

Helping Patients and Their Family Caregivers Cope With Cancer

Laurel L. Northouse, PhD, RN, FAAN
2012 Mara Mogensen Flaherty Lectureship

Family caregivers face multiple demands as they care for their loved ones with cancer, and these demands have increased dramatically in recent years. Patients with cancer now receive toxic treatments in outpatient settings and return home to the care of their family members. Some patients receive in-home infusions, which were unheard of a few years ago. Family caregivers provide tasks that were previously provided by nurses; however, caregivers lack the educational preparation that nurses receive.

Many family caregivers want more information because they feel unprepared to provide the care expected from them. In a large study of caregivers (N = 667) of newly diagnosed patients with cancer, van Ryn et al. (2011) found that almost half of the caregivers reported needing, but not receiving, training for administering medications, managing nausea and pain, changing dressings, and managing other symptoms. These caregivers also wanted more information about ways to deal with patients' emotional concerns (only 50% of them felt confident addressing patients' emotional needs). Family caregivers have difficulty dealing with patients' depression, anxiety, and uncertainty, and they need more guidance from health professionals on how to deal with the emotional aspects of cancer (Giarelli, McCorkle, & Monturo, 2003).

Family caregivers also lack the support they need to deal with their own emotional distress. Since 1988, in every study that my research team and I have conducted (e.g., Northouse, 1988; Northouse, Mood, Montie, et al., 2007), family caregivers reported receiving less support than patients. Although cancer is not in caregivers' bodies, its impact affects their lives and all aspects of their quality of life. Family caregivers are co-sufferers who also need support.

Having a well-prepared, confident family caregiver is beneficial. Research has documented that when caregivers feel more confident in providing care, patients have better symptom management (Campbell et

al., 2004), spend less time in bed, have more energy, and have higher physical quality of life (Keefe et al., 2003). In addition, more confident caregivers facilitate better patient medication management (Lau et al., 2010), and have less fatigue themselves, less caregiver strain, and more positive moods (Keefe et al., 2003).

Key Concept of Interdependence

As we consider the role of caregivers, one key concept does stand out—interdependence. Patients with cancer and their family caregivers have an interdependent relationship. Each person affects the other. Two meta-analyses (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hodges, Humphris, & Macfarlane, 2005) reviewed a large number of studies and found that a reciprocal relationship (i.e., correlation) existed between the emotional distress reported by patients with cancer and their spouse caregivers ($r = 0.29-0.35$). Their findings indicated that patients' distress affected spouses' distress and, conversely, spouses' distress affected patients. In another study, Segrin, Badger, Dorros, Meek, and Lopez (2007) examined how anxiety was transmitted between patients with cancer and their caregivers and found that the pathway from caregiver to patient had a greater effect on the transmission of anxiety within couples than did the pathway from patient to caregiver. According to Segrin et al. (2007), the pathway of influence from caregiver to patient often goes unrecognized by healthcare professionals. Their findings suggest that interventions that decrease caregivers' anxiety may decrease patients' anxiety and, subsequently, have a calming effect on patients.

Because patients with cancer and their family caregivers have an interdependent relationship, healthcare professionals need to treat the patient-caregiver dyad as the unit of care. Research indicates that the more we, as healthcare professionals, help caregivers, the more we will help patients (Bultz, Specia, Brasher, Geggie, &