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Acute postoperative and cancer-related pain management

**Patients experiences and perceptions in relation to
health-related quality of life and the multidimensionality of pain**

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ABSTRACT

This thesis describes patients in acute postoperative pain as well as patients with acute cancer-related pain in palliative care, and their experiences and perceptions of pain management in relation to HRQOL and the multidimensionality of pain. A combination of qualitative and quantitative methods was chosen. Data were collected using interviews and questionnaires; APS, SF:36 and a new developed questionnaire PC-PPQ measuring care related to pain management in palliative care. For assessing pain VAS and Pain-o-Meter were used. The study group consisted of 100 patients on their second postoperative day, and of 75 patients with cancer-related pain from two palliative care teams.

The result showed that at the time of the interview 29 of the patients with postoperative pain reported a pain > 3 on VAS and 79 reported VAS > 3 as worst pain past 24 hours. The higher the intensity of pain the less satisfied the postoperative patients were with the nurses' way of treating their pain. Thirty-three patients stated that they had received information regarding the importance of pain relief.

Patients with postoperative pain as well as patients with cancer-related pain had been prescribed analgesics mostly a combination of Paracetamol, NSAID and opioid.

Of the 75 patients with cancer-related pain and in palliative care 22 patients reported pain >3 on POM-VAS and 47 patients reported >3 on POM-VAS as worst pain past 24 hours. Twenty-eight patients reported an average pain > 3 on POM-VAS past 24 hours. Twenty-four patients used the words troublesome or tiring when describing their affective pain. Sensory pain was described as prickling or sore by 15 patients. The patients perceived their pain as "aching all over" and expressed a wish for pain relief as well as a fear for increased pain. HRQOL especially physical functioning decreased for patients with average pain > 3. Being cared for by a nurse-led or a physician-led palliative care team indicated no statistically significant differences for patients' HRQOL or pain intensities. The patients had experienced a statistically significant better care after being referred to a palliative care team, despite that pain control had not been optimized. Patients expressed a need for communication, planning and trust in order to improve pain management. Continuity of care and the opportunity to talk increase the patients feeling of security, as well as improved their perceived pain control.

Structured ongoing discussion concerning pain management from an early stage of the disease or already preoperatively can provide an important intervention to meet the results of this thesis. Pain assessment covering the multidimensionality of pain, and pain treatment plans including both pharmacological and non-pharmacological treatment are further important interventions.

Key words: American Pain Society, cancer-related pain, Health-Related Quality of Life, nursing care, pain management, perceptions, Pain-o-Meter, postoperative pain, SF-36.

This thesis is based on the following papers, referred to in the text by their Roman numerals:

- I** Boström B, Ramberg T, Davis B, Fridlund B. (1997) Survey of postoperative patients' pain management. *Journal of Nursing Management*, 5, 341-349

- II** Boström B, Sandh M, Lundberg D, Fridlund B. A comparison of Pain and Health Related Quality of Life between two groups of cancer patients with differing average levels of pain. *Accepted for publication in Journal of Clinical Nursing*

- III** Boström B, Hinic H, Lundberg D, Fridlund B. Pain and health related quality of life among cancer patients in final stage of life: A comparison between two palliative care teams. *Journal of Nursing Management in press*

- IV** Boström B, Sandh M, Lundberg D, Fridlund B. Cancer patients' experiences of care related to pain management, before and after referral to palliative care. *Submitted*

- V** Boström B, Sandh M, Lundberg D, Fridlund B. Patients with cancer-related pain, in palliative care and their perceptions of pain management. *Submitted*

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ABBREVIATIONS

APS	American Pain Society
BP	Bodily pain (a health dimension in SF-36)
GH	General health (a health dimension in SF-36)
HRQOL	Health-Related Quality of Life
MH	Mental health (a health dimension in SF-36)
NSAID	Non-Steroid-Anti-Inflammatory Drug
PC	Palliative care
PCT I	Nurse-led palliative care team
PCT II	Physician-led palliative care team
PF	Physical functioning (a health dimension in SF-36)
POM	Pain-o-Meter
POM-VAS	Visual Analogue Scale on POM
POM-WDS	Word Descriptor Scale on POM. Affective and sensory words
PC-PCQ	Pain Control in Palliative Care Questionnaire
QA	Quality assurance
RE	Role functioning-emotional (a health dimension in SF-36)
RP	Role functioning-physical (a health dimension in SF-36)
SF	Social functioning (a health dimension in SF-36)
QOL	Quality of Life
SF-36	Medical Outcomes Study Short Form 36 questionnaire
VAS	Visual Analogue Scale
WHO	World Health Organization
VT	Vitality (a health dimension in SF-36)

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INTRODUCTION

Pain is one of the most common symptoms of illness for which people request health care. Patients in pain ought to be treated quickly and adequately in order to avoid developing a chronic state (Bonica, 1987; Melzack, 1999). Acute pain is most often associated with trauma, internal pathology or surgery. When its useful role as a warning of injury or illness has passed, it only represents an unnecessary burden for the patient (Cousins, 1994). Pain is also a common feature for patients with a cancer disease. Interventions for patients with cancer-related pain in palliative care have all the characteristics of interventions for patients with acute pain (Peruselli et al., 1997). Frequent or persistent experiences of pain and discomfort have a negative impact on daily functioning and overall enjoyment of life (Portenoy et al., 1994). The best judge of whether HRQOL is achieved or not, is the patient himself (Bowling, 1995). It is a common misconception to regard pain as a single, clear-cut entity when it is in contrast, usually a complex, highly individual experience made up of several parts (Melzack, 1999). Therefore patients' views of matters such as need of information, interpersonal and organisational aspects of care, and value of treatment will be essential to evaluate.

No distinct line can be drawn between the work of the physicians and the nurses for a patient in pain; their jobs are largely overlapping. The science of nursing is in some respects similar to the science of medicine, especially in the fields of physiology and pharmacology (McCaffery & Pasero, 1999). However, as mostly nurses have the overall responsibility for patients frequently suffering pain, the patients' chances of receiving effective pain control depend heavily on the nurse (Benner, 1984).

This thesis is based on the fact that acute pain is the dominator of both postoperative and cancer-related pain. Even though cancer-related pain frequently becomes long lasting, the importance of accurate pain management of the acute phases is most urgent (Cherney & Portenoy, 1994). Furthermore, the approaches for managing postoperative and cancer-related pain are to some equal extent (IASP, 1992; Cherny & Portenoy, 1994; Cousins, 1994):

- The pathophysiology being mainly nociceptive, interrupting or preventing activation of the pain pathways is the aim (Portenoy, 1992).
- The multidimensional assessment of pain.
- Treating the underlying disease if possible and the pharmacotherapy being mainly Paracetamol, NSAID and opioid.
- Supporting the patients by including the multidimensionality of pain in all caring actions performed.

BACKGROUND

Definition of pain

According to International Association for the Study of Pain (1979, p.249) pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. “The person with pain is the only authority about the existence and nature of that pain, since the sensation can only be felt by the person who has it” (McCaffery & Beebe, 1994, p 14). Acute pain is defined as “a constellation of unpleasant perceptual and emotional experiences and associated autonomic reflex responses and psychological and behavioural reactions. “ (Bonica, 1987, p 1).

Physiology of acute pain

Acute pain is provoked by tissue-damaging stimulation produced by injury or disease. In most tissues, there is a network of free nerve endings that are the terminals of unmyelinated C-fibres and thin myelinated A-delta fibres. These nerve terminals function differently in relation to different nociceptive stimulus. Nociceptors are defined as receptors responding to stimuli, which may cause tissue damage. The nociceptive stimulus may be intense mechanical, thermal, or chemical. A-delta fibres give rise to the first localized sharp pain, while C-fibres give rise to the second aching, dull and poorly localized pain. The nociceptive information is transmitted through the dorsal horn of the spinal cord and further through pathway systems terminating in the brain. Nervous pathways run partly from the thalamus to the sensory cortex where knowledge, memory of previous pain experience and cultural influences exert their effects on the perception of pain. This journey continues partly to the hypothalamus and limbic system, important in determining the individual's emotional reaction to pain (Woolf, 1994). Melzack and Wall (1965) propose that there is a neuronal mechanism in the dorsal horn of the spinal cord, which acts as a gating mechanism through which peripheral information passes. This Gate Control Theory has greatly enriched the understanding of pain mechanisms and takes account of both physiological and psychological dimensions of pain. The Gate Control Theory has undergone revision since it was first proposed in 1965, and been further developed to the proposed neuromatrix theory of pain (Melzack, 1999). The neuromatrix theory of pain proposes pain as a multidimensional experience produced by influences not only from injury, inflammation or other tissue pathology but also from areas in the brain. The brain possesses a neural network determining the particular qualities of the pain experience and behaviour as well as the cognitive interpretation of the situation. The activity of the endocrine, autonomic, immune and endogenous opioid system is conceptualized as a type of chemical gating mechanism, very effective in reducing pain (Melzack, 1999). The tissue damage initiating nociceptive stimuli and acute pain experience occurs due to both surgery and tumour (Carr & Goudas, 1999). Repeated nociceptive stimulation sensitizes the neurons of the dorsal horn of the spinal cord and

is referred to as “wind up” or “central sensitization”. This mechanism increases the level of pain, and may produce continuous pain and sometimes develops a chronic condition (Gottschalk & Smith, 2001). Furthermore, the pathophysiological complications of unrelieved acute pain also include significant impairment of mobility, of pulmonary, bowel, and mental functions, of nutritional status and immunity. Further effects of unrelieved acute pain include increased morbidity and/or delayed recovery from illness or surgery as well as a diminished perception of overall health (Carr & Goudas, 1999; Melzack, 1999).

Postoperative pain

Postoperative pain continues to be a clinical problem (Kehlet, 1999). Many patients expect and accept pain as a natural consequence of surgery and their expectations are often met (Miaskowski et al., 1994; Carr & Thomas, 1997). Several studies have reported that 25% to 50% of patients suffer from moderate to severe pain after surgical procedures (Abbott et al., 1992; Oates et al., 1994; Svensson et al., 2000; Carr, 2001) although the necessary tools to manage postoperative pain are available, including analgesics and guidelines (Rawal & Berggren, 1993). Most patients are unaware of the serious consequences of unrelieved pain, bought about by lack of information (Carr & Thomas, 1997), inadequate pain assessment and documentation contributing ineffective pain control (Carr & Thomas, 1997).

Cancer related pain

Cancer is a global problem and the outspread of cancer can be expected to rise all over the world due to a general increase in the average age (Chochinov & Kristjanson, 1998; WHO, 1990). The number of people in Sweden with cancer diagnosed has now reached over 40.000 (half male half female) each year. For men, prostate cancer is most common, followed by lung cancer and colon cancer. Most frequent forms of cancer for women are breast cancer and colon cancer. Lung cancer is the fifth most frequent cancer form among female cancer patients in Sweden 1998 (National Board of Health and Welfare, 2000). Cancer-related pain is a pain that is both acute and chronic (Twycross, 1997; Gordin et al., 2001). A pain that is permanent or frequent for over 60% of patients with advanced cancer (Thomason et al., 1998). More than 90% of patients dying in cancer suffer from pain in the final phase of life (Cleeland et al., 1994; Addington–Hall & McCarthy, 1995; Bernabei et al., 1998; Kaasa et al., 1999) despite the availability of treatment capable of greatly reducing pain (WHO, 1996; National Board of Health and Welfare, 2001a).

Multidimensionality of pain

The sensation of pain is individual, consequently what one person may experience as a slight discomfort may be agony for another. The common bond linking most people's experiences of pain is its affect on daily life, making it difficult to take pleasure in simple activities. This can be caused either through restricted physical ability, fear of exacerbating pain, or anxiety that pain will become impossible to control (Vaino & Auvinen, 1996; Strang, 1998; Meuser et al., 2001). If pain persists unrelieved for several days, adaptation may occur, and the patient's behavioural and physiological responses to pain will become minimal or cease to exist for periods of time, even if the pain is severe. Lack of response to pain does not necessarily mean a lack of pain. Instead pain persisting unrelieved for several days increases anger, depression, anxiety, fear, helplessness and sleep deprivation (Cousins, 1994).

McGuire (1992) has presented six dimensions of pain experience applicable to persons in all sorts of pain-caused conditions. The dimensions are physiologic, sensory, affective, cognitive, behavioural and socio-cultural. The physiologic dimension is proposed by Ahles et al. (1983) and deals with the organic etiology of pain and the location, onset, duration, and general endocrine metabolic stress response, (the impulses sent from the site of physical damage, as previously outlined). Although there are many physiological events which occur concurrently with the experience of pain, many may be general responses to stress and not unique to pain (Melzack & Katz, 1994; Tywcross, 1997). The sensory dimension deals with how a person feels about pain, pain intensity and quality of pain (Melzack, 1999). Different diseases or syndromes of pain may give rise to different patterns of pain. It is important to identify whether the pain is acute or chronic, nociceptive or neurogen (Melzack & Katz, 1994) as these patterns are important components in the sensory dimension (Ferrell et al., 1994; Sela et al., 2002). Pain manifests itself in a variety of ways, whether postoperative or cancer-related, and may be described with sensory words like: sharp, burning, sore, constant, intermittent and spasmodic (Gaston-Johansson, 1996). The affective dimension deals with the influence of pain on emotions, how emotions affect pain and the consequences of pain for the individual (Melzack, 1999). It has to do with factors like state of mood, anxiety, depression, and well-being (Strang, 1998; Sela et al., 2002). Affective or emotional aspects are always involved in the pain experience but may vary in severity from an unpleasant or annoying feeling to agonising or excruciating distress (Craig, 1994) and can be described with words like: troublesome, tiring, torturing, killing or dreadful (Gaston-Johansson, 1996). All severe pain confronts the individual with the threat of death. During the acute phase of pain a person usually feels worried and reacts with anxiety. If the pain becomes long lasting and treatment proves to be of no use, it may affect all aspects of the person's life. The cognitive dimension deals with the meaning of pain and the skills to cope with it. A person may have gained such skills thanks to his previous background (Melzack, 1999). In the actual pain experience, knowledge of previous suffering and previous

treatment are reflected. The meaning and symbolism of pain become very important for the sufferer (Ferrell et al., 1994; Strang, 1998; Calvin et al., 1999). The behavioural dimension deals with the method of communication, verbal or nonverbal, and with the relationship between feeling and behaviour (Ahles et al., 1983). Pain behaviour can cause a lack of activity and muscle wastage, disturbed sleep, no social contact and no distraction (Ferrell et al., 1994). Compliance to medication is also part of pain behaviour (McGuire, 1992). Socio-cultural dimension deals with a person's attitudes and beliefs, including family and social life as well as environmental factors such as the ability to work and perform leisure activities. In care of patients in pain, it is important that their culture is taken into account (Strang, 1992; Ferrell, 1995; Strang, 1998). Each person, throughout his life, becomes familiar with the expectations of his culture and believes that his perceptions and reactions to pain are the only ones correct and normal (Helman, 1998). The dimensions of pain interact so that they gain in strength and stability. These interactions contribute both to the transformation of acute pain into chronic pain, and to the spread of pain effects into diverse domains of life, which is the basis for pain to affect QOL.

Health-related Quality of Life

The concept QOL is multidimensional and to some extent a vague and difficult to define (Cella, 1994). However, like the concept health, QOL reflects different aspects of well-being, but QOL is one thing for a healthy person and another for a sick person (Sullivan, 1994; 2001). WHO's (1997) definition of health as a "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" is a demanding definition. A restriction of interpretation of QOL is often made in healthcare being the concept HRQOL, as the goal of healthcare is to maximize the health component of QOL (Nordenfeldt, 1991; Bowling, 1995; Strang & Beck-Fries, 1996). The gain from a HRQOL assessment is to learn the outcomes of different treatments affects on the patient (Nordenfeldt, 1991; Clohisy et al., 1997). Treatment can be considered efficacious if it improves HRQOL even in the absence of survival benefit (Cella, 1995). HRQOL refers to the level of well-being, satisfaction, and opportunity associated with events or conditions in a person's life as influenced by disease, accident, or treatment (Cella, 1994; Bowling, 1995). The multidimensionality of HRQOL includes physical well-being, functional ability, emotional well-being, and social well-being (Cella, 1994). Physical well-being refers to how the person perceives their bodily function or disruption. Different disease symptoms can be incorporated in physical well-being (Cella, 1994; Ferrell, 1995). Functional well-being involves a person's ability to perform daily activities including everything from dressing and feeding oneself to going to work. The emotional well-being refers to a person's state of mood and reflects positive as well as negative affects (Cella, 1994). The social well-being is a diverse dimension and refers to family functioning, intimacy, perceived

social support, and maintenance of leisure activities (Ferrell, 1995). The individual's perception of illness, treatment and expectations of self is required to ascertain the true HRQOL (Bowling, 1995; Cella, 1995). The dimensions of pain and of HRQOL converge on patients in pain irrespective of cause (Portenoy, 1990). A negative relationship between pain intensity and duration and their impact on HRQOL was reported by Portenoy et al. (1994) and Wang et al. (1999). Wang et al (1999) found that patients with moderate or severe pain had lower HRQOL compared with patients with only mild or no pain. However, Klepstad et al. (2000) reported a decrease in pain intensity among patients receiving morphine therapy, without a subsequent increase in HRQOL. Therefore an assessment of HRQOL leading to an early detection of pain has become more important in evaluating the consequences of care (Bowling, 1995; Tamburini et al., 1996).

Pain management

Pain management consists of: assessment of pain, planning and treatment of pain and evaluation and reassessment of pain (APS, 1995; McCaffery & Pasero, 1999). As in all other medical conditions assessment is the first critical step to defining a treatment strategy. It is based on the patient's own description and objective signs assessed by the nurse and/or the physician, including the use of pain measuring tools such as VAS. VAS can help determine the level of pain intensity, above which treatment is considered (Crowley et al., 1991, Rawal & Berggren, 1993; APS, 1995; SPRI, 1997). Measurement tools assist communication and sharing of information. By identifying the physiological, sensory, affective, cognitive, behavioural, and socio-cultural expressions of pain it becomes possible to explore what is behind a certain pain intensity numbered and measured with VAS (Ferrell et al., 1994; Strang, 1998). With this broader assessment of patients' pain problems and with a clear identification of individual goals, a treatment plan can be performed. Interventions for pain treatment should then be delivered in a timely, logical and coordinated fashion (APS, 1995) including both pharmacological and non-pharmacological interventions (Oates et al., 1994; Carr & Goudas, 1999; Reid, 2001). The pharmacology of pain treatment is now better understood than ever before and there is an arsenal of medications available for use alone and in combination. Guidelines for effective pain relief based on use of appropriate drugs in the right doses at correct intervals for both postoperative (Swedish Physician Association, 2001) and cancer-related pain (WHO, 1996; SPRI, 1997; National Board of Health and Welfare, 2001a) have been published. In addition, the Swedish Nurse Organization (SSF, 1999) has published guidelines for the use of non-pharmacological interventions for cancer-related pain and Cousins (1994) for acute and postoperative pain. They have been shown to be effective although seldom used (Ferrell et al., 1994; McMillan & Tittle, 1995; Garbee & Beare, 2001). Evaluation of all interventions is crucial and should occur at regular intervals. Changes in pain pattern or the development of new pain should trigger diagnostic evaluation and modification of the treatment plan (IASP, 1992; McCaffery & Pasero, 1999).

Postoperative pain management is aimed to: provide subjective comfort for the patient, reduce nociceptive-induced responses, avoid and effectively manage side-effects, improve recovery and reduce the postoperative morbidity and overall cost (Kehlet, 1997; Rawal, 1999). For the patient the aims are: to be pain-free, nausea-free, relaxed and to be able to feel some control over their care (Sherwood et al., 2000). As every patient going through a surgical intervention should expect both pre- and postoperative pain control, the postoperative care ought to start preoperatively. Starting with information about the importance of pain relief and providing premedication, continuing with effective analgesic treatment throughout the surgery and initial postoperative period (Kissin, 2000; Swedish Physician Association, 2001). The postoperative care including not only pain control but also control of vital bodily functions is mostly performed in some sort of postoperative unit. Effective postoperative care requires a well-organized team of healthcare professionals (Rawal & Allvin, 2001). The postoperative period continues until the patient is discharged from hospital without complications or uncontrolled pain (Rawal, 1999).

In *Palliative care* all aspects of active care of patients no longer responding to curative treatment are included (Hedvall, 2000). Pain management is paramount, but also control of other symptoms such as psychological, social and spiritual problems. The primary function of palliative care is to maintain quality of life for patients and their families up to the time of the patient's death (Doyle et al., 1993; Hedvall, 2000). For patients with advanced cancer the need for palliative care is an increasing one (WHO, 1996; Chochinov & Kristjanson, 1998). There is a rapid growth of different palliative care services performed by healthcare professionals in varying compositions (Chochinov & Kristjanson, 1998; Hearn & Higginson, 1998, Hedvall, 2000). A pain related problem is the main reason for most patient referrals to palliative care (Ellershaw et al., 1995) as pain is experienced by 60 % of referrals (Vaino & Auvinen, 1996). The multidimensionality of pain influences the range of different objectives embodied in palliative care such as: control of symptoms, support of the family, improved communication and co-ordination, spiritual care, choice and control over care (Mino, 1999). However, there are still barriers to good pain control (Ward et al., 1993; Ersek et al., 1999; Gunnarsdottir et al., 2002) as more than 30% of patients with advanced cancer report that they suffer from unacceptably severe pain despite being referred to a palliative care unit (McMillan, 1996; Twycross et al., 1996). Every patient with cancer should expect pain management as an integral aspect of his/her care throughout the course of the disease. This should not be confined to the terminal stages of the disease (SSF, 1999)

Quality assurance procedures can be used in order to ensure that pain management is adequate. The APS has published Quality Assurance Standards for relief of Acute and Cancer Related Pain (APS, 1991). Standards developed in order to perform QA include indicators for structure, process, and outcome (Crowley et al., 1991; Idvall,

2001). In standards set for improvement of pain management, structure indicators reflect availability of resources and equipment such as: competent staff, uniform documentation of pain management, analgesics and adjuvant medications ordered. Process indicators address two main areas: Firstly the appropriateness of assessment and actions (Crowley et al., 1991) such as uniform and regular assessment of pain intensity and pain behaviour. Secondly, the patients' own descriptions of their pain experiences. Process indicators assume that patients are informed about effective pain relief as an important part of their treatment and that staff respond quickly to patients' complaints about unrelieved pain (APS, 1991; SPRI, 1997; Swedish Physician Association, 2001). The APS (1991) pain relief standards are structured around five standard statements for QA of acute and cancer-related pain management (Table 1). These are equal to the Swedish standards for both postoperative and cancer-related pain (SPRI, 1997; Swedish Physician Association, 2001).

Table 1.

Standards performed by the Committee on Quality Assurance Standards of The American Pain Society

<ol style="list-style-type: none"> 1. Recognize and treat pain promptly <ul style="list-style-type: none"> • Chart and display pain and relief (Process) • Define pain and relief levels to initiate review (Process) • Survey patient satisfaction (Outcome) 2. Make information about analgesics readily available (Process) 3. Promise patient attentive analgesic care (Process) 4. Define explicit policies for use of advanced analgesic technologies (Process) 5. Monitor adherence to standards (Process)
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Nursing care

Patients in pain, is a problem that nurses almost everywhere, often encounter. Most of the time nurses have the closest contact with patients on a daily basis and are often directly responsible for adequate and appropriate pain management, irrespective of cause. The responsibility of the nurse is fundamental for pain management as the nurse is the link between the patient and his family and with other healthcare professionals (National Board of Health and Welfare, 2001a; Swedish Physician Association, 2001). The effects of the different interventions on behalf of the patient in pain are greatly dependant on the nurse's ability and knowledge, even though the responsibility for pain management is shared with a physician (Benner, 1984; Mahon, 1994). Nurses are responsible for performing QA in their practical work; therefore they are also responsible for evaluation of the outcome of their practice. Standardization and

stabilization of nursing practice related to pain management is an essential aspect of improving patient clinical outcomes (SSF, 1999; Rawal & Allvin, 2001). Most nurses denote pain relief as an important part of their role, but in order to improve pain management both patient and nurse need to share opinions about the quality of care delivered (Idwall, 2001). Nurses have to be aware of possible cultural conflicts between themselves and the patients. The most important and difficult aspect of helping the patient with pain is to accept and appreciate that only the patient can feel the pain. The patient's information is necessary for the nurse to know about the pain and the effects of the pain treatment (McCaffery & Pasero, 1999). But, the patient does not always know how to describe pain (Strang, 1998) and can be hesitant to tell about it. When a patient indicates having pain, the nurse must respond positively, interpret the signs and respond in such a way that the patient feels helped in a good way (McCaffery & Pasero, 1999). Nurses should encourage patients to be active participants in their care as well as in discussing goals for pain control and planning interventions (Ashby & Dowding, 2001). This patient-nurse relation is fundamental for the model of this study as shown in Figure 1 and also provides the basis for the clinical implications.

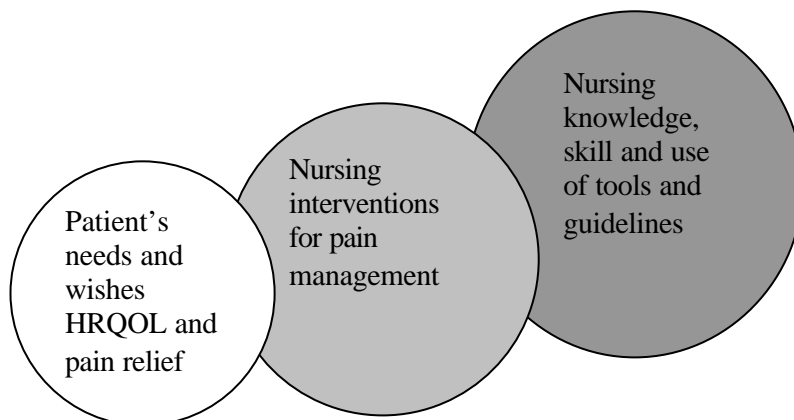


Figure 1.

The proposed model. This model shows the outcome of patient pain management in the centre (white). The quality of the patient outcome depends immediately on the nursing interventions for pain management but also on the patient's ability and willingness to express and communicate his needs and wishes, the patient-nurse relation. The quality of nursing interventions is partly subject to the competence of the nurse, partly to the guidelines, tools and prescribed treatment available.

AIMS

The main aim was to describe patients' experiences and perceptions of pain management, in patients with postoperative pain or cancer-related pain, in relation to HRQOL and the multidimensionality of pain.

In particular the aims were to explore, evaluate or compare:

1. Patients with postoperative pain and their experiences of pain and its management (I).
2. Patients with cancer-related pain, in palliative care and their pain and HRQOL (II, III)
3. Patients with cancer-related pain in palliative care, their pain and experiences of care related to pain management, before and after referral to palliative care (IV).
4. Patients with cancer-related pain in palliative care and their perceptions of pain and pain management (V).

METHODS

Design and study description

This thesis has a descriptive study design with both explorative and evaluative starting points. In papers I-IV quantitative analysis methods were used while in paper V a qualitative analyse method with a phenomenographic approach was used. Initially pain management for patients in postoperative care was described with focus on pain intensities, medication routines, satisfaction and information needs (paper I). Paper I was the idea-giving-study that raised a lot of questions concerning both pain and the patients experiences of pain management. I found that many patients were still in pain despite receiving what seemed to be competent care. According to APS's guidelines for acute and cancer-related pain (APS, 1991) there were many similarities between cancer-related and acute pain over the whole pain management process. However, before performing the study for paper I, I conducted a pilot study where patients with cancer-related pain and postoperative pain were included. Then I found that the patients with a cancer diagnosis refused to fill in the questionnaire, they simply did not want to answer all the questions. Probably this was due to not being aware of the diagnosis. Therefore, after completing paper I, I decided to interview patients with cancer-related pain in PC because they were aware of their cancer diagnoses and would not hesitate in discussing pain. Papers II-V were then performed with patients with cancer-related pain and in PC. Paper II had a descriptive and comparative study design. The comparison was made between two groups of patients with either mild or moderate to severe average cancer-related pain in PC. As the patients received care from two PC teams papers III and IV were performed with descriptive, comparative and evaluating study designs. In paper III a comparison concerning pain and HRQOL

was made between two groups of patients with cancer-related pain, one group from each of the two PC teams. Paper IV evaluated the patients' experiences of care before and after being referred to a PC team as well as describing correlations between pain control and other aspects of care. Finally, paper V, with a descriptive and explorative study design focused on how patients with cancer-related pain, in PC perceived their pain management.

Context

The studies were performed in a council of southwest Sweden with a catchment area of 370 000 inhabitants.

Postoperative care (paper I):

The study was carried out in a district county hospital with medical, surgical and psychiatric units. The hospital has a postoperative unit with room for ten patients and six wards for surgical patients in which gynaecologic and orthopaedic patients are admitted. The patients were usually transferred to one of the wards late on the operating day or early the day after. The hospital had no general routines about how pain treatment was to be carried out. Usually the prescription for postoperative pain was an injection of strong opioid on request of the patient. This prescription was unchanged when the patient was transferred to the surgical ward. The nurse in charge decided when to change to orally administered analgesic medication usually Paracetamol and/or a weak opioid and/or a NSAID.

Palliative care teams (papers II-V)

PC was performed by two different teams both hospital based. The PC teams were organized differently and each associated with a different hospital. They provided homecare service, service to inpatients and were available on a consultancy basis to staff at the hospital and in the community. They received their patients after consultation from either the patient's own physician or from a nurse caring for the patient. Patients themselves or relatives were also able to initiate contact with one of the PC teams. The most common reason for contacting the care team was a pain-associated problem. *Palliative care team I* was associated with a district county hospital. PCT I included two nurses, one social worker and access to the pain clinic at the hospital. This team was nurse-led and a part of the rehabilitation clinic. *Palliative care team II* was associated with a county hospital. PCT II included two nurses, one physician (anaesthetist), one social worker and one priest. This team was led by the anaesthetist and was a part of the pain clinic. The objectives of the PCTs were to make an assessment of the patient's problems and needs. And, to suggest, initiate and perform pain relief interventions while preventing negative side effects of medication. The teams were to continuously support the nurses and physicians who were caring for

patients, while reconciling the gaps between health care professionals and patients. And finally, to educate, support and counsel patients, families and healthcare professionals accordingly.

Patients

Patients in postoperative care (paper I)

One hundred consecutively selected postoperative inpatients from general surgical, gynaecological and orthopaedic wards, on their second postoperative day were included (Table 2). The inclusion criteria for the postoperative patients were as follows: to be oriented to person and place, able to read and speak Swedish and to be at least 18 years of age. Involvement of the pain clinic in the patient's pain management was an exclusion criterion.

Table 2.
Characteristics of the patients in postoperative care (n=100) (paper I)

Characteristic	N
Age years:	
Mean	62
Range	21-83
Gender:	
Men	32
Women	68
Civil status:	
Cohabiting	74
Single	26
Occupation:	
Working	59
Pensioner	41
Education:	
Graduate school	73
High school	19
College	8
Operations:	
General surgery	34
Gynaecology	29
Orthopaedics	37

Patients in palliative care (papers II-V)

A consecutive selected sample of 75 patients with cancer-related pain and cared for by PC teams were included (Table 3). How the patients were selected in each paper in this thesis is shown in Figure 2. The inclusion criteria for patients were as follows: to be orientated to person and place, without major sensorial defects, able to speak Swedish, and at least 35 years of age; i.e. in line with the SF-36 Swedish norm data (Sullivan et al., 1994). Furthermore patients had to be in need of analgesic treatment, assessed as being in the final stage of life and with one of the following diagnoses: lung cancer, colorectal cancer, breast cancer or prostate cancer. The patients also needed to be aware that they had diagnosed cancer and that they would receive palliative care, not primarily curative care.

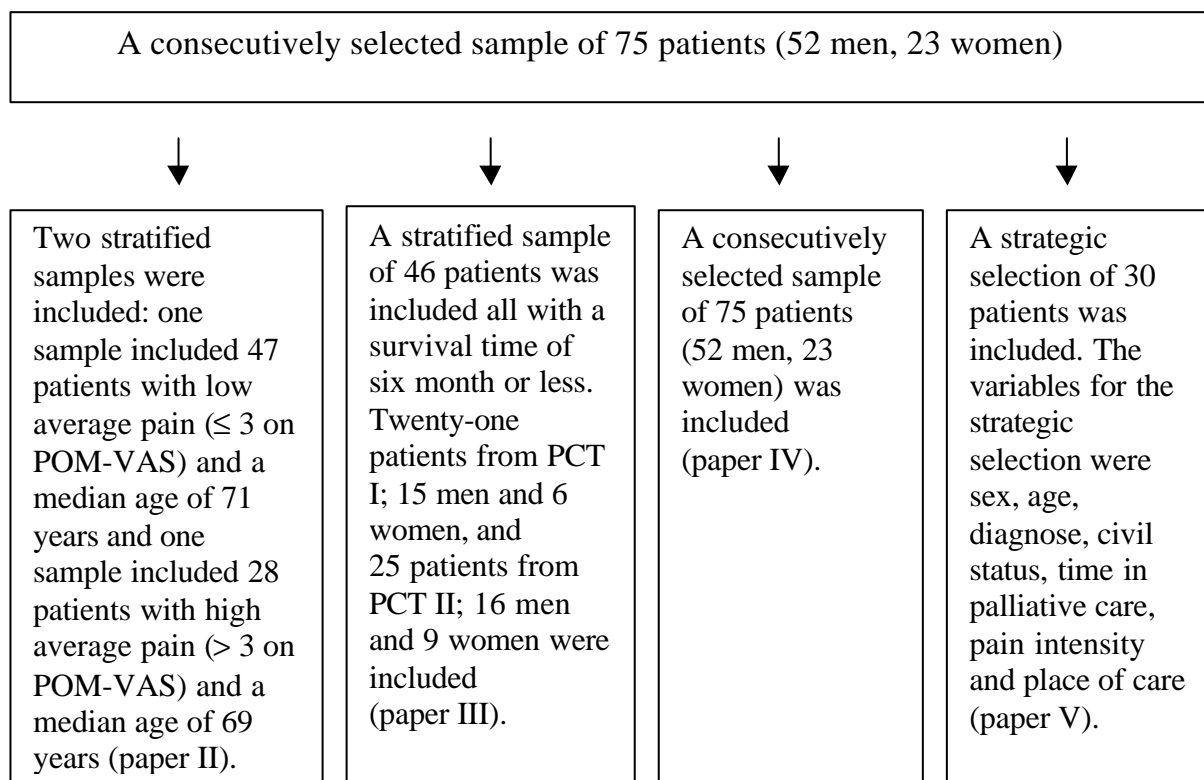


Figure 2.
Overview of patients with cancer-related pain in palliative care, included in papers II-V

Table 3.

Characteristics of the patients with cancer-related pain and in palliative care (n=75)
(papers II, IV)

Characteristics	n
Age years:	
Mean	70
Sd	10,1
Median	70
Range	35-88
Gender:	
Men	52
Women	23
Civil status:	
Cohabiting	51
Single	24
Diagnosis:	
breast cancer	13
colorectal cancer	20
lung cancer	15
prostate cancer	27
Place of care:	
at home	49
at hospital	19
mix of hospital and at home	7
Help from:	
relatives	29
home-care	8
at hospital	19
mix of hospital, relatives and home care	7
no help	12
Time with PC, months:	
Mean	3
Sd	1,9
Median	2
Range	1-8

Data collection

Instruments

The APS Quality of Care Committee Patient Outcome Questionnaire (APS 1991; 1995) (papers I-IV, Table 4)

The APS Patient Outcome Questionnaire was first published in 1991 as a patient satisfaction survey with the purpose of evaluating pain management. In 1995 a developed version was presented with further items adopted from various instruments e.g. the Brief Inventory (Daut et al., 1983). Items from the APS:s questionnaire may be selected, modified or added to suit the needs of a particular patient population. Several studies have been based on the APS questionnaire (Miaskowski et al., 1994; Ward & Gordon, 1994; Bookbinder et al, 1996; Adams McNeill et al., 1998; Calvin et al., 1999). The APS questionnaire, as a whole or in part, was used in papers I-IV. Content and construct validity tests have been found satisfactory by a panel of experts consisting of members of the American Pain Society (1991). Promising reliability and validity have been reported by Calvin et al. (1999). The modification of the questionnaire to a Swedish version motivated a construct validity test. An explorative factor analysis was performed in paper I resulting in four factors with eigenvalue above 1.0 (cumulative 60% of total variance) representing *pain intensity level and satisfaction* (factor 1) with factor loadings 0.53-0.72. *Presence of pain and need for pain medication* (factor 2) with factor loadings 0.62-0.88. *Information and asking for pain medication* (factor 3) with factor loadings 0.45-0.77 and *medication routine* (factor 4) with factor loadings 0.66-0.68. Internal consistency reliability was tested on the Swedish version by Cronbach's alpha and found to be 0.72 (Kerlinger, 1986).

Table 4.

Outcome Questionnaire developed by the APS (1991) and used in this thesis with regard to the following four papers.

1. At any time during your care, have you needed treatment for your pain? <i>Yes No</i>	papers	I-IV
2. Have you experienced pain in the past 24 hours? <i>Yes No</i>	paper	I
3. On this scale, how much discomfort or pain are you having right now? Using visual analogue scale <i>1..2..3..4..5..6..7..8..9..10</i>	papers	I-IV
4. On this scale, please indicate the worst pain you have had in the past 24 hours. Using visual analogue scale <i>1..2..3..4..5..6..7..8..9..10</i>	papers	I-IV
5. On this scale, please indicate how much relief you generally obtained from the medication or other treatment you were given for pain. Using visual analogue scale <i>1..2..3..4..5..6..7..8..9..10</i>	paper	I
6. Select the phrase which indicates how satisfied or dissatisfied you are with the way your nurses treated your pain. <i>Very satisfied, satisfied, slightly satisfied, slightly dissatisfied, dissatisfied, very dissatisfied.</i>	paper	I
7. Select the phrase which indicates how satisfied or dissatisfied you are with the way your doctors treated your pain. <i>Very satisfied, satisfied, slightly satisfied, slightly dissatisfied, dissatisfied, very dissatisfied.</i>	paper	I
8. When you asked for pain medication, what was the longest time you had to wait for it? Record answer, or choose from: <i>15 minutes or less, 15-30 minutes, 30-60 minutes, more than one hour, never asked for pain medication.</i>	paper	I
9. Was there a time when the medication you were given for pain didn't help and you asked for something more or different to relieve the pain? <i>Yes No</i>	paper	I
10. Early in your care, did your doctor or nurse ask you to be sure to tell them when you had pain? <i>Yes No Who?</i>	papers	I, III
11. Early in your care, did your doctor or nurse discuss with you that we consider treatment of pain very important? <i>Yes No Who?</i>	papers	I, III
12. Do you have any suggestions for how your pain management could be improved?	paper	I
<hr/> Further questions used from APS: s version from 1995:		
How clear are the instructions about the following?		
13. Schedule for taking pain medications (how much of each and when) <i>No instructions? – Instructions are unclear to me, or I forgot .-</i> <i>Instructions are fairly clear – Instructions are absolutely clear</i>	paper	IV
14. What to do if the current medication schedule does not relieve your pain or produces side effects (on demand) <i>No instructions? – Instructions are unclear to me, or I forgot .-</i> <i>Instructions are fairly clear – Instructions are absolutely clear</i>	paper	IV
15. Whom to call about your pain if you have any questions <i>No instructions? – Instructions are unclear to me, or I forgot .-</i> <i>Instructions are fairly clear – Instructions are absolutely clear</i>	papers	IV
16. Please indicate the average pain you have had in the past 24 hours Using visual analogue scale <i>1..2..3..4..5..6..7..8..9..10</i>	papers	II-IV
17. Please indicate the pain interrupting your sleep Using visual analogue scale <i>1..2..3..4..5..6..7..8..9..10</i>	papers	II-IV

SF-36 (papers II, III)

The Medical Outcome Study, 36- items short form questionnaire was suitable as the interest in this thesis was an overall evaluation of HRQOL and as an outcome of pain management. Not as a disease specific outcome. SF-36 was developed by the Medical Outcomes Study led by John Ware Jr (Ware & Sherbourne, 1992). The SF-36 is a general health questionnaire and constructed to measure physical, social and mental aspects of HRQOL. It is designed for use with both the general population and populations with chronic diseases. SF-36 is composed of 36 items including 8 dimensions: Physical functioning, Role functioning-physical, Bodily pain, General health, Vitality, Role functioning-emotional, Social functioning, and Mental health (Ware et al., 1993, Table 5).

Table 5.
Health-Related Quality of Life Dimensions of SF-36

Dimensions	Items	Meanings of measure
Physical functioning (PF)	10	Limitations in performing concrete physical activities because of health
Role functioning-physical (RP)	4	Problems with work or daily activities because of physical health
Bodily pain (BP)	2	Extent of pain or limitations because of pain
General health (GH)	6	Perception of health/health outlook
Vitality (VT)	4	Level of energy
Role functioning-emotional (RE)	3	Problems with work or other daily activities because of emotional problems
Social functioning (SF)	2	Extent and frequency of interference with social activities because of physical and emotional problems
Mental health (MH)	5	Feelings of nervousness and depression

The scales are scored in such a way that a higher score indicates a better state of health. The highest score is 100 and the lowest 0. The questions refer to effects in “ the past seven days”, the acute version. SF-36 can either be self-administered or administered by an interviewer with help from a special interview guide. It has been validated extensively on general populations and different diseases in USA as well as in Sweden, demonstrating high reliability and good construct validity (Ware et al., 1993; McHorney et al., 1994; Sullivan et al., 1995). When using SF-36 it is possible to reach 80% power and detect a 15-20-point difference between two groups as a post-intervention measure, despite a small sample (Sullivan et al., 1994). In paper II, Cronbach’s alpha was 0.70 for the whole questionnaire while the internal consistency

coefficients were between 0.76 and 0.88 for each of the dimensions of PF, RP, BP, and RE and between 0.40 and 0.50 for GH, VT, SF and MH.

Pain Control in Palliative Care Questionnaire (PC-PCQ, paper IV).

A 12-item questionnaire was developed containing questions about palliative care related to pain management. Each item had both a before (before PC) and now (with PC) perspective. The questionnaire was aimed to cover the 6 dimensions of pain (Ahles et al, 1983; McGuire, 1992), the pain management process and objectives of palliative care (Table 6). The first part of PC-PCQ included 9 items regarding the patient's experiences of the care process related to pain. The responses were scored on Likert scale (very good to very poor). The second part included 3 items selected and modified from the APS (1995), regarding instructions about pain medication. These responses were also on Likert scale (no instructions to absolutely clear instructions). As this was a new questionnaire a construct validity test was motivated as well as testing for internal consistency reliability. An explorative factor analysis was carried out resulting in five factors with eigenvalue above 1.0 (cumulative 62% of total variance). Factor 1 represented *pain control before PC* (factor loadings 0.48-0.77, Cronbach's alpha coefficient 0.44). Factor 2 represented *symptom control before and with PC* (factor loadings 0.51-0.82, Cronbach's alpha coefficient 0.83). Factor 3 represented *medication routines with PC* (factor loadings 0.64-0.82, Cronbach's alpha coefficient 0.79). Factor 4 represented *pain control with PC* (factor loadings 0.59-0.75, Cronbach's alpha coefficient 0.70). Factor 5 represented *socio-cultural contacts before and with PC* (factor loadings 0.88-0.91, Cronbach's alpha coefficient 0.87). Cronbach's alpha on the whole PC-PCQ was found to be 0.76.

Table 6.

The new established questionnaire; Pain Control in Palliative Care Questionnaire (PC-PCQ).

Part one	
How did you experience?	
1. Pain relief	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
2. Contact with your own doctor	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
3. Contact with home care, social worker etc.	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
4. Feeling of security	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
5. Support to relatives	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
6. Opportunity to talk	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
7. Help with physical problems such as constipation, nausea, lack of appetite etc.	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
8. Help with psychological problems like anxiety, worries, fear etc.	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
9. The continuity of care	
a) now with PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
b) before PC	<i>very good – good – quite good – quite poor – poor – very poor</i>
Part Two	
How clear are the instructions?	
10. Schedule for taking pain medications (how much of each and when)	
a) now with PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>
b) before PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>
11. What to do if the current schedule medication does not relieve your pain or produces side effects (on demand)	
a) now with PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>
b) before PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>
12. Whom to call about your pain if you have any questions	
a) now with PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>
b) before PC	<i>No instructions? – Instructions are unclear to me, or I forgot – Instructions are fairly clear – Instructions are absolutely clear</i>

VAS (paper I)

A variety of pain measurement tools, which have been successfully used in clinical settings are available (Grossman et al., 1992; Herr & Mobily, 1993) and the tool that was shown as mostly used in Sweden is VAS (Rawal & Berggren, 1993; Rawal, 1999). VAS has been referred to as “golden standard” for pain measuring (Williams et al., 2000). The scale consists of a straight line, ten centimetres long, one end is marked "no pain" and the other end "worst possible pain". The scale side should face the patient, who is asked to report pain intensity by drawing a vertical line at the correct point on the horizontal line. The pain intensity scores are determined by the investigator, in numbers from 1-10, at the reverse side of the scale. There are a number of advantages to using VAS, such as the opportunity for patients to express their exact level of pain, quickly and easily. VAS is also simple, reproducible and universal (Grossman et al., 1992; Rawal & Berggren, 1993; Rawal, 1999). There are however reports indicating that confused patients, elderly patients and patients with severe pain could find it difficult to use the VAS scale (Herr & Mobily, 1993). The need for abstract thinking has been suggested as a factor of great importance (Bondestam et al., 1987). Rawal and Berggren (1993) recommended the use of VAS as an instrument for QA. When examining post-operative pain the patients ought to be informed of VAS prior to their operation (Rawal, 1999). VAS appears to be a reliable and valid tool to measure pain intensity (Herr & Mobily, 1993; Flaherty, 1996).

POM (papers II-IV)

Pain-o-Meter (POM) has been especially designed by Gaston-Johansson (1985; Gaston-Johansson & Asklund-Gustavsson, 1985) in order to provide a comprehensive method of assessing clinical pain. POM provides information about the intensity, quality (affective and sensory dimension), location and duration of pain. The POM is a plastic tool that measures 8 inches long, 2 inches wide and 1 inch thick (Gaston-Johansson, 1996). A vertical 10 cm VAS is located on the front of POM (POM-VAS). This represents a pain intensity continuum and has anchors on each end, representing no pain at the lower end and worst possible pain at the upper end. Patients indicate their pain intensity by moving an adjustable marker along the front. A centimetre scale is located on the back of POM numbered from 0 to 10. A word descriptor scale (POM-WDS) is the list of 12 sensory and 11 affective word descriptors located on the back of POM. These words represent common pain words. Each word has an assigned intensity value (range 1-5) with 1 representing lowest intensity and 5 representing the highest most severe pain (Table 7). The POM has been tested on a variety of patients with different diagnoses (Gaston-Johansson et al., 1991; Gaston-Johansson & Fall-Dickson, 1995). Test-retest reliability, concurrent validity, and construct validity for POM have been demonstrated (Gaston-Johansson, 1984; 1996). Patients with cancer-related pain in palliative care were asked to describe their pain in both sensory and affective words by using POM (papers II - IV) in order to provide a multidimensional assessment of pain.

Table 7.
Affective and sensory words on POM-WDS.

11 words reflecting the affective aspect of the pain

- worrying [1],
- irritating [2],
- troublesome [3], tiring [3],
- terrifying [4], unbearable [4],
- torturing [5], killing [5], suffocating [5], dreadful [5], and excruciating [5]

12 words reflecting the sensory aspect of the pain

- prickling [1], sore [1],
 - pinching [2], nagging [2], teasing [2],
 - aching [3], gnawing [3],
 - cramping [4], pressing [4], burning [4],
 - tearing [5] and cutting [5]
-

Interview performed for phenomenographic analysis (paper V)

Open and semi-structured interview questions can constitute the basis for gathering data when using a phenomenographic approach (Wenestam, 2000; Sjöström & Dahlgren, 2002). As the focus in this study was on patient perceptions a phenomenographic approach was chosen ascertaining the qualitative variation as expressed in the patients' answers. Phenomenography was developed at the Department of Education and Educational Research at University of Gothenburg by Marton and co-workers (Marton, 1981). The ultimate purpose of phenomenographic research is to see how something is perceived, i.e. a way of experiencing something (Marton & Booth, 1997). A distinction is made between the first-order perspective that starts with externally observable facts, and the second-order perspective that starts with the individual's experiences of something or how something appears to the person. Phenomenography describes perceptions using the second-order perspective, representing something that is implied, or something that does not need to be said or cannot be said, as it has not previously been reflected upon (Marton & Booth, 1997). In phenomenography, perceptions constitute the frame of reference within which knowledge is gathered and the foundation on which reasoning is built. Perceptions are created by experiences and constitute the reality. Phenomenography is substance-oriented and the essence of phenomenography is to describe "how" people perceive something (Marton & Booth, 1997). In this study the interview plan consisted of some entry questions within the phenomenon of multidimensionality of pain and cancer related pain management (McGuire, 1992; Ferrell et al; 1994; Strang, 1998). With these questions as a basis an interview more like a conversation with the patient was carried out: *Tell me, what is pain for you? How does pain affect you? Tell me about your treatment for pain relief? What has it been like? Treatment other than analgesics,*

what about that? Tell me, what are your own strategies for reducing pain? How do you perceive your own opportunities to participate in your pain treatment? How do you perceive the information you have received from healthcare professionals about your pain and your pain treatment? What about the environment that you have encountered, how do you see it?

Procedure

Patients in postoperative care (paper I):

One of the co-authors was engaged as interviewer, a registered nurse with special education in pain management working at the pain clinic. As a result of his experiences with patients in pain, he was familiar both with interview technique and the use of VAS. The purpose, content, and layout of the APS questionnaire as well as the VAS were thoroughly explained to the patients. This nurse together with the patient filled in the questionnaire. Data was collected over a period of one month.

Patients in PC

Papers II to V: All data collection was performed by myself, (the author) an intensive care nurse and nurse teacher, with special interest in pain management. The purpose, content, and layout of the SF-36 questionnaire, the PC-PCQ as well as the POM instrument were thoroughly explained to the patients. First the patients were asked to complete the SF-36 questionnaire, which most of the patients were able to do without assistance and without omitting any items. However, sometimes the SF-36 questionnaire was administered in interview form because the patient was in a weak physical state or expressed a preference for an interview. Three patients declined to complete the SF-36 questionnaire due to confusing or upsetting questions. All three were in an extremely weak condition and died within a few days after the interview. After completing the SF-36 questionnaire, the patients were interviewed for demographic and clinical data. The patients were also asked to carefully describe their pain, using POM and choosing from both the sensory and affective word groups. Using POM-VAS they indicated their pain intensity by moving the adjustable marker along the 10 cm line. The PC-PCQ was filled in, in conjunction with interviewing the patients. The qualitative interviews were performed last.

The stratified samples: For paper II two stratified samples were constructed: One group of patients rating average pain in the past 24 hours at a mild intensity level of ≤ 3 on VAS (low pain group) and one group rating average pain in the past 24 hours at a moderate to severe intensity level of > 3 on VAS (high pain group). The reason for selecting VAS 3 as the value for dividing the groups was based on recommendations from a Swedish guideline designed under government auspices, stating this value as a quality outcome indicator when treating cancer-related pain (SPRI, 1997; National Board of Health and Welfare, 2001a) as well as the statement from Mantha et al.

(1993, p.1041) that “the range 0-3 cm may be thought of as a zone of analgesic success”.

For paper III: Seven months after all data had been collected, a follow-up was carried out with the help of the Patient Record Office, to find the patients survival times from time of interview. The patients that had died within 6 months of the interview were then included in study III.

The strategic sample: For paper V; Twenty patients were interviewed in their homes and 10 patients at hospital. The effective interview time lasted between 30 and 90 minutes. The interviews were audio taped and transcribed verbatim.

Ethical considerations

Paper I was approved by the Local Committee of Ethics at the hospital involved. The Committee of Ethics in Medical Investigations, Universities of Lund and Gothenburg, Sweden, approved papers II-V.

Patients were asked if they were willing to participate by the head nurse of the wards (paper I) or by the staff of the palliative care teams (papers II-V). Patients were given oral and if they wanted also written information about the studies before they gave their consent. When the patients had agreed to participate they were contacted for an interview. The postoperative patients were interviewed at the hospital in a place as calm as possible (paper I). Patients in palliative care decided time and place for the interviews, mostly in their homes (papers II-V). The patients were informed that participation in the studies was voluntary and that their answers would be treated in confidence. They were also informed that they could withdraw at any time without giving a reason. The data collection for paper I was made by one of the co-authors, a registered nurse working at the pain clinic. The nurse had no connection with the staff of the wards in question. The data collection for papers II-V was made by myself, who like the co-authors has no connection with the palliative care teams. The principle of anonymity could not be achieved since the data collection methods were face-to-face interviews. On the other hand, the patients were fully aware of the fact that no names were recorded and no coding was made. Furthermore, the interviewers did not report to the staff of the wards or in the palliative care teams.

Data analysis

Statistical methods

Descriptive statistics (frequency tables and cross tables) were used in papers I-IV to summarize the information, describing the demographic characteristics of the samples, types of medication and pain intensities. For SF-36 raw scores for each question were transformed into a scale from 0 to 100, with higher scores representing better levels of functioning and state of health measured (Sullivan et al., 1995). Mean and median

scores and standard deviations and ranges were calculated for the SF-36 dimensions of all subgroups of patients. In applied research there has been a tradition of treating data from rating scales such as VAS as at an interval level, if skewness and kurtosis does not exist (Grossman et al. 1992; Burns & Grove, 1997), using parametric methods, which was followed in paper I. However, as data from POM-VAS, SF-36 and PC-PCQ are in fact qualitative (lacking well defined size and distance) they should be treated as data on ordinal level (Svensson, 2001), which was the case in papers II -IV.

Inferential statistics were used to show relations between variables. In paper I Student's t-test was used. Due to variables on ordinal scale level and with skewed distributions, non-parametric methods were used in papers II-IV. Mann-Whitney U-test and Chi-2 were used to test for statistical differences between groups of patients as well as within the groups. Spearman correlation coefficient was used to assess the association among pain intensity scores as well as correlations between pain intensity scores and SF-36 dimensions. Multivariate stepwise regression analysis was then used to identify which combination of variables provided the most predictive power. The level of statistical significance was ascertained to be $p < 0.05$ (Kerlinger, 1986).

Phenomenographic approach

The analysis for the interviews with phenomenographic approach in paper V was performed in the following steps with collaboration between myself and two of the co-authors.

1. Each interview was processed by looking for expressions by patients that described perceptions of pain and pain management. There were a total of 632 quotes, and saturation of the perceptions was reached when 10-15 interviews had been analysed. However, because of the sample being strategic and occurrence of short interviews due to patients in weak condition, all 30 interviews were meaningfully analysed.
2. The analysis entailed comparisons of different expressions to identify similarities and differences, in relation to the study aim.
3. In order to get an overall picture of how these similarities and differences could be connected, they were grouped into patterns with common features.
4. These patterns were carefully examined in order to detect dimensions, in which new formulations and categories were needed to describe perceptions.
5. The outcome space (Wenestam, 2000), which constitutes the description categories and perceptions was further examined to ensure consistency. Finally, perceptions with representative expressions and quotes were formed into three description categories.

RESULTS

Pain management in postoperative care (paper I)

For the 100 patients on their second postoperative day, the mean pain intensity score at the time of the interview was 2.7 on VAS. The mean worst pain in past 24 hours was 6 on VAS, and mean pain intensity despite pain medication was 2 on VAS. No statistically significant differences were found between the patients in the three operation groups or between men and women. The division among intensity scores is shown on Table 8.

Table 8.

Pain intensity levels rated on VAS and experienced by patients in postoperative care (n=100)

Variables	No pain		VAS (score 0-10)								worst pain	
	0	1	2	3	4	5	6	7	8	9	10	
Pain at time of interview (N=100)	0	37	19	15	14	6	5	2	1	1	0	
Worst pain past 24 h (N=100)	0	9	7	5	14	14	7	16	14	6	8	
Pain despite pain medication (n= 97)	0	36	27	9	15	5	2	1	0	0	2	

All 100 patients had a prescription of either strong opioid injected or Paracetamol and weak opioid orally, mostly “on request”. A combination of Paracetamol and weak opioid orally, was administered to 60 patients, only Paracetamol to 10 patients, a strong opioid to eighteen patients and NSAID to seven patients. Eighty-one patients reported that they had asked for pain medication and 29 patients had requested a change of pain medication. Fifty patients reported that they were very satisfied and 33 satisfied with the way the nurses treated their pain. Thirty-eight patients stated that they were very satisfied and 26 satisfied with the way the physicians treated their pain. The higher intensity of pain the patients experienced, the less satisfied they were with the way nurses treated their pain ($p < 0.001$). No correlation was found between satisfaction with physicians and pain intensity. Statistically significant correlations were found between the three pain intensity items *at time of interview*, *worst pain past 24 hours* and *pain despite pain medication* (all $p < 0.001$). Ninety-two of the 100 patients verified have been asked to make it known when suffering from pain while 33 patients remembered having received information about the importance of pain relief.

Thirty-eight of the 100 patients made comments, the following were the most common: “*The waiting time between injections was too long*” (6 patients), “*The waiting for pain medication in the casualty department before operation was too long*”

(4 patients), “*I had Epidural Analgesic Catheter during the operation but it was not used post-operatively because of the inability of the staff to use it. Was given injections instead with bad effect*” (3 patients), “*I asked for better pain relief when waking up after the operation*” (3 patients), and; “*I have no pain when lying absolutely still*” claimed by 4 patients.

Pain and HRQOL among patients in palliative care (papers II, III)

Paper II: For the 28 patients with average pain intensity past 24 hours > 3 on POM-VAS (high pain group), the pain items *at the time of the interview*, *worst pain* and *pain interrupting sleep* were significantly higher compared with the 47 patients with average pain ≤ 3 on POM-VAS (low pain group) (Table 9). For patients in the low pain group, the four pain intensity items correlated with each other to a statistically significant level (all $p < 0.01$). For patients in the high pain group, *worst pain*, *average pain*, and *pain interrupting sleep* showed statistically significant correlations between each other (all $p < 0.01$) while *pain at time of interview* showed no statistically significant correlations with the other pain intensity items. A statistically significant longer survival period was found from study period among the patients in low pain group compared to those in high pain group ($p < 0.01$).

Table 9.

Pain intensity, evaluated by patients with cancer and in palliative care, with low or high average pain (paper II) or cared for by either a nurse-led or a physician-led palliative care team (paper III)

Pain items	Paper II			Paper III	
	Low pain group (n=47)	High pain group (n=28)	<i>p</i> -value	PCT I (n=21)	PCT II (n=25) <i>p</i> -value
Pain at time of interview					
mean/sd	1,8/1,3	3,9/1,9		2,9/1,7	3,1/2,1
median/range	2,0/0-5	4,0/1-8	<0.001	3,0/0-6	3,0/1-8 n.s
Worst pain in the past 24 hours					
mean/sd	3,3/2,3	6,2/1,6		4,6/2,1	5,0/2,7
median/range	3,0/0-9	6,0/3-9	<0.001	4,0/1-8	5,0/1-9 n.s.
Average pain in the past 24 hours					
mean/sd	1,8/1,0	5,0/1,4		3,3/1,8	3,5/1,9
median/range	2,0/0-3	4,0/4-8	<0.001	3,0/1-8	3,0/1-8 n.s
Pain interrupting sleep					
mean/sd	1.9/1.6	3.5/2.3		2,7/2,2	2,6/ 1,8
median/range	1.0/0-7	3.0/1-9	0.001	2,0/0-9	2,0/0-7 n.s

Low pain group = Patients with average pain intensity ≤ 3 rated on POM-VAS

High pain group = Patients with average pain intensity >3 rated on POM-VAS

PCT I=Patients cared for by a nurse-led palliative care team

PCT II=Patients cared for by a physician-led palliative care team

For patients in the high pain group the dimensions PF, RP and BP were statistically-significantly lower compared with patients in low pain group (Table 10).

Paper III: No statistically significant differences were found regarding patients' health dimensions (Table 10), pain intensities (Table 9) or pain quality descriptions when comparing the two PCT groups.

Table 10.

HRQOL dimensions scored by patients with cancer in palliative care, with low or high average pain (paper II) or cared for by either a nurse-led or a physician-led palliative care team (paper III).

SF-36 dimensions	Paper II		<i>p</i> -value	Paper III		<i>p</i> -value
	Low pain group (n=47)	High pain group (n=25) ^α		PCT I (n=21)	PCT II (n=22) ^α	
Physical functioning (PF)						
mean(sd)	36.3 (22.3)	25.0 (20.1)		27,7 (18,3)	23,4 (20,3)	
median (range)	35 (0-90)	20 (0-70)	0.027	22 (0-65)	22(0-70)	n.s
Role-physical (RP)						
mean(sd)	21.2 (30.3)	8.0 (22.5)		11,9 (24,5)	7,9(17,9)	
median (range)	0 (0-100)	0 (0-100)	0.027	0 (0-100)	0 (0-75)	n.s
Bodily pain (BP)						
mean(sd)	65.9 (24.2)	35.7 (12.1)		54,3 (26,1)	46,9 (19,6)	
median (range)	62 (21-100)	32 (12-62)	<0.001	44 (22-100)	41(22-100)	n.s
General health (GH)						
mean(sd)	44.1 (15.7)	36.9 (9.3)		36,1 (13,9)	40.1 (12,3)	
median (range)	40 (20-77)	40 (10-50)	n.s.	37 (10-72)	36 (25-75)	n.s
Vitality (VT)						
mean(sd)	42.7 (17.9)	34.8 (17.0)		34,2 (18,2)	40.0 (16,1)	
median (range)	40 (15-75)	35 (0-80)	n.s.	30 (0-80)	37 (10-75)	n.s.
Social functioning (SF)						
mean(sd)	61.7 (28.3)	56.0 (27.5)		59,5 (28,2)	55,6 (27,7)	
median (range)	62.5 (0-100)	50 (0-100)	n.s.	50 (0-100)	50 (0-100)	n.s.
Role-emotional (RE)						
mean(sd)	62.4 (44.2)	48.0 (43.1)		46,0 (45,3)	63,6 (41,0)	
median (range)	100 (0-100)	33 (0-100)	n.s.	33 (0-100)	83 (0-100)	n.s
Mental health (MH)						
mean(sd)	63.9 (17.7)	58.7 (17.1)		61,3 (17,5)	58,0 (17,5)	
median (range)	64 (20-96)	60 (28-92)	n.s.	64 (20-92)	60 (28-96)	n.s.

Low pain group = Patients with average pain intensity ≤ 3 rated on POM-VAS

High pain group = Patients with average pain intensity >3 rated on POM- VAS

PCT I = Patients cared for by a nurse-led palliative care team

PCT II = Patients cared for by a physician-led palliative care team

^α = 3 missing patients

Pain management in PC (paper IV)

Paper IV: For the 75 patients with cancer-related pain in palliative care, the mean and median pain intensity scores *at the time of the interview* were 2,6 and 2,0 on POM-VAS while the mean and median *worst pain* the 75 patients had experienced *past 24 hours* was 4,4 and 4,0 on POM-VAS. Both the mean and median scores for *average pain past 24 hours* were 3,0. For pain intensity scores *interrupting sleep* the mean was 2,5 and median 2,0. The division among intensity scores is shown on Table 11.

Table 11.

Pain intensity levels rated on POM-VAS experienced by patients with cancer in palliative care (n=75).

Variables	VAS (score 0-10)										
	No pain							Worst pain			
	0	1	2	3	4	5	6	7	8	9	10
Pain time of interview	7	18	15	13	9	8	1	3	1		
Worst pain past 24 h	4	7	7	10	10	13	6	8	4	6	
Average pain past 24 h	5	12	14	16	15	6	1	3	3		
Pain interrupting sleep	6	22	17	16	3	2	1	6	1	1	

The patients expressed the quality of their pain by choosing affective and sensory pain words from POM-WDS, the first word each patient replied when asked to describe their pain is shown on Table 12. Some patients preferred their own words and some could not describe their pain with an exact word.

Table 12.

Patients with cancer in palliative care and words used to describe their pain quality (n=75).

Pain descriptors	Number of patients
Affective words	
• Worrying	13
• Irritating	7
• troublesome, tiring	24
• terrifying, unbearable	6
• torturing, killing, dreadful, excruciating	6
• own words	8
• couldn't express it	11
Sensory words	
• prickling, sore	15
• pinching, nagging, teasing	13
• aching, gnawing	13
• cramping, burning, pressing	6
• cutting, tearing	4
• own words	14
• couldn't express it	10

Pain and fear of future pain was the most disturbing factor for 27 of the 75 patients, irrespective of reported pain intensity. Seventy-two of the 75 patients in palliative care had been requested to tell when they were in pain and 24 of the 75 patients expressed that they had received an explanation regarding the importance of treating pain.

All 75 patients were prescribed analgesics in accordance with the WHO guidelines, the so-called analgesic ladder, specifically: An opioid was prescribed for 65 patients, NSAID for 20 patients, paracetamol for 61 patients and a complement of on demand analgesics for 57 patients. Three patients reported a non-pharmacological treatment: one patient had received massage, one tactile massage and one transcutan nervstimulation.

After receiving the opportunity of PC patients stated that they had been given absolutely clear instructions of: *scheduled medication* (Wilcoxon; $Z = -6.68$, $p < 0.001$), *on demand medication* and *who to call* about pain (Wilcoxon; $Z = -7.33$, $p < 0.001$) compared with before PC. *Pain control* was stated as *good* with PC compared to *quite poor* before PC (Wilcoxon; $Z = -6.55$, $p < 0.001$). Statistically significant improvements after referral to PC ($p < 0.01-0.001$) were shown concerning all caring aspects related to pain (Table 6). *Continuity of care* was stated as being *good* with PC compared to *quite poor* before PC (Wilcoxon; $Z = -6.68$, $p < 0.001$). Patients' description of *pain control* with PC, had a statistically significant correlation with their description of *feeling of security* ($p < 0.05$), and *continuity of care* ($p < 0.05$) with PC. As *feeling of security* with PC was the only item, providing a statistically significant correlation with all the other items (Table 6) concerning PC ($p < 0.05 - 0.001$) was therefore chosen as dependent variable. Two independent variables were statistically significant predictors to *feeling of security* with PC, specifically: *Opportunity to talk*, the best predictor explaining 35% of the variance (R square = 0.35, $F = 36.43$, $p < 0.001$). Together with *continuity of care* another 10 % was explained (R square = 0.46, $F = 27.70$, $p < 0.001$).

Perceptions concerning pain management (Paper V)

The three description categories formed communication, planning and trust, with perceptions and expressions are shown on Table 13.

Table 13.

Descriptive chart showing categories, perceptions and expressions related to pain management for patients with cancer-related pain in palliative care.

Categories	Perceptions	Expressions
Communication	Aching all over	Pain influences the behaviour Pain can be expressed with emotions Pain can be expressed with certain behaviour Pain can be expressed as sensations from the body
	Ability to talk about aches and discomfort	Being believed Seeing the whole person Using the right tool
	Freedom from pain	Gaining from pain relief Interpretation of pain Influence from personality
Planning	Taking drugs is unavoidable	Large amount of different drugs Around the clock Information need
	Uncertainty concerning non-pharmacological treatment	Staff recommendations Patients attitudes
	Pain killer causing trouble	Problematic side-effects Fear of side-effects
	Suffering from caring actions	Pain from treatment Waiting for treatment
Trust	Need for humanity	Depending on the organisation Being treated politely Depending on who you meet
	Necessity of own initiative	Being an active part in the care Taking responsibility for care
	Personal painkilling tricks	Keeping spirit up Doing something concrete

Communication

The perceptions showed a need for an open and honest dialogue between patients and healthcare professionals about all the patients' problems concerning pain. A need appeared for improvement of verbal communication and an understanding of patients' non-verbal communication. Lack of communication prevented patients from being believed and being able to discuss things like dreams, previous experiences, knowledge, fears and learned behaviour about pain. When communication worked well, patients perceived they gained an understanding of their pain as well as with problems concerned with treating their pain.

The perception *Aching all over* described patients' expressions of pain and showed that there were several ways of expressing the acute pain patients had felt and sometimes continued to feel.

Pain influences the behaviour

"There have been times when I haven't been able to stand or sit. Coughing has been impossible... Pain affects me so that I am frightened to do anything"

The perception *Ability to talk about aches and discomfort* described patients' expressions of problems they had experienced in conjunction with having pain assessed. The need for frequent assessment of pain was shown, including all pain dimensions, by using the patient's self-report along with adequate tools for pain measurement.

Being believed

"I was in so much pain that I went in by ambulance and yet they said it was psychosomatic! It turned out to be a relapse. They are poor communicators I have thought this the whole time. I still believe that patients' input can be a big help, it is after all the patient who knows her body best."

Seeing the whole person

"Since the body is a whole, I think that they are working too much with isolated parts of the body. It's as if they weren't connected."

The perception *Freedom from pain* described the patients overall wish to experience freedom from pain or to have as much relief as possible from pain and their interpretations of the consequences of pain. Patients talked about the benefits of pain relief and were aware that their personality and attitudes to analgesics constituted an influence on quality of pain relief. They also expressed a wish for an early and ongoing discussion about their pain and its relief.

Gaining from pain relief

"I couldn't understand it was true, I just lay and enjoyed not having it. To be rid of this problem was paradise. It was an experience in and of itself."

Interpretation of pain

"If I have a certain dose which works and then the pain returns, then it must be because the disease has got worse but the longer the pain carries on the more difficult it is to stop it."

"The disadvantage of pain for the body is that all energy is used to work on the pain, so resistance is reduced."

Planning

The perceptions showed an urgent need for a structured planning of all caring actions around the patients and a need to discuss and plan for pain treatment earlier in the course of disease. The patients' were more positive toward analgesics once the planning and information about their pain treatment improved.

The perception *Taking drugs is unavoidable* showed the patients' expressions of the different medication routines they had gone through from:

Large amount of different drugs

"I received a lot of tablets –nerve tablets for my back, and Panodil (Paracetamol) was a part of the prescription. I ate Artrotec (NSAID), it was a whole bloody mountain of tablets."

Information need

"Now we learned, one should take tablets all the time... build up the pain relief, so to speak".

The perception *Uncertainty concerning non-pharmacological treatment* showed that patients and – as patients perceived it even healthcare professionals – had limited knowledge concerning interventions such as radiation therapy, transcutan nervstimulation, massage and acupuncture.

The perception *Painkiller causing trouble* showed that patients expressed a fear for side effects, especially from opioids. There were patients that had experienced so many problems with constipation, nausea, vomiting, dizziness, fatigue and dry mouth that it made them reluctant to take further analgesics.

Fear of side-effects

"I was given morphine....thought I would stop - it's a drug for god's sake. But they say as long as you are in pain you won't get addicted"

The perception *Suffering from caring actions* showed that different treatment procedures related to the disease such as radiation, waiting for investigations or being under consideration also made the patients suffer.

Pain from treatment

"The radiation therapy was terrible, they said it would take three quarters of an hour, but it couldn't then I would have died."

Waiting for treatment

"The worst thing is waiting without being given a date, but if I have a fixed date it doesn't matter if it's one month away or two."

Trust

The perceptions showed patients needed to trust in themselves as well as trusting in the healthcare organisation as a whole and in nurses and physicians in particular – to whom they perceived they were extremely dependent upon. When the patients felt a lack of trust in the healthcare organisation and in healthcare professionals their ability for self-determination decreased. While when they felt trust, they expressed improved ability and willingness to participate in pain management.

The perception *Need for humanity* showed that the patients feeling of security and pain relief improved when they received care from a PC team, immediate help in hospital and continuity of contact with the physician. Concerning healthcare professionals, patients expressed a range of important matters such as being pleased with being treated kindly, meeting engaged and competent nurses and physicians and receiving truthful information.

Being treated politely

“One thing that’s missing in healthcare is the lack of respect. It’s lacking on a humanitarian level. Technically they are very capable ... but it’s people they work with”.

Depending on who you meet

“So I admire the nurse that I find to be very competent ... sat down on the edge of the bed and gave me all the time I needed”.

“When I was in that much pain ... thought I was going to die with this cancer, doctors are powerless...than I met the palliative care team, then I saw things from a new angle, why should I need this when I could just as well be at home with my children?”

The perception *Necessity of own initiative* described how the patients expressed their ability and/or willingness for self-determination, but also a fear of being forced to take too much responsibility.

Being an active part in the care

“It’s difficult to have influence if you don’t know what you should influence. You don’t know what the possibilities are”.

The perception *Personal pain killing tricks* described the tricks patients expressed they had in order to reduce pain. They expressed a need to keep their spirits up as well as developing tricks for pain relief.

Doing something concrete

“It gets better if I go out hiking... but you can’t hike all night”

DISCUSSION

Methodological issues

In study design using both qualitative and quantitative analysis, the general concepts of importance for scrutinising a study are: applicability, reliability or trustworthiness, validity or reasonableness, accuracy and objectivity (Fridlund & Hildingh, 2000).

Concerning applicability pain treatment is equally important irrespective of the type of operation patients had undergone or the type of cancer diagnosed. Therefore in paper I patients having any type of operation were included, and in papers II-V, patients with the four most common cancer diagnoses were included. The assumption was that an equal sample of men and women should appear, as in paper I, when choosing patients with breast cancer, colon cancer, lung cancer and prostate cancer as in papers II-IV. Notably, the sample (papers II-IV) was biased in favour of men. To what extent this has influenced outcome is unknown but according to Gordin et al. (2001) it may be troubling as women tend to have their cancer pain undertreated more frequently than men. A further limitation could be the rather small sample sizes of patients, especially in papers II and III, sometimes limiting the possibility of detecting differences. With a small sample a type II error can occur. Therefore, the sample size should be based on some kind of estimated optimum in order to determine “true differences” between groups. No such power analysis was performed in this thesis. However, concerning paper II, statistically significant differences were shown despite the small samples, this was not the case in paper III. The stratified samples (paper II) were based on an estimate of how high-average-pain influenced HRQOL. This predetermined difference otherwise known as effect size, is determined from experience and published data, which strengthens the power analysis. For the stratified samples in paper III, neither experience nor published data indicate a difference. However the sample sizes in paper I with 100 patients and paper IV with 75 patients, might be insufficient for examining psychometric properties of the 12-item questionnaires used. A further analysis using Cramer’s V, phi coefficient or contingency coefficient might have shown further qualitative relationships (Burns & Grove, 1997). However, as 100 postoperative patients (paper I) consecutively selected by the head-nurse were included without any dropouts, it is likely that the result in paper I provided adequate description of pain after surgery. The patients with cancer-related pain were already referred to PC. The PC staff selected patients consecutively and asked for verbal consent at a suitable opportunity depending on the patient’s condition. This may also be a limitation but could explain why there were no dropouts when the patients were contacted for their interviews by the author. However, three patients cared for in hospital dropped out before the author had made contact, due to having become too ill to participate. Therefore, the samples in papers II-IV may not be representative of all cancer patients with pain, and not even of all patients receiving palliative care. Furthermore, as the inclusion criteria “assessed being in final stage of life” is difficult to assess, the

patients might have been in either an early or late palliative stage, as classified by National Board of Health and Welfare (2001b). On the other hand, the study probably provides a good description of the relationship between pain and HRQOL, the differences that occur with increased intensity of pain (Paper II) and when patients receive care from a palliative care team (Papers III, IV). The phenomenographic approach used in paper V is considered applicable as the findings led to three concrete description categories with representative perceptions and underlying expressions – both meaningful and of clinical value (Marton & Booth, 1997) for healthcare professionals improving pain management.

Concerning validity, the result in paper I shows that the questionnaire did not cover all dimensions of patients' pain experiences (McGuire, 1992). Pain intensity in the sensory dimension of pain, is the only measured component. Other dimensions of pain may influence patients' own report of pain intensity. The patients' expectations and previous experience of pain and pain relief, which might influence their assessment of pain, were not investigated in paper I. Furthermore, the relationship between analgesics prescribed and those patients actually received, was not intended to be investigated in this study and was therefore not analysed. Other studies report low prescribed doses of analgesics by the physicians and nurses, only amounting to 30-35% of the maximum doses of prescribed analgesics (Closs, 1990). Preoperative information and preoperative medication are both interventions for reducing postoperative pain (Richmond et al., 1993). Since pre-operative medication was not focused upon in paper I, it is impossible to say whether it could have influenced the pain intensity level. Concerning preoperative information, in paper I the only examined information was about the importance of postoperative pain relief. The SF-36 questionnaire (Sullivan et al., 1995) as well as VAS (Grossman et al., 1992) and POM (Gaston Johansson, 1996) are well established measuring methods. The PC-PCQ questionnaire used in paper IV showed sufficient construct validity – considering it is a recently developed questionnaire, if used as a current measurement as in this case. Concerning content validity, the questionnaire together with measurement of pain quality and intensity covered all pain dimensions (McGuire, 1992; Ferrell et al, 1994) and palliative care objectives as described by Mino (1999). According to Svensson (1997) the reasonableness of the findings in paper V increased as several patients expressed most of the perceptions.

Concerning reliability, Cronbach's alpha showed a sufficient reliability coefficient, of 0.72 (Kerlinger, 1986) for the APS questionnaire in paper I and 0.70 for the SF-36 in paper II. This is consistent with the reliability coefficient ranging from a low level of 0.65 to a high level of 0.94, as reported for SF-36 by McHorney et al. (1994). Perhaps the SF-36 is not a sensitive enough instrument for cancer patients in palliative care. The low internal consistency coefficients for some dimensions may indicate that some of the questions were difficult for the patients to understand or answer, as also reported by Cella (1995). Three patients in extremely weak condition declined to complete the

SF-36 questionnaire due to confusing or upsetting questions (papers II, III). On the other hand, the dimensions concerning PF, RP, BP and RE showed good internal consistency reliability (Cronbach's alpha > 0.76). The dimensions PF, BP and RP are the ones that showed a significant difference between the high pain and low pain group (paper II). The reliability for the result in paper IV is debatable, as the patients were asked to recall their experiences of care from memory, from the time before PC referral. The PC-PCQ questionnaire used in paper IV showed sufficient reliability in terms of Cronbach's alpha (0.76) considering it is a recently developed questionnaire (Burns & Groves, 1997). There was a strong concordance in the answers, concerning before and after (with) PC worth noting as well as the fact that all patients appeared to have a clear recollection of the time they got in touch with PC. It may be argued that reliability might have been better if patients had also been interviewed before referral to PC. However, prior to PC referral the patients are often in pain and a very weak condition making it difficult to ask for their participation and as stated by Daniels and Exley (2001) casts doubt over a truly informed consent. Deaths are to be expected in this group of patients therefore it was only realistic to perform one data collection, on one convenient occasion, after patients' referral to PC. Objective measurement of a patient's pain intensity cannot be obtained. However, a patient's self-rating of pain intensity is a well-established method used by health professionals for pain assessment (Zalon, 1993). Both VAS (Grossman et al., 1992) and POM (Gaston Johansson, 1996) have shown high reliability. The trustworthiness of the findings in paper V can be evaluated together with the following facts: Three authors with competence in pain management and qualitative research methods analysed and discussed the interviews in a systematic methodological and reflective manner checking the accordance of categories, perceptions and expressions. The number of patients interviewed (paper V) was enough to reach a broad understanding of how they perceived the concept pain management. Saturation of the perceptions was reached before all interviews had been performed – despite interview times being restricted by the weak condition of most patients. Therefore, 30 interviews were carried out, some lasting 30 minutes some for one and a half hour.

Concerning accuracy; In order to assure high quality of data in papers II and III, I administered the questionnaire personally (Sullivan et al., 1995). The same careful instructions were given to all patients explaining how to use POM and how to fill in the SF-36. A special interview guide was used for SF-36 when the patients were not able to manage on their own (McHorney et al., 1994). In paper V, only one interviewer – the author, performed all interviews, which were transcribed verbatim with quotations shown, providing conscientiousness throughout the research process (Fridlund & Hildingh, 2000). It can be difficult to obtain unbiased answers if the researcher is involved in the patients' care (Miaskowski et al, 1994; Daniels & Exley, 2001), therefore the interviewers assured both postoperative patients and patients in palliative care that none of their answers would influence the care they were receiving. This provides the studies with sufficient objectivity.

Result issues

More than one third of the patients in postoperative care (paper I) reported unnecessarily high levels of pain which is in accordance with other studies (Svensson et al., 2000; Huang et al., 2001) The patients who reported high intensity pain in their early postoperative period also reported high levels of *pain at the time of the interview* and poor *pain relief after pain medication* (Table 8). This revealed that many patients had suffered from persistent pain and were obviously under medicated also emphasised by statements regarding need for stronger pain medication and complaints about long waiting times, without pain medication in the casualty ward. All patients were prescribed postoperative analgesics and almost everyone had actually received analgesics. Miaskowski et al. (1994) reported that many patients think that they have to accept pain in the postoperative period and often do not complain or ask for more analgesics even when they are in need. Unfortunately, only 33 of the 100 patients in postoperative care remembered being informed about the importance of relieving pain. On the other hand, almost all patients had been requested to inform the nurse in charge when they were in pain, which also 81 patients had done and almost one third had requested a change of pain medication. Nevertheless, the pain intensity levels were up to 10 on VAS. Apparently, it is of no great advantage to ask patients to make it known when they are in pain if they do not know how much pain they are supposed to tolerate or how much pain relief they can expect to receive. It seems likely that the patients in postoperative care were not aware of the importance of being up and about as soon as possible after surgery and were pleased with being pain free by lying absolutely still. Therefore they were ignorant of the urgency to tell about their pain in time – in order to prevent the pain from taking a firm hold. The patients' evaluation of how satisfied they were with the way nurses and physicians treated their pain did not fully correspond with their reported pain intensities. The fact that patients do not know what they can expect in terms of pain relief may be one reason for expressing satisfaction with their pain treatment even while their pain remained. Ward and Gordon (1994) suggested that patients' satisfaction might be associated with the traditional peak and trough cycle of pain, representing relief from pain and return of pain following analgesia.

When comparing patients with average pain > 3 on POM-VAS (high pain group) with patients with average pain ≤ 3 on POM-VAS (low pain group) the high pain group reported the highest levels of *worst pain in past 24 hours* (paper II). Also, they more frequently reported that *pain interrupted their sleep* compared with patients in the low pain group. Patients in both low and high pain group reported high levels of *pain interrupting sleep* (Table 9). Not being able to sleep due to pain has a wide impact on daily life and energy. "Pain kept me from sleeping" (Bookbinder, 1996 p 345) was a frequently reported concern found by Bookbinder et al. (1996) and is in accordance with patients reporting fatigue and lack of energy. This is alarming as these patients

need energy in order to live their lives as well as their cancer will permit them. However despite an *average pain* intensity of ≤ 3 on POM-VAS, many of the patients in low pain group also reported *pain at time of interview* and *worst pain* as up to 9 on POM-VAS. Especially high levels of *worst pain* might indicate a so-called breakthrough pain, which is expressed as either severe or excruciating and can increase the average pain intensity level as reported by Ferrell et al. (1999). Strang (1997) found that the longer the patients had been in pain the more they worried about increased pain coming. Pain and anxiety about increasing pain, together with fatigue and lack of energy, were also aspects that disturbed more than one third of the patients the most (paper II).

When exploring pain among palliative care patients as a whole group (paper IV), the result showed that too many patients reported moderate to severe pain, particularly high *worst pain* (Table 11). The prevalence of *worst pain* in this study was almost as frequent as reported by Wang et al. (1999) but lower compared to the findings of McMillan (1996) when examining patients in hospice. The median and mean ratings of *pain at time of interview* and *average pain in past 24 hours* were acceptable. But as there were wide ranges – up to 9 on POM-VAS (Tables 9 and 11) there were still patients with unacceptable and persistently high levels of pain. By asking for the affective and sensory component of pain as stated by Gaston Johansson and Fall-Dickson (1995), the severity of the pain can become obvious. This was confirmed by the frequent expressions of the affective pain being described as worrying or troublesome. Also, 6 patients used the word terrifying or unbearable and 6 patients used the word torturing, dreadful, excruciating or killing (Table 12) when describing affective pain. The sensory pain was frequently described as prickling or sore, but also as cramping, burning or pressing as did 6 patients (Table 12). The presence of high levels of both physical/sensory pain and affective reactions in patients with advanced cancer were shown by Sela et al. (2002). The reason for 22 patients choosing to describe their pain with own words instead of those from POM-WDS could be that any given sensory or affective word does not necessarily have the same meaning for each person. Or one particular word may be completely unknown for some people, as stated by Sela et al. (2002).

Pain had a significantly negative impact on HRQOL (paper II, table 10). The severity of pain appeared to be a significant factor reducing patients' levels of functioning. Pain particularly affected the dimensions of PF, RP and BP, which may reduce the ability to perform daily activities. Pain must be discussed and treated in view of the ability to function in daily-life, including emotional, social and physical functioning (Wang et al., 1999; Owen et al., 2000).

Neither patients' HRQOL, nor their pain intensity levels differed significantly whether they were cared for by PCT I or PCT II (paper III, tables 9 and 10). No main differences were explored between the two teams concerning patients' analgesic

administration. As pain treatment often centres on medication, it can be seen primarily within the medical domain. While the drug prescription is a physician's responsibility, the PCT I nurses had a vital role in assessing patients' pain and observing medication effects. Also a vital role in initiating a physician's prescription of the necessary analgesics and controlling actual medication as reported by Mackintosh and Bowles (1997). When Mackintosh and Bowles (1997) evaluated nurse-led acute pain teams they found that more patients received the benefit of better pain relief. Hopkins et al. (2000) pointed out that nurses' ability to synthesize elements of care and treatment as well as coordinate complex care, mean that they play a key role in cancer treatment.

The aim of paper IV was to evaluate PC, especially pain management. It was found that all 75 patients were prescribed analgesics in line with WHO-guideline (1996). And that the pain medication schedule had obviously been optimised after referral to PC, with the result that almost all patients stated that the analgesic medication instructions were perfectly clear. The discrepancy between high pain intensities and statements of clear instructions however, indicates that some patients may not have followed the instructions, or avoided asking for more pain medication despite knowing whom to call. Patients' compliance with scheduled analgesics or use of on-demand analgesics – aspects included in the behavioural dimension of pain (McGuire, 1992) were not investigated, the study was only based on the prescriptions made. Obviously, the analgesic treatment was not optimised as it could have been, if the WHO-guidelines had been followed (Meuser et al., 2001). The reason for this may have been barriers created by nurses and physicians, although this seems rather unlikely of palliative care staff, as they ought to be specially trained in pain treatment. Instead, possible explanations are patient and family member related barriers such as: fear of addiction or side effects, patients' desire to be a 'good' patient or a misconception about the inevitability of pain as reported in previous studies (Ward et al., 1993; Riddell & Fitch, 1997; Meuser et al., 2001). The fact that two thirds of the patients in palliative care were cared for at home could also be a potential risk for the failure in pain assessment, especially if only the current pain is reported (Owen et al., 2000). This stresses both the importance of the nurses' role in patient education and the need for nurses to improve the methods of pain assessment and pain relief, even if they do not meet the patients daily (Bookbinder et al., 1996). Interventions for treatment were shown to need further improvements, as only three patients stated that they had received a non-pharmacological intervention. Ferrell et al. (1994) found that both patients and their families considered the non-pharmacological pain treatment important in addition to analgesics treatment.

Despite unacceptably high worst pain levels the patients described *pain control* with PC as good (paper IV). One interpretation is that the patients were unable to distinguish between an overall better level of care and pain control as discussed by Miaskowski et al (1994) and in paper I. The correlation between *pain control*, *feeling of security* and *continuity of care* with PC revealed a further correlation, a correlation between sensory, affective and socio-cultural dimensions of pain. Coupled with the

fact that *opportunity to talk* appeared to be the strongest predictor for *feeling of security*, this enforces the importance of considering the cognitive dimension of pain, confirmed by Calvin et al (1999). The increased *pain control* may therefore have been a result of patients' opportunity to discuss their understanding of the situation, allowing them to collect further information (Ellershaw et al. 1995, Milberg & Strang, 2000). The fundamental importance of communication as well as taking time to talk with the patients has been stressed and is considered central to nursing in PC. Nurses have to facilitate patients and their families to engage in decision making over a wide range of issues in PC, from goals for treatment to where to stay. For 49 of the 75 patients who stayed at home (Table 3) it was the nurse who was required to maintain continuity of care. The importance of *continuity of care*, clear instructions *whom to call* contributing to *feeling of security* was revealed, and this is supported by Milberg and Strang (2000).

The paper V findings – that patients perceived communication, planning and trust as fundamental for pain management, support the result from paper IV. The patients expressed a wish to be free from pain but they also expressed doubt, that it may not be possible. There were also patients convinced that pain was an unavoidable part of their disease. One unique aspect of cancer-related pain is the fear that pain indicates disease progression. This is not an irrational fear since pain may in fact, be a symptom of the spread of disease (Twycross, 1997). However as argued by Weiss et al. (2001) there is no sign of equality between the variability of pain and the variability of disease. Therefore, a disparity between the person's interpretation of the significance of their pain and their actual physical condition may exist. Patients perceived that they had not been believed when they complained of pain, despite the fact that they themselves and the physician or nurse knew of their cancer diagnosis. Pain was expressed in many different ways, probably in order to make it endurable and as a way to deal with it. Obviously, inadequate communication has often contributed to a suspicious patient and suboptimal pain management. Instead as reported by Calvin et al. (1999) more favourable opinions of pain management mean patients are more willing to ask for analgesics and therefore more likely to be satisfied with the overall experience of health care. The patients were aware of their need for analgesics but they expressed needing the opportunity to discuss their pain and the available pain treatment. They perceived themselves as lacking in knowledge about possible pain treatment alternatives while seeking well-structured plans. During the course of their disease there were patients that had been offered many different types of analgesics and just informed to take them *when needed*. Mostly, this lack of discussion, information and planning had continued until the patients came in contact with a palliative care team, which was extremely late in the course of their disease.

There were patients who had experienced side effects, usually constipation from opioid, as being so painful that they were afraid of taking further analgesics. This is in line with previous work by Thomason et al. (1998) finding that far too often, pain medication made patients "feel bad". The occurrence of procedure-related pain is a

further discomfort. It concerns for example the kind of reception the patients expressed they had been met with, unpleasant treatment or investigations and difficulties reaching nurses or physicians. Patients are well aware that pain treatment directives depend on which healthcare professional they meet as well as upon themselves. The desire for self-determination is somewhat conflicting as there were patients for whom having to decide about pain treatment interventions came as a burden. Other patients however, expressed frustration over not being able to make their own decisions. This is due to insufficient information about what treatment is available, what they will gain from it and how to take it. This frustration comes with a feeling of being an object – not a person, in the healthcare environment. As the pain treatment often has failed during the course of the patient's disease, there were patients that had lost confidence in healthcare professionals and even ceased to believe that pain relief was achievable. Each acute pain episode the patients had gone through may have elevated their levels of frustration and increased the physical-sensory pain (Sela et al., 2002). In turn contributing to difficulties with improving pain relief later in the patients' course of cancer. Lack of knowledge and skill concerning pain management among healthcare professionals may still be the reason for not taking the patient's pain seriously. This is confirmed by other studies (Strang, 1998; Meuser et al., 2001). Although patients believe in their own ability, they express a strong need for support, someone to call, someone to trust and discuss with, similar to Ersak et al. (1999) reports. There were patients for which this was not accomplished until they came in contact with a palliative care team.

GENERAL DISCUSSION

After all the studies involved in this thesis I realized that it was not just pain relief that was key for the patients. Instead, most important was the feeling of control the patient perceived having over the situation. In other words pain management means to help by coaching the patient to a point where he/she can feel control over their pain – in all dimensions. It became quite clear after the qualitative study (paper V) that to be pain free was one thing, but the feeling of having control over the pain and in extension their whole situation, was even more important. What's more the feeling of control itself seems like an antidote to the pain. It is easy to believe that the patients in postoperative care (paper I) did not perceive this control. For most of the patients with cancer-related pain this perceived pain control hadn't occurred at all, until they were referred to a palliative care team. Similarly, Adams McNeill et al. (1998) suggested that patients are more satisfied when they feel that healthcare professionals are placing a priority on managing their pain. It is quite clear and well supported by other studies that the pharmacological treatment for the physiologic and sensory pain is basic and fundamental for both postoperative pain (Oates et al., 1994; Kehlet, 1999) and cancer related pain (Portenoy et al., 1994; WHO, 1996; Meuser et al., 2001). Despite the fact that it is possible to reach optimal pain pharmacological treatment outcomes (Huang et al., 2001; Meuser et al., 2001), many barriers still remain (Pargeon & Hailey, 1999; Berry & Dahl, 2000). As shown in this thesis there were so many things that impeded an effective analgesic treatment. Almost all patients in this thesis (paper I, II) had been requested to tell when in pain and they did, but despite this, too many of them continued to suffer. Furthermore there were patients that perceived that they had not even been believed about their pain. Clearly, the patients must feel that they have control over their analgesic treatment and what can be gained by it, which demands further exploration of pain such as the behavioral (McGuire, 1992), cognitive (Calvin et al., 1999) and affective (Sela et al., 2002) dimensions. As few patients remembered discussing the importance of pain relief, an assessment of the multidimensionality of pain could not possibly have occurred. For example, problems with constipation and dry mouth strongly associated with analgesic medication, especially opioids (Morita et al., 1999; Klepstad et al., 2000) as shown in paper V. And, patients who had experienced side effects so painful that they were afraid and reluctant to take further analgesics.

Being sent to radiation therapy without enough analgesic or lack of information caused the patients a lot of pain and reduced their confidence in health care, as did unnecessary waiting. For example long waiting times in the casualty department and waiting to hear results of investigations or for appointments. If the patients themselves are not able to keep control over their well-being they at least expect the healthcare professionals to maintain an overall control of the situation and know how to act. Statements from both patients in postoperative care (paper I) and palliative care (paper V) show that patients perceived a lack in competence among the healthcare professionals. On the other hand patients could clearly identify what it was that

benefited them, but only after having experienced it. The main problem therefore, is that patients cannot request better care – certainly not describe it – if they have not had it or heard of it. As Socrates (Day, 1994 p, 2) concluded: “How can we search for things we do not know?”

Patients with cancer-related pain had benefited from the care provided by a palliative care team (paper IV) regardless how it was organized (paper III). A trusting relationship with nurses and physicians, including the opportunity to discuss thoughts and beliefs concerning pain and its treatment, from an early point in the course of disease, was perceived fundamental by patients. The need for early assessment followed by an individualized pain treatment plan still remains for both patients in postoperative care (Kehlet, 1997) and patients with cancer-related pain in palliative care (paper V). Furthermore, continuity of care and opportunity to talk increased the patients feeling of security (paper IV) also fundamental for managing postoperative pain (Kehlet, 1997).

NURSING IMPLICATIONS

Benner (1984) has identified seven domains of nursing practice by observing and interviewing nurses with different nursing experiences. Each domain contains 3-8 competencies specifying nursing practice. Experiences refer to a very active process of refining and changing one’s knowledge, when confronted with actual situations. Experience does not necessarily depend only on the length of time a person works in one position. On the contrary Sjöström et al. (1997) found that nurses with long experience more often failed in assessing the patients pain compared to nurses with relatively short experience. According to Benner (1984) the requirements for nurses to work in clinical situations, apart from being highly experienced with adequate knowledge and skill, are to be motivated to perform well, while aware of the resources and constraints associated with the situation. For nursing implications in this thesis some of the domains as well as competencies within the domains (Benner, 1984) are interpreted together with the thesis results shown on Figure 3.

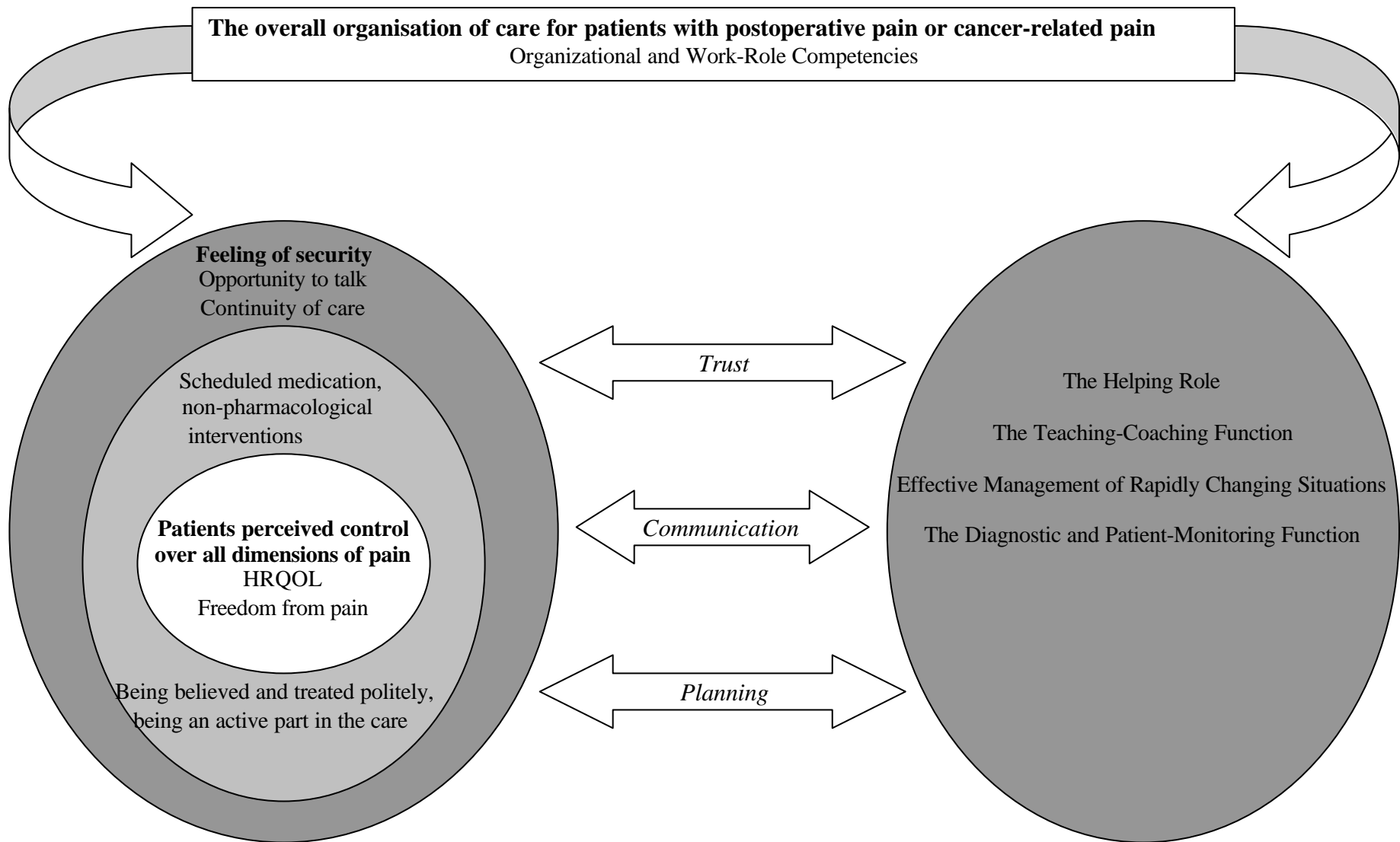


Figure 3.
A model based on Benner's domains (1984) for how nursing interventions as well as the overall organisation can meet the results of this thesis.

The overall organization of care for patients with postoperative pain or cancer-related pain in each hospital can be included in the domain *Organizational and Work-Role Competencies* (Benner, 1984, p 145). There are four clear guidelines in Sweden, one for acute postoperative pain management, two for cancer related pain management, and one for non-pharmacological treatment. All these guidelines can easily be implemented in the care, but there is a need for continuous evaluation of compliance. Each institution must develop an organized programme in order to evaluate the effectiveness of pain assessment and treatment and to continually educate staff. Without such a QA programme, the efforts of nurses and physicians to treat pain may become sporadic and ineffective. *Building and Maintaining a Therapeutic Team to Provide Optimum Therapy* (Benner, 1984, p 149) is one of the competencies within the domain *Organizational and Work-Role Competencies* and underlines the importance of creating multidisciplinary teams in both palliative care and postoperative care. As long as a nurse has a close and immediate contact with a physician about the pain medication, the nurse could very well be responsible for both an acute pain team and a palliative care team.

The domain *Diagnostic and Monitoring Function* (Benner, 1984, p 95) might be applicable to assessment of pain and planning of interventions for pain relief. The nurse's careful monitoring and early detection of a patient's possible problems are of great importance. Patients must be believed and their pain monitored and recorded with the same vigilance that heart rate, temperature, blood pressure, and respiratory rate are recorded. By using the VAS or POM-VAS from the beginning, pain becomes visible and therefore easier to discuss. It is not only current pain intensity that should be asked for and recognized, but also average past pain, worst pain, relief of pain and the influence of pain on sleep and daily activities. Pain can be recognized by setting limits on pain intensity and relief, forming the basis for review and follow-up of the efficacy of the pain treatment. Patients cannot know the so called "right" way to express pain, which challenges healthcare professionals to interpret patients' pain signals. The SF-36 questionnaire appeared to be a relevant point of departure for discussing the impact pain has on daily life as well as assessing several of the pain dimensions. Questions about physical functioning can be used in postoperative care in order to help the patients understand the importance of moving and being up and about. The sensory and affective words on POM-WDS are an excellent basis for discussing patients feelings associated with pain and its influence on HRQOL.

The domain *The Teaching- Coaching Function* (Benner, 1984, p 77) is probably the most important when nursing the patient in pain. Educational interventions regarding pain management should occur immediately after diagnosis or with surgical interventions, already preoperatively. However, the effectiveness of patient teaching depends on where a patient is, how open he is to information as well as how much information he wants and needs, and whether the nurse uses a vocabulary that the patient understands. These key aspects are explored in the competencies *Timing:*

Capturing a Patient's Readiness to Learn (Benner, 1984, p 79) and *Providing an Interpretation of the Patient's Condition and Giving a Rational for Procedures* (Benner, 1984, p 86). Interventions aimed to increase patients' knowledge of pain management may improve self-determination and help patients to interact effectively with healthcare professionals. This in turn may improve pain relief for patients. Nurses can significantly improve patients' knowledge of pain by reviewing with them their previous experiences of pain and methods of relief. Also informing them about available pain relief interventions and why analgesics should be taken on a regular basis and not just when pain occurs. Patient cooperation is often prompted by explaining two things: Firstly, the importance of pain relief to recovery and even reduced morbidity. Secondly, how preventing pain is easier than providing relief for pain already established. Physicians must also ask for results of the multidimensional pain assessment before prescribing analgesics.

In the domain: *The Helping Role*, Benner (1984, p 47) describes several competencies that involve the art of nursing, as well as the unique possibility the nurse has to make interventions for pain management covering all pain dimensions. One of the competencies is *Interpreting Kinds of Pain and Selecting Appropriate Strategies for Pain Management and Control* (Benner, 1984, p 62). As nurses often have the closest contact with the patients they can have the greatest impact on patients' adherence to the treatment plan, as well as developing a patient's role in treatment decisions. Although medical rules serve as guidelines for nurses, they must use their own judgement in order to provide the best possible care for the patients, not simply carry out medical orders by rote (Benner, 1984).

In the competence *The healing Relationship: Creating a Climate for and Establishing a Commitment to Healing* (Benner, 1984, p 49) the following interventions are suggested: help the patient to find an acceptable interpretation or understanding of pain or other stressful emotions and help the patient to use social and emotional support. The need for trust and feeling of security as expressed by the patients in this thesis can be implemented by using these interventions and the intervention presented in the competence *Presencing: Being with the patients* (Benner, 1984, p 57) the person-to person contact between patient and nurse. By dealing with the patient as a person, not as a problem, allowing the patient to ventilate ideas, beliefs, experiences and feelings – often just listening – the patient's feeling of security improves. Furthermore, nurses urge implementation of further interventions such as massage, cold and heat, distraction techniques and TENS in pain management. As patients perceived that both they and the healthcare professionals were uncertain about the use of those interventions there is a need for education, so that nurses and physicians place the same importance on non-pharmacological interventions as on pharmacological interventions.

In the domain *Effective Management of Rapidly Changing Situations* (Benner, 1984, p 109) the need for outcome evaluation of treatment and reassessment of pain can

clearly be interpreted. A change or complement of treatment interventions have to be made due to insufficient pain relief, problematic side effects and/or influence on further dimensions of pain.

If these clinical interventions were implemented in the care of patients, with postoperative pain and with cancer-related pain, they would probably perceive having control over all dimensions of pain.

FURTHER NURSING RESEARCH

Further research is needed to explore how patients in postoperative care as well as cancer patients without care from a palliative care team, perceive their pain and its management. It is also necessary to examine the reluctance of healthcare professionals to seriously assess and discuss patients' pain from the beginning of the disease and/or preoperatively. Even their reluctance to adhere to available guidelines and treatment plans needs further attention. This is a great problem as an increasing number of surgical interventions are performed as day surgery and an increasing number of patients with severe cancer are cared for at home. The different composition of the teams being nurse-led or physician-led is worth further research from both patient and healthcare professionals view points, their may also be a cost-benefit worth examining. This research must include exploration of the management of other symptoms such as fatigue, dyspnoea, nausea and constipation also influencing patients' HRQOL. Also worthy of further research are referral strategies in the following terms: time for referral to palliative care, initiator of palliative care and the choice of patients concerning gender, diagnosis, severity of illness and problems.

In order to find out how to improve clinical use of the existing pain research knowledge, educational and organisational programmes for both patients and healthcare professionals need implementing. Nurses must feel that they have the knowledge and the opportunity – as well as the expectations of others, to take an increased responsibility for patients' pain management. Patients must feel that pain management is a part of their treatment and they must know what they can gain from it.

CONCLUSION

- Thirty-five percent of patients with postoperative pain and 30 % of patients with cancer-related pain had experienced persistent pain in past 24 hours; VAS > 3 with frequent episodes of severe worst pain.
- Analgesics were prescribed for all patients both with postoperative pain, or with cancer- related pain, but non-pharmacological treatments were seldom used.
- All patients, both with postoperative pain and cancer related pain, had been told to tell when experiencing pain, but few patients had received an explanation as to the importance of not suffering pain.
- For patients with cancer-related pain, pain had a negative impact on HRQOL, especially physical functioning. Pain increased and HRQOL decreased as patients reached the final stage of life.
- There were no statistically significant differences in pain intensities, pain qualities or HRQOL between the patients cared for in a nurse-led or a physician-led palliative care team.
- The patients had experienced a statistically significant improved care in relation to pain after being referred to a palliative care team.
- Continuity of care and opportunity to talk increased the patients' feeling of security.
- The patients with cancer-related pain expressed a wish to be pain free, or attain as much pain relief as possible with as few side effects as possible.
- For many patients with cancer-related pain the discussion about pain and its treatment seems to have occurred late in the course of disease, mostly not until contact with a palliative care team.
- Communication, planning and trust were fundamental concepts for perceived pain control for patients with cancer-related pain.

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SVENSK SAMMANFATTNING

Vård och behandling av akut postoperativ och cancer-relaterad smärta: Patienters erfarenheter och uppfattningar i förhållande till hälsorelaterad livskvalitet och smärtans dimensioner

Trots att det finns effektiva behandlingsmetoder för patienter med postoperativ smärta och cancer-relaterad smärta så lider många patienter av smärta. Denna avhandling beskriver patienter med postoperativ smärta samt patienter inom palliativ vård med cancer-relaterad smärta samt deras erfarenheter och uppfattningar av vård och behandling, med avseende på hälsorelaterad livskvalitet och smärtans dimensioner. Både kvalitativa och kvantitativa metoder användes. Datainsamlingen bestod av intervjuer och frågeformulär; APS Outcome Questionnaire för värdering av smärta, SF:36 för skattning av hälso-relaterad livskvalitet (HRQOL) och ett frågeformulär PC-PCQ för utvärdering av vård av smärta inom palliativ vård. Visuella Analog Skalan (VAS) och Pain-O-Metern (POM) användes för smärtskattning.

Undersökningsgruppen bestod av 100 patienter, andra postoperativa dygnet (studie I) samt 75 patienter med cancer inom palliativ vård (studier II-V). Av dessa 75 patienter inom palliativ vård ingick ett stratifierat urval av 46 patienter i studie III samt ett strategiskt urval av 30 patienter i studie V. Dataanalysen var i huvudsak beskrivande och både parametriska och icke parametriska analysmetoder användes. Fenomenografisk ansats användes i den kvalitativa analysen (studie V).

Resultatet visade att 29 patienter inom postoperativ vård vid intervjutillfället värderade sin smärta till > 3 på VAS medan 79 patienter angav > 3 som värsta smärta senaste 24 timmarna. Ju högre smärtintensitet ju mer missnöjda var patienterna med sjuksköterskans sätt att behandla deras smärta. Alla 100 postoperativa patienter hade uppmanats att säga till vid smärta. Trettio tre patienter ansåg att de fått information om varför det var viktigt att få smärtbehandling.

Av de 75 patienterna inom palliative vård så angav 22 patienter vid intervjutillfället en smärta > 3 med POM-VAS och 47 patienter angav > 3 som värsta smärta senaste 24 timmarna. Den genomsnittliga smärtan senaste 24 timmarna angav 28 patienter till > 3 med POM-VAS. Tjugo-fyra patienter använde orden besvärlig och tröttande medan 6 patienter använde orden torterande, mördande eller fruktansvärd när de beskrev sin emotionella smärta. Vid beskrivning av den sensoriska smärtan så angav 15 patienter den som stickande eller ömmande medan 4 patienter angav smärtan som skärande eller sönderslitande. Patienternas uppfattning om smärtan var "värk överallt" samt att de önskade bli smärtfria. De uttryckte även en rädsla för ökad smärta. HRQOL var sänkt för patienter med genomsnittssmärta > 3, statistiskt signifikant minskad var fysisk funktion samt antalet månader som patienterna levde efter intervjutillfället. Det visades inga statistiskt signifikanta skillnader avseende HRQOL och smärta beroende på om patienterna vårdades av ett sjuksköterskelett eller läkarlett palliativt vårdteam.

Patienterna angav att vården inklusive smärtbehandlingen statistiskt signifikant hade förbättrats när de fick hjälp av ett palliativt vårdteam. Patienterna uttryckte ett behov för kommunikation mellan patient och vårdgivare angående smärta och smärtbehandling samt en planering för hur vården och smärtbehandlingen skulle genomföras. Trots att patienterna uttryckte att de ville klara sig själva så hade de ett starkt behov av stöd, någon att ringa och någon som de kunde lita på.

Alla patienter inom både postoperativ vård och palliativ vård hade ordinerad analgetika vanligen en kombination av Paracetamol, NSAID och opioid. Det förelåg ett statistiskt signifikanta samband mellan smärta vid tid för intervjuerna, värsta smärta och genomsnittssmärta senaste 24 timmarna samt smärta som väcker patienten. Kontinuitet i vården och möjlighet för samtal ökade patienternas känsla av trygghet vilket var viktigt för att patienterna skulle känna att de hade kontroll över smärtbehandlingen.

Sammanfattningsvis: Ju högre smärtintensitet patienterna inom postoperativ vård kände ju mer missnöjda var de. Cancer-relaterad smärta hade en negativ inverkan på HRQOL speciellt patienternas fysiska funktion. Smärtan ökade ju kortare tid patienten hade kvar att leva. Vården från ett palliativt vårdteam var viktig för att förbättra vården och behandlingen av patienternas smärta. Möjligheten att få diskutera smärta och smärtbehandling ansågs ha påbörjats sent i sjukdomsförloppet och många patienter hade upplevt biverkningar av smärtstillande läkemedel som gjorde att de var skeptiska till ytterligare smärtlindringsförsök.

Kliniska implikationer: Strukturerade smärtanalyser som täcker smärtans alla dimensioner och som sker tidigt i sjukdomsförloppet eller preoperativt. Fortlöpande diskussion om smärta och smärtbehandling samt väl planerad och genomförd farmakologisk samt komplementär smärtbehandling. Smärtan måste synliggöras och ingå som en del av vård och behandling oavsett om det är i samband med ett kirurgiskt ingrepp eller en cancersjukdom.

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