




# Social Media Use Among Parents and Caregivers of Children With Cancer

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## Abstract

Social media as an effective source of information and support among parents and other caregivers of children with cancer has not been explored. The purpose of this cross-sectional study was to describe caregivers' reasons for using social media, social media sites used, and predictors of social media usage. This study sample included 215 caregivers (96% parents) of children with cancer receiving cancer-related care at a tertiary children's hospital in the Intermountain West. Most of caregivers (74%) reported using social media in relation to their child's cancer and reported using social media to provide and receive support and information about their child's diagnosis or treatment. Our findings suggest that social media could be a delivery platform for future interventions seeking to meet the informational and emotional needs of caregivers of children with cancer. An awareness of how parents and caregivers of children receiving cancer-related treatment use social media can help nurses understand their ongoing informational and emotional needs. Nurses can also support parents and caregivers in selecting reputable sources of support that are accessible via social media.

## Keywords

social media, caregivers, parents, childhood cancer

## Introduction

Caregivers (e.g., parents or guardians) of children with cancer are faced with the challenge of navigating logistical issues and medical decisions related to their child's medical care, while simultaneously managing psychosocial distress throughout the process. Numerous studies demonstrate that caregivers report stress, anxiety, and lower quality of life throughout children's cancer diagnosis, treatment, and remission (Best, Streisand, Catania, & Kazak, 2001; Boman, Lindahl, & Björk, 2003; Dockerty, Williams, McGee, & Skegg, 2000; Rodriguez et al., 2011; Salvador, Crespo, Martins, Santos, & Canavarró, 2015; Sklenarova et al., 2015; Vrijmoet-Wiersma et al., 2008). Increasing access to social support could help caregivers effectively manage their stress and other needs. For example, caregivers of children with cancer have expressed need for emotional (e.g., coping) and informational (e.g., prognosis, financial information) support (Adams, Boulton, & Watson, 2009; Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; Love et al., 2012).

Prior studies have highlighted a range of unmet emotional and informational needs expressed by caregivers of children with cancer (Adams et al., 2009; Eysenbach et al., 2004; Love et al., 2012). However, social media, defined as a web-based platform for the exchange of user-generated content, which is used by nearly two thirds of American adults, has not been previously explored as a potential source of information and emotional support for this caregiver population (Kaplan & Haenlein, 2010; Perrin, 2015). Studies of adolescents with cancer and other chronic illnesses have suggested that social media

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can facilitate peer support and information exchange (Eysenbach et al., 2004; Love et al., 2012). Caregivers of children with cancer may also benefit from peer support via social media. For example, caregivers could use social media sites to connect with other families to exchange information about cancer treatment experiences, to provide and receive emotional support, or to participate in online support groups. In order to understand whether social media could be a useful source of support to meet the needs of caregivers of children with cancer, it is necessary to first understand caregiver's usage and preferences for social media sites. The aim of the current study was to describe social media usage among caregivers of children with cancer.

## Method

### Design

This study used a cross-sectional design to explore caregivers' social media usage. We used an investigator-developed questionnaire with caregivers of children with cancer to describe their preferred social media sites, reasons for social media use, and predictors of social media sites used (e.g., caregiver age and gender) related to a child's cancer experience.

### Setting

Participants were recruited through Primary Children's Hospital in Salt Lake City, Utah. This Children's Oncology Group-affiliated hospital serves as the main pediatric tertiary care hospital for the Intermountain West, which also includes Utah, as well as parts of Idaho, Wyoming, Nevada, Colorado, Arizona, and Montana. The hospital's Cancer Transplant Center treats around 300 children and adolescents with cancer each year, including 150 newly diagnosed patients.

### Participants

Caregivers were eligible to participate in the current study if they were at least 18 years of age, able to speak and read English, and were the parent, legal guardian, or identified as the primary caregiver of a child who received cancer-related treatment at least once between 2012 and 2014.

### Procedure

All procedures were approved by the University of Utah Institutional Review Board. A waiver of documentation of informed consent was granted. A cover letter was included with questionnaires and explained that completing and returning the questionnaire implied informed consent. Data were collected between January and May

2015. Eligible participants were recruited using two methods. First, eligible participants were mailed a cover letter describing the study and a copy of the study questionnaire. Second, potentially eligible patients were approached for recruitment at scheduled clinic appointments. A total of 254 caregivers were mailed a letter and/or were approached at an appointment, and 215 completed the questionnaire (response rate = 84.6%).

### Materials and Measures

Participants were asked to complete a self-reported questionnaire assessing demographic information, information about the child's cancer (type, year of diagnosis), child's current treatment status (e.g., receiving disease directed therapy, off therapy), child's relapse status, and the caregiver participant's use of social media related to the child's cancer. Investigator-developed questions targeting participant's social media use assessed the types of social media sites used, reasons for using social media, and length of time spent using social media sites (e.g., number of hours per day). Questions were close-ended but participants were allowed to choose multiple responses to describe reasons for using social media.

### Data Management and Analysis

Analyses were conducted using STATA 14.1. Descriptive statistics (frequencies, means, standard deviations) summarized demographic characteristics and social media use. Chi-square analyses explored associations between demographic/illness factors (e.g., caregiver gender, child's treatment status), reasons for social media use, and social media site preferences. Logistic regression explored whether caregiver age, caregiver gender, or child's treatment status predicted social media site preferences and reasons for using social media.

## Results

### Participant Characteristics

The vast majority of participants (96%) reported being the biological parent of a child with cancer. Forty-one percent of children were receiving disease-directed therapy and 50% were currently off therapy. On average, children were 2.2 years (standard deviation [*SD*] = 1.8; range 0-12 years) from their initial cancer diagnosis. Caregiver and patient demographic characteristics are presented in Table 1.

### Caregiver Use of Social Media

Caregivers reported using social media for personal use (96%) and use related to their child's cancer (74%). Of

**Table 1.** Caregiver and Child Demographic Characteristics (N = 215) and Child Cancer Characteristics.

Demographic Characteristic	n (%) unless otherwise noted
<i>Caregiver</i>	
Age (years)	
18-24	2 (<1.0)
25-29	18 (8.5)
30-39	103 (48.6)
40-49	72 (33.9)
50+	17 (8.1)
Gender	
Male	31 (14.5)
Female	183 (85.5)
Race	
White	197 (91.6)
Native American	1 (<1.0)
Asian	5 (2.3)
Native Hawaiian, Pacific Islander	1 (<1.0)
Hispanic/Latino	13 (6.1)
Black or African American	1 (<1.0)
Highest level of education	
Less than high school	1 (<1.0)
Some high school	5 (2.3)
High school or equivalent	28 (13.1)
Some college, no degree	62 (28.9)
Two-year degree	27 (12.6)
College graduate	70 (32.7)
Graduate school	21 (9.8)
Annual household income	
<\$25,000	25 (11.7)
\$25,000-49,999	42 (19.6)
\$50,000-74,999	48 (22.4)
\$75,000-99,999	42 (19.6)
\$100,000-149,999	34 (15.9)
≥\$150,000	23 (10.8)
Marital status	
Married	184 (85.9)
Divorced	8 (3.7)
Single	7 (3.3)
Single, living with partner	7 (3.3)
Separated	5 (2.3)
Widowed	3 (1.4)
Number of children living at home	
0-1	33 (15.7)
2-3	102 (48.3)
4-5	64 (30.3)
6+	12 (5.7)
Caregiver's relationship to child	
Biological parent	204 (94.9)
Adoptive parent	3 (1.4)
Foster parent	1 (<1.0)
Grandparent	3 (1.4)
Caretaking relative	1 (<1.0)
Legal guardian	3 (1.4)

(continued)

**Table 1. (continued)**

Demographic Characteristic	n (%) unless otherwise noted
<i>Child</i>	
Gender	
Male	129 (60.3)
Female	85 (39.7)
Years since child's cancer diagnosis	2.2 (24)
<i>M (SD)</i>	
Cancer diagnosis type	
Leukemia/lymphoma	109 (50.7)
Solid tumor	88 (40.9)
Other	18 (8.4)
Treatment status	
Receiving disease directed therapy	90 (41.9)
Off therapy	108 (50.2)
Deceased	2 (0.93)
Not specified	15 (6.9)
Relapse status	
Yes	10 (4.6)
No	205 (95.4)
Current age, years <i>M (SD)</i>	9.1 (5.1)

the 4% who reported not using social media sites, common reasons for nonuse included preferring other methods of socializing (67%), concerns about privacy (33%), and limited time (33%). Social media sites used by caregivers are presented in Figure 1. Facebook was the most common social media site used by caregivers for personal use (91%) and in relation to their child's cancer (80%). The most common cancer-specific internet sites were Make-a-Wish Foundation (58%), a local pediatric cancer Facebook group (35%), and HopeKids (29%). Caregivers reported spending an average of 1.3 hours ( $SD = 1.1$ ) a day using social media.

### Reasons for Cancer-Related Social Media Use

Figure 2 presents caregivers' reasons for using social media. In relation to their child's cancer, caregivers commonly reported using social media to gain satisfaction from providing support to others (80%), to connect with other families (68%), to give support to others (68%), and to receive support from others (68%). Fifty percent of caregivers reported using social media in relation to their child's cancer to both receive and provide information.

### Demographic and Illness Predictors of Social Media Sites Used

Caregiver age significantly predicted the types of social media sites used. Specifically, caregivers aged 40 to 49 years and those older than 50 years were less likely to use Facebook compared with caregivers aged 30 to 39 years

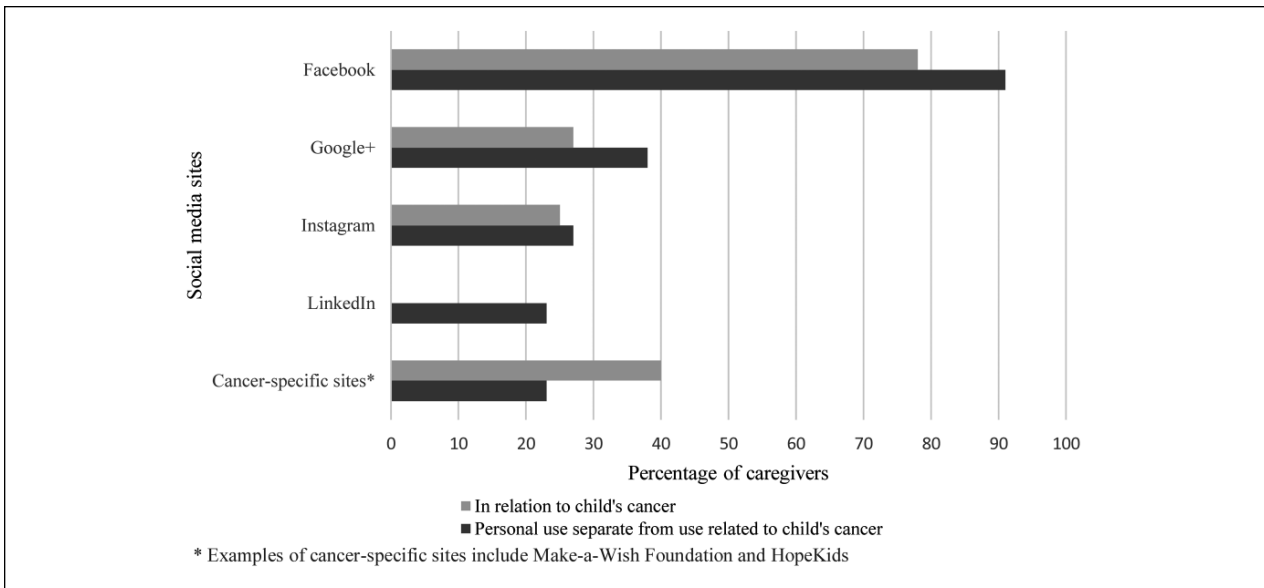


Figure 1. Social media sites used by caregivers.

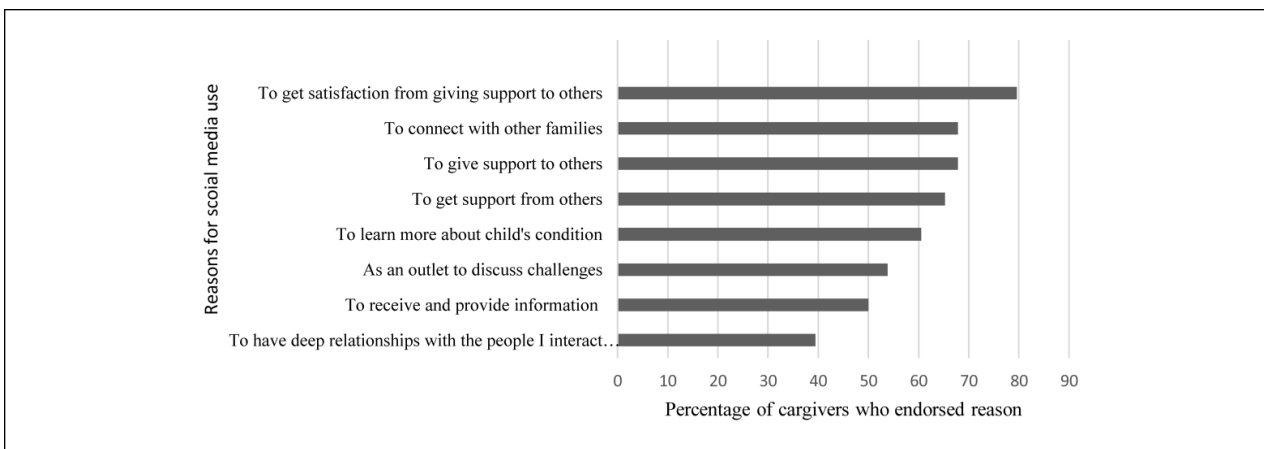


Figure 2. Caregivers' reasons for using social media.

(odds ratio [OR] = 0.46, 95% confidence interval [CI] = [0.24, 0.90],  $p = .02$  and  $OR = 0.23$ , 95% CI = [0.08, 0.69],  $p = .008$ , respectively). Conversely, younger caregivers aged 24 to 29 years and 30 to 39 years were less likely to use cancer-specific websites than caregivers older than 50 years ( $OR = 0.22$ , 95% CI = [0.05, 0.96],  $p = .04$ ;  $OR = 0.27$ , 95% CI = [0.09, 0.80],  $p = .02$ ). Caregiver age was not a predictor of caregiver's endorsement of reasons for social media use. There was no association between caregiver gender or child's treatment status and reasons for social media use or preferences for sites used.

**Discussion**

The current study is among the first to describe social media use among caregivers of children with cancer, including in

relation to their child's cancer experience. Within our study sample, social media was used by most caregivers of children with cancer for personal use (96%) and in relation to their child's cancer (74%). Caregivers reported using a range of social media sites and reported a variety of reasons they use social media.

In relation to their child's cancer, the most commonly cited reasons for caregivers was to gain satisfaction from providing support, to connect with other families, and to provide and receive support. These findings emphasized caregiver's use of social media in terms of support related to their child's cancer and raised the possibility that caregivers in this population continue to have unmet emotional needs. Although previous literature has not evaluated social media as a means for social support for caregivers of individuals with cancer, use of social media

has been effective at increasing perceived social support and reducing distress patients with cancer and survivors (Attai et al., 2015; Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Gibson et al., 2016; Hong, Peña-Purcell, & Ory, 2012; Klemm et al., 2003; Maher et al., 2014).

The use of social media among caregivers could be an effective way to increase social support and reduce stress and anxiety associated with a child's cancer diagnosis and treatment. Additionally, our results suggest that social media-based interventions should potentially be tailored to caregivers of different ages. Because caregivers older than 40 years were less likely to report using Facebook, cancer-specific websites with interactive components could be a useful platform for reaching these caregivers. At the same time, social media-based interventions need to be responsive to emerging social media platforms and changes in the general demographics of individuals using each type of platform.

Another commonly cited reason for social media use in relation to their child's cancer in the current study was to provide and receive information from other cancer families and garner practical tools or knowledge to help with their child's cancer treatment. This finding highlights the opportunity that social media provides for bidirectional exchange of information, which could help address caregivers' informational and emotional needs (Adams et al., 2009; Eysenbach et al., 2004; Love et al., 2012; Solomon, Wagner, & Goes, 2012). Social media provides a more interactive platform for information exchange, which contrasts traditional means of information provision which are one directional (e.g., informational brochures, websites containing information alone). This interactive platform can then be balanced with the desire for privacy by some caregivers.

The current study has a few limitations worth noting. First, this study used a cross-sectional study design and, therefore, only captured caregivers' use of social media sites at one time point. The study relied on self-report from questionnaires to gain an understanding of social media use and reasons for using social media. Although the study largely reflected the racial and ethnic composition of the geographic area served, the sample had limited racial/ethnic diversity, which could reduce the generalizability of the study results. Because the questionnaire was in English, the social media use of non-English-speaking caregivers was not assessed. Finally, the majority of the participants were female caregivers, so the data may not reflect the opinions of male caregivers.

### *Implications for Practice and Future Research*

Although attention has been given to workplace-related use of social media by health care professionals (Boyce, Davis, Gerdy, & Pool, 2011), less effort has been made to support frontline staff, including nurses, in guiding

families to social media-based resources. An awareness of parents' and caregivers' rationale for social media use can help nurses understand caregivers' ongoing informational and emotional needs. Nurses and other pediatric oncology clinicians can also support parents and caregivers in selecting reputable sources of information support that are accessible via social media.

Results of this study support the notion that social media could be a potential platform for delivering information or interventions to caregivers of children with cancer. Because most caregivers are already using social media and it can be accessed from home or other locations and on their own time, social media-based interventions may be an innovative and convenient way to provide information and support that caregivers may need. Developing social media-based interventions could help provide caregivers with accurate cancer information to reduce misinformation found online and create a space in which caregivers can have positive interactions with other families who have a child with cancer. Social media-based interventions also have the potential for harmful online interactions; this should be minimized and monitored if incorporated into practice (Keith & Steinberg, 2017). The utilization and popularity of social media among caregivers of children with cancer as a way to exchange information and support presents a unique opportunity for the development of social media-based interventions. However, future interventions that are delivered via social media should consider caregiver privacy concerns (Keith & Steinberg, 2017). Future research could evaluate whether the use of social media is a helpful tool in improving feelings of perceived support among caregivers and whether it can be an effective delivery method for coping and stress management interventions to reduce caregiver distress.

The use of different study design methodologies would also be helpful. For example, a longitudinal, repeated measures design may be better to understand caregivers' use of social media over time. Inclusion of larger, more diverse samples would aid better understanding of social media usage as would inclusion of non-English-speaking groups. Additionally, collecting qualitative data from caregivers (e.g., through focus groups) may also add to this knowledge by allowing deeper examination of caregivers' reasons for using social media and actual information exchanged.

### **Authors' Note**

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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