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# The Impact of Cancer Pain on Family Caregivers

by Ann Goelitz, CSW

Today, there are an estimated 25 million family caregivers in the United States<sup>1</sup> and these numbers are expected to rise as early hospital discharges accelerate. Despite the evidence of the crucial function these caregivers perform, the healthcare system has not kept pace with their need for information, education, and support, particularly with regard to pain.

Numerous studies have documented the negative effect that pain has on an individual with cancer, but the effect on the family caregiver is oftentimes more insidious. Watching a loved one suffer unrelieved pain causes family caregivers distress. In turn, these caregivers may become depressed or anxious, or may have negative changes in their physical health or energy level. As cancer care professionals, it is our responsibility to support and educate the family members caring for our patients.

Many family caregivers report feeling simultaneously responsible for and powerless to help relieve and cope with cancer patients' pain.<sup>2</sup> One area of concern can arise when family caregivers are responsible for administering pain medications to the patient with cancer. Research has found that family caregivers are often uncertain about administering such medications—sometimes out of fear of addiction and sometimes out of worry about side effects.<sup>2,3</sup> These same fears may also make the patients hesitant to use pain medications.

Another factor that interferes in pain management is the belief that pain is inevitable or a sign of progressing disease,<sup>3</sup> a potential reality that is difficult for both the individual with cancer and his or her family caregiver to accept.

Special attention should be given to the communication aspect of the home care situation. Healthcare providers often need to facilitate this communication in order to effectively assess and manage pain in their patients with cancer. For example, some patients may not communicate openly about their pain to family members and/or professionals for reasons such as a desire to hide the true extent of their suffering. Patients with higher levels of concern about pain are less likely to report accurately to caregivers, potentially causing incongruent pain reports<sup>3</sup> and influencing treatment outcome.<sup>4</sup> Since incongruent pain reports have been shown to affect quality of life and mood for patients and caregivers, healthcare providers need to use interventions which promote open effective communication—alleviating distress and improving quality of life.

Communication problems can also occur when family members become the primary reporters when patients cannot communicate. Caregivers can misinterpret existential suffering as pain. In addition, the caregivers' own fear, distress, and exhaustion can affect their assessment. As healthcare professionals, we should not assume that caregiver assessments are more accurate than patient self-reports. Patient care can be complicated if, in an effort to be helpful, medications are administered based on the caregivers' rating of pain even when patients are able to communicate.

The bottom line is that we, the oncology experts, must provide assistance to our family caregivers to ensure that our patients remain at home comfortably and with adequate pain management. Fortunately, we are not alone in this effort. Many organizations, such as the American Pain Society, the American Geriatric Society, and the Joint Commission on Accreditation of Healthcare Organizations, promote pain education, including training on

how to assess and communicate about pain.

Stress management strategies and supportive counseling to reduce caregiver anxiety can also benefit family caregivers. Teaching family members integrative approaches to pain control, such as relaxation techniques, breathing exercises, and massage, is another way experts can contribute.<sup>4</sup> Finally, the cancer community needs to promote the involvement of family members in pain care, develop comprehensive methods to convey accurate and useful pain information, and offer opportunities for ongoing guidance on pain management to caregivers.

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## REFERENCES

<sup>1</sup>Levine C, ed. *Always on Call*. 1st Edition. New York, NY: United Hospital Fund; 2000.

<sup>2</sup>Lin CC. Barriers to the analgesic management of cancer pain: A comparison of attitudes of Taiwanese patients and their family caregivers. *Pain*. 2000;88:7-14.

<sup>3</sup>Lin CC. Congruity of cancer pain perceptions between Taiwanese patients and family caregivers: Relationship to patients' concerns about reporting pain and using analgesics. *J Pain Symptom Manage*. January 2001;21(1):18-26.

<sup>4</sup>Glajchen M, Blum D, Calder K. Cancer pain management and the role of social work barriers and interventions. *Health Soc Work*. August 1995;20(3):200-206.