

Society for the Study of Social Problems

In Pursuit of Social Justice



“The Art of Activism”
62nd Annual Meeting
August 16-18, 2012
Denver, CO

Can New Forms of Social Media Enhance Collaborations Among Health Care Professionals, Researchers, and Advocates? An Examination of the Popular Twitter Tweetchat, Breast Cancer Social Media (#BCSM)

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Breast Cancer Social Media, or #BCSM, is

an online, weekly discussion about issues related to breast cancer diagnosis, treatment and recovery that takes place on *Twitter*, a social networking site that allows anyone with an account the ability to exchange information through brief (140 characters) messages called Tweets. Through the use of what’s called a hashtag, in this

TweetChat # BCSM

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case **#BCSM**, members can participate in a virtual discussion about breast cancer that takes place every Monday evening at 8 pm CDT in real time.

The discussion format was modeled on two existing healthcare discussion chats, health care social media (**#HCSM**) and hospice and palliative care (**#HPM**) that are directed primarily

to healthcare professionals.

#BCSM, on the other hand, is a mixture of both cancer survivors and health care professionals.

Established on July 4, 2001 by two cancer survivors and patient advocates, **#BCSM** is now a thriving online community of global reach with a moderated discussion by the two co-founders and a board certified breast

Session 129: Radicalism in the 21st Century: Networking and Social Activism
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surgeon, who joined the team officially last fall.

In this paper, we examine the use of the Tweet chat as an avenue for patient advocacy and communication as well as some of BCSM's unique features.

THEMES:

1. Empowering patients through evidence-based information, an open, supportive forum for expression of views and experiences, and an understanding of each individual in the context of the breast cancer experience.

Discussions frequently focus on:

- What it “means” to be sick or have cancer
- The incapacity of others to be helpful, understanding, and supportive
- Feelings about the language of cancer (e.g., cancer as a gift, staying strong and positive, facing the challenges god gives you)
- Offering information and resources to others, or explaining aspects of these
- Dealing with medical expenses
- Sharing with honesty, collegiality, and often a sense of humor

2. The cancer experience itself, and recovery from that, is the binding thread.

- Participants ask questions, offer words of caring and support, share tips and insights from their experiences, discuss information and resources, and act as a sounding board.
- In this “peer to peer” healthcare the #BCSM community itself plays an advocacy role (e.g., discussion on patient-centered care on 11/14/11).
- Honoring the challenges and uplifts of community members, and grieving their losses.

3. The combined involvement of intersecting views and engagement makes #BCSM a forum for increasing patient/professional communication that promotes more cooperative relationships.

- BCSM facilitates the dissemination of information through transparent discussions and by making experts from various aspects of oncology, from surgeons to medical oncologists to psychologists, available for questions and commentary (e.g., medical oncologist shares findings from American Society of Research Oncology's annual meeting (6/11/12), veteran health journalist discusses how to evaluate health news on 2/20/12, and others).
- These professionals interact with each other and with survivors to deepen understanding of their experience, to hear patients' stories as they deal with breast cancer treatment, recovery, and also end of life, and to share evidenced-based knowledge.
- As survivors discuss their daily lives, frustrations, and share their stories they not only accelerate their own emotional recovery but provide insight to care providers, especially about issues which often overlooked in treatment settings.

#BCSM July 4, 2011

- 55 Participants
- 732 Tweets
- 585.6 Avg Tweets/Hour
- 13.31 Avg Tweets/Participant
- 2,571,855 Impressions

#BCSM June 25, 2012

- 70 Participants
- 1004 Tweets
- 803.2 Avg Tweets/Hour
- 14.34 Avg Tweets/Participant
- 2,568,089 Impressions

#BCSM 12-month Period *

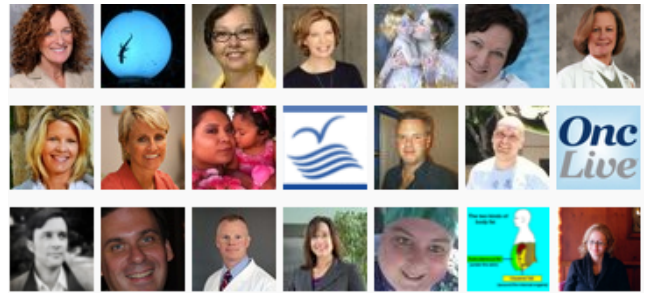
- 3239 Participants
 - 62,469 Tweets
 - 7.29 Avg Tweets/Hour
 - 19.29 Avg Tweets/Participant
 - 186,320,835 Impressions
- * **NOTE:** 12-month totals include ALL #BCSM tweets (i.e., those that take place during and after the 1-hour discussion.

#BCSM has become the most popular health care Tweet chat.

With 1215 fewer participants than the *second top*

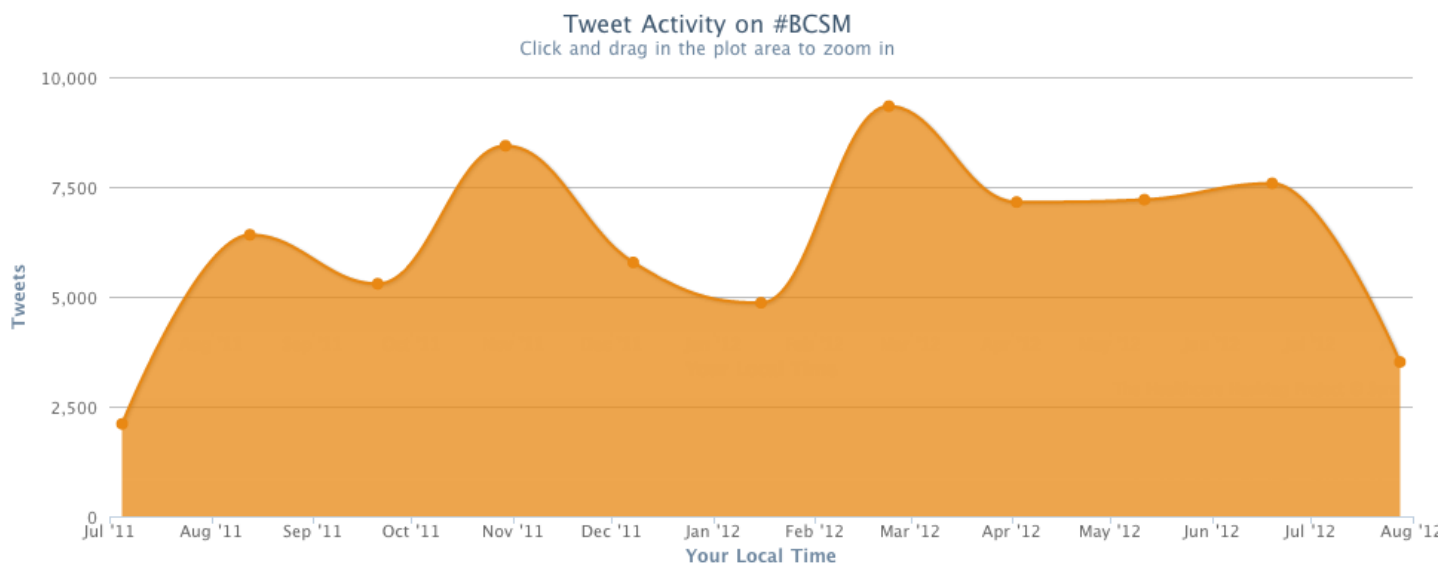
trender (#hitsm), participants average 6.68 more tweets and #BCSM had more than 29 million more *impressions* (i.e., an estimate of the total possible number of times a person on twitter could have viewed a tweet – calculated using the number of “followers” in each participant’s network plus the networks of any “retweeters” who shared the original message.)

- Also interesting is the number who follow #BCSM whether or not they participate in a particular night’s Tweet chat. In the 12-month period of analysis there were more than 3000 twitter users who used the #BCSM hashtag, contributing to more than 186 million *impressions*.



The chart “Tweet Activity on #BCSM” (below) shows an increase in the number of tweets during the 12-month period of analysis.

- Reaching nearly 2500 tweets the week of the first chat, #BCSM activity peaked at about 9000 the week of March 12th when the topic, “parenting through cancer treatment,” coincided with reporting from an international Social Health Summit that two of BCSM’s facilitators participated in.
- Participation grew from 55 participants at inception to 106 at its peak, and averaging 53 participants per Tweet chat (with many returners) each week.



The primary goal of this research is to describe the functioning and implications of the #BCSM Tweet chat as an exemplar of social media within a specific health care context.

The aims of this research are to:

- Report on the issues important to breast cancer survivors, advocates, and health care providers who use the #BCSM Tweet chat forum.
- Identify the networks involved in #BCSM, clarify their roles, and explore how those roles shift over time.
- Explore how peer-to-peer networks function in the Tweet chat context and beyond.
- Understand how #BCSM engenders community, social support, improved patient/professional communication, and advocacy.

We analyze the weekly #BCSM Tweet chat archives for a 12-month period, from its inception July 4, 2011 to August 25, 2012. This period includes 49 sessions, which have been downloaded in their entirety in PDF format (approximately 70 pages each). Using content and narrative analysis techniques we will code the content areas and their key themes. In addition, we will interview BCSM's co-founders about facilitation strategies and challenges, and a sample of regular #BCSM participants about the role of #BCSM in their lives, their work, and their survivorship and/or advocacy.

#BCSM Tweet chats are organized around a set of 4-6 questions each week.

- Facilitators keep the discussion on target.
- Participants respond to tagged questions.

Q1: You're the teacher. What would you tell a group of oncology residents about being a cancer patient? #BCSM

Q1: This is a partnership. LISTEN first! #bcsm

Q1: Remember, there's a person attached to the diagnosis. #bcsm

Q1: We're like business partners & the business is my health. #bcsm

Q1: Brush up on empathy. Tell the truth. #bcsm

Q1: Explain the 50-cent words. #bcsm

Q1: That cancer patients are humans first and foremost. #bcsm

Presenters:



Melissa Travis, MLS, is a doctoral candidate at Georgia State University (Ph.D. expected 2012) with a focus on gender, sexuality, and the culture of medicine. Her dissertation is a qualitative analysis of, "Discipline Lifestyle Narratives: Changes In Identity And Meaning Over Time and Social Space." A passionate teacher and researcher, Melissa is driven to understand and explore people's stories. As a patient and a patient advocate, her personal, professional, and community life intersect to bring reflexivity and compassion to her work.



Gayle Sulik, M.A., Ph.D., is a medical sociologist and Research Associate at the University at Albany (SUNY). She is the author of numerous articles on medical consumerism, care work, survivorship, and breast cancer culture as well as the book, *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health* (Oxford University Press, 2011). A public scholar, Dr. Sulik works to bridge academic and advocacy communities to work toward the betterment of public health. Website: www.gaylesulik.com

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