

In Their Own Words: Experiences of Caregivers of Adults With Cancer as Expressed on Social Media

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PURPOSE: To explore caregivers' writings about their experiences caring for adult individuals with cancer on a social media health communication website.

PARTICIPANTS & SETTING: Journal entries (N = 392) were analyzed for 37 adult caregivers who were posting on behalf of 20 individuals with cancer. CaringBridge is a website used by patients and informal caregivers to communicate about acute and chronic disease.

METHODOLOGIC APPROACH: A retrospective descriptive study using qualitative content analysis of caregivers' journal entries from 2009 to 2015.

FINDINGS: Major categories identified in caregivers' online journals included patient health information, cancer awareness/advocacy, social support, caregiver burden, daily living, emotions (positive and negative), and spirituality.

IMPLICATIONS FOR NURSING: Nurses often recommend using social media as a communication strategy for patients with cancer and their caregivers. The findings from this study provide potential guidance nurses may wish to offer caregivers. For example, nurses may talk with caregivers about how and what to post regarding treatment decisions. In addition, nurses can provide support for caregivers struggling with when and how often to communicate on social media.

KEYWORDS CaringBridge; social media; sharing; caregivers; communication; social support

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More than 1.7 million people in the United States were diagnosed with cancer in 2018 (American Cancer Society, 2018). Most of these individuals will, at some point, require the help of a family caregiver who volunteers to provide unpaid care to patients (U.S. Department of Health and Human Services, 1998). A family caregiver is described by the National Academies of Sciences, Engineering, and Medicine (2016) as someone who takes on a helping role to an ill individual. Caregivers of adults diagnosed with cancer are often women and aged 55 years and older (National Cancer Institute [NCI], 2019).

Caregiving roles and tasks vary based on the individual's cancer diagnosis, symptoms, and comorbidities (Ellis, 2012; van Ryn et al., 2011). Caregivers may be involved in assisting the patient with activities of daily living (Saria et al., 2017) and financial and household tasks, helping the patient to navigate the healthcare system, providing symptom management, and monitoring for side effects (DuBenske et al., 2008; Given, Given, & Sherwood, 2012; Gofton, Graber, & Carter, 2012; Saria et al., 2017; Shaw et al., 2013). Caregivers may alter their work life and experience financial and legal stressors during times of transition (DuBenske et al., 2008). The emotional toll can result in depression and anxiety (Lambert, Girgis, Lecathelinais, & Stacey, 2013; Saria et al., 2017).

Having good support can help ameliorate the negative effects of caregiving, and social media is an avenue where many caregivers look for support. The use of social media for general communication and, specifically, for health-related information and communication is increasing (Prestin, Vieux, & Chou, 2015). Caregivers are at the forefront of health-related users, and they use social media in great numbers (Pew Research Center, 2013). Several social media