sluggishness that could cause a depression [2].

Patients are required to go through a series of face-to-face interview session for psychological evaluation to discuss any related symptoms such as mood and emotional changes, negative thoughts, nightmares, and peculiar behaviors. Patients may be provided with multiple sets of questionnaires to identify the specific category since there are more than 20 dominant types of mental illness. However, the difficulty to diagnose specific type of mental health problem is often overlapped due to the indicated symptoms. The treatment of mental illness could be psychiatric medications, psychotherapy, brain-stimulation, and for the worst cases, the patients might have to admit to residential treatment programs.

Untreated depression can lead to suicidal risk, often coexists with other physical illness and disorders. Approximately, a quarter of breast cancer patients suffer from comorbid depression [3]. One-fifth of coronary heart disease patients experience significant depression [4]. About 10–15% people with diabetes are diagnosed with depressive disorder [5] and 94% of eating disorder patients while under treatment have a mood disorder [6]. Mental disorder is at the top of the list of the most burdensome and costly illnesses in the United States at over $200 billion a year, well exceeding the cost burden of heart disease, stroke, cancer, and obesity [7]. One-third of the mental health cost burden is related to productivity losses, including unemployment, disability, and lower work performance.

Thus, the current popularity of social media presents a new possibility for early detection and identification of mental disorder. The posts on social media sites could show the user's contemporary psychology and emotions states. The
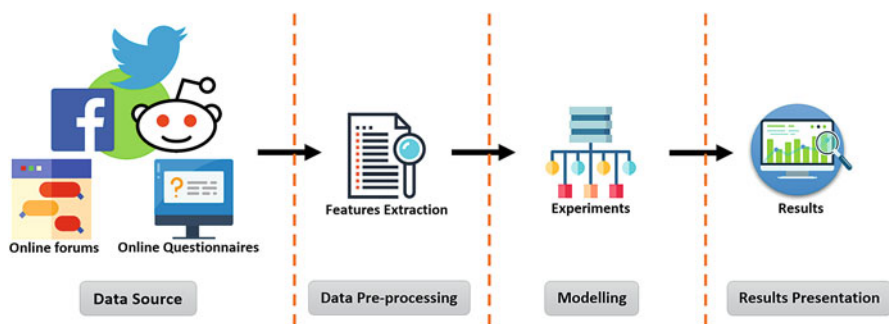
Fig. 9.2 A general framework of identification of mental health problems from online social media sites

language and words used by users in social media texts postings may display the current psychology state at that point. The psychological and emotional suffering are triggered by negative feelings such as stress, guilt, sadness, hopeless, and loss of interest in any activities. The mental disorder can also cause physical pain, sensitivity, sleep problems, fatigue, loss of appetite, and high risk of heart attack. By having a social media account, mentally ill users who shared their feelings on timeline could offer insight into symptoms of mental health problems.

Nevertheless, there are few processes involved in conducting mental health research on social media. There are data collection, data preprocessing, and data analysis. Figure 9.2 shows the general framework on mental health problems identification on social media. This chapter is presented on the considered data sources, features, and prediction methods from previous studies. The rest of this chapter is organized as follows: Section 9.2 introduces the relevant platforms for data collection to establish psychology status. Section 9.3 presents the data collection ground truth. Section 9.4 introduces features that include users' linguistic style as frequencies of each word in the corpus. Section 9.5 introduces prediction methods to analyze the extracted features. Section 9.6 concludes the chapter with some possible directions of future work.

9.2 Data Sources

Various techniques have been applied for collecting online social media dataset containing information about the mentally ill people. The participants involved in studies can be divided into two groups. First, participants with psychological issues were identified after answering depression questionnaires and given consent to share online social media activities. Second, participants who are publicly sharing their social media timeline. In this section, we present four different types of online data sources for mental health problems detection.

9.2.1 Self-Administered Screening Questionnaire

There are several depression screening measures used for diagnosis. For self-reported patients, several instruments for depression diagnosis are available through healthcare providers in questionnaire format. This procedure is to level the symptoms and used as a guide for treatment decisions. The popular self-administered depression screening tools are Patient Health Questionnaire (PHQ-9), Center for Epidemiologic Studies of Depression Scale (CES-D), and Beck Depression Inventory (BDI-II). It requires the subject to answer all the questions that are then scored to measure the severity of the depressive disorder. Nowadays, these screening tests can be done online and immediately showing respondents' results.

PHQ-9 comprises a nine-item depression module for screening, monitoring, diagnosing, and measuring the mental health status [8]. For severity measure, the PHQ-9 possible score range is from 0 to 27 since each item can be scaled from 0 (not at all) to 3 (nearly every day) [9]. It can detect eight significant facets of depression such as major depressive disorder, panic disorder, anxiety disorder, bulimia nervosa, other depressive disorder, probable alcohol abuse, somatoform, and binge eating disorder. For example, PHQ-9 was distributed to the patients every time before the online text-based chat therapy begins. The objective of this approach is to identify the patients' current mental conditions before the chat-based therapy session begins. This therapy session is an essential part of depression treatment. The chat-based therapy provides a significant amount of chat dialogues data between patients and qualified psychologists. With such information, early symptoms of severe depression and anxiety can be identified by analyzing the linguistic style of the patients [10]. In other work, PHQ-9 has been used to determine 42 individuals with PTSD can be classified as a severe mental problem condition, but only a few sufferers received proper care. Online-based treatment for PTSD has displayed encouraging results as an alternative medium for care and treatment [11].

CES-D contains six scales of the 20-item and consumes 5–10 min to complete. The items reveal several types of major depression in the general population: depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. It has been used in many works related to the epidemiology of depressive symptomatology and cancer patients. CES-D was assessed by healthy women and women with breast cancer through results comparison to test its reliability [12]. Meanwhile, CES-D is used to collect dataset through crowd-sourcing from Twitter users diagnosed with Major Depressive Disorder (MDD). It is the primary tool to determine the depression level of crowd-workers [13]. In addition, CES-D questionnaire is used to identify depression symptoms among breast cancer patients. The test set items were derivable of negative emotions and behaviors affecting mental health issues [14]. Online invitations were submitted on social media, and they required to complete the CES-D questionnaire via a web link. The aim is to measure and retrieve the information about depression symptoms in the general population. 0 is set as a minimum score whereas 60 is maximum score for this questionnaire. Three different

levels of depression can be identified based on given marks: low level (0–15), mild-to-moderate level (16–22), and severe level (23–60) [15].

BDI-II has 21-item to present the depression symptoms. Similar with CES-D, it also takes about 5–10 min to complete the questions, but it might take a lot longer for severe depression patients. This set of the questionnaire also includes items that are able to capture the symptom of severe depression that would require hospitalization. BDI-II has a good reputation, and due to that it has been widely used by the health sector for almost four decades and highly reliable on the population [16]. BDI-II acts as an ancillary screening test after CES-D test survey. Ideally, parallel survey scores are crucial in identifying participants suffered from PTSD [13].

The existing survey tests work excellently in classifying mental health issues in general population and specific groups [17]. However, an evidence showed that CES-D as useful level of depression symptoms measure may not be an excellent tool for screening for clinical depression or major depression. CES-D works poorly in identifying MDD among combat veterans with co-occurring PTSD. It is due to the high degree of symptoms that are similar between both depression problems [18].

9.2.2 Publicly Self-Proclaimed with Mental Issues

Self-declared patients are social media users who publicly mention that they have been diagnosed with a mental health problem. They usually make that statement to get pieces of information, supports, and advice from their friends-list or followers. The self-proclaimed users will make a visible statement such as "I just came back from the hospital, and the doctor said, I have PTSD" or use related hashtags in the postings. The user's timeline has to be in public view to capture more information about them.

Schizophrenia is a mental health problem that disturbs the person's thinking and emotional response. The study was conducted by crawling the Twitter public postings using words represent self-stated schizophrenia such as "schizo" or a close phonetic approximation to be present; our expression matched "schizophrenia," its subtypes, and various approximations: "schizo," "skitzo," "skitso," "schizotypal," "schizoid," etc. For the ground truth dataset, the human annotator was assigned to manually check whether the statements are reflecting a person with schizophrenia or otherwise [19].

Twitter tweets with self-mentioned were crawled under four conditions which are depression, bipolar disorder, seasonal affective disorder (SAD), and PTSD. One example of the sentence is "I was suffered from X." The matched diagnosis tweets are then labeled as valid data for diagnosed group [20]. Meanwhile, the three groups of depression, PTSD, and control were compared regarding the linguistic style and words used. The data were taken from self-proclaimed social media users that were currently having depression and PTSD. The two conditions were selected since they frequently appeared on Twitter. This trend reflected our society that many of us suffer from a variety of mental health problems [21, 22].

9.2.3   Online Discussion Sites

The online forum sites contain rich text information about their users. The widespread use of Internet as an alternative medium of communication has significant influences in psychiatry and medicine fields [23]. These sites have been frequently used as a target spot by the mental health researchers for data collection. The mental health studies that involved online depression forum can be divided into two contexts. First, to study the consequence of depression online forum usage of their registered users especially mental health patients. Second, to examine text postings of members of the community who posted about psychological issues.

Online forum and chat room are online discussion sites where the moderators and registered members can open peer discussion by posting questions, messages, and opinions on boards. The debate grows over an interaction among members and the author in the commenting section. Some forum sites provide setting for users to be anonymous but still able to make postings, commenting, and voting. Facebook, the famous social media has a new feature that is similar with forum called "page." Any Facebook user can create "page" for any purposes and allows other Facebook users to be a member. Reddit is a popular discussion site and the registered members are allowing to submit messages, comments, and votes. The forum structure has attracted their members to join the discussion on desired topics and very convenient platform in getting helps and advices from others [24].

The remaining section, respectively, will assert selected depression forums to study the implications of joining the online community. "Psycho-Babble" is an online self-help group that aims to sustain the encouraging milieu among members in the community. The statistics results on forum usage show the effectiveness and the benefits obtained by their active users [25]. The other previous work explored four different online discussion forums on mental health in Norway. The objectives of this work are to investigate the three main "W" questions: who are the users, why, and what benefits they obtain from these forums. Seventy-eight percent of all participants (predominately women) respond that the online forums are helpful for information seeking, socializing, and getting support from people who were currently facing similar issues such as eating disorder, abuse, psychiatry, anxiety, and depression. A three-quarter of respondents feel more comfortable and open to discuss personal issues online compared to face-to-face discussion [26].

Several studies have explored the effectiveness of online treatment in reducing PTSD symptoms. For example, a website (www.virtualclinic.org.au) for online-based treatments of PTSD patients was observed. The analysis results show the significant positive effects to PTSD sufferers [11]. "Bosom Buddies" is an online support group for breast cancer patients to help them to reduce the stress level and assist them to lead better lives. Dealing with breast cancer can lead to serious depression after the diagnosis. Women who joined the breast cancer support group have shown significant improvement in their mental health condition [14]. "Reach Out!" is an Australian online community forum focusing on mental health that is targeting young population ages 16–25 years. The forum supplies a pleasant

environment for them to discuss, communicate, and interact with others to develop positive energy and reduce mental health stigma rather than to keep stressing alone. The professional staffs also contribute to this online forum by providing advice and are always available and can be reached by those who are in need. The study is conducted to explore the challenges and opportunities of potential dangers to mental health patient user [27].

The study is conducted to investigate the explicit and implicit information that users want from an online depression support forum. Nearly 3000 posts were collected from three discussion forums related to mental health on an online depression bulletin board (blueboard.anu.edu.au). The dataset was analyzed to discover the explicit and implicit knowledge behind it. The open requests on mental health information by users presenting the explicit needs. While users that have a psychological problem in the past or current time reflecting the implicit needs [28]. The other similar research explored the online discussion activities in three "Doktor Online" (www.doktoronline.no) forums. The selected mental health forums are general psychiatry, weight and eating disorder, and abuse. All postings of 4 weeks duration were collected. The data analysis was performed based on four feelings categories, "constructive/positive," "negative," "neutral," and "destructive," to describe online interaction [29].

9.2.4   Symptoms Annotation in Text

Cancer diagnosis can affect the mental and emotional health with depression, anxiety, stress, loss, and grief, due to a significant change in life. Emotions and feelings can be revealed or shown from the written text on social media [30]. People with mental health issues usually tend to have a negative sentiment towards everything. This distinct characteristic of mentally ill people has an insight for researchers to explore and study more about them. Thus, Twitter tweets and conversations on other social media sites were crawled using keywords and hashtags related to mental health symptoms.

Data is collected using 14 words with the potential to stigmatize mental health to study the language of mental health. All data comes from publicly available Twitter data collected using Twitter Application Program Interface (API). The stigmatizing words used in this study are "bonkers," "insane," "mad," "nuts," "schizo," "crazy," "loony," "mental," "nutter," "wacko," "deranged," "lunatic," "nutcase," and "psycho." These terminologies are frequently mentioned in articles and publications by the National Alliance on Mental Illness (NAMI) [30]. The Twitter dataset was obtained using self-stated mental health diagnosis in the tweets. For example, tweets contained clear statements such as "I have been diagnosed with this condition." The conditions are an Attention Deficit Hyperactivity Disorder (ADHD), Generalized Anxiety Disorder (Anx), Bipolar Disorder, Borderline Personality Disorder (Border), Depression (Dep), Eating Disorders (Eating; includes anorexia, bulimia, and eating disorders not otherwise specified

[EDNOS]), obsessive-compulsive disorder (OCD), PTSD, schizophrenia (Schizo; to include schizophrenia, schizotypal, schizophreniform), and seasonal affective disorder (Seasonal). The gathered tweets were then analyzed to explore the language contrast between these ten conditions [31].

The specific signals for data crawling purpose were developed to capture the corpus from an online forum for veterans with post-military mental health problems. The PTSD label signs of this group were derived from DSM-IV guidelines [32]. The labels were divided into five general categories: Stress Exposure (e.g., Combat Exposure, Traumatic Loss, Captivity), Affect (e.g., Anger/Rage/Frustration/Contempt, Fear, Worthlessness), Behavior (e.g., Social Isolation, Sleep problems, Excessive Drug Use), Cognition (e.g., Intrusive Thoughts and Memories, Homicide Ideation, Posttraumatic Amnesia), and Domains of Impairment (e.g., Legal Problems, Financial Problems, Occupational Impairment) [33].

Users' tweets were randomly selected through annotation scheme by using the Twitter API of 1-month period. After that, for each day of the 1-month period, 300 tweets containing one or more keywords from the LIWC lexicon "die," "pain," and "tired" once again were randomly selected. The LIWC "sad" category keyword list and several additional keywords corresponding to this category selected by a board-certified clinical psychologist are used. For example, the keyword "insomnia" might represent the symptom for disturbed sleep. A total of 110 lexicons containing depression keywords were identified in this work [34]. Tweets about depression were collected using Twitter Firehose that were able to retrieve the complete desire Twitter data containing mental health data. The presence of depression symptoms identified by referring to the depression items in DSM-5 including depressed mood or irritable most of the day, nearly every day, decreased interest or pleasure in most activities, significant weight change or change in appetite, change in sleep, psychomotor agitation or retardation, fatigue or loss of energy, guilt or worthlessness, diminished ability to think or concentrate or indecisiveness, and self-harm/suicidal signals [35, 36].

9.3 Ground Truth of Data Collection

The data collection process on social media platform is easier compared to traditional process such as face-to-face interview and survey distribution. Data can be easily crawled from the keywords that represent specific topic using Twitter API or Firehose. However, with a massive amount of data collection, the reliable mechanism for data validation is essential. It is a crucial part in data preprocessing because the data quality does affect the data modeling output. The current technique for data ground truth is by using human knowledge as an annotator and total score from depression survey.

9.3.1 Human as an Annotator

In the most related work, the annotation task will be conducted by one of the authors of the paper. A large number of matching tweets gathered during data collection were manually reviewed one by one to determine the true statement about depression [37]. This task aims to identify the text postings on social media containing negative language and symptoms that represent users with mental health issues. This task has to be conducted carefully to avoid misclassification of the correct statements which later will affect the trained model and classification results. By using human capability for annotation, the process might take some time to complete the task that normally involves hundreds of thousands of corpus to be read. It is because they have to classify the statements not only for a diagnosed group but also for a health control group.

9.3.2 Depression Survey Score

In other works, the author started the data collection by employing crowd-sourcing mechanism from Amazon's Mechanical Turk (AMT) service. Crowd-sourcing is a mechanism to gain access to behavioral data from the wide population. By logging into AMT account, the user will design human intelligent tasks for crowd-workers. For the depression work on social media conducted previously [13], the crowd-workers need to take standard depression survey, provide demographics information and history record of depression. They also will ask whether to provide the Twitter user-name (if they set the profile as a public) or not. The consent given by crowd-workers will allow authors to crawl and analyze the crowd-workers' tweets. The depression score should meet the specific target score to qualify them as depression users. This mechanism is not free but it is less time consuming.

9.4 Features Extraction Approach to Identify Psychological Problems

Many studies in mental health have shown concrete evidence that word and language used in social media have significant influence on the author's feelings and behaviors [20, 30]. A mental health problem can be identified from written text on social media sites and websites. The text posting contains unsaid information about the author that can be modeled in Natural Language Processing (NLP) to describe their characteristics such as personality, demographic data, and mental health state [38].
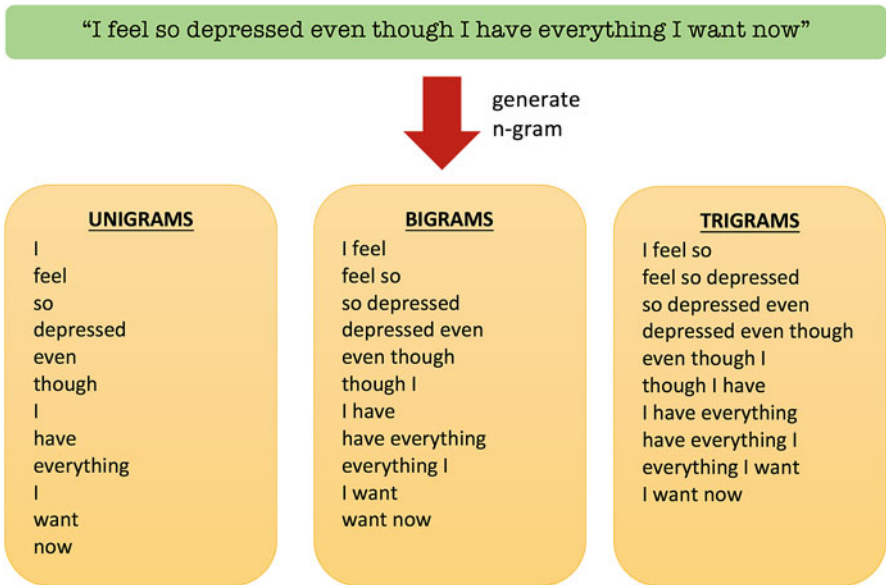
Fig. 9.3 N-gram text representation

9.4.1 N-Gram

Text classification is a major task in document and file processing to automatically supervise various documents online. N-gram is an N-token slice of a linear sequence of character or word in the text. N-gram approach for text categorization is a core task in document classification and must work reliably on all text input. The systems built using n-gram approach have achieved high classification accuracy in document processing. The system is based on calculating and comparing different settings of n-gram and the rate of occurrence in input documents. One significant element of document processing is text categorization, in which a new document is assigned to some preexisting setting. N-grams can be created in several different lengths simultaneously. For example, the sentence "I feel so depressed although I have everything I want now" can be composed in the word N-grams setting in Fig. 9.3.

The challenges of text classification using n-gram are textual errors such as spelling, grammatical mistakes, and characters errors. Text classification should be able to handle this problem to work efficiently. This technique is fast, cheap, and suitable for text and document classification [39].

The analysis of two dataset types which are the control group and diagnose group (PTSD, depression, bipolar disorder, and SAD) used two different n-gram language models (LM). First, they used 1-gram LM (ULM) to inspect the frequency of each word that appeared in tweets, and it produced ULM+ ULM-. Second, they also used characters 5-gram LM (CML) to check 5 characters in sequences, and it produced

CLM+ CLM-. Then, each tweet was classified into a positive or negative class based on the highest probability value. For example, for every given tweet, they computed the probabilities and categorized it. If ULM- is higher than ULM+, it marked as ULM->ULM+ [20]. Characters of a 5-grams technique were used to observe the sequence of characters that were to be generated by the given two types of user schizophrenic and non-schizophrenic. They demonstrated that character n-gram featured over specific user's history tweets performed reasonably in differentiating schizophrenia and control group [19].

The uni-, bi-, and trigram approaches were applied on text postings by Reddit throwaway account and regular account users. This work aims to identify the mental health discourse from both accounts [40]. The throwaway account allowed a person to become anonymous to others and might be used to express their true self without having to care about judgments or critics given by other people. The users' characters from this account are considered as having lowered self-esteem, high negativity emotions, and self-attention seeker. The postings from throwaway user normally show negative sentiment with expression of strong words such as hate, die, lost, suicide, and kill. The n-grams were used to identify posts that express their mental health state [40]. The n-grams (1–5) approach was used as binary features for classification in automatic detection of psychological distress indicators and severity assessment from an online forum post. For examples, phrases for the label Suicidal Ideation include: "thought about jumping," "me suicidal," "end their life," "feel like killing myself" [33].

To identify the mental well-being among universities students, the n-gram was applied in the experiments. It recognized the top 20 uni-, bi-, and trigram words that frequently appeared in university subreddit posts. Those are the words mostly used by college students who have mental health problems. As a result, they are able to capture the negative thoughts, mental health expression, and seek help statements from their postings [24]. N-grams were applied for predicting suicidal ideation and psychiatric problems in Madrid, Spain. They used uni-grams, bi-grams, and trigrams during NLP algorithm development. They found out that the settings for single and bi-grams will increase the sensitivity, but at the same time, the specificity decreased. The predictions were based on a contiguous sequence of n-grams words set. N-grams were then fed into a machine learning method to train the prediction model [41].

9.4.2 Linguistic Inquiry and Word Count (LIWC)

LIWC is a paid text analysis tool to capture human social language and psychological conditions. It reads a given statement and counts the percentage of each word that reflects different types of emotions, thinking styles, social concerns, and even parts of speech. This program is created in the Java programming language. LIWC reads written or transcribed verbal texts which are stored in a digital, computer-readable form in text files. The text analysis module then compares each word

in the text against a user-defined dictionary. The dictionary identifies words that are associated with psychologically relevant words from several categories. After the processing module has read and accounted all words in a given text, it will calculate the percentage of total words that match each of the dictionary categories. For example, if LIWC analyzed a single speech that was with 2000 words and compared them to the latest version of the built-in LIWC2015 dictionary, it might find that there were 150 pronouns and 84 positive emotion words used. It would convert these numbers to percentages, 7.5% pronouns and 4.2% positive emotion words. LIWC2015 comes with three internal dictionaries systems which are the LIWC2015, LIWC2007, and LIWC2001. The LIWC2015 master dictionary is composed of almost 6400 words, word stems, and selected emotion icons. For each dictionary word, there is a corresponding dictionary entry that defines one or more word categories. For example, the word "cried" is part of five-word categories: Sadness, Negative Emotion, Overall Affect, Verb, and Past Focus. Hence, if the word "cried" was found in the target text, each of these five sub-dictionary scale scores would be incremented. The ability of LIWC in justifying the sentiment words has encouraged the researchers to study a linguistic style of society in social media. The ways people use words in their daily lives can provide precious information about their beliefs, fears, thinking patterns, social relationships, and personalities [42].

LIWC used to analyze the linguistic differences of people living with schizophrenia as a positive group and general population as a negative group. They discovered that the language of schizophrenia used lots of words from negative words category such as COGNITIVE MECHANISMS, DEATH, FUNCTION WORDS, NEGATIVE EMOTION, and in the following subcategories: ARTICLE, AUXILIARY VERBS, CONJUGATIONS, DISCREPANCIES, EXCL, HEALTH, I, INCL, INSIGHT, IPRON, PPRON, PRO1, PRONOUN, TENTATIVE, and THEY. Fewer words used in positive phrase category are HOME, LEISURE, and POSITIVE EMOTION, and in the subcategories of ASSENT, MOTION, RELATIVE, SEE, and TIME [19].

Tweets taken from ten different mental health problems (ADHD, anxiety, bipolar, borderline, depression, eating, OCD, PTSD, schizophrenia, seasonal affective) were analyzed comprehensively using LIWC. LIWC provides the proportion of each lexicon used by each user that falls into any category in this tool. The frequency of word tokens in several LIWC classes have shown different mental health states. For example, ANXIETY, AUXILIARY VERBS, COGNITIVE MECHANISMS, DEATH, FUNCTION, HEALTH, and TENTATIVE categories of words. They concluded that the users might not give specific symptoms of their mental problem in most cases. While for eating disorder problem, the tweets have shown evident signs because most of the lexicons are corresponding to INGEST, and NEGATIONS words categories [31]. To get a better understanding of self-disclosure from Reddit postings, the evaluation of linguistic elements in the content was conducted. By using psycholinguistic lexicon provided by LIWC comes from several semantic categories, they are able to list out the 45 most frequent words and their count of usage in mental health topics from reddit [43]. LIWC as a sentiment tool used to

quantify the level of depression among Twitter users. It counts words that exist in several psychological categories. Each word is then scaled across six different groups: social, affective, cognitive, perceptual, biological processes, and relativity. Each group has several chains of sub-group, for example, the word "cry" associated with sadness that falls under negative affect sub-group, and negative affect is a sub-group of affective group [15].

9.4.3   Sentiment Analysis

Sentiment analysis aims at determining the emotional state of the author behind a written text and used icons on timeline posts [44, 45]. This procedure helps us to increase understanding of the behaviors, feelings, attitudes, and opinions expressed in virtual life through social media. Sentiment analysis on social media is useful in several fields including sociology and psychology because, in real life, depressed people are hard to be noticed. However, online social media features have offered a comfortable environment for people to voice out their feelings, experiences, etc. Thus, this information is full of knowledge and learning about the complexity of human language would benefit in spotting people with mental health problems.

Twitter tweets have been examined to capture the users' true feelings of positive, negative, or other coded feelings behind their posts. The collected data were all related to mental health discourse, and a set of search terms were used during data crawling. This work aims at discovering the sentiment of Twitter mental health conversation. The output of analysis shows most of the discussion about stigma and awareness. People seem positive and supportive by showing an interest in mental health issues [46]. In other work, the online chatting therapy for patients with depression becomes a new treatment method in the United Kingdom. They discovered that patients tend to use negative sentiment words during the chatting session with a therapist. Patients with high proportions of negative sentiment also have greater anger in their inner self, while patients with positive attitude in their chatting statements show an excellent continuing psychological recovering [10].

Sentiment analysis method is applied on social media dataset to detect users with depression. This work is conducted using subject-dependent analysis on Twitter data. The tweets were labeled by calculating the pre-defined weight of each lexicon appeared in tweets to decide its polarity [47]. Two mental disorders, bipolar and depression characteristics, were identified by studying the linguistics used in Twitter. The python package Afinn used for sentiment and TextBlob for polarity purposes [48]. A total of 125 words features were gathered after the data preprocessing approach in detecting PTSD among veterans with combat experience. Sixty-eight lexicons were extracted from LIWC that include groups corresponding to practical and emotional processes (e.g., positive/negative emotions), Cognitive Processes (e.g., causation), and Social Processes (e.g., friends) among others. Another 57 lexicons were extracted from the General Inquirer (GI) system that includes positive/negative and motivation-related words [33].

9.5   Automated Detection Method

The mental health problems automated detection system on social media sites is constructed from selected features and appropriate algorithms. The frequently used features are composed of a score of the questionnaire, demographic information, online activities, and linguistic style. Features are then fed to the algorithms to learn and train the characteristics of mentally ill people. In such a way, the extracted model is capable of perceiving mentally ill user from a healthy population. Many methods are available for modeling mental health problems. For example, statistical methods, machine learning, and a deep neural network. In this section, we will discuss these three approaches to modeling mental health.

9.5.1   Statistical Method

The statistical method involved mathematical formulas, algorithms, techniques, and models that are used to analyze the input dataset. This method will extract knowledge from a clean dataset and present it in various angles which are generally in tabular and figure format as an analysis output [49]. In NLP and psychology researches, statistical methods are essential in most cases to distinguish the vital features of control and healthy groups.

To compare the behavior of women with breast cancer and women with no cancer history, their psychometric properties in CES-D were evaluated. The CES-D validity was evaluated by analyzing the test-retest reliability and measuring internal consistency. The first test of CES-D internal consistency was examined using alpha coefficient. Next, for test-retest reliability, the answers were evaluated by measuring the correlation of both tests [12]. The other similar work on mental health also been studied in Reddit throwaway accounts. People who used throwaways seem to be more interested in mental health forums than other discussions. T-stats is applied to the dataset to see the difference between a throwaway account and regular Reddit account in identifying mental health posts. The throwaway account users tend to have characteristics of lowered self-esteem, negative thought, and self-attention focus [40]. A statistical technique, the negative binomial regression was selected as a prediction approach in mental health discourse on Reddit. This approach could handle the countable-dependent parameters which are karma and comments [43].

Mental health expressions by students in university subreddits posts were explored using linear least squares model and t-test. The linear least squares model was applied to the dataset to study the relative temporal changes in mental health expression. To filling the gaps of insufficient subreddit data, they used two one-sided t-tests technique on before-after yearly rates with chosen different interval from both sides. Independent sample t-test shows the difference in mental well-being index between public and private universities [24]. In other similar work related to predicting suicidal ideation and psychiatric symptoms on text answers

from the survey, a t-test was adopted to differentiate the target participants with normal participants [41]. The research in depressive moods of users portrayed in Twitter has applied multiple regression algorithm for model development. From the model, they are able to understand the statistical correlation of depression condition and word usage between healthy and depressed groups. All 37 sentiment categories were involved in the modeling process. They also applied stepwise regression to select the best model in predicting Twitter users' CES-D scores [15].

The dissimilarity of depression treatment among different races was studied to provide evidence of this controversy in health care. Descriptive statistics of the dataset were presented by summarizing the treatments received by people from four different races, non-Latino white, Latino, Asian, and African-American. After that, they estimate a two-stage regression model which is the first stage was for evaluating the connection of getting mental health treatment by each race/ethnicity in the previous year. The second stage was for determining the association between quality depression treatment during the last year for patients with a history of psychological care. The bootstrap test was also used to get predictive intervals and compare the predicted probabilities of all race and ethnicity [50]. The mental health problem study is conducted on veterans who returned from combat duty in Iraq and Afghanistan. The survey responses were analyzed using SPSS statistical tool and multiple logistic regression algorithms were used to handle different demographic characteristics of the participants before and after deployment [51].

9.5.2 Traditional Machine Learning

Machine learning is a data analysis technique that teaches computers to learn and make decisions like humans [52]. It can improve their learning by inputting new data and information into the current model. Machine learning can be divided into different learning styles like supervised learning, unsupervised learning, and semi-supervised learning. It also can be distinguished by function similarity such as regression, classification, clustering, and deep learning [53, 54]. This section will introduce several machine learning algorithms used in mental health and social media studies. Supervised learning is frequently used for understanding the text including online text postings on social media sites.

The machine learning experiments were conducted using Support Vector Machine (SVM) approach and Maximum Entropy (MaxEnt) methods in quantifying the language of schizophrenia in social media. The extracted features were fed into these methods, and both SVM and MaxEnt results were compared. The learning models were then able to identify the people with schizophrenia from tweets. SVM obtained 82.3% classification accuracy and MaxEnt obtained 81.9% classification accuracy [19]. The scheduled online chatting-based therapy conducted by professional therapists with their patients is a part of the regular psychological treatment. It contains lots of text statements from the chat conversation. This has opened up the opportunity to conduct an initial investigation to identify the

symptom of severe depression. Thus, the WEKA machine learning toolkit was used for the experiments. Decision tree (J48), a logistic regression model, and SVM from WEKA were applied on the pre-process dataset to train the models with tenfold cross-validation. For this work, logistic regression has outperformed the other methods by obtaining the highest classification accuracy of 71% [10].

To automatically identify the Reddit posts containing mental health expressions, they applied an inductive transfer learning technique on the dataset. The classification techniques involved in this work are random forests, Ada Boost, SVM, and logistic regression. To evaluate the robustness of the selected method, they used k-fold cross-validation and linguistics features during training [24]. SVMs was used to detect lexicons that represent PTSD symptoms in statements corpus. This algorithm can handle the multi-label classification directly. It used to train a model that can automatically detect psychological disorder signs from text posting in online forum [33]. SVM and logistic regression were used for tweets classification. Logistic regression function is used to justify features that influence the classification output. SVM function is used to group tweets with similar characteristics into the same group. In this work, the trained model can identify tweets in two different groups of mental health and control [48].

9.5.3 Deep Learning

Deep learning is part of machine learning that involves multiple processing layers to learn representations of data. It can be categorized as supervised, semi-supervised, and unsupervised learning which the models learned to do data classification and identification from dataset during the experiment phase. For traditional machine learning approaches, the important features will be identified by an expert to decrease the data complexion and make the extracted features more easy for algorithms to learn for prediction. Figure 9.4 visualizes the differences of tasks involved in machine learning and deep learning. Deep learning methods such as multilayer perceptron (MLP), convolutional neural network (CNN), and recurrent neural network (RNN) are frequently used. These methods require a significant amount of data to perform well for classification. Deep learning has shown promising results in NLP and RNN that can handle sequential data including text and speech [55].

During data preparation stage, all the retweets, URL's, @mentions, and all the special characters, stop words were removed. Before the dataset was fed into a deep neural network, the Word2Vec produces word embedding. The two Word2Vec models, Skip-gram and Continuous Bag-Of-Words (CBOW), are used to construct vector values from words in input tweets. Interestingly, CNN performed better than RNN and SVM as a baseline for depression detection [56]. Deep learning models are able to construct important features from unstructured data such as text, audio, and video. This approach is capable of containing the semantic meaning of the given input text for a better training model later. In this work, deep learning approach has
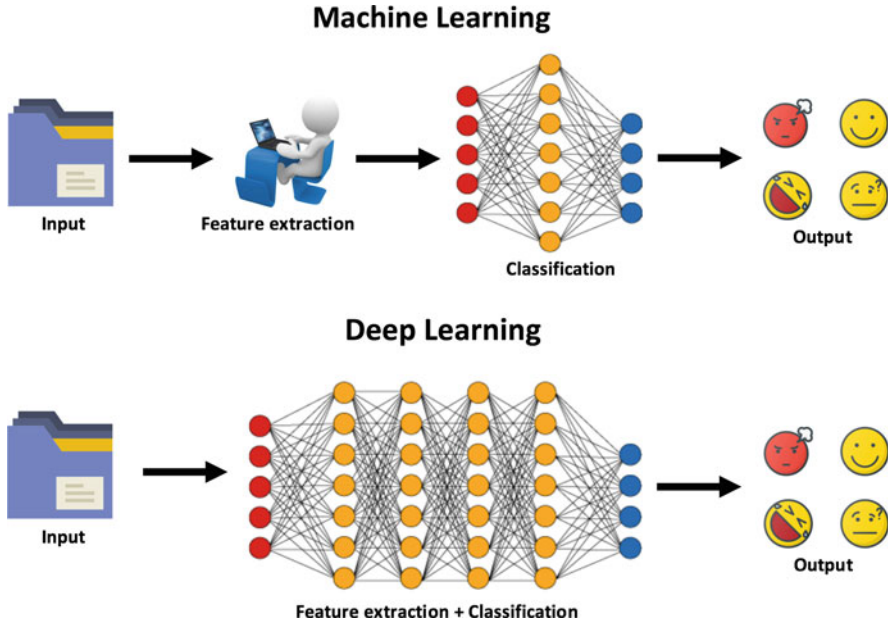
Machine Learning

Deep Learning

Fig. 9.4 The overview of tasks involved in machine learning and deep learning

been used to created vectors for each word using Word2Vec CBOW model before the experiments. The result shows that the classification was done with manually generated features that achieved an average accuracy of 85%. Compared with tweet classification using Word2Vec achieved a better accuracy with 90% for mental health analysis [57].

The informed CNN deep learning approach has been used to identify mental health conditions from Reddit posts. The tasks for classification can be divided into two. The first task was to distinguish posts either written by a user with a mental health problem or not. The second task was to classify the mental health problem posts into eleven different categories. The eleven types are borderline personality disorder, bipolar, schizophrenia, anxiety, depression, self-harm, suicidewatch, addiction, cripplingalcoholism, opiates, and autism. From the experiments, CNN shows the best accuracy of 71.37% compared to feed-forward, linear, and SVM [58]. Deep learning network with gated recurrent unit (GRU) layer model was compared with the SVM model in early depression detection on social media research. GRU is a sequential model that considered the depression symptoms in one of the user's posts before the time t and classified whether the user is suffering depression or not. While SVM is a non-sequential model that considered all the users' posts before the time t and classified the users' label [59].

9.6   Conclusions and Future Work

Online social media and forum discussion sites contain a significant amount of information. The popularity of social media, advanced NLP systems, and excellent methods for text classification have opened up a great opportunity for researchers to explore more about linguistic style in virtual life. In this chapter, we present a comprehensive review by introducing general tasks and items involved in predicting mental health problems in several online environments. The hidden knowledge behind the written text is very precious in several cases including mental health problems and threat cases (bomb threats, school threats, etc.). For mental health issues, an early depression identification with an alarming system will inform the social media users to take action by seeking the doctor immediately for diagnosis and treatments.

Although the field of online mental health detection is advancing rapidly, there are still lots of future work needed to do in order to further promote the progress of this field. (1) The detection algorithms are often regarded as black-boxes and criticized by their lacking of interpretability [60]. More interpretable models are demanded to increase the acceptance of users for detection models. (2) Accurate prediction requires an analysis of a massive amount of factors, including demographic information, medical history, and other information that could contribute to mental health problems. (3) Using automated machine learning (AutoML) [61] in medical field is possible and suitable because it provides techniques and methods for non-machine learning experts without having to code. AutoML also is capable of processing a significant amount of data, identifying the important features, and extracting pattern for modeling which are more accurate and work faster than classic models. All of these characteristics are important in diagnosis of mental health problems which require precise prediction in a real-time manner on social media.

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Chapter 10
Analysis by Multiclass Multilabel Classification of the 2015 #SmearForSmear Campaign Using Deep Learning

Check for
updates

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Abstract *Background*: Cervical cancer is the second most common cancer among women under 45 years of age. To deal with the decrease of smear test coverage in the UK, a Twitter campaign called #SmearForSmear has been launched in 2015 for the European Cervical Cancer Prevention Week. Its aim was to encourage women to take a selfie showing their lipstick going over the edge and post it on Twitter with a raising awareness message promoting cervical cancer screening. The

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estimated audience was 500 million people. In a previous study (Lenoir et al., J Med Internet Res 19(10):e344, 2017, https://doi.org/10.2196/jmir.8421, http://www.jmir.org/2017/10/e344/), we identified the tweets delivering a raising awareness message promoting cervical cancer screening (sensitizing tweets) and understood the characteristics of Twitter users posting about this campaign.

Objective: The objective of this new study is to investigate the interest of deep learning methods to automatically categorize tweets according to themes and users' status.

Methods: We conducted a 4-step content analysis of the English tweets tagged #SmearForSmear and posted on Twitter for the 2015 European Cervical Cancer Prevention Week. 18,292 messages were collected using the Twitter Streaming API between the period of January 2017 and November 2017. In order to produce training and test data sets, we annotated the messages according to themes and users' statuses.

These messages have been analyzed by two independent researchers using a thematic analysis, validated by a strong Cohen kappa coefficient. A total of seven themes were coded for sensitizing tweets and seven for Twitter users' status. Based on this annotation, we compared by cross validation the predictive performances of traditional classification techniques against more advanced deep learning methods.

Results: Deep learning models were able to predict efficiently the seven themes and seven users' status. More specifically, the deep learning models performed better than traditional approaches.

Conclusions: Deep learning methods can efficiently predict themes and users' status. These predictive models could be used as a powerful tool to automatically analyze social data such as twitter streams for medical perspectives. This study also demonstrates that the success of a public health campaign using a social media platform depends on its ability to get its targets involved. It also suggests the need to use social marketing based on efficient predictive approaches to help its dissemination. The clinical impact of this Twitter campaign to increase cervical cancer screening is yet to be evaluated.

Keywords Social media mining · Deep learning · Public health campaign

10.1 Introduction

Cervical cancer is the second most common cancer type among women under 45 years of age and leads to significant mortality [5]. Cervical cancer is caused by human papillomavirus [22]. Smear test (Papanicolaou test) detects precancerous changes and early-stage cervical cancers. Its introduction has allowed a dramatic decline of cervical cancer incidence and death rates in many countries, especially the developed countries [20].

However, the organized screening established in 1988 is not intrinsically strong enough to keep a high coverage rate. From 1999 to 2013, the number of women who

did not attend their smear test for a 5-year period has progressively increased from 16% to 22% [12].

Social media would have a great potential to improve behavior change as interactive tools, encouraging participation and self-engagement instead of a descending information [2, 14, 19]. They are also seen as an opportunity to promote adherence to cancer prevention programs and a new way to screen at-risk population based on their personalized profiles [21]. For example, Twitter had more than 317 million monthly active users in December 2016, with more than 500 million traded tweets every day.

Public health campaigns have already tried to take advantage of the ability of social media to make a campaign viral. The amyotrophic lateral sclerosis (ALS) Ice Bucket Challenge's goal was to mediatize and raise funds for the ALS association.[1] The campaign had involved many celebrities worldwide. On September 1, 2014, more than 17 million videos had been shared on Facebook and had been watched more than 10 billion times by more than 440 million people. Thanks to this campaign, more than US $100 million had been raised by the ALS association. Hundreds of thousands of people had tweeted daily about ALS, which is a much higher number of tweets than those emitted about multiple sclerosis, a disease better known to the public [9].

To deal with the decrease of smear coverage in the UK, a Twitter campaign called #SmearForSmear has been launched in 2015 by the Jo's Cervical Cancer Trust for the European Cervical Cancer Prevention Week. Its goal was to encourage women to take a picture of themselves (selfie) showing their lipstick going over the edge and post it on Twitter with an awareness message promoting cervical cancer screening. The estimated audience was 500 million people [15].

This chapter is an extension of the paper [10], in which we conducted a manual tweet analysis. The objective of this new study is to automatically identify the tweets that are delivering raising awareness messages about cervical cancer screening and to understand the characteristics of the users posting about this campaign.

Moreover, we focus on more advanced methods in order to automatically classify tweets in themes and users' status. Text classification is a classic NLP topic, which consists of assigning predefined categories to free-text documents. Many research focused on defining the best features and choosing the best machine learning classifier. Most of the techniques are based on words, lexicons, and are specific to one particular task. Lately, for many text classification tasks, deep learning methods were effective. For example, these systems have been well ranked in recent evaluation campaigns such as SemEval 2015 [16] and SemEval 2016 [13]. In this chapter, we will compare the efficiency of traditional classification methods and several deep learning architectures.

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[1]http://www.alsa.org/.

10.2   Methods

10.2.1   Overview

The methodology of this study involved four steps: (1) data collection and extraction, (2) manual annotation by two experts, (3) model for category prediction, and (4) performance evaluation.

10.2.1.1   Data Collection and Extraction

We conducted a content analysis of the English tweets posted on Twitter during the 2015 European Cervical Cancer Prevention Week.

To collect the tweets, we used the Twitter Streaming API. It allows the user to conduct an automatic real-time crawling of tweets using some keywords or specific parameters such as hashtags, language, etc. In this research, we used the following: #SmearForSmear and English language.

We automatically collect 18,292 tweets from January 2017 to November 2017. For manual annotation, we focus on 1910 tweets, corresponding to the European Cervical Cancer Prevention Week, between the period of January 25, 2015, and January 31, 2015, both dates inclusive. Only original tweets were analyzed.

For the 1910 tweets, the verbatims were transcribed. Hashtags and content preceded by "@" were removed if that action did not make the verbatim unintelligible. We also considered all hypertexts linked to another verbatim on another Web platform (e.g., Instagram). The corresponding verbatims were transcribed only if they were informative.

10.2.1.2   Manual Annotation

A total of 1910 tweets that met the search criteria are imported for data extraction. An analysis grid had been created based on the first 200 original collected tweets and thematically analyzed by two independent researchers to extract the themes (topics) of tweets and Twitter users' statuses. Then, this grid had been tested on 50 new tweets. No new themes had been identified, confirming that category saturation was achieved [6]. The thematic analysis methodology consists of transforming qualitative content into a quantitative form by establishing coding categories. The number of data units that fall into each coding category was counted (such as phrases, messages, and responses). Finally, they were categorized based on similar meanings and overt or inferred communication [7, 8]. Themes were not restricted to preexisting ones. They emerged through an inductive process whereby open coding of data revealed themes that moved from the specific to the general [4]. The two researchers were general practitioners and trained in qualitative study. We elaborated a 7-theme codebook, based on tweets, to identify if the tweets

deliver raising awareness messages about cervical cancer. If a tweet had at least one of these awareness-raising messages, it was considered as a sensitizing tweet. Reproducibility of the classification of the first 300 original tweets by the two independent researchers was tested and calculated with Cohen's kappa coefficient. The agreement was strong and varied between 0.8842 and 1.

For each tweet, we collect the following information: verbatim, posting date, retrieval date, presence of a selfie with lipstick going over the edge, picture or video referring to the campaign, users' sex, users' location, number of followers at the date of retrieval, and users' status. These information were used to elaborate a 14-status codebook to classify the users. If the Twitter status did not exist or was incomplete, we extracted this information from links on their Twitter profile, whenever possible. The analysis grid enlisted 14 themes regarding Twitter users' status. The "unknown" status was attributed when no information to categorize the user was available. Only the "unknown," "general public," or "NHS" statuses were exclusive. An initial global description of the sample has been performed and described in [10]. The 14 classes were reorganized according to semantic proximity by the expert into 7 classes to obtain a balanced data set.

In Table 10.1, we summarize the list of classes defined after the manual annotation phase, as well as the corresponding percentage in the data set and the number of tweets. Each message can be associated with one or several themes. Similarly, messages can be associated with one or several user statuses. These classes will be used as output for the category prediction.

Table 10.1 Output of the classification

Themes (% and #)	
Incentive to carry out the smear test	0.420 (440)
Evocation of smear test importance without any precision	0.060 (63)
Reminder of the smear test preventive nature	0.207 (217)
Reminder of the low incidence of smear test	0.026 (27)
Allusion to the mortality or morbidity of cervical cancer	0.128 (134)
Reminder of the incidence of cervical cancer	0.039 (41)
Testimony of an experience related to smear test or cervical cancer	0.088 (92)
Other	0.420 (440)
Users' status (% and #)	
Company	0.583 (1096)
Blogger or YouTuber	0.139 (262)
Health professional	0.028 (53)
Politician	0.204 (383)
Woman with an unspecified cancer or relatives with a similar status	0.053 (99)
General public	0.041 (77)
Unknown	0.235 (442)

10.2.1.3 Models for Category Prediction

In this study, we explore the use of deep learning methods to predict the seven themes and the seven users' status based on the 1910 collected tweets. We compared the results of our deep learning models against the traditional methods. In this section, we detail how each model is built.

Models The models used in our study are summarized in Table 10.2. In the following, we first discuss the deep learning models. All our models are built with an embedding input layer and an output layer containing as much neuron as there is in the classes of our data set. Then, we describe the intermediate layers of our different neural network models. We invite the reader to consult more detailed reviews such as the one of Schmidhuber [17].

Basic neural network (BNN) directly connects the input layer with the output layer.

Multilayer perceptrons (MLP) is the simplest model in deep learning. It is realized by one hidden layer of neurons.

Deep multilayer perceptrons (DMLP) is based on twenty hidden layers.

Long short-term memory (LSTM) is a subtype of RNN. Recurrent neural networks allow the study of data sequences. These networks, composed of several layers, estimate their outputs according to the states of their previous layers using an intermediate memory. LSTM is based on designed memory blocks that are used as units in the recurrent layer to capture longer-range dependencies.

Bidirectional long short-term memory (BLSTM) allows to use the information after and before the data studied by the network at time t.

Gated recurrent unit (GRU) is a neuron network allowing a faster study than the LSTM while retaining the qualities of this one.

Long-term recurrent convolutional networks (LRCN) associates in series a convolutional network and an LSTM network.

Convolutional neural network (CNN) is structured by two operations: convolution then max-pooling. Convolution is based on multiple filters combined together

Table 10.2 Classification models

Non-deep learning models	Deep learning models
SVC (SVC)	Basic neural network (BNN)
MultinomialNB (MNB)	Multilayer perceptrons (MLP)
SGDClassifier (SGDC)	Deep multilayer perceptrons (DMLP)
AdaBoost (AB)	Long short-term memory (LSTM) RNN
Decision tree (DT)	Bidirectional long short-term memory (BLSTM) RNN
LinearSVC (LSVC)	Gated recurrent unit (GRU) RNN
BernoulliNB (BNB)	Long-term recurrent convolutional networks (LRCN)
KNeighborsClassifier (KNC)	Convolutional neural network (CNN)
Passive aggressive (PA)	Serial convolutional neural network (SCNN)
Random forest (RF)	Parallel convolutional neural network (PCNN)

to extract the many properties associated with the data. The second operation compresses the results of the previous operation to extract dense information.

Serial convolutional neural network (SCNN) sequentially places two convolutional networks one after the other.

Parallel convolutional neural network (PCNN) is based on three different convolution networks with different kernel. Then finally we associate the output to a single layer to build a single-layer output.

Input of the Models The input of the models are the messages. First, we apply three preprocessing steps: stopword removing, lemmatization, and stemmatization. Then, we use two distinct preprocessing for the two types of studied classification methods. For traditional classification methods, we apply a vectorization based on Tf-Idf measure. For deep learning methods, we keep the 3000 most frequent words and we represent each document by a sequence of words.

Output of the Models The output of both models consists in seven classes for theme classification and seven classes for users' status classification. Considering the themes, a large number of samples are not labeled. We perform on these samples a resample of the size of the majority class. Considering the users' status, the initial annotations phases provide 14 classes. These classes are grouped by the expert according to semantic proximity in order to rebalance the number of samples by classes. A description of the final classes is given in Table 10.1.

Data Partitioning and Training In order to evaluate the different models, we apply a fivefold cross validation. The data set is divided into five subsets. We use four subsets for the training phase and one subset for the validation phase. We repeated this process five times. For each fold, we use a subset of different validation phases and we calculated the metric used for performance evaluation.

For classical classification algorithms, we use the sklearn tool[2] with the default parameters and we tune some hyperparameters, for example, we used 500 estimators for the méta-classifier random forest (RF). For the deep learning algorithms, we used the Keras tool.[3] For all architectures, we used the default parameters for mini-batch size (i.e., how many training instances to consider at one time), embedding dimension (each word is described by a dimension vector n), max epoch (maximum number of iterations over the training set), and dropout ratio (ratio of hidden units to turn off in each mini-batch training). Then, we use a configuration with a mini-batch of size 64, an embedding dimension of 300, a dropout ratio of 0.2, a hidden layer of size 256, and max epoch 50.

Performance Evaluation For all models, we are based on a commonly used metric in data mining. Each output is a label of n dimension corresponding to the number of classes. Accuracy is computed as proportion of correct predictions from all predictions made.

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[2]http://scikit-learn.org/stable/.

[3]https://keras.io/.

10.3 Results and Discussion

As shown in Tables 10.3 and 10.4, the traditional classifiers performed worse than
the models based on deep learning. The best traditional classifier is LinearSVC with
an accuracy of 0.697 for theme classification and 0.266 for users' classification. The
best deep learning architecture is LSTM for both classification tasks.

Impact on Social Media Analysis We present an original approach of multiclass
multilabel classification of tweets in order to analyze the impact of social media on
public health campaigns. Social media is highly prevalent in contemporary society,
and has been shown to impact patients' behaviors. Therefore, health researchers
are exploring social media to better understand patients' roles and feeling about
medical question. A major bottleneck for this research is that current approaches for
studying social data require intensive manual work by human experts. Furthermore,
huge social data sets dealing with medical questions are emerging. These social data

Table 10.3 Classifiers comparison (themes)

Statistical classifier	Classifier	SVC	MNB	SGDC	AB	DT
	Accuracy	0.0	0.556	0.681	0.683	0.586
	Standard deviation	0.0	0.0410	0.0112	0.0243	0.0417
	Classifier	LSVC	BNB	KNC	PA	RF
	Accuracy	**0.697**	0.536	0.509	0.649	0.659
	Standard deviation	0.0105	0.0340	0.0260	0.0107	0.0221
Deep learning classifier	Classifier	BNN	MLP	DMLP	LSTM	BLSTM
	Accuracy	0.721	0.621	0.0	**0.792**	0.744
	Standard deviation	0.491	0.0289	0.0	0.0362	0.0484
	Classifier	GRU	LRCN	CNN	SCNN	PCNN
	Accuracy	0.679	0.710	0.775	0.701	0.751
	Standard deviation	0.0434	0.0356	0.0332	0.0437	0.0361

Table 10.4 Classifiers comparison (users' status)

Statistical classifier	Classifier	SVC	MNB	SGDC	AB	DT
	Accuracy	0.0	0.251	0.273	0.238	0.157
	Standard deviation	0.0	0.0289	0.0402	0.0473	0.0416
	Classifier	LSVC	BNB	KNC	PA	RF
	Accuracy	**0.266**	0.181	0.197	0.229	0.213
	Standard deviation	0.0400	0.0330	0.0322	0.0355	0.0367
Deep learning classifier	Classifier	BNN	MLP	DMLP	LSTM	BLSTM
	Accuracy	0.236	0.230	0.137	**0.300**	0.245
	Standard deviation	0.0318	0.0326	0.123	0.0338	0.0217
	Classifier	GRU	LRCN	CNN	SCNN	PCNN
	Accuracy	0.200	0.294	0.256	0.287	0.233
	Standard deviation	0.113	0.0423	0.0338	0.0377	0.0383

are a great opportunity for health research, but to achieve this paradigm shift, it is necessary to develop new algorithms and tools to analyze this type of data.

As explained in the results, our findings supported the feasibility of using social data to interpret streams of tweets. These findings were by no means aiming to substitute well-studied approaches. Improved algorithms, such as the ones we presented in this study, for big data issued from social data analysis can lead to a paradigm shift in the study of social media.

Our research showed that deep learning performed better than classical methods in terms of learning useful patterns for categorizing social data. More research needs to be done to understand why deep learning performs better, which eventually can help in identifying new factors influencing social media behavior of the users.

Our study provided an early example of how advanced deep learning methods could be used to infer new insights from social data. Our focus on theme and user's status prediction can help design new eHealth applications.

Strengths and Limitations To the best of our knowledge, except our previous study, no study analyzing the content of the #SmearForSmear campaign on Twitter has been published yet. Our findings are corroborated by the content analysis of others health campaigns on Twitter. We used a content analysis method based on a double analysis of the sensitizing capacity of each tweet, in an exploratory process. We also mined Twitter to gather information about users' characteristics and complete the tweets' content. This highly demanding method for annotation made us decide early to restrict our study to 1 week. This choice was also relevant, as this campaign had been created for the European Cervical Cancer Prevention Week. Compared with other Twitter campaigns, our relatively high results must question its ability to keep a high proportion of sensitizing tweets in other countries (particularly where the cervical cancer screening is not organized) and if it remains high over time.

The choice to collect the tweets based on the hashtag #SmearForSmear may have limited their number, by omitting those not using it. As for the content analysis, two safeguards have been used: analyzing the content of tweets to create the categories before the study and evaluating the reproducibility of the classification by two independent researchers with Cohen's kappa coefficient, which was strong in this study. The shortness of Twitter posts, limited to 140 characters, may have created a loss of information as users often used hyperlinks to be exempt from this limit. Then, we chose to manually mine Twitter to complete the tweets' content and gather information about users' characteristics.

Our research has also many limitations considering classification approaches.

The main limitation is in the interpretation of deep learning. Deep learning models are "black boxes" and do not provide explanation even if the prediction is efficient [18]. However, this study showed that the performance of traditional models was much lower than the performance of deep learning. New techniques in deep learning are being researched to facilitate the interpretation of such models [11]. There were also some limitations in our study regarding the generalization of our results. As explained before, the number of tweets manually annotated is limited

and the task is very specific to the topic of the campaign and the format of the tweets. Our methodology and results can be used as the baseline for further studies looking into categories from social data.

10.4 Conclusions and Perspectives

Our study showed the efficiency of deep learning architectures to predict theme and user's status using twitter data. The feasibility of our approach can lead to new health applications based on social media and also to the development of more complex eHealth applications for both professionals and patients.

The #SmearForSmear campaign has allowed to disseminate sensitizing messages about cervical cancer screening and to become viral. It was based on a well-designed campaign, on a facilitating audience, and a facilitating health system using an organized screening. Choosing a social media platform adapted to the target is a major concern for a successful campaign. Twitter is interesting as it is well suited for appointment campaigns such as #SmearForSmear or the ALS Ice Bucket Challenge. It also is a social media platform used by young adults to keep up in real time with news.[4] But its audience is mainly men, living in urban areas. Although diverse, its percentage of users with college educations and incomes over US $50,000 is much higher than those of Facebook or Instagram. Users of Instagram are mainly female, but 72% of online American adults use Facebook, and its audience is the most engaged with 70% logging on daily.[5] Health campaigns on social media platforms should be a way to reduce social inequities in health.

In the UK, the main decline in screening was about 25- to 49-year-old women and black and Asiatic ethnic minorities [12]. Targeted audience must be on the social media platform chosen and then adapt to the shift of the evolution of their audiences. The impact of facilitators is to be studied. As previously shown, many Twitter users of this campaign did not engage in this campaign as they did not post sensitizing tweets. But they participated and helped broadcasting to their audience. Models such as Cara Delevingne also posted a selfie to support the campaign and to raise awareness among her millions of followers (8.5 million in May 2017).[6] They may boost a campaign as influencers and a role model.

Our findings show a clear need for studies that are capable of automatically analyzing the data and extracting useful insights from the #SmearForSmear Twitter campaign. We propose the use of machine learning to tackle these challenges, and we suggest three perspectives for future directions. First, we plan to undertake a

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[4]https://www.investopedia.com/articles/markets/100215/twitter-vs-facebook-vs-instagram-who-target-audience.asp. Accessed 2018/02/15.

[5]https://www.investopedia.com/articles/markets/100215/twitter-vs-facebook-vs-instagram-who-target-audience.asp. Accessed 2018/02/15.

[6]https://twitter.com/caradelevingne. Accessed 2018/02/15.

large-scale analysis using a collection of tweets that we are currently collecting since February 2017. This analysis will include the application of the latent Dirichlet allocation to extract the themes emerging from the discussions about the campaign, as well as the exploration of the linguistic style of the Twitter' users [23–25]. Second, we think that when data set are small for efficient learning, a significant improvement would be the implementation of active learning techniques. Indeed, in this type of task, it is important to optimize the available and efficient information to be used by the classification systems during the learning phase while remaining sparing on the acquisition of new labeled samples. Lastly, active learning techniques would enable to significantly optimize the relationship between the global improvement of the classification and the labeling [3].

Moreover, within a sufficiently large data set, we can take advantage of machine learning models to use features that are more complex to characterize the users tweeting about the campaign. We suggest focusing on user groups including health professionals, celebrities, general public, and politicians. This will lead us to understand which group of users is prominent, so that it could influence others, making them to retweet the messages relevant to the campaign, to like and reply to tweets, or more importantly donate money. Third, we plan to investigate the temporal distribution of messages to focus on the campaign dynamics over time. We may study the temporal correlations between the reactions of twitter users and real-world events such as media coverage of the campaign. This analysis is exploratory, and it could help in identifying the factors contributing to raising the awareness. For example, a televised promotion of the campaign or a promotion published by a celebrity may stimulate a huge volume of tweets and reactions online. Beyond this, we can also analyze the geographical distribution of tweets during the campaign.

Health campaigns on social networks may raise awareness of public health issues. Becoming viral is not an end in itself. Long-term effect of social media campaigns to raise people's awareness of health conditions is to be evaluated. The ALS Ice Bucket Challenge has proven to be disappointing as after 2 years, the level of Web-related activities about ALS has remained practically the same as it was before the campaign [1]. The campaigns' clinical impact is also yet to be evaluated. It will be a difficult task in a hyperconnected world to be able to individualize the effect. This scientific step is important to convince stakeholders, health professionals, and general public to get involved and use Web 3.0 as a collective intelligence to drive back chronic diseases, particularly for the most fragile ones.

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Chapter 11
How to Improve Public Health via Mining Social Media Platforms: A Case Study of Human Papillomaviruses (HPV)

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Abstract Since its inception, the use and impact of social media have occurred with incredible speed. Over the last decade, social media has also become a major source of health-related information and discussions, which offers researches a great opportunity to (1) increase the reach and effectiveness of health education, communication, and surveillance and (2) study public health issues with unique insights that cannot be captured by traditional survey methods. Vaccination is a good example in which there are existing controversies and public debate. And social media is a key source of misinformation about vaccines including some of the more recent and controversial vaccines on the market that prevent Human Papillomavirus (HPV). HPV is the most common sexually transmitted disease in the USA, while HPV vaccine is available to help prevent infections with HPV. However, the HPV vaccination coverage rate remains low and varies greatly by state in the USA. To

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increase HPV vaccination initiation and coverage, we first need to understand the behavioral factors that influence an individual's decision-making process regarding HPV vaccination. Recognized by Integrated Behavior Model (IBM), individuals' intention is the most important determinant of their health behaviors, while behavior intention is subsequently determined by constructs such as attitude and perceived norms. Social media offers a complementary data source that can be used to monitor public's health communication in real time to better understand these behavioral factors that affect their decision-making processes about HPV vaccination. Overall, this chapter aims to provide readers with an overview of studies using the social media platform to improve public health, especially those related to the HPV. We also present a case study that aims to test the feasibility of mapping Twitter data to behavioral factors compared with results obtained from a national representative survey.

Keywords Social media · Public health · Twitter · Human papillomavirus vaccine · Topic modeling · Integrated Behavior Model

11.1 Introduction

Since its inception, the use and impact of social media has occurred with incredible speed. Social media is now an indispensable part of the Internet and people's daily lives. According to *Statista*, in 2018, Facebook, one of the most popular social media websites, had more than 2.2 billion monthly active users [1]. Twitter, another well-known social network, had over 326 million monthly active users in Q3 2018 [2] and 500 million tweets posted per day in 2013 [3, 4]. Social media has become a ubiquitous source of information, which covers almost all aspects of human life. For example, according to a study from the Pew Research Center, about 68% American adults get their news from social media [5].

Over the last decade, social media has transformed the communication landscape not only for people's daily interactions, but also for health communication. People want their voices to be heard and voluntarily share a massive amount of information about their health history, experiences with healthcare and services, and many other user-generated health data on social media platforms. For example, millions of individuals have shared personal health experiences on Facebook groups covering a wide range of conditions such as breast cancer, diabetes, sexual health, and vaccination [6]. There's also a substantial proportion of people who access health information on social media even if they don't share it. This isn't just seeking advice on Facebook and Twitter, but on other forum-based sites that are "health specific." More recently, researchers have started to recognize that social media platforms are invaluable sources to study public health issues. The real-time nature and accessibility of the social media platforms—in contrast to traditional survey methods—can provide "big data" to improve public health research and services [7].

Moreover, these social media platforms also provide new channels to increase the reach and effectiveness of health education, communication, and surveillance [8].

In particular, for public health issues with considerable controversies or quick-shifting public opinions, social media offers unique insights. Vaccination is a good example in which there are existing controversies and public debate. For the public, social media is a key source of misinformation about vaccines including some of the more recent and controversial vaccines on the market that prevent Human Papillomavirus (HPV). Interestingly, HPV vaccines have received public scrutiny above and beyond that of other vaccines. The primary reason for this seems to be the sexual nature of HPV itself.

HPV is the most common sexually transmitted infection (STI). In the USA, approximately 79 million individuals are infected with HPV, and nearly 14 million people become newly infected each year [9]. It is transmitted through skin-to-skin sexual contact with an infected person who may or may not have signs or symptoms. A small percentage of these infections can result in clinically significant disease cases. In these cases, depending on the HPV subtype, infections can result in anogenital warts or cancer. Persistent infection with oncogenic subtypes can lead to a variety of cancers including cancers of the anus, cervix, oral cavity, penis, and vulva, among others. HPV vaccines, which include the bivalent, quadrivalent, and nonavalent vaccines, have been shown to be safe and effective at preventing the oncogenic HPV subtypes responsible for the majority of these cancers. In addition, the quadrivalent and nonavalent vaccines prevent two of the HPV subtypes responsible for the majority of anogenital warts.

The U.S. Advisory Committee on Immunization Practices (ACIP) currently recommends routine HPV vaccination for males and females at 11 or 12 years of age. If not vaccinated, the ACIP recommends catch-up vaccination through age 26 [10]. In 2017, about 49% of adolescents were up-to-date on the HPV vaccine, and 66% of adolescents (i.e., aged 13–17) received the first dose of the vaccine series [11]. However, vaccine initiation and coverage widely vary by state. In many states, vaccine initiation (i.e., 27 states <66%) and coverage (i.e., 22 states <49%) are significantly lower than the national average [11]. Coverage with ≥1 dose of HPV vaccine ranged from 46.9% in Wyoming to 91.9% in District of Columbia (DC); and, coverage with up-to-date HPV vaccine ranged from 28.8% in Mississippi to 78.0% in DC.

To increase HPV vaccination initiation and coverage, we first need to understand the factors that affect people's vaccination behavior. In addition to barriers affecting access to vaccination and recommendations from healthcare providers, behavioral determinants such as beliefs and attitudes towards HPV vaccination are key factors in the decision-making process that influence individuals' vaccination decisions [12–14]. Recognized by the Integrated Behavior Model (IBM [15]), a general theory of behavioral prediction, individuals' intention is the most important determinant of their health behaviors (i.e., HPV vaccination uptake in our case), while the intention is subsequently determined by attitudes (e.g., feelings about the behavior), perceived norms (e.g., the social pressure one feels to perform or not perform the behavior), and personal agency (e.g., self-efficacy and perceived control). Other factors such as

knowledge (i.e., skills to carry out the behavior), environmental constraints, habits, and salience of the behavior (i.e., whether the behavior is important to one) can also directly affect individuals' health behaviors. However, using traditional methods (i.e., surveys and focus groups) to assess these behavioral factors is laborintensive and expensive [16]. Social media offers a complementary data source that can be used to monitor public's health communication in real time to better understand these behavioral factors that affect their decision-making processes about HPV vaccination [17, 18] as well as other important health behaviors such as smoking [19].

In this chapter, we first give a brief overview of health-related studies using social media platforms. Second, we systematically identify and review studies on PubMed—the biggest biomedical literature database maintained by the US National Library of Medicine—that examine the representation of HPV vaccination on social media. Third, we present a case study that maps Twitter data to determinants of health behavior about HPV and results obtained from the Health Information National Trends Survey (HINTS). Finally, we discuss some of the limitations of using social media data compared with using traditional survey data.

11.2 A Brief Overview of Health-Related Studies Using Social Media Platforms

The increasing popularity of social media offers great potential for public health professionals and researchers to expand and enhance public health services [20], including health communication, public health surveillance, health education, and linking people with health resources [21]. To assess the field, we searched the extant literature in PubMed using the following keywords in article titles or abstracts: "*social media*" and names of popular social media platforms including "*Facebook*", "*Twitter*", "*Instagram*", "*YouTube*", "*Reddit*", "*Pinterest*", "*Tumblr*", "*Snapchat*", and "*Google plus*". We found more than 12,195 studies related to social media in the last 10 years. Figure 11.1 depicts the number of retrieved articles published between 2008 and 2018. The number of publications related to health and social media has increased more than 80 times over the last decade. Social media data have been used for various purposes. As discussed above, social media offers a unique opportunity to study factors related to users' health decisions. On the other hand, social media also provides a new platform to increase the reach of public health interventions such as those that aim to reduce health disparities through well-developed and targeted social media campaigns [22]. Through our literature review, we classified social media studies into three categories: (1) studies that analyze social media data, (2) studies that use social media platforms as a recruitment channel, and (3) studies that deliver health interventions through social media.

In social media analysis (SMA) studies, social media serves as a data source for downstream analysis such as sentiment analysis [8, 17, 19, 23] and content analysis
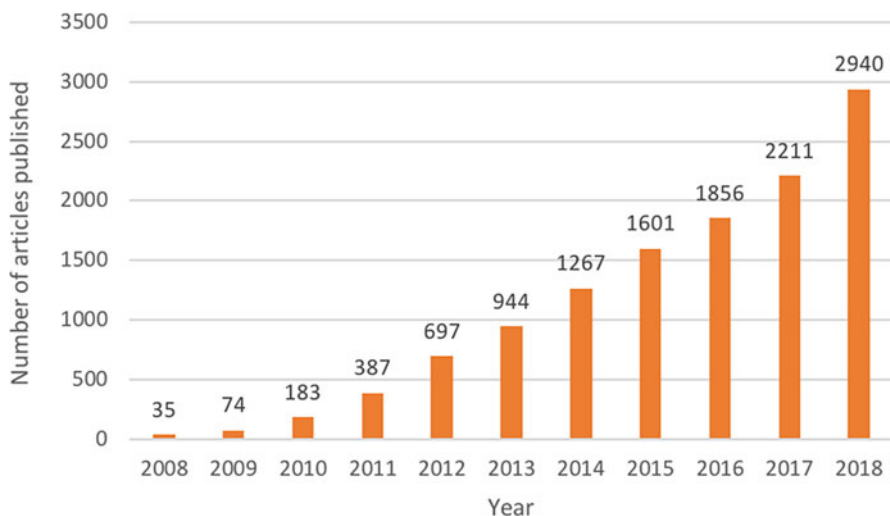
Fig. 11.1 The number of social media-related articles in PubMed between 2008 and 2018

[18, 24–26]. For example, Du et al. leveraged a machine learning-based approach to identify people's different types of sentiment about HPV vaccination in 2017. They also provided a system to extract public opinions, especially individuals' concerns towards HPV vaccination on Twitter [17]. In terms of content analysis, Keelan et al. developed a content analysis pipeline to study the HPV vaccine debate on Myspace blogs in 2009. They categorized these HPV-related blogs into three categories (i.e., positive, negative, and ambivalent) and analyzed the types of supporting arguments. Their study attested the potential of using social media data (i.e., blogs) to monitor public opinions and attitudes toward immunization [26].

In recruitment studies, researchers often utilize the interactive features of social media platforms to attract participants [27–30]. For example, in 2014, Nelson et al. used Facebook advertisements to recruit survey participants to study the geographic variations in HPV vaccine uptake [30]. In intervention studies [13, 31, 32], social media platforms are often used to deliver interventions (typically behavioral interventions) to participants. We will focus on SMA studies in this chapter of the book. If you are interested in how to use social media to conduct recruitment and intervention studies, please refer to the Chap. 2.

11.3 An Overview of HPV-Related Studies Using Social Media Data

We retrieved 84 articles related to HPV and social media using keywords "*human papillomavirus*" and its variations such as "*HPV*" in combination with "*social*
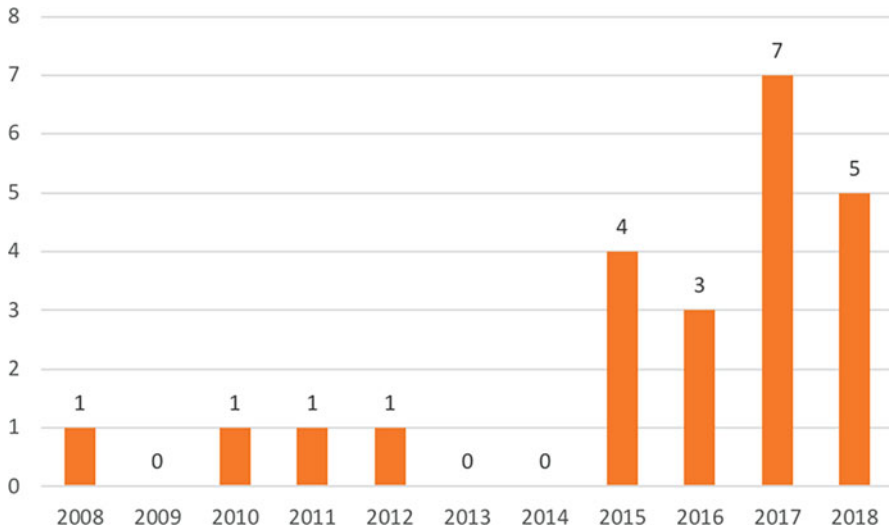
Fig. 11.2 The number of HPV-related social media analysis studies published between 2008 and 2018

media" and the various names of social media platforms from PubMed published between 2008 and 2018. We filtered out recruitment and intervention social media studies and focused on studies that used social media data for analyses. This resulted in 23 articles that focused on studying various aspects of HPV using social media data [17, 18, 23, 26, 33–49].

Publication trends Figure 11.2 shows the number of HPV-related SMA publications in PubMed from 2008 to 2018. Most articles were published within the last 5 years. The very first HPV-related SMA article in PubMed was published in 2008 by Briones et al. [26] who analyzed HPV-related video content and associated public comments in YouTube. They found that there is a wide variety of information on YouTube regarding HPV vaccination and cervical cancer, while the majority (75%) of the videoclips portrayed HPV vaccination in a positive light.

Social media platforms Twitter is the most frequently used (i.e., 15 articles) data source in HPV-related SMA studies as shown in Fig. 11.3. The popularity of Twitter is aligned with the fact that Twitter is one of the leading social media platforms with 326 million monthly active users [2, 50]. Interestingly, we did not identify any SMA studies using Facebook, even though Facebook is the most popular social media platform [51]. One possible explanation is that crawling public Twitter data is fairly straightforward, while Facebook has put in place security controls to prohibit data crawling. Other social media platforms that have been used in HPV-related SMA studies include Myspace (1), Instagram (1), YouTube (4), and Spinn3r (1). Two studies used data from social media in combination with other sources. Bahk et al. [47] developed an open-access system to collect vaccination-related content
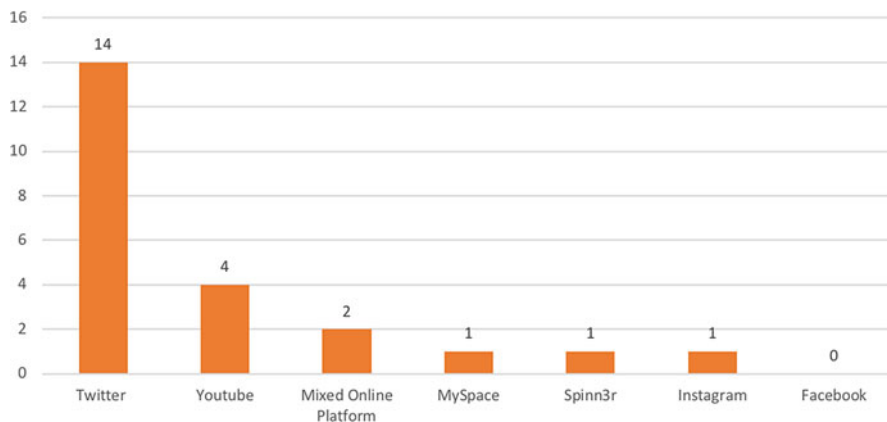
Fig. 11.3 Social media platforms used in HPV-related social media analysis studies

in both mainstream media sources (i.e., online news sites, blogs, expert-curated discussions, and validated official reports) and Twitter. Mahoney et al. [48] collected their data from both Twitter and Google News to explore how the new media (i.e., Google News) influences the type of public health information that users access (i.e., Twitter) and the impact of a major controversial event (i.e., Michele Bachmann's controversial comment on HPV vaccine) on these platforms.

Analysis methods We categorized the analysis methods used in these studies into 6 groups: content analysis ($n = 10$, 43.48%), image analysis ($n = 1$, 4.35%), text classification ($n = 10$, 43.48%), text clustering ($n = 2$, 8.70%), dictionary-based sentiment analysis ($n = 1$, 4.35%), and semantic network analysis ($n = 3$, 13.04%). For studies in the text classification category (i.e., the task of assigning tags or categories to text documents according to its content), classification-based sentiment analysis ($n = 7$, 30.43%) is the most frequently used method, where these studies aimed to identify consumer's attitudes towards HPV vaccination. For studies using text clustering (i.e., the task of finding groups of similar documents in a collection of documents), topic modeling ($n = 2$, 8.70%) is the commonly used algorithm to discover the themes of people's discussions on these social media platforms. Table 11.1 shows the number of studies in each category across different social media platforms. Note that some studies used multiple methods for data analysis. Among all the methods, we found that content analysis is the most frequently used SMA method. However, in Twitter studies, computational methods such as text classification (e.g., classification-based sentiment analysis) are used more often possibly due to the big volume of the data.

Research topics In Table 11.2, we summarize the topics studied in these HPV-related SMA articles. As we observed, most studies sought to understand consumers' attitudes toward HPV vaccination ($n = 15$, 65.22%) and how attitudes and beliefs about HPV vaccine are related to HPV vaccine uptake ($n = 3$, 13.04%). In

Table 11.1 The number of studies categorized by their data analysis method across different social media platforms

Social media platforms	Content analysis	Machine learning				Network analysis[c]
		Image analysis	Text mining		Dictionary-based sentiment analysis	
			Text classification[a]	Text clustering[b]		
YouTube	[18, 26, 35, 52]					
Twitter	[33, 38, 41]	[36]	[17, 23, 33, 37, 39, 41, 43, 44, 49]	[34, 42]		[40, 42–44]
Spinn3r			[45]			
Myspace	[46]					
Mixed platforms	[48]				[47]	
Instagram	[53]					

[a]Text classification represents the task of assigning tags or categories to text documents according to its content
[b]Text clustering represents the task of finding groups of similar documents in a collection of documents
[c]Some studies use mixed methods, such as [42] used both text clustering and network analysis methods

Table 11.2 The number of HPV-related SMA studies categorized by research topics

Research topics	Referenced articles
Attitudes/sentiment/opinion	[17, 18, 23, 26, 35, 38, 39, 41–49, 52, 53]
Beliefs	[18, 41, 52]
Concerns (e.g., susceptibility, benefits, severity, and barriers)	[33]
Vaccine coverage	[34]
Burden of disease in terms of gender and racial disparities	[36]
Intentions/motivation	[37]

the field of health behavior research, behavior theories such as Health Belief Model (HBM) [54], Theory of Planned Behavior (TPB) [55], Theory of Reasoned Action (TRA) [56], and Integrated Behavioral Model (IBM) [15] are well-established theoretical approaches to help researchers understand and predict individuals' health behaviors (e.g., HPV vaccine uptake) using constructs including knowledge, attitudes, and beliefs. However, only two studies [18, 33] explicitly applied HBM to help understand how people's attitudes are related to the acceptance of the HPV vaccine.

Further, we only found one study that compared and validated their social media findings with survey results. Dunn et al. studied HPV vaccination coverage using Twitter data and validated their results using HPV vaccine coverage reported in the National Immunization Survey in 2014 and 2015 [34].

11.4 Mapping Twitter Data to Behavioral Factors and Compared with Results Obtained from a National Representative Survey: A Case Study on HPV

11.4.1 Background

Based on our literature review above, we found that researchers have used different social media platforms and analytical approaches to understand HPV vaccination and related behavioral factors. Nevertheless, these studies are limited in three aspects: (1) they lack a theoretical basis (e.g., using a health behavioral theory such as IBM and HBM); (2) they often did not separate the different types of users (e.g., health organizations vs. general consumers' discussions) who posted the information; and (3) they rarely validate their findings from their social media data against other data sources.

To fill these important gaps, we conducted a case study to (1) test the feasibility of mapping SMA results from Twitter data to behavioral factors informed by the IBM, and (2) compare with results obtained from a national representative

survey. We first separated Twitter posts into promotional HPV-related information vs. general consumers' discussions of HPV. Many public health stakeholders (e.g., health organizations, news media, and pharmaceutical companies) use social media platforms to disseminate HPV-related health information and facilitate the national discussions on HPV vaccination. Separating out tweets from organizations seeking to promote HPV vaccination from other discussions about HPV vaccination on Twitter may help identify tweets that are related to IBM-based behavioral factors. Second, we compared our Twitter analysis results with the results obtained from the Health Information National Trends Survey (HINTS) [57] to assess the feasibility and validity of using social media data to study the determinants of health behavior. Third, we also mapped survey questions to the behavioral factors according to IBM to help us categorize the social media results mapped with HINTS responses. We aim to answer two main research questions (RQ).

1. RQ1: What are the most common topics that characterize HPV and HPV vaccination-related tweets?
2. RQ2: Are the geographic distribution of topics in general consumers' HPV-related discussions comparable to the responses in HINTS?

11.4.2 Method

11.4.2.1 Data Sources

We used three data sets collected independently from Twitter using the Twitter application programming interface (API) based on a set of HPV-related keywords. As shown in Table 11.3, the three data sets covered overlapping dates from 1 January 2014 to 23 April 2018 and comprised a total of 2,846,495 tweets. After removing duplicates, 2,598,033 HPV vaccine-related tweets remained.

Table 11.3 The three HPV-related Twitter datasets, their date ranges, keywords, and total number of tweets

Data source	Data range	Keywords[a]	Total number of tweets
Zhang et al. (collected for this project)	2016/01–2017/10	HPV, vaccine, human papillomavirus, gardasil, cervarix	2,238,433
Dunn et al. [34]	2014/01–2016/12	gardasil, cervarix, hpv + vaccin*, cervical + vaccin*	423,594
Du et al. [23]	2015/11–2016/03	HPV, human papillomavirus, gardasil, cervarix	184,468

[a]"hpv + vaccin*" means a tweet has to contain both the word "hpv" and a word starts with "vaccin"

Further, we obtained the survey data from both HINTS 4 Cycle 4 (i.e., collected from August 2014 to Novemeber 2014) and HINTS 5 Cycle 1 (i.e., collected from January 2017 to May 2017). HINTS is a nationally representative survey of American adults supported by the National Cancer Institutes (NCI) that collects data about the public's use of cancer and health-related information and specifically to track changes in health communicaton and information technology. In this study, we extracted and merged responses for 8 HPV-related questions from HINTS 4 Cycle 4 and HINTS 5 Cycle 1 data. Overall, 6962 respondents answered these eight questions. We also obtained the geographic information (i.e., specific to an US state) and the full-sample weight (i.e., to calculate the population and subpopulation estimates) of each respondent.

11.4.2.2   Data Analysis

As shown in Fig. 11.4, we conducted the data analysis in four steps: (1) data preprocessing by removing non-English tweets and then geocoded the tweets to a US state; (2) classification of the tweets into two categories (i.e., promotional HPV-related information and general consumers' discussion of HPV) based on a set of rules; (3) applying topic modeling (i.e., Latent Dirichlet Allocation (LDA) [58]) to discover major discussion themes and mapping these topics to the responses from the 8 HPV-related questions in HINTS; and (4) based on these analyses, we aimed to answer the two RQs.

Step 1: Data Preprocessing

We first removed non-English tweets based on a two-step process. The raw Twitter data contain a "*lang*"attribute specifying the language of the tweet, as identified by
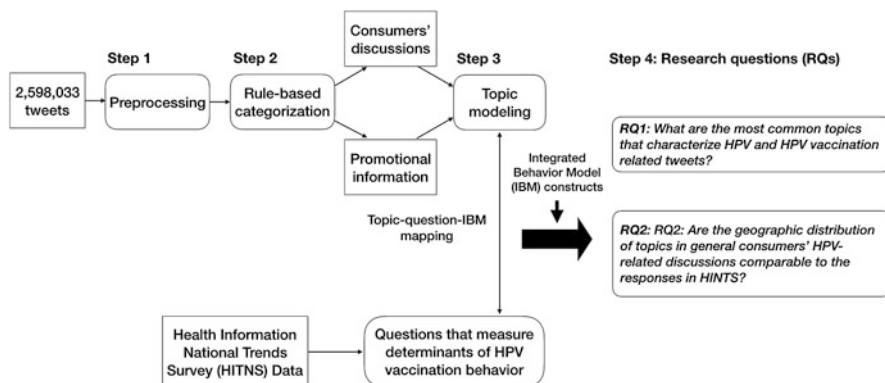
Fig. 11.4 The overall data analysis workflow

Twitter's internal language detection algorithms [59]. If the "*lang*" attribute was not available, we used the Google's language detection algorithm to identify the language of the tweet [60]. Then, we removed the hashtag symbols (i.e., "#"), Uniform Resource Locators (URLs, e.g., "*http://t.co/*"), and user mentions (e.g. "*@username*") from each tweet. We geocoded each tweet and assigned it to a US state based on the geographic information encoded in each tweet if it exists using a Twitter geocoder tool we have developed previously [61].

Step 2: Rule-Based Categorization of the Tweets

Even though we collected the tweets using specific HPV-related keywords, not all tweets are relevant to the discussion of HPV due to the nature of ambiguity in English words. In our previous studies [62, 63], we often built classifiers to filter out irrelevant tweets. Nevertheless, in some cases [64], the keywords used for data collection were specific enough; thus, very few tweets were false positives (i.e., irrelevant). Thus, we randomly annotated 100 tweets to assess whether it is necessary to build complex classifiers for filtering out irrelevant tweets. We found that only two tweets were irrelevant to HPV (i.e., 98% of the tweets were relevant). Therefore, we considered all the collected tweets were relevant.

Then, we created a set of rules to categorize the tweets into promotional HPV-related information and general consumers' discussions as shown in Fig. 11.5. We found that tweets containing URLs are more likely to be promotional information, where the URLs are links to HPV-related news, research findings, and health promotion activities. We randomly annotated 100 tweets and found 95 tweets contain URLs showing promotioinal information (i.e., 95% of the tweets were promotional HPV-related information). Further, users can "quote" another tweet or other online resources (e.g., a web page) to express their own opinion, and the original quoted tweets (or web pages) are converted into URLs (e.g., "*this gave me HPV https://t.co/0wWHM1sRv0*"). Twitter users can also "retweet" another tweet (i.e., starts with "*rt*"); nevertheless, the original tweet is not converted into a URL (but URLs in the original tweet were preserved). If a tweet does not include a URL, it is considered as a consumer discussion. Even if it is a retweet (i.e., starts with "rt"), the retweet is consumers' discussions as we considered the user who retweeted agrees with the original user discussion and the original tweet is also consumers' discussions (since there is no URLs). When a tweet contains URLs, the rules are more complex: (1) if a tweet is quoting another tweet or web resources (i.e., "is_quote_status" = True) and not a retweet, it is considered as consumers' discussions. In the special case where the tweet is a retweet of a quoting tweet, we consider this as promotional information because we are unable to determine which of the comments the current user agrees with. In essence, when a tweet is a retweet, we classified the retweet based on the original tweet; and (2) if a tweet is not a quoting tweet, it is considered as promotional information. Note that these rules were applied on the original tweets before removing URLs.

Step 3: Topic Modeling

Topic modeling, a statistical approach in natural language processing (NLP) and machine learning, is widely used in text mining to find the abstract, underlying (often called latent) topics in a collection of documents. We used latent Dirichlet allocation (LDA) model [65] to explore the unobserved topics for overall tweets. Since LDA is an unsupervised clustering method, the number of topics in the model is selected a priori. We tested three statistical models to find the best number of topics [65–67]; however, they did not converge. One possible reason is that Twitter messages are short and the number of message is huge; thus, we may need a large number of topics to obtain a reasonable model [68]. Alternatively, to identify all possible topics, we choose a relatively large number of topics (i.e., 150) based on the parameters used in similar studies that applied LDA on Twitter data [60, 61]. We
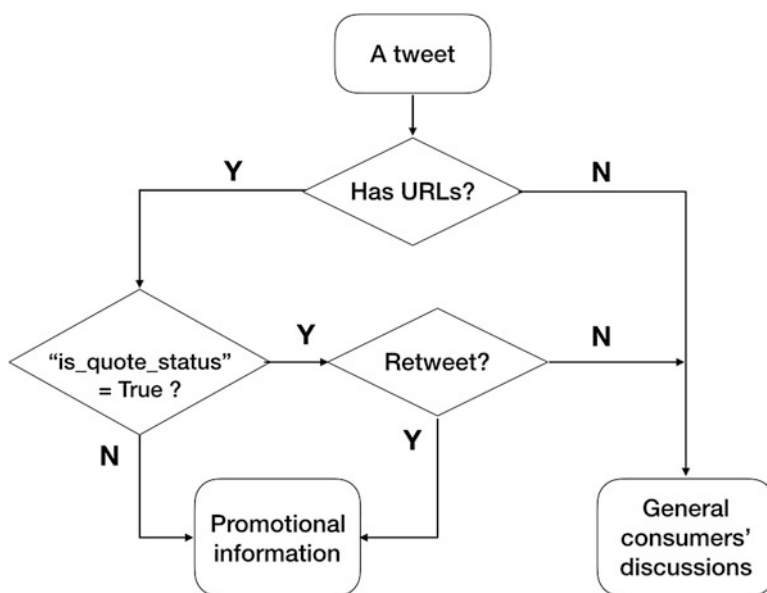
Fig. 11.5 A rule-based categorization of the tweets into promotional HPV-related information and general consumers' discussions. If a tweet does not include a URL, it is considered as a consumer discussion. Even if it is a retweet (i.e., starts with "rt"), the retweet is consumers' discussions as we considered the user who retweeted agrees with the original user discussion and the original tweet is also consumers' discussions (since there is no URLs). When a tweet contains URLs, the rules are more complex: (1) if a tweet is quoting another tweet or web resources (i.e., "is_quote_status" = True) and not a retweet, it is considered as consumers' discussions. In the special case where the tweet is a retweet of a quoting tweet, we consider this as promotional information because we are unable to determine which of the comments the current user agrees with. In essence, when a tweet is a retweet, we classified the retweet based on the original tweet; and (2) if a tweet is not a quoting tweet, it is considered as promotional information

then visualized each learned topic using the top 20 words as word clouds, where the size of each word is promotional to its probability in that topic.

Based on the geocoding results, we aggregated the tweets of the same state and derived state-level topic distribution normalized by the total volume of the tweets in each state. The nature of topic models allows all topics (derived from the entire collection of tweets) to occur in the same tweet with different probabilities, while topics with low probabilities might not actually exist in the tweet. Thus, we needed to determine a cutoff probability value to select the most representative and adequate topics for each tweet. We tested a range of cutoff values and manually evaluated a random sample of tweets (i.e., 100) for each tested cutoff value to determine whether the learned topics (whose probabilities were larger than the cutoff) assigned to each tweet were correct. We selected the lowest cutoff value where more than 80% of topic assignments were adequate.

Further, after assigning topics for each tweet, we manually evaluated each topic's word cloud and a sample of tweets associated with the topic to determine: (1) the quality of the topic (i.e., the topic is of low quality if more than half of the tweets are not relevant to the assigned topic); (2) the theme of the topic; and (3) the corresponding survey question in HINTS.

11.4.3 Results

11.4.3.1 Step 1: Data Preprocessing

In the preprocessing step, we first removed 958,483 non-English tweets. There were 2,598,033 tweets left for geocoding. After geocoding, 335,681 (12.92%) tweets were able to be geocoded to a US state and retained for further analysis.

11.4.3.2 Step 2: Rule-Based Categorization of the Tweets

To assess the performance of our rule-based categorization method, we annotated 100 random tweets. Our simple rules achieved a precision of 84.21%, a recall of 86.00%, and a F-measure of 85.10%. We applied the rules on the geocoded tweets. Out of the 335,681 geocoded tweets, 93,693 (27.91%) tweets were classified as general consumers' discussions, where 241,988 (72.09%) tweets were classified as promotional information.

11.4.3.3 Step 3: Topic Modeling

We manually evaluated each learned topic's word cloud and ten associated random tweets to determine its quality (i.e., the topic was of low quality if more than half of the tweets were not relevant to the assigned topic). We found that 28 out of the 150

topics were of low quality and we eliminated these low-quality topics for further analysis. Further, through manual review, we determined that the cutoff probability for topic assignment is 0.15, where 84% of the 100 randomly selected tweets' topic assignments were adequate. As a result, we were able to assign topics to 83.11% (i.e., 278,974) of the geocoded tweets.

11.4.3.4   Research Questions

RQ1: What are the most common topics that characterize HPV and HPV vaccination-related tweets?

We calculated the percentage of each topic's tweet volume for both promotional HPV-related tweets and general consumers' discussion. The word clouds for the top three topics and associated example tweets are shown in Fig. 11.6.

RQ2: Are the geographic distribution of topics in general consumers' HPV-related discussions comparable to the responses in HINTS?

We first grouped similar HPV-related HINTS questions into five question groups (e.g., we grouped the first three questions in Table 11.4 as they are related to the knowledge of whether HPV is linked to different types of cancer), and then mapped the five question groups to the determinates of health behavior in the IBM as shown in Table 11.4. We then extracted key terms from the survey questions (e.g., "*HPV*," "*anal,*" and "*cancer*" were extracted from "*Do you think HPV can cause anal cancer?*") and mapped the topics learned from general consumers' HPV-related Twitter discussions to the survey question groups based on keyword matching. To establish a mapping between the Twitter topics and a survey question group, the top 20 words in a topic have to contain all the key terms. In Fig. 11.7, we list one mapped topic word cloud for each survey questions.

   To measure correlations between topics extracted from discussions of HPV vaccination on Twitter and the population estimates derived from HINTS responses, we calculated the normalized geographic distribution of each matched topic at the state level (i.e., divided the number of tweets for each topic in a state by the total number of tweets in that state). For survey data, we divided the number of respondents who answered "*Yes*" (e.g., "*Do you think HPV can cause anal cancer?*"—"*Yes*") or who chose the answer that expressed their attitudes (e.g., "*In your opinion, how successful is the HPV vaccine at preventing cervical cancer?*"—"*Not at all successful*") by the total number of respondents for each state considering each respondent's full-sample weight in HINTS. We then calculated the Spearman's rank correlation coefficient between the geographic distributions of the Twitter topics and the determinants measured in HINTS. Table 11.4 shows the Spearman's rank correlation coefficients between the mapped topic distributions in general consumers' discussions on Twitter and the topic distributions of the determinants
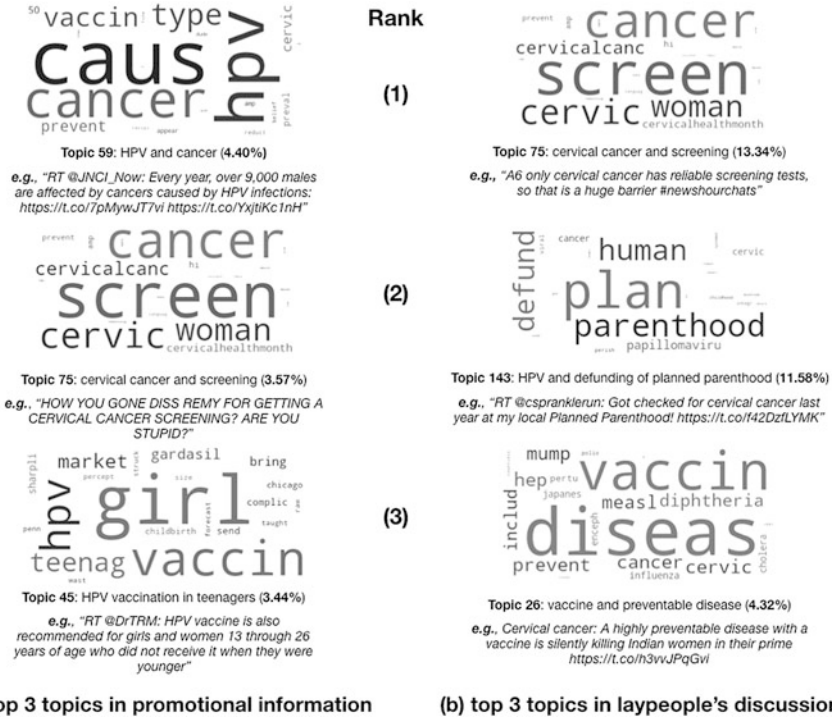
Fig. 11.6 The most popular topics in (**a**) promotional information and (**b**) general consumers' discussions related to HPV and HPV vaccination

measured from survey data. Note that, considering that we grouped survey questions into question groups, we also combined answers for all questions in that question group (i.e., if the respondent responds with the interested answer for any question in that question group).

11.4.4 Case Study Discussion

In this case study, we set to test the feasibility of mapping Twitter data to behavioral factors compared with results obtained from HINTS. Specifically, we used topic modeling on HPV-related tweets to answer the two research questions. We found that consumers on Twitter have a lot of discussions on "*cervical cancer screening*" and "*defunding of planned parenthood*" -related topics which account for 24.92% of all the general consumers' discussions tweets. Further, the topic "*defunding planned parenthood*" is highly related to the cervical cancer screening because planned parenthood provides more than 270,000 Papanicolaou tests for cervical cancer screening every year [69]. In promotional HPV-related tweets, the most

Table 11.4 Mapping topics in general consumers' discussions to the HPV-related survey questions in HINTS and corresponding constructs in the Integrated Behavior Model

HPV-related survey questions in HINTS	# of mapped topics	Integrated Behavior Model Construct	Correlation for mapped topics[a]
1. HPV causes cancers: (a) Do you think HPV can cause anal cancer? (b) Do you think HPV can cause oral cancer? (c) Do you think HPV can cause penile cancer?	3	Knowledge	Topic 81: HPV and oral cancer (ρ: 0.29; $P < 0.05$)
2. Do you think that HPV is a sexually transmitted disease (STD)?	6	Knowledge	No statistically significant topics
3. Do you think HPV requires medical treatment or will it usually go away on its own without treatment?	2	Knowledge	No statistically significant topics
4. In your opinion, how successful is the HPV vaccine at preventing cervical cancer?	26	Attitude	Topic 5: Pap smear test (ρ: 0.32; $P < 0.05$) Topic 43: early detection of cervical cancer (ρ: 0.33; $P < 0.05$) Topic 55: HPV vaccine prevents cervical cancer (ρ: 0.35, $P < 0.01$) Topic 89: cervical cancer awareness month (ρ: 0.32; $P < 0.05$) Topic 112: HPV vaccine protects against cancer (ρ: 0.28; $P < 0.05$)
5. Professionals suggestions: (a) In the last 12 months, has a doctor or healthcare professional ever talked with you or an immediate family member about the HPV shot or vaccine? (b) In the last 12 months, has a doctor or healthcare professional recommended that you or someone in your immediate family get an HPV shot or vaccine?	2	Perceived Norm	No statistically significant topics

[a]Only topics that have significant correlations ($p < 0.05$) with the survey question groups are listed
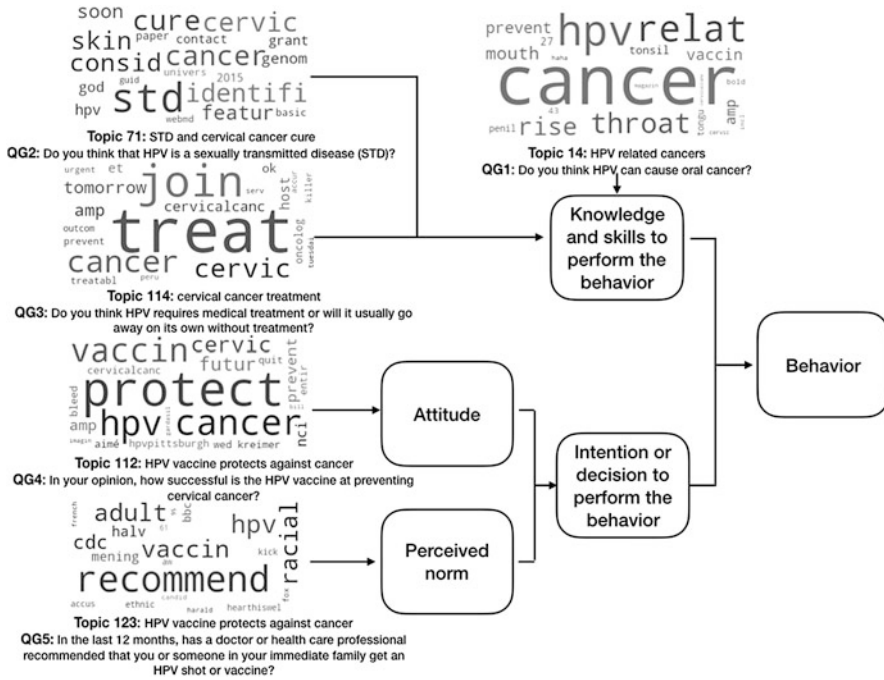
Fig. 11.7 Mapping the five question groups (QGs) and corresponding topics learned from general consumers' Twitter discussions to the constructs in the integrated behavior model

popular topics are related to topic 59: "*HPV causes cancer*", topic 75: "*cervical cancer screening*", and topic 45: "*HPV vaccination in teenagers*".

Further, for each survey question, we found at least one mapped topic from general consumers' discussion. We then assessed the correlations between the topics learned from Twitter data and the survey responses from HINTS in terms of Spearman's rank correlation. We found that most of the mapped topics showed a negligible correlation (i.e., ≤ 0.3). The highest correlation we found is 0.35 between topic 55: "*HPV vaccine prevents cervical cancer*" and question group 2: "*how successful is the HPV vaccine at preventing cervical cancer?*" (ρ: 0.35, $P < 0.01$), which is still considered as a weak correlation. One potential reason is that the topics learned using LDA can contain multiple themes (e.g., Topic 71: "*STD and cervical cancer care*", contains two themes "*STD*"—sexually transmitted disease and "*cervical cancer care*"). However, each survey question in HINTS often measures a very specific theme (e.g., Topic 71 was mapped to question group 2, "*Do you think that HPV is a sexually transmitted disease (STD)?*"). Thus, the tweets related to the themes that were not captured in the survey question (e.g., "*cervical cancer care*" in this case) will affect the true correlations between the two. To assert the true correlations, a method that can further separate each topic into subthemes is needed (e.g., supervised classification models). Further, based on the different

Topic 87: HPV vaccine mandate in RI and people's attitudes towards mandate vaccination

determinants that the survey questions measured, we need to treat them separately. For example, for survey questions measuring attitudes, only counting the tweets that contain "attitudes" using methods such as sentiment analysis is a more sensible approach.

Furthermore, topics emerged from tweets provide discussion on Twitter may provide a richer and more nuanced characterization of attitudes and beliefs about HPV vaccination. For example, from the topics matched to the survey questions measuring a specific knowledge of HPV, we can tease out what other knowledge topics that people are interested in learning. As shown in Fig. 11.7, topic 14: "*HPV-related cancers*" is mapped to question group 1: "*Do you think HPV can cause oral cancer?*", where from its word cloud, we not only found words related to "oral cancer" (e.g., "throat cancer"), but also keywords related to other cancers (e.g., "*penile cancer*"). Through examining tweets that fell into that topic, we found positive examples, where users are linking HPV to not only oral cancer but also other types of cancer (e.g., "*I'm making health calls: HPV infection can cause penile cancer in men; and anal cancer, cancer of the back of the throat.*").

Moreover, we found topics that cannot be mapped to survey questions can be mapped directly to the constructs in IBM and these unmapped topics are also valuable. For example, Rhode Island has a very high vaccination coverage rate, where HPV vaccination coverage among adolescents aged 13–17 years is 88.9% [70]. We found that 18.08% of the tweets in Rhode Island are related to topic 87: "*HPV vaccine mandate in RI and people's attitudes towards vaccination mandate.*", as shown in Fig. 11.8. The keyword "*mandate*" is an important keyword in this topic besides "*vaccine*". In fact, all seventh, eighth, and ninth-grade students in Rhode Island are required by law to get vaccinated [71]. Examining general consumers' discussion tweets in topic 87, we found that many tweets were complaints of the mandatory HPV vaccination (e.g., "*@username … We are working hard here against the HPV vaccine mandate #NOHPVmandateRI #ShowUpDay*"). Thus, this topic can potentially be mapped to "attitude" in the IBM.

11.5   Limitations

There are several major gaps and challenges remaining for researchers who make use of social media data for public health applications including analysis of attitudes and behaviors. One of the most crucial questions for researchers is how to align the findings from social media to the results obtained from traditional methods such as surveys. In the 23 HPV-related social media analysis studies we reviewed, researchers have just started to design methods to accomplish the alignment process [34]. Even though Schober et al. [72] conducted a study in 2016 to help researchers to understand the alignment between survey findings and social media analyses, they have not been widely adopted and a number of limitations of social media studies are worth discussing.

First, users actively posting on social media platforms and respondents to surveys might understand the activities they engaged in differently [72]: expressing their opinion anytime when they want to versus making responses according to predesigned questions. For example, the participants in survey research usually present themselves in a way to make them more likely to be evaluated as positive. They also have the potential to manipulate their answers. Social media users, such as Twitter users, are more likely to express their real thoughts [72]. Conversely, representativeness and the presence of bots and fake accounts on social media platforms may distort the representation of attitudes and behaviors.

Second, survey and social media data vary in many ways: (1) the sampled units of social media (e.g., user posts) are different from survey research (e.g., individuals, organizations, and households). For example, in our Twitter data, a user can have multiple posts, even multiple accounts. However, in HINTS, the sample units are individuals. This hints at an alternative—we like to examine users' "information diets" by estimating the kinds of topics they are likely to be more often exposed to rather than counting up the number of tweets. We know that some people post lots of tweets, but have very few followers. Other users (e.g., "*WHO*" or "*NBC*" or "*Obama*") post very few HPV-related tweets, but they reach a lot more people. Studies that measure proportions of topics based on counting tweets are unable to account for the "influence" of those tweets on different people in different places. Ultimately, we are estimating people's opinions and attitudes through what they "express" rather than the "information floating around within their communities," which is a limitation that suggests alternative approaches; (2) the sampling frame for social media is the posts available to researchers which is not an exhaustive enumeration of all the posts of interest. For example, in our case study, the available tweets do not contain the population who do not use Twitter and only users self-select as posters (i.e., many Twitter users do not actively post messages); (3) population coverage for social media might not be aligned with survey data. In our case study, our survey data (i.e., HINTS) only contains people that are older than 18 years. However, Twitter users who discussed HPV-related issues may contain individuals who are less than 18 years old, and younger people tend to be overrepresented on Twitter compared to the general population [73]; and

(4) data from the survey questions are more direct to answering the specific research questions. On the other hand, we have to deal with tweets irrelevant to HPV.

Third, the analytic practice is different [72]. Rather than testing for significance between survey responses and linked health outcomes, social media studies deal with noisy observations. A common approach in social media studies is to learn the set of factors capable of predicting population-level health outcomes in unseen data. For example, Dunn et al. [34] studied the association between state-level differences in exposure to information on Twitter about HPV vaccines and state-level differences in HPV vaccine coverage in the USA to understand how the representation of HPV vaccines in media may influence or reflect vaccine behaviors. An alternative approach in social media studies is to recruit participants and link their social media data to individual health outcomes and survey responses. For example, Choudhury et al. [74] recruited users from Twitter and studied the tweets of them who had been diagnosed with major depressive disorder (MDD) according to self-report responses. The study explored the potential of using Twitter to detect and diagnose major MDD in individuals.

11.6 Conclusion

Social media has already become a crucial data source for researchers to explore research questions related to public health issues [75]. Our case study demonstrated that mapping Twitter data to behavioral factors and comparing social media analysis results with results obtained from a national representative survey are not only feasible but also can yield additional insights. More importantly, we also showed the potential of assessing determinants of people's health behavior using Twitter data. Further, based on these "real-world evidence" data, we also believe that it is possible to deliver tailored interventions and influence individuals' health behaviors through social media platforms. Nevertheless, it is important for public health researchers and professionals to fully understand and engage in the development and application of social media-based research and public health initiatives.

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Chapter 12
Learning Hormonal Therapy Medication Adherence from an Online Breast Cancer Forum

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Abstract Online health communities (OHCs) have become popular online environments for patients seeking and sharing treatment experiences. These platforms enable us to move beyond traditional sources of clinical information for learning about a patient's long-term adherence to treatment. In spite of this opportunity, large-scale self-composed online free text brings challenges in processing and understanding patients' health-related behaviors. Additionally, it has been shown that social support from trusted relationships (e.g., family and friends) positively influences treatment adherence in offline environments, but much less is known about the online setting. In this chapter, we showed that user activities in online health communities can be applied to learn about their medication adherence. Specifically, we focused on a 5-year hormonal therapy, a highly prevalent long-term treatment for breast cancer, with varying completion rates, in the breastcancer.org OHC. We characterized online user activities with emotion of self-disclosure and

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social interaction and focused on learning how these activities are associated with different adherence behaviors. To do so, we first designed a machine learning classifier to extract three types of adherence behaviors (taking, interruption, and completion of hormonal therapy), and then studied how emotions differ when patients mentioned different adherence behaviors. To examine the effect of social interaction, we relied on reciprocity (specifically in the form of reciprocal response to each other) to measure the social support between each other in this OHC. We first examined how reciprocity is related to time active in the OHC and the tones communicated by authors in their posts (e.g., emotions, writing styles, and social tendencies), and then assessed if such reciprocity is associated with treatment adherence. We found that patients in online health communities tend to exhibit fear with taking events, anger with interruption events, and joy (with a tinge of sadness and disgust) with completion events. We also found that the volume of the reciprocity is positively associated with completing the 5-year protocol, rather than the rate of the reciprocity or the fraction of the posts that received replies. We anticipate that our methodology can be applied to study treatment adherence for other diseases using online self-reported information.

12.1   Introduction

In this chapter, we summarized our research in applying user-generated content in online environment to learn people's health-related behaviors. While we focused on hormonal therapy medication adherence, our methodologies can be applied to learn other potential health issues, such as depression and diabetes. Breast cancer is the most prevalent cancer among American women [1] and the second leading cause of death among women with cancer (just behind lung cancer) [2]. It is estimated that close to 12% of American women will eventually develop invasive breast cancer during their lifetime [3]. A common initial treatment for breast cancer is surgical intervention (e.g., lumpectomy or mastectomy), while adjuvant therapy (i.e., treatment after surgical intervention) is often invoked to reduce the risk of cancer recurrence [4]. In particular, hormonal adjuvant therapy is a popular treatment with a proven track record of significantly improving the long-term survival rate of patients with hormone-receptor-positive breast cancer [5]. This is notable because this disease subtype comprises 75% of all breast cancer cases [1]. To maximize this benefit of hormonal therapy, patients are prescribed a regimen of medication that is expected to continue for a minimum of 5 years [6]. For instance, taking tamoxifen (an oral hormonal therapy drug) for 5 years reduces breast cancer mortality by 33% in the decade after initial treatment [7]. Moreover, more recent evidence [8] suggests that maintaining a tamoxifen regimen for an additional 5 years can further reduce mortality by approximately 50%.

Despite the benefit of hormonal therapy for women, only around half complete a full 5-year treatment [9]. There are various reasons why breast cancer patients fail to complete the regimen, ranging from adverse side effects [10] to progression of the disease into a terminal form [11, 12]. Still, there are many women who fail to stay on a recommended regimen for less obvious reasons [10]. As such, learning the factors associated with why women choose to stop (as well as stay on) hormonal therapy is critical to improving a patient's treatment experience. While there have been various investigations into regimen adherence [11, 13–17], most studies rely on traditional clinical resources and methodology, such as formal survey-based studies [13, 15, 16, 18], electronic medical records (EMRs), and other clinical resources [11, 17, 19]. Though such traditional methods and data are valuable in healthcare research, there are certain drawbacks that should be recognized. First, survey-based methods are limited in that they typically incur high costs in time and money, often restricting a study to a smaller number of participants. Second, considering that breast cancer patients with hormonal therapy generally only have follow-up with their doctors every 6 months, this leads to a large information and time gap in traditional EMR systems about the patients' treatment (e.g., their feelings and experiences) between two visits.

The Internet, and social media in particular, has provided patients with the opportunity to seek and share treatment experiences in online environments [20–23]. For instance, the BreastCancer.org website maintains an online discussion board for breast cancer patients to discuss any aspect of their daily lives they deem relevant. This includes, but is not limited to, their concerns, diagnoses, treatments, side effects, and social support structure. This self-reported information provides a new opportunity to learn about breast cancer patients' treatment adherence—and on a much larger scale. With thousands of patients posting and interacting regularly and accumulating tens of thousands or greater (up to millions) of posts on discussion boards such as BreastCancer.org, one immediate research challenge that arises is how to efficiently leverage such rich text, ideally in an automated and less labor-intensive manner. More concretely, notable research challenges in this domain include: (1) mapping behavioral and health research questions to ad hoc self-reported information and (2) examining the extent to which the posting behavior associates with those breast cancer's hormonal therapy treatment.

Thus, in this chapter, we present our work on learning hormonal therapy adherence (HTA) from patients' self-reported information on the breastcancer.org online discussion board [24, 25]. For the purposes of this research, we label HTA behaviors as three types of events: (1) taking—where a prescribed medication is consumed according to an oncologist's recommendation, (2) interruption—where the patient stops (or pauses) a regimen, or switches to a different medication (with or without clinician advice), and (3) completion—where a patient achieves the end-point of a 5-year treatment protocol. Given these types of events, we summarize our research from four perspectives: (1) building a classifier to effectively identify different HTA behaviors, which can help process a large-scale dataset (e.g., approximate 130,000 posts) so that further analysis can be efficiently conducted; (2), To what extent breast cancer patients' emotions are correlated with different treatment decisions,

which examined HTA from the perspective of an individual patient; (3), factors that are related to the way that patients communicated with each other; (4), The association between these communication patterns and HTA, which examined HTA from perspective of the interaction between breast cancer patients.

Specifically, we begin by extracting statements related to adherence events via a combination of rule-based filtering and statistically informed classification models. Next, we apply a one-way ANOVA test on the emotion scores of sentences that mention adherence events. Then, we construct a social interaction graph consisting of patients and their interactions through their responses. We then investigate reciprocity (regarding the overall volume and rate—see definitions in Table 12.1) and its associated factors, which include the time that the individual is active in the OHC and the writing tones implied by their posts. We focus on writing tones in this work because they allow us to capture the emotional state of the individual and their writing styles and social tendencies [26]. Note that social tendencies have received a substantial amount of attention in their association with social interaction [27, 28]. Finally, we investigate how reciprocity is associated with adherence status, in terms of completing a 5-year therapy.

Based on the research to date, we summarize our findings as follows:

- Different HTA events can be effectively extracted using machine learning method. Patients in OHCs tend to exhibit fear with taking events, anger with interruption events, and joy (with a tinge of sadness and disgust) with completion events.
- Breast cancer patients who exhibit any reciprocity are more likely to communicate higher amounts of extraversion and conscientious social tendencies in their posts. At the same time, these individuals often display higher amounts of anger and joy emotions.
- Breast cancer patients who complete the 5-year therapy are more likely to exhibit a greater volume of reciprocity; however, their adherence status is not significantly associated with the reciprocity rate.

Table 12.1 Notation used in the chapter

Variable	Name	Description
T_{active}	Active time	Time period (in days) between the time of the publication of the first and last post
V_{recip}	Volume of reciprocal contacts	The number of unique users with which a user had reciprocal responses
V_{given}	Volume of support recipients	The number of unique users to whom a user provided responses
V_{recei}	Volume of support providers	The number of unique users from whom a user received responses
R_{recip}	Rate of reciprocal contacts	$V_{\text{recip}}/(V_{\text{given}} + V_{\text{recei}})$
R_{given}	Rate of provided responses	$V_{\text{given}}/(V_{\text{given}} + V_{\text{recei}})$
R_{recei}	Rate of support providers	$1 - R_{\text{given}}$

The following sections are organized as follows: we first review the related literature that motivates our investigation in Sect. 12.2, and then present our investigation for each research question in Sects. 12.3–12.6. Finally, we discuss and conclude our work in Sects. 12.7 and 12.8.

12.2 Background and Motivation

In this section, we review how treatment adherence, with a focus on breast cancer, has been studied through traditional surveys, secondary EMR analysis, and (more recently) in online environments. We highlight the limitations of these studies, but also the main findings, which we used to guide our own investigations.

12.2.1 Factors Associated with HTA

There are many factors that associate with low HTA. For instance, side effects are known to be important factors leading to hormonal therapy discontinuation [10]. Wu et al. [29] showed that high healthcare costs are associated with suboptimal adherence. Neugut et al. [30] observed that patients with nonadherence experiences for chronic diseases are less likely to adhere to hormonal therapy. It has also been suggested that patients with stage IV cancer, as opposed to earlier stages, are more likely to exhibit lower HTA [11, 12].

Personality traits have also been studied for their connections to treatment for numerous health issues [31–34]. Recently, Song et al. [35] showed that breast cancer patients with a lower trust in their oncologist and a lesser ability to cope with potential hormonal therapy toxicity tend to have low HTA. However, these investigations are limited in scale and the intensive nature of survey design and collection make them cost-prohibitive. To the best of our knowledge, this was the first work to investigate the association between personality traits and HTA through patients' self-reported information in an OHC.

Various associations between negative habits and HTA have also been discovered. For instance, Brito et al. [11] showed that patients who drink alcohol tend to have low HTA. There are some studies that have investigated the association between emotions and HTA. Generally, these studies have found that negative emotions are related with low HTA [36, 37]. These studies are limited, however, in that they focus solely on interruption behaviors. Online social platforms, by contrast, may enable us to observe a potentially more diverse set of patients than may be included in studies where the cohort is carefully selected.

12.2.2   HTA Study on Social Media

Social media and online forums are increasingly relied upon to conduct health-related studies. These studies have a broad range, including flu trends [38, 39], mental health [11, 12], extracting languages related to the medical domain [40], how to build online communities to provide local cancer support [41, 42], and privacy issues associated with health mentions [20, 43]. Given the unstructured nature of the data source, researchers have started applying clustering and topic modeling to further standardize the concepts mentioned in online environments, thus providing better interpretations with the derived latent structures and emerging patterns, such as symptoms and risk factors [44].

Pertinent to our investigations, there is a growing body of research that focuses on breast cancer treatment and social media and we refer readers to the excellent review by Zhang et al. [45]. We highlight that Marshall et al. [46] illustrated breast cancer symptoms reported on MedHelp.org exhibit consistency with symptoms reported in the clinical setting. Attai et al. [22] demonstrated that breast cancer patients have reductions in anxiety when attending patient-support groups via Twitter. Similarly, Portier et al. [47] found that breast cancer patients tend to report more positive emotions as they engage in online discussion.

Internet-based interventions have been applied to improve patients' adherence with mental health [48] and antiretroviral medications [49]. However, these investigations are limited in that they have neglected how inferred personality traits influence adherence. While there have been studies focusing on the breastcancer.org forum [45, 50, 51] that we use in this work, none investigated treatment adherence. Still, it should be recognized that Freedman et al. [52] studied a large number of posts mentioning cancer treatments (including hormonal therapy) and identified treatment barriers that manifest from various aspects, including emotions, preferences, and religious belief. Mao et al. [53] found that joint pain is the main reason patients stop taking aromatase inhibitors (AIs, a type of hormonal treatment) in online discussions of drug side effects and HTA discontinuation.

Our study is substantially different in that we characterize HTA along three types of events: taking, interruption, and completion. These are notable because taking events may provide insight into a patients' current state (i.e., when they are in the midst of treatment), and interruption and completion events allow for characterizing the difference between low and high adherence patients. While Freedman et al. [52] focused on sentiment analysis, compared to tone analysis in this study, we also learned the impact of reciprocity on treatment adherence.

12.2.3   Reciprocity and Treatment Adherence

There is evidence that treatment adherence can be improved through certain interventions and support systems. In particular, it has been shown that social support

[54] provided by trusted relations (e.g., family and friends) is often positively associated with health outcomes. For instance, encouragement and assistance for regular physical activity from family members and friends are associated with treatment adherence in type 2 diabetics [55]. Furthermore, family members, together with close friends and coworkers, are the main sources (due to social stigma) for military veterans with Hepatitis C for social support in treatment adherence [56].

According to equity theory and the concept of reciprocity norms (e.g., people expect exchanges to be equally reciprocal), reciprocity (more formally, reciprocal exchange of social support) is more positively associated with well-being than under-reciprocating and over-reciprocating exchanges [57]. In the offline environment, a balanced reciprocal support among trusted relationship (e.g., family members) is positively associated with better mental health [58], while a lack of reciprocal support is associated with poor health [59]. A recent study based on online intervention suggests that online reciprocal social support among HIV patients can be positively correlated with drug use [49]. However, the social interactions in this situation are often organized, as well as controlled, by the investigators of the study.

In this chapter, we consider how social support manifests in an OHC in the wild and its influence on health outcomes. Specifically, we study the interactions of individuals in a large longitudinal online breast cancer forum, where we delve into the impact of support on adherence to a 5-year hormonal therapy, a highly prevalent long-term treatment for breast cancer that has varying completion rates [9].

12.3 HTA Events Detection

In this section, we describe how we collect the data, annotate data, and build an effective classifier to identify HTA events from the posts.

12.3.1 Data Collection

Breastcancer.org is a nonprofit organization that disseminates information about breast cancer to healthcare consumers. Additionally, it operates an online discussion board where breast cancer patients can seek, share, and respond to information about their experiences. The discussion board is organized into 80 forums, with more than 135,000 annotated topics. In this chapter, we focus on the Hormonal Therapy—Before, During, and After[1] forum. We collected all topics and posts within this forum published before June 22, 2016. In total, there are 9996 patients who participated in 5995 topics with more than 130,000 published posts.

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[1]https://community.breastcancer.org/forum/78

12.3.2 Data Annotation

We investigated discussions related to seven hormonal therapy drugs[2]: Arimidex (generic name: anastrozole), Aromasin (generic name: exemestane), Femara (generic name: letrozole), Tamoxifen, Evista (generic name: raloxifene), Fareston (generic name: toremifene), and Faslodex (generic name: fulvestrant). Since the same drug may be referred to in a variety of ways, we standardized the data by replacing the aliases of each medication (e.g., brand name) with their corresponding generic names. This study was deemed to be a nonhuman subjects investigation and granted exemption by the IRB in Vanderbilt University Medical Center.

There were 913,493 sentences voiced in the forum. We found 123,633 sentences (13.5%) contained at least one of the chemical names of interest. These sentences were communicated in 66,617 posts, published by 8563 patients. We selected 1000 sentences, at random, for annotation by human reviewers. The reviewers were asked to assign each sentence to one of seven options: (1) Action: Taking medication, (2) Action: Stopped taking medication, (3) Action: Switched medications, (4) Plan: Take medication in future, (5) Plan: Do not take medication in future, (6) Plan: Not yet decided, and (7) None of the Above.

These options were based on our observation of how patients discuss treatments in this forum and guidance in a decision making codebook introduced by Beryl and colleagues [16]. For the purposes of our investigation (which focuses on two-class prediction), we labeled all of the first six options as relevant sentences and the final None of the Above option as nonrelevant sentences.

We employed a majority rule annotation strategy with three reviewers who spent at least 1 month in this forum and were familiar with this topic. The first two reviewers annotated every sentence, while the third reviewer was employed to break ties. The primary two reviewers exhibited a very good agreement (Cohen's $k = 0.82$) at relevant vs. nonrelevant level; good agreement (Cohen's $k = 0.72$) at the level of the seven options. After the third reviewer broke ties, we obtained 604 relevant sentences and 396 nonrelevant sentences. The distribution of different options after annotation is shown in Table 12.2.

Table 12.2 The distribution of options in the 1000 labeled sentences (after the third annotator broke ties)

	Relevant						Nonrelevant
Option	a:taking	a:stop	a:switch	p:take	p:not taking	p:undecided	None-of-above
#Sent.	403	41	62	40	25	33	396

The relevant versus nonrelevant classes are approximately 3:2 in size. Note that in the Option row, 'a' represents action and 'p' represents plan

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[2]http://www.breastcancer.org/treatment/hormonal/for_you

12.3.3   Adherence Event Extraction

To document adherence events with high precision, we adopted a hierarchical methodology similar to that invoked by others [60, 61], which works as follows: First, we built an LR model to distinguish relevant from nonrelevant sentences. Second, we applied a rule-based method to search relevant sentences for each adherence event. It should be noted that adherence events may not align with labeled actions.

12.3.3.1   Relevant Sentence Classification

To distinguish between relevant and nonrelevant sentences, we translated each sentence into a low-dimensional representation. This representation serves as the features for a LR model (as described below). We used the mean of the low-dimensional representation vectors of words, namely, word2vec [62], in a sentence to represent the feature set for the classification model. We restricted our word2vec representation to words with a frequency of at least five instances in the hormonal therapy forum. We set the dimensionality of the word vectors to 100. We use skip-gram model with negative sampling implemented in gensim [63] to fit the word2vec model.

We used the LR model implemented in sklearn [64] and applied a stratified shuffle/split method to create five cross-validation iterations. In each iteration, 80% of the instances were used to fit the LR model and the remaining 20% were used for testing purposes. All parameters of the LR model were set to their default values in the software package. The LR model achieved an AUC of 0.932 ± 0.010.

By adjusting the class weights, we tuned the LR model to achieve a precision of 0.882 ± 0.023 and recall of 0.882 ± 0.022. We then refit the model with all of the 1000 labeled sentences before applying it to extract the relevant sentences from the entire forum. Upon doing so, we obtained 80,510 relevant sentences that were distributed across 51,826 posts and authored by 8023 patients.

12.3.3.2   Rule-Based Event Extraction

To extract additional sentences for each adherence event, we created patterns that were based upon annotation experience. For example, when patients mentioned stopping a medication, the possible patterns could be (1) Took me off, (2) Stop taking, and (3) Being off a medication. Similarly, when patients mentioned that they were taking a treatment vacation,[3] the possible patterns could be (1) Vacation, (2) Holiday, and (3) Took a break from a medication. When patients mentioned taking a

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[3]It should be noted that vacation events for certain medications were not captured by any label in the initial annotation task. However, upon re-examination, we determined that this group of

Table 12.3 A sample of the patterns applied for extracting adherence events

	Pattern	k:	Prec.
Completion	5 years, finished, ended, completed, done, . . .	0.86	0.83
Interruption	Back on, vacation, switch, took a break, took me off, gave up, stopped taking, . . .	0.82	0.85
Taking	Started, been on, stay on, . . .	0.76	0.89

We account for variations in the spelling of a discovered word by applying word2vec (e.g., years for years, vacations, and vaca for vacation)

medication, the possible patterns could be (1) Started and (2) Been on a medication. We refer the reader to Table 12.3 for additional examples of the patterns applied in our model.

To ensure high precision, we iteratively labeled events as follows: First, we extracted and labeled the completion events and removed these from further consideration. Second, from the remaining set, we extracted and labeled interruption events, which again were removed from further consideration. The remaining sentences were used to extract taking events. We followed the same process to extract patient groups with different adherence events. To assess the performance of this methodology, we directed two of the reviewers to assess 100 randomly selected sentences from each classified event category. The agreements, in terms of the Cohen's kappa, between these two reviewers and the precision for each type of events are summarized in Table 12.3. Finally, we obtained 1172 posts published by 513 patients for completion events, 8681 posts published by 2525 patients for interruption events, and 15,116 posts published by 4826 patients for taking events.

12.4 Emotion Analysis

To investigate if there exist significant differences in emotions between adherence event types when patients mentioned them, we randomly selected 500 sentences from each of the three adherence event categories. We chose sentences instead of entire posts because, in this forum, sentences are sufficiently verbose to convey information of interest (see examples below). By contrast, posts are too long to obtain precise emotion scores. These sentences were fed into the IBM Watson Tone Analyzer Service[4] to obtain emotion scores for each sentence, which together with IBM Watson Personality Insights service (see below) have been recently adopted for many emotion and personality-related studies [65–67].

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sentences was not labeled as non-relevant. This is notable because it means that we can still extract such instances from the set of relevant sentences through a deterministic rule-based method.

[4]https://www.ibm.com/watson/developercloud/tone-analyzer.html

The service returns scores with a range of 0 (the weakest) to 1 (the strongest) for five emotion categories: anger, disgust, fear, joy, and sadness. After obtaining emotion scores, we apply a one-way ANOVA test, with a significance level of 0.05, for each category. In this hypothesis test, the null hypothesis is that there is no significant difference in emotion when different adherence events are mentioned.

Figure 12.1 depicts barplots of the emotion scores for each adherence event, emotion pair. Table 12.4 reports on the one-way ANOVA test results for each of the five tests. Each of the p-values is smaller than the predefined significance level of 0.05. This implies that there exists a significant difference between the emotions across the adherence event type.

Figure 12.1 shows that patients tend to exhibit a relatively higher degree of anger when mentioning interruption events. This may be due to multiple reasons, such as frustration with the side effects of medications. A clear example of this phenomenon is in the following patient post:

> I hated the side effects and figured I'd die with or without the Letrozole so stopped after a couple months.

We also note that mentions with completion events tend to exhibit a slightly higher level of disgust in comparison to the other two events. This may arise because, after 5 years of treatment, some patients may refuse to continue further treatment after rebalancing their quality of life and cancer recurrence. As one patient noted:

> I finished 5 years of Tamoxifen and declined the Letrozole because my chance of recurrence was very low and I wanted to feel more alive than the Tamoxifen allowed.

Yet, it appears that completing a 5-year treatment makes patients relatively less fearful and more joyful. This is not unexpected because, in spite of various side
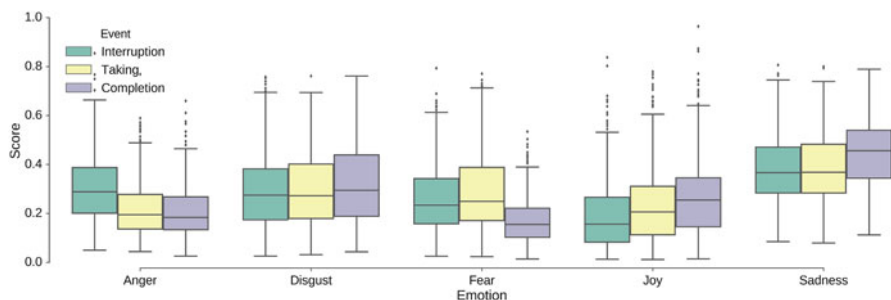
Fig. 12.1 A boxplot of the emotion scores for adherence events, emotion pairs. Mentions with interruption events tend to exhibit greater levels of anger. By contrast, mentions with completion events tend to exhibit greater levels of disgust, joy, and sadness and lower levels of fear

Table 12.4 The results of the one-way ANOVA test on five emotions for the three types of adherence events

	Anger	disgust	Fear	Joy	sadness
F	100.449	6.866	107.977	25.327	40.592
p	<0.001	0.001	<0.001	<0.001	<0.001

effects, approximately half of the women on hormonal therapy medications achieve this goal. For example:

> I am happy to be done with the Anastrozole—but I am so glad I made the whole 5 years!

At the same time, completing a 5-year treatment does not necessarily imply the end of hormonal therapy. Instead, it may just be the beginning of a second 5-year treatment period. Moreover, the cancer may reoccur after the initial 5 year period. As one patient noted:

> On a side note I was on Tamoxifen for five years and still got a recurrence so I'm not married to the idea of taking pills anyway.

Interruption and taking events did not exhibit a significant difference on disgust or sadness. However, there was a relatively higher joy score in taking event mentions, in comparison to interruption events. This is because patients who continue taking a medication may experience side effects that are quite different to the degree that patients who stop the medication do. As was voiced in one post:

> I have been on Fulvestrant since January of 2014, very little side effects.

Still, not everyone voices a lower degree side effects when taking hormonal therapy medications. It should be noted that some patients who start taking medication often fear the side effects. As one patient noted:

> I just started tamoxifen 3 days ago and i am sitting here in fear of getting fat …

12.5 Factors Associated with Reciprocity

In this section, we start to present the investigations on learning the impact of social interaction on HTA. Specifically, we first introduce how to build social interaction graph, extract writing tones from posts, and measure the reciprocity. We then describe to what extent that writing tones are related to reciprocity. In Sect. 12.6, we present investigation on learning association between reciprocity and HTA.

12.5.1 Building Social Interaction Graph

In this study, we rely on responses to the posts in the forum to construct social interaction groups. However, in this OHC, there are no explicit rules regarding the forum's webpage structure to indicate how posts were composed in response to one another. As such, we assume that if a post p_i published by patient u_i in topic t_i mentioned the username of patient u_j, then u_i responded to the latest post by u_j before p_i was published in topic t_i. We believe this assumption is reasonable because (1) the posts in this OHC are always displayed in a reverse chronological order, and (2) we only focus on the fact that u_i responded to u_j instead of the responding

content. We applied the Stanford Named Entity Recognizer [68] to identify the usernames mentioned in the context. This allowed us to find the patients who use nicknames (or signatures) that are not consistent with their usernames. Upon cataloging all of the nicknames and usernames that a patient may use, we applied fuzzy string matching, in the form of Levenshtein distance that is implemented in fuzzywuzzy [69], to identify patients' relationships via their responses. We set the threshold to 85, with 100 as perfect matching as documented in the package. This process yielded a graph involving 6384 patients with 101,734 interactions.

12.5.2 Measuring Posts with Writing Tones

Next, we extracted writing tones for each post in the forum. We relied on the IBM Watson Toner Analyzer service [24, 26], which performs linguistic analysis on a given input (i.e., post) to detect three types of tones: (1) emotions, in the form of anger, disgust, fear, joy, and sadness, (2) writing styles, in the form of analytical, confident and tentative, and (3) social tendencies, in the form of openness, conscientiousness, extraversion, agreeableness, and neuroticism. Each tone was scored on a continuous scale from 0 (least likely) to 1 (most likely). We refer the reader elsewhere [26] for details on the theory behind, and accuracy of, this service.

12.5.3 Statistics of Reciprocity

We measure reciprocity using volume V_{recip} and rate R_{recip}. V_{recip} is defined as the raw number of unique users with whom a user had reciprocal responses. It measures the size of a user's set of reciprocal contacts in this OHC. R_{recip} is defined as the ratio of V_{recip} to the number of the users that a user either provided responses to or received responses from. This variable measures the percentage of a user's reciprocal contacts in her circles.

We observed that 65.6% of patients in the social interaction graph had no reciprocal responses with others (e.g., $V_{\text{recip}} = 0$), suggesting a loosely connected social network. Figure 12.2 illustrates the log-log plot of V_{recip} when it is greater than zero, where the x-axis is V_{recip} and the y-axis is the corresponding fraction of patients. The figure shows a clear heavy-tailed distribution, which is consistent with many online social activities [70]. Notably, 89% of this population has volume greater than 10. Note the maximum V_{recip} is 123 and the median is 2.

Figure 12.3 depicts the density of R_{recip} for values that are greater than zero. There are three modes illustrated in the figure, which occur at approximately 0.1, 0.5, and 1.0. Most of the R_{recip} values are within the range (0.0, 0.4). However, it

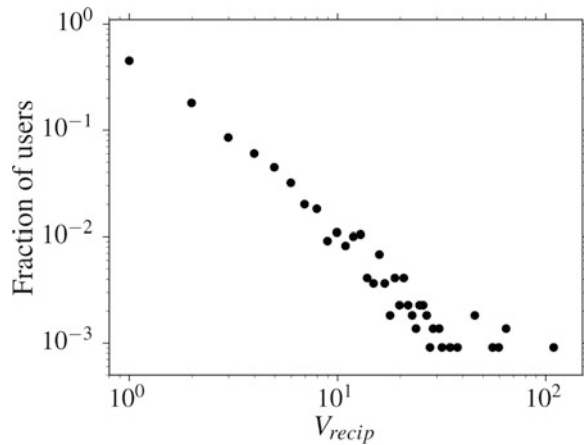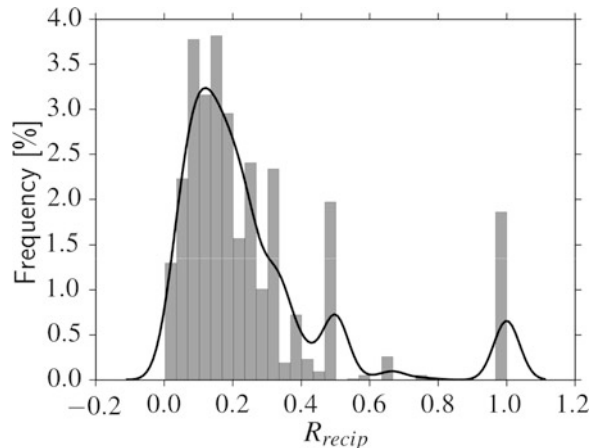**Fig. 12.2** Distribution of V_{recip} for values greater than zero

Fig. 12.3 Distribution of R_{recip} for values greater than zero

should be noted that 90.4% of the 139 patients with $R_{recip} = 1.0$ only interacted with one other patient, confirming the heavy tail distribution for V_{recip}.

12.5.4 Writing Tones and Reciprocity

Given that only around 35% of users in this study exhibit reciprocal responses with others, it is worthwhile to investigate what factors are associated with this behavior. While there may exist many potential factors, such as sharing similar treatment experiences, in this chapter, we focus on writing tones. In contrast to the content of interactions, the inferred writing tones can provide insight into the patient's emotional state, writing styles, and social tendencies. To do so, we built a logistic regression model, where the dependent variable is a binary indicator for whether

a given patient has reciprocal responses with others. The independent variables consisted of (1) the average writing tones for all of the posts published by this patient, (2) T_{active} and R_{given}. The latter two variables were included based on the expectation that the longer amount of time people are in the forum, the more likely they are to generate reciprocal responses.

Table 12.5 reports on the model performance and the statistical significance of the predictors for the logistic regression model. There are several notable findings.

First, according to a likelihood ratio test ($p < 0.0001$), the explanatory power of the writing tones and active time are statistically significant when compared to a baseline null model of only an intercept. Second, the model suggests that patients who exhibit reciprocity tend to express higher quantities of the joy and anger emotions in their posts. Patients with reciprocity also tend to present a higher amount of extraversion. Interestingly, extraversion has already been shown to be positively associated with more frequent use of Facebook to communicate with others [71].

Second, the model also suggests that patients lacking reciprocity tend to exhibit slightly higher conscientiousness. This is aligned with many studies [21, 72, 73], where conscientiousness has been shown to be negatively associated with online social network usage.

Finally, while active time is positively associated with reciprocity, its effect (in terms of an absolute coefficient value) is the weakest among these predictors. This suggests that the longer that a patient stays in the forum, the more likely she will generate reciprocal responses with others. However, the influence of active time is not as strong as the other factors mentioned above.

Table 12.5 Logistic regression model performance, along with variable significance, for predicting reciprocity that are greater than zero

Predictors	b	Std. Err.	z
Joy	2.305***	0.546	4.222
Extraversion	1.523***	0.345	4.418
Anger	1.023*	0.306	3.344
Conscientiousness	−0.892*	0.381	−2.341
T_{active}	0.192***	0.009	21.342
No. observations			6384
Log-likelihood			−3363.8
LL-null			−4109.0
LLP p-value			***

Predictors are ranked by their absolute coefficient values
*$p < 0.05$, **$p < 0.01$, ***$p < 0.0001$

12.6   Linking to Treatment Adherence

12.6.1   Impact of Reciprocity

Table 12.6 shows the distribution of patients according to their treatment adherence and reciprocity status. It can be seen that the existence of reciprocity increases the proportion of patients with completion events from 0.169 to 0.206. To assess if the difference is statistically significant, we ran a Chi-square test with a null hypothesis (at a 0.05 level of significance) that there is no difference between the proportions. The result ($\chi^2 = 4.728$, df $= 1$ and $P = 0.03$) shows that the null hypothesis is rejected. This suggests that there is a positive correlation between having reciprocity and completion events.

However, when we control for patients' active time on the forum, a binary logistic regression (on predicting a completion event) shows that reciprocity status (a binary indicator) is no longer significant ($\beta = 0.149$, $P = 0.197$). Considering the positive association between active time and reciprocity (see Sect. 12.5.4), this implies that active time is a strong confounding factor ($\beta = 0.023$, $P = 0.027$) when predicting a completion event based on reciprocity. This finding provided evidence for a more specific investigation into treatment adherence in the situations when reciprocity does and does not exist.

12.6.2   Impact of Greater Levels of Reciprocity

Based on the findings in Sect. 12.6.1, we investigated the two groups (i.e., with and without reciprocity) separately. Figure 12.4 shows the difference for R_{given} between the two groups. Most of the R_{given} values for the group with reciprocity are concentrated in the (0.4, 0.8) range. By contrast, most of the R_{given} values for the group without reciprocity are concentrated on the boundaries of the range at 0 and 1. This indicates that many patients in the latter group either received or provided a very limited number of responses.

To investigate the group without reciprocity in greater depth, we built a binary logistic regression model to predict completion events using T_{active}, V_{given}, R_{given}, and writing tones as covariates. It was found that the model was not significantly different than the baseline null model at the 0.05 significant level (likelihood ratio

Table 12.6   Distribution of treatment adherence for patients with reciprocity

		Treatment adherence				Total
		Completion		Interruption		
Non-zero	Yes	230	(20.6%)	885	(79.4%)	1115 (100%)
Reciprocity	No	188	(16.9%)	922	(83.1%)	1110 (100%)
Total		418	(18.8%)	1807	(81.2%)	2225 (100%)

Fig. 12.4 Distribution of R_{given} for the two groups
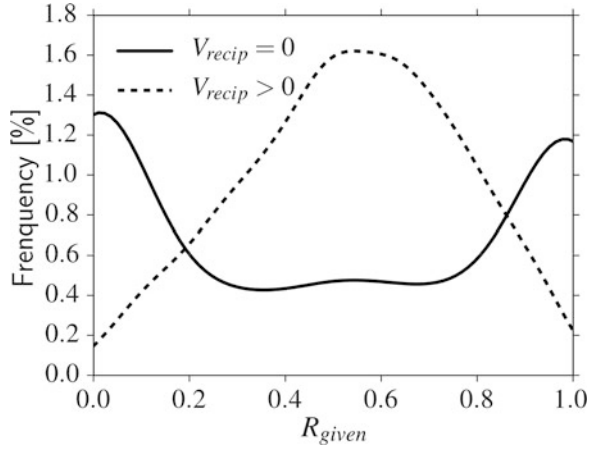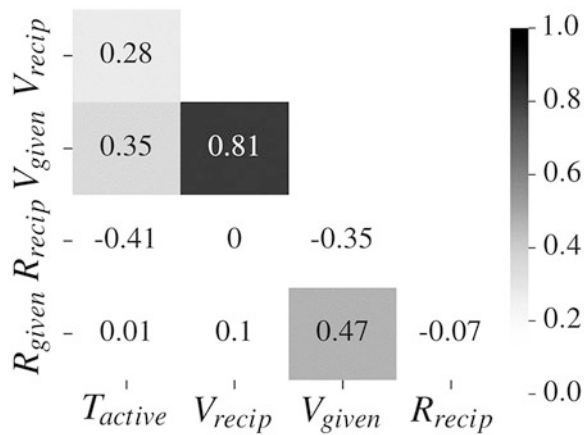

Fig. 12.5 Correlation between variables in the group exhibiting reciprocity

test, $P = 0.305$). This is notable because it suggests that even active time is no longer significant for this group.

Next, we examined the association between the group with reciprocity and treatment adherence. Figure 12.5 shows the correlation between several variables in the group with reciprocity. It can be seen that both V_{recip} and V_{given} are weakly positively associated with T_{active}, while R_{recip} is moderately negatively associated with T_{active}. This finding implies that the more time a patient stays in the forum, the more likely they provide a response and grow their reciprocity volume. However, at the same time, their reciprocity rate is more likely to gradually decrease. It should be noted that V_{recip} exhibits a very strong correlation with V_{given} in this group, indicating the more response to be provided, the more reciprocity to be generated.

We investigated the association between reciprocity and treatment adherence status using a logistic regression model. We predicted completion events with T_{active}, V_{recip}, R_{recip}, and R_{given} as independent variables. We dropped V_{given} due to its strong

Table 12.7 Model
performance and significant
predictors for predicting
completion event with a
logistic regression model

Predictors	b	Std. Err.	z
Agreeableness	10.113***	2.264	4.467
Extraversion	−7.443***	1.634	−4.555
Neuroticism	−6.983**	2.322	−3.008
Conscientiousness	−5.205**	1.878	−2.772
Openness	5.173*	2.499	2.070
Analytical	2.520*	0.797	3.164
V_{recip}	0.382***	0.082	4.672
T_{active}	0.287***	0.080	3.565
No. observations			1115
Log-likelihood			−516.3
LL-null			−567.5
LLP p-value			∗ ∗ ∗

The significant level is set to 0.05. Predictors are ranked by
their absolute coefficient values
*$p < 0.05$, **$p < 0.01$, ***$p < 0.0001$

correlation with the variables that we are interested in. We also included writing
tones as confounding factors because social tendencies have been shown to associate
with treatment adherence [31, 74]. Table 12.7 summarizes the model performance
and the statistically significant predictors.

The results show that the predictors provide more statistically significant
explanatory power in comparison to the baseline null model under a likelihood
ratio test ($P < 0.0001$). The most significant predictors in the model are the
five social tendencies. Among these predictors, agreeableness and openness are
positively associated with completion events, while extraversion, neuroticism, and
conscientiousness are negatively associated with completion events. Analytical
writing style is also a positive factor for completion events. And, active time in the
forum is positively associated with a completion event, however, with the weakest
effect.

After controlling for these confounding factors, we still observe that reciprocity
has a significant positive correlation with a completion event. However, the model
results show that it is the volume of reciprocity ($\beta = 0.382, P < 0.0001$), rather than
the rate of reciprocity, that provides a significant positive explanatory power for a
completion event. Note that neither R_{given} nor emotions are significant.

These results imply that neither the proportion of social contacts who reciprocally
exchange support with respondents, nor the proportion of social contacts who
receive support from respondents matter to respondents' treatment adherence.
Rather, it is the total number of social contacts who reciprocally exchange social
support with respondents that may contribute to treatment adherence.

12.7   Discussion

In this section, we summarize and discuss our findings, limitations, and potential future work.

12.7.1   Emotions and Treatment Adherence

The research reported in this chapter is based on self-reported patient information in an online health forum. Self-reported information has the potential to provide a candid view of patients' daily experiences, thus allowing for more nonclinical insights into the understanding of HTA. For instance, our emotion analysis shows that patients who mentioned interruption events often exhibit a strong emotion of anger. If care providers could continuously monitor patients' posts (or be provided with interpretation services in the event patients do not wish doctors to listen to everything they have to say), they may be provided with signs of potential interruption events before they occur (e.g., through rising rates of an anger emotion).

Our findings indicate that long-term consistent support may be needed to correct patients' perspectives and improve their overall treatment experience. Given that the common practice in breast oncology clinics is to see patients twice per year while they are receiving long-term hormonal therapy, ancillary triggers for impending HTA problems, such as prompting patients for reflective comments through consumer health informatics interfaces, should be pursued.

12.7.2   Factors Associated with Reciprocity

This investigation relies heavily on the notion of reciprocity for distinguishing support from reciprocal contacts and unilateral contacts (e.g., support recipients and support providers only). While there may be many factors driving reciprocity, we find that the reciprocity status is positively associated with active time in the forum and extraversion. We believe this is intuitive because extroverts are often talkative and communicate a large quantity of emotional expressions [75]. This might further explain why both anger and joy, two seemingly opposite emotions, were positively associated with reciprocity in our model. Finally, we find that conscientiousness is negatively associated with reciprocity status, which is aligned with related literature [21, 72, 73].

12.7.3 Reciprocity and Treatment Adherence

We find that reciprocity volume, as opposed to the reciprocity rate, is significantly associated with treatment adherence. We observed this significance while controlling for active time, R_{given}, and writing tones. This implies that, in this OHC, patients with completion events are more likely to actively engage in reciprocal responses with others, and thus, have more reciprocal contacts. We also find that these patients tend to be more agreeable and open, write more analytically, and show less extraversion, neuroticism, and conscientiousness.

12.7.4 Limitations and Future Work

Despite the notable findings, there are certain limitations in this collection of investigations we wish to highlight.

First, we did not control our models with all possible factors that may influence treatment adherence (e.g., stage of cancer or side effects encountered). It is important to investigate if volume of reciprocity remains a significant predictor after controlling with these factors.

Second, we only focused on the writing tones of posts, rather than their actual content. Yet, the content of the posts may provide more insight into why reciprocity exists (or fails to). Thus, there is an opportunity to examine if similar topics are more likely to incur reciprocal responses.

Third, we relied on a rule-based method to extract treatment adherence status, which may exclude patients whose posts did not follow such patterns. A more efficient model could be developed to extract treatment adherence status.

Finally, we make a strong assumption that reciprocity based on responses of posts in an online forum is equivalent to some form of social relationship. While we believe that responses show that the patients are interacting, it is unclear if such relationships are similar to those fulfilled by people in the physical world (e.g., family members or care providers).

12.8 Conclusion

In this chapter, we presented a collection of investigations into hormone therapy adherence (HTA) based on patient self-reported information in a large, longitudinal online breast cancer forum. We focused on a dataset collected from breastcancer.org and characterized adherence behavior with three types of events: taking (medication), interruption (of the treatment regimen), and completion (of 5-years of treatment). From an emotional perspective, we found that when patients mention taking (medication) events, they have a relatively higher rate of fear (for potential

side effects); when patients mention interruption events, they have a relatively higher rate of anger; and when patients mention completion events, they exude more joy and less fear, but also experience relatively higher sadness. We further investigated reciprocity (in terms of reciprocal responses to forum posts), as well as the extent to which it is associated with treatment adherence, in an online breast cancer community.

Our investigations, which covered data from a 9-year period, suggest that breast cancer patients who exhibit reciprocity are more likely to realize higher levels of extraversion, but lower conscientiousness in social tendencies. At the same time, these patients often reveal higher anger or joy emotions in their posts. Through analysis on association between reciprocity and treatment adherence, we find that patients who complete treatment are more likely to generate reciprocal responses with other patients. However, we did not observe any significant explanatory power for the treatment adherence status for patients who lack reciprocity. We believe that a fruitful direction for future investigations would be to apply causal inference on the impact of reciprocity on treatment adherence while controlling on factors beyond writing tones and active time in this forum.

While we demonstrated that it is feasible to study the adherence behavior of breast cancer patients undergoing hormonal therapy by analyzing their posts in an online community, the methodologies and user-generated content in online environment can be applied to learn health-related behaviors regarding other health issues, especially those with long-term treatments.

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Chapter 13
Ethics in Health Research Using Social Media

Rupa Valdez and Jessica Keim-Malpass

Abstract Over the past decade, scholars have been able to actively engage with patients, informal caregivers, and providers through social media sites and patient-centered groups in ways that are reshaping patient-centered research design and recruitment. As with the introduction of any new technology, there exists both potential for new modes of inquiry and unforeseen ethical quandaries. This chapter presents researchers with the types of questions, ongoing points of debate, and nascent solutions relevant to a research platform in which ethical considerations have yet to be well defined.

Keywords Social media · Online health communities · Ethics · Recruitment · Patient-centered · Consent · Privacy · Human subjects · Public space · Research

13.1 Introduction

Over the past decade, social media has changed the way that we communicate with others and access information, reshaping the daily routines of the lay public and scholars alike. The influx of new information available on general sites such as Facebook, Twitter, Reddit, Instagram, and online health communities such as PatientsLikeMe and QuitNet represents a wide range of current events, viewpoints, opinions, and virtual communities. These social media sites allow otherwise "ordinary" citizens both an active voice and an accessible medium in

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which to express themselves. As a result, they have emerged as some of the most comprehensive archives of written material available for scholarly study of health-related phenomena. Additionally, scholars are able to actively engage with patients, informal caregivers, and providers through social media sites and patient-centered groups in ways that are reshaping patient-centered research design and recruitment [1].

When online communications are treated as data, and social media sites as spaces for recruitment and engagement, the proliferation of social media represents a new and innovative medium for understanding the naturalistic experiences of participants, providers, and researchers, as well as the interactions that occur within these online communities [2]. Such experiences cover a large range of health problems and issues, making textual internet data and social media users potentially rich sources of data for researchers in the health sciences, social sciences, and engineering [3–6]. Qualitative inquiry using data published online or gained through researcher-guided interactions with social media users can be used to understand needs, values, and concerns of patients and health care professionals that may have otherwise not been voiced. Additionally, qualitative analyses using data acquired through social media may be used to understand broad-scale health-related phenomena such as disease outbreaks and engagement in health behaviors [7, 8]. Despite the relative ease with which users of social media can share information, access emerging views, or retrieve archived material, the rapid influx of new technologies and social realities has made the study of social phenomena using online information, recruitment, and engagement nuanced. As with the introduction of any new technology, there exists both potential for new modes of inquiry and unforeseen ethical quandaries [9]. The purpose of this chapter is to explore relevant ethical and scholarly issues for researchers participating in social media-based health-related inquiry. Our goal is to present researchers with the types of questions, ongoing points of debate, and nascent solutions relevant to a research platform in which ethical considerations have yet to be well defined [10].

13.2 Current State of Formal Ethical Oversight Regarding Social Media-Based Research

Privacy, confidentiality, and informed consent are core ethical tenets of human subjects research [11]. But what do these tenets require in the context of internet data derived from social media sites? Do individuals have an expectation that their material is protected by confidentiality and privacy considerations, even if the content is publicly available? Do data management and presentation practices need to change for social media-based research? Basic ethical principles for the conduct of human subject research are codified in guidelines such as the UN Declaration of Human Rights, the Nuremburg Code, the Declaration of Helsinki, the Belmont Report, and the U.S. Common Rule for the Protection of Human Subjects [6, 12].

However, the types of information, participants, and exchanges on social media sites force us to reconsider how traditional ethical principles of research now fit within expanding modes of communication. To answer some of these emerging questions, the Association of Internet Researchers, in partnership with their Ethics Working Committee, formulated general principles to guide online research [6, 13]. While this document presents overarching ethical considerations relevant to social media-based research, a comprehensive determination of ethical principles and best practices has yet to be developed.

Furthermore, debate continues as to whether or not some forms of social media-based research, namely analysis of existing textual archives, fall within the parameters of human subject research or constitute an alternative form of humanistic inquiry [14]. Moreover, this form of research is also conducted by investigators with technical expertise (e.g., engineers and computer scientists), but minimal training in human subjects inquiry [12], yielding additional perspectives related to the ethical use of data acquired through social media sites. A recent review of Twitter use for health research found that only 32% of included articles mentioned ethical approval and only 12% mentioned participant consent [15]. Similarly, a recent review of studies using predictive analytics in mental health found that less than 25% obtained Institutional Review Board (IRB) approval and informed consent [8]. Thus, the research community has not yet reached a consensus as to when formal ethical oversight is required.

Even when researchers seek formal oversight from an Ethics Committee or IRB, the lack of clearly defined ethical practices leads to significant variation in recommendations and permissions [12]. Little guidance has been issued either from federal institutions or the research community in terms of how IRBs should review protocols involving social media research [16]. Many IRBs having limited "social media literacy" rely instead on their experiences with clinical or traditional social science research [17]. Moreover, regulations pertinent to privacy, confidentiality, and informed consent vary by state and country, further yielding inconsistent ethical oversight [5, 16, 18, 19].

13.3 Making Sense of Public and Private Spaces on Social Media

A key challenge of conducting ethical social media research is defining what constitutes a public versus a private space [4, 6]. Guidelines for the ethical conduct of human subjects research offline posit different forms of researcher/participant interaction depending upon where the space falls along a private-public continuum. Offline, a coffee shop or health fair may be characterized as public environments, a library or clinic waiting room as semi-private environments, and boardroom or chronic disease support group meetings as private environments. Thus, a necessary step before beginning social media research is to characterize online spaces along

a similar continuum [2]. Malin Elm describes the following applied definitions for online environments: (1) a *public environment* is open and available for anyone with an internet connection, such as a web page or open chat room, (2) a *semi-public environment* is one that is available to most people, but requires a user-generated account for membership and registration, such as many social networking sites and web communities, (3) a *semi-private environment* is only available to some people, requiring membership, registration, and membership in a certain group, such as a professional organization, and (4) *private online environments*, which are hidden or unavailable to most people with access restricted to the creator of the content and invited guests, such as private blogs or private online photo albums that are password-protected [20]. It is important to recognize that any sense of privacy online has to be defined within these environments as degrees of social behavior rather than an absolute location on the continuum [21]. As a consequence, the *perception* of privacy becomes the primary indicator of the nature of the online space [20].

There is a profound dichotomy that exists in the public nature of much of the Internet and the private experiences that are shared through social media. As one example, young women with advanced cancer explained the anonymity of the Internet allowed them to share extremely private encounters with their body that they would not have shared with the same level of detail if delivered face-to-face with clinicians [24]. Additionally, the young women with advanced cancer were able to form their own social networks that allowed for meaningful relationships with other young people living with similar experiences, and often they used a relatively public space on social media as the first form of contact to eventually meet in more private spaces offline [23, 24]. The use of first-name only accounts or aliases for user-generated content may also give online authors more mechanisms for asking and receiving health-related content for potentially stigmatizing topics [25–28].

The characterization of an online space as public versus private has far-reaching implications for what constitutes ethical research behavior. In spaces other than those considered public, a conservative interpretation of ethical behavior would guide a scholar to approach potential participants only after acquiring formal permission from a moderator or other gatekeeper [22]. Once such permission is obtained the next question becomes one of if and how to acquire informed consent. A decision should be informed by:

1. The nature of the research. Social media research can consist of analyzing existing content, creating a space for the generation of new content on social media, and recruiting individuals on social media for research activities that will take place off the platform. The former two types of research require consideration of the other factors below; in contrast, informed consent for subsequent research activities would always be needed if social media is only being used to recruit participants for other forms of interaction such as interviews or surveys.
2. The population. In contrast to informed consent obtained in person, informed consent obtained online does not always allow for a dialogue between the researcher and participant. This difference is of particular concern for pop-

ulations with low cognitive maturity (e.g., youth, individuals with cognitive disabilities) or those experiencing cognitive decline (e.g., individuals with dementia or traumatic brain injury). In these cases, the informed consent process may need to occur offline and involve additional parties such as a parent or caregiver [14].

3. The number of users. The feasibility of obtaining informed consent is shaped by the number of individuals participating in the particular social media space. A community that boasts hundreds, if not thousands, of users would be more difficult to engage in an informed consent process. In this case, alternative methods may be used to promote ethical use of data. For example, a researcher could post a notification to all community participants stating that previous or future posts will be extracted for research purposes beginning on a specific date, enabling individuals to delete existing posts or refrain from writing posts if they do not want to participate [17].

4. The role of anonymity. In many situations online, the person who posts a message or initiates a blog may choose to remain completely anonymous by only choosing an alias without any way of contacting the individual. Additionally, there are many cases where actually seeking informed consent by email could give the researcher more information about the person (e.g., last name, contact information) than necessary to conduct the study [2].

5. The sensitivity of the data. In some social media spaces, discussion content is often sensitive in nature, as topics include individuals' prognoses, treatment, and changes in their bodies [23, 24]. More importantly, this online "place," even if relatively public, is one where the users would not expect their words and intimate details to be used for research without their knowledge or approval. For such situations, informed consent should be obtained whenever possible.

Finally, given that participants are likely to have differential understanding of privacy on social media and that privacy parameters evolve with the addition of new features, researchers should learn about privacy settings and the privacy implications of certain types of actions and communicate them in lay terms to participants [17]. Thus, the nuances of engaging in spaces that may appear on first glance to be private should be made transparent. When a user logs in to a semi-public Facebook breast cancer group, for example, they may have the perception that the group is not only exclusive to breast cancer survivors, but also that their stories and dialogues are private because each user has to register with Facebook, login to receive access, and be granted permission to join the group. The perception of privacy provided by use of approval to join the group may encourage verbal intimacies that would not otherwise be seen in face-to-face interactions and exchanges [21]. Furthermore, content on social media can flow between different types of spaces that may give the illusion of more privacy than is actually present [29]. Consequently, researchers should inform participants about ways in which privacy settings may be circumvented by those outside the research team (e.g., another participant copying a post from a closed group and reposting it to a public space). Researchers should also inform participants about how actions on social

media have repercussions in terms of privacy: clicking a recruitment ad can alert others to a participant's interest in a given topic [6]. Similarly, joining a group such as one created specifically for research activities can alert others to group affiliation [22].

13.4 Building Trust in Social Media Research

In addition to considerations stemming from notions of privacy, the concept of trust must be accounted for when conducting ethical social media research. Particularly in cases where the research consists of direct interaction with participants, researchers must make informed choices regarding personal disclosure and the nature of researcher-participant interaction. On many platforms, researchers can choose between using an established, personal account or creating a new account solely for research purposes. Use of a new account may have benefits in terms of protecting researcher privacy and safety, but may be viewed as lacking the authenticity required to build rapport and to conduct high-quality interpretive research [17]. Similarly, researchers may be required to make decisions about whether or not to formalize their relationship in the language of the social media platform (e.g., friending on Facebook, following on Twitter). Participants may initiate such requests [17, 22], in part to establish the authenticity of the researcher. If researcher initiated, participant interpretations of the request should be considered, since such a formalization may imply a level of closeness unintended by the researcher [16]. In either case, researchers should be transparent about the purpose of the formalization and consider discontinuing the connection after project completion [17], although long-term community-based participatory research models may require continuation of the connection [30]. Finally, in our study of health information communication on Facebook [22, 31, 32] establishing trust with participants online often required rapidly generating written responses to participant inquiries. While traditional research paradigms rely on IRB-approved written communication, formal approval is rarely feasible in this environment and is contrary to evolving an interactive ethos of social media [33]. Instead, we sought and obtained approval for guiding principles and overarching content that informed these in-the-moment interactions with participants.

13.5 Authentication and Representation in Social Media Research

Ensuring that data obtained through social media are authentic and representative is an ongoing challenge with implications that vary based upon epistemological perspective. The anonymity that allows individuals to openly express themselves

directly impacts the verifiability of the data; there is no way of externally authenticating the author, or determining if that person meets study-specific inclusion and exclusion criteria for a particular research study [2]. When the research subject and data are not attached to a physical body as they are in traditional research contexts, the questions become "Are they who they say they are?" and "Is their data reliable?". Markham argues that the answer to the latter question depends on the study purpose as well as the researchers' underlying epistemological assumptions [34]. From a post-positivist perspective, the inability to authenticate the author may be viewed as a limitation of research, posing a threat to internal validity. Often, events and experiences expressed on social media cannot be verified and it can even be difficult to piece together known demographics about the sample of interest. In contrast, post-modern research perspectives suggest that computer-mediated constructions of self, other, and social structure are just as necessary and critical to study and would not require authentication to proceed [34]. From this epistemological perspective, as with any encounter with qualitative research data, the narratives of participants must be taken at face-value.

The question of who is included in social media research represents another question that researchers must address. The population most likely to use the Internet, and therefore participate in social media, is skewed by gender, race, literacy, and geographical distribution relative to the general population, which could lead to biased findings or exclude certain groups from adequate study [14, 35]. Conversely, discussion related to the potential benefits of social media research has highlighted that these platforms may enable inclusion of traditionally hard to reach groups including those that are stigmatized and at-risk [14, 18, 36, 37].

Another critique of validity/scholarliness in using online data for research purposes involves problems of bias and choices in editing. Because there is such a wide expanse of data, drawing boundaries around the research context, or "identifying the field," may be a more subjective process, with the ability to introduce bias to a greater degree [34]. In discussing methods of online data, Markham stated, "[W]e go there to learn something about Other and when we think we have something figured out, to decide how to tell others what we think we know. To accomplish this goal, we must stop for a moment in the flood of experience, extract a sample of it for inspection, and re-represent it in academic terms with no small degree of abstraction" [34]. When text is the primary means of negotiating self in online environments, researchers have even greater ability to reconfigure the data to be put into the context of the research account rather than within the overall context of the narrative [34]. This question of the method's integrity has direct implications for its use in academia and its ability to be left open to numerous critiques [when text is used to serve the purpose of the research], rather than accurately giving the appropriate voice to the group who is 'speaking' online. If we as researchers remain self-aware and note that our own voices as researchers are often privileged, the notion that data derived from social media can erase sociocultural boundaries represents one ethical advantage of introducing this data source into research [38]. Moreover, when approached reflexively, social media research may yield

conclusions drawn from more representative data surrounding sensitive issues, or issues that are difficult to fully gauge in traditional research settings [23, 24, 39].

13.6 Publishing Social Media Research Findings

When publishing social media research findings, researchers should attend to the implications for anonymity, attribution, and transparency. Norms for the presentation of rigorous qualitative research encourage the presentation of verbatim quotes from participants [40]. However, use of verbatim quotes should be considered in light of how the data were obtained when conducting social media research. In cases where the text was posted in an online space that was likely deemed private, researchers should consider paraphrasing or aggregating quotes in a way that captures the essence of the original quotes instead of including them verbatim [14, 19, 41]. Such a practice prevents a quote that participants deem private from being discoverable by a search engine and traced back to the author [19, 42]. In contrast, individuals publishing on a blog or through highly public spaces like Twitter and Instagram and using their real names may prefer to have their contributions credited [2, 14, 19, 42]. In these cases, researchers should approach the author for informed consent to use the text and any identifiable information.

13.7 Balancing Participant, Scholarly, and Societal Needs

In many disciplines that are using social media for naturalistic inquiry, predictive analytics, and surveillance, researchers want to observe publically accessible archives in an effort to study people's actions and interactions in their natural online environment [2, 5, 7, 8]. By requiring informed consent for such inquiry, most of this research would be prohibited because of the inability to obtain consent. Are we willing to forgo sharing this wealth of information to answer previously unanswerable questions? As noted, despite the challenges, there are many ways in which social media research enables new forms of inquiry. On one hand, data may be more representative of multiple viewpoints and lay voices that are not confined by various barriers. Respondents may be members of a population who may otherwise not share a certain aspect of their disease or care in traditional settings. Additionally, participants may be able to offer naturalistic feedback generated in real-time [43]. Data can be viewed as it is generated, or as archived responses, placing the narrative within the context of the social, political, economic, and cultural forces that correspond with the mood of the user. Further, data are not limited by the standard restraints of geographic location, as people from all over the world can respond in mere seconds [2]. When used for public health purposes, the societal benefit in terms of an averted epidemic or crisis may also be viewed by some as significantly

outweighing the ethical repercussions of not obtaining individual inform consent [5, 7] on relatively public online spaces.

Thus, as the scope of social media research continues to grow, it is imperative for the research community to balance the sometimes competing priorities of participants, scholarship, and society. Determining the appropriate balance will require answering the question of how we can protect human subjects in social media research, in addition to others focusing on scholarly and societal benefit. We encourage researchers to be transparent about their methodological decisions, and to describe how participant voice, advocacy, and action are prioritized in social media research [34, 44]. Such transparency will allow the research community to create more refined ethical guidelines as social media grows in popularity as research modality [45].

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