People With Breast Cancer Use Twitter to Share Their Experiences

Analysis of a week's worth of tweets paints a mixed picture of by individuals and institutions.

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Twitter is a place many cancer patients go to share and discuss their experiences with the disease, according to a recent exploratory study presented at the European Society for Medical Oncology (ESMO) 2018 Congress taking place this week in Munich. The study analyzed the contents of over 6,000 tweets and retweets about breast cancer.

Social media today has become an echo chamber in which every societal issue reverberates many times over—including cancer. Study author Rodrigo Sánchez-Bayona, MD, of Clinica Universidad de Navarra in Pamplona, Spain, said, "Many of the patients we see in daily practice use social media to search for information about their disease, so, as care providers, we wanted to know what kind of content they find there. At the same time, the sheer volume of posts on Twitter represents a rich pool of data we can use to assess attitudes and discourses surrounding cancer."

For this analysis, all tweets posted with the hashtag #BreastCancer over a seven-day period were collected and categorized according to their content, aim, user information and whether they displayed a stigmatizing attitude towards breast cancer. The tweets were also grouped into four subthemes: diagnosis, treatment, prognosis and prevention.

"This study was part of a larger, multidisciplinary project to observe the presence of different diseases on social media," Sánchez-Bayona said in an ESMO press release. "In 2014, we found that cancer was the most mentioned pathology on Twitter globally. We decided to look more closely at breast cancer first, because it is one of the three most common tumors worldwide and the primary cause of cancer deaths in women."

The data collected included 3,703 original tweets and 2,638 retweets.

"When examining the original tweets, we found that only one in three had medical content," said Sánchez-Bayona. "However, 90 percent of this medical information was appropriate, which is likely owed to the fact that 40 percent of tweets came from institutions and public accounts."

The categorization of tweets by aim showed that the most frequent motive was patients sharing their experiences, followed closely by patient advocacy. The most common subtheme by far was

prevention (44.5 percent of tweets).

Out of the 2,559 non-medical tweets analyzed, less than 15 percent contained stigmatizing statements about the disease. “The numerous breast cancer awareness campaigns over the years have certainly contributed to reducing the stigma associated with this illness,” said Sánchez-Bayona. “For many other tumors, there is still an unmet need. Going forward we would also like to explore and compare the social media presence of different tumors types.”

“Although it would be interesting to do further research into the profiles of social media users who are the most active in the discussion about cancer, these initial findings may prove useful in themselves,” he continued. “In particular, advocacy organizations can draw on them to create relevant medical content and counseling about cancer that will be more accessible to users. Social media can be used as a new way of providing information on cancer prevention and health education—not just to patients, but to a much broader audience.”

Marina Garassino, MD, of Istituto Nazionale dei Tumori in Milan, Italy, commented for ESMO: “Twitter is a high-level platform that is much more credible than other social networks like Facebook, so I was not surprised to see that the majority of the news published there are accurate.”

“This analysis also illustrates the presence of patients in large numbers on Twitter,” she said. “We should take that as corroboration of a new reality: patients now use the web to find information, and social media must be an integral part of our communication with them. Academic institutions and key opinion leaders need to be even more active in spreading their findings through these channels to counteract the many ’fake news’ circulating online.”

ESMO executive board member Evandro de Azambuja, MD, PhD, further commented: “I agree that the volume of reliable medical content published on Twitter should increase. Healthcare professionals and organizations really need to use appropriate social media as a way of sharing relevant information—both between them and with patients—because that is where it has the potential to be picked up fastest and most broadly.”

“Personally, I check Twitter daily for announcements of the latest publications of leading academic journals and fellow oncologists. I can then go and read the articles I’m interested in, knowing exactly where to find them. It’s an efficient way of obtaining medical information as it is published,” de Azambuja added. “When it comes to bringing the best evidence available in cancer research to the attention of as many people as possible, this platform is as powerful a tool as it gets.”

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