



Global Year Against Cancer Pain

OCTOBER 2008 – OCTOBER 2009

Partners and Caregivers of Cancer Patients Having Pain

The Impact of Cancer Pain on Partners and Caregivers

Pain is a major concern not only for cancer patients, but also for their partners and caregivers [6]. Providing care for a cancer patient with severe or persistent pain is one of the most challenging and stressful tasks anyone can face; seeing a loved one suffer can be extremely emotionally demanding [5]. Research has shown that caregivers of cancer patients who are experiencing pain have much higher levels of tension, depression, and mood disturbance than caregivers of cancer patients who are pain-free [8].

Caregiving often involves multiple, unfamiliar tasks [4]. These may include monitoring pain and other symptoms, giving medications, dealing with side effects, providing help with positioning, and communicating with health professionals. In addition to dealing with the emotional and physical demands of providing care, partners and caregivers must adjust and cope with disruptions in their own daily lives.

People vary in their ability to cope with the demands of the caregiving role [4]. Some partners and caregivers are able to master caregiving tasks and seem to cope well with the challenges involved. Others, for a variety of reasons (e.g., child care and work responsibilities, health problems, and emotional distress), have more difficulty coping with these demands and report higher levels of depression and strain.

Involving Partners and Caregivers in the Medical Management of Cancer Pain

Given the profound impact of cancer pain on partners and caregivers, there is growing interest in involving these individuals in cancer pain management efforts [2]. Often, however, there are barriers to effectively engaging partners and caregivers in cancer pain management [9]. Barriers to the use of pain medications, the mainstay of cancer pain management, have been identified in both patients and their partners and caregivers [9]. For some, negative beliefs, attitudes, and misconceptions that they have about pain medication may lead them to underuse pain medications. For example, patients and their partners and caregivers may mistakenly assume that most cancer patients become addicted to pain medication, or they may believe that the side effects of pain medications are always severe and unmanageable. Patients and caregivers also may think that pain is part of having cancer and is something that simply must be endured and be tolerated. Patients often have concerns that if they complain about pain they will not be considered a "good patient." Collectively, these concerns can interfere with open communication about pain with health care providers, which is necessary to ensure an effective pain medication regimen.

Given these common concerns and misconceptions about pain medications, it is very important that patients, as well as their partners and caregivers, are educated about the importance of letting clinicians know about their pain and their concerns about pain medication [2]. Clinicians can then address these concerns, making it more likely that patients will take pain medications as prescribed, thereby enhancing pain control.

Educational programs have been developed to address patients' negative attitudes and beliefs about cancer pain medications [7,10]. These programs not only improve patients' knowledge about cancer pain and its management, but also reduce their pain [1]. Increasingly, these programs are involving partners and caregivers in the educational program. Caregivers who participate in such programs often report decreases in their psychological distress and improvements in their well-being.

Involving Partners and Caregivers in Psychological Management of Cancer Pain

There several reasons to involve partners and caregivers in psychological treatments for cancer pain [5]. First, when a partner or caregiver is involved in such treatments, he or she can learn how thoughts, feelings, and behaviors can influence the cancer pain experience and the role that the patient's own coping skills can play in

managing pain. Second, partners and caregivers can serve as coaches, reminding and reinforcing patients' practice and application of learned pain coping skills (e.g., relaxation, imagery, or activity pacing). Finally, when partners and caregivers learn coping skills along with the cancer patient, they then have the ability to use these skills to manage their own stress and negative emotions.

Negative beliefs and attitudes also can affect the willingness of cancer patients and caregivers to make use of psychological (and other nonpharmacological) pain management approaches [3]. Patients and their partners and caregivers may believe, for example, that if they admit that emotions such as anger or fear affect their pain, then the pain will not be taken seriously. Another fear is that if a psychological intervention (e.g., imagery) is effective in reducing pain, then the pain will be assumed to be psychological, rather than cancer-related. A partner or caregiver also may have negative attitudes toward psychological treatment and may discourage the patient from making use of psychological treatments that might be helpful.

Before using psychological pain management techniques (e.g., relaxation, imagery, or activity pacing) it is important to ask patients and their caregivers about their beliefs and concerns about these techniques [3]. It is helpful to provide educational information that addresses how the mind and body interact to influence cancer pain. The role that psychological factors (e.g., thoughts, beliefs, feelings, and behaviors) can play in the cancer pain experience needs to be discussed. One of the most effective educational tools is to give patients and caregivers opportunities to practice using specific pain coping skills and to provide guidance and feedback on how to adapt the skills to their specific needs. Programs for teaching cancer patients and caregivers psychological methods of pain control have been shown to increase caregivers' confidence in their abilities to help patients manage pain and other cancer symptoms [5].

References

1. Abernethy AP, Keefe FJ, McCrory DC, Scipio CD, Matchar DB. Behavioral therapies for the management of cancer pain: a systematic review. In: Flor H, Kalso E, Dostrovsky JO, editors. Proceedings of the 11th World Congress on Pain. Seattle: IASP Press; 2006. p. 789–98.
2. Gordon DB, Dahl JL, Miaskowski C, McCarberg B, Todd KH, Paice JA, Lipman AG, Bookbinder M, Sanders SH, Turk DC, Carr DB; American Pain Society Quality of Care Task Force. American Pain Society recommendations for improving the quality of acute and cancer pain management. *Arch Intern Med* 2005;165:1574–80.
3. Keefe FJ, Abernethy, AP, Campbell LC. Psychological approaches to understanding and treating disease-related pain. *Annu Rev Psychol* 2005;56:601–30.
4. Keefe FJ, Ahles T, Porter L, Sutton L, McBride C, Pope MS, McKinstry E, Furstenberg C, Dalton J, Baucom DA. The self-efficacy of family caregivers for helping cancer patients manage pain at end-of-life. *Pain* 2003;103:157–62.
5. Keefe FJ, Ahles TA, Sutton L, Dalton J, Baucom D, Pope MS, Knowles V, McKinstry E, Furstenberg C, Syrjala K, Waters SJ, McKee D, McBride C, Rumble M, Scipio C. Partner-guided cancer pain management at end-of-life: a preliminary study. *J Pain Symptom Manage* 2005;29:263–72.
6. Lin CC, Chou PL, Wu SL, Chang YC, Lai YL. Long-term effectiveness of a patient and family pain education program on overcoming barriers to management of cancer pain. *Pain* 2006;122:271–81.
7. Miaskowski C, Dodd M, West C, Schumacher K, Paul SM, Tripathy D, Koo P. Randomized clinical trial of the effectiveness of a self-care intervention to improve cancer pain management. *J Clin Oncol* 2004;22:1713–20.
8. Miaskowski C, Zimmer EF, Barrett KM, Dibble SL, Wallhagen M. Differences in patients' and family caregivers' perceptions of the pain experience influence patient and caregiver outcomes. *Pain* 1997;72:217–26.
9. Ward SE, Berry PE, Misiewicz H. Concerns about analgesics among patients and family caregivers in a hospice setting. *Res Nurs Health* 1996;19:205–11.
10. Wilkie DJ, Williams AR, Grevstad P, Mekwa J. Coaching persons with lung cancer to report sensory pain. Literature review and pilot study findings. *Cancer Nurs* 1995;18:7–15.

