Tracking and Journaling the Cancer Journey

Carol J. Hermansen-Kobulnicky, PhD, RPh, and Mary Anne Purtzer, PhD, RN

Many clinicians suggest that their patients keep track of something related to their illness. This article presents ideas pertaining to patients’ journaling or tracking aspects of their cancer experience. Drawing from a definition by Wilde and Garvin (2007), self-monitoring is the intentional measuring, recording, or observing of symptoms, sensations, daily activities, and/or thoughts and emotions. Greater awareness helps provide information to the patient and the health professional, improving the patient’s ability to self-manage (Wilde & Garvin, 2007). About one-third of patients with cancer do some form of self-monitoring without outside intervention (Hermansen-Kobulnicky, 2009; Hermansen-Kobulnicky, Wiedeholt, & Chewning, 2004), which nurses (and other health professionals) should consider in the process of care. The goal of the current article is to create a greater awareness of patients with cancer who self-monitor, along with the potential benefits (and shortcomings) of self-monitoring, and to help nurses to consider the potential opportunities for self-monitoring in their practice sites.

Patient self-monitoring is discussed in the context of various illnesses including asthma (Myers, 2002), migraine headaches (Baos et al., 2005), mental illness (Finnell & Ditz, 2007), and diabetes (Rossi et al., 2009). For example, patients who suffer from migraine headaches may track their migraines, writing down variables, such as time of day and diet, to better determine what triggers the headaches. Regarding patients with cancer, one opportunity for patient self-monitoring is in the area of pain management (de Wit et al., 1999; Marceau, Link, Jamison, & Carolan, 2007; Schumacher et al., 2002); however, researchers are beginning to show the importance and potential for patient self-monitoring throughout the cancer continuum (Hermansen-Kobulnicky, 2009; Hermansen-Kobulnicky et al., 2004; Hermansen-Kobulnicky & Purtzer, 2013; Hoekstra, de Vos, van Duijn, Schadé, & Bindels, 2006; Maunsell, Alnard, Dorval, & Labbé, 2000; Purtzer & Hermansen-Kobulnicky, 2013).

Self-monitoring is known to benefit patients; however, less is known about the direct benefits to practitioners. Patient benefits include a greater sense of control through better use of information and patients’ improved ability to resume normal activities, as well as empowered ability to self-advocate through the complex healthcare system (Purtzer & Hermansen-Kobulnicky, 2013). In addition, self-monitoring has been shown to improve symptom management (Hoekstra et al., 2006; Schumacher et al., 2002). Anecdotal reports and studies also highlight the usefulness of patient self-monitoring for improving communication between patients and providers (Fayers, 1995; Hermansen-Kobulnicky et al., 2004; Maunsell et al., 2000; Schumacher et al., 2002; Tucci & Bartels, 1998).

Although the literature supports the use of self-monitoring, what oncology professionals think or the extent to which they apply self-monitoring principles when working with their patients is not known. The current pilot study was intended to gather nurse perspectives on patients with cancer who self-monitor and the potential for self-monitoring to impact patient care.

Methods

A cross-sectional, descriptive pilot study of oncology nurses’ beliefs and behaviors regarding patients with cancer who self-monitor was conducted using an anonymous, self-administered survey. The study received institutional review board approval, and researchers gained access to oncology nurses via contacts made through two regional Oncology Nursing Society (ONS) affiliates. Data were collected from the sampling frame during an eight-week period. Hard-copy survey booklets were distributed to nurses attending a professional dinner program, with some nurses taking copies back to their practice sites. In total, 45 copies of the hard-copy survey were distributed; however, how many individual survey copies reached a potential...