special article

Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities

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abstract

Twitter use has increased among patients with cancer, advocates, and oncology professionals. Hashtags, a form of metadata, can be used to share content, organize health information, and create virtual communities of interest. Cancer-specific hashtags modeled on a breast cancer community, #bcsm, led to the development of a structured set of hashtags called the cancer tag ontology. In this article, we review how these hashtags have worked with the aim of describing our experience from 2011 to 2017. We discuss useful guidelines for the development and maintenance of health-oriented communities on Twitter, including possible challenges to community sustainability and opportunities for future improvement and research.

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INTRODUCTION

Social media allows users to interact with others to view, create, and comment on online content. To make specific content easier to find, hashtags that are generated by users have been widely used. Such hashtags allow spontaneous organization. Rather than a planned structure, these hashtags are often used on social media on the basis of meaning to individual users, referred to as a folksonomy.[1]

Hashtags are a specific type of metadata tag. First used on Twitter in 2007,[2] hashtags have become increasingly common to organize people around groups, topics, or current events. By adding the hash (#) symbol to words or strings of characters, social media users can create information channels to bring focused information—narrowcast—around a specific issue or create new communities with a common interest.

More than two thirds of US adults who go online use the Internet to find health information,[3] but unfortunately some may be misled by false, inaccurate, or overhyped content.[4] As some health-oriented hashtags began to emerge on Twitter, many saw potential value in using these hashtags to bring people together; however, another question was raised: Could an organized set of hashtags make it easier to find reliable health information if people and institutions can narrowcast to an interested community?

Through observation and direct engagement online, some of the authors developed a set of cancer-specific hashtags to facilitate information sharing on Twitter. Hashtags may help people and organizations provide and find reliable disease-specific health information on some social media Web sites. We have also observed health professionals begin to organize themselves using hashtags, both at academic meetings and on the basis of specialty-oriented topics.

The aim of the current study is to describe how hashtags can provide access to accurate health information. In this article, we review the evolution of disease-specific and specialty-specific hashtags used on Twitter that have grown substantially in use since 2013.[5] We also outline current challenges, practical solutions, and potential areas of research that may help achieve the goal of ensuring that people can find the reliable and relevant information they need to make informed health decisions.

EVOLUTION OF THE CANCER TAG ONTOLOGY

The original model for using hashtags for health care topics was the Twitter-based chat around the tag #hcsm, shorthand for health care communications and social media. Dana Lewis (Twitter: @danamlewis) started #hcsm in January 2009 and the weekly 1-hour live chats attracted many health-oriented participants (D. Lewis, personal communication, August 2017). Two and a half years later, breast cancer advocates Alicia Staley (Twitter: @stales) and Jody Schoger (Twitter: @jodyms) adapted the model to start a disease-specific chat that focused on breast cancer with the use of the hashtag #bcsm.[6] Moderators of the #bcsm chats had a large number of diverse connections and were able to attract survivors of breast cancer and advocates, physicians, and other professionals. The success of #bcsm inspired a brain tumor–oriented chat (#btsm) to form in May 2013.[7]

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

To describe how disease-specific hashtags may help organize online health information and create communities of interest.

Knowledge Generated

Cancer tag ontology evolved from patient-centered, disease-specific, Twitter-based chats as a cooperatively designed system that has grown in use from 2011 to 2017. This article provides guidelines, challenges, and opportunities for using hashtags to develop online communities of interest.

Relevance

It is increasingly important to understand how to find and share reliable health information online in an organized, evidence-based fashion.

After participating in #bcsm since inception and seeing the #btsm chat continue to grow, two authors (M.S.K. and P.F.A.) saw the potential to broaden the concept into a curated set of hashtags for different types of cancer. The initial framework was suggested in a July 2013 blog post for ASCO,[5] and an updated version emerged in November 2013 on Symplur.com, which collects data on Twitter use in health care through its hashtag project.[8] Since then, it has been referred to as the cancer tag ontology (CTO).

The proposed set of hashtags were adopted for gynecologic cancers (#gyncsm), lung cancer (#lcsm), and multiple myeloma (#mmsm). For these diseases, Twitter-based advocates were aware of the original ASCO blog post and chose to adopt these hashtags for their chats. First presented at the ASCO 2015 Annual Meeting, a short descriptive report of the 25 original tags in the CTO was published in 2016.[9] Four additional hashtags have been added to the current list in the CTO: #amsm, #gencsm, #mpnsm, and #skcsm (Table 1).

HASHTAG USE, 2011 TO 2017

To quantify the use of CTO hashtags, we used Symplur's Signals analytic software, which accesses Twitter's application program interface for hashtags submitted to the company. We analyzed data for activity from January 2011 through December 2017 to quantify changes in tweet activity and differences in stakeholder use over time. We also compared the time periods 2011 to 2013 with 2014 to 2017 on the basis, in part, of more widespread adoption facilitation by online publication of the CTO, marking the transition from a bottom-up to a hybrid top-down approach to hashtag use.[8] Symplur identifies individual Twitter accounts by different health care categories on the basis of the interpretation of each account biography/profile. We included unclassified accounts in overall activity, but focused on confirmed stakeholders for stakeholder analysis and reporting more detailed data on CTO hashtag use.

In total, CTO hashtags were used in 1,813,515 tweets with a median of 14,706 tweets per hashtag (range, 46 to 612,768 tweets). Hashtags had a median of 3,733 users (range, 38 to 60,011 users). The eight hashtags with moderated Twitter chats accounted for 1,167,009 (87.3%) of all tweets. Annual volume rose each year from 28,277 in 2011 to 446,026, with the largest absolute annual increase occurring in 2014, after the November 2013 publication of the CTO hashtag collection (Fig 1).

Among the 27 tags with enough use to look at the top 100 users of each tag, there was a diverse range of stakeholder participation (Fig 2). The three most actively involved individual users were patients (18%), doctors (15%), and caregivers or advocates (5%). Media organizations, including medical journals, accounted for 6% of tweets, with health care provider or research organizations accounting for 5% and 2% of CTO use, respectively. Hashtag use has grown substantially among all stakeholders, with doctors and health care provider use equaling patient use as of 2017 (Fig 3). Among individual stakeholder categories, doctors had the largest increase in users and activity (Table 2).

GUIDELINES FOR CREATION

Development of the health care hashtag system, or CTO, was a deliberate attempt to create an ontology—a structured system with formal naming and categories—to organize cancer information by disease. The success of the CTO, in part, was fortunate timing; however, we believe that some factors can be identified that may help make disease-specific hashtags create similar kinds of communities that emerged with the use of #ayacsm, #bcsm, #btsm, #gencsm, #gyncsm, #lcsm, #mmsm, and #pancsm.

First, we focused not only on the specific diagnosis but also on the disease experience. A purely diagnosis-based system has been proposed using International Classification of Diseases, Tenth Revision, codes to codify physician blogging,[10] but using a diagnostic billing code is not the most attractive tactic with which to bring clinicians, patients, other stakeholders, and the public together. Breast cancer and lung cancer are common enough to have many people online with a shared experience to form a coherent, sustainable community. For gynecologic cancer, there are some shared patient experiences regardless of specific cancer type—for example, ovarian, cervical, and uterine

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TABLE 1. Hashtags Included in the Cancer Tag Ontology

Hashtag	Disease	Regular Online Chat
#adcsm	Adrenal cancer	
#amsm	Advanced metastatic cancer	
#ancsm	Anal cancer	
#ayacsm	Adolescent and young adult cancer	Yes
#bcsm	Breast cancer	Yes
#blcsm	Bladder cancer	
#btsm	Brain tumors	Yes
#crcsm	Colorectal cancer	
#esocsm	Esophageal cancer	
#gencsm	Genetic/hereditary cancer	
#gyncsm	Gynecologic cancers	Yes
#hncsm	Head and neck cancers	
#hpbcsm	Hepatobiliary cancer	
#kcsm	Kidney cancer	
#lcsm	Lung cancer	Yes
#leusm	Leukemia	
#lymsm	Lymphoma	
#melsm	Melanoma	
#mmsm	Multiple myeloma	Yes
#mpnsm	Myeloproliferative neoplasms	
#pancsm	Pancreatic cancer	Yes
#pedcsm	Pediatric cancer	
#pcsm	Prostate cancer	
#scmsm	Sarcomas	
#skcsm	Skin cancers (nonmelanoma)	
#stcsm	Stomach cancer	
#thmcsm	Thymoma and thymic cancer	
#thycsm	Thyroid cancer	
#tscsm	Testicular cancer	

cancers. Therefore, it was decided to group these cancers together so that more participants could share their insights and support each other. In rarer diseases, such as anal cancer (#ancsm) and testicular cancer (#tscsm), attempts to build community did not work as well. Some hashtags focus much less on specific diseases than shared experiences: #ayacsm for adolescent/young adults; #amsm for advanced metastatic disease; and #gencsm for genetic cancers and addressing cancer risk for people with *BRCA* mutations, Lynch syndrome, or other genetic conditions.

Second, we designed the initial hashtags to start with the disease group, often followed by a 'c' for cancer, then ending in a root of '-sm'. We used the -sm suffix for consistency with the #hcsm hashtag so that it would be familiar to active health care–oriented people on Twitter in 2013. We also believed that including the -sm suffix is an important reminder to participants that they are sharing health information on social media, which risks the loss of anonymity with sharing too much personal data.

Third, we found that short hashtags were more useful. At the time when many of these communities were developed, Twitter had a 140-character limit for all tweets, including usernames and hashtags. Now, 280-character tweets are permitted for all users; however, there may still be advantages to shorter hashtags, as they are easier to remember and leave more room for content, discussion, and the inclusion of multiple hashtags in one tweet. The expanded 280-character limit on Twitter now allows for more natural language use for hashtags. The best approach to combine ease of use with content clarity, minimizing spam, remains unknown.

Finally, we felt that uniqueness was important. We checked candidate hashtags on Twitter's search engine to see whether that hashtag was already in use. We ruled out using some hashtags because of unanticipated uses for events, abbreviations in other languages that were widely used, or pornography. These types of content ideally should not cross into a health care conversation. If a proposed health care hashtag has minimal non–health care use, we considered that our intended use would become the default use and may lessen future use by others.

There are currently no ownership rights or enforceable restrictions for hashtag use; therefore, even a well-designed hashtag system risks being used for other purposes. We will discuss this concern in the section below on sustainability.

The CTO was designed to cover neoplastic disease. Despite our initial efforts to make it a true ontology, which comprehensively categorizes and organizes information in a perfectly consistent manner, it is more accurately described as a structured tag collection. For other major categories of human illness, it is unknown whether this system will work. We suspect that this system may work for common chronic diseases. Cardiovascular disease remains the leading cause of death in the United States[11] and discussions often center around hashtags, such as #heartdisease and #cardiovascular. Diabetes has two specific hashtags, #T1D and #T2D, with regular use to discuss type I and type II diabetes, respectively, and #DSMA for diabetes social media advocacy, building community through a regularly scheduled Twitter chat.[12]

GUIDELINES FOR IMPLEMENTATION AND ENGAGEMENT

After the initial design of hashtags, we recommend that direct outreach to key stakeholders be considered to see how the hashtags may be improved before use.

For the CTO, there was a period of 4 months from the initial proposal to the finalized version being released. Hashtags #lcsm and #gyncsm already had collaborators who were active in the respective communities and with established leadership structures. For the other tag communities, two authors (M.S.K. and P.F.A.) engaged with patients, health

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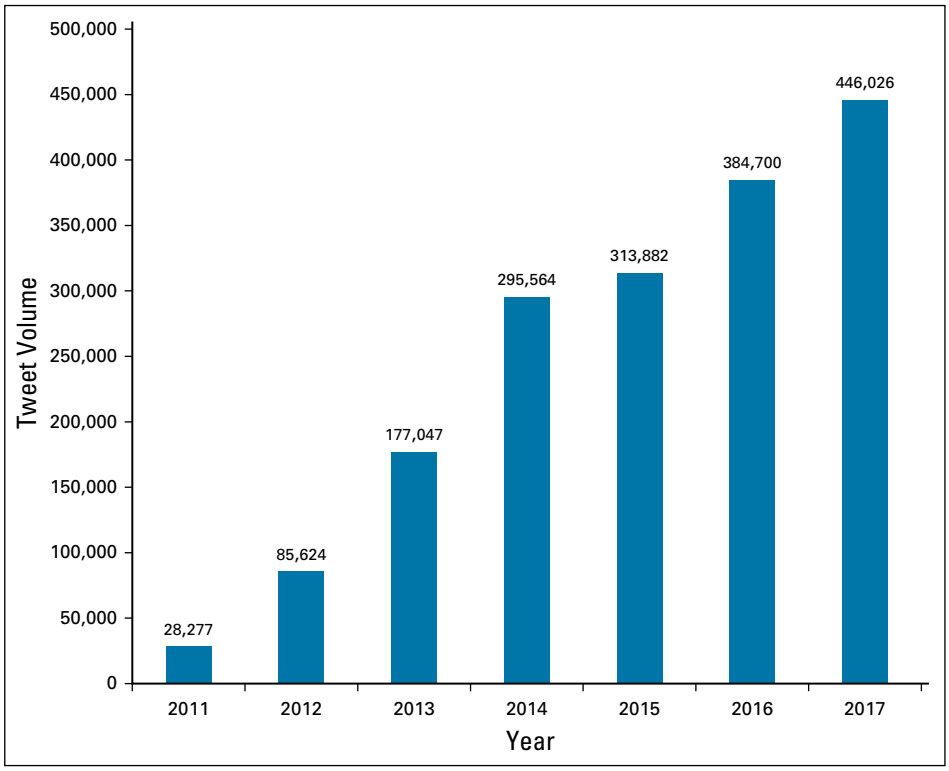

FIG 1. Annual number of tweets including cancer tag ontology hashtags, 2011 to 2017.

professionals, advocates, and others who were interested in the concept on Twitter, both publicly and with direct messaging (not visible to the public). Two Google+ communities were set up, one private and one public, to generate feedback and share information.[13]

For CTO hashtags with chats, different strategies emerged for starting and maintaining active communities. Although primarily on Twitter, five (62.5%) of the eight hashtags with chats maintain content on other digital platforms for continuity. All five hold 1-hour tweet chats at regular time intervals and organize content with planned topics of discussion. Chat topics have included patient education, support during and after treatment, new research, timely advocacy and health policy issues, and coping with grief and loss.

As more people become aware of these communities and start contributing to them, the communities become a better resource for finding thought leaders who readers

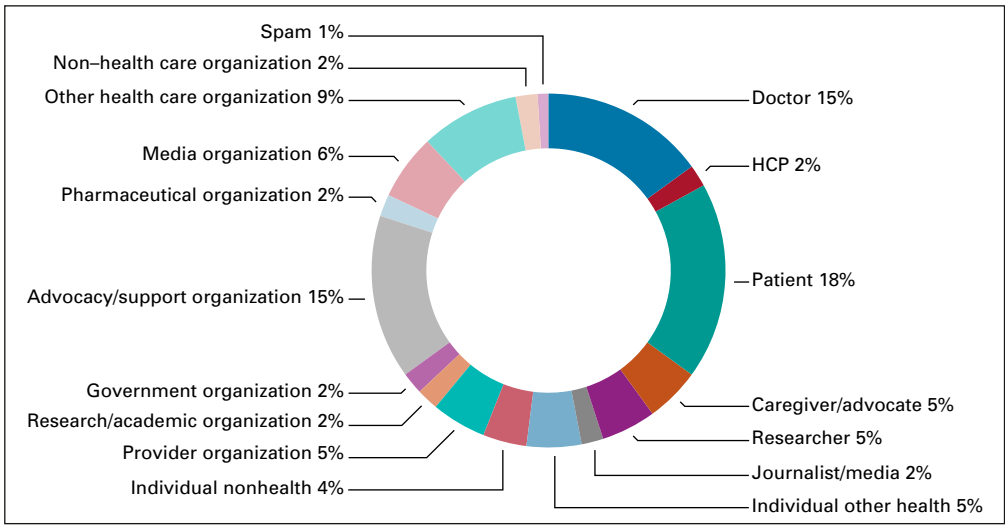

FIG 2. Distribution of the top 100 users of each hashtag in the cancer tag ontology, 2011 to 2017. HCP, health care provider (non-doctor).

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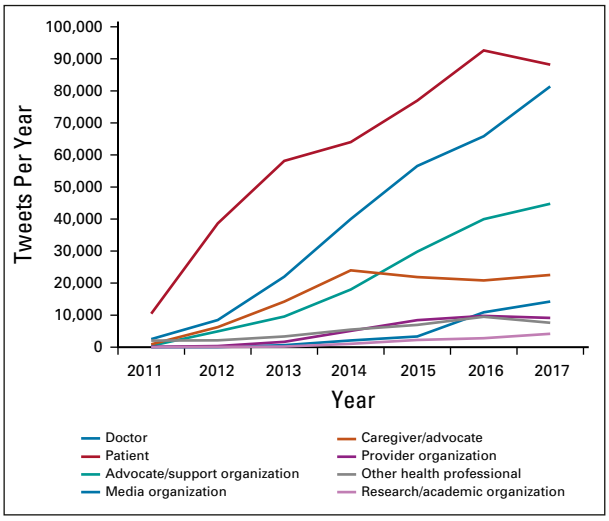

FIG 3. Changes in Twitter use by differing health care stakeholders, 2011 to 2017.

can follow for information on topics of interest: live tweeting from conferences, new development in the field, educational videos, or journal articles of interest—for example, breast surgery, immunotherapy in lung cancer, or brain cancer clinical trials.

CHALLENGES TO COMMUNITY SUSTAINABILITY

Several hashtags have successfully maintained active communities on Twitter for several years. With increasing use, we see five potential challenges to remaining viable and valuable: limitations of Twitter as a platform, dilution, community turnover, stagnation, and participant targeting by third parties (Table 3).

One of the biggest hurdles may be Twitter itself. Although popular for the authors, Facebook and other platforms are used more regularly.[14] Twitter's strength for live discussion is well suited for attracting people to live chats or conversations, but high Web site traffic slows down active live chats, which limits what participants can share. Retrieving valuable health information is difficult given the immediate but fleeting nature of the content. There is currently no easy way for users to find archived, previously shared content; it helps identify the most shared content, but that may not guarantee that it represents what is accurate and relevant. Twitter recently made it easier to post longer content, permitting more in-depth content to be shared, including 'tweetorials', a string of tweets that serve as a public tutorial on a specific topic. Nonetheless, it does not change the ephemeral, real-time nature of the Web site's user interface, requiring some hashtag communities to use other Web sites to archive links to the transcript and list resources.

TABLE 2. Number of Individual Stakeholders Using the Cancer Tag Ontology, 2011 to 2013 Versus 2014 to 2017

	No. of Users	
Stakeholder	**2011-2013**	**2014-2017**
Caregiver	258	995
Doctor	1,117	8,793
Patient	1,219	3,953

As more journals and health care organizations share content with a specific hashtag, there is a risk of diluting the conversational component that attracted many current users. Particularly disruptive are tweets by organizations during a live chat that are often unrelated to the topics being discussed. Unless there are signs of active conversations with real people taking place, hashtags remain relevant but may not foster and maintain a genuine community of interest.

Community turnover may be more problematic for disease-specific, patient-centered hashtags. Some people may be interested in participating when initially diagnosed for some short-term support or conversation; however, it is likely that only a minority of people have a sustained interest in discussing disease diagnosis, treatment, or the many aspects of survivorship. Among patients with cancer, use of support groups is low[15,16] and online support groups may have skewed participation.[17,18]

Participant illness or death depletes the active disease-specific communities, particularly in those patients whose disease has a high mortality rate. Although Internet-based communities may help decrease isolation, there is a risk that increased exposure to Internet-based friends and colleagues' deaths could contribute to higher rates of grief, anxiety, or depressive symptoms. Shared suffering being experienced by community members may deter some participants, whereas for others it may strengthen their relationships.

Current research suggests that psychosocial outcomes in patients who participate in online communities are not clearly worse.[19-21] Strong social ties may help lessen stress and anxiety and could be helpful in robust communities.[22,23] No strong evidence exists that using social media increases stress levels.[24] Given the limited data for hashtag-based communities, research on the influence of social media on psychosocial outcomes seems to be promising but warrants continued study.

Lack of diversity, both in chat participants and topics, can lead to stagnation. As an increasing number of institutions and organizations use hashtags, there is also a risk of losing a critical mass of patients who are affected by a particular disease within a community, as well as a dilution of their voices, leading to a more informational rather than interactive community. Conversations evolve, but it is ideal to keep the community's mission focused. Periodically asking the community for feedback on maintaining that focus may be useful for maintaining healthy engagement.

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TABLE 3. Challenges to Sustainability and Opportunities for Potential Benefit From Using Disease-Specific Hashtags in the Cancer Tag Ontology

Challenges and Opportunities	Hashtag				
	#bcsm	#btsm	#gyncsm	#lcsm	#mmsm
Challenge					
Twitter character limit	X	X	X	X	X
Lag time/slowdowns for live Twitter chat sessions	X	X	X	X	X
Losing patient members (death)	X	X		X	
Losing patients members (other)	X	X			
Community turnover	X	X		X	
Generating fresh topics to discuss for each chat	X				
Attracting patient involvement	X	X	X	X	X
Attracting caregiver involvement	X			X	X
Attracting health care professional involvement		X			X
Attracts spam/malware (in general)	X	X			
Attracts spam from health care delivery organizations or individuals during live chat	X				
Attracts spam/malware from for-profit organizations or individuals at any time	X	X		X	
Attracts spam/clickbait from active Twitter community members		X		X	
Privacy/data mining concerns for community	X				
Chat software issues (eg, not showing all tweets in tweet chats)		X	X.	X	
Opportunity					
Regular hashtag use by health care delivery organizations	X	X		X	
Regular hashtag use by patient advocacy organizations	X			X	
Regular hashtag use by research organizations	X	X		X	X
Regular hashtag use by medical journals	X	X	X	X	X
Adoption by Twitter influencer (> 100,000 followers)	X			X	X
Access to clinical trial participation	X				X

Abbreviations: #bcsm, breast cancer; #btsm, brain tumors; #gyncsm, gynecologic cancers; #lcsm, lung cancer; #mmsm, multiple myeloma.

In active chats, certain people have emerged as leaders, informally or formally. Successful hashtags need champions who consciously cultivate their use with intended meanings. These leaders are active members of the online community and may serve as chat moderators, or they may advocate for specific issues using these hashtags. We have not observed the current hashtag communities deter participants from becoming active leaders, but there are no mechanisms in place to monitor or provide feedback to community members as the data are not easily available without purchase from a data analytics company. For some chats, active chat moderators do not live in the same geographic area. Moderators have developed various communication tools for remote coordination of chat topics and other community tasks (Table 4).

Participation in hashtag-based communities also risks exposing people and organizations to unwanted attention. Popular hashtags, once discovered, may be targeted by marketers, competing patient communities, or spammers. Each type of unwanted participant may interfere with the community's norms of interaction or seem intrusive. They often design content to attract people for clicks or purchases, not substantive interaction. Malware exposure and data mining by visiting Web sites raise concerns about the transparency of the intent on the part of these participants. Some perceived intrusions are not intentional. Given the concerns about viral negative coverage and reputation risk,[25] people or organizations who are labeled as spammers or intruders find it distressing, especially when they may simply be trying to join the conversation. Currently, these hashtag communities do not have clearly established rules of engagement that advise new users on appropriate etiquette.

Data mining is another potential long-term risk to online participation on Web sites that are designed for public use. Social media platforms are not Health Insurance Portability and Accountability Act compliant, nor are they well designed for privacy. Twitter is a public square and any posted content is discoverable through Twitter's application program interface so that content can be extracted for analysis. Interactive health research online offers both potential practical and ethical challenges, which are

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TABLE 4. Remote Collaboration Tools for Moderators/Leaders of Selected Tag Communities

	Hashtag				
Tool	**#bcsm**	**#btsm**	**#gyncsm**	**#lcsm**	**#mmsm**
Twitter	X	X	X	X	X
Google+			X	X	
Google Hangout		X		X	
Skype/phone	X	X		X	
Texting	X	X		X	
Other	E-mail	Google Docs, Facetime	Google Docs	E-mail, Facetime	E-mail, linking to Facebook
Slack	X				

Abbreviations: #bcsm, breast cancer; #btsm, brain tumors; #gyncsm, gynecologic cancers; #lcsm, lung cancer; #mmsm, multiple myeloma.

evolving quickly,[26,27] but people may not want to share content online if it can be used against them. Many do not understand what a privacy policy means[28]; that may change if their trust is violated. Currently, searching for content with a specific hashtag does not risk the loss of privacy, but once content is tweeted with it, one can be monitored and tracked (J. Moffitt, personal communication, August 2017).

Awareness has increased with multiple recent concerns about privacy on Facebook, including third-party access to health information in closed groups, such as BRCA Sisterhood.[29] Twitter's approach to having all content publicly available creates debate over what is appropriate to post, but flattens traditional hierarchies and may allow users to expand their health-based knowledge. Recent data suggest that employees develop better ideas for work if they have more diverse Twitter networks.[30] The ability for patients to lurk and listen without participating means that they may be able to learn information by searching with the CTO hashtags without being easily tracked. Whether this practice improves informed decision making on the basis of accurate health information remains unknown.

COMPONENTS OF POSSIBLE SUSTAINABLE SOLUTIONS

If structured health hashtags can create a network of active health-oriented communities, they may provide a partial solution to the difficulty people have of finding reliable health information online or in remote areas.[31] However, substantive success requires both pragmatic solutions and rigorous research into whether hashtag use provides value to people who are looking for health information online.

Practical Use

First, people searching for health information need easier access. The hashtag system seems to have a better signal-to-noise ratio compared with natural language use on Twitter (J. Moffitt, personal communication, August 2017), but finding these hashtags requires Twitter use and following the right people to learn about it. Easier access by raising awareness may help address some of the concerns about community turnover.

Second, educational training on how to use hashtags to participate in disease-specific communities may lower barriers to participation and lessen unintended intrusions. High-quality educational resources could make it easier for people to learn and communicate effectively on Twitter. Essential components would include the mechanics of using both the Twitter Web site or mobile application, the ethics of how to use these wisely, and etiquette for using these effectively with different people interested in health care.

Advocacy group and patient and health professional participants in the online space also need to be more transparent regarding their relationships with industry, especially if we are to earn and maintain public trust. Recent research highlights how conflicts of interest (COIs) often exist for both advocacy groups and health professionals.[32,33] Thought leaders, both traditional and those on social media, may be more likely to have relevant COIs.[34-36] The US Open Payments program provides transparency on physicians' conflicts.[37] Despite some limitations,[38] the high prevalence in industry payments in cancer care makes transparency essential.[39] Perhaps the expectation that all public health care advocates of any background should provide some link to any COIs should be set to demonstrate transparency of intent. Public disclosure of industry payments does not influence the patient's opinion of physician competence, but has a negative effect on the perception of physician honesty and fidelity.[40]

Research Agenda

Despite the observed growth in hashtag use and our sense that it provides a benefit to all health care stakeholders, we currently do not have firm evidence of efficacy or value. Rigorous qualitative and quantitative studies are needed to answer important questions about the roles that digital communities play in providing support and information to people with health conditions. We are using Facebook, Twitter, and other platforms on the basis of interest and need rather than on the basis of evidence.

Validating hashtags' utility will require studying existing hashtag communities or conducting clinical trials using new hashtags to measure improvements in the disease-specific knowledge base and confidence in medical

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decision making. It will be important to consider the risks of sharing information online, effects on distress levels, and other potential benefits and toxicities of participation.

Part of assessing efficacy includes investigating the optimal mix of stakeholders, content discussed, and the format of presentation. Hashtags work on some other social media Web sites, but cancer experience varies dramatically and viable solutions will likely differ substantially and may need testing to optimize the best patient-focused approach. Research that evaluates whether hashtag-related health information lessens or worsens health disparities will also be important. Strategies and tactics may differ depending on socioeconomic, education, or ethnic background. Limiting access on the basis of English language also is a barrier, both within the United States and globally.

If viability depends on physician participation, finding more professional participants will require some proof of value. At a time when many oncologists experience burnout,[41] more online work may worsen it and have a detrimental effect on empathy, safety, and work productivity.[42,43] The clinician authors in this paper (D.A., D.C., D.D., M.F., M.K., and M.T.) all agree that participating in hashtag communities has improved their awareness of patient needs, listening skills, and openness to new ideas which they can then bring to their own patients to improve care. Communication skills training may improve oncologist satisfaction and lessen burnout,[44] but whether Twitter is the right way to learn better communication skills requires evidence.

CONCLUSIONS

Twitter provides many opportunities for patients, physicians, and health care professionals to come together to share high-quality, evidence-based information. A cancer-specific structured tag collection has been demonstrated to be effective in organizing cancer-related information and bringing together those affected by specific diseases for education and support. Lessons learned in the development and evolution of these communities may be helpful for other patient and professional online groups. However, more research is necessary to learn whether health-oriented online communities are helpful to patients and professionals, particularly on open social media platforms, such as Twitter, where content is public domain. Participation may add value, but there are both ethical concerns and privacy concerns that must be considered and managed.

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