Social media (SM) has emerged as a powerful tool for patients with brain tumor (BT) and their healthcare providers. Patients increasingly use SM to join online peer-based communities, share their experiences, and seek information pertaining to their diagnosis and treatment.1–4 However, public access to high-quality, evidence-based information on SM networks is an area of concern.5–7 Accessibility could be improved with increased SM presence and optimal utilization by medical professionals.7 Given the academic nature of neurooncology and lack of high-quality online information pertaining to this field,3,6 personal and institutional effort is imperative to increasing public accessibility to evidence-based information.1,7,8

The benefits of a professional SM presence by medical professionals is a growing field of study. SM platforms, such as Facebook with 2.5 billion users and Twitter...
with 386 million users,\textsuperscript{9} provide efficient “one to many” communication channels and allow for recruitment and maintenance of patient engagement with providers.\textsuperscript{3,10–13} Furthermore, SM presence is positively correlated with patient referrals and academic impact.\textsuperscript{13–15} Thus, optimal utilization of SM platforms by medical professionals can have a positive impact on all stakeholders in the BT community.

The nuances of how to optimally use each SM platform, including appropriateness of content, are not immediately apparent to most medical professionals. This potentially creates a disconnect between individuals with BT and their care partners, thereby diminishing the potential of each platform. Previous studies have used cross-platform thematic analysis to study SM utilization by stakeholders and to formulate guidelines for optimal use of each platform.\textsuperscript{16–19} By implementing a similar approach, this is the first qualitative and quantitative study to evaluate cross-platform SM utilization by BT stakeholders in order to develop evidence-based, platform-specific guidelines for medical professionals.

**Methods**

**Platform Selection and Search Strategy**

The interest levels of a set of BT terms were compared by using Google Trends\textsuperscript{20} on June 3, 2020. Interest levels were determined according to Google’s search volume and was given a score of 0 to 100. Increased search volume translated to a higher interest level. A 16-year period was selected for this evaluation, and the term “Brain Tumor” had the highest interest level between January 2004 and June 2020 (Fig. 1). There were two notable spikes in the search volume for BT, as presented in Fig. 1, that appear to have occurred after two major news stories. The first spike occurred in May 2008, when Ted Kennedy was diagnosed with glioblastoma. The second spike occurred in July 2017, after John McCain’s brain surgery and his later diagnosis with glioblastoma.

Facebook, Twitter, and YouTube are the most commonly studied SM platforms and were selected for this study.\textsuperscript{8,18,19,21,22} We queried these platforms by using the term “Brain Tumor” on June 3, 2020. The search was conducted with a clean browser history and a virtual private network (VPN) set to New York City in order to minimize the impact of previous online behavior on the search results. Filters on each platform were used to return Facebook pages, publicly accessible Twitter users, and YouTube videos. Data in a preliminary database containing the results pages of the search engine were extracted and imported into a Microsoft Excel spreadsheet.

**Data Extraction**

For each Facebook page, the title, username, description, presence of other SM platforms, number of likes, and geographical location were collected. A 5-month retrospective analysis of previous posting behavior was conducted for this evaluation, and the term “Brain Tumor” had the highest interest level between January 2004 and June 2020 (Fig. 1). There were two notable spikes in the search volume for BT, as presented in Fig. 1, that appear to have occurred after two major news stories. The first spike occurred in May 2008, when Ted Kennedy was diagnosed with glioblastoma. The second spike occurred in July 2017, after John McCain’s brain surgery and his later diagnosis with glioblastoma.
to the joined date of the Facebook page or Twitter account or the published date of the YouTube video. Total video interactions, representing engagement, were identified by summing each video’s likes, dislikes, and comments. A 12-month retrospective analysis was conducted on June 3, 2020. Data were collected by one reviewer (N.H.) and independently confirmed by a second reviewer (B.K.).

Eligibility Criteria
The extracted data set was screened for Facebook pages with more than 500 likes, YouTube videos with average annual views of 5000 or more, and Twitter accounts with frequent BT postings (more than 7 of 10 tweets related to BT at any given time). Posts that were not in English were excluded from the study. To account for disparities between the numbers of users on each platform (2.3 billion on Facebook, 1.3 billion on YouTube, and 380 million on Twitter9), findings are presented as numerical values and percentages.

Personal profiles on Facebook are private and were excluded from this study. Facebook pages and groups allow users to join online communities and follow entities of interest, and there is overlap in how people use these two features of Facebook. A Facebook page often serves as the professional SM face of a public figure or an organization, whereas Facebook groups organize users around a topic or theme of interest. Although all Facebook pages are publicly accessible, groups can be open (public) or closed (private). We observed a large number of private BT groups with an above-average audience size (Supplemental Table 1). This observation led us to exclude Facebook groups from this study, because including only publicly accessible groups would not have been a good representation of this category.

Qualitative and Thematic Analysis
YouTube videos, Facebook pages, and Twitter accounts were evaluated by two independent reviewers (N.H. and B.K.). Videos on YouTube were watched, and the 50 most recent posts on Facebook and Twitter were screened; saturation is typically reached in such analyses with this amount of data.18,19 The aforementioned entities were categorized into mutually exclusive groups of stakeholders on the basis of apparent ownership. Public figures, such as medical professionals and organizations, were previously identified as SM stakeholders.16 Apparent ownership was identified by using information on the Facebook page and the biography associated with the Twitter account, along with the descriptions of the YouTube videos. After considering previously identified qualitative themes pertaining to neurooncology,6,19 the first author (N.H.) identified qualitative themes during the initial screening of the data, and these were confirmed by the second author (B.K.). As many as two themes were assigned to each Facebook page, YouTube video, and Twitter account.

Quantitative Analysis
The mean audience size on each platform was calculated for each theme. Audience size was determined by the number of Facebook page likes, Twitter account followers, and YouTube video views and was used as a metric to determine popularity. The top qualitative themes were those that were the most popular on each platform. As a measure of performance, the mean annual increase in audience size was calculated by dividing the audience size of each entity by the number of active years. Linear models were built, and correlation was assessed with the Pearson’s test to identify factors that contributed to increased popularity and performance on Facebook, Twitter, and YouTube. A p value < 0.05 was set as the significance threshold.

Results
Sixty-seven Facebook pages (total [mean] audience size 304,581 [4546] likes), 25 Twitter accounts (total [mean] audience size 69,283 [2731] followers), and 128 YouTube videos (total [mean] audience size 43.3 million [337,989.4] views) met our inclusion criteria. Audience sizes greater than 4546 likes on Facebook, 2731 followers on Twitter, and 337,989.4 views on YouTube were considered above average in our sample. Facebook pages with 10,000 likes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity &amp; fundraising</td>
<td>Providing donation &amp; fundraising opportunities</td>
<td>“...the year since our charity was founded, we’ve raised nearly $100,000, and have served...”</td>
</tr>
<tr>
<td>Education &amp; research</td>
<td>Promoting a study, presenting research, or providing educational content</td>
<td>“...Neuro-oncologist Dr. E— shares the signs and symptoms of a brain tumor...”</td>
</tr>
<tr>
<td>Experience &amp; support</td>
<td>Sharing personal experiences &amp; seeking nonmonetary online support</td>
<td>“...onto UCSF to get my MRI. Again, breathtaking to see my MRI was looking better, way better...”</td>
</tr>
<tr>
<td>Practice promotion</td>
<td>Promoting clinical practice</td>
<td>“...What Makes Dr. G—the Best Spine Surgeon in Delhi?...”</td>
</tr>
<tr>
<td>Event promotion</td>
<td>Promoting awareness or fundraising for annual events</td>
<td>“...volunteers and participants who come out each year and to see that commitment shared...”</td>
</tr>
<tr>
<td>Procedural</td>
<td>Showcasing neurosurgery procedures related to BT</td>
<td>“...patient presents with...”</td>
</tr>
<tr>
<td>Alternative medicine</td>
<td>Promoting unconventional treatments, including use of cannabis for healing &amp; in religious rituals</td>
<td>“...This little boy was sent home to die of his brain tumor, after doctors could not do anything else to help him. But Jesus took his case and healed him in less than 3 weeks...”</td>
</tr>
</tbody>
</table>

UFC = University of California, San Francisco.
or more (8 of 68 pages) belonged to entities that had a prominent presence on other SM platforms, such as Twitter, YouTube, and Instagram.

Persons, organizations, and medical professionals were identified as our stakeholders. Organizations in our sample included journals and for-profit and nonprofit organizations. In this study, physicians (those with an MD or DO degree) were considered medical professionals; other individuals, including researchers and other health-care professionals, were considered persons with personal accounts. Seven major themes emerged in our qualitative analysis. Definitions of themes and examples (Table 1), platform-specific prevalence rates (Table 2), and associated audience sizes (Table 3) are presented. Each account was assigned as many as two qualitative themes. “Charity & fundraising” was assigned to content that provided the user with the opportunity to make monetary contributions to an organization or patient, either directly or indirectly, through the sale of merchandise. Educational content for patients and medical professionals, along with research promotion and news, was coded as “research and education.” “Experience sharing,” which consisted of posts or videos in which patients shared their experiences, and “support seeking,” which consisted of patients who were looking for nonmonetary support such as advice on a course of treatment or prayers from their online peers, were common themes on all three platforms; these were combined and coded as “experience and support.” “Practice promotion” consisted of content related to the promotion of hospitals, clinics, and private practices, and “alternative medicine” consisted of content promoting unconventional approaches to the treatment of BT; both were also observed across platforms. “Event promotion” of an annual event was only observed on Facebook. “Procedural” themes consisted of videos related to surgical management of tumors and were only observed on YouTube.

### Facebook

BT societies and organizations accounted for the majority of the Facebook pages (43 of 67 pages [64%]), 212,017 of 304,581 [71%] likes), and charity and fundraising was the prominent theme on Facebook (228,122 [75%] likes). This theme was prominently embedded in awareness campaigns. Although equal numbers of pages included themes such as education and research and experience and support (33 of 67 pages [49%] for both themes), our data showed that these themes had low popularity among Facebook users, as represented by audience size (38,307 [13%] and 57,469 [19%] of 304,581 likes, respectively). However, findings may differ in private Facebook groups that were not included in our study.

Ten of the 11 most popular (more than 5000 likes) Facebook pages had a unique username (www.fb.com/username). Multiplatform SM presence was correlated with increased popularity (rho = 0.61) and performance (rho = 0.59) (p < 0.05). The average (range) number of posts per month on these pages was 19.5 (2.6–42.8). Average monthly activity and length of activity did not significantly impact popularity (rho = 0.16) and performance (rho = 0.15) (p > 0.05). Media utilization was a common practice for 54 of 68 (79%) pages on Facebook. Pages with the greatest popularity (more than 10,000 likes) linked nearly all their posts to their website or an appropriate external uniform resource locator (URL).

### Twitter

Organizational (13 of 25 accounts; 31,313 followers) and personal (11 of 25 accounts; 68,283 followers) accounts had relatively equal levels of presence and popularity on Twitter. Education and research was identified as the top theme on Twitter. This theme was prominent on 18 of 25 (72%) accounts and attracted 25,232 of 68,283 (37%) followers. In contrast to Facebook, Twitter’s average monthly activity was strongly correlated with popularity (rho = 0.66) and performance (rho = 0.64) (p < 0.05). More importantly, media utilization had a strong impact on popularity (rho = 0.78) and performance (rho = 0.71) (p < 0.05). Although length of activity on Twitter was not related to performance, it had a moderate relationship with popularity (rho = 0.44, p < 0.05).

### Table 2. Platform-specific prevalence rates of the qualitative themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Facebook (n = 67)</th>
<th>Twitter (n = 128)</th>
<th>YouTube (n = 25)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity &amp; fundraising</td>
<td>45 (67)</td>
<td>11 (44)</td>
<td>4 (3)</td>
</tr>
<tr>
<td>Education &amp; research</td>
<td>33 (49)</td>
<td>18 (72)</td>
<td>59 (46)</td>
</tr>
<tr>
<td>Experience &amp; support</td>
<td>33 (49)</td>
<td>18 (72)</td>
<td>62 (48)</td>
</tr>
<tr>
<td>Practice promotion</td>
<td>2 (3)</td>
<td>0 (0)</td>
<td>10 (8)</td>
</tr>
<tr>
<td>Event promotion</td>
<td>6 (9)</td>
<td>2 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Procedural</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>19 (15)</td>
</tr>
<tr>
<td>Alternative medicine</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>7 (5)</td>
</tr>
</tbody>
</table>

### Table 3. Platform-specific audience sizes of the qualitative themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Facebook (n = 304,581)</th>
<th>Twitter (n = 68,283)</th>
<th>YouTube (n = 43,262,641)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity &amp; fundraising</td>
<td>228,122 (75%)</td>
<td>26,513 (39)</td>
<td>2,372,003 (5)</td>
</tr>
<tr>
<td>Education &amp; research</td>
<td>38,307 (13)</td>
<td>25,233 (37)</td>
<td>8,834,675 (19)</td>
</tr>
<tr>
<td>Experience &amp; support</td>
<td>57,470 (19)</td>
<td>20,030 (29)</td>
<td>26,287,213 (61)</td>
</tr>
<tr>
<td>Practice promotion</td>
<td>21,869 (7)</td>
<td>0 (0)</td>
<td>134,021 (0.3)</td>
</tr>
<tr>
<td>Event promotion</td>
<td>2,185 (1)</td>
<td>1,283 (2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Procedural</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>6,017,015 (14)</td>
</tr>
<tr>
<td>Alternative medicine</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>360,000 (0.8)</td>
</tr>
</tbody>
</table>

All values are shown as number (percentage). Audience size was measured according to the total number of likes (Facebook), number of followers (Twitter), and number of views (YouTube) associated with each theme and was considered a representation of the popularity of each theme on each platform. Qualitative themes were assigned nonexclusively, and thus some percentages may not sum to 100%.
YouTube

Organizations accounted for half the reviewed videos (64 of 128 [50%]) but were significantly less popular (12 million [27%] views) than personal videos (26.7 million [61%] views). The education and research (59 of 128 [46%] videos) and experience and support (62 of 128 [48%] videos) themes had equal presence on YouTube, but experience and support was significantly more popular on YouTube. This theme accounted for 26.3 million (60%) views and 1.5 million (82%) interactions. Total video interactions (comments, likes, and dislikes) by theme are presented in Fig. 2.

We found a number of videos dedicated to the demonstration of neurosurgical procedures; this finding was unique to YouTube. This theme was assigned to 19 of 128 (15%) videos and accounted for 6 million (14%) views and 109,448 (23%) comments. These levels of popularity and engagement are considered good despite the 15% prevalence rate of the procedural theme on YouTube. These videos were posted before our qualitative analysis of Facebook and Twitter, and thus they were not included in our sample posts. Only one account had a concurrent presence on Facebook and Twitter. Nine of 19 videos were published by one YouTube account.

Discussion

The increase in the popularity and ease of access to SM platforms has encouraged patients and care partners to use such entities as a source of information, to share their stories, to ask questions, and to expand their circle of support.1-3,21 Beyond the utility of such platforms for delivering patient-centered care, recent studies suggest a link between SM presence and increased readership of publications and referral volume.13-15,23 The influence of SM, along with its utility for public education and patient empowerment,24 makes SM an important communication channel for medical professionals.

The principal findings of this study are the identified themes and their popularity levels across SM platforms (Tables 2 and 3). Producing content with the appropriate theme for each platform may help better connect BT stakeholders on SM. Furthermore, the findings of qualitative and quantitative analyses of current SM use by different BT stakeholders have been used to develop general and platform-specific guidelines that medical professionals can use to better connect with their respective communities.

SM platforms differ in how they present content. For example, YouTube is a video-sharing platform, whereas Facebook and Twitter allow diverse content presentations in the forms of plain text, external URLs, images, and short videos. Multiplatform SM utilization, defined as using two or more platforms, has previously been studied.1 We observed that entities that utilized two or more platforms were the most popular on Facebook. Multiplatform SM presence exposes such entities to a larger potential audience pool and leads to more recruitment opportunities.

In our qualitative analysis of themes and variables, we identified platform-specific factors and practices that may
increase popularity and performance. Similar to previous studies on SM utilization by stakeholders in the prostate cancer and epilepsy communities, we found that the themes associated with BT differ in popularity and demand across SM platforms. Creative approaches to producing content with embedded themes that are popular and in high demand on specific platforms may increase popularity and performance. By combining our findings with those in the current literature, we outline our recommendations for optimal SM utilization below.

General Recommendations

Previous guidelines regarding SM utilization by medical professionals typically addressed security and privacy concerns. To move the professional doctor-patient relationship online, personal and professional accounts should be separate and efforts must be made to prevent patients from accessing personal profiles. To adhere to these recommendations, we suggest medical professionals use a professional Facebook page to promote their professional practice and to reduce the visibility of their personal Facebook profile (Fig. 3). On Twitter, users commonly provide a link to their professional Twitter account to redirect traffic and to keep their personal account private.

In our qualitative analysis, the most popular content centered around patient experience across all platforms. Mindfulness of the targeted audience and their expectations is highly recommended when generating content. Kotsenas et al. suggested delivering content in a “bite size” manner and with easy-to-understand terminology. We observed similar practices on Facebook and Twitter, and Bitly was used to provide external links with more information. Bitly, which shortens URLs and tracks engagement, was used more often on Twitter because each tweet has a character limit. Given the significant correlation of media utilization with audience size in our study, utilization of appropriate images and videos may significantly enhance content.

The hashtag is a type of SM metadata tag that allows organization of user-generated content. It can also be used as a live communication channel on Twitter or used simultaneously with other platforms, such as YouTube Live, to run webinars. In healthcare, hashtags are used to start or join conversations about healthcare themes, topics, or shared experiences. Naturally, embedding hashtags into a post can increase searchability and better connect BT stakeholders.

Facebook

We found that organizations were the most popular on Facebook, similar to the findings of a previous study. They accounted for 67% of Facebook pages and 71% of likes. This may largely be due to the diversity of features on Facebook. As observed in our sample, Facebook can be utilized to organize events and fundraising campaigns and to provide information to users. Given the prominence and popularity of the charity and fundraising theme (67% of pages and 75% of likes), Facebook offers a strong, low-cost method for creating virtual fundraising campaigns.

One of 67 pages in our Facebook sample belonged to a medical professional. This page ranked as number 8 in terms of overall popularity, with an audience size of 17,169 likes (6%). This suggests a potential underrepresentation and demand for medical professionals’ pages on Facebook.

Twitter

Organizational (52%) and personal (44%) accounts had relatively equal presence on Twitter. Moreover, the relatively equal levels of popularity among themes on Twitter (39% of followers were engaged with the charity and fundraising theme vs 37% with education and research vs 29% with experience and support) makes this an optimal platform for creating content with diverse themes.

Our analysis reinforced the importance of consistent and frequent posts on Twitter, as explored in previous studies. Linzey et al. recommend daily Twitter activity and weekly content generation. In our study, Twitter accounts with 1000 or more followers (15 of 26 accounts) had an average (range) of 75 (7–469) tweets or retweets per month. Tweets posted on weekends or after work hours generally produce the highest levels of engagement (retweets, likes, and comments).

Frequency of activity can be optimized by exploring and engaging with conversations that are trending.
or happening in real-time, or by using relevant hashtags. Medical professionals and their expertise can add significant value to such conversations, and public engagement in these conversations is key to the dissemination of evidence-based information. Companies such as symplur track healthcare-related hashtags and can provide medical professionals with the most popular hashtags used in their field. Finally, given the significant correlation between media utilization and audience size, we recommend extensive utilization of hashtags and media when creating content pertaining to BT on Twitter.

YouTube

The experience and support theme had the highest levels of popularity (76% of audience size) and engagement (76% of likes, dislikes, and comments) on YouTube. This suggests a significant demand for patient experiences and stories on YouTube. Organizations and medical professionals can use the experiences of their patients to better connect with their respective audiences and help disseminate evidence-based information. This can be in the form of tying clinical advancements to a patient’s success story, such as the video titled, “Brain Tumor Treatment | Advances Over 10 Years: Carlos Luceno’s Story.”

Our qualitative analysis suggests that popular YouTube content can be produced at a low cost. With only one exception, all the top videos (> 1 million views or annual increase of > 500,000 views) in our study were all created as vlogs. Vlogs are produced by one person with a handheld camera or phone. The effectiveness of such videos on YouTube is not related to their high production value, but instead due to the relatability and delivery of content in an emotionally impactful manner.

Study Limitations

Only publicly accessible content in English was collected and included in this study. Facebook groups, personal Facebook pages, and private Twitter accounts were excluded. Analysis of public BT groups would not have been representative of this category, and thus we limited our study of Facebook to its pages. The study was limited to SM platforms that have identifiable user information and have been commonly studied. Blogs and other platforms, such as Instagram, were excluded. Search criteria were based on web popularity and thus limited to the term “Brain Tumor.” New SM platforms, such as Instagram and TikTok, have emerged and can quickly gain popularity among the BT community. Inclusion of such platforms and evaluation of tumor-specific terms, such as diffuse intrinsic pontine glioma or glioblastoma, could be used in future studies to evaluate utilization of these newly emerging SM platforms and subpopulations of users.

This study did not find extensive incidents of self-promotion by medical professionals. However, guidelines regarding ethical utilization of SM and quality posting should be presented to better help medical professionals navigate these popular SM platforms.

The search results provided by Facebook, Twitter, and YouTube are affected by the user’s location and prior online behavior. The degree that these factors affect search results is unique and not disclosed because these platforms compete to build more personalized search experiences for their users. In an attempt to minimize the effect of the previous online behavior of our investigators on our search results, the search was conducted with a cleared browser history, cache, and cookies, as well as with a VPN. The VPN provided secure access to the internet while shielding the investigator’s location. The results may have been affected by these factors.

Despite these limitations, this is the first study of its kind to evaluate multiphase SM utilization by different BT stakeholders in order to develop platform-specific guidelines for the optimization of SM content pertaining to BT.

Conclusions

The importance of SM in connecting medical professionals to their patient communities cannot be underestimated. In our qualitative and quantitative analysis of themes and variables, we found that concurrent SM presence and media utilization, along with awareness of popular themes on each platform, may increase popularity and performance. We observed that themes differ in popularity and demand across SM platforms, and we recommend that medical professionals be mindful of such differences when generating content. Content centered on patients and their experiences was the most popular across all SM platforms.

References


Disclosures
Dr. Zacharia is a consultant for Medtronic Inc. and serves on the speakers bureau of Nico Corp.

Author Contributions
Conception and design: Mansouri, Hamidi. Acquisition of data: Hamidi, Karmur, Sperrazza, Alexieva. Analysis and interpretation of data: Hamidi, Karmur. Drafting the article: Hamidi. Critically revising the article: Mansouri, Hamidi, Karmur, Sperrazza, Alexieva, Salmi. Reviewed submitted version of manuscript: all authors. Statistical analysis: Hamidi, Karmur. Study supervision: Mansouri.

Supplemental Information
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