Examining Social Media Use among Parents of Children with Cancer

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ABSTRACT

Americans are increasingly using social media for health-related communication. Facebook is the most widely used social media platform in the US. Much of the previous research on social media and health communication has focused on Facebook Groups related to a specific disease, or Facebook Pages related to an advocacy organization. However, less is known about how people communicate about health on personal Facebook Pages. In this study we expand upon previous research by examining the patterns of Facebook use among one unique population: parents caring for a child with cancer. We examined themes in cancer-related exchanges through a content analysis of 12 months of data from 18 publically available Facebook Pages hosted by parents of children with Acute Lymphoblastic Leukemia (15,852 total posts). Four categories of health-related Facebook usage emerged: documenting the cancer journey, (2) promoting awareness and advocacy about pediatric cancer, (3) sharing emotional strain associated with caregiving, and (4) mobilizing symbolic and instrumental forms of support. Our findings show that Facebook Pages offer a platform for people to share their cancer experiences, promote advocacy and awareness, and mobilize social support. Information professionals, particularly those who work with consumer and patient populations, should remain aware that social media platforms can provide layperson-generated, user-centered content that meets the informational, emotional, and logistical needs of caregivers and patients.

Keywords
Social media, social support, health information, cancer.

INTRODUCTION

Americans are increasingly using social media (such as Facebook, YouTube and Twitter) for health-related communication (Chou et al., 2009; Hamm et al., 2013; Moorhead et al., 2013). Social media platforms enable users to develop and share their own content and comment on others’ posts (Weaver, Lindsay, & Gitelman, 2012). Due to this, content on social media is interactive, where patients and caregivers are able to obtain information while also contributing to a networked process of content development and diffusion (Chou et al., 2013). Recent research documents that patients and their caregivers use social media as a way to share their illness experiences (Gage, 2013; Gomez-Zuniga et al., 2012; Chou et al., 2011; Clerici et al., 2012; Greene et al., 2011; Greaves et al., 2013; Wicks et al., 2013) and engage in health-related discussion (Bravo & Hoffman-Goetz, 2015; Chou, Prestin, & Kunath, 2014; Tsuya et al., 2014).

With the rise in social media use, research has examined how people use one particular platform, Facebook, for health-related matters. Much of this research has focused on Facebook groups related to a specific disease, or Facebook pages related to an advocacy organization. However, less is known about how people communicate about health on personal Facebook pages. In this study we expand upon previous research by examining the patterns of Facebook use among one unique population: parents caring for a child with cancer. Childhood cancer is the number one cause of death by disease in children in the US (Siegel et al., 2014) and having a child diagnosed with cancer is a traumatic experience for families (Kagawa-Singer, 2011). Treatment protocols can extend for months or years, and commonly include chemotherapy, radiation, surgery, or stem cell transplant (Trask et al., 2013). After a child is diagnosed with cancer, their parents must quickly learn how to navigate the cancer care system and manage their child’s cancer care (Markides, 2011). Childhood cancer has a lower incidence compared to many other pediatric diagnoses, making it an isolating experience for families (Gage, 2013). Families often have to travel to major hospitals and cancer centers for their children’s care, which can distance them from their usual support networks. These factors may make social media a convenient and useful way to share their experiences, communicate with others, and connect with support. Through a content analysis of personal Facebook pages created by parents of childhood cancer patients, we examined trends and themes in these cancer-related exchanges.
METHODS
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 pages (as opposed to groups) that were publically available. We selected the first 25 pages and reviewed the information section in the pool of potential pages to identify pages that were administered by a parent of a child with Acute Lymphoblastic Leukemia (ALL). 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. 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 used a grounded theory approach to data analysis and allowed codes, themes, and patterns to emerge from the data (Glaser & Strauss, 1967). Two coders (second and third authors) independently free coded each data file allowing codes to emerge from the data (Charmaz, 2006). Each coder wrote coding memos that reflected on the codes, patterns among the codes, and early ideas about themes in the data (Charmaz, 2006). After independent coding was complete the two coders met and discussed themes at peer debriefing meetings (Weis & Fine, 2000). Throughout data analysis we continued to refine early codes and themes.

RESULTS
Four categories of pediatric cancer parents’ Facebook usage emerged: (1) documenting the cancer journey, (2) promoting awareness and advocacy about pediatric cancer, (3) sharing emotional strain associated with caregiving, and (4) mobilizing symbolic and instrumental forms of support.

One of the primary ways parents of cancer patients used Facebook was to document their child’s cancer journey. Parents shared the story of their child’s cancer diagnosis, updates on the progression of their treatment, upcoming appointments and procedures, their child’s current treatment protocol, and the outcome of recent tests. Parents also documented their own experiences managing the side effects and unexpected complications that arose throughout their child’s treatment. Parents highlighted cancer-related milestones such as counting down number of treatments or celebrating the end of a treatment cycle.

Related to sharing their own experiences through treatment updates, parents of pediatric cancer patients used Facebook as a vehicle to promote awareness of childhood cancer. These posts took the form of describing the difficult day-to-day realities of caring for a child with cancer, including feelings of social isolation associated with caring for a child with cancer. Parents lamented a perceived lack of sufficient funding for childhood cancer and posted messages that encouraged increased efforts to secure more funding for this type of cancer research.

Another common usage of Facebook by parents of pediatric cancer patients was to share the emotional strain of caring for a seriously ill child. These posts found parents expressing difficulty watching their child go through painful treatments, and feeling powerless to ease their child’s suffering. Physical fatigue associated with managing their children’s cancer care, in addition to maintaining a household and work responsibilities was a topic of discussion. Related to emotional strain, parents experienced frustration navigating the health care system, including perceived hospital errors, complaints about hospital protocols, and inconsistencies among clinicians.

Parents used Facebook posts to mobilize two types of support: symbolic and instrumental. Symbolic forms of support primarily took the form of parents asking for prayers and positive thoughts. Parents also frequently asked for “likes” of a picture or status in order to lift the spirits of the family or the patient themselves (e.g. “Let’s see if we can get to 1000 likes by the end of the day!”) Requests for instrumental support included 1) logistical (e.g. help with childcare, household chores, and meal preparation), 2) informational (e.g. tips for caregiving and navigating the healthcare system), and 3) financial (e.g. fundraisers).

CONCLUSION
Facebook, as one particular form of social media, is used by parents of children with cancer to share various types of content. Due to the socially isolating and resource-intensive nature of caring for an ill child, Facebook can serve as an efficient mode of communication, information dissemination, and social support among parents. These findings lend support to the notion that social media platforms, like Facebook, may supplement other commonly used, unidirectional sources (i.e. websites) of online health-related information. Information professionals, particularly those who work with consumer and patient populations, should remain aware that social media platforms can provide layperson-generated, user-centered content that meets the informational, emotional, and logistical needs of caregivers and patients.

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REFERENCES