Striving to Respond to Palliative Care Patients’ Pain at Home: A Puzzle for Family Caregivers

Anita Mehta, RN, PhD, S. Robin Cohen, PhD, Helene Ezer, RN, PhD, Franco A. Carnevale, RN, PhD, and Francine Ducharme, PhD

Patients with cancer at the end of life often experience pain. Patients with advanced cancer report a higher frequency and intensity of pain than patients with cancer at an earlier stage, with 20%–34% of those with advanced disease experiencing severe pain (Davis & Walsh, 2004). Pain is one of the most frequently reported physical symptoms for patients with advanced cancer (Coyle, Adelhardt, Foley, & Portenoy, 1990; Dobratz, 2001; Vallerand, Collins-Bohler, Templin, & Hasenau, 2007) and, perhaps, the most distressing (Davis & Walsh, 2004; Mercadante, Villari, Ferrera, & Casuccio, 2006). To date, many patients are receiving end-of-life care in their own homes and the day-to-day responsibility of pain management ultimately falls on their family caregivers (Aranda & Hayman-White, 2001; Aubin et al., 2006; Lobchuk & Vorauer, 2003; Redinbaugh, Baum, DeMoss, Fello, & Arnold, 2002; Vallerand et al., 2007). Pain management often presents as one of the most challenging aspects of the caregiver role (Vallerand et al., 2007). Part of this challenge is intervening for pain control, an ongoing issue for family caregivers because of the variability, number, and types of pain they are managing.

Background

Patients with advanced cancer often have many separate types of pain, varying in intensity, frequency, and location (Davis & Walsh, 2004; Lema, 2001; Portenoy, 1989). In fact, Twycross & Fairfield (1982) revealed that most patients with advanced cancer reported that they experience more than one type of pain; of these, 34% reported three or more types. Patients continue to experience and describe a number of distinct pains ranging from mild to severe in intensity (Davis & Walsh, 2004), and may, at times, have features of two different types of pain (e.g., nociceptive, neuropathic pain) (Christo & Mazloomdoost, 2008). The pain they experience may or may not be a result of their cancer or their cancer treatment (Christo & Mazloomdoost, 2008; Davis & Srivastava, 2003; Portenoy, 1989; Turk, Monarch, & Williams, 2002; Twycross & Fairfield, 1982; Twycross, Harcourt,