Case 3. In 2012, a young adult man with history of Klinefelter syndrome presented with intermittent chest pain and was found to have a 15-cm primary mediastinal NSGCT. He was treated with 4 cycles of VIP followed by resection of residual mediastinal mass, which revealed teratoma. In 2014, he was found to have leukocytosis (WBC, 44,000/μL [44.0 × 10⁹/L]). Bone marrow examination confirmed chronic-phase CML by morphologic characteristics, and a t(9;22)(q34;q11) was identified by chromosome analysis. The patient started treatment with dasatinib and achieved a hematologic response. To date, his BCR/ABL transcript declined appropriately from 55% to 9%. He continues to be in remission for his GCT.

Discussion | There have been reports of chemotherapy-related Philadelphia-chromosome leukemias in patients with antecedent malignant neoplasms. Past treatments for GCT with cisplatin-etoposide–containing regimens or HDCT with carboplatin-etoposide have been linked to an increased risk of secondary acute leukemia and solid tumors. A review of the literature reveals 7 cases of GCT with subsequent development of CML. In this series, we present 3 cases of patients with GCT who achieved remission with chemotherapy and later developed BCR/ABL-positive CML. These findings raise the question of a causal relationship between etoposide and/or platinum-containing chemotherapy and the development of CML with t(9;22)(q34;q11).

Etoposide-based chemotherapy in patients with GCT is leukemogenic. It is not clear whether combination chemotherapy with cisplatin and bleomycin contribute to this result. While its association with AML is well established, questions regarding the connection of etoposide and cisplatin-containing combination chemotherapy and secondary CML are posed herein. The relatively low risk of secondary leukemia in patients treated with potentially curative combination chemotherapy for GCT continues to be reassuring. However, physicians should be aware of possible late toxic effects of these treatment regimens and the need for diligent follow-up in these patients.

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Disease-Specific Hashtags for Online Communication About Cancer Care

Increasingly, patients, caregivers, and health care professionals (HCPs) go online to learn about and discuss cancer care. However, finding other people or organizations with similar interests can be difficult without some structure. Hashtags are user-generated tags that can organize and aggregate content on social networks. In July 2011, 2 patient advocates started a breast cancer chat on Twitter using the tag #bcsm (breast cancer social media); one of us (D.J.A.) joined as a comoderator. This same model but with hashtag #btsm was used to discuss brain tumors in January 2012. Both tags are now regularly used on Twitter by patients, caregivers, and HCPs.

Dedicated hashtags may make it easier to engage in relevant conversations online for other types of cancer. In this study, we describe a way to use disease-specific hashtags similar to #bcsm and #btsm to organize and increase online discussion of cancer care.

Methods | Based on the models using the #bcsm and #btsm hashtags, 2 of us (M.S.K. and P.F.A.) developed a set of 23 new cancer-specific tags that met the following criteria: disease specific, short, unique or minimally used on Twitter, and ending in “sm” for “social media” (as a prompt that online use is public). We selected this design to balance practical use with the ability to organize content. Initially proposed in July 2013, this cancer tag ontology (CTO) was posted on Symplur in November 2013 after public commentary and engagement (Table). We analyzed the number of tweets and users of the tags quarterly from April 2011 through June 2015 using Symplur.

Downloaded From: https://jamanetwork.com/ on 06/19/2022
Signals, which accesses Twitter’s application program interface. One of us (M.S.K.) classified the most active 100 users as patients, caregivers and/or advocates, physicians, nonphysician HCPs; individuals not otherwise specified, hospitals, other health care organizations, and spam accounts. Patients were defined by self-identification with the disease associated with each CTO tag. To assess hashtag adoption by well-known institutions, we evaluated the prevalence of CTO use by the National Comprehensive Cancer Network (NCCN)- and National Cancer Institute (NCI)-designated cancer centers as well as the NCI and American Society of Clinical Oncology (ASCO).

Results | During the study period, there were 762,103 tweets by 117,064 user accounts. The hashtags #bcsm and #lcsm had the most use, with 323,720 and 143,089 tweets, respectively.

After mid-2013, the most active tags had organized live chats: #ayacsm, #gyncsm, #lcsm, #mmsm, and #pancsm, accounting for 92.2% of all CTO hashtag activity. Among the top 100 users, 34% were patients, 17% caregivers and/or advocates, 14% physicians, 8% nonphysician HCPs, 7% individuals, 2% hospitals, 14% other organizations, and 4% spam generators.

Quarterly tweet activity for all 25 CTO tags increased from 13,778 tweets in the third quarter of 2011 to 87,319 in second quarter of 2015 (Figure). Among 26 NCCN cancer centers, 80.7% used the CTO tags in tweets (median, 86; range, 18-2555). For 44 NCI-designated comprehensive cancer centers, 63.6% used the CTO. The most active organizations were Dana-Farber Cancer Institute (2555 tweets, 4 accounts) and MD Anderson Cancer Center (1771 tweets, 12 accounts). The NCI (749 tweets, 13 accounts) and ASCO (3238 tweets, 4 accounts) also used the CTO frequently.

Discussion | In this report, we describe a way to use hashtags to organize disease-specific health information on Twitter. Most hashtag use develops ad hoc rather than in an organized fashion, but some studies suggest that structured tags can be a successful way to share.3,4 We observed a 13% compound quarterly growth rate in Twitter activity, indicating widespread adoption of disease-specific hashtags by a variety of stakeholders.

The CTO creates a practical way to facilitate patient, clinician, and institutional access to health information and engagement. Preliminary data from the #bcsm hashtag suggest that interaction through Twitter may improve patient knowledge and reduce anxiety.5 We have described feasibil-

Table. Hashtags in the Cancer Tag Ontology

<table>
<thead>
<tr>
<th>Hashtag</th>
<th>Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>#adcsm</td>
<td>Adrenal cancer</td>
</tr>
<tr>
<td>#ancsm</td>
<td>Anal cancer</td>
</tr>
<tr>
<td>#ayacsm</td>
<td>Adolescent and young adult cancer</td>
</tr>
<tr>
<td>#bcsm</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>#blcsm</td>
<td>Bladder cancer</td>
</tr>
<tr>
<td>#btcm</td>
<td>Brain tumors</td>
</tr>
<tr>
<td>#crcm</td>
<td>Colorectal cancer</td>
</tr>
<tr>
<td>#esocm</td>
<td>Esophageal cancer</td>
</tr>
<tr>
<td>#gyncm</td>
<td>Gynecologic cancer</td>
</tr>
<tr>
<td>#hncm</td>
<td>Head and neck cancer</td>
</tr>
<tr>
<td>#hpbcsm</td>
<td>Hepatobiliary cancer</td>
</tr>
<tr>
<td>#lcsm</td>
<td>Lung cancer</td>
</tr>
<tr>
<td>#leusm</td>
<td>Leukemia</td>
</tr>
<tr>
<td>#llym</td>
<td>Lymphoma</td>
</tr>
<tr>
<td>#melm</td>
<td>Melanoma</td>
</tr>
<tr>
<td>#mmcm</td>
<td>Multiple myeloma</td>
</tr>
<tr>
<td>#pcsm</td>
<td>Pancreatic cancer</td>
</tr>
<tr>
<td>#pcdm</td>
<td>Pediatric cancer</td>
</tr>
<tr>
<td>#scsm</td>
<td>Sarcoma</td>
</tr>
<tr>
<td>#stcm</td>
<td>Stomach cancer</td>
</tr>
<tr>
<td>#thcm</td>
<td>Thymoma &amp; thymic carcinoma</td>
</tr>
<tr>
<td>#tscm</td>
<td>Thyroid cancer</td>
</tr>
<tr>
<td>#lscsm</td>
<td>Testicular cancer</td>
</tr>
</tbody>
</table>

Figure. Quarterly Tweets Using the Cancer Tag Ontology, July 2011 Through June 2015
The study is needed to determine whether the CTO can improve health literacy or other meaningful outcomes.

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Correction: This article was corrected on December 23, 2015, to fix an author’s affiliation name.


COMMENT & RESPONSE

Pathologic Abnormalities Behind Ductal Carcinoma In Situ Terminology

To the Editor

Esserman and Yau1 make important points about the therapeutic approach to the lesions currently labeled by pathologists as ductal carcinoma in situ (DCIS), but even these experts might be confused about the nature of the actual pathologic abnormalities shrouded behind the DCIS terminology. As the authors know, the term cancer has traditionally been applied to breast lesions that invade, metastasize, or have the high-grade cytological features associated with clinically overt cancers. Pathologists do encounter a type of DCIS that shows strikingly malignant cytological features, but increased identification of these lesions (also referred to as comedo intraductal carcinoma) is not the only explanation for the DCIS epidemic. In fact, a substantial portion of the epidemic is due to a completely different lesion that lacks all 3 of these classic malignant features. In these latter cases, pathologists abandoned the classic morphological cancer definition that was tightly linked to behavior familiar to patients and clinicians and began diagnosing large numbers of low-grade mammographically detected intraductal breast abnormalities as cancer. These latter diagnoses were based on a long list of difficult-to-agree-on cytological and architectural features.2

For a number of reasons, pathologists accepted these criteria as sufficient to justify the term cancer. Prominent among these reasons was the high rate of subsequent invasive breast cancer demonstrated in a small but influential long-term observational study of a cohort of such patients.2,3 However, when the alarming follow-up results of that premammography cohort were used in clinical decision making for more modern patient populations, epidemiologists had difficulty identifying the anticipated clinical benefits of the often aggressive therapy designed to prevent invasive disease. Like medications that are highly successful in small studies and then fail in larger studies, this small pathology study’s finding did not “scale up” for use in routine clinical practice. Unfortunately, we now know that the study simply proved that it was risky to be one of the 28 patients in that particular study. It is now apparent that applying malignant terminology to low-grade intraductal lesions has been a specialty-wide pathologic diagnostic error.4,5 However, pathology is like clinical medicine in that deeply entrenched practices are difficult to uproot.

Currently, when both patients and their doctors are faced with a “black-letter” diagnosis of “breast cancer (DCIS subtype),” they often reflexively enter “breast cancer” into their informal risk prediction models. This understandable response can have an inappropriate impact on the patient’s emotional well-being, the therapy she is offered, and the therapy chosen.

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