JOURNAL OF PALLIATIVE MEDICINE
Volume 23, Number 1, 2020
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2019.0077

"It Makes People Uneasy, but It's Necessary. #BTSM": Using Twitter to Explore Advance Care Planning among Brain Tumor Stakeholders

Nathan R. Cutshall, BA,[1] Bethany M. Kwan, PhD, MSPH,[2] Liz Salmi,[3,4] and Hillary D. Lum, MD, PhD[5,6]

Downloaded by University of Colorado at Denver-Auraria from www.liebertpub.com at 10/05/21. For personal use only.

Abstract

Background: Advance care planning (ACP) often occurs too late in the disease course of those who are affected by brain tumors. Furthermore, the perspectives of brain tumor stakeholders on ACP are not well described. We reviewed a social media tweet chat to understand barriers to ACP experienced by brain tumor stakeholders.
Methods: We used qualitative methods to analyze a tweet chat (real-time virtual discussion) of brain tumor stakeholders. The one-hour tweet chat was hosted by Brain Tumor Social Media chat (@BTSMchat), a patient-run Twitter community, in January 2018. Participants reflected on four questions about ACP by including the hashtag ''#BTSM'' in tweets. Unique tweets and stakeholder type (i.e., patient, caregiver, advocate or organization member, clinician or researcher, or @BTSMchat leader) were coded. The tweet chat was qualitatively analyzed to identify key themes.
Results: A total of 52 participants from four countries contributed 336 tweets. Most participants were patients (people with brain tumors), followed by clinicians or researchers, and advocates or organizations. Three key themes emerged regarding brain tumor stakeholder perspectives about ACP: (1) attitudinal barriers prevent discussions of death; (2) need to ensure one's voice is heard; and (3) Goldilock's approach to timing—fearing ACP is too early or too late.
Conclusions: Various stakeholders, including people with brain tumors, shared perspectives on ACP through a tweet chat and highlighted important challenges and opportunities. Twitter is a new avenue for patients, clinicians, and advocates to engage with each other to better understand each other's perspectives related to ACP.

Keywords: advance care planning; brain cancer; social media; stakeholder engagement; twitter

Introduction

Social media is a dynamic frontier where patients and other stakeholders form communities, exchange information, share stories, and organize for support and advocacy.[1–3] Existing social media platforms can engage stakeholders in the care and experiences of people affected by brain tumors, including the Twitter community's Brain Tumor Social Media (BTSM), a patient-run Twitter community with dedicated organizers. BTSM convenes monthly live discussions on Twitter, called tweet chats, in which Twitter users can participate by including ''#BTSM'' in tweets. Tweet chats range in purpose from discussion of specific topics, such as sharing perspectives on health care and the experience of living with a brain tumor, to disseminating information or resources. One topic covered by the BTSM community in January 2018 was advance care planning (ACP).

ACP is associated with improved quality of life at the end of life, less aggressive medical cares, and improved satisfaction with care.[4] Studies among persons with brain tumors have highlighted the need for earlier communication about ACP and care preferences.[5,6] ACP may be challenging in patients with brain tumors due to high symptom burden and rapid or unpredictable cognitive decline.[7,8] Social media has

[1]University of Colorado School of Medicine, Aurora, Colorado.
[2]Department of Family Medicine, University of Colorado School of Medicine, Aurora, Colorado.
[3]OpenNotes, Beth Israel Deaconess Medical Center, Boston, Massachusetts.
[4]Brain Cancer Quality of Life Collaborative, Aurora, Colorado.
[5]Division of Geriatric Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora, Colorado.
[6]VA Eastern Colorado Geriatric Research Education and Clinical Center, Aurora, Colorado.
Accepted May 8, 2019.

Downloaded by University of Colorado at Denver-Auraria from www.liebertpub.com at 10/05/21. For personal use only.

been utilized by patients with serious illnesses for community building, digital legacy, or illness narrative formation, as well as by clinicians and researchers to identify stakeholder perspectives in various oncological fields.[3,9,10] We analyzed a BTSM tweet chat of brain tumor stakeholders related to perceived barriers to ACP conversations.

Methods

Context

The @BTSMchat organization consists of five patients and one caregiver. As a group, they sponsor monthly tweet chats with one of the organizers designated as the #BTSM leader for the tweet chat. @BTSMchat hosted a tweet chat (Sunday, January 7, 2018) about ACP among brain tumor stakeholders. The BTSM tweet chat leader introduced four questions for one hour: (1) Why might people, regardless of health status, want to have an ACP conversation with their loved ones? (2) What do you think prevents people from having ACP conversations and creating an advance directive? (3) Have you had an ACP conversation with your loved ones? Why or why not? (4) What qualities do YOU look for in choosing someone to be your medical decision maker/health care proxy? Followers of #BTSM engaged in a live discussion, answering each question, and responding to each other's tweets. After the tweet chat, with support from the @BTSMchat organization, the authors downloaded the publicly available tweet chat transcript and conducted a qualitative descriptive analysis. The project was determined to be Not Human Subjects Research by the Colorado Multiple Institutional Review Board. Content in a public tweet chat is accessible. This analysis, although not research, most closely resembles a retrospective qualitative analysis of observed behaviors based on existing documentation.

The chat was voluntary, accessible, open, and available to any Twitter user. Participants were Twitter users who joined the tweet chat by including ''#BTSM'' in tweets during the scheduled time (6–7 PM Pacific Standard Time). The authors identified participants' stakeholder types based on their public Twitter profile or self-identification during the chat. Categories included patient, caregiver, advocate or organization member, clinical provider or researcher, @BTSMchat tweet chat leader, and unknown. Participants contributed their own thoughts to the discussion, called a unique tweet, or they could repost what another participant had written, which is known as a ''retweet.'' There were 11 participants who were unable to be categorized based on their Twitter profile or tweet chat participation. The tweets (5) and retweets (11) from these 11 individuals were excluded from analysis.

Data analysis

We used qualitative approaches because our primary goal was to seek an understanding of a particular phenomenon from the perspective of those experiencing it (e.g., Brain Tumor Stakeholder Twitter community). The analysis focused on unique tweets rather than retweets. Using thematic analysis methods,[11] two authors inductively and deductively developed a codebook of 22 codes to identify meaningful or common ideas (online Supplementary Appendix A1). They then independently coded unique tweets and met multiple times to identify key themes.

Results

There were 52 tweet chat participants, including 21 patients, 5 caregivers, 12 advocates or organizational members, and 14 clinicians or researchers. Table 1 shows the gender, country of origin, and number of tweets from each stakeholder category, including the BTSM tweet chat leader. Brain tumor type and disease status were infrequently reported. Multiple types of brain tumors were represented (glioblastoma, astrocytoma, meningioma, ependymoma, and ganglioma), as well as a few participants with other forms of cancer. Participants generated 536 tweets, including 336 (63%) unique tweets and 200 retweets. Most unique tweets were from patients, followed by advocates and organization members.

Three key themes emerged from brain tumor stakeholders relating to ACP. Table 2 highlights quotes from the tweet chat relating to each theme.

Theme 1: Attitudinal barriers prevent discussions of death

Attitudinal barriers to discussing death and dying were described by multiple stakeholders and identified as significant obstacles to ACP. Stakeholders recognized seemingly pervasive discomfort in discussing death and dying. They also shared a belief that death and dying is only relevant to those who are old or unhealthy. To reduce the impact of these beliefs on death and dying as barriers to ACP, stakeholders discussed the need to normalize mortality and ACP conversations. For example, as noted in the title quotation: ''(ACP) makes people uneasy, but it's necessary. #BTSM.''

Table 1. Description of Participants and Number of Tweets by Stakeholder Category

Characteristics[a]	n *(%)*	*Unique Tweet* (n)	*Retweet* (n)	*Total*
Stakeholder type				
Patient[b]	21 (33)	141	73	216
Tweet chat leader		45	13	58
Caregiver	5 (7.9)	32	33	65
Clinical provider or researcher[c]	14 (22)	20	13	33
Advocate or organization	12 (19)	98	68	166
Unknown	11 (17)	5	11	16
		336 (63%)	200 (37%)	536
Gender				
Female	30 (48)			
Male	16 (25)			
Unknown	17 (27)			
Geography				
Australia	3 (4.8)			
Canada	2 (3.1)			
New Zealand	2 (3.1)			
United States	41 (65)			
Unknown	15 (24)			

[a]Characteristics based on self-description during tweet chat or public Twitter profile.
[b]Includes BTSM tweet chat leader.
[c]Medical specialties or disciplines included oncology, hospice and palliative medicine, neurosurgery, and pharmacy.
BTSM, Brain Tumor Social Media.

Table 2. Themes with Examples of Stakeholder Tweets

Themes	*Stakeholder tweets*
Theme 1: Attitudinal barriers to discussing death	''I tried to bring up advance care planning with an oncologist and they told me I was too healthy and didn't need to worry about it. OMG.'' (#BTSM Leader) ''Seems it is socially taboo to talk about death. There are also cultural & spiritual traditions or beliefs that may hinder the conversation. Fear. Lack of awareness of how the conversation should be started.'' (Advocate) ''One issue caregivers have is raising the issue of AD at or near time of diagnosis. We have a problem across all cancers of patients not discussing AD early because it implies 'not fighting'. Thoughts from the community?'' (Clinician)
Theme 2: Need to ensure one's voice is heard	''I talked with hubby and sister about what's life means to me, what losses I would tolerate, when I'll be ready to go.'' (Patient) ''When that moment arrives, often the 'clear head' scenario you would like to have had, is engulfed with emotion and other challenges. Planning ahead allows a more objective view.'' (Patient)
Theme 3: Goldilock's approach to timing	''By the time I could [have ACP], he had so many cognitive difficulties. Very fast progression. If I could change one thing, I'd have wanted to talk about it more, so I didn't wonder where he would stand on my life going forward once he was gone.'' (Advocate, Caregiver) ''My experience is that patients are reluctant to discuss AD when they are 1st learning of their disease, difficult information about prognosis & need for neurosurgical intervention. Difficult to discuss AD when we are educating patient regarding disease and how to fight.'' (Clinician) ''I'd guess fear that talking about it makes it more 'real' while you are still trying to get an initial grasp on the fact that you may be needing it shortly.'' (Patient)

ACP, advance care planning; AD, advance directive.

Downloaded by University of Colorado at Denver-Auraria from www.liebertpub.com at 10/05/21. For personal use only.

Theme 2: Need to ensure one's voice is heard

The concepts of autonomy, agency, and control were important throughout the tweet chat. Expressing preferences to decision makers and loved ones relieved stakeholders of uncertainty and allowed patients to preserve autonomy and choose their course of care after they were unable to express themselves. Stakeholders shared that ACP helped to decrease confusion and emotional decision making, especially in emergency situations, and allowed for more objective decision making based on previous discussions. ACP aided loved ones in focusing on the person who is dying, rather than struggling to make decisions to which they may or may not know the answers. Stakeholders discussed the importance of objectivity in preserving the patient's voice to avoid allowing the decision maker's emotions and beliefs to impact decisions.

Theme 3: Goldilock's approach to timing—fearing ACP is too early or too late

The concept of ''Goldilock's approach to timing'' was demonstrated by stakeholders' descriptions of lacking a time that was ''just right'' for ACP discussions. In the tweet chat, physician stakeholders discussed difficulties of having ACP conversations too early in the diagnosis, and other stakeholders viewed early ACP as the physician ''giving up'' on the patient. Alternatively, caregivers stated how they sometimes waited too long to have ACP conversations, and by the time they realized the need for conversations, their loved ones had already cognitively declined past the ability to discuss their preferences. Some patient stakeholders stated that talking about ACP made it more ''real'' and that engaging in such discussions felt as though they were giving up.

Discussion

A diverse and international group of brain tumor stakeholders engaged in ACP discussions with a range of knowledge and comfort. The interactive virtual discussion highlighted attitudes and knowledge gaps that stakeholders must overcome to have ACP discussions. Brain tumor stakeholders identified challenges and suggestions for how clinicians can better meet the ACP needs of patients and caregivers.

Tweet chats are an accessible format in which people from different backgrounds, areas of expertise, viewpoints, and geographic locations can engage in discussions with each other about their experiences. As such, tweet chats may be an innovative virtual platform for stakeholder engagement in research. Tweet chats may represent a novel form of a focus group, creating a setting where individuals can share perspectives on topics such as ACP, death, and dying. Social media permits users a free and egalitarian digital voice in which power dynamics, which may exist during in-person interactions, are potentially restructured. Given that many social media-based advocacy communities already exist, researchers can develop partnerships to answer questions that are meaningful to stakeholders from broad geographic regions. Importantly, use of virtual forums for research studies should appropriately inform potential participants of the nature and process of participating in research.

Our analysis has specific limitations. First, the attitudinal barriers identified are potentially specific to Western culture and the culture of Western biomedicine, thus limiting the generalizability to those of similar backgrounds as the participants. Second, the stakeholders were not specifically recruited as in a research study and those who participated are limited to those who use social media and know about the BTSM Twitter community. Finally, we have limited demographic information and cannot determine if certain populations are under- or over-represented.

In conclusion, we described brain tumor stakeholder perspectives on ACP as shared during an organized tweet chat hosted by a brain tumor stakeholder organization. Next steps include research to determine how brain tumor stakeholders approach ACP discussions before and after utilizing social media as a resource, including whether ACP engagement (e.g., advance directive completion) increases outside of the digital space for participants. A stakeholder-engaged research tweet chat could also focus on crowdsourcing ways to improve ACP discussions in clinical settings.

Acknowledgments

We thank the Brain Tumor Social Media (BTSM) community and all of the brain tumor patients, family members, and advocates for engaging with this important topic. We extend special thanks to the organizers of the @BTSMchat tweet chat who helped to ensure that the facilitator questions were open ended and reviewed this article for accuracy: Charlie Blotner, Adam Hayden, MA, Lisa O'Leary, Esq, Sabine Schwab, PhD, and Jeremy Pivor. We also thank Ms. Sarah Jordan for assistance with critical reading and article preparation. Dr. Kwan and Ms. Salmi are supported by the Patient Centered Outcomes Research Institute (Grant No. 7718189). Dr. Lum is supported by the National Institute on Aging of the National Institutes of Health (Grant No. K76AG054782).

Author Disclosure Statement

No competing financial conflicts of interest exist. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or the Department of Veterans Affairs.

Supplementary Material

Supplementary Appendix A1

References

1. Taylor J, Pagliari C: Deathbedlive: The end-of-life trajectory, reflected in a cancer patient's tweets. BMC Palliat Care 2018;17:17.
2. Granger K: Death by social networking: The rising prominence of social media in the palliative care setting. BMJ Support Palliat Care 2014;4:2–3.
3. Katz MS, Utengen A, Anderson PF, et al.: Disease-specific hashtags for online communication about cancer care. JAMA Oncol 2016;2:392–394.
4. Wright AA, Zhang B, Ray A, et al.: Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA 2008;300:1665–1673.
5. Pollom EL, Sborov KD, Soltys SG, et al.: Advance care planning needs in patients with glioblastoma undergoing radiotherapy. J Pain Symptom Manage 2018;56:e6–e8.
6. Song K, Amatya B, Voutier C, Khan F: Advance care planning in patients with primary malignant brain tumors: A systematic review. Front Oncol 2016;6:223.
7. Fritz L, Dirven L, Reijneveld JC, et al.: Advance care planning in glioblastoma patients. Cancers (Basel) 2016;8:pii: E102.
8. Koekkoek JA, Chang S, Taphoorn MJ: Palliative care at the end-of-life in glioma patients. Handb Clin Neurol 2016; 134:315–326.
9. Nwosu AC, Debattista M, Rooney C, Mason S: Social media and palliative medicine: A retrospective 2-year analysis of global Twitter data to evaluate the use of technology to communicate about issues at the end of life. BMJ Support Palliat Care 2015;5:207–212.
10. Lowney AC, O'Brien T: The landscape of blogging in palliative care. Palliat Med 2012;26:858–859.
11. Vaismoradi M, Turunen H, Bondas T: Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci 2013;15: 398–405.

Address correspondence to:
Hillary D. Lum, MD, PhD
Division of Geriatric Medicine
Department of Medicine
University of Colorado School of Medicine
12631 East 17th Avenue, B-179
Aurora, CO 80045

E-mail: hillary.lum@ucdenver.edu

Downloaded by University of Colorado at Denver-Auraria from www.liebertpub.com at 10/05/21. For personal use only.

This article has been cited by:

1. Claire de Forcrand, Mara Flannery, Jeanne Cho, Neha Reddy Pidatala, Romilla Batra, Juanita Booker-Vaughns, Garrett K. Chan, Patrick Dunn, Robert Galvin, Ernest Hopkins, Eric D. Isaacs, Constance L. Kizzie-Gillett, Margaret Maguire, Martha Navarro, Dawn Rosini, William Vaughan, Sally Welsh, Pluscedia Williams, Angela Young-Brinn, Corita R. Grudzen. 2021. Pragmatic Considerations in Incorporating Stakeholder Engagement Into a Palliative Care Transitions Study. *Medical Care* **59**:Suppl 4, S370-S378. [Crossref]
2. Riti Shimkhada, Deanna Attai, AJ Scheitler, Susan Babey, Beth Glenn, Ninez Ponce. 2021. Using a Twitter Chat to Rapidly Identify Barriers and Policy Solutions for Metastatic Breast Cancer Care: Qualitative Study. *JMIR Public Health and Surveillance* **7**:1, e23178. [Crossref]
3. Liz Salmi, Hillary D Lum, Adam Hayden, Maija Reblin, Shirley Otis-Green, Grace Venechuk, Megan A Morris, Megan Griff, Bethany M Kwan. 2020. Stakeholder engagement in research on quality of life and palliative care for brain tumors: a qualitative analysis of #BTSM and #HPM tweet chats. *Neuro-Oncology Practice* **7**:6, 676-684. [Crossref]
4. Leonard L. Sokol, Sarah R. Jordan, Allison J. Applebaum, Joshua M. Hauser, Jodi Forlizzi, Moran Cerf, Hillary D. Lum. 2020. Social Media Perceptions of Legacy-Making: A Qualitative Analysis. *Palliative Medicine Reports* **1**:1, 326-330. [Abstract] [Full Text] [PDF] [PDF Plus]
5. Catherine M. Giroux, Katherine A. Moreau. 2020. Leveraging social media for medical education: Learning from patients in online spaces. *Medical Teacher* **42**:9, 970-972. [Crossref]
6. Josemari T Feliciano, Liz Salmi, Charlie Blotner, Adam Hayden, Edjah K Nduom, Bethany M Kwan, Matthew S Katz, Elizabeth B Claus. 2020. Brain Tumor Discussions on Twitter (#BTSM): Social Network Analysis. *Journal of Medical Internet Research* **22**:10, e22005. [Crossref]

Downloaded by University of Colorado at Denver-Auraria from www.liebertpub.com at 10/05/21. For personal use only.