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Is Cancer Information Exchanged on Social Media Scientifically Accurate?

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Abstract

Background—Cancer patients and their caregivers are increasingly using social media as a platform to share cancer experiences, connect with support, and exchange cancer-related information. Yet, little is known about the nature and scientific accuracy of cancer-related information exchanged on social media.

Methods—We conducted a content analysis of 12 months of data from 18 publically available Facebook Pages hosted by parents of children with Acute Lymphoblastic Leukemia ($N = 15,852$ posts), and extracted all exchanges of medically-oriented cancer information. We systematically coded for themes in the nature of cancer-related information exchanged on personal Facebook Pages, and two oncology experts independently evaluated the scientific accuracy of each post.

Results—Of the 15,852 total posts 171 posts contained medically-oriented cancer information. The most frequent type of cancer information exchanged was information related to treatment protocols and health services use (35%) followed by information related to side effects and late effects (26%), medication (16%), medical caregiving strategies (13%), alternative and complementary therapies (8%), and other (2%). Overall, 67% of all cancer information exchanged was deemed medically/scientifically accurate, 19% was not medically/scientifically accurate, and 14% described unproven treatment modalities.

Conclusions—These findings highlight the potential utility of social media as a cancer-related resource, but also indicate that providers should focus on recommending reliable, evidence-based sources to patients and caregivers.

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Keywords

United States; Health Communication; Information Seeking; Social Media; Caregiver; Psychosocial Oncology; Pediatrics

Social media is becoming an increasingly prominent platform for health-related communication in the United States.¹⁻³ In contrast to expert-generated, static, content on traditional websites, social media platforms such as Facebook, YouTube, Twitter, CaringBridge, and PatientsLikeMe are characterized by their interactive nature. Users are able to develop and share their own content and react to content created by others.³⁻⁵ Due to this, social media users participate in a networked process of accessing, creating, and disseminating information.⁴ Social networking sites are the most commonly used form of social media, and were used by 74% of American adults in 2014.⁶ Facebook is the most widely used social networking site, and seventy-one percent of US adults have a Facebook account.⁶

Patients and their caregivers are increasingly using social media as a way to share their illness experiences,^{2,3,7-13} and engage in health-related discussion.¹⁴⁻¹⁶ As such, social media is becoming a prominent source of cancer-related information and communication. People use social media platforms to “crowd source” information, relying on social arbitration among hundreds or thousands of connected social media users to access information, make decisions, cope with hardship, and solve problems.¹⁷ Social media sites also democratize information dissemination through enabling patients and caregivers to connect directly with each other and share information that is not mediated or filtered by health care professionals or experts.¹⁸

Health professionals express mixed reactions to the increase in health communication on social media. While previous research documents that patients and caregivers value social media as a platform to share and obtain health-related information¹⁹⁻²² health-related professionals have concerns about the loss of control of information being shared and the potential for the spread of misinformation on social media.²³ Patients may choose to share personal health information on social media that exposes physicians to scrutiny and/or criticism,²⁴ use social media to promote perspectives that are not based upon sound science,²⁵ or access information through social media about treatment options not applicable to the patient’s particular care.²⁶ Yet, little is known about the nature and scientific accuracy of cancer-related information exchanged on social media. In this study we fill this gap in knowledge by systematically characterizing: (1) the types, and (2) scientific accuracy of medically-oriented cancer information posted on personal Facebook Pages of cancer caregivers.

Method

Due to the intensive demands of caring for a child with cancer,²⁷ we focused our analysis on personal Facebook Pages hosted by parents of children with Acute Lymphoblastic Leukemia. We used the Facebook search engine function to identify Facebook Pages for analysis using the search terms “Acute Lymphoblastic Leukemia” and “Childhood.” We

restricted search results to personal Pages that were publically available. Facebook Groups enable connection around a common interest, and group membership is publically available, moderated by a Group administrator, and/or available by invitation.²⁸ In contrast to Facebook Groups, Facebook Pages are profiles of people, businesses, or organizations.²⁸ We selected the first 25 Pages and reviewed the information section in the pool of potential Facebook Pages to identify Pages that were administered by a parent of a child with Acute Lymphoblastic Leukemia. This process yielded 18 Facebook Pages for analysis. We extracted the content from the *information* and *wall* sections of each Page from May 2012 to May 2013. The wall section of a Facebook Page is a space where Page administrators and public commenters can post messages. All Pages were publically available, and therefore consent to analyze posts and comments was not required by the Institutional Review Board. We extracted a total of 15,852 unique posts and comments from the Facebook Pages. Of these posts, 2,030 were posts by the Page administrators (the parent of the cancer patient) and 13,822 were comments from other Facebook users.

We conducted a content analysis of the Facebook Pages, and extracted all exchanges of medically-oriented cancer information. The coders (first, second, third, and fifth authors) pilot coded 10 pages of the same data file to ensure consensus on the interpretation of what constituted medically-oriented cancer information. At this stage we refined our definition of medically-oriented cancer information to be verifiable information about cancer or cancer treatment. For example, we excluded information about caregiving strategies (for example, “My child loves Ramen after procedures”) that could not be evaluated as medically/scientifically accurate by a panel of oncology experts. Two coders independently reviewed each data file and extracted any data excerpts that included medically-oriented cancer information into an Excel file. To ensure inter-coder reliability each team of coders met to discuss any discrepancies in data extracted, resolved conflicts, and achieved consensus on the final data excerpts to be included for analysis.²⁹

Two coders (first and second authors) conducted a second round of data analysis to characterize the types of cancer information exchanged. Each coder independently reviewed the data and conducted in vivo coding.²⁹ After coding the data independently, the two coders had coding meeting where they discussed codes, assessed inter-coder reliability, and achieved consensus on a final codebook. Both coders then conducted a second round of independent coding and used the codebook to systematically analyze each post. After independent analysis the two coders met to discuss any discrepancies in coding and achieve consensus.²⁹

Finally, two oncology experts, a pediatric oncologist (fourth author) and an oncology nurse practitioner (third author), then systematically evaluated each post to analyze the medical and scientific accuracy of information exchanged on personal Facebook Pages. Each expert independently evaluated the first 25 data excerpts, met to discuss codes, and achieved consensus.²⁹ The two experts then independently coded each data excerpt as (1) medically/scientifically accurate, (2) not medically/scientifically accurate, or (3) unproven treatment modalities. Facebook posts were coded as *medically/scientifically accurate* if they contained information that represented correct medical information that was based upon current scientific evidence (for example, “Itching is a side effect of morphine based drugs”). Posts

were coded as *not medically/scientifically accurate* if they contained incorrect medical information (for example, “Brain tumors are the deadliest form of childhood cancer”). Posts were coded as *unproven treatment modalities* if they described information for which there is not a definitive base of scientific evidence (for example, “Have you tried Frankincense essential oil on her feet? Everyone I know that has battled cancer swears by it, helps them bounce back from chemo and gives them energy”). The oncology experts verified the medical and scientific accuracy of information using peer-reviewed publications and national clinical guidelines. After independent evaluation the two oncology experts met to discuss and resolve any conflicts and achieve consensus on the final data analysis.

Findings

Of the 15,852 total posts 171 posts contained medically-oriented cancer information. Twenty-five codes were identified to categorize the cancer information exchanged on cancer caregivers’ personal Facebook Pages. As shown in Table 1, the 25 codes were condensed to 6 themes: (1) alternative and complementary therapies, (2) medication, (3) treatment protocols and health services use, (4) side effects and late effects, (5) medical caregiving strategies, and (6) other. The most frequent type of cancer information exchanged was information related to treatment protocols and health services use (35%) followed by information related to side effects and late effects (26%), medication (16%), medical caregiving strategies (13%), alternative and complementary therapies (8%), and other (2%) (Table 2). Overall, 67% of all cancer information exchanged was deemed to be medically/scientifically accurate. Examples include “It is not uncommon for pediatric cancer children to need to see an Endocrinologist for hormone irregularities” and “MRI came back w/signs of AVN, Avascular Necrosis... bone death. If it is caught early enough some can be reversed.” Nineteen percent was not deemed medically/scientifically accurate, for example “When undigested sugars get into his intestines it throws water trying to neutralize it so that caused the severe diarrhea.” Fourteen percent of posts described unproven treatment modalities, for example “Are you doing the cool mist humidifier at night too to thin the mucous?” For specific types of cancer-related information exchanged, all information related to alternative and complementary therapies was based upon information related to unproven treatment modalities (Table 3). Seventy-eight percent of information exchanged related to medication was medically/scientifically accurate, and 22% was not medically/scientifically accurate. Seventy-five percent of information exchanged related to treatment protocols and health services use was medically/scientifically accurate, 23% was not medically/scientifically accurate, and 2% described unproven treatment modalities. Eighty percent of information exchanged related to side effects and late effects of cancer treatment was medically/scientifically accurate, and 20% was not medically/scientifically accurate. Fifty percent of information exchanged related to medical caregiving strategies was medically/scientifically accurate, 9% was not medically/scientifically accurate, and 41% described unproven treatment modalities.

Discussion

Cancer patients and their caregivers are increasingly using social media as a platform to share cancer experiences, connect with support, and exchange cancer-related information.

2,3,7–16,30–31 Yet little is known about the nature and scientific accuracy of cancer-related information exchanged on social media. We took a critical step forward by systematically characterizing the scientific accuracy of different types of medically oriented cancer information exchanged on social media. Of the 15,852 total posts, only 171 posts contained medically-oriented cancer information, indicating that exchange of this type of informational support is not a primary use of social media for cancer caregivers. We found that most cancer information exchanged in this sample was deemed to be based upon sound medical or scientific evidence by our panel of oncology experts. This finding highlights the potential utility of social media as a cancer-related resource, and could be a helpful resource for caregivers within specific communities. We did find, however, that 19% of the medically-oriented cancer information shared on Facebook was scientifically inaccurate, indicating that patients should be cautioned that some information shared on social media is incorrect. Clinicians should evaluate specific online resources and communities before recommending them to cancer patients and their caregivers. Regardless, these findings are a first foray into this topic, and show that clinicians could refer cancer patients and caregivers to specific credible social media sites as a cancer-related resource.

Some data limitations should be noted when interpreting these findings. There may be differences in the types and scientific accuracy of cancer information users exchange on social media sites other than Facebook. Future research should compare user behavior across popular social networking sites such as Facebook, CaringBridge, and PatientsLikeMe. Similarly, there may be differences in user practices by the social media users' relationship to the cancer patient (e.g. patient vs. caregiver) or by disease site (e.g. breast cancer, colon cancer). Future research should compare cancer information practices on social media comparing social media users of different social, demographic, and disease characteristics. Two oncology clinicians reviewed each social media post and assessed the medical and scientific accuracy of information exchanged. The judgments of these two clinicians may not represent the perspectives of all oncology experts. Finally, the types and scientific accuracy of cancer information may vary by type and by host of Facebook Page or Group. Our findings related to caregivers' personal Facebook Pages may be different than the types and scientific accuracy of cancer information posted to Facebook Groups formed around a cancer-related advocacy organization, or a Group dedicated to providing cancer-related support. Systematically examining these differences is an important avenue for future research.

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Table 1

Themes and Codes Related to the Types of Medically Oriented Cancer Information Exchanged on Social Media

Theme	Codes
Alternative and Complementary Therapies	Alternative Health Services/Treatments Complementary Health Services/Treatments
Medication	Description of Child's Medications Information about Medications Suggestion of Medications to Ask For
Treatment Protocols and Health Services Use	Medical Procedures Diagnostic Tests Description of Treatment Options Suggestion of Treatment Options Health Services Use/Navigating Health Care System Prognosis Suggestion of Possible Diagnosis for Symptoms Information/Facts about Childhood Cancer
Side Effects and Late Effects	Description of Child's Side Effects Suggestion Related to Side Effects Late Effects
Medical Caregiving Strategies	Minimizing Exposure to Germs and Infection Medication Administration Diet Managing Symptoms at Home Adapting Home to Accommodate Medical Care Adapting Family Routines to Accommodate Medical Care
Other	Medical Question Update on Caregiver's Health Physician Soliciting Patients

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Table 2

Frequency of Types of Medically Oriented Cancer Information Exchanged on Social Media

Theme	Frequency <i>N</i> (%)
Alternative and Complementary Therapies	13 (8%)
Medication	27 (16%)
Treatment Protocols and Health Services Use	60 (35%)
Side Effects and Late Effects	45 (26%)
Medical Caregiving Strategies	22 (13%)
Other	4 (2%)
Total	171 (100%)

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Table 3

Medical and Scientific Accuracy Medically Oriented Cancer Information Exchanged on Social Media

Theme	Medically/ Scientifically Accurate N (%)	Not Medically/ Scientifically Accurate N (%)	Unproven Treatment Modalities N (%)	Total N (%)
Alternative and Complementary Therapies	0 (0%)	0 (0%)	13 (100%)	13 (100%)
Medication	21 (78%)	6 (22%)	0 (0%)	27 (100%)
Treatment Protocols and Health Services Use	45 (75%)	14 (23%)	1 (2%)	60 (100%)
Side Effects and Late Effects	36 (80%)	9 (20%)	0 (0%)	45 (100%)
Medical Caregiving Strategies	11 (50%)	2 (9%)	9 (41%)	22 (100%)
Other	2 (50%)	2 (50%)	0 (0%)	4 (100%)

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