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

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**P**atients 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 &

**Purpose/Objectives:** To describe the types of pain patients in palliative care at home experience and how family caregivers assess them and intervene.

**Research Approach:** Qualitative using grounded theory.

**Setting:** Family caregivers' homes.

**Participants:** 24 family caregivers of patients with advanced cancer receiving palliative care at home.

**Methodologic Approach:** Semistructured interviews and field notes. Data analysis used Strauss and Corbin's recommendations for open, axial, and selective coding.

**Main Research Variables:** Pain, pain management, family caregivers, palliative care, and home care.

**Findings:** Caregivers assessed different types of pain and, therefore, were experimenting with different types of interventions. Not all family caregivers were able to distinguish between the different pains afflicting patients, and, consequently, were not selecting the most appropriate interventions. This often led to poorly managed pain and frustrated family caregivers.

**Conclusions:** The accurate assessment of the types of pain the patient is experiencing, coupled with the most appropriate intervention for pain control, is critical for optimal pain relief as well as supporting the confidence and feelings of family caregivers who are undertaking the complex process of cancer pain management.

**Interpretation:** Nurses involved with patients receiving palliative care and their family caregivers should be aware of all types of pain experienced by the patient and how caregivers are managing the pain. Nurses should be knowledgeable about different pain relief interventions to help family caregivers obtain accurate information, understand their options, and administer these interventions safely and effectively.

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,