

Talking With Death at a Diner: Young Women's Online Narratives of Cancer

Jessica Keim-Malpass, PhD, RN, and Richard H. Steeves, PhD, RN, FAAN

The current focus on young adult patients with cancer (patients aged 20–39 years at diagnosis) began with Bleyer (2002), who highlighted the deficits in the care and survival of adolescents and young adults with cancer. Young adult women survivors share similar concerns as other cancer survivors, such as lingering late effects of treatment, need for general social support, and access to healthcare services for general surveillance purposes. Because of patients' ages at diagnosis, special emphasis is placed on needs concerning reproduction and fertility worries, lack of adequate health insurance, risk of secondary malignancy, and disruption in educational and career attainment.

Although definitions vary regarding the age range associated with cancer in young adults, the focus of this study was on those aged 20–39 years at diagnosis (Geiger & Castellino, 2011). Bleyer helped to define this range when he first identified the disparities in cancer survival, as well as the unique psychosocial challenges that members of this age group share (Bleyer, 2002; Bleyer & Barr, 2009). Because of the general lack of age-specific support groups, many young adults are unable to fully engage in traditional clinic-based support groups because of what they perceive as age differences among themselves and other participants (StupidCancer.org, 2010). As a result, many young adults begin social networking through blogs and social media sites such as Twitter and Facebook to connect online. The online community for young adults with cancer is thriving, with many patients exchanging information and sharing their narratives through individual illness blogs that often act as diaries of the illness experience.

Background

Internet support groups and resources, including patient-initiated cancer blogs, have recently emerged among patients with cancer and are used in a number of different ways (Thielst, 2007). Some use the blog to

Purpose/Objectives: To gain a unique perspective of the experiences of young women with cancer (age 20–39 years at diagnosis) through analysis of their online illness blogs.

Design: A qualitative analysis of online narratives based on hermeneutic phenomenology.

Setting: Online illness blogs found through young adult cancer Web sites and social media sites such as Twitter.

Sample: 16 women, aged 20–39 years, who self-identified as being diagnosed with cancer and who initiated and maintained an illness blog based on their cancer experience.

Methods: Ethnographic immersion in online culture, thematic analysis based on line-by-line coding, and construction of themes and meanings.

Main Research Variables: Transitions from diagnosis, through treatment, to long-term survivorship.

Findings: Themes were identified as the women processed their diagnosis: living in the middle, new normal, urgency, and transition into the abyss.

Conclusions: The narratives shared on illness blogs offer an online place for expression of emotion, information exchange, and online social support. Emotional catharsis in the young women's narrative elucidated the experiences of transition through diagnosis, treatment, and survivorship that allow a better understanding of their emotional and psychosocial needs.

Implications for Nursing: Illness narratives are a naturalistic form of inquiry that allow nurses to understand the experience of the patient beyond the traditional clinic setting. This initial study provides a point for understanding the content of online narratives and has vast implications for nursing-based interventions.

share their own health-related narrative (Thielst, 2007), others initiated the blog as a way to keep family and friends updated on their care, and some began their blog as a way to promote advocacy and knowledge among the population of young adults with cancer. Uses of illness blogs also include seeking opinions about or validating information given by health providers and preparing information for upcoming visits