

## PATIENT EDUCATION

# The PRO-SELF<sup>®</sup>: Pain Control Program— An Effective Approach for Cancer Pain Management

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**Purpose/Objectives:** To describe the PRO-SELF<sup>®</sup>: Pain Control Program, an educational approach that provides patients and family caregivers with the knowledge, skills, and nursing support needed to improve pain relief.

**Data Sources:** Published research studies, articles, and conference abstracts.

**Data Synthesis:** Patients with cancer and family caregivers lack knowledge about pain management and side effects. Engaging in self-care behaviors improves patients' health outcomes.

**Conclusions:** The PRO-SELF: Pain Control Program is an effective approach that can be used to help patients with cancer and their family caregivers obtain the knowledge and skills that are needed to manage pain. Three key strategies for delivering the PRO-SELF program are (a) provision of information using academic detailing, (b) skill building with ongoing nurse coaching, and (c) interactive nursing support.

**Implications for Nursing:** Adequate pain relief is vital to decreasing cancer morbidity and improving patients' quality of life. The PRO-SELF: Pain Control Program should be implemented in all settings where cancer care takes place.

### Key Points . . .

- Cancer pain is undertreated and interferes with daily activities, social interactions, sleep, and mood state, resulting in reduced quality of life.
- Patients with cancer and their family caregivers lack knowledge and skills about cancer pain management.
- The PRO-SELF<sup>®</sup>: Pain Control Program uses education along with repeated reinforcement, skill building, and ongoing nursing support to improve self-care pain management in patients with cancer and their family caregivers.
- Cost-effective adaptations of the PRO-SELF: Pain Control Program in a variety of settings must be tested and implemented.

Pain occurs in 30%–70% of patients with cancer (Bonica, 1985; Miaskowski & Dibble, 1995; Portenoy et al., 1992). Unrelieved pain interferes with performance of daily activities and results in altered mood states, such as anger and depression, and a diminished quality of life (QOL) (Burrows, Dibble, & Miaskowski, 1998; Glover, Dibble, Dodd, & Miaskowski, 1995). Despite the prevalence of cancer pain and its impact on individuals, negative attitudes and lack of knowledge on the part of healthcare professionals, patients, and family caregivers result in the undertreatment of cancer-related pain (Cleeland, 1984; Ward et al., 1993).

A number of efforts have been directed toward changing healthcare professionals' knowledge and attitudes about pain management, including the development of clinical practice guidelines and standards (American Geriatrics Society Panel on Chronic Pain in Older Persons, 1998; Jacox, Carr, Payne, et al., 1994; Joint Commission on Accreditation of Healthcare Organizations, 1999). However, little has been done to change

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patients' or family caregivers' knowledge, attitudes, and behaviors regarding cancer pain management.

The PRO-SELF<sup>®</sup>: Pain Control Program was designed to provide patients and family caregivers with the knowledge, skills, and nursing support needed to better assess and manage their own pain. "Pro-self" means "for you" and is based on the assumption that people who participate in self-care activities can improve their health outcomes (Orem, 1991). The PRO-SELF: Pain Control Program is the third in a series of self-care interventions in the PRO-SELF Program that were developed and tested in large randomized clinical trials (Dodd et al., 1996, 2000, in press; Larson et al., 1998). The PRO-SELF Program consists of three dimensions: provision of information, skill building, and interactive nursing support aimed at teaching patients how to prevent and manage the side effects of their disease and treatment.

The PRO-SELF: Pain Control Program used these three dimensions and was enhanced by the use of nurse coaching (Carrieri-Kohlman, Gormley, Douglas, Paul, & Stulbarg, 1996; Gilliss et al., 1993; Gortner et al., 1988) and an educational strategy called academic detailing (Soumerai & Avorn, 1990). Because of the nature of the skills (e.g., modifying the analgesic administration schedule for improved pain relief) and the changes in attitudes (e.g., regarding the use of opioid analgesics) that patients were developing, nurse coaching was a more active component of the skill-building dimension in this intervention than in the previous PRO-SELF programs. These enhancements were considered natural evolutionary steps in the development of the PRO-SELF Program as it was tested and used in a wide range of self-care applications.

The effectiveness of the PRO-SELF: Pain Control Program was tested in a large randomized clinical trial with patients with cancer who had metastatic bone pain and their primary family caregivers (if they had one) (Miaskowski et al., submitted for publication). Patients were randomized to receive either the PRO-SELF: Pain Control Program ( $n = 115$ ) or standard care ( $n = 97$ ). At the end of each day, patients recorded their pain scores and all analgesic medication taken. The PRO-SELF group received individualized teaching and coaching about cancer pain management during three home visits and three telephone calls over six weeks. Intake of all analgesic medications increased significantly ( $p = 0.001$ ) in the PRO-SELF group. The intake of around-the-clock opioid medications increased on average by 50 mg per day (expressed in morphine equivalents) in the PRO-SELF group, whereas opioid analgesic intake in the control group did not change over the five weeks of data collection. Although clinically significant, this difference was not statistically significant. The PRO-SELF patients' average, least, and worst pain intensity scores decreased an average of 1.3 ( $p = 0.0001$ ), 0.7 ( $p < 0.0001$ ), and 1.4 ( $p = 0.04$ ) units, respectively, on a 0–10 numeric rating scale. Hours per day in pain decreased an average of 5.5 hours per day.

The purpose of this article is to provide a detailed description of all of the components of the PRO-SELF: Pain Control Program for use by nurses who care for patients with cancer.

## Background

### Knowledge and Attitudes About Pain and Pain Management: Patients With Cancer

A limited amount of information is available on the knowledge that patients with cancer have of pain and its treatment.

Ferrell and Schneider (1988) evaluated 75 patients with chronic cancer pain. Eighty-three percent of patients at home and 60% of hospitalized patients took their pain medication less frequently than ordered because of fears of addiction and tolerance, misunderstandings about dosages, and feelings that their pain could not be treated adequately.

The current study's research group compared the knowledge and attitudes of outpatients, with and without cancer pain, about pain and pain management (Yeager, Miaskowski, Dibble, & Wallhagen, 1997). Patients with cancer-related pain knew significantly more about pain and its management than pain-free patients. However, in both groups of patients, mean knowledge scores were below 60% on a 0%–100% scale. Older people had significantly less knowledge about pain and pain management than younger people. In addition, patients with more education and those with higher pain intensity ratings scored higher on the knowledge questionnaire. The results of the current study demonstrated that outpatients with cancer with or without pain have limited knowledge about pain and negative attitudes about pain management. These findings suggested that patients need more education about pain and effective pain management strategies.

Despite this need, few studies have tested the effectiveness of patient-education strategies to manage pain. Ferrell, Ferrell, Ahn, and Tran (1994) developed an educational intervention for elderly patients with cancer ( $N = 80$ ) and their primary family caregivers that consisted of information about pain and pharmacologic and nonpharmacologic treatments. An RN provided the intervention during three home visits over two weeks. Study outcomes were evaluated at one and three weeks after the intervention visits. The investigators found an increase in knowledge about pain, increased opioid intake, and decreased pain intensity and distress. However, a control group did not exist and little information was provided on how patients were instructed to tailor their pain prescriptions to best meet their needs.

Other than the randomized clinical trial of Miaskowski et al. (submitted for publication), only two randomized clinical trials have tested the effectiveness of a patient intervention to improve cancer pain management. DeWit et al. (1997) studied patients with cancer ( $N = 313$ ) who were experiencing chronic pain to determine whether a Pain Education Program (PEP) could improve patient outcomes. Patients were recruited from an inpatient oncology unit and stratified based on whether they would receive district (i.e., public health) nursing at discharge. Following stratification, patients were randomized to receive either a PEP or standard care. The PEP was tailored to meet the individual needs of patients and consisted of educating patients about pain management and how to report pain using a pain diary, communicate about pain, and contact healthcare providers. Specially trained nurses administered the PEP in the hospital and by telephone at three and seven days postdischarge. Follow-up assessments were completed at two, four, and eight weeks postdischarge. Results demonstrated a significant increase in pain knowledge ( $p < 0.01$ ) and a significant decrease in pain intensity ( $p < 0.001$ ) in the patients in the intervention group. However, the decrease in pain intensity was seen only in the group without district nursing. No evaluation of analgesic intake was done as part of this study, so determining what factors contributed to the improvement in pain intensity scores is difficult.

Clotfelter (1999) studied the effectiveness of an instructional videotape on the pain intensity of a small group of elderly patients with cancer (N = 36). The patients were randomized to view the videotape and receive a copy of the consumer version of *Management of Cancer Pain* (Jacox et al., 1994) or standard pain management instruction by their physicians or other clinic staff. The videotape was 14 minutes long and covered information on addiction, tolerance, communicating pain and effectiveness of pain management to healthcare providers, types of pain medication, timing of administration, routes of administration, benefits and risks, side effects and their management, and nonpharmacologic interventions. Both groups of patients were asked to rate their pain on a 100 mm visual analogue scale just prior to receiving the videotape or standard care and two weeks after the intervention at two different points on a single day. The results indicated that the pain intensity measured two weeks after the intervention was significantly lower in the experimental group than in the control group ( $p = 0.021$ ), although both groups experienced an increase in pain during the two-week period compared with baseline. Clotfelter did not measure a change in analgesic intake before or after the intervention, making it difficult to evaluate what factors accounted for the decrease in pain scores. Additionally, the pain intensity ratings were obtained in only three single moments in time, making it difficult to determine if the difference in pre- and post-test pain ratings represented a real pattern of reduced pain intensity.

## The Role of Family Caregivers in Pain Management

Several studies (Ferrell, Cohen, Rhiner, & Rozek, 1991; Ferrell, Ferrell, Rhiner, & Grant, 1991; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Ferrell, Rhiner, Cohen, & Grant, 1991; Yeager, Miaskowski, Dibble, & Wallhagen, 1995) have shown that family caregivers, not just patients, experience the crisis of cancer-related pain. Family caregivers of patients with cancer who are experiencing pain often have different perceptions of patients' pain intensity and the effect of pain on their daily activities. Ferrell, Cohen, et al.; Ferrell, Ferrell, et al. (1991); Ferrell, Rhiner, et al.; and Yeager et al. (1995) found that family caregivers often rated patients' pain intensity and distress higher than the patients did. Family caregivers also have limited knowledge of cancer pain and its management, receiving a mean score of 57% on the knowledge and attitudes subscale of the Pain Experience Scale (Yeager et al., 1995) and 53% on the Family Pain Questionnaire (Ferrell et al., 1995). Yeager et al. (1995) found that family caregivers more often than patients believed that pain medications interfered with breathing. Ferrell et al. (1995) found that family caregivers were more likely than patients to believe that cancer pain could not be relieved. From interviews with 85 family caregivers, Ferrell, Cohen, and colleagues discovered that family caregivers are involved actively in their family members' pain management and have concerns about deciding what to give and when, have fears of addiction, are engaged in reminding and encouraging patients, and sometimes feel they are responsible to do "everything." Given the different perceptions of family caregivers about patients' pain and the role they play in patients' pain management, including family caregivers in any intervention is essential to improving patients' knowledge and skills in pain management.

## Academic Detailing

Academic detailing is an outreach education strategy found to be effective in changing physicians' performance, particularly their prescribing behaviors, and improving their patients' health outcomes (Soumerai & Avorn, 1990; Thomsen O'Brien et al., 2001). Academic detailing is based on adult learning principles and includes the following approaches: (a) determining baseline knowledge and motivations that support the current behavior, (b) defining clear educational and behavioral objectives, (c) using a credible individual to deliver the information, (d) stimulating active participation of the learner in the process, (e) using concise teaching materials, (f) highlighting and repeating key information, and (g) providing positive reinforcement of behavior changes in follow-up visits (Soumerai & Avorn).

Outreach education is defined as one or more personal visits by a trained person to a healthcare provider in the provider's own setting (Soumerai & Avorn, 1990; Thomsen O'Brien et al., 2001). The visit consists of the provision of focused information (either case based or research based), clinical practice guidelines, and written or audiovisual materials or publications; the information is delivered by a credible individual such as a pharmacist, physician, educator, or other knowledgeable person. The outreach visit may be combined with other strategies, such as auditing and feedback on the individual's performance in a certain area (e.g., prescription of antibiotics), reminders, sharing information from opinion leaders (i.e., acknowledged experts in the area), patient-mediated education via printed information or counseling, and postintervention follow-ups or evaluations.

To date, no randomized clinical trials have investigated the effectiveness of academic detailing in changing patient health behaviors where patients are the primary target of the intervention. A few uncontrolled studies, however, included patient education in addition to the physician-mediated strategies (Blackstien-Hirsch, Anderson, Cicutto, McIvor, & Norton, 2000; Preston, Scinto, Grady, Schulz, & Petrillo, 2000; Rabin et al., 1994; Stergachis, Fors, Wagner, Sims, & Penna, 1987). Blackstien-Hirsch et al. used academic detailing with a volunteer group of primary care physicians in an effort to increase their use of corticosteroids relative to beta-adrenergic agonists. The physicians' patients with asthma (N = 195) were invited to participate in two educational sessions, two weeks apart, that were provided by their physicians and focused on self-management. In addition to the teaching, the patients were given an asthma symptom and medication diary to use for two weeks. At the six-month follow-up, statistically significant improvements resulted in the physicians' prescribing behaviors and patients' knowledge of asthma and QOL, although no change occurred in patients' health services use. The investigators did not describe the content of the teaching sessions or the methods used to teach the patients.

## Nurse Coaching

Gortner and colleagues (1988) and Gilliss and colleagues (1993) demonstrated the efficacy of a psychoeducational intervention with nurse coaching, administered via telephone, to improve patient outcomes following open-heart surgery. The purposes of the telephone coaching, completed weekly for four weeks following discharge and again at six and eight weeks, were to (a) provide frequent and individualized support to patients and partners during the immediate home recovery period, (b) reinforce the educational content of the intervention provided prior to discharge from the hospital, and

(c) provide information for the formation of self-efficacy expectations, particularly regarding walking, lifting, stair climbing, general exertion, and, where appropriate, working. The patients in the coaching intervention group reported increased activity in the form of walking compared with the control group who received standard postoperative care. The authors suggested that their study must be replicated using a “more intense approach” to change patient behaviors.

### The PRO-SELF: Pain Control Program

The PRO-SELF: Pain Control Program consists of teaching and coaching patients how to tailor their prescribed and over-the-counter analgesics to best relieve their pain. As outlined in Table 1, the intervention was provided in three home visits and three telephone calls during a six-week time period, with either a visit or a phone call occurring each week. The majority of the teaching and the initial coaching to optimize the analgesic regimen for improved pain relief occurred during the first home visit. Evaluation of the effects of recommended changes, reinforcement of the teaching, and further coaching to change the analgesic regimen occurred in the subsequent home visits and telephone calls.

Before receiving the intervention, patients recorded their pain every day before bedtime for seven days. They recorded their least, average, and worst pain for the day using a 0 (no pain) to 10 (worst pain imaginable) numeric rating scale. Also at baseline, patients and their family caregivers completed a questionnaire (Ferrell, 1994) that assessed their knowledge of and attitudes toward cancer pain and its management, side effects of analgesics, and the concepts of addiction, tolerance, and dependence. Figure 1 displays the items on the question-

naire and the correct responses. During the final home visit, patients and family caregivers again completed the knowledge and attitudes questionnaire as a means of evaluating the effectiveness of the PRO-SELF: Pain Control Program.

Three research nurses provided the intervention, each to a different group of participants that lived within a one and one-half hour driving distance from the nurses’ own homes. These nurses were experienced in oncology, pain management, or both. After being hired, the nurses received a six-hour orientation to the study, teaching materials, and data collection procedures. The orientation attempted to be comprehensive regarding how the nurses should advise patients around common pain control issues that might arise. However, less common issues occasionally were encountered, and each nurse’s particular level and type of pain management experience determined some of the counseling in these cases.

### Provision of Information (Academic Detailing)

During the first home visit, the research nurses used the academic detailing approach to provide the information needed for patients to change their knowledge, attitudes, and behaviors regarding the use of analgesic medication. During this visit, the research nurses reviewed the patients’ and family caregivers’ responses to each of the items on the knowledge and attitude questionnaire. The nurses identified specific areas of knowledge deficit and focused the education in these areas. To illustrate the correct responses to the knowledge and attitude questionnaire and provide reinforcement of the teaching, the research nurses gave the patients and family caregivers the PRO-SELF: Pain Control Booklet. The PRO-SELF: Pain Control Booklet was written at an eighth-grade reading level and contained each item on the knowledge and attitude

Table 1. Components of the PRO-SELF®: Pain Control Program

Time Period	Intervention
Week 1	Nurses meet patients and family caregivers in their homes. <ol style="list-style-type: none"><li>1. Conduct the academic detailing session.<ul style="list-style-type: none"><li>• Review answers to questions on the knowledge and attitude questionnaire.</li><li>• Review the PRO-SELF: Pain Control Booklet and use the teaching guide to enhance information in the booklet.</li></ul></li><li>2. Review baseline pain scores and pain pattern.</li><li>3. Review pain medications and drug administration schedule.</li><li>4. Coach patients regarding optimal administration of pain medications; set up medications in the pillbox.</li><li>5. Instruct patients on how to complete daily PRO-SELF Pain Management Diary.</li><li>6. Review side effects checklist and discuss prevention and management of side effects.</li><li>7. Coach patients on how to discuss with their healthcare providers the need for change in the pain management plan, if appropriate.</li><li>9. Review how to contact nurses for pain management questions.</li></ol>
Week 2	Nurses telephone patients and family caregivers. <ol style="list-style-type: none"><li>1. Review pain scores and medication use during the previous week.</li><li>2. Reinforce teaching and coaching about use of analgesics, side effects management, and concerns about addiction, if needed.</li><li>3. Determine if patients had to see healthcare providers for pain management or if analgesic prescription changed during the previous week.</li><li>4. Answer questions about pain management.</li></ol>
Week 3	Nurses visit patients and family caregivers at home. <ol style="list-style-type: none"><li>1. Review pain scores and medication use during the previous week.</li><li>2. Reinforce teaching and coaching about use of analgesics, side effects management, and concerns about addiction, if needed.</li><li>3. Determine if patients had to see healthcare providers for pain management or if analgesic prescription changed during the previous week.</li><li>4. Answer questions about pain management.</li></ol>
Week 4	Telephone call—Same as week 2
Week 5	Telephone call—Same as week 2
Week 6	Home visit—Same as week 3

1. Cancer pain can be effectively relieved. ☐ **Agree** ☐ Disagree
2. Pain medicines should only be given when pain is severe. ☐ Agree ☐ **Disagree**
3. Addiction refers to a person's desire to use drugs for their effects on the mind or emotions rather than for the medical use of relieving pain. Most cancer patients on pain medicines will become physiologically addicted to the medicines over time. ☐ Agree ☐ **Disagree**
4. Drug dependence means that a person would go through withdrawal if a pain medicine were stopped. Most cancer patients on pain medicines will become physically dependent on the medicines over time. ☐ **Agree** ☐ Disagree
5. It is better to give pain medicines around the clock (on a schedule) rather than only when needed. ☐ **Agree** ☐ Disagree
6. It is better to give the lowest amount of medicines possible early on so that larger doses can be used later as pain increases. ☐ Agree ☐ **Disagree**
7. Treatments other than medicines (such as massage, heat, and relaxation) can be effective for relieving pain. ☐ **Agree** ☐ Disagree
8. Pain medicines can often interfere with breathing. ☐ Agree ☐ **Disagree**
9. Patients are often given too much pain medicine. ☐ Agree ☐ **Disagree**

### Figure 1. Items From the Patient Pain Questionnaire

Note. From *Patient Pain Questionnaire*, by B.R. Ferrell and City of Hope National Medical Center, 1994, <http://prc.coh.org>. Copyright 1994 by B.R. Ferrell. Adapted with permission.

Correct responses are highlighted in bold and underlined.

questionnaire, the correct responses with a rationale, and key points regarding each item that reinforced the teaching. No provisions were made for participants whose reading level was less than an eighth-grade level because earlier studies with similar patient populations indicated that the mean educational level achieved was one to two years of college. To ensure consistency in the teaching among the research nurses, the nurses used a teaching guide that included the same information as the PRO-SELF: Pain Control Booklet and additional supporting information. The booklet and teaching guide were based on a clinical practice guideline, *Management of Cancer Pain*, which was developed by an expert panel convened by the Agency for Health Care Policy and Research (Jacox et al., 1994). Both items can be retrieved from <http://nurseweb.ucsf.edu/conf/cancerpain>.

During the teaching, when differences occurred in responses from patients and family caregivers on particular knowledge items, the nurses encouraged discussion of these differences so that the patients and family caregivers were aware of each other's beliefs and attitudes. Also during the first home visit, the nurses reviewed all medications that patients were using for pain, both prescribed and over-the-counter, and how they were being taken. These medications included opioids, nonopioids, and coanalgesics (e.g., antidepressants, anti-convulsants, anxiolytics, antispasmodics). The nurses taught the patients and family caregivers how to use the PRO-SELF Pain Management Diary, which patients completed at bedtime each day. The PRO-SELF Pain Management Diary can be retrieved from <http://nurseweb.ucsf.edu/conf/cancerpain>. As illustrated in Figure 2, the upper half of each page was used to record patients' least, average, and worst pain for that day, us-

ing the 0–10 scale, and the number of hours per day they experienced pain. The nurses then taught the patients and family caregivers how to record the analgesic medications on the bottom half of the diary, categorizing them as “routine” or “extra” (i.e., as needed [PRN]). The nurses recorded the information found on the prescription label of each medication (i.e., the name of the medication, the dosage, number of tablets, frequency of administration). Usually, the nurses recorded this information on the first few pages for the patients to use as a prototype and instructed them to complete each page in the same manner. If one or more of their pain medications was discontinued or another one added, patients were instructed to record this information on that day's diary.

In the second column, the nurses recorded the times the patients usually took their routine medications. For example, if they were prescribed MS Contin® (Purdue Pharma, Stamford, CT), 30 mg, one tablet, twice a day, and patients usually took the medication at 8 am and 8 pm, the nurses recorded these times. The nurses taught patients to record at the end of each day the times they took their PRN medications. To indicate that they had, in fact, taken the medications, patients were asked to circle the time recorded in the diary. The family caregivers were encouraged to assist the patients in completing the diary. Patients' adherence with completing the diary was quite high (approximately 90%). This was attributed to the support of the family caregivers and the follow-up visits and telephone calls by the nurses.

The nurses also gave the patients a weekly pillbox (One-Day-at-a-Time Weekly Medication Organizer Tray™, Apothecary Products, Inc., Burnsville, MN) to remind them to take their pain medications. As seen in Figure 3, the pillbox is organized by the days of the week and each day has four time

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Please fill out this page before going to bed, keeping in mind how your pain was during the day.

0	1	2	3	4	5	6	7	8	9	10
no pain		mild			moderate			severe		worst pain imaginable

1. Using the scale above, choose a number that best describes
  - A. The average amount of pain you experienced today.
  - B. The least amount of pain you experienced today.
  - C. The worst amount of pain you experienced today.
2. How many hours did you have pain today? \_\_\_\_\_  
(0–24 hours)

Directions: At the end of each day, please indicate the times you took your routinely scheduled pain medicine and any extra pain medicine you needed.

	Medicine	Time
Routine		
Extra		

### Figure 2. Example of One Day From the PRO-SELF® Pain Management Diary

Note. From *PRO-SELF Pain Management Diary*, by C. Miaskowski, 1995. Copyright 1995 by C. Miaskowski. Reprinted with permission.



**Figure 3. One-Day-at-a-Time Weekly Medication Organizer Tray™**

slots for medications. One day's medications can be conveniently removed from the organizer and carried separately. The nurses taught patients to fill the pillbox for the week, placing their routine and PRN analgesics and stool softener in the time slots according to the schedule agreed upon.

An analysis of the patients' perception of the effectiveness of the pillbox indicated the vast majority of patients liked using the pillbox. It reminded them when their pain medications were due and when it was time to refill the prescription (Miaskowski et al., 2001).

### Skill Building

The nurses worked with the patients to build their skills in (a) assessing their pain and its response to the analgesics, (b) developing an analgesic regimen that best met their pain management and lifestyle needs, (c) planning strategies for the prevention and treatment of analgesic side effects, and (d) speaking with their healthcare providers if the analgesic prescription was not adequate. The nurses used frequent reinforcement and coaching strategies to assist patients and family caregivers in implementing the new skills. These strategies began with the first home visit as the nurses helped patients see that they could experience improved pain relief by altering the times and frequency of their analgesic intake (while staying within the parameters of the prescription). Such advice always was accompanied by instructions on how to prevent and treat the side effects that could occur with the increased amount of medications.

Most of the coaching took place during subsequent telephone calls and home visits as patients tried to incorporate the new information and skills into their daily lives. For example, while reviewing a patient's pain and analgesic prescription during the first home visit, a nurse may have ascertained that the patient often awoke in the middle of the night in pain. The nurse would coach the patient to add a dose at bedtime if the patient had doses left over or to shift the medication schedule to allow coverage during the nighttime hours. In subsequent telephone calls or home visits, the patient would inform the nurse of her or his pain scores for the previous week and how effective the earlier advice had been. The nurse would help the patient solve any problems with implementing the plan, such as forgetting to take the medication before bedtime. The nurse assessed if side effects increased and what the patient did about them. If necessary, the earlier teaching would be repeated and the new skills reinforced.

To integrate the new behaviors into the way they dealt with their pain, patients had to be able to assess their pain and its response to the analgesic regimen. Use of the pain management diary helped patients think about their pain, its relationship to the day's activities, and the effect of changing the analgesic plan. Patients did not know intuitively how to use the diary in this way, and they needed coaching to do so (Schumacher, Koresawa, West, Dodd, et al., 2002).

Often, patients were taking minimal amounts of their analgesics and experiencing worst or average pain scores in the moderate-to-severe range (i.e., five or higher) (Miaskowski et al., submitted for publication). When the nurses questioned the patients as to why they were not taking more medication when their prescription allowed them to take more, they gave a variety of reasons. Lack of information on how to take pain medications was a common response. Many patients stated they were not aware that they could take a PRN drug on a routine basis, or otherwise manipulate their medication schedule. Many expressed fears of side effects, with constipation and sedation cited as the most common. Others described negative experiences with pain medications in the past. A few indicated a need to have a certain level of pain, which they used as an indicator of how much activity they could do without "overdoing it." Occasionally, patients expressed fears of addiction or dependence, but, for most patients and family caregivers, these fears were put to rest with the teaching in the first home visit. Rarely, patients expressed a resistance to taking medication of any sort, of adding more "chemicals" to their systems (Schumacher, West, et al., 2002).

If patients were reluctant to increase their analgesic intake to cover most or all of the day, the nurses negotiated a gradual increase in their intake to one or two tablets twice, three times, four times, or more per day. The nurses coached the patients to evaluate their pain a day or two after each increase and to proceed with the next increase if the pain score was above 2.5 or remain at the current dose if the pain was 2.5 or lower. The nurses also provided concurrent information about strategies to prevent or treat the anticipated constipation (see Figure 4). Family caregivers were encouraged support the change in analgesic intake and to remind patients about their medication schedule, as well as the prevention and treatment of side effects.

The nurses attempted to elicit pertinent history related to the patients' and family caregivers' experience with pain medications and offered strategies for dealing with issues of concern to them. If patients had had a previous negative experience

9. Pain medicines can often interfere with breathing. ☒ **Disagree** ☐ Agree

- Pain medicines given to treat cancer pain usually do NOT affect your breathing.
- One of the major problems with pain medicines is CONSTIPATION.
- Some things you can do to prevent constipation are
  1. Drink four to six glasses of water a day.
  2. Drink a small glass of prune juice every day.
  3. Eat fruits and vegetables.
  4. Take the following medicines: Colace® (Shire US, Inc., Florence, KY) 100 mg–200 mg two or three times per day; senna 1–2 pills before bed.

**Figure 4. Item 9 From the PRO-SELF®: Pain Control Booklet**

Note. From *PRO-SELF Pain Control Booklet*, by C. Miaskowski, 1995. Copyright 1995 by C. Miaskowski. Reprinted with permission.

Correct response is highlighted in bold and underlined.

with pain management, the nurses tried to explore the nature of the experience with them. Teaching alone often was sufficient to overcome patients' reluctance. Occasionally, though, patients related a history of intractable side effects to a particular class of analgesics that made them extremely apprehensive to try again, or stigmatization of either themselves or a family member around the issue of chronic opioid administration (Schumacher, West, et al., 2002).

In the case of intractable side effects, the nurses coached patients on more aggressive prevention and management of these side effects or offered information about alternative analgesics that they could suggest to their healthcare providers. In this study, fears of addiction or stigmatization were not common barriers to adequate analgesia after the initial teaching was complete, but when present, they impeded adequate analgesia in the few patients who held onto these fears and whose attitudes could not be altered. In this situation, the nurses reinforced the notion that addiction is the use of a drug for its effect on the mind or the emotions and it rarely occurs in the treatment of cancer pain. The nurses reminded patients that a difference exists between psychological addiction, physical dependence, and tolerance. Physical dependence (i.e., the experience of withdrawal symptoms if an opioid is abruptly discontinued) and tolerance (i.e., increasingly larger doses of an opioid are needed over time to obtain pain relief) are the expected pharmacologic effects of opioid medications and can be managed. Additionally, patients were helped to see that adequate pain control was important to enable them to perform their work and the activities they enjoy, as well as spend time with the people they love. A qualitative analysis of the clinical interactions between nurses, patients, and family caregivers documented the many difficulties that patients encountered when trying to put a pain management plan into effect. This analysis is reported elsewhere (Schumacher, Koresawa, West, Hawkins, et al., 2002).

As patients followed the nurses' advice and began to experience increased side effects, primarily constipation and sedation, they often became discouraged and wished to go back to their previous level of pain medication. The nurses reminded them of specific strategies to prevent and treat these side effects and helped them see the improvement in their pain scores and the increased activity that this allowed them. Persuading the patients to change their behaviors in this way was not an easy or simple task. A qualitative analysis of the audiotaped interactions among the patients, family caregivers, and research nurses found that some patients would rather live with their pain than the side effects of their analgesics (Schumacher, Koresawa, West, Hawkins, et al., 2002). For example, patients who were employed, had young children, or frequently drove their cars were reluctant to allow themselves even a few days to become tolerant to the sedative effects of their analgesic medications. The nurses tried to help them strategize around these constraints, such as suggesting that they increase their medications when they had a weekend off or someone was available to take care of the children.

Occasionally, patients were taking their prescribed analgesics at the maximal amount recommended and experiencing inadequate relief or the number of hours per day that they were in pain necessitated the use of long-acting opioids. When this situation occurred, the nurses coached patients on how to speak with their healthcare providers to obtain a change in the analgesic prescription. A number of studies have

shown that some people have difficulty speaking with their healthcare providers about their pain (Brockopp, Warden, Colclough, & Brockopp, 1996; Coward & Wilkie, 2000; Ward et al., 1993). A recommended script (see Figure 5) was given to patients to use that stated succinctly what patients' pain scores were with optimal use of the prescribed analgesics and the effect of the pain on their ability to function. The script can be retrieved from <http://nurseweb.ucsf.edu/conf/cancerpain>. One of the benefits of this script was that it could be used as a template for discussing other symptoms with healthcare providers.

Many patients were quite liberated by the teaching. Once they received the information and understood their lack of knowledge, they were willing to change their approach to taking analgesic medications or speak with their healthcare providers about a change in their pain prescription. It was as if the nurses had given them "permission" to make changes in something they had always viewed as the sole province of healthcare providers. Other patients, however, had compelling reasons why they were not taking adequate analgesics, and the provision of information and persistent coaching did not alter their approaches (Schumacher, West, et al., 2002). For example, several of the patients who had had a stigmatizing experience with previous opioid use could not be persuaded to take their prescribed opioids.

## Interactive Nursing Support

Supportive, interactive nursing care was integral to successful implementation of the provision of information and skill-building dimensions of the PRO-SELF: Pain Control Program. The program called for complex changes in knowledge, attitudes, and behaviors that often were difficult to initiate and sustain for many patients. Nurses' skills as expert clinicians, teachers, and coaches were the foundation for helping patients see the negative impact of pain on their lives and the ways they could more effectively manage their analgesic regimens. Beyond that, however, the nurses' underlying concerns for and persistence in helping the patients and their family caregivers deal with their individual pain issues promoted a necessary trust relationship. This relationship facilitated the steps patients needed to take to internalize the information and implement the new behaviors (e.g., increase analgesic use or alter timing of medication intake, manage side effects, speak with healthcare providers). Although the nursing support was provided with the structure of the three home visits and three telephone calls, the patients and family caregivers also had the option of telephoning the research nurses with questions or validation of their behavior changes. Most of them made at least one additional telephone call to the research nurses.

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Hello, Dr. \_\_\_\_\_, this is \_\_\_\_\_. I'm calling to talk with you about the pain I'm having. Over the past week, my pain has been a(n) \_\_\_\_\_ on a 0–10 rating scale. The pain has been so severe that I have not been able to sleep, do my usual activities, or visit with my friends. I've been taking my pain medicine as you prescribed it. I've also been taking \_\_\_\_\_ additional doses of medicine every day. The medicine isn't working. Can we change the pain medicine so I can get better pain control?

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### Figure 5. Script for Patients to Use With Healthcare Providers

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## Implications for Practice and Research

Optimally, the PRO-SELF: Pain Control Program should be implemented at all points along patients' pain trajectories and in the settings where their health care takes place. This type of information needs to be reiterated and behavioral changes reinforced on a regular basis to achieve and maintain those behaviors that lead to adequate pain control. Such a plan requires the ongoing education of all healthcare providers in the knowledge and skills needed to teach and coach patients and family caregivers, and the expectation that the program will be implemented on a continuous basis in all oncology settings. Although the program was tested only in patients with metastatic bone pain and in the ambulatory care setting, minor adjustments to the program would make it feasible to implement with other patient groups or in other settings.

The clinic nurses at the research sites saw patients throughout the course of their disease and treatment and, therefore, would have been the logical people to provide the teaching and coaching with regard to pain management or other symptoms. However, the intervention required significant time in one-on-one contact with patients and family caregivers that would have been difficult for the clinic nurses to provide in the current healthcare economic climate. The mean length of time for the first home visit was 107 minutes (including approximately 20 minutes to complete the study questionnaire); the week-three visit took a mean of 48 minutes; and the week-six visit lasted a mean of 69 minutes (including approximately 20–30 minutes to complete the study questionnaire and exit interview). The three telephone calls averaged 13–16 minutes each.

Adequate pain management, as well as management of other symptoms, is vital to improving QOL of patients with cancer. It can influence patients' ability to withstand the rigors of their cancer treatment and, thereby, influence the effectiveness of therapy. The Joint Commission on Accreditation of Healthcare Organizations and various professional organizations have determined that pain relief is a critical component of patient care. Justification exists for healthcare organizations to budget sufficient funds to support the nursing time and other resources needed to provide patients and their family caregivers with intensive teaching and coaching around pain management. The potential cost savings from decreased healthcare use would further justify this initial expenditure.

Investigators in the area of pain management need to study the cost-effective adaptation of the PRO-SELF: Pain Control Program in the acute-care, oncology clinic, and homecare settings. For example, research needs to examine the number, length, and frequency of the teaching and coaching sessions; the timing of the sessions (e.g., beginning the program during

an acute hospitalization with follow-up in the clinic or home); the use of small groups of patients and family caregivers or computer programs to convey some of the general information; and the inclusion of other healthcare professionals, such as clinical pharmacists.

## Conclusion

Cancer pain often is undertreated, partly because many patients do not report their pain and partly because they lack knowledge of effective cancer pain management and have unwarranted fears of addiction, physical dependence, and tolerance. Family caregivers of patients with cancer play an important role in helping to manage patients' pain, and most also share the same misconceptions and lack knowledge about cancer pain. For these reasons, patients must receive adequate individualized teaching and coaching in the skills needed to manage their pain, and such interventions must include family caregivers. However, the knowledge and skills needed to develop effective pain management behaviors are complex and require repeated reinforcement.

The PRO-SELF: Pain Control Program is an effective approach to help patients with metastatic bone pain and their family caregivers obtain the knowledge and skills to increase analgesic intake and lower the severity of pain and number of hours per day in pain. Three key strategies for delivering this program were (a) academic detailing with patients and family caregivers together to identify areas of knowledge deficit and provide focused, concise information that can be reinforced over a period of several weeks, (b) ongoing nurse coaching to help patients and family caregivers develop new self-care skills, and (c) interactive nursing support to facilitate and maintain the skills and behavior changes. A combination of face-to-face sessions and telephone calls was used to provide the teaching and coaching sessions.

Adequate pain relief is vital to decrease cancer morbidity and to improve patients' QOL. Healthcare organizations must acknowledge pain relief as a priority by budgeting for sufficient nursing time and other resources to implement an intensive teaching and coaching program to help patients and family caregivers achieve enhanced control of their pain.

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## References

- American Geriatrics Society Panel on Chronic Pain in Older Persons. (1998). The management of chronic pain in older persons. *Journal of the American Geriatrics Society*, 46, 635–651.
- Blackstien-Hirsch, P., Anderson, G., Cicutto, L., McIvor, A., & Norton, P. (2000). Implementing continuing education strategies for family physicians to enhance asthma patients' quality of life. *Journal of Asthma*, 37, 247–257.
- Bonica, J.J. (1985). Treatment of cancer pain: Current status and future needs. In H.L. Fields, R. Dubner, & F. Cervero (Eds.), *Advances in pain research and therapy*, Vol. 9. *Proceedings of the Fourth World Congress on Pain* (pp. 589–616). New York: Raven Press.
- Brockopp, D.Y., Warden, S., Colclough, G., & Brockopp, G. (1996). Elderly hospice patients' perspective on pain management. *Hospice Journal*, 11(3), 41–53.
- Burrows, M., Dibble, S., & Miaskowski, C. (1998). Differences in outcomes among patients experiencing different types of cancer-related pain. *Oncology Nursing Forum*, 25, 735–741.
- Carrieri-Kohlman, V., Gormley, J.M., Douglas, M.K., Paul, S.M., & Stulbarg, M.S. (1996). Exercise training decreases dyspnea and the distress and anxiety associated with it: Monitoring alone may be as effective as coaching. *Chest*, 110, 1526–1535.



- Cleeland, C. (1984). The impact of pain on the patient with cancer. *Cancer*, 58, 2635–2641.
- Clotfelter, C.E. (1999). The effect of an educational intervention on decreasing pain intensity in elderly people with cancer. *Oncology Nursing Forum*, 26, 27–33.
- Coward, D., & Wilkie, D.J. (2000). Metastatic bone pain. Meanings associated with self-report and self-management decision making. *Cancer Nursing*, 23, 101–108.
- DeWit, R., van Dam, F., Zundbelt, L., van Buuren, A., van der Heijden, K., Leenhouts, G., et al. (1997). A pain education program for chronic cancer pain patients: Follow-up results from a randomized controlled trial. *Pain*, 73, 55–69.
- Dodd, M.J., Dibble, S.L., Miaskowski, C., MacPhail, L., Greenspan, D., Paul, S.M., et al. (2000). Randomized clinical trial of the effectiveness of three commonly used mouthwashes to treat chemotherapy-induced mucositis. *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, and Endodontics*, 90, 39–47.
- Dodd, M.J., Larson, P.J., Dibble, S.L., Miaskowski, C., Greenspan, D., MacPhail, L., et al. (1996). Randomized clinical trial of chlorhexidine versus placebo for prevention of oral mucositis in patients receiving chemotherapy. *Oncology Nursing Forum*, 23, 921–927.
- Dodd, M.J., Miaskowski, C., Greenspan, D., MacPhail, L., Shih, A., Shiba, G., et al. (in press). Radiation-induced mucositis: A randomized clinical trial of micronized sucralfate versus salt and soda mouthwashes. *Cancer Investigation*.
- Ferrell, B.R. (1994). *Patient pain questionnaire*. Retrieved November 4, 2002, from [http://www.cityofhope.org/prc/web/pdf/pt\\_pain.pdf?DROP=%23#](http://www.cityofhope.org/prc/web/pdf/pt_pain.pdf?DROP=%23#)
- Ferrell, B.R., Cohen, M.Z., Rhiner, M., & Rozek, A. (1991). Pain as a metaphor for illness. Part II: Family caregiver's management of pain. *Oncology Nursing Forum*, 18, 1315–1321.
- Ferrell, B.R., Ferrell, B.A., Ahn, C., & Tran, K. (1994). Pain management for elderly patients with cancer at home. *Cancer*, 74, 2139–2146.
- Ferrell, B.R., Ferrell, B.A., Rhiner, M., & Grant, M. (1991). Family factors influencing cancer pain management. *Postgraduate Medical Journal*, 67(Suppl. 2), S64–S69.
- Ferrell, B.R., Grant, M., Chan, J., Ahn, C., & Ferrell, B.A. (1995). The impact of cancer pain education on family caregivers of elderly patients. *Oncology Nursing Forum*, 22, 1211–1218.
- Ferrell, B.R., Rhiner, M., Cohen, M.Z., & Grant, M. (1991). Pain as a metaphor for illness. Part I: Impact of cancer pain on family caregivers. *Oncology Nursing Forum*, 18, 1303–1309.
- Ferrell, B.R., & Schneider, C. (1988). Experience and management of cancer pain at home. *Cancer Nursing*, 11, 84–90.
- Gilliss, C.L., Gortner, S.R., Hauck, W.W., Shinn, J.A., Sparacino, P.A., & Thompkins, C. (1993). A randomized clinical trial of nursing care for recovery from cardiac surgery. *Heart and Lung*, 22, 125–133.
- Glover, J., Dibble, S.L., Dodd, M.J., & Miaskowski, C. (1995). Mood states of oncology outpatients: Does pain make a difference? *Journal of Pain and Symptom Management*, 10, 120–128.
- Gortner, S.R., Gilliss, C.L., Shinn, J.A., Sparacino, P.A., Rankin, S., Leavitt, M., et al. (1988). Improving recovery following cardiac surgery: A randomized clinical trial. *Journal of Advanced Nursing*, 13, 649–661.
- Jacox, A., Carr, D., Payne, R., et al. (1994). *Management of Cancer Pain, Clinical Practice Guidelines No. 9* (AHCPR Publication No. 94-0592). Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service.
- Joint Commission on Accreditation of Healthcare Organizations. (1999). New standards to assess and manage pain. *Joint Commission Perspectives*, 19(5), 5.
- Larson, P.J., Miaskowski, C., MacPhail, L., Dodd, M.J., Greenspan, D., Dibble, S.L., et al. (1998). The PRO-SELF<sup>®</sup>: Mouth Aware Program: An effective approach for reducing chemotherapy-induced mucositis. *Cancer Nursing*, 21, 263–268.
- Miaskowski, C., & Dibble, S.L. (1995). The problem of pain in outpatients with breast cancer. *Oncology Nursing Forum*, 22, 791–797.
- Miaskowski, C., Dodd, M.J., West, C., Schumacher, K., Paul, S.M., Tripathy, D., et al. A randomized clinical trial of the effectiveness of the PRO-SELF<sup>®</sup>: Pain Control Program in improving cancer pain management. Manuscript submitted for publication.
- Miaskowski, C., Koresawa, S., Schumacher, K., West, C., Dodd, M., Paul, S.M., et al. (2001). [Patients' comments on use of the pillbox]. Unpublished data.
- Orem, D. (1991). *Nursing concepts of practice*. St. Louis, MO: Mosby Yearbook.
- Portenoy, R.K., Miransky, J., Thaler, H.T., Hornung, J., Bianchi, C., Cibas-Kong, I., et al. (1992). Pain in ambulatory patients with lung or colon cancer. *Cancer*, 70, 1616–1624.
- Preston, J.A., Scinto, J.D., Grady, J.N., Schulz, A.F., & Petrillo, M.K. (2000). The effect of a multifaceted physician office-based intervention on older women's mammography use. *Journal of the American Geriatrics Society*, 48, 1–7.
- Rabin, D.L., Boekeloo, B.O., Marx, E.S., Bowman, M.A., Russell, N.K., & Willis, A.G. (1994). Improving office-based physicians' prevention practices for sexually transmitted diseases. *Annals of Internal Medicine*, 121, 513–519.
- Schumacher, K.L., Koresawa, S., West, C., Dodd, M., Paul, S.M., Tripathy, D., et al. (2002). The usefulness of a pain management diary for oncology outpatients with cancer-related pain. *Oncology Nursing Forum*, 29, 1304–1313.
- Schumacher, K.L., Koresawa, S., West, C., Hawkins, C., Johnson, C., Wais, E., et al. (2002). Putting cancer pain management regimens into practice at home. *Journal of Pain and Symptom Management*, 23, 369–382.
- Schumacher, K.L., West, C., Dodd, M.J., Paul, S.M., Tripathy, D., Koo, P., et al. (2002). Pain management autobiographies and reluctance to use opioids for cancer pain management. *Cancer Nursing*, 25, 125–133.
- Soumerai, S.B., & Avorn, J. (1990). Principles of educational outreach ("academic detailing") to improve clinical decision-making. *JAMA*, 263, 549–556.
- Stergachis, A., Fors, M., Wagner, E.H., Sims, D.D., & Penna, P. (1987). Effects of clinical pharmacists on drug prescribing in a primary care clinic. *American Journal of Hospital Pharmacy*, 44, 525–529.
- Thomsen O'Brien, M.A., Oxman, A.D., Davis, D.A., Haynes, R.B., Freemantle, N., & Harvey, E.L. (2001). Educational outreach visits: Effects on professional practice and healthcare outcomes [Cochrane review]. In *The Cochrane Library*, 2, 2001. Oxford, UK: Update Software.
- Ward, S.E., Goldberg, N., Miller-McCauley, V., Mueller, C., Nolan, A., Pawlik-Planek, D., et al. (1993). Patient-related barriers to management of cancer pain. *Pain*, 52, 319–324.
- Yeager, K.A., Miaskowski, C., Dibble, S.L., & Wallhagen, M. (1995). Differences in pain knowledge and perception of the pain experience between outpatients with cancer and their family caregivers. *Oncology Nursing Forum*, 22, 1235–1241.
- Yeager, K.A., Miaskowski, C., Dibble, S.L., & Wallhagen, M. (1997). Differences in pain knowledge in cancer patients with and without pain. *Cancer Practice*, 5, 19–45.

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- Cancer Pain Management in Children  
[www.childrencancerpain.org](http://www.childrencancerpain.org)
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