The Perceived Value of Online Cancer Resources Among Loved Ones of People With Cancer

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OBJECTIVES: To examine the experiences with, opinions of, and reactions to online cancer information of loved ones of people with cancer.

SAMPLE & SETTING: 10 loved ones of people with cancer recruited from a pool of participants who completed a survey about cancer website experiences.

METHODS & VARIABLES: Qualitative, semistructured interview questions concerned the perceived value of and reactions to online cancer information. Responses were analyzed using a grounded theory approach.

RESULTS: Cancer websites play an important role, often serving as a first source of information. All participants said the Internet was helpful but could lead to negative emotions or misinformation. Future efforts should seek to mitigate the negative effects associated with the use of such websites.

IMPLICATIONS FOR NURSING: Healthcare providers should direct people with cancer and their loved ones to reputable websites that provide support in conjunction with information, or work toward developing their own in-depth resources.

Keywords: loved ones; online cancer resources; online cancer information; cancer

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LOved ones of people with cancer are vulnerable, demonstrating lower quality of life and higher anxiety than those actually diagnosed with the disease (Kuenzler, Hodgkinson, Zindel, Bargetzi, & Znoj, 2011). Many loved ones receive less information about cancer than they need (Friðriksdóttir et al., 2011), which is concerning because they are often relied on to provide cancer information to the patient (Nagler et al., 2010). This lack of information, coupled with feelings of anxiety, may lead loved ones to seek out cancer information online (Kinnane & Milne, 2010), with research finding that 77% of loved ones had viewed online cancer information at least once (Lauckner, 2016). Among Internet-using caregivers for individuals with serious illness, 84% sought online health information, and 52% said this information helped them to cope with stress (Fox, Duggan, & Purcell, 2013). Seeking health information online has also been found to empower individuals to make healthcare decisions (Seçkin, 2010).

However, viewing online cancer information may also cause distress for loved ones (Klemb et al., 2003) as a result of seeing frightening content (Han & Belcher, 2001). Research in this area with patients’ loved ones is scarce, but a study of parents of children with cancer found that many avoided the Internet because of fear of what they might find, uncertainty over information accuracy, and the potential for information overload (Gage & Panagakis, 2012). In addition, an observational study of college students (N = 34) found that 44% of respondents felt confused when they last searched for health information, 26% felt frustrated, and 15% felt frightened (Buhi, Daley, Fuhrmann, & Smith, 2009). The literature suggests that loved ones of people with cancer will likely seek out online information about cancer, but the usefulness and effects of doing so are unclear. Using interviews with loved ones of people with cancer, this exploratory study used a grounded theory framework (Glaser, 1992) to examine experiences with, opinions of, and reactions to online cancer information.