Pain, coping, and barriers to pain management in outpatients with cancer

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1 General introduction and literature review

In 2006, Norway had a population of 4.7 million, consisting primarily of white Caucasians but with about 9% being immigrants from more than 200 countries. According to the Cancer Registry [1], 24 488 new patients were diagnosed with cancer in 2006. The most common forms of cancer are prostate cancer in men and breast cancer in women. Colon and lung cancer are the second or third most common cancers in both sexes. These four cancers account for about half of all cancer in Norway. Cancer rates increase with age, and about 80% of cancer occurs in individuals older than 55 years. Survival five years after a cancer diagnosis differs considerably depending on the diagnosis. The five-year survival rate is generally higher for cancers where early detection and treatment is possible (e.g., frequently occurring neoplasms such as breast and colorectal cancer). The overall survival rate of cancer is estimated to be 57% and 65% for men and women, respectively. The difference in overall survival between women and men reflects the more frequent occurrence of tumors associated with better prognosis in women than in men [1].

Cancer patients may experience many symptoms associated with the cancer and treatment. Unrelieved pain remains a significant clinical problem and one of the most feared consequences of cancer [2]. A recent meta-analysis of 52 studies reported a prevalence of pain of 33% to 64% in cancer patients [2]. The differences in prevalence depend on whether the patients are studied 1) after curative treatment, 2) while under treatment, or 3) with advanced disease. The pooled prevalence of pain is > 50% in all cancer types.[2].

Although cancer pain usually has a physical origin such as injury or disease progression, the subjective response to pain has both psychological and social components. These psychological and social mediators influence the experience of pain and how the

patient copes [3]. Research on psychological factors that influence cancer pain have focused on two main areas—psychological distress, including anxiety and depression, and pain coping [4]. Various pain coping strategies, such as catastrophizing, diverting attention, reinterpretation, and active and passive coping, have been studied in cancer patients but the relationship between pain and these coping strategies is not clear because of inconsistent findings, and further clarification is needed [5-8]. A positive relationship between catastrophizing and pain is the most likely [4].

Self-efficacy (SE) is another emerging psychological factor that can explain the variation in pain between cancer patients. Few studies have examined SE in cancer patients, but a consistent strong relationship between SE and pain has been reported in patients with chronic pain [4].

Barriers to pain management, such as beliefs and attitudes toward pain treatment and the patient's adherence to the prescribed pain medication, are also important areas in relation to pain management because beliefs and attitudes may serve as cues for the patient not to report pain and to be less willing to follow the medical regimen.

Nurses meet cancer patients as both hospitalized patients and outpatients. The prevalence of cancer pain remains high despite advances in pain management, and it is a great challenge to help patients alleviate and cope with pain. Nurses are important members of the health-care team because the continuity of care and availability of a health professional are important for assessing pain and follow-up strategies for pain treatment. Nurses are present at the initiation of pain management and during the follow-up and evaluation of the pain treatment program, and have a major responsibility in pain management.

Based on the results of earlier research, the overall aim of this study was to describe the prevalence of pain in outpatients with cancer and the patients' reported causes of pain. Because cancer pain is influenced by both physical and psychological variables, the study

focused particularly on exploring the barriers to pain management such as the patient's beliefs and misconceptions together with the adherence to pain medication. Other factors such as the patient's perceived SE and coping with pain were also explored. A further aim was to describe the interactions between these variables and their relationship with patients' pain experiences. This knowledge has clinical implications for nurses and other health-care personnel working in the area of pain assessment and pain management.

1.1 Cancer pain

Pain is a subjective and individual experience [9]. The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" [10].

Models of the different causes of cancer pain are based on physiology and give new insight into how cancer pain is generated and maintained, and how sensory information is processed as it moves from the sense organs to the cerebral cortex [11].

In the primary afferent sensory neurons, individual primary neurons of the pain pathway can detect a wide range of stimuli through a diverse repertoire of transduction molecules. Progress in this area has helped in the understanding of the signaling mechanisms and specific molecules used by nociceptors, such as vanilloid receptors, to detect noxious stimuli [11].

Tumor cells secrete a wide range of factors such as prostaglandins, interleukins, and different growth factors that directly excite or sensitize the primary afferent neuron. Insufficient vascular supply to tumor cells causes ischemia and local acidosis, which may directly excite sensory neurons. Inflammation, nerve injury, or tissue injury can stimulate the sensory neurons primarily through the release of growth factors from the injured site. At the same time, the local environment can influence the molecules that tumor cells express and release. Because of differences in the local environment around tumors, the same tumor may

be painful at one site but not at another. This may explain why patients with the same kind of cancer may have different symptoms [11].

Tumor growth can entrap and injure nerves, causing mechanical injury and compression of the nerves. Cancer pain is induced and maintained partly by central sensitization, which can lead to the perception of normally nonnoxious stimuli as noxious. These different models may explain why the severity of cancer pain can vary widely between patients, tumors, and sites [11].

Cancer pain may be classified based on the structures involved (e.g., somatic, visceral, or neuropathic) and according to the time (e.g., acute, chronic, and breakthrough pain (BTP)). Acute pain may be caused by diagnostic or treatment interventions including surgery; biopsy; reactions to anticancer therapies such as chemotherapy or the infusion technique; radiotherapy (e.g., mucositis in response to chemotherapy toxicity); hormonal therapy; immunotherapy; and infection [12]. Chronic pain is pain that persists over more than three months or recurs over several months beyond the usual course of an acute illness or injury. Chronic pain syndrome may be caused by the disease itself, for example bone pain caused by metastasis, muscle pain, chronic headache, peripheral neuropathic pain, and pain syndrome of the viscera. Chronic pain syndrome is also associated with cancer therapy such as hormonal therapy, chemotherapy, or surgical therapy [12]. BTP is a transient exacerbation of pain that occurs in addition to the otherwise stable persistent pain [13] and is common in both the acute and the chronic pain states. In this study, pain was classified by its duration and whether the patients had BTP.

Cancer pain is conceptualized as a multidimensional experience with physiological, sensory, affective, cognitive, behavioral [9], and sociocultural dimensions [14]. The relevance of the different dimensions varies by time, place, person, and situation. The dimensions

influence each other and the product of the different dimensions is defined as the patient's pain experience in accordance with the IASP definition of pain [10].

The multidimensionality of cancer pain [9] is influenced by a set of variables. In this study, the sensory component of pain is described in terms of e.g. pain intensity, location, and pain quality. The affective component of pain is defined as the emotional response to pain and was assessed using measures of anxiety and depression. The cognitive component of pain refers to the meaning of and attitude toward pain and was assessed by recording the patient's beliefs and attitudes toward pain management, the patients' SE toward pain management, and cognitive coping strategies. The behavioral component refers to the patient's behavior when experiencing pain and was assessed by recording the patient's adherence to pain medication and behavioral coping strategies. Quality of life (QoL) was assessed as an outcome measure of living with pain.

1.2 Pain prevalence

Highly variable prevalence rates for pain have been reported in oncology outpatients in the past 10 years, ranging from 20% to 60% [15-18]. Many factors contribute to these differences including the cancer diagnoses, stage of disease, and etiology of the pain.

1.2.1 Differences in prevalence of pain by diagnosis

Clinical experience suggests that patients with breast cancer experience pain frequently [19]. Three studies of outpatients with breast cancer found a pain prevalence of 47% [20, 21] and 35% [22]. In a comparison of patients with and without pain, Glover found that significantly more patients with lung and breast cancer reported pain than did patients with other cancer diagnoses [23]. In the study with the lowest prevalence of pain in outpatients [18], 26.1% of the patients with pain had breast cancer. In the study with the highest prevalence of pain, 35% of the patients with pain had breast cancer [15]. A large study

of 1308 consecutive outpatients with recurrent or metastatic cancer found no relationship between the proportion of patients with pain and disease site [24], but another study of 1635 cancer patients referred to a pain clinic found that symptom prevalence was influenced by tumor site [25]. In a recent review of pain prevalence over the past 40 years, bivariate regression analysis showed no significant association between pain prevalence rate and cancer type [2]. Because of these conflicting results, one may assume that the cancer diagnosis is not the primary reason for the differences in pain prevalence reported in these studies.

1.2.2 Differences in prevalence of pain by stage of disease

In this study, the stage of disease was described indirectly in terms of whether the patient had metastasis or whether the treatment had a palliative or curative intent. Palliative treatment is given to a patient when the disease is no longer responsive to curative treatment [26]. Cancer with metastasis and palliative treatment apply to cancer patients with more advanced disease [15, 27]. Patients with more advanced disease have higher prevalence of pain [27-29], which may be as high as 100% in a patient's last days of life [30]. Ahles and colleagues [27] divided the patients into groups according to disease progression: local, regional, or metastasis. They found that more than 50% of patients with metastases had pain, a rate that was significantly higher than in patients with local and regional disease [27]. Others have also reported that patients with metastases have more pain [31, 32], but some researchers have not found such a relationship [17, 25, 33]. One explanation for the conflicting reports is that metastasis inflicts different problems and that the sensation of pain depends on the area affected.

In the most recent studies of the prevalence of pain in outpatients with cancer, the highest prevalence was in a group of patients where all patients were in a palliative phase but not hospitalized [15]. Metastasis or treatment intention was not reported in the study with the lowest prevalence [18]. In another study, 29% of the patients had advanced disease, but the

prevalence of pain was not higher in these patients than in patients with less advanced disease [17]. It is difficult to draw conclusions about the relationship between pain prevalence and the stage of cancer. The most recent review of pain prevalence found no differences in pain prevalence between patients undergoing active anticancer treatment and patients with advanced disease [2].

1.2.3 Differences in prevalence of pain by the etiology of pain

Cancer patients may have pain because of causes other than cancer. To give sufficient and proper pain management, it is important to distinguish between pain caused by the cancer and pain caused by other conditions.

Ahles and colleagues emphasized the importance of early differentiation between pain caused by cancer and other causes [27]. In a cross-sectional multicenter study of 1095 cancer patients from 25 countries in various clinical settings, 92.5% of patients had pain due to the tumor and 2.3% had pain unrelated to the tumor or cancer treatment; all patients required opioid medication for their pain [34]. As in the rest of the population, patients with cancer may have pain from chronic diseases such as osteoarthritis, rheumatoid arthritis, or back pain, or acute conditions such as headache. In a study of cancer patients and noncancer patients, 51% of the patients without cancer reported pain, and 64% of the patients with cancer had pain [15].

A study of pain prevalence in the general Norwegian population reported that overall 28.3% had pain and that 24.4% of these people had chronic pain (pain > 3 months duration); only 2% reported cancer as the cause of their pain [35]. In both inpatients and outpatients with cancer, the prevalence of pain from causes other than cancer or its treatment varies from 2.3% to 17% [15, 20, 24, 27, 31, 34, 36-40]. Because a cancer patient may have pain from causes other than cancer, it is important to first identify and assess the cause of pain because not doing so may skew the prevalence rate by including both noncancer pain and cancer pain.

Even more importantly, patients may receive unsatisfactory pain treatment because different types and causes of pain need different treatment strategies.

Most current cancer pain therapy is based on the analgesic ladder of the World Health Organization (WHO) [41]. Pain is divided into mild, moderate, and severe pain, and pain is treated with a combination of opioids, nonopioids, adjuvant medication, and other adjuvant therapies. Optimal pain assessment and treatment in outpatient care settings depend on the patient's report of pain and the use of available analgesics.

1.3 Adherence to pain management

Appropriate use of the WHO guidelines for pain management can relieve pain in most cancer patients [42-44], but pain is still a common experience for cancer patients. Recent studies suggest that patients are often prescribed adequate analgesics for their level of pain but still experience unrelieved pain [45]. Adequate pain management is dependent on the patient's willingness and ability to follow advice from health personnel, and poor adherence to the analgesic regimen may be an important reason for unrelieved pain.

According to Turk and Meichenbaum [46], "adherence implies an active, voluntary collaborative involvement of the patient in a mutually acceptable course of behavior that produces a desired preventive or therapeutic result" (p. 251). This perspective suggests that patients must be engaged in making choices about how to implement therapeutic interventions (e.g., taking an analgesic medication).

They also stated that imposing a dichotomy of adherers versus nonadherers could be an oversimplification [46]. Even in one patient, adherence may vary for different aspects of treatment or change from one time to another. This may be true for cancer patients who often have a complex pain management regimen that may involve long-acting medication for persistent pain and shorter-acting medication as needed for BTP. An adequate or optimal level of adherence is not known for most medical problems. Before labeling patients nonadherent,

one should determine the minimum standards necessary to achieve the desired health benefit (i.e., pain management). Given this lack of definition, multiple indicators of adherence were included to increase the validity of this study [46].

Cancer patients living at home encounter many challenges when dealing with pain as they make judgments and choices about the best pain management on a daily basis. Their judgments and choices are based on the information and knowledge they receive from health-care workers and from friends, family, and other sources. A patient may be nonadherent for many valid reasons such as possible unpleasant side effects, confusion about dosage, and concerns about deterioration of the QoL. For example, if a medication has side effects that interfere with socializing, a patient may choose not to take the medication, or delay taking the medication, if socializing is more important. Thus, many patients may be intentionally nonadherent [46].

Among oncology patients, the reported rates of adherence to an analgesic regimen range from 0% to 90% [18, 39, 47-60]. This large variation in adherence rates may be related to differences in a variety of clinical (e.g., stage of the patient's disease) and pain (e.g., cause of the pain) characteristics. This variability may also reflect differences in the definition of adherence (e.g., taking the correct dose at the correct time [56]), percentage of the prescribed dose taken [39, 51], or the method used to assess adherence [39, 48, 53, 58].

There is no "gold standard" for measuring adherence, and there is a lack of consensus about which medication behaviors should be defined as adherent. This makes it difficult to compare results from different studies, and the question remains about which patients should be labeled nonadherent. To compare results from other studies, the present study measured adherence with two different instruments used in prior research on cancer patients [48, 53, 54]. One instrument views adherence as dichotomous—patients are viewed as either adherent

or nonadherent—and the other defined adherence indirectly by assessing the reasons for omitting pain medication.

Reluctance to report and use available analgesic medication is often based on a patient's erroneous beliefs or misconceptions about pain and pain medication; this is called "patient-related barriers to pain management".

1.4 Patient-related barriers to pain management

Fear of addiction and tolerance to pain medication may lead to patients choosing to withhold pain medication until the pain is stronger [61] or not taking the prescribed dose [18, 62, 63]. Fear of side effects may be another barrier because 10% to 80% of patients worry about fatigue and constipation [61, 62, 64], confusion [64], and nausea [62, 64], and 4% are afraid of losing control or having difficulties breathing [61, 62]. These side effects may be prevented or treated most of the time. Lack of information and follow-up from health-care personnel can make the patient believe that the problems are unsolvable, and the patient may stop the medication or alter the dosage.

Patients also express fear of distracting the doctor by addressing issues of pain: they wish to be "good patients" or to not appear to be complaining to doctors or nurses [61, 62, 64, 65]. Others do not wish to complain about a lack of effect [36, 66]. Some patients avoid talking about pain because they perceive pain as a sign of disease progression [61, 64, 66, 67] and fear that the physician will stop the treatment if the doctor believes the pain indicates no further hope for a cure [64].

Some patients are unaware that there are efficient medications available when pain becomes worse and they "save" pain medication for a later time. Some patients view pain as inevitable and think that pain medication should only be used to treat severe pain [61], or they may feel there is little to be done [61, 64, 68]. Other patients feel that taking medication is a bother or they forget to take the medication [18].

Some patients see pain as a warning signal that they should protect the part that hurts, and they want to be able to monitor their symptoms [63]. Patients with a former addiction are afraid of becoming addicted again [47]. Patients in pain may also fear injections [64], and some are concerned about the cost [61].

The ways in which barriers to pain management influence pain intensity are unclear. Barriers to pain management may influence pain intensity both directly and indirectly. Direct influence may involve a patient having misconceptions that lead patients to be less responsive to a pain management regime. This is consistent with research on nonmalignant chronic pain [69]. Indirect influence may involve a patient's negative beliefs about pain affecting his or her ability to communicate about the pain, which, in turn, affects the adherence to the analgesic regimen. The research is conflicting about whether barriers to pain management influence pain intensity. Some studies have found that patients with more or stronger barriers to pain management have higher pain intensity scores [64, 70, 71], whereas other have failed to find any association [72, 73].

Since the introduction of the gate control theory the focus of pain management has shifted from a biomedical to a multidimensional model of pain. The gate control theory postulates that pain perception may be inhibited by nerves which do not transmit pain signals. Specialized cells in the dorsal horn of the spinal core "open and closes" the transmission of pain stimuli [74]. This shift to a multidimensional model of pain is reflected in the recommendations to use psychological adjuncts for cancer pain management by agencies such as the WHO and the American Pain Society [26, 75]. The cognitive dimension of pain is recognized as an important factor influencing pain perception and adjustment to pain [4, 76]. The relevant concepts in this study are coping strategies and SE.

1.5 Coping strategies

Coping is viewed as constantly changing cognitive and behavioral activities to manage external or internal stressors that a person appraises as taxing or exceeding his or her resources [77]. The interest in coping derives from observations that some patients living with pain report greater dysfunction and disability whereas others seem to adjust reasonably well to the stress of ongoing pain [78]. Cognitive and behavioral coping strategies may explain some of these differences in adjustment to cancer and cancer pain.

In this study, coping strategies are defined as either cognitive or behavioral, in accordance with the definitions of Lazarus and Folkman [77]. Cognitive strategies are strategies involving distraction and self-statements, and behavioral strategies refer to actions performed to manage pain, such as taking pain medication, being active, or resting. It is not always easy to distinguish between these two; for example, taking pain medication could be viewed as both a behavioral coping strategy and a result of a cognitive attempt to cope with pain.

Whether the different coping strategies are adaptive or maladaptive depends on factors such as the individual patient, the nature and chronicity of the disease, the patient's situation, and the patient's anticipation of pain relief [79].

The literature on cancer pain refers frequently to coping, but the relationship between coping and cancer pain is not clear because the association between coping strategies and pain varies [5, 7, 80]. The most certain relationship is found between catastrophizing and pain [4]. Catastrophizing refers to a negative response style characterized by a tendency to ruminate on aspects of the pain experience, to exaggerate the threat value of pain, and to adopt a helpless orientation to pain [81, 82]. Catastrophizing may be viewed as a coping strategy because the patient seeks attention and support from others [83]. Others distinguish coping from catastrophizing because the latter it is not viewed as being goal directed or a strategy [84].

Zaza and colleagues [85] found that three of four studies examining coping strategies in patients with cancer pain showed that catastrophizing is significantly associated with more intense pain. However, they concluded that the evidence of an association was inconclusive because of the small number of studies reviewed and the low to moderate correlations observed.

Four more recent studies of coping and cancer pain reported an association between catastrophizing with increased pain intensity [7, 8, 76, 80].

1.6 Self-efficacy for managing pain and other symptoms

SE is another cognitive concept that has emerged as an important factor influencing the patient's pain experience. SE refers to "beliefs in one's capability to organize and execute the courses of action required to produce given attainments"[86]. Bandura [86] also noted an important difference between intent and efficacy, and recommended the use of "can" as a judgment of ability and not "will" as a measure of intention when assessing SE. In this study, SE was measured as proposed by Bandura and included three areas: pain management, other symptoms, and physical function.

Bandura [86] proposed that given sufficient motivation to execute a task, the person's SE beliefs determine whether the patient actually performs the task, how much effort the patient will put into the task, and how long the patient will continue the task when facing obstacles and problems. A patient's behavior is therefore mediated by his or her SE beliefs. SE is not a personality characteristic but a judgment of one's ability to perform specific behavior in a particular situation, and SE may vary between situations and the behavior needed to respond to the specific situation. A person's SE is influenced by enactive mastery experiences, vicarious experiences, verbal persuasion, and physical and affective states. Enactive experiences refer to the person's experience and are considered the most dependable source of SE expectations, which are the key to future capability. Former success serves as a

cue to expected success in similar situations. Vicarious experiences occur when a person becomes persuaded of his or her ability to perform an action by observing the ability of others to do the action. Verbal persuasion occurs when another person convinces a person that he or she possesses the capabilities needed to perform the task; this way of enhancing SE is not effective over time unless it is followed by personal experience of success. Lastly, physiological and affective states are a source of information to the person about his or her capability, strength, and vulnerability that influence the person's judgment of his or her SE. These states may influence the person's SE expectations in threatening situations and the behavior needed to respond to such situations. The cancer diagnosis, treatment, and accompanying symptoms may cause physiological and emotional reactions, and may lessen the person's SE.

SE is an integral part of social cognitive theory, but SE has also been integrated into other theories such as the health promotion model [87], stages of change theory [88], the theory of planned behavior [89], and the health belief model [90].

Chronic pain patients with higher perceived SE about pain management, symptoms, and function have lower levels of pain, disability, and levels of psychological distress and more positive outcomes of educational intervention [91-95]. In cancer patients, SE may influence outcomes such as adjustment to cancer, QoL, and behavioral dysfunction [96-100]. Only two studies have investigated the relationship between pain intensity and SE in cancer pain patients [5, 101], and these studies showed that patients with higher SE reported lower pain intensity.

One reason for the varying levels of SE between patients could be their different ways of coping with pain. In a study of patients with chronic arthritis pain, Keefe and colleagues [94] found that several coping strategies predicted a significant proportion of the variance in SE even after controlling for pain intensity and demographic variables. Ignoring pain

sensation was related to higher SE for pain, coping self-statements were related to higher SE for other symptoms, and catastrophizing was related to lower SE for pain and other symptoms [94]. Chronic patients with higher SE use more active pain coping strategies and fewer passive coping strategies [102, 103]. Only one study [5] has studied the relationship between patients' SE and coping. In this study, patients' perceived self-efficacy to use a coping behavior was consistently positively correlated with their use of that coping behavior.

1.7 Quality of life

QoL is used widely as an outcome measure for cancer patients both in relation to research in medical treatment and in the nursing literature. Although the definition of QoL varies and there is no universally accepted definition of QoL [104], there is agreement on some characteristics [105]. QoL is a subjective experience that reflects the person's view of the situation. It is a multidimensional concept concerning the physical, psychological, and social dimensions of life. Further, QoL is a normative concept based on values, expectations, goals, and the meaning of life [105]. QoL in general can be distinguished from health-related QoL. QoL in general captures a person's perception of life in general, whereas health-related QoL captures the effects of health-related problems in relation to several life domains. The focus is usually on the effects of illness and treatment [106]. In the present study, QoL refers to the patient's perception of his or her physical, emotional, and social function as well as the disease and treatment-related symptoms and not to QoL in general.

The relationship between QoL and cancer pain is not clear. Intuitively, one could assume that higher pain intensity affects QoL negatively. However, Klepstad and colleagues [107] found a decrease in pain intensity without a subsequent increase in QoL in patients receiving morphine therapy. Bostrøm and colleagues [108] found that pain affects general health more directly in patients who have little pain than in patients who experience a lot of pain. Rustøen and colleagues [109] found that cancer patients who report a higher pain

intensity have lower QoL compared with patients with less pain; however, QoL is predicted only by depression and social and physical function, but not by the intensity or duration of pain. Others have found that higher pain intensity have negative impacts on QoL [70, 110].

When judging the relationship between pain and QoL one must consider how QoL and pain are operationalized because different aspects of QoL may be affected by pain differently. In a recent study, pain together with fatigue explained 48.5% of the variance in physical QoL and pain together with depression explained 31% of the variance in social QoL, but pain did not explain the variance in role function, cognitive function, or overall QoL [111]. In an earlier study that clustered cancer patients according to their symptoms, QoL (i.e. physical, psychological, social, and spiritual well-being) scores did not differ between patients with high fatigue and low pain ratings and patients with low fatigue and high pain ratings [112].

SE is another variable that may influence QoL. Cancer patients with high SE have significantly better physical and functional well-being [101]. Campbell and colleagues found a positive correlation between SE and QoL (i.e., physical functioning and mental health) [99]. An intervention study to promote SE reported that high SE is associated with increased QoL and decreased symptom distress for women diagnosed with breast cancer [100].

Taking a stress-coping perspective, Ward and colleagues [70] examined the links between a patient's beliefs (patient-related barriers to pain management), coping behavior (analgesic use), and QoL. QoL was measured by recording depression, pain interference with activities, and perceived health. The purpose was to test the concepts relevant to analgesic use such as pain intensity and side effects. Barriers had an indirect impact on QoL because more barriers were associated with inadequate analgesic use. Analgesic use influences QoL both directly and indirectly by modifying pain intensity. Side effects can influence QoL directly. Gunnardottir [113] found that more patient-related barriers to pain management (measured by

the BQ-II) are related to poorer QoL (Quality of Life Index-Cancer Version) and to negative mood.

Another study of 15 patients with prostate cancer found no correlation between active and passive coping and QoL measured using the The European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC QLQ-C30) [80].

Cancer pain is multidimensional and variables such as barriers to pain management, SE, coping, and adherence to pain management strategies are hypothesized to influence the pain experience and QoL. The literature is not clear about how these different variables interact and contribute to the pain experience, and further research is needed.

2 Aims of the study

Paper I:

- To determine the prevalence rates for cancer, noncancer, and both cancer and noncancer pain.
- To determine whether demographic, clinical, and pain characteristics differ between patients with cancer pain, noncancer pain, and both cancer and noncancer pain.

Paper II:

- To evaluate the psychometric properties of the Norwegian version of the BQ-II in patients with cancer pain in terms of completeness of the data, construct validity, and internal consistency.

Paper III:

- To describe patient adherence to an analgesic regimen.
- To determine whether demographic characteristics (age, sex, education level) are related to adherence.
- To determine whether adherence is related to clinical characteristics (presence of metastasis) and pain characteristics (cause of the pain, presence of BTP, pain intensity, pain relief, pain interference with function, use of a strong opioid analgesic).
- To determine whether adherence is related to the patient's SE and barriers to cancer pain management.
- To evaluate the direct and indirect effects of demographic, clinical, and pain characteristics, SE, and barriers on adherence to an analgesic regimen.

Paper IV:

- To identify a single pain severity cutpoint using average pain intensity.

- To determine whether demographic, clinical, and pain characteristics differ between patients classified according to the pain severity cutpoint.
- To determine whether SE and coping strategies for pain management, perceived barriers to cancer pain management, and QoL differ between patients classified according to the pain severity cutpoint.
- To determine which combination of variables provides the optimal prediction of the cutpoint for pain severity.

3 Materials and methods

3.1 Samples and sampling procedure

The patients were recruited from the outpatient oncology clinics (i.e., general, gynecology, lung, pain clinic, chemotherapy, radiation therapy) in a large, tertiary referral cancer hospital in Norway from December 2004 to May 2005. Most of the patients treated at this facility had solid tumors and required multimodal therapies for primary or metastatic disease. Patients were also seen for regular follow-up visits.

Oncology outpatients were included in this study if they were > 18 years of age; had a diagnosis of cancer; self-reported pain or used analgesics; and were able to read, write, and understand Norwegian.

The sample was recruited using a method that was designed to reduce the likelihood of systematic selection bias. All patients who came to an outpatient clinic during the selected periods of time were given written information about the study. Recruitment times were coordinated with clinic schedules to obtain a random, representative sample of outpatients with regard to diagnosis, stage of disease, and treatment and follow-up regimens.

In each outpatient clinic, a specially trained nurse screened all available charts for eligible patients and placed study information on the chart. The next day, when the patient came to the clinic, the receptionist gave him or her the study information sheet. After reading the information sheet, the patient completed a screening questionnaire about pain and the use of analgesics. Patients who did not have pain or were not taking analgesics were thanked for completing the screening questionnaire. Those patients who reported pain or the use of analgesics were invited to participate in the study. These patients signed the informed consent form and completed the study questionnaires either in the outpatient clinic or at home and then returned the questionnaires in a prepaid envelope. Patients who did not return the

questionnaires within three weeks were phoned by the researcher and reminded to return the questionnaires.

Over the six months of data collection, about 4404 patients were seen in the outpatient clinics and 1790 (40.6%) patients were screened for inclusion in this study. Figure 1 gives an overview of the recruitment process.

Figure 1. Information on sample selection and exclusions (n=1790)

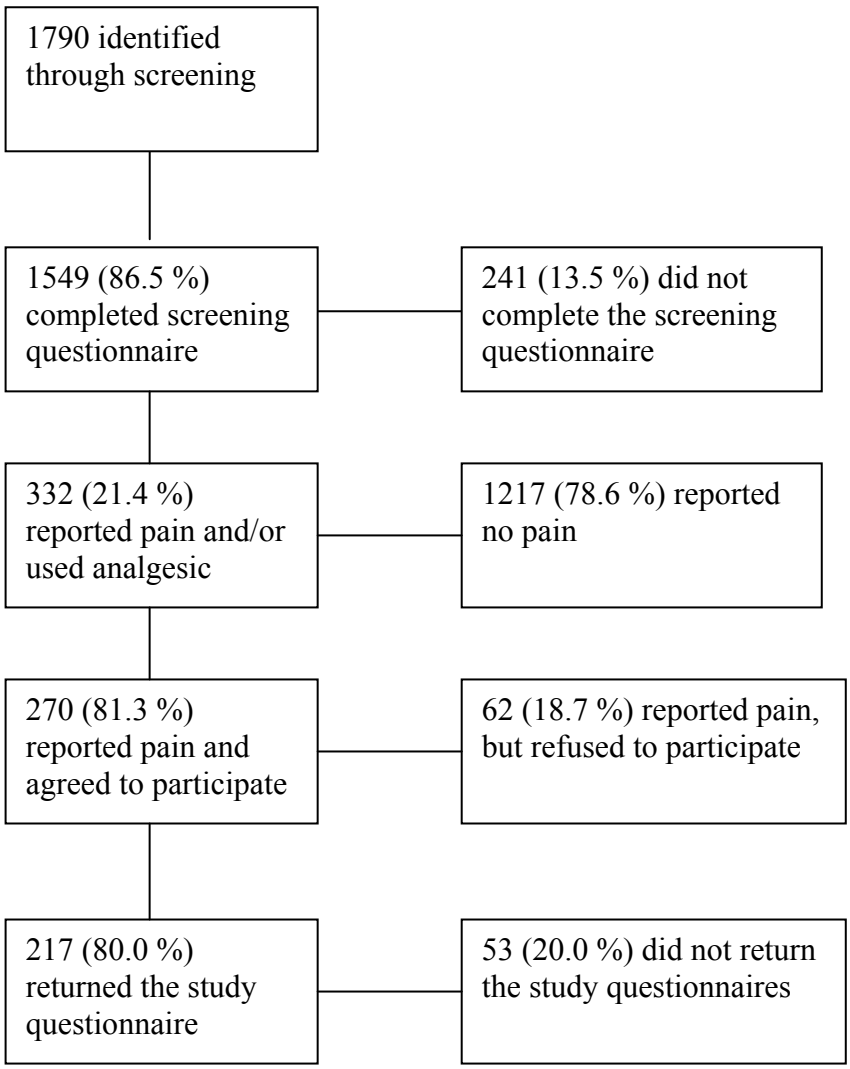

Table 1 gives an overview of the number of patients included in the four papers. In Paper II, data from another sample of hospitalized cancer patients were merged with the data from outpatients to maximize the number of questionnaires available for testing the psychometric properties of the Norwegian version of the Barriers Questionnaire-II (NBQ-II). This additional sample was recruited from St. Olavs Hospital in Trondheim as part of another study. The inclusion criteria were the same, except that all patients were taking opioid analgesics. In Paper III, only patients using pain medication were included in the analysis of adherence. In Paper IV, only patients who provided information about the average pain intensity score were included in the analysis.

Table 1. Number of patients in the four papers

Paper	**Number of patients included in the analysis**	**Reasons for the different numbers of patients**
Self-reported prevalence, etiology, and characteristics of pain in oncology outpatients (Paper I)	217	Outpatients only
Cancer patients' barriers to pain management and psychometric properties of the Norwegian version of the Barriers Questionnaire-II (NBQ-II) (Paper II)	321	Outpatients (n = 217) Hospitalized patients (n = 104)
Prevalence rates for and predictors of self-reported adherence of oncology outpatients to analgesic medications (Paper III)	164	Only outpatients using pain medication
Demographic, clinical, and pain characteristics are associated with average pain severity in a sample of oncology outpatients (Paper IV)	210	Outpatients giving scores for both average pain and pain interference with function

3.2 Instruments

Different questionnaires were selected to measure the variables in the study. Table 2 gives an overview of the questionnaires used. Some of the questionnaires used had been translated into Norwegian and validated, such as The Brief Pain Inventory (BPI), EORTC QLQ-C30, and Karnofsky's Performance Status (KPS). The other questionnaires (i.e.,

Coping Strategy Questionnaire (CSQ), NBQ-II, Self-efficacy for Pain Management, Adherence Measure I (AM-I) and adherence measure II (AMI-II)) were translated into Norwegian by two bilingual persons and backward translated by a bilingual person and a professional translation company. The backward and forward translation procedures were repeated until the translated version was congruent with the original [114, 115].

Table 2. Overview of the questionnaires and variables used in the study

Questionnaire	Paper	No. of items (item nb)	Scoring range	Cronbach's alpha	Appendix
Sociodemographic characteristics					I
Sex	All papers	1			
Age	All papers	1			
Education	I, III, IV	1			
Married/partnered	I, III, IV	1			
Cohabitation	I, IV	1			
Employment status	I, III, IV	1			
Disease characteristics					
Cancer diagnosis	All papers				II
Presence of metastasis	I, III, IV				
Current treatment	I				
Intent of treatment	I, IV				
Comorbidity	I, IV	16	0–48		III
Number of side effects	III	14	0–14		IV
Pain characteristics					
Pain intensity	All papers	4	0–10	0.87	V
Pain interference	All papers	7	0–10	0.89	V
Pain cause	I, III, IV	1	0–100		V
Pain relief	III, IV	1			V
Pain descriptors	I, II, III	18			V
Pain location	I, III, IV	body map			V
Pain duration	I	1			V
Breakthrough pain	I, III, IV	1			V
Type of analgesic	I, III	18			VI
Responsible for pain treatment	I	1			VII
Tell about pain	IV	1			VII
Help/information about pain	IV	1			VII
NBQ-II Total score	II, III, IV	27	0–5	0.89	VIII
Self-efficacy scale	III, IV		0–100		VIIII
SE for coping with other symptoms		8 (1–8)		0.87	
SE for pain management		5 (9–13)		0.81	
SE for physical function		9 (14–22)		0.88	

Adherence AM-I AM-II	III	 4 1	 0–4	 0.68	X
CSQ Diverting attention Reinterpreting pain sensation Coping self-statements Ignoring pain sensation Praying or hoping Catastrophizing Increasing behavioral activities	IV	 6 (3,10,13,30,31,43) 6 (1,4,11,18,34,46) 6 (6,8,23,26,36,37) 6 (20,22,24,27,35,40) 6 (15,17,21,25,32,41) 6 (5,12,14,28,38,42) 6 (2,7,39,44,45,47)	0–6	 0.83 0.82 0.77 0.74 0.75 0.84 0.70	XI
EORTC QLQ-C30 Physical function Role function Emotional function Cognitive function Social function Global health function Fatigue Nausea and vomiting Pain Dyspnea Insomnia Appetite loss Constipation Diarrhea Financial difficulties	IV	 4 (1,2,3,4,5) 2 (6,7) 4 (21,22,23,24) 2 (20,25) 2 (26,27) 2 (29,30) 3 (10,12,18) 2 (14,15) 2 (9,19) 1 (8) 1 (11) 1 (13) 1 (16) 1 (17) 1 (28)	0–100	 0.75 0.83 0.83 0.67 0.77 0.83 0.82 0.61 0.74	XII
Karnofsky's Performance Status	I, II, IV		40–100		XIII

3.2.1 Brief Pain Inventory short form

BPI [116] is one of the most frequently used tools to assess multidimensional cancer pain. It is designed to measure the subjective intensity of pain and the impairment caused by pain. Pain intensity scores (now, least, average, and worst pain in the past 24 hours) were scored using a numeric rating scale from 0 (no pain) to 10 (worst pain imaginable). Pain relief was rated from 0% (no relief) to 100% (complete relief). Pain interference with daily activity, mood, walking ability, normal work, relations with others, sleep, and enjoyment of life was scored from 0 (does not interfere) to 10 (complete interference). Both the single items and a total interference score are presented in this thesis. As a part of the BPI, patients were asked to indicate their beliefs about the cause of their pain, which was categorized as cancer pain only, noncancer pain only, or both cancer and noncancer pain. Pain location was obtained using the body map, which was scored using the procedures described by Rustoen et al. [117, 118]. The BPI has been translated into Norwegian and has satisfactory psychometric properties [119]. Values for Cronbach's alpha are given in Table 2.

3.2.2 The Norwegian Barriers questionnaire-II

The Barriers questionnaire (BQ-II) is a 27-item self-report instrument that measures a patient's beliefs about cancer pain and the use of analgesics and categorizes these into different areas (addiction, tolerance, side effects, fatalism, impairing immune function, being good (i.e., "good" patients do not complain about pain), distracting the medical doctor, and the notion that analgesics may block or mask one's ability to monitor symptoms [64, 113].

Participants rated the extent to which they agreed with each statement on a Likert scale that ranged from 0 (do not agree) to 5 (agree very much). A total NBQ-II score was calculated as the mean of the 27 items, with higher scores indicating greater perceived barriers. The

validity and reliability of the BQ-II have been established in several studies [113, 120]. Cronbach's alpha of the total score was 0.89 (Table 2).

3.2.3 Self-efficacy scale

The Self efficacy scale is a modified version of the validated Chronic Pain Self-Efficacy Scale developed by Anderson [121]. The questionnaire comprises 22 items, each of which is presented as a question (e.g., "How certain are you that you can decrease your pain quite a bit?") and is rated on a numeric rating scale of 10 (very uncertain) to 100 (very certain). Three subscales scores (SE for pain management (five items), SE for physical function (nine items), and SE for coping with other symptoms (eight items)) were calculated, with higher scores indicating higher levels of SE [121]. The Self efficacy scale has been used to measure SE about cancer pain management in patients and in family caregivers of patients with cancer pain [99, 101, 122]. The values for Cronbach's alpha for the different subscales are outlined in Table 2.

3.2.4 Adherence questionnaire I and II (AM-I and AM-II)

Because the literature is not clear about the best questionnaire to measure adherence, two different instruments were used to measure adherence to cover all aspects.

AM-I was designed originally to assess adherence with antihypertensive medications [123]. This questionnaire is based on the assumption that errors of drug omission could occur in any or all of the following ways: forgetting, being careless, stopping the medication when one feels better, or stopping the medication when one feels worse from the medication. The patient answers "yes" (scored as 0) or "no" (1) to the four questions about the different ways that drug omissions can occur. The total score ranges from 0 to 4, with higher scores indicating a higher level of adherence. The total score reflects the patient's relative level of adherence rather than a precise measurement of when and how the patient took the medication

[123]. The AM-I was used in two previous studies of patients with cancer pain [54, 124], one of which produced a Cronbach's alpha of 0.78 [124]. Cronbach's alpha for the AM-I was 0.68 (Table 2).

AM-II dichotomizes patients into adherent and nonadherent patients [53]. The patients were asked to select one of five statements that best reflected their level of adherence with analgesic medications in the past seven days. Adherent patients answered "yes" to the first item "took all pain medication as prescribed". All other patients were categorized as nonadherent. This adherence measure was developed for a study with patients with cancer pain and had a test–retest reliability coefficient of 0.93 over 48 hours [53].

These two measures assess either the end result of the decision made by the patient to take pain medication or the reasons for drug omission. To my knowledge, no instrument exists that assesses adherence from the perspective of how patients engage in making choices about how to take analgesic medication as cited by Turk and Meichenbaum's definition of adherence [46].

3.2.5 Coping Strategies Questionnaire

The CSQ was developed in 1983 by Rosenstiel and Keefe [125] and is one of the most frequently used measures of coping in chronic pain patients [126]. The questionnaire was developed by a review of the literature on coping with pain. The authors identified eight coping strategies and generated a list of six representative items for each coping strategy in each category. The cognitive coping strategies are: diverting attention, reinterpreting pain sensation, coping self-statements, ignoring pain sensation, praying or hoping, and catastrophizing. The behavioral coping strategy is named "increased behavioral activity".

The dimensions are scored on a seven-point scale to indicate the frequency with which the patient uses each strategy, where 0 represents never, 3 represents sometimes, and 6 represents always. Two single items assess the patient's perceived ability to control or

decrease pain by using different strategies. The Cronbach's alpha values of the subscales from this study are given in Table 2.

3.2.6 Quality of Life—The European Organization for Research and Treatment of Cancer Quality of Life questionnaire

The EORTC QLQ-C30 was developed to assess health-related quality of life in cancer patients. It was designed to be cancer specific, multidimensional, appropriate for self-administration, and applicable across a range of cultural settings. The core questionnaire (C30) comprises five function scales (physical, role, cognitive, emotional, and social); seven symptom scales (fatigue, pain, nausea and vomiting, dyspnea, insomnia, appetite loss, and constipation); a financial difficulties scale; and a global health function scale. It also has modules for different cancer diagnoses such as head and neck or breast cancer [127]. In this study, the EORTC QLQ-C30 raw scores were transformed linearly to a 0–100 scale using the algorithm from the EORTC QLQ-C30 scoring manual. Higher scores on the function scales and the global health function scale indicate a better level of functioning and overall QoL. In contrast, higher scores on the symptom scales indicate more severe symptoms [128]. The EORTC QLQ-C30 was translated into Norwegian previously and has acceptable validity and reliability [129, 130]. The Cronbach's alpha values of the subscales from this study are given in Table 2.

3.3 Data analysis and statistical methods

The Statistical Package for the Social Sciences (SPSS) for Windows, versions 14 and 15 (SPSS Inc., Chicago, IL) was used to analyze the data. Different statistical analyses were used depending on the research questions answered in the papers, and these analyses are described either below or in Papers I–IV. In all analyses, a p-value of less than 0.05 was considered significant.

3.3.1 Descriptive analysis

Descriptive and frequency distributions were generated for the demographic, clinical, and pain characteristics (Papers I–IV), and the adherence level was assessed in Paper III. The completeness, floor and ceiling scores, skewness, and kurtosis of the NBQ-II were evaluated by descriptive analysis in Paper II.

3.3.2 Comparisons and correlations

Chi-square analysis was used to compare the categorical variables of adherence and demographic, clinical, and pain characteristics between the three pain groups (only cancer pain, only noncancer pain, and both cancer and noncancer pain) (Papers I and III). One-way analysis of variance (ANOVA) using the Mann–Whitney or Kruskal–Wallis test was used to test the differences in means (Papers I and III). Post hoc contrasts were performed using the Bonferroni procedure to control the overall family alpha level for the three possible pair-wise contrasts. The p-value presented for each pair-wise contrast was adjusted so that values less than 0.05 indicate significance (Paper I).

To evaluate the construct validity of the NBQ-II (Paper II), correlations between barrier scores and pain intensity, pain interference, and age were calculated using Pearson's r. Pearson's r was also used to evaluate the relationship between the adherence measures and pain intensity, pain interference, SE to pain management, barriers to pain management, and the number of side effects (Paper III).

In Paper IV, the cutpoint of pain severity was determined using multivariate analysis of variance (MANOVA). All possible single cutpoint scores from 3 to 8 were considered, and the cutpoint with the largest F-ratio for the between-category effect on the seven interference items as indicated by Pillai's trace, Wilks's lambda, and Hotelling's trace F statistics was considered to be optimal.

3.3.3 Regression

To evaluate the impact of the various variables hypothesized to influence adherence in the health belief model (Paper III), a blockwise regression analysis was performed. Sex, age, and education level were seen as background variables and entered in Block I. In Block II, the total barriers score and the SE subscales were entered and, finally, the variables assumed to be cues to action were entered in Block III.

Paper IV includes multiple logistic regression that concentrates on the odds ratios (OR) and their 95% confidence intervals (CI) to evaluate the impact of demographic, clinical, and pain characteristics, perceived barriers, SE, and coping strategies on pain severity group membership, defined as pain > 4 versus pain ≤ 4). All variables that were significantly related to pain group membership in the univariate analyses were entered into the multiple logistic regression analysis.To construct parsimonious models, variables were removed systematically until only the significant predictors remained in the two final models.

3.3.4 Exploratory factor analysis

As part of the evaluation of the construct validity of the NBQ-II, factor analysis was performed. To explore the factor solution of the NBQ-II, the correlation matrix of the 27 items with estimated communalities as diagonal elements was factorized using the principal axis method with oblique rotation (Paper II). Oblique rotation was selected because the factors were assumed to be correlated [131].

3.4 Ethical aspects

A fundamental ethical principle is that patients are not harmed by the research. This principle encompasses multiple dimensions such as freedom from harm, exploitation, benefits from research, and assessment of risk versus benefits [132].

3.4.1 Principle of beneficence

In this study, patients were not exposed to physical harm, but psychological consequences may have arisen as the patients were asked to answer questions about their personal views and fears when in a vulnerable situation such as being diagnosed with cancer. The outpatients in this study were in different stages of disease, and their physical and psychological states were not known when asked to participate in the study. To avoid inflicting psychological harm on the patients, they were given written information that acknowledged that, in the process of answering the questionnaires, questions about the cancer, treatment, or other matters might arise, which the patients would want to discuss with health personnel. If so, the patients were asked to contact the physician or nurse in charge at the outpatient clinic. Patients were also told that they could contact the researcher at any time to receive answers to any questions about the questionnaires.

Patients need to be assured that information provided cannot be used to their disadvantage or expose them [132]. Information given by the patients was anonymized, and the patients were informed that health personnel at the outpatient clinic did not have access to any information given by the patient. Patients were asked to give their telephone number in case the researcher needed to contact them for any clarification of their answers to the questionnaire; only patients who gave their telephone number could be contacted.

Patients agree to participate in research for different reasons; some may perceive that there is direct benefit, but more often the benefits accrue to other patients as knowledge from previous studies is used to improve patient care [132]. To allow the patients to reflect on the possible benefits before deciding whether to participate, the information sheet listed the goals and potential benefits of the study (e.g., to increase knowledge about how outpatients living with pain cope in order to improve the treatment and follow-up care of cancer patients). Many patients who agreed to participate expressed that they wanted to participate to be helpful.

3.4.2 Principles of respect for human dignity and justice

The ethical principles of respect for human dignity and justice include the rights to self-determination, full disclosure, and fair treatment and privacy [132].

When asked to participate in a research study, patients must be assured that their decision to participate is voluntary and without any pressure. The relationship between the patients and health-care personnel is one where patients are the dependent party who may feel pressured to participate. To lessen this pressure, patients were not contacted by the researcher or the health-care personnel in charge of the treatment. Receptionists at the outpatient clinic delivered written information about the study to the patients and, after reading this information, the patients contacted the researcher. The written information described thoroughly the nature of the study, what participation would demand of the patient, and the patient's right to refuse to participate. After reading the written information, the patient signed an informed consent form, which emphasized that the patient could withdraw from the study at any point without any personal disadvantage.

The study was approved by the Regional Ethics Committee, the Norwegian Radium Hospital's protocol review system, and the Data inspectorate.

3.5 Main results and summary of the individual papers

The main findings of the study are presented in the following section and in Figure 2. A total of 1790 patients were available for screening of pain and 1549 completed the screening questionnaire. Of these patients, 332 (21.4%) reported pain or used analgesics, and 217 completed the study questionnaires. The sociodemographic and clinical characteristics are described in Table 3. As stated in the introduction, cancer rates increase with age and about 80% of all cancer occurs in patients older than 55 years. In this sample, the mean age was 58.1 ± 11.1 years. A higher percentage of women participated in the study. This is also

reflected by the high percentage of patients with breast cancer (38.7%). More than 50% of the participants were not receiving active cancer treatment, 41% of the patients had metastasis, and the treatment intention was palliative for 35.6% of the patients.

About 50% of the patients had experienced pain for more than seven months. The mean average pain intensity was 4.5 ± 2.1, and the mean score of pain interference with function was 4.3 ± 2.3 (both on a 10-point scale).

Table 3. Demographic and clinical characteristics of the total sample (n = 217)

Characteristics	**Total sample (n = 217)**
	Mean ± SD
Age (years)	58.1 ± 11.1
	%
Sex	
Men	25.3
Women	74.7
Education level	
Primary school	20.3
Secondary school	43.4
College/university	36.3
Married/partnered	
Yes	70.2
No	29.8
Cohabitation	
Yes	77.4
No	22.6
Employment status	
Not working	79.3
Working full-time/part-time	20.7
Cancer diagnosis	
Breast	38.7
Prostate	7.4
Gynecologic	10.1
Colorectal	6.5
Ear, nose, and throat	8.3
Sarcoma	7.8
Other	21.2
Current treatments	
No treatment	55.3
Surgery	0.9
Radiation therapy	18.4
Chemotherapy	11.5
Hormonal therapy	12.9
Other	0.9
Presence of metastasis	
Yes	40.9
No	59.1
Treatment intention	
Curative intention	64.4
Palliative intention	35.6

3.5.1 Self-reported prevalence, etiology, and characteristics of pain in oncology outpatients (Paper I)

The aim of this paper was to describe the prevalence of self-reported pain in oncology outpatients. It also explores whether demographics and clinical and pain characteristics differed between patients who experience cancer-related pain, non-cancer-related pain, and both cancer-related pain and non-cancer related pain.

The overall self-reported pain prevalence was 21.4%. When the patients were asked to describe the pain cause, 53% answered that the cancer or the treatment of cancer was the reason for their pain, 25% had only noncancer pain, and 22% had both cancer and noncancer pain.

Pain intensity did not differ significantly between the three pain groups, but patients with both cancer and noncancer pain had higher scores for pain interference with function, higher severity scores for various pain descriptors, and more pain locations. These findings suggest that outpatients with a combination of cancer and noncancer pain are at greater risk for undertreatment of pain. Because 37% of the patients thought the doctors at the oncology clinic were responsible for their pain treatment and 44% thought their general practitioner was responsible, both oncology clinicians and primary care providers should collaborate to perform a comprehensive pain assessment of all oncology patients to formulate an effective pain management plan.

3.5.2 Cancer patients' barriers to pain management and psychometric properties of the NBQ-II (Paper II)

The aim of this paper was to evaluate the psychometric properties of the BQ-II in a sample of Norwegian cancer patients. The BQ-II was translated into Norwegian and pilot tested on eight oncology outpatients. The patients were interviewed about any ambiguities or

difficulties with any of the items on the NBQ-II. After feedback from the patients, the statement "Do you believe" was placed on top of each page of the questionnaire to emphasize that patients were to respond in terms of their beliefs and not their knowledge. To help the patients understand the questions about the immune system, an explanation of the term was added in brackets.

A convenience sample of 321 cancer patients from two different sites was recruited to maximize the number of questionnaires available for the psychometric analyses.

Construct validity of the NBQ-II was evaluated using exploratory factor analysis. A seven-factor solution was found that was more consistent with the original version of the BQ. Construct validity of the NBQ-II was demonstrated through positive correlations between most of the subscale and total scores on the NBQ-II and pain intensity and pain interference scores. A significant but weak negative correlation was found between both the total NBQ-II score and most of the subscales and the pain management index score, suggesting that patients with an adequate analgesic prescription perceived fewer barriers. Finally, Cronbach's alpha coefficients of ≥ 0.70 for six of the seven subscales and 0.89 for the total scale demonstrated acceptable levels of internal consistency. The NBQ-II demonstrated adequate psychometric properties, although further revision and testing of the questionnaire is needed to confirm the factor structure identified in this study.

3.5.3 Prevalence rates for and predictors of self-reported adherence of oncology outpatients to analgesic medications (Paper III)

The aim of this paper was to describe oncology outpatients' level of adh erence to an analgesic regimen using two self-report questionnaires. Inadequate adherence to an analgesic regimen may be one reason why oncology patients experience unrelieved pain. Using concepts from the health belief model, this study evaluated the direct and indirect

effects of selected demographic variables, pain characteristics, barriers to pain management, and SE on adherence to an analgesic regiment.

Only 41% of the patients adhered to their analgesic regimen. In the univariate analysis, patients with cancer pain had higher adherence scores than patients with noncancer pain, and patients with BTP had higher adherence scores than patients without BTP. BTP management did not correlate significantly with adherence. Regression analysis found that 29.9% of the variance in adherence was explained. Higher adherence scores were associated with being male, lower SE for physical function scores, higher average pain intensity scores, higher pain relief scores, and the use of strong opioid analgesics.

3.5.4 Demographic, clinical, and pain characteristics are associated with average pain severity groups in a sample of oncology outpatients (Paper IV)

The aim of this paper was to determine the cutpoints for pain severity and to evaluate whether patients grouped according to pain severity differ on selected demographic, clinical, and pain characteristics. A further aim was to investigate which factors may be amenable to psychoeducational interventions such as SE for pain management, coping strategies, and barriers to pain management. Cutpoints for pain severity are useful because they may help clinicians identify patients with clinically significant pain.

An optimal cutpoint of 4 was found for the average pain intensity scores. Significantly more women, patients who lived alone, patients with metastasis, and patients with more comorbidities had a pain intensity score > 4. The cause of pain, the total number of pain locations, the amount of pain relief taken, or the frequency of telling the doctor about pain did not differ between patients with pain intensity scores > 4 and ≤ 4.

In the multiple logistic regression analysis, the variables that provided a unique contribution to the prediction of membership in the pain intensity score groups were sex,

presence of BTP, comorbidities, barriers to pain management, and total SE score for pain management. These variables explained about one-quarter of the variance in pain intensity score group membership. In addition, patients in the > 4 pain intensity score group reported lower scores on physical, role, cognitive, and global health function.

This study shows that an average pain intensity score > 4 could be used to screen oncology outpatients with clinically significant pain. The effectiveness of psychoeducational interventions aimed at barriers and the patient's SE for pain management need to be tested in future studies.

4 Discussion

This section discusses the findings of the thesis in relation to methodological issues, clinical implications, and ideas for further research.

4.1 Methodological issues

The study has a cross-sectional design, which is appropriate for describing the status of a phenomenon or the relationship between variables at one point in time [133]. This type of design limits the ability to draw conclusions about causality if there is no evidence or logical reasoning that one variable precedes the other or if there is no strong theoretical framework guiding the analysis [133]. The results must be interpreted with caution because they are based only on the patients' views of their situation at one particular time.

Concerns could be raised about whether a cross-sectional design is the most appropriate design when doing research on a phenomenon such as pain and coping, which may be seen as unstable or dynamic and variable between situations or over time. On the other hand, the design allows the inclusion of a sufficient number of patients in the available time frame of a doctoral thesis, and, in that way, strengthens the data and conclusions.

4.1.1 Sample and representativity

External validity is attained when the results can be generalized beyond the patients participating in the study to the broader population [133]. The following section discusses the threats to the studies' external validity.

The Cancer Clinic at Rikshospitalet is a comprehensive cancer center and is responsible for those living in the southern part of Norway. For geographic reasons, most follow-up examinations after treatment at the hospital are performed at the patient's local

hospital. However, a patient will be treated at Rikshospitalet if the necessary resources are not available near his or her home.

In Norway, the most prevalent cancer is breast cancer (23%) in women and prostate cancer (27%) in men [1]. Of all the patients identified through the screening in the present study (n = 1790), 31% had breast cancer and 14% had prostate cancer. This points to an overrepresentation of breast cancer and an underrepresentation of prostate cancer compared with the percentage of cancer in Norway in general. This may represent a threat to the external validity. The reason for this underrepresentation is not apparent. The sample was recruited using a method designed to reduce the likelihood of systematic selection bias, and no differences in diagnoses were found between the patients participating in the study and patients declining to participate. A previous study reported that patients in this hospital are somewhat representative of the cancer population in Norway [134].

Because of the apparent overrepresentation of women with breast cancer in this study, and because women in the general population report a higher prevalence of pain than do men [135], a higher prevalence of pain due to causes other than cancer pain could have been reported in this study. About 40% of the patients with breast cancer reported only noncancer pain. On the other hand, because women have a higher prevalence of pain in general [109], one could expect that the overall pain prevalence in this study would have been higher than in other prevalence studies, but it was not.

To reduce the likelihood of systematic selection bias, all patients attending the outpatient clinic on selected days were screened for pain and asked to participate. To minimize the effect of certain patient groups coming to the outpatient clinic on certain days of the week, all days of the week was used to assess data in the different outpatient clinics.

The relatively high percentage of patients completing the screening questionnaire (86.5%) strengthens the ability to generalize from the results.

4.1.2 Instruments

Several questionnaires were used in this study (Table 2). Of these, the BPI and EORTC QLQ-C30 will be discussed less than other instruments because they have been validated in Norwegian cancer patients and have shown adequate psychometric properties. The following section discusses the data quality and threats to reliability, validity, and responsiveness.

4.1.3 Reliability and validity

Reliability indicates that a scale or measurement yields reproducible and consistent results [133]. In this sample, internal consistency reliability was evaluated using Cronbach's alpha, and a coefficient value > 0.70 is considered satisfactory [133].

Validity is the degree to which the measure reflects what it is intended to measure, and whether it is useful [133]. Validity was evaluated through judgment of construct and content validity and factor analysis.

4.1.3.1 AM-I and AM-II

Adherence was measured by two different questionnaires, as recommended [46]. The AM-I was used to measure adherence to pain medication and had a Cronbach's alpha of 0.68, which is lower than the value reported in cancer patients in Taiwan [124]. This may relate to the somewhat different scale used in Taiwan compared with the original questionnaire [123] and the one used in this study. In the Taiwanese questionnaire, the last question asks the patient to indicate whether he or she initiates taking pain medication when feeling worse, and in this study, the patient was asked if he or she stopped taking pain medication when feeling worse.

In this study, question 1 ("Do you ever forget to take your pain medicine?") was not significantly not correlated with question 4 ("Sometimes if you feel worse when you take the

medicine, do you stop taking it?") (r = 0.018). Deleting either of these items gave a Cronbach's alpha value > 0.70.

The question with the highest rate of no response (missing) was question 4 (8%). This could be a threat to face validity and may reflect a lack of clarity of the question or that it was not meaningful to the patients.

The AM-I was developed to monitor patients' adherence to taking blood pressure medication, and its concurrent and predictive validity has been demonstrated [123]. In this study, the variables that contributed uniquely to explain the variance in adherence (e.g., use of opioids, average pain intensity, and the amount of pain relief) indicate that the instrument has construct validity for assessing adherence in cancer patients.

It is suggested that more than 250 factors may affect a patient's adherence to a medication regime [46]. The reasons for omission of medication reported by the patients in this study do not necessarily explain the construct of omission of medication in all situations, but the questionnaire seems to provide a valid measure of some dimensions of adherence behavior in cancer patients.

The second adherence measure (AM-II) was developed to assess the relationship between a cancer patient's beliefs about pain and adherence to the medication regime [53]. This measure has been used in only one previous study of cancer patients, which found that the belief that medication is best or necessary for dealing with pain and the belief that one can control pain significantly predicted adherence [53]. Prediction of adherence according to the patient's belief may support the construct validity of the AM-II because belief was also a strong predictor of adherence (using another adherence measure) in patients with asthma, renal, cardiac, and cancer disease; belief was a stronger predictor than clinical and sociodemographic factors [136].

Another reason for using two adherence measures was the lack of consensus about the best way to measure adherence and a wish to increase the validity of the assessment of adherence. The results using the two methods were consistent in both the adherent and the nonadherent patients: 88.6% of patients categorized as adherent also had high adherence on the instrument measuring reasons for drug omission, and 83.3% of patients categorized as nonadherent had low adherence. This supports the validity of both adherence measures used.

4.1.3.2 EORTC QLQ-C30

The EORTC QLQ-C30 shows satisfactory reliability in most subscales except for cognitive function (0.67) and nausea and vomiting (0.61) (Table 2). Cognitive function is measured on a two-item scale that assesses problems with concentration and memory. One reason for the somewhat low internal consistency may be that problems with concentration are not necessarily accompanied by problems with memory and vice versa. However, the items correlated to some degree; the correlation between the two items of cognitive function was 0.5, which is a fair correlation between the items (data not shown). Cronbach's alpha is also dependent on the number of items, and the scale of only two items would be expected to have low reliability. Previous studies to validate the psychometric properties of the EORTC QLQ-C30 have reported similar results [127, 137]. Nausea and vomiting is also a two-item scale, which may influence the internal consistency. As discussed for cognitive function, patients do not necessarily vomit even if they have nausea. The correlation between the items was 0.55, indicating a fair correlation between the items. Both scales had problems with a floor effect because most of the patients did not have cognitive problems or nausea and vomiting.

Previous research supports the validity of the EORTC QLQ-C30 [129, 130], and this is not discussed further.

4.1.3.3 The Self efficacy scale

The Self efficacy scale was developed originally to assess SE in arthritis patients [93]. Construct validity has been shown for the modified scale in both chronic and cancer pain patients [121, 122]. In the present study, construct validity was supported because the OR of a patient with a pain intensity score > 4 was higher in patients with lower SE than in patients with higher SE. However, the relationship between a patient's adherence to the analgesic regimen and SE was in the opposite direction than expected because patients with higher SE had lower adherence. One possible explanation is that the patients who had a lower sense of being able to manage their physical problems might have seen this deficit as a cue to action to increase their analgesic intake. They might have perceived that increased intake could help improve their functional status. However, this poses a threat to validity because the direction of the relationship was unexpected and further validation of this instrument is needed.

The amount of missing data was low overall. The item missed most frequently was item 19 ("How certain are you that you can participate in social activities?"), which nine patients did not answer. This indicates that the patients did not have difficulty completing the questionnaire.

4.1.3.4 NBQ-II

The Barriers questionnaire II was translated into Norwegian and as part of the validation process, construct validity was examined through exploratory factor analysis. However, the factor structure differed from the Barriers Questionnaire II, and the variations in the magnitude of the item loadings together with some cross-loadings within the factors suggest possible threats to the validity of the NBQ-II. Data from two samples (hospitalized patients and outpatients) were merged to obtain a larger sample to evaluate the psychometric properties of the NBQ-II, and this may be one reason for some of the differences in factor loadings. Although the factor loadings were somewhat unstable, the construct validity of the

NBQ-II was supported to a degree by the positive correlations between several barriers and pain intensity and interference scores, as hypothesized.

Because of the unstable factor structure, only the total sum of the score from the questionnaire was used in the analysis. Additional studies are needed to refine the items and to confirm the underlying factor structure of the questionnaire.

4.1.3.5 CSQ

The CSQ was originally developed to evaluate coping strategies used by patients with chronic pain [125]. It has been evaluated in a number of studies and found to be a valid and reliable measure [81, 125, 126, 138-140], but a stable factor structure has been difficult to replicate [78]. The CSQ has also been used to evaluate cancer pain [6, 21, 80, 141]. The factor structure of the CSQ was not evaluated in any of these previous cancer pain studies, although the results of a Norwegian study evaluating the psychometric properties of the questionnaire are soon to be published.

Some patients did not answer the questionnaire as instructed. Seven patients answered "yes" to the coping strategies used, and some left the question about coping strategies blank instead of answering 0 ("never do that"). The item with the most missing answers (10%) was item 18 (i.e., I try not to think of it as my body, but rather as something separate from me). This indicates threats to the reliability of the questionnaire.

4.2 General discussion

4.2.1 The prevalence and cause of pain

In this study, only 21.4% of the patients reported pain of any kind. This result is surprising because the prevalence of pain in the general Norwegian population is 28.3% [35]. This difference in the prevalence of pain raises several questions about the true pain prevalence both in the normal population and in cancer patients, and why these outpatients

with cancer had a lower prevalence than the general Norwegian population. One explanation for this inconsistency may be that patients with cancer define pain differently than the normal population and that cancer or the meaning of cancer influences how the patients view and define pain. Pain is defined as a subjective perception, and the subjectivity may explain differences between patients and the general population. Pain perception is the end result of several mechanisms involved in the transduction, transmission, and modulation of sensory input. These mechanisms are filtered through a person's genetic composition and prior learning history, and modulated further by his or her current physiological status, appraisal, expectations, mood state, and the sociocultural environment [142]. A cancer diagnosis affects both patient and family in many different ways because a cancer diagnosis connotes death, uncertainty, and loss of control [142]. Cancer patients may no longer view "ordinary" daily pain as pain but more as "discomfort" when facing the threats of cancer. More research is needed to increase our knowledge about how patients define pain as pain and how they differentiate pain from discomfort.

Cancer pain treatment is often decided on the basis of the patient's rating of pain intensity, often by using the recommended WHO ladder of pain medication [26]. The results of this study reflect the importance of assessing pain in a broader sense than just pain intensity before initiating and during pain management. In this study, of those patients having pain, 25% reported only noncancer pain and 22% reported both cancer-related and non-cancer-related pain. The treatment of cancer pain and pain due to other causes may differ. Cancer pain management relies primarily on removing the underlying pathology and, when this is not possible, on managing the pain itself [4]. Specialized treatment strategies have been developed, such as the "back pain schools" schools in Norway, for treating noncancer pain.

Another interesting finding is the lack of difference in self-reported pain intensity between the three groups (only cancer pain, only noncancer pain, and both cancer and

noncancer pain). However, the patients with both cancer pain and noncancer pain had higher scores for interference with function and severity of pain than the patients in the other groups. This suggests that patients with both cancer and noncancer pain may be at higher risk for undertreatment of their pain. This finding supports the need for thorough pain assessment beyond just pain intensity because, regardless of the cause of pain, too many cancer patients have pain and need help with their pain management.

4.2.2 Barriers to pain management

The use of analgesics is one of many ways to manage pain. This study showed that many patients have fears and misconceptions about pain and pain management. The single most feared consequence of pain management was addiction, which agrees with previous reports [55, 64]. Most patients did not have a fatalistic view of cancer pain. A fatalistic view on cancer pain seems to be less common in Norway and in the American population [57, 61, 64, 113, 143, 144] than in other parts of the world [49, 58, 59, 145-147]. Another interesting finding is that patients are concerned that pain medication could mask changes in their condition. Avoiding or using less pain medication may be one way for the patient to feel more in control of the disease as he or she is then able to detect changes and monitor pain. Drowsiness was the most feared side effect, and some patients experience drowsiness when starting pain treatment, although the drowsiness usually diminishes after some time. It is crucial that patients are prepared for this side effect to prevent them from stopping the medication. Nausea and constipation, which are common side effects, were feared less, suggesting that patients receive help dealing with these problems. The results also showed that barriers to pain management remain a concern in cancer patients and may be one reason for insufficient pain treatment. Education is needed to give patients realistic and trustworthy knowledge about pain and pain management. Cancer patients need to have access to consultations where they are allowed to express their thoughts regarding pain management.

The BQ may be one way of screening patients about their beliefs and misconceptions about pain management, and thus give nurses information about the topics to discuss with the patients.

4.2.3 Adherence to pain management

As noted earlier, barriers such as beliefs and misconceptions about pain and pain management are one possible reason for patients not taking pain medication as recommended. However, barriers were not significantly related to adherence in this study. Two earlier studies found a relationship between hesitancy to use medication and barriers [49, 55]. Lin and colleagues [54] found that an education program for cancer patients and their family reduced barriers and increased adherence to medication. Others have not found a relationship between barriers and adherence [57, 143]. These conflicting results may reflect individual differences between patients—even if a patient exhibits barriers to medication, he or she does not always act on them [18]. The way pain medication is prescribed could also be a mediating factor because patients prescribed pain medication "as needed" adhere less to the medication regime than do patients prescribed medication "around the clock" [56]. This should be taken into account in future studies.

Patients with cancer-related pain were more adherent than patients with non-cancer-related pain when adherence was measured using the AM-I but not the AM-II. The patient groups did not differ on forgetfulness or stopping pain medication when feeling worse, but patients with noncancer pain were more careless and stopped taking pain medication more often when they felt better than did patients with cancer-related pain. Forgetfulness is a common reason for nonadherence [18], and this could explain why the AM-II failed to detect a difference in adherence between patients grouped according to the cause of pain. Another explanation for the difference in adherence pattern in relation to the cause of pain may be that

some patients perceive that taking pain medication on a regular basis for cancer pain is more acceptable and important than taking pain medication for pain from other causes.

Lack of adherence contributes to ineffective pain management [56], and it is reasonable to expect that adherent patients may report lower pain intensity. However, a patient's report of pain intensity relies on many factors besides adherence. Health-care personnel do not always follow the guidelines for pain management. One study showed that patients with higher adherence to a pain algorithm had significantly lower pain scores, whereas adherence to a standard treatment had no influence on pain intensity [51]. This emphasizes the importance of providing sufficient pain treatment and guidelines. In this study, average pain intensity uniquely explained only 3% of the variance in adherence in the direction that patients with higher pain intensity were more adherent. One interpretation is that patients with higher pain intensity adhere to the medication in hope of and need for more pain relief.

Adherence should be viewed in connection to different outcome measures that are desirable for the patient's health. Patients need ongoing education and explanations about how to deal with different types of problems associated with pain management. It is not enough to tell a patient about the dosage and when to take the pain medication; health-care personnel should also discuss with the patient the different ways of dealing with problems that can and will arise. Health-care professionals must also ask the patient about his or her goals and explain how to cope with the medication and other health concerns while trying to achieve these goals.

4.2.4 SE for pain management and coping strategies

In this study, patients' perceived SE and coping were examined as important psychological factors associated with pain severity in chronic noncancer pain [148-150]. The results of this study support previous studies showing that SE is an important psychological

factor in the experience of pain in cancer patients. Patients with higher SE in this study had lower pain intensity. Further development and research on strategies to enhance SE in cancer patients are needed.

Perceived SE was also evaluated as a mediator of adherence. In the regression analysis, only SE for physical function was a significant predictor of adherence. This relationship was in the opposite direction of that expected. The relationship between adherence, pain intensity, pain medication, barriers, and SE needs further investigation to understand the interrelationships between these variables.

The most used coping strategy involved coping self-statements and the least was reinterpreting pain sensation. This is consistent with a study of prostate cancer patients [80]. In this thesis, catastrophizing was the second least-used coping strategy, but only catastrophizing and the ability to reduce and control pain were related to pain intensity and pain interference. Patients with higher scores on catastrophizing and lower scores on ability to control and reduce their pain had higher scores on pain intensity and pain interference with function. This is also consistent with other studies [5, 6, 151]. Catastrophizing reflects pessimism and helplessness in dealing with pain, and suggests that cancer patients with pain perceive their pain as a threatening symptom.

4.2.5 Pain intensity cutpoint and QoL

In this study, patients with a pain intensity score > 4 (the cutpoint) had poorer QoL than patients with a pain intensity score of 4 or less. Patients with a higher pain intensity score had significantly lower scores on several of the QoL scales such as physical, role, and cognitive function, and global health. Emotional and social function did not differ between patients with pain intensity scores above and below the cutpoint of 4. Living with pain affects different aspects of life differently, and these data underpin the need to use different dimensions to measure the outcome of pain [152].

This study used a cutpoint of 4 on the 10-point scale of average pain severity. Previous studies establishing two cutpoints of pain intensity in cancer patients grading the pain as mild, moderate, or severe pain [153, 154], also found a cutpoint of 4 between mild and moderate pain. A cutpoint of 4 was found even if they used "worst pain intensity" and not "average pain intensity" as in this study, to define the cutpoint. A cutpoint of 4 may therefore represent a useful clinical value to guide the management of cancer pain. This is supported by Wang and colleagues [110], who found that the health and well-being (measured using the Medical Outcomes Study 36-Item Short-Form Health Survey) of cancer patients with no or mild pain were significantly less impaired than in patients with moderate or severe pain. It is also interesting to note that the impairment of patients with moderate and severe pain did not differ.

Most studies of noncancer pain intensity have used two cutpoints and have found a pain intensity of 4 as the cutoff between mild and moderate pain [155-160]. A cutpoint of 4 may represent a useful clinical measure for patients with cancer pain and possibly for other pain conditions; this should be explored further.

The factors contributing to and explaining the variation in pain intensity and QoL in outpatients with cancer are unclear. A variety of factors, such as physical, emotional, cognitive, and social factors, influence the pain experience [9], and the interrelationships between them are unclear. This thesis included some of these variables to provide new insight into the complex phenomenon of cancer pain.

4.3 Implications for nursing practice

Outpatients and their families are faced with a greater challenge than hospitalized patients when making decisions about pain and pain management on a daily basis. As outpatients, they often have less opportunity to obtain answers to questions when problems arise. This highlights the need for them to be given thorough information when discharged from hospital and at follow-up at the outpatient clinic. Even though outpatients in this study had a lower prevalence of pain than the patients in previous studies, too many patients have pain and have an obvious need for improved pain management. Sufficient pain management is dependent on systematic pain assessment and structured routines. Nurses play an important role providing continuity of care in the processes of pain assessment, initiation of pain management, follow-up care, and evaluation of the pain management program. Ongoing assessment of pain intensity is needed at both the initiation and the evaluation stages. Nurses have an obligation to routinely screen all cancer patients for pain because the disease, treatment, and other factors may inflict new pain during treatment and follow-up. A numeric rating scale could be a useful screening tool to identify those patients needing help with pain and follow-up. In this study, a cutpoint pain intensity of 4 seemed to differentiate patients whose pain had little impact on QoL from patients experiencing more pain and thus needing help and guidance.

In this study, the factors that identified vulnerable groups, especially those at risk of undertreatment and higher pain intensity, were women and patients having more comorbidities, more pain locations, BTP, higher severity scores in the pain descriptors, greater pain interference with function, and pain caused by other diseases. Not all these factors are necessarily linked to the cancer. This underscores the need to determine the etiology of pain as a cornerstone of effective pain management [20] and suggests that

identifying the underlying cause of pain should be an integrated part of a patient's pain assessment.

This study also showed that a patient's beliefs about and attitudes to pain management might be barriers to improved pain management. The barriers questionnaire may be a valuable tool because it gives nurses better insight into a patient's knowledge and thoughts about pain and medication. The questionnaire might help identify the topics that are important to patients and what they need more information about. It could also provide a tool for initiating goal-directed discussion of topics that may not have been discussed with patients earlier, such as addiction or the belief that pain is inevitable. Structured pain education may also improve pain management indirectly because the patient's beliefs may shape the pain experience by inhibiting his or her willingness to report pain. Patients who withhold information about pain because of their beliefs and misconceptions about pain management may find it difficult to improve their pain management. Nurses should discuss with the patients whether they are satisfied with the recommended analgesic prescribed and the level of adherence. Many patients do not adhere to the medication regimen because they feel they have valid reasons for not following the advised regimen. A cooperative program whereby patients and nurses can discuss different opportunities for pain management may help. Such programs should focus on identifying the optimal regimen for each patient. Previous research shows that patients prescribed pain medication around the clock are more likely to adhere [19]. Nurses should use their influence as part of the pain management team to suggest pain regimens administered around the clock when suitable.

Nonpharmacological methods of pain management should also be discussed and initiated. Information and discussions with patients should focus on increasing patient SE by educating and encouraging patients to take certain actions to relieve pain and by discussing what patients have done in the past that has helped. The goal is to increase the patient's

experience of mastery. Other ways of enhancing a patient's SE is to relate other patients' experiences when dealing with pain and to try to persuade the patient that he or she possesses the capability to master the various pain-reducing tasks.

A dialogue between nurse and patient that addresses the patient's thoughts and reactions gives the nurse an insight into what is important to the patient and what expectations he or she has. This knowledge will help the nurse tailor the pain management regimen to the individual patient's wishes and needs.

4.4 Implications for further research

This study gives new insight into the needs of cancer patients living with pain and poses new questions needing further investigation. About half of the patients rated pain intensity > 4 on the 10-point scale, and effective cancer pain management remains an ongoing clinical challenge. Research is needed to identify additional factors that contribute to increased pain severity in patients with cancer pain because only about one-quarter of the variance in the rating of pain intensity (above and below the cutpoint of 4) was explained by the independent variables.

When a patient's adherence is not at a level that is satisfactory for improving pain management, the reasons for nonadherence should be investigated further by focusing on personal and other factors that may improve patient adherence. This study found a sex difference in that women were more careless than men as they more often answered "yes" to the question "Are you careless at times about taking your medicine?", and they stopped taking medication when feeling better or worse more often than men. Both men and women were equally forgetful. Previous research on cancer patients has found no sex differences in adherence, but the sex difference observed in this study is consistent with other studies of other patients groups. This difference between patient groups and studies suggests that

additional research is needed to determine the specific risk factors that influence men's and women's adherence to an analgesic regimen.

What patients do when in pain may depend on their SE. Specific strategies to improve cancer patients' SE for managing cancer pain should be developed and tested.

Barriers and adherence were both related to higher pain intensity, but barriers to pain management were not correlated with adherence as expected. The relationship between adherence and barriers may be mediated by other factors and should be explored further.

This study was based on Ahles's multidimensional view of pain, which includes sensory, affective, cognitive, and behavioral components that influence the pain experience in cancer patients[9]. This study explored the relationships between variables related to the different components of this model; other interesting relationships, such as how adherence or coping strategies are related to QoL, were not explored.

The research in this thesis has been more empirically driven than theory driven because the multidimensional description of the pain experience does not predict which variables have a greater or lesser impact on a patient's pain and QoL. QoL is often used as an outcome measure in cancer research. Future research that builds on a model with QoL as the dependent variable and explores how the different variables influence each other and the outcome could be important for prioritizing the factors that have the greatest impact on QoL in cancer patients.

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