Barriers to optimal cancer pain management exist among clinicians and patients and within the healthcare system. This article examines patient barriers to effective management of cancer pain. Unrelieved pain remains a major problem for patients with cancer and other diseases. Recommendations and guidelines for effective cancer pain management are widely available; however, patients continue to hold misconceptions about the use and effects of drugs commonly used to manage cancer pain. Although interventions designed to raise the awareness of patients seem to help in controlled research studies, much still needs to be done to address this problem.

Researchers have advocated that control of cancer pain can be improved through patient education by helping patients have more control over their pain and by improving the patients’ adherence to the scheduling of pain medications. Limited research efforts have been directed toward developing or evaluating the effectiveness of pain education programs that focus on patient-related barriers to pain management for patients with cancer.

KEY WORDS
attitude
barriers
beliefs
cancer pain
pain management

More than 15 years ago, a worldwide review of cancer pain statistics concluded that 50% of patients at all stages of the disease and 70% of patients with advanced cancer reported experiencing pain. At the same time, approximately 95% of cancer patients could be free of significant pain if that pain were managed effectively. Several studies have continued to report that a significant number of cancer patients experience moderate to severe levels of pain. These studies demonstrate that nearly one-third (30%) of cancer patients are in pain when the disease is diagnosed; however, as the cancer progresses, this percentage increases to between 65% and 85%.

The magnitude of the problem of cancer pain has been recognized by the World Health Organization, and a number of guidelines for cancer pain management have been established; for example, from the US...
National Comprehensive Cancer Network (NCCN), the American Pain Society (APS), and the Agency for Healthcare Research and Quality. Research on using these guidelines had demonstrated that good pain relief is possible for more than 70% of patients. Despite policy advances in cancer pain management and improvements in treatments, research suggests that many patients with cancer continue to experience unnecessarily high levels of pain. Pain control merits high priority for two reasons. First, unrelieved pain causes the individual unnecessary suffering because pain diminishes activity, appetite, and sleep. Second, the psychological effect of cancer pain can be devastating. Patients with cancer often lose hope when pain emerges, believing that pain heralds the inexorable progress of a feared, destructive, and fatal disease. Chronic unrelieved pain can lead patients to reject active treatment programs. When patients experience severe pain or depression, they consider suicide to end the suffering. Besides mitigating suffering, pain control is important because even when the underlying disease process is stable, uncontrolled pain prevents patients from working productively, enjoying recreation, or taking pleasure in their usual role in the family and society. Pain control, therefore, merits a high priority not only for those with advanced disease but also for the patient whose condition is stable and whose life expectancy is long.

However, the undertreatment of pain is a widely recognized, well-documented healthcare problem. Unrelieved pain is associated with adverse physiologic and psychosocial consequences, and management of pain has become a priority in healthcare in recent years. In the US, the NCCN and APS published the Clinical Practice Guideline on the Management of Cancer Pain, emphasizing the numerous and complex barriers to pain management. Three problem areas were identified: those related to the healthcare system, to healthcare professionals, and to patients and families. These factors are likely to contribute to the extent of facilitating self-care. However, the nature of cancer pain and its effective treatment require active involvement of patients in managing their own conditions, including pain management. The purpose of this research article is to examine patient-related barriers to effective management of cancer pain.

**METHODS**

To critically examine the body of knowledge related to patient-related barriers to the management of cancer pain and interventions, a comprehensive literature review was conducted using the electronic databases of CINAHL and Medline for articles published between 1998 and 2007. The following key words were used to search the electronic databases: cancer pain, pain management, barriers, attitude, beliefs. The key words were used in multiple combinations to conduct an extensive search of these databases. Computerized listings from CINAHL and Medline contained 20 and 33 research articles, respectively. All were obtained and reviewed for possible inclusion in this research review based on the specific inclusion criteria established. Article inclusion criteria for the integrative research review were the following:

1. It is a research-based study.
2. It included a patient population of adults with cancer.
3. It investigated patient-related barriers to effective pain management.
4. It is written in the English language.

Based on the inclusion criteria, a total of 11 articles published from 1998 to 2007 were selected and formed the basis for this review. The earliest study included was published in 1998, with most studies published from 2003 through 2007. Most articles were published in nursing journals. Studies included in this review focused on the effect of patient-related barriers to management of cancer pain. Countries within which the studies for this review were conducted include the United States, Australia, Taiwan, Hong Kong, and Korea.

**Methodological Characteristics**

The 11 studies composing this integrative research review were quantitative studies. Ten studies were descriptive, and one study was a randomized clinical trial. Although only 11 studies were included in this research review, a wide variety of instruments was used to measure concepts related to barriers to management of cancer pain. The most common questionnaire used in these studies collected information to measure the extent to which people hold beliefs about reporting cancer pain and using analgesics that can act as barriers to pain management. Few of the studies were specifically based on a theoretical model and tested variables articulated by the theorist. Studies based on a theoretical model most often used cognitive behavioral theory and the attitudinal barriers and quality of life (QOL) model.
Sample Characteristics

The sample sizes in the 11 studies in this review ranged from 38 to 655 adult cancer patients aged between 15 and 87 years. Most (around 60%) of the population were women. Cancer sites in women were mainly breast, ovary, uterus, lymphoma, head and neck, and lung. Cancer sites in men were lymphoma, head and neck, prostate, lung, melanoma, and colorectal. Six studies were conducted in the United States, two studies were conducted in Australia, and the remaining studies were conducted in Taiwan, Hong Kong, and Korea.

RESULTS

Despite advances in pain management, there is evidence that cancer pain remains inadequately treated worldwide. The prevalence of inadequately treated pain is estimated to be anywhere from 16% to 91%. Several barriers to achieving adequate cancer pain management have been identified in the literature, despite decades of work to reduce unrelied pain. Many clinicians believe that patient-related barriers inhibit adequate management of pain. A review of the available clinical literature pointed to eight beliefs that were thought to be important. These include the following concerns that may prevent patients from reporting pain and taking medication: (1) fear of addiction, (2) concern about drug tolerance, (3) belief that adverse effects from analgesics are even more bothersome than pain, (4) fatalism about the possibility of achieving pain control, (5) belief that “good” patients do not complain about pain, (6) fear of distracting a physician from treating the disease, (7) belief that pain signifies disease progression, and (8) fear of injections.

Ward et al assessed concerns about reporting pain and using pain medication in 270 cancer patients. Patients were given a 27-item self-report measure called the Barriers Questionnaire (BQ) and were given the Brief Pain Inventory (BPI) to measure pain intensity. The BQ included eight specific concerns about pain management, such as concerns regarding addiction to pain medication, adverse effects, and being a good patient by not complaining about pain to providers. Between 37% and 85% of the patients surveyed expressed some concerns over issues related to pain management, with concerns about addiction to medications receiving the highest mean score. In addition, 45% of the patients agreed that a good patient should not complain or talk about pain with providers. There were more concerns among those with less education, lower incomes, and higher levels of pain and among those who were undermedicated. Gunnarsdottir et al revised the BQ to reflect changes in pain management practices, resulting in the Barriers Questionnaire-II (BQ-II), a 27-item, self-report instrument. The responses of 27 nurses trained in pain management were compared with the responses of a convenience sample of 12 patients with cancer. The results indicated that patients with cancer had higher mean scores on the BQ-II than did nurses trained in pain management.

Also in this study, a convenience sample of 172 patients with cancer responded to the BQ-II and a set of pain and QOL measures. A factor analysis supported four factors. Factor 1, physiological effects, consists of 12 items addressing the beliefs that adverse effects of analgesics are inevitable and unmanageable, concerns about tolerance, and concerns about not being able to monitor changes in one’s body when taking strong pain medications. Factor 2, fatalism, consists of three items addressing fatalistic beliefs about cancer pain and its management. Factor 3, communication, consists of six items addressing the concern that reports of pain distract the physician from treating the underlying disease and the belief that good patients do not complain of pain. The fourth factor, harmful effects, consists of six items addressing fear of becoming addicted to pain medication and the belief that pain medications harm the immune system. The BQ-II scores were related to measures of pain intensity and duration, mood, and QOL. Patients who used adequate analgesics for their levels of pain had lower scores on the BQ-II than did patients who used inadequate analgesics. Findings supported the BQ-II as a reliable and valid measure of patient-related barriers to cancer pain management.

Research from other countries supports the notion that unrelied cancer pain is a universal problem. Furthermore, attitudinal barriers to pain management have been found to be widespread. This observation has been supported with data from Taiwan, Hong Kong, and Australia, in addition to the United States.

In Taiwan, Lai et al conducted a pilot cross-sectional study aimed to explore pain beliefs and adherence to prescribed analgesics in Taiwanese cancer patients and examine how selected pain beliefs, pain sensory characteristics, and demographic factors predict analgesic adherence. A convenience sample of hospitalized cancer patients with pain (N = 194), recruited from four
teaching hospitals in Taipei, included 119 men (61.3%) and 75 women (38.7%) with ages ranging from 18 to 82 years. Pain beliefs were measured by the Chinese version of the Pain and Opioid Analgesic Beliefs Scale—Cancer and the Survey of Pain Attitudes. Analgesic adherence was measured by patient self-report of all prescribed pain medicine taken during the previous 7 days. They found that only 66.5% adhered to their analgesic regimen. Overall, patients had relatively high mean scores in beliefs about disability, medications, negative effects, and pain endurance and low scores in control and emotion beliefs. Medication and control beliefs significantly predicted analgesic adherence. Patients with higher medication beliefs and lower control beliefs were more likely to be adherent. Findings support the importance of selected pain beliefs in patients’ adherence to analgesics.

Chung et al25 studied pain management and its barriers in Hong Kong. The overall aim of this study was to evaluate the patient-related barriers to cancer pain management in Hong Kong. The study used the quantitative research method; cancer patients (N = 39) with pain were chosen by an opportunity sampling method in a palliative setting in Hong Kong. The participants consisted of 61.5% (n = 24) men and 38.5% (n = 15) women. Their age levels ranged from 39 to 77 years. Using an interview technique, several measures were employed to understand the level of patients’ concern about pain, the patients’ hesitancy in reporting pain, use of analgesics, and adequacy of medication for pain. They identified a total of nine barriers, which include addiction, tolerance, adverse effects, physician distraction, being a good patient, fear of injection, time interval, fatalism, and disease progression. When the findings in Taiwan and the US were compared, it was found that the cancer patients in Hong Kong had a higher level of concern toward the patient-related barriers. The study also found that the level of concern was generally higher in the group with hesitancy in reporting pain and using analgesics.

Yun et al26 evaluated the prevalence, severity, and proportion of undertreatment of cancer pain and identified the barriers to the adequate management of cancer pain in Korea. The sample consisted of 655 cancer patients drawn from eight university hospitals in Korea. There were 242 (33.3%) men and 212 (46.7%) women. Their age levels ranged from 15 to 87 years. The Korean BPI and the BQ were completed by the patients. Among all patients, 70.8% (464/655) reported pain. Among those who had pain, 63.6% (295 of 464) reported pain rated 5 or higher on a scale of 0 to 10 (0 = no pain and 10 = worst pain). Thirty-nine percent of the patients had not received any analgesics, and 53.2% were not receiving optimal pain management. Regarding patient-related barriers, the authors found that between 50% and 90% of the patients in this study reported various concerns that have been suggested as possible barriers to pain management. The highest percentage (90.0%) was found for the progression factor, indicating that the patients equated degree of pain with progress of disease. More than 19% of the patients had hesitated to notify the physician or nurse of their pain during the previous month, and 121 (27.5%) patients had hesitated to take their prescribed analgesic during the previous month, although 343 (76.2%) patients had been advised to tell the physician or nurse when the pain appeared.

When the findings in Korea and the United States were compared, it was found that among the seven factors composing the BQ index, concerns about progression and addiction represented the most problematic misconceptions and concerns about the use of analgesics for pain. Most subscale scores for the Korean patients were similar to the scores reported for US patients,27 but the mean score of the progression subscale for the Korean sample was higher than that for the US sample. Patients may hesitate to report pain because they believe that an increase in pain signifies disease progression. From these results, it is evident that large numbers of patients have misconceptions and concerns about the use of analgesics for pain.

Recently, Yates et al17 examined attitudinal barriers to effective pain management in a recruited cohort of 114 cancer patients from four Australian hospitals. The researchers found that 38.6% of patients would wait until pain was bad before asking for help, and almost 32.5% agreed that pain-relieving medication should be saved in case pain gets worse. Similarly, 33.3% of the sample agreed that it was important to be strong and not talk about pain, whereas 17.5% were unsure about their response to this item. Negative perceptions regarding pain and pain treatments were also commonly expressed. More than three-fourths (83.3%) of the patients agreed that being in pain prevented them from enjoying hobbies and social activities, and 91.2% indicated that experiencing pain was a sign that something is wrong with the body. Moreover, many patients expressed concern about the effects of pain-relieving medication. Seventy-one percent believed that it is easy to become addicted to pain-relieving medication, and 64% believed that there is a real danger of addiction. A trend for older patients to
experience more severe pain was also identified. These older patients reported being more willing to tolerate pain and perceived less control over their pain.

More recently, Potter et al. surveyed the prevalence of concerns about analgesics and fears about the implications of pain, which may hinder open communication. They also investigated associations with inadequate pain control. Ninety-three Australian adult patients with cancer undergoing treatment at a teaching hospital completed the patient BQ and a self-report questionnaire to determine pain severity, interference with daily activities, use of analgesics and alternative therapies, and hesitation to report pain. Overall, there was a highly significant agreement with the BQ scales assessing concerns about communication and analgesic use. Seventy-six percent had concerns that were significantly related to fear of addiction, 71% feared that pain equates with progression of disease, and 67% were concerned about the medication's adverse effects. There was a close correlation between the concerns identified in the US and Australian populations.

Compared to a US study of attitudinal barriers to the treatment of pain, similar findings were observed by Gunnarsdottir et al. in a general population-based survey of 244 patients with cancer in Iceland. In addition to evaluating the psychometric properties of the BQ-II, the feasibility of using the instrument in its Icelandic translation was also examined. This study was designed to identify any additional barriers that might be present in the Icelandic population beyond those addressed in the BQ-II. The study found that not only were there attitudinal barriers to cancer pain management among people in Iceland, but these attitudinal barriers were stronger than those identified in another similar group using a parallel instrument. There was no evidence of a need to add additional items to the instrument for use with a general population sample.

Randall-David et al. used focus groups of hospice and home healthcare nurses and patients to elucidate factors contributing to inadequate pain management. They conducted focus groups among hospice and home healthcare nurses (two groups; n = 22) and patients (six groups; n = 54) using a standardized question guide. Barriers identified by patients in this study overlap the eight concerns identified by Ward et al. The cost of pain medications was identified as a barrier that was described but not previously evaluated in actual patients. They were also able to identify several barriers that have received little attention in the literature, including patients’ fears of abuse of medications by family members and fear of worrying their family by complaining of pain, concerns about providers’ judgment on the validity of either the patient’s or nurse’s concerns or reports of pain, lack of access to the provider, and lack of providing individualized care to patients. The consequences of unrelieved pain are well documented. Severe pain is associated with significant functional impairments including disturbed sleep, activity, and mood; loss of appetite, poor sleep, increased depression and anxiety, and decreased QOL.

Ward et al. found that patients (N = 182) with higher attitudinal barriers were more likely to use inadequate analgesics than were persons with lower barriers. In turn, these patients had higher pain severity and poorer QOL. The investigators suggested that attitudinal barriers to cancer pain management interfere with reports of pain and use of analgesics, resulting in poorer pain management.

Vallerand and associates conducted a cross-sectional study to examine the relationships between pain level, beliefs about pain (for the purposes of this study, two indicators were used to define the patient’s beliefs about pain: knowledge regarding pain and barriers to pain control), symptom distress, perceived control over pain, and functional status in 304 ambulatory cancer patients who experienced cancer-related pain within the past 2 weeks. There were 119 (39%) men and 185 (61%) women. Their age levels ranged from 18 to 86 years. Participants completed standardized questionnaires during regularly scheduled clinic visits. Study findings indicated that a patient’s pain level was positively related to increased distress and decreased perceived control over pain and functional status. Structural equation modeling indicated that symptom distress mediated the relation between pain level and functional status. Perceived control over pain had a direct effect on symptom distress and mediated the effect of beliefs about pain and pain level on symptom distress.

Sun et al. conducted a prospective, longitudinal clinical trial to test the effects of the “Passport to Comfort” innovative intervention on pain and fatigue management. This 5-year study was designed in three phases. Phase 1 assessed usual care to describe the current status of barriers to pain management. A total of 38 cancer patients were accrued for Phase I—nine (24%) men and 29 (76%) women. The mean age of these participants was 57 years. Patients who reported a pain rating of 4 or more were accrued. Study participants were recruited from the Medical Oncology Adult Ambulatory Care Clinic at a designated comprehensive
CONCLUSION

Unrelieved pain remains a major problem for patients with cancer and other diseases. Recommendations and guidelines for effective cancer pain management are widely available; however, patients continue to hold misconceptions about the use and effects of drugs commonly used to manage cancer pain. Although interventions designed to raise the awareness of patients seem to help in controlled research studies, much still needs to be done to address this problem. Researchers have advocated that control of cancer pain can be improved through patient education by helping patients have more control over their pain and by improving patients’ adherence to the scheduling of pain medications. Limited research efforts have been directed toward developing or evaluating the effectiveness of pain education programs that focus on patient-related barriers to pain management for patients with cancer.

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