

# The Internet as a Source of Health Information: Experiences of Cancer Survivors and Caregivers With Healthcare Providers

Maria C. Dolce, PhD, RN, NEA-BC, FACHE

Data from the Health Information National Trends Survey examining health and cancer information seeking in the United States revealed divergent patterns between actual and preferred sources of health information during cancer survivorship (Hesse, Arora, Beckjord, & Finney Rutten, 2008; Hesse et al., 2005). Although cancer survivors reported their healthcare provider as their preferred source, the Internet was the first and most common source of health information. Little is known about how the Internet as a source of health information and resources is changing healthcare relationships in cancer survivorship.

Dissatisfaction with information and communication during clinical encounters with healthcare professionals has propelled cancer survivors to search for health information and resources on the Internet (Chen & Siu, 2001; Pereira, Koski, Hanson, Bruera, & Mackey, 2000; Sharf, 1997; Ziebland, 2004; Ziebland et al., 2004). Factors contributing to dissatisfaction and demand for health information include insufficient time spent on communication during the clinical encounter and healthcare providers' inability to keep up with the most current information and advances in cancer care (Anderson, Rainey, & Eysenbach, 2003).

Survivor empowerment emerges as a major construct in healthcare relationships in the context of Internet information seeking (Broom, 2005b; Dickerson, Boehmke, Ogle, & Brown, 2006; Pitts, 2004; Sharf, 1997; Ziebland et al., 2004). Well-informed survivors report increased confidence in their interactions with healthcare providers and greater engagement in care decisions as evidenced by asking more questions, requesting tests and treatments, and being better prepared for discussions (Bass et al., 2006; Broom, 2005b; Dickerson et al., 2006; Newnham et al., 2006). Empowering behaviors such as bringing information from online searches to the clinical encounter and questioning healthcare providers have been perceived by both survivors and healthcare providers as challenging the boundaries of medical expertise (Broom, 2005b;

**Purpose/Objectives:** To describe the experiences of cancer survivors and caregivers with healthcare providers in the context of the Internet as a source of health information.

**Research Approach:** Qualitative description.

**Setting:** Online cancer communities hosted by the Association of Cancer Online Resources.

**Participants:** Purposive sample of 488 cancer survivors, with varying cancer types and survivorship stages, and caregivers.

**Methodologic Approach:** Secondary data analysis using Krippendorff's thematic clustering technique of qualitative content analysis.

**Main Research Variables:** Survivorship, healthcare relationships, and the Internet.

**Findings:** Disenchantment with healthcare relationships was associated with failed expectations related to evidence-based practice, clinical expertise, informational support, and therapeutic interpersonal communication. Survivors and caregivers exercised power in healthcare relationships through collaboration, direct confrontation, becoming expert, and endorsement to influence and control care decisions.

**Conclusions:** Disenchantment propelled cancer survivors and caregivers to search the Internet for health information and resources. Conversely, Internet information-seeking precipitated the experience of disenchantment. Through online health information and resources, concealed failures in healthcare relationships were revealed and cancer survivors and caregivers were empowered to influence and control care decisions.

**Interpretation:** The findings highlight failures in cancer survivorship care and underscore the importance of novel interdisciplinary programs and models of care that support evidence-informed decision making, self-management, and improved quality of life. Healthcare professionals need to receive education on survivors' use of the Internet as a source of health information and its impact on healthcare relationships. Future research should include studies examining the relationship between disenchantment and survivorship outcomes.

Brotherton, Clarke, & Quine, 2002; Dickerson et al., 2006; Pitts, 2004; Sharf, 1997; Ziebland et al., 2004).

Current evidence suggests a paradoxical influence of the Internet on healthcare relationships. Several studies