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# ELDERLY PATIENTS' EXPERIENCES OF PAIN AND DISTRESS FROM THE PATIENTS' AND NURSES' POINTS OF VIEW

Marie Louise Hall-Lord



Göteborg 1999

Department of Geriatric Medicine, Vasa hospital,  
Göteborg University, Göteborg, Sweden



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## Abstract

The aims of these studies were to investigate some aspects of elderly patients' pain and distress, related to their sense of coherence (SOC), need for social support, functional ability, and background variables and to compare patients' reported experiences of pain and distress with nurses' assessments.

The first study investigated pain and distress from elderly patients' perspective using a grounded theory approach in intensive care. Interviews and observations were conducted with 18 patients. A model, developed from the analysis of data, describes elderly patients' experiences of pain and distress as four interrelated aspects: a sensory, an intellectual, an emotional, and an existential dimension. Sixteen categories form the four dimensions. Questionnaires derived from this model were used in studies II-V.

Study II compared elderly patients' (n = 51) reported experiences of pain and distress with nurses' (n = 44) and enrolled nurses' (n = 37) assessments in intensive care. The patients' self-reported experiences of pain and distress did not agree completely with the nurses' and enrolled nurses' assessments. Nurses overestimated some of the patients' experiences; whereas enrolled nurses tended to underestimate the patients' pain and distress and assessed the interventions as more sufficient than did their patients.

The third study explored postoperative experiences of pain and distress in elderly patients. One-hundred patients who had undergone elective surgery in two orthopaedic and two surgical units were interviewed, using a structured interview format on three occasions. Logistic regression analyses showed that pain and distress were significantly related above all to type of surgery and SOC. Three different clusters of patients, who showed variations in their experiences of pain and distress, were identified.

Study IV compared experiences of pain and distress among older chronic pain patients in the community with enrolled nurses' assessments and related potential differences to patient and enrolled nurse characteristics. Data were collected through personal interviews with 38 patients and questionnaires completed by 38 enrolled nurses. Enrolled nurses underestimated patients' experiences of physical pain and discomfort, breathing problems, resignation, and dependency. Personality as a nurse characteristic seemed to influence the enrolled nurses' assessment of patients' pain and distress.

The fifth study identified various profiles of experiences of pain and distress experiences among older chronic pain patients and compared if background variables, SOC, functional ability, and experiences of interventions aimed at reducing pain and distress varied between the profiles of patients. Interviews were carried out with 42 elderly patients. A cluster analysis yielded three clusters, each representing a different profile of patients. One profile, with subjects of advanced age, showed a decreased functional ability, and favourable scores in most of the categories of pain and distress. Another profile of patients showed favourable mean scores in all categories. The third cluster of patients showed unfavourable scores in most categories of pain and distress.

In conclusion, the assessment of patients' pain and distress could be more systematic in acute health care as well as in the community. Nurses need to become aware of possible biases related to pain and distress assessment as a result of personality factors and other variables. Patients in postoperative care, as well as in the community, with less favourable scores of pain and distress had a weaker SOC compared with patients with more favourable pain and distress scores. The differences suggest that there is a need to treat the patients in different ways in the caring situation.

**Key words:** *Elderly, pain, distress, intensive care, postoperative, chronic pain, nurses, assessment, sense of coherence, functional ability, need for social support, personality, grounded theory*

# CONTENTS

INTRODUCTION .....	7
Main concepts .....	7
Definition and models of pain .....	7
Different types of pain .....	8
Acute pain .....	8
Chronic pain .....	9
Definition of distress .....	10
Different types of distress .....	10
Physical distress .....	10
Emotional distress .....	11
Intellectual distress .....	11
Existential distress .....	12
Pain, distress and the elderly .....	12
Related concepts .....	14
Sense of coherence .....	14
Social support .....	15
Functional ability .....	16
Assessment .....	16
Assessment of physical and emotional aspects .....	17
Assessment of pain and pain control .....	17
Assessment of intellectual aspects .....	17
Assessment of spiritual aspects .....	18
Influencing factors in connection with nurses' assessment .....	18
Patient characteristics .....	18
Nurse characteristics .....	19
Personality .....	19
Summary of the literature review .....	20
AIMS OF THE THESIS .....	23
SUBJECTS AND COLLECTION OF DATA .....	24
Patients in intensive care .....	25
Patients in postoperative care .....	25
Patients in the community .....	26
Nurses .....	26
ETHICAL ASPECTS .....	27

METHODS AND DISCUSSION OF THE METHODS .....	28
The interview and observation process .....	28
Measurements .....	28
Pain and Distress Scales .....	28
The Sense of Coherence Questionnaire .....	29
Five Factor Personality Inventory .....	31
The ADL-Staircase .....	31
Need for Social Support .....	32
Data analyses .....	32
Grounded theory .....	32
Statistical analyses .....	33
RESULTS AND DISCUSSION OF THE RESULTS .....	34
The model of pain and distress .....	34
Patients' experiences and nurses' assessments of pain and distress in intensive care .....	36
Pain and distress in postoperative care .....	39
Patients' experiences and enrolled nurses' assessments of chronic pain and distress .....	42
Chronic pain and distress in the elderly .....	44
GENERAL DISCUSSION .....	46
Nursing implications .....	47
Future research .....	48
CONCLUSIONS .....	49
ACKNOWLEDGEMENTS .....	50
REFERENCES .....	51
APPENDIX 1: Pain and distress scales .....	62
APPENDIX 2: Need for social support .....	70
PAPER I	
PAPER II	
PAPER III	
PAPER IV	
PAPER V	

# ABBREVIATIONS

ADL	Activities of daily living
I-ADL	Instrumental activities of daily living
P-ADL	Personal activities of daily living
FFPI	Five-Factor Personality Inventory
ICU	Intensive Care Unit
SFS	Svensk författningssamling
SOC	Sense of coherence
SOSFS	Socialstyrelsens författningssamling
WHO	The World Health Organization

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- IV. Hall-Lord ML, Larsson G, Steen B. (1999). Chronic pain and distress among elderly in the community: Comparison of patients' experiences and enrolled nurses' assessments. *Journal of Nursing Management*, 7: 45-54.
- V. Hall-Lord ML, Larsson G, Steen B. Chronic pain and distress in older people – a cluster analysis. Submitted for publication.

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Marie Louise Hall-Lord



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Department of Geriatric Medicine, Vasa hospital,  
Gothenburg University, Gothenburg, Sweden

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

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# INTRODUCTION

The Swedish population is ageing. Predictions are that the number of elderly will increase from the year 2005 for more than 10 years. The number of people aged 80 and older will increase by 21 per cent by the year 2010 with more women than men. These predictions are based on mortality statistics and the demographic history of Sweden (Statistics, 1995). Population studies show that many functions remain relatively unchanged in elderly people until the age of 70-75 years with great variation between different individuals and different functions (Steen, 1997). Improved physical and mental health has been noted today among the youngest old (65-75) compared to some decades ago (Mellström & Steen, 1990; Steen & Djurfeldt, 1993; Steen, 1996). In a study by Grimby & Wiklund (1994), the majority of ambulant 76-year olds felt healthy and reported a satisfactory quality of life. However, an increasing number of elderly people will have a longer life, which leads to an increased risk of illness among people of advanced years (Mellström & Steen, 1990). Elderly people constitute a large proportion of the patients in acute health care (Fulmer & Walker, 1990), and the number of elderly patients undergoing surgery is increasing (Zuccalà et al., 1994). With no great changes in medical treatment and technology, the need for different forms of care and service will increase from 4 to 22 per cent from 1991 to 2000 (van den Berg Jeths & Thorslund, 1994).

Epidemiological studies have shown that chronic pain constitutes a major health problem (Von Korff et al., 1988; Brattberg et al., 1989; Crombie et al., 1994). A common problem among elderly is pain (Crook et al., 1984; Brattberg et al., 1989; Brattberg et al., 1996). Over 80 per cent of elderly people living in their own homes reported pain experience of some type and 59 per cent had multiple pain complaints (Mobily et al., 1994). Depression, sleeping difficulties, and decreased locomotion are examples of consequences of pain (Ferrell, 1991). However, relatively little attention has been paid to pain problems among the elderly when it comes to education and research within geriatric medicine and nursing care (Harkins et al., 1990; Ferrell, 1991).

## MAIN CONCEPTS

The two main concepts in this study are pain and distress. However, the definitions of these concepts are ambiguous, and the concepts are to some extent overlapping. For example, pain can be described as a form of distress as well as causing different forms of distress. In dictionaries, the concepts are treated synonymously. The word 'distress' in Swedish has the meanings *pain, agony, sorrow, torment, anguish, anxiety, and worry* (The Comprehensive English-Swedish Dictionary, 1980). Pain is translated as *pain, ache, torment, suffering, sorrow, and anxiety* (The Comprehensive English-Swedish Dictionary, 1980). In this literature review an attempt has been made to describe the concepts as they usually appear in the literature. The literature review will mainly focus on patients in intensive and postoperative care as well as patients with chronic pain.

## Definition and models of pain

The Taxonomy Committee of the International Association for Study of Pain defines pain as an "unpleasant sensory and emotional experience associated with actual or potential tissue

damage, or is described in terms of such damage" (IASP 1979, p. 250). Pain is always a subjective experience, and the meaning of the emotional part in the definition is the unpleasant experience (IASP, 1979). However, pain seems to be a multidimensional phenomenon, and it has been conceptualised in physical, psychological, social, cultural, and existential models (Bonica, 1990; Brattberg, 1995; Haegerstam, 1996). The physical model of explanation has been predominant during the last century but this model does not explain all aspects of pain (Morris, 1991).

Physiological explanation models are based on the assumption that pain can be explained by means of morphological structures in both the peripheral and the central nervous system (Haegerstam, 1996). Psychological factors have an influence on, and are closely linked to, the experience of pain. Worry, fear, depressed mood, and anxiety may increase the pain but pain may also generate these emotions (Brattberg, 1995). These emotions have a great impact on the individual's understanding and control of pain. An individual's reaction to pain is determined by past experiences, personality traits, state of health, level of growth and development, expectations from relatives and friends, and one's current situation (McCready et al., 1991). Cultural differences play an essential role in how people perceive and express pain. In cultures where emotional expression is not encouraged, people try to restrain their emotions in connection with pain, while the opposite is true in other cultures (Finer, 1984). Existential pain involves some kind of deeper suffering. When individuals experience different kinds of suffering, they frequently ask questions about life, death, the meaning of life and its lack of meaning (Eriksson, 1991). Seen from the perspective of religion, pain and suffering can be something positive. The needs of the body are ignored, the focus instead being on spirituality. Pain can be viewed as a message from God, thereby giving life a new meaning (Sternbach, 1987).

No single theory on pain adequately explains all that is known about pain production, pain transmission, pain perception, and pain behaviours (Donovan, 1990). The gate control theory of pain proposed by Melzack and Wall (1965) more than three decades ago, still seems to be the best attempt to integrate the physiological, pathophysiological, and cognitive-emotional interactions of the pain experience. Loeser (1982) and Donovan (1990) proposed models that expand on the basic tenets of the gate control theory. Loeser's model involves nociception, pain, suffering, and pain behaviour. Suffering is a complex affective response generated by pain and other situations that induce negative emotional reactions, and it becomes integrated into a person's life style. Suffering involves functions such as memory, emotion, and meaning (Loeser, 1982). Donovan's (1990) model also involves social factors, for example, family, culture, and care delivery. These factors influence how pain is perceived and interpreted.

## Different types of pain

### Acute pain

Bonica (1990) defines acute pain as "a complex constellation of unpleasant sensory, perceptual, and emotional experiences and certain associated autonomic, psychological, emotional, and behavioural responses." (p. 19). Acute pain is in general characterised by being related to a specific event: (1) trauma, e.g. sports damage, brain damage, and damage cause by accidents, (2) diseases, e.g. myocardial infarction, gout, and migraine, (3) treatments, e.g. surgery, dental treatments, and diagnostic operations (Donovan, 1990).

Pain with a sudden onset involves an acute warning signal, a complex chain of movements when the threatened body part is withdrawn, and a personal perception of pain (Finer, 1984). The sympathetic nervous system is activated and the body reacts with a quick pulse and higher breathing frequency. Acute pain can be perceived as extremely disagreeable. There is also anxiety and fear that the pain may be aggravated and that the pain or disease will affect health and the ability to function (Sternbach, 1987). The psychological reactions in conjunction with acute pain plays an important role, and the pain behaviour is determined by the damage, earlier experiences of pain, the beliefs, meanings and illusions in the situation, the social situation, cultural background, and personality factors (Bonica, 1990).

One form of acute pain is postoperative pain. It is a well-known fact that postoperative patients suffer from pain (Cohen, 1980; Sriwatanakul et al., 1983; Seers, 1987; Kuhn et al., 1990; Harrison, 1993; Sjöström, 1995). Postoperative pain consists of an aversive sensation and emotional stress. The most frequent emotional distress seen with postoperative pain is fear and anxiety (Barber, 1959; Egan, 1989; Boeke et al., 1991). However, the pain can also lead to insomnia (Donovan et al., 1987; Closs, 1992) and insecurity as well as to undesired physiological effects, such as stress and negative effects on the heart and the circulation of the blood. These physiological effects can be more or less eliminated by means of adequate pain relief. It is obvious that "pain breeds pain"; unless the pain is treated, the tactile organs of the pain system gradually become more sensitive, muscular cramp and deteriorated blood circulation cause lack of oxygen and lowered acidity level in the body tissue, which leads to increased pain (Arner, 1983).

Anxiety has been found to be a predictor of postoperative pain. Anxious patients seem to perceive more pain and recover more slowly after an operation (Chapman & Cox, 1977; Sternbach, 1987). Scott et al. (1983) found that state but not trait anxiety was a predictor of postoperative pain. In contrast, Taenzer et al. (1986) found a relationship between higher levels of trait anxiety and increased pain perception. On the other hand, no connection was found between pain intensity and patients' sex, age, and previous number of operations. There are studies showing no relationship between anxiety and pain perception (Bruegel, 1971; Wise et al., 1978).

Despite the fact that the majority of patients expect to feel postoperative pain (Francke et al., 1996), there is a tendency to underestimate the degree of intensity (Cohen, 1980; Carr, 1990; Carr & Thomas, 1997). Donovan (1983) found those patients dissatisfied with pain relief was worried about the cause of the pain, and several did not think that the pain would go away. Seers (1987) described how patients' experiences of pain were linked to how they perceived their progress and recovery. The more pain patients had, the lower they rated their own recovery. No differences between the sexes were found in pain intensity for children, adults (Lander et al., 1989), or in adults, aged 50-80 (Duggleby & Lander, 1994).

## Chronic pain

In dictionaries, 'chronic' is described as something that is protracted, lasting, incurable, or constant. This means in practice that an acute pain that lasts longer than three to six months is regarded as chronic pain (Brattberg, 1995). Bonica (1990), on the other hand, argues that the pain has become chronic when "pain that persists a month beyond the usual course of an acute disease or an injury to heal or that is associated with a chronic process that causes continuous pain or the pain recurs at intervals for months or years." (p. 19). The pain is no longer a warning signal when the tissue damage perhaps no longer remains. Frequently, the worry and anxiety, which may be perceived in conjunction with acute pain, turns into symptoms of depression (Brattberg, 1995).

Chronic pain may lead to sleeping problems (Asmundson et al., 1996), increased

fatigue, reduced mobility, less social activity, and feelings of guilt (Nesse & Nortvedt, 1989; Brattberg, 1995). The social situation both within and outside working life is of importance. Being motivated and feeling appreciated at work as well as a well-functioning social network reduce the risk of the pain becoming chronic (Brattberg, 1995).

There are several causes of pain. Arner (1983) divides chronic pain into four categories but emphasises that their boundaries are blurred. The first category consists of patients who have had some form of damage, which has healed locally, but who continues to feel pain. The second category can be explained by neurological disturbances, e.g. phantom pain. The third category is body damage or disease, e.g. cancer pain or chronic inflammation, with constant pain signals. The last category comprises patients, whose pain arises without there being or having been a physical cause. Also inefficient treatment of acute pain can turn the pain into chronic pain (Bonica, 1990; Brattberg, 1995). White et al. (1997) found differences in a sample of 371 hospitalised patients who experienced acute pain. The group of 171 patients, who developed chronic pain, had higher pain intensity, more distress, longer hospital stay, and less functional ability than the group of 200 patients whose pain had disappeared.

Several psychological models have attempted to establish the causes of pain becoming chronic, namely the psychodynamic/personality, behavioural, cognitive-/behavioural, and psycho-physiological models (Adams et al., 1996). The first type of model explains the development of pain by emotional and personality characteristics, while the second model is based on the assumption that behaviours are learned and reinforced. The proponents of the third type of model make a statement about the relationship between cognitive processes and behaviour. The last model suggests an interaction of physiological and psychological factors in the development of chronic pain. Gamsa (1994) claims that all these models have both strengths and weaknesses and that none is better than the other is.

## Definition of distress

In the literature dealing with stress, Selye (1985) denotes the positive aspects of stress 'eustress' and the negative and unpleasant ones 'distress'. Similarly, Frankenhauser (1986) described two components of stress; distress and effort. Effort is probably less damaging than distress.

Being an intensive care patient could be perceived as frightening and stressful (Stanton, 1991). In a study by Bergbom-Engberg et al. (1988), about 50 per cent of the patients recalled the respirator treatment as discomfoting and stressful. There are patients who suffer from distress following surgery, which is an important factor in recovery (Seers, 1987; Egan, 1989; Boeke et al., 1991). Patients with chronic pain experience distress in various forms (Bonica, 1990; Brattberg, 1995; Walker & Sofaer, 1998).

## Different types of distress

### Physical distress

Physical distress can be referred to the presence of problems with the body. Intensive care patients have reported complaints, such as pain, sleeping difficulties, tiredness, and breathing problems (Elpern et al., 1992; Jones et al., 1994). Pain has been mentioned as one of the most distressing experiences by patients in intensive care (Ballard, 1981; Cochran & Ganong, 1989; Cornock, 1998). Puntillo (1990) described that more than 60 per cent of the patients in

intensive care reported moderate to severe pain.

As mentioned before, patients suffer from postoperative pain (e.g. Boström et al., 1997; Carr & Thomas, 1997). Fatigue after surgery is a common problem (Duggleby & Lander, 1994). de Groot et al. (1997) found that fatigue was a predictor of more postoperative physical complaints in patients undergoing lumbar surgery. Aarons et al. (1996) did not find that fatigue increased after major joint arthroplasty. However, preoperative fatigue was the best predictor of postoperative fatigue as well as deteriorated emotional and physical state.

In a sample of chronic pain patients, 85 per cent were never free of pain (Sofaer & Walker, 1994). Bonica (1990) refers to investigations of Sternbach, who found that sleep disturbances were one of the most common problems among patients with chronic pain. The patients felt exhausted due to lack of sleep and continuous pain. Other distressing problems were appetite disturbances and constipation.

## Emotional distress

Studies in intensive care have shown that patients experienced emotional distress such as worry, fear, and dependency (Bergbom-Engberg & Haljamäe, 1989; Elpern et al., 1992).

In postoperative care preoperative distress seems to be a predictor of postoperative emotional distress (O'Hara et al., 1989; de Groot et al., 1997). O'Hara et al. (1989) found that more patients had higher levels of psychological distress three months after surgery than the day before surgery. Younger age, being male, and poorer postsurgery health were predictors of psychological distress after surgery. Despite the fact that anxiety decreased, other forms of emotional distress, such as depression and hostility, increased. Operation type was no predictor of psychological distress. Psychological distress may arise from lack of sleep after surgery (Duggleby & Lander, 1994).

Patients with chronic pain may develop emotional distress, such as anger (Fernandez & Turk, 1995), anxiety (Wade et al., 1990), depression (Turk et al., 1995), frustration (Wade et al., 1990), and hostility (Sofaer & Walker, 1994). In a chronic pain sample the most common negative feelings were tension, irritability, and worry (Sofaer & Walker, 1994). A significant proportion of the emotional disturbance in chronic pain patients was associated with psychosocial factors, such as fear of the future, regrets about the past, and relationship problems (Walker & Sofaer, 1998). These factors were secondary to, or concurrent with, the pain. No gender differences in levels of psychological distress were found.

## Intellectual distress

Intellectual distress includes for example communication and memory difficulties, disorientation and insufficient information. Intensive care patients have particular difficulty in describing their experiences, as many of them are unable to communicate verbally (Leisifer, 1990; Puntillo, 1990; Albarran, 1991). Many of these patients are intubated or have a tracheostomy at some time during their hospital stay. Patients found it distressing not to be able to communicate (Bergbom-Engberg et al., 1988; Hafsteindottir, 1996).

There are differences in results regarding recollection of patients' stay in intensive care. Many patients do not afterwards remember the time in the unit (Jones et al., 1979; Bergbom-Engberg et al., 1988; Compton, 1990; Daffurn et al., 1994; Jones et al., 1994). Patients could be too physically ill or too sedated to perceive and remember what is going on around them (Cochran & Ganong, 1989). Patients may undergo a process of denial; therefore, they do not remember or block out negative aspects of their stay. Other studies have shown a high proportion of patients who did remember their visit in the intensive care unit (Puntillo, 1990; Turner et al., 1990; Elpern, 1992). O'Hara et al. (1989) found changes in memory complaints



in connection with surgery. More patients rated their memory as poorer three months after surgery than before.

Some patients in intensive care considered that they did not receive enough information or that they did not understand the information given (Compton, 1990). Also within postoperative care the information to patients has been reported as being deficient. Just under half of the patients received information about expected postoperative pain (Kuhn et al., 1990) or pain relief (Owen et al., 1990). Half of the patients with chronic pain, who were treated in a pain clinic, wished to have more information about their condition and pain treatment (Sofaer & Walker, 1994).

An alteration in mental status, so-called intensive care syndrome, is another distressing experience among some patients in intensive care (Helton et al., 1980; McGonigal, 1986). McGonigal (1986) described various clinical signs of the syndrome: confusion, disorientation, aggression, hallucinations, paranoia, and delusions. The syndrome, which is reversible, is related to psychological distress, sleep deprivation, overmedication, lack of information, and excessive stimulation (Easton & MacKenzie, 1988). Some patients reported terrible nightmares, which for a few patients had continued after intensive care (Jones et al., 1994).

## Existential distress

Existential or spiritual distress may be described as a failure to invest life with meaning, hope, a will to live, belief and faith in oneself (Tillich, 1952; Travelbee, 1971; Frankl, 1974, 1986; Watson, 1985). Spirituality and religiosity are not identical. Human beings have a spiritual dimension, which covers a broader scope than institutionalised religion (Soeken & Carson, 1987). Hope has been related to having value, meaning, and a desire to live. Hope generates energy that enables individuals to continue functioning in the midst of chronic illness (Travelbee, 1971).

In a study of oncology patients and their spiritual health, the patients reported moderately high levels of spiritual health (Highfield, 1992). Older patients with fewer distressing symptoms experienced a higher degree of spiritual health compared to younger patients with distressing symptoms.

## Pain, distress and the elderly

Harkins (1996) concluded that chronic pain occurs frequently in older adults. However, in a Swedish population, Brattberg et al. (1996) found that people in the age group 45-64 reported pain more frequently than people over 65 years of age. In a group of elderly living in their own home, nearly 70 per cent had pain complaints (Roy & Thomas, 1987). In studies of elderly residents in a nursing home, 83 per cent had pain-related problems and 71 per cent pain complaints (Roy & Thomas, 1986; Ferrell et al., 1990). In a more recent study, almost 76 per cent of the elderly reported trouble with pain (Ross & Crook, 1998). Temporary pain seems to decrease with decreasing age, whereas persistent pain seems to increase (Crook et al., 1984).

It has been found that more women than men reported more severe and more persistent pain (Crook et al., 1984; Brattberg et al., 1997). However, in another study, no such differences were found (Brattberg et al., 1989). Studies have been carried out to try to find out whether elderly people experience pain in a different way compared to younger people (Nation & Warfield, 1989). The results are, however, contradictory. No age differences were found between elderly and younger chronic pain patients regarding measures of pain intensity (Sorkin et al., 1990). Harkins et al. (1984, 1996) concluded that there are no differences

related to age when it comes to experimental pain among the elderly compared with younger people. In contrast, Roy and Thomas (1987) found that approximately 78 per cent of the 60-69 year olds reported a current pain complaint but only 64 per cent of 80-89 year olds. In a comparison between younger and elderly patients with chronic back pain, the elderly patients suffered pain fewer hours per day compared with the younger patients (Herr et al., 1993). Watters et al. (1993) found that older patients had less postoperative pain than younger patients did. However, the difference was less when comparing older and younger patients who received epidural anaesthesia. Walmsley et al. (1992) found that elderly patients expected postoperative pain in relation to their prior pain experiences.

Studies have shown that elderly patients perceived pain relief as more effective than did younger patients (Bellville et al., 1971; Moore et al., 1990). Kaiko et al. (1982) found the duration of doses of morphine to be longer in elderly than in younger patients. However, elderly patients seemed to be an exposed group in terms of pain and insufficient pain relief. It has been found, for instance, that elderly patients can have more continuous pain following an operation compared with younger people (Melzack et al., 1987). Most of the patients had less pain on the fourth postoperative day but one third of the patients continued to suffer from moderate to severe pain (Duggleby & Lander, 1994). In spite of this, elderly patients seemed to receive smaller doses of analgesics than younger patients do (Faherty & Grier, 1984; Short et al., 1990; Closs et al., 1993; Watters et al., 1993). Younger patients were more likely to ask for and to have more control over their own pain relief than older patients (Winefield et al., 1990).

The presence of pain may affect the possibility of moving and thereby the performance of activities of daily living (Simon, 1989). Elderly people with back pain were found to have limitations in different functions and activities (Lavsky-Shulan et al., 1985). In a study of elderly people living in a nursing home, the elderly reported that pain affected their functional ability, which in turn made it difficult for them to take part in enjoyable activities (Ferrell & Ferrell, 1990). Penninx et al. (1996) found that physical impairment in elderly people is a potential factor for psychological distress among patients with osteoarthritis, rheumatoid arthritis, and stroke. Elderly patients in the community with chronic pain perceived lack of ability to perform tasks such as cooking and cleaning as a distressing factor (Walker et al., 1990). In another study, pain was related to functional competence, global function, sleep impairment, and life satisfaction (Ross & Crook, 1998). However, no association between pain and disability was found.

Psychological distress, such as anxiety, frustration, anger, and fear, is associated with chronic pain (Harkins, 1996). The pain experience in elderly patients could be worse due to poor physical health, grief over lost relatives, and loneliness (Harkins et al., 1990). Among elderly people living in institutions, those with higher anxiety levels reported more pain complaints and pain of greater intensity than those with lower levels of anxiety (Parmalee et al., 1991; Casten et al., 1995). The results vary when it comes to differences between younger and older patients and between emotional distress and chronic pain. The emotional response to pain, or the perception of how pain interferes with one's life, was similar for older and younger adults (Davis, 1989; Sorkin et al., 1990). Herr et al. (1993) found no differences between age and depressed mood, while Turk et al. (1995) reported a strong association between pain severity and depression in older patients. No such associations were found in the younger group.

Age was found to have no influence regarding the ability to recall the respirator treatment in intensive care (Bergbom-Engberg et al., 1988). However, the males over 60 years recalled the treatment better than elderly females. Older patients had more memory complaints three months after surgery than younger patients (O'Hara et al., 1989). Patients had more difficulties remembering things like names and faces. More than one-third of the

patients had impaired mental status the first and second day after surgery (Duggleby & Lander, 1994). Pain was the major predictor of mental status. Confusion in elderly orthopaedic surgical patients is a common problem (Bowman, 1997). Elderly patients undergoing hip surgery, who experienced confusion, had the highest scores of pain and poorer sleep satisfaction compared to patients without confusion (Bowman, 1997).

The fact that many elderly people are not informed about the cause of chronic pain (Walker et al., 1990), believing it to be a consequence of ageing (McCaffery & Beebe, 1989), may lead to resignation to the pain (Yates et al., 1995). Information about the cause and progress of a painful condition is an important factor in coping with chronic pain (Marcer et al, 1990).

Chronic illness can disrupt the elderly person's sense of wholeness and lead to either a positive or a negative impact on spiritual growth (Soeken & Carson, 1997). Events, such as retirement or the death of a spouse, can challenge the elderly's spirituality (Bianchi, 1982) and lead to feelings of melancholy (Hedelin & Svensson, 1993). Older individuals need to find meaning in ageing (Blazer, 1991). They need to find answers to why they are losing their roles, identities, and capacities. Spirituality can help them to find meaning in these late-in-life struggles.

## RELATED CONCEPTS

### Sense of coherence (SOC)

Antonovsky (1979, 1987) describes a salutogenic model, which view health as a resource for the individual. The model attempts to explain why certain people perceive that they enjoy health despite being exposed to severe stress. Antonovsky describes health as a continuum between the two poles; disease and ease. The human being continuously moves between these two poles during the life span. The concept of sense of coherence is a factor that has a strong influence on where individuals find themselves on the continuum. Sense of coherence consists of three dimensions: Comprehensibility, Manageability, and Meaningfulness. The concept is primarily developed through life experiences and can be regarded as a stable person-related characteristic in adult people. People who view their life as meaningful and comprehensible and their life situation as manageable are more able to deal successfully with stressful situations.

These people have developed a high degree of so-called general resistance resources as well as an understanding of life experiences made and can in each stressful situation choose the coping strategy that appears to be most suitable. General resistance resources include, e.g., stability, social relations, knowledge, and material resources. Antonovsky suggested that sense of coherence be related to the general health and well-being of an individual. The three dimensions are to be regarded as a whole, although Antonovsky claims that it is possible, in certain situations, for individuals to position themselves high within one dimension and low within another. However, there is a relative position among the components. Meaningfulness, which is the concept's motivational component, seems to be the most important component, followed by comprehensibility and manageability. Being able to manage a situation requires understanding. On the other hand, without meaningfulness, a high degree of understanding or manageability does probably not persist for very long. From previously having had a cognitive emphasis, meaningfulness has later acquired a more emotional meaning. An individual with a strong sense of meaningfulness probably has the motivation and will to tackle difficult tasks, seeing them more as a challenge than a burden.

Although not regarded as a personality trait by Antonovsky (1987), sense of coherence appears to reflect personality-like characteristics. The concept is for instance assumed to be highly stable across different situations and over time. It has been shown to be strongly inversely related to general anxiety (Carmel & Bernstein, 1989).

Several studies have been conducted in various contexts, exploring the relation between sense of coherence and health. People with a stronger sense of coherence seemed to manage stress in a better way and had a more favourable feeling of well-being and health than people with a weaker sense of coherence (Antonovsky, 1993; Larsson et al., 1994; Larsson & Kallenberg, 1996). Old people with a strong sense of coherence have also been shown to be more satisfied with their health (Sarvimäki & Ojala, 1994). Chamberlein et al. (1992) investigated recovery following surgery for joint replacement. Patients who had a stronger sense of coherence reported more positive feelings of well-being and lower levels of distress compared with patients with a weaker sense of coherence.

Studies have shown that cancer patients and elderly patients with lower limb fractures, who had a weak sense of coherence, also showed a higher level of psycho-social functional impairment, lower self-rated health as well as experiencing the symptoms as more severe (Langius et al., 1994; Forsberg et al., 1995; Larsson et al., 1995; Larsson & Kallenberg, 1996). Cancer patients with a weaker sense of coherence perceived psychological symptoms as more severe than patients with a stronger sense of coherence (Mullen et al., 1993). Sense of coherence seemed to be more related to mental and social functions than to physical ones (Antonovsky, 1987; Johansson et al., in press). In a survey of nearly 4000 people aged 25-79, a low sense of coherence was more common among older compared to younger people (Lundberg & Nyström Peck, 1994). However, findings by Larsson and Kallenberg (1996) contradict these results.

## Social support

Literature reviews have indicated that social support is a factor which has been shown to be related to improvements in mental and physical health (Broadhead et al., 1983; Thoits, 1985; Ganster & Victor, 1988). The relationship seems to be strongest for mental health (Ganster & Victor, 1988). The concept of social support is a complex and transactional process between individuals and their environment (Vaux, 1990). There has been a large variety of definitions and interpretations of the concept. Although not the same terminology is used, the definitions have some common characteristics. All of the definitions imply some type of interaction with, or helpfulness shown towards, individuals in need of support (Rook & Dooley, 1985).

Social support may be viewed as structural or functional (Cohen, 1988). Structural aspects deal with the existence of fundamental social relationships as evidence of the presence of other people in their lives. For example, number of relationships and marital status. Functional aspects reflect the functions and qualities of social relationships. Social support can be described in terms of four components (Thoits, 1985; Barrera, 1986). Emotional support includes support through love, caring, and empathy. Instrumental support can be described as concrete assistance through actions or materials. Informational support includes not only help with problem solving but also giving advice, feedback, and information. Appraisal or esteem support, finally, means that a certain person is confirmed and accepted.

Empirical reviews of the relationship between surgical recovery and support delivered by health-care professionals demonstrate that such support generally facilitates recovery (Mumford et al., 1982). Social support, i.e. emotional and informational support, seemed to be important to breast cancer patients. The patients developed feelings of safety and reduced anxiety (Pålsson & Norberg, 1995).

The need for social support may differ due to variation in personality characteristics and earlier perceptions of support. People who need much support are not always likely to get all the support they need. Koomen et al. (1990) found that social support seemed to be especially effective regarding recovery for heart patients who least need the support.

## Functional ability

The World Health Organization (WHO) describes the consequences of chronic injury and disease in a model known as the International Classification of Impairments, Disabilities, and Handicaps (WHO, 1980). Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p.28). Verbrugge and Jette (1994) defined disability as difficulty in performing activities due to health and physical problems. Activities of daily living (ADL) are an important indicator of disability, which is often measured in terms of dependence and independence (Sonn & Hulter Åsberg, 1991). ADL can be described through instrumental activities (I-ADL), such as shopping and cooking as well as personal daily activities (P-ADL), such as bathing, dressing, and eating. Dependence in P-ADL increases with age and affects people's lives. Elderly people living in institutions have a greater need for assistance with ADL (Bondevik & Skogstad, 1995; Sonn, 1995). Among 76-year-old ambulant people, mobility problems had the most negative impact on daily activities (Grimby & Wiklund, 1994). The most prominent impairments were physical functioning and ability to carry out ADL in elderly patients over the age of 85 and living in a home setting (Krach et al., 1996). Among elderly patients with chronic pain, physical and psychosocial disability also affects their lives (Hopman-Rock et al., 1997).

In population studies, ADL assessments are mainly used for descriptive purposes (Sonn, 1995). Many instruments have been constructed that measure ability and disability in ADL, and no uniform method exists. Jette (1994) found that different disability scales might have a great impact on prevalence estimates of disability in older age groups. One well-known instrument often used in Sweden is Katz' index of ADL (Katz et al., 1963). Hulter Åsberg and Sonn (1989) further developed this scale by adding four instrumental activities. The advantage of the scale is that dependency within I-ADL can also be detected, which means that the instrument is more complex than others (Sonn & Hulter Åsberg, 1991; Sarvimäki & Ojala, 1994).

## ASSESSMENT

Assessment is a process by which a conclusion is reached about the nature of a problem. Planning effective pain and distress management is a crucial part of the nurses' role. In order to achieve this it is necessary to identify and assess the level of patient's pain and distress in an attempt to identify a potential course of action (Yura & Walsh, 1988). The assessment is part of a problem-solving model, which may be suitable for use within nursing care (SOSFS 1993:17). It is of vital importance that all health care personnel regard the human being from a holistic perspective, not merely focusing on their state of ill health (SOSFS 1993:17). An important component for satisfactory alleviation of the patients' pain is nurses' assessment of a patient's situation (Walker et al., 1990; Nash et al., 1993; Simon, 1996). A holistic approach is desirable for the treatment of patients with pain, who have a diversity of physical, psychological, and social needs (Akinsanya, 1985; Walker et al., 1989).

## Assessment of physical and emotional aspects

Patients and nurses show variation in their perceptions of caring. Elderly patients with persistent pain and nurses in the community perceived the contribution of the nurses' management in different ways (Walker, 1994). The patients valued caring aspects, such as empathy and kindness, the most, while the nurses appeared to rely upon medical treatments. Patients in somatic care perceived task oriented care as the most important while the nurses stressed emotionally oriented care as the most important (von Essen, 1994). On the other hand, in the care of cancer patients, nurses tended to rank physiological needs as the greatest needs, while patients rated emotional, social, and spiritual needs higher (Lilley, 1987). Farrell (1991) found that nurses in general and psychiatric care overestimated patients' emotional needs, that nurses in general care tended to perceive the physical needs more correctly and the psychiatric nurses the emotional needs. Other studies have shown that nurses rated psychological distress higher than physical distress in hypothetical patients (Mason, 1981; Dudley & Holm, 1984). Nurses also assessed higher levels of psychological distress than their patients did (Husted & Johnson, 1985; Walker et al., 1990).

Nurses rated stressors in intensive care unit environments as being more stressful compared to patients (Cochran & Ganong, 1989). The nurses had a tendency to overestimate the items which they considered that they could control, while the patients regarded that the items which were related to their disease as well as physical distress were the most stressful (Cornock, 1998).

## Assessment of pain and pain control

Despite the fact that much progress has been made in the last few decades when it comes to mastering pain, many patients experience pain in different nursing contexts (e.g. Balfour, 1989; Donovan et al., 1987; Puntillo, 1990). Several studies show that nurses' assessments of patients' pain and distress are not always in accordance with the patients' own experiences. Nurses have a tendency to underestimate patients' physical distress as pain (Cohen, 1980; Iafrati, 1986; Bondestam et al., 1987; Walker et al., 1990; Harrison, 1993; Zalon, 1993; Stephenson, 1994; Sjöström, 1995). Nurses' assessments of pain seem to be inversely related to the degree of pain experienced by patients. Nurses tended to underestimate severe pain and overestimate mild postoperative pain (Zalon, 1993; Sjöström, 1995).

LeVasseur and Calder (1994) found a difference between patients' and nurses' ratings of pain control; patients perceived that they had less pain control compared to nurses' perceptions. Saxey (1986) found that nurses understood the importance of the assessment of postoperative pain. However, individual assessment was not current practice. The nurses did not know how to carry out the assessment and they were not aware of the factors influencing pain perception. Patients could not remember a nurse from the ward discussing their pain management with them (Donovan et al., 1987; Paice et al., 1991; Carr & Thomas, 1997). Dalton (1989) found that nurses to a low degree assessed how pain influenced patients' sleeping, eating, and other activities.

## Assessment of intellectual aspects

The nurses assessed the information received by breast cancer patients as more positive compared to the patients (Suominen et al., 1994). In another study of the nurse's role in

patient education, patients preferred a physician to teach them to interpret the information about their condition and identified a general teaching function for nurses. Nurses chose a nurse as the most desirable patient teacher and assumed that the desires of their patients were similar to their own (Tilley et al., 1987). In intensive care the staff perceived patients as having more problems regarding communication and disorientation compared to patients (Riggio et al., 1982).

## Assessment of spiritual aspects

Nurses' assessment of oncology patients' needs of spiritual health showed incongruity between paired nurse and patient scores and that they identified different spiritual caregivers (Highfield, 1992). In another study of nurses' assessment of cancer patients' spiritual coping strategies, the nurses could identify only a few of patients' strategies but several of the patients' resource people (Soderstrom & Martinson, 1987). Only a few of the nurses used to assess their patients' spiritual needs in their daily nursing care. Ross (1994) found that spiritual care was given on different levels. Some of the nurses, who could identify spiritual care at a deep level, had experienced crises, were aware of the spiritual dimension and were more sensitive/perceptive than those nurses who identified spiritual needs at a more superficial level.

## Influencing factors in connection with nurses' assessment

In some studies influencing factors in connection with the assessment of patients have been examined. Studies have suggested that there are some factors which may influence nurses' assessments; patient characteristics such as age (Davitz & Pendleton, 1969; Mason, 1981), gender (Davitz et al., 1977; Cohen, 1980; Rankin & Snider, 1984; Martin & Belcher, 1986), and signs of physical pathology (Taylor et al., 1984), as well as nurse characteristics such as culture (Davitz & Pendleton, 1969; Martin & Belcher, 1986; Highfield, 1992), education (Zalon, 1993), experience in caring (Mason, 1981; Chonière et al., 1990; Sjöström, 1995), how long they had known the patient (Walker et al., 1990), and personal pain experience (Ketovuori, 1987; Holm et al., 1989).

### Patient characteristics

In studies using hypothetical patients, nurses inferred less suffering in older patients (Davitz & Pendleton, 1969; Mason, 1981). Studies have suggested that females were perceived as having more pain and asked for more pain medication than males (Davitz et al., 1977; Rankin & Snider, 1984). Cohen (1980) found that nurses selected less medication for female patients, and Martin and Belcher (1986) showed that nurses believed that males experienced more pain than females. Dudley and Holm (1984) found that only the category of illness/injury influenced nurses' inferences of suffering. Nurses assessed less intense pain when the patients had no sign of pathology (Taylor et al., 1984; Halfens et al., 1990) and for patients with chronic pain (Taylor et al., 1984). Teske et al. (1983) and von Baeyer et al. (1984) found that nurses assessed patients with a high level of non verbal pain expressiveness with higher ratings of pain compared to patients with a low level of expression.

## Nurse characteristics

Davitz & Pendleton (1969) and Highfield (1992) found differences in assessments among nurses from different cultures. American nurses believed that screaming indicates that patients are in extreme pain, while South Africans held that quietness indicated severe pain (Martin & Belcher, 1986). In the same study, the authors demonstrated that nurses from different clinical specialities did not differ in their inferences of patient suffering.

Student nurses in the first year of their education assessed less pain in patients compared to registered nurses and student nurses in the last two years of their education (Halfens et al., 1990). In contrast, Lenburg et al. (1970) and Mason (1981) found that first-year nursing students and nurses with less nursing experience inferred the greatest degree of physical suffering. Nurses who were less experienced in the care of burned patients tended to overestimate the patients' pain, while nurses who had worked for a longer time in the burn unit tended to underestimate the pain (Choniere et al., 1990). In postoperative care, nurses with a high level of education were more accurate in their assessment of pain (Zalon, 1993). Nurses with experience of nursing seemed to be more sensitive to variations in their assessments of the postoperative patient's level of pain compared to a group of less experienced nurses (Sjöström, 1995). However, there are studies that did not find any relationship between nursing experience and assessment (Dudley & Holm, 1984; Rankin & Snider, 1984; Halfens et al., 1990). Nurses' tendency to overestimate levels of low level pain in elderly patients in the community was less if they had known the patients for more than a year, but the tendency to underestimate the patients' worst level of pain remained (Walker et al., 1990). Nurses who had experienced severe pain appeared to be more sympathetic to patients in pain (Holm et al., 1989). Nurses in postoperative care, who had experienced wound pain, estimated their patients' pain as less intense compared to nurses who did not have that experience (Ketovuori, 1987).

### *Personality*

The health service should, among other things, promote good contact between patients and health care personnel (SFS 1982:763). This requires a professional approach among, for example, nurses and places great demands on powers of observation, knowledge and understanding of patients' reactions as well as of the nurses' own reactions and behaviour when dealing with patients (Peplau, 1952; Henderson, 1969; Travelbee, 1971; Paterson & Zderad, 1976; Watson, 1988). Nurses' personality is of importance, when it comes to their ability to act in different nursing situations (Orlando, 1990). Authors of various nursing models find the core of nursing to be the ability of nurses to create a good relationship between themselves and their patients. The quality of the relationship between caregivers and patients could be of great importance when it comes to how the help is perceived. Whether a good relationship to a patient is established is due, among other things, to the caregivers' capability of showing empathy, their sincerity, and their ability to create a reassuring atmosphere. This, in turn, implies that it may be favourable for nurses to have a good self-image and self-knowledge (Watson, 1985). Personality traits, such as empathy, self-knowledge, self-reflection, kindness, patience, and helpfulness, are important factors in the caring process (Henderson, 1969; Watson, 1985; Landstingsförbundet, 1990; Orlando, 1990; Morrison, 1991).

Theories saying that there are individual differences between human beings and that it is possible to divide people into different types or categories have existed since Antiquity. For a review of various theories on personality, see for example Mayer & Sutton (1996). A common classification scheme, based on empirical findings from factor analytical studies, is



the five-dimensional, or five-factor model (Costa & McCrae, 1985; Goldberg, 1990; Hendriks, 1997). It is now becoming common practice to refer to the Big-Five personality dimensions as Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Autonomy/Intellect.

Research into personality and nurses has, for example, been focused on defining the personality characteristics of nurses at various stages in their career (Lewis, 1980), with the aim to find relationships between personality and burnout (Eastburg et al., 1994), personality and professional autonomy (Schutzenhofer & Musser, 1994), personality and stress and coping (Lewis et al., 1994), links between personality type and occupational choice (Jain & Lall, 1996), and differences between nurses' personality characteristics in various nursing contexts (Atkins & Piazza, 1987; Levine et al., 1988; Bean & Holcombe, 1993; Bean et al., 1995). Research into personality and nursing students has, among other things, treated students' development and education (Houldin & Forbes, 1990; Larsson & Hall-Lord, 1993; Sivberg & Petersson, 1997), selection of candidates to enter nursing training (Leach, 1988), and personality and successful education in nursing (Dyer, 1987).

## SUMMARY OF THE LITERATURE REVIEW

As mentioned earlier, there is no clear distinction between pain and distress, and the concepts are partly overlapping. In the literature, pain is most commonly described in terms of physical pain, while distress is primarily described in terms of emotional and psychological distress, which in turn may be caused by pain. In this study, the distress concept is used in an informal rather than in a strict psychological sense.

Despite the fact that pain is often described in the literature as multidimensional, there appear to be few studies available that focus on pain in this perspective. True, there are instruments measuring pain which are regarded as multidimensional, for example the McGill Pain Questionnaire (Melzack, 1987) and Pain-O-Meter (Gaston-Johansson, 1984). These instruments measure sensory and affective/emotional pain based on the gate control theory (McGuire, 1997). The literature review shows that pain and distress mainly have been studied seen from a physiological and/or psychological perspective. From a nursing perspective, a person will be viewed as a holistic being. In the assessment of an individual, the nurse is involved with human needs and problems that affect the whole person rather than one aspect or one problem. Consequently, it is important to investigate pain and distress looking at several aspects.

In intensive care, pain and distress are significant problems, which have mainly been investigated among patients treated in a respirator. However, all patients in intensive care are not treated in a respirator and therefore the sample of patients also may include these patients. Several earlier studies have been constructed so as to let the patients rate what they perceive as most stressful of a number of predefined items. Since patients answered questions after their nursing time in the intensive care unit, which means that they do not always remember what they have experienced, it would be valuable to investigate the phenomena during their treatment time in intensive care instead of retrospectively. There are few studies focusing on elderly patients, despite the fact that approximately half of the patients treated within intensive care are 65 years of age or older. Therefore, there is a need to specify elderly patients' experiences of pain and distress in intensive care in order to identify basic qualities of the phenomena.

Pain in elderly people is a common problem but has been given limited attention (Harkins et al., 1990; Ferrell, 1991; Closs, 1993). Few studies focus on elderly patients'

experiences in connection with surgery and on their perception after discharge, as seen from a holistic perspective. It would be important to investigate elderly patients' experiences of pain and distress postoperatively, when they are residing in the ward, as well as after discharge.

Chronic pain is a complex health problem, which is influenced by psychological, social and existential factors. Despite the fact that many elderly people suffer from chronic pain, there is limited research applying such a perspective. Morrison (1992) argued that there is too little research of existential pain in patients who are not terminally ill. We have not been able to find any study dealing with existential distress in connection with elderly, chronic pain patients. Relatively few elderly people have access to pain clinics (Roy, 1987). This means that elderly people are obliged to resort to the primary care and the community help services.

Patients need to receive individual help and support in order to improve their state of health and life situation. It is therefore also important to investigate how patients perceive the help and support they receive.

Sense of coherence is related to the general health and well-being of an individual (Antonovsky, 1987). Earlier studies have reported a relationship between a strong sense of coherence and health, well-being, and recovery (Chamberlein et al., 1992; Antonovsky, 1993; Larsson et al., 1994; Larsson & Kallenberg, 1996). People with a weak sense of coherence rated their health as less favourable as well as reported more severe symptoms compared to people with a strong sense of coherence (Langius & Björvell, 1994; Forsberg et al., 1996; Johansson et al., in press). Surgery can be regarded as a stressful event for most patients. An elderly person may be faced with several problems following surgery (Nicaise et al., 1993; Zuccalà et al., 1994). Also elderly patients with chronic pain may perceive their situation as difficult as well as experience problems in coping with their situation. People with a stronger sense of coherence are probably able to handle their situation better than people with a weaker sense of coherence. It would therefore be valuable to examine whether sense of coherence influences the way in which elderly patients with chronic pain and elderly patients undergoing surgery perceive pain and distress. Sullivan (1989) concluded that the salutogenetic model suggests adaptability for nursing, because the framework lies in its perspective of health rather than illness.

The presence of pain in elderly may cause limitations in different functions and activities (Lavsky-Shulan et al., 1985; Simon, 1989; Ferrell & Ferrell, 1990). Dependence increases with age and may negatively affect the life situation. Functional ability may be one important factor in the nursing care of patients with chronic pain in order to be able to assess patients' need of help.

Studies comparing nurses' assessments with patients' perceptions show varying results; sometimes nurses overestimate patients' perceptions, while in other studies they tend to underestimate them. For example, within intensive care, nurses overestimated patients' perceptions of the extent to which the environment was stressful (Cochran & Ganong, 1989) and, within municipal care, nurses overestimated chronic pain patients' emotional distress while underestimating their pain (Walker et al., 1990). However, no study is available comparing enrolled nurses' assessments and patients' perceptions, despite the fact that enrolled nurses frequently are in daily contact with their patients in the community. Generally, it is the enrolled nurses who follow the elderly's state of health and they should, therefore, be able to assess the patients' health status as well as any changes thereof (Tuulik-Larsson, 1992). Further, within intensive care, enrolled nurses are the group of nursing staff who is in continuous contact with the patients during each shift. Enrolled nurses provide care under the supervision of a registered nurse. Communication of assessment findings and effective interventions between nurses and enrolled nurses then becomes critical (Boström et al., 1992). In several earlier studies, nurses assessed either simulated patient cases (e.g. Mason, 1981; Taylor et al., 1984; Halfens et al., 1990) or 'their own' patients (Ketovuori,

1987; Cochran & Ganong, 1989; Suominen et al., 1994; Cornock, 1998). Holm et al. (1989) argue that studies comparing patients' perceptions and nurses' assessments ought to be performed in real patient situations.

Several of these studies have also investigated whether or not different factors influence nurses' assessments. The results of these investigations are partly contradictory. If patients and nurses differ in their perceptions of pain and distress, it is important to identify which factors influence their assessment and to increase the awareness of these factors. Despite personality qualities being emphasised as important factors in the caring process, we have not found any studies on the influence of personality qualities on nursing staff's assessments.

## AIMS OF THE THESIS

The aims of the thesis were:

- to develop a theoretical understanding of elderly patients' experiences of pain and distress in intensive care (I);
- to compare elderly patients' reported experiences of pain and distress, as well as of interventions aimed at reducing these conditions, with nurses' assessments (II, IV) and to relate potential differences to patient and enrolled nurse characteristics (IV);
- to explore postoperative experiences of pain and distress in elderly patients (III);
- to identify various profiles of pain and distress experiences among elderly patients with chronic pain and to compare these profiles in order to identify variations in terms of background variables, sense of coherence, functional ability, and experiences of interventions aimed at reducing pain and distress (V).

## SUBJECTS AND COLLECTION OF DATA

This is a study of acute and chronic pain as well as various forms of distress among elderly patients in different contexts. Nurses' assessments and patients' experiences of pain and distress have been compared. Initially, a theoretical model of elderly patients' experiences of pain and distress was developed in intensive care (I). Then, the model was used to compare nurses' and patients' perceptions in intensive care (II). The next study investigated postoperative patients on three occasions (III). Finally, enrolled nurses' assessments and patients' experiences of pain and distress in the community were compared (IV) and patients with chronic pain in the community were studied (V). In all studies, the patients were chosen consecutively. Data was collected during September 1992 to March 1993 (I), from January 1994 to March 1995 (II), from January to May 1995 (III), and from December 1996 to May 1997 (IV, V). The number of subjects in the respective studies is presented in Table 1.

*Table 1. Description of the studies.*

Study	Respondents (n)	Data collection
I	Patients (18)	Interviews and Observations
II	Patients (53) Nurses (44) Enrolled nurses (38)	Interview - Pain and distress form - 53 items Questionnaire - Pain and distress form - 53 items
III	Patients (100)	Interview - Pain and distress form - 18 items - SOC - 9 items - Need for Social Support - 8 items
IV	Patients (38) Enrolled nurses (38)	Interview - Pain and distress form - 35 items Questionnaire - Pain and distress form - 35 items - FFPI - 100 items - SOC - 13 items
V	Patients (42)	Interview - Pain and distress form - 18 items - SOC - 9 items - Functional ability - 10 items

## PATIENTS IN INTENSIVE CARE

This study comprised 18 patients in an intensive care unit (ICU) (I). Seven women and eleven men were included in the study. Their average age was 76.5, ranging from 70 to 85 years. The average nursing time in the intensive care unit was 15 days (median 8.0 days), range 3-79 days. Interviews and observations were conducted in daytime. Observations were made of eleven patients at an early stage following the patients' admittance to the ICU. Before observations were initiated of patients who were not able to give their consent, their next of kin were asked for permission to carry out the observations. When the patients' condition made interviews possible, they were informed and asked if they wished to take part in the study. Before observations of a patient were started, an assessment was made of whether the patient would be able to take part in an interview at a later stage.

Fifty-one patients in two intensive care units were invited to take part in an interview study about their experiences of pain and distress during their intensive care stay (II). The patients consisted of 16 women and 35 men, mean age 70.5 (range 65-85 years). The average length of stay in the units was 7.1 days (median 6.0 days), varying from 3 to 31 days. The interviews were conducted by the investigator and two intensive care nurses. Usually the patients were interviewed the day before or on the same day they left the intensive care unit. Five patients were interviewed after leaving the unit due to lack of time to conduct the interviews while they were still in the unit. These interviews were conducted within 24 hours after the patients had left the ICU.

Patient inclusion criteria for the studies in intensive care were:

- age (65 years or older)
- treatment (at least 3 days of treatment in the intensive care unit)
- condition (the patients were awake, oriented, and medically able to respond to questions).

The patients had various medical diagnoses and were attended by physicians in the departments of surgery, infectious, and medical diseases.

## PATIENTS IN POSTOPERATIVE CARE

The sample comprised 100 patients, 31 men and 69 women, who had undergone elective surgery in two orthopaedic and two general surgical units of one hospital (III). The patients took part in an interview about their experiences of pain and distress, conducted on three occasions. Twenty-six patients had undergone hip arthroplasty, 24 knee arthroplasty, 27 abdominal surgery, and 23 patients had had surgery in connection with verified or suspected breast cancer. Mean age was 74.3 years (range 65-91 years). Nine patients were only interviewed on two occasions. During the investigation, which was carried out during a period of five months, eight patients declined to participate for health reasons and two patients were not communicable. The average duration of stay in the units postoperatively was ten days (median 9.0 days), range 3-44 days. Patients undergoing breast surgery had a significantly shorter mean stay than the other three groups.

The interviews were conducted by the investigator and one lecturer in nursing by personal interviews at the ward on the first and the second day after surgery, and by telephone about ten days after discharge from hospital. The same person interviewed each patient on every occasion. The fact that the third interview was chosen to be conducted via telephone and not by personal interview was due to the patients living in different parts of the county concerned.

## PATIENTS IN THE COMMUNITY

These studies were carried out in seven primary health care districts in a county in the mid-western part of Sweden (IV, V). Elderly patients with chronic pain were invited to take part in an interview. In paper IV the number of patients was 38 (5 men and 33 women), mean age 81 years, range 65-94 years) and in paper V 42 (5 men and 37 women, mean age 80.1 years, range 66-94 years). Patient inclusion criteria for the studies were:

- age (65 years or older)
- chronic pain (pain during at least three months)
- communicability (being able to understand and answer questions)
- community help services (assistance from enrolled nurse/nursing auxiliaries (IV) and assistance from district nurse/enrolled nurse/nursing auxiliaries in the municipality (V).

The exclusion criteria for participation were severe heart failure, cancer with clinical manifestations, and depressive mood. District nurses in the primary health care districts made the selection of patients. During the time the study was conducted, about ten patients declined to participate for health reasons. The interviews were conducted by the investigator in the patients' homes.

## NURSES

Forty-four registered nurses and 37 enrolled nurses (enrolled nurses were labelled as assistant nurses in study II in order to adapt to American standard), who worked within intensive care, answered a questionnaire about how they assessed their patient's pain and distress (II). Most of the registered nurses (60%) had worked for 10 years or longer in intensive care, while only ten per cent had worked less than four years. Of the enrolled nurses, 54 per cent had worked for ten years or longer and 29 per cent had worked less than four years. Six registered nurses and eight enrolled nurses participated in the survey on more than one occasion. On one occasion, the nurse did not have the time to fill in the form, and on four occasions only a nurse was responsible for the patient.

The study in the community included 25 enrolled nurses and 13 nursing auxiliaries who filled in a questionnaire on how they assessed their patient's pain and distress (IV). In this study they were all classified as enrolled nurses. Mean age for the enrolled nurses was 37.5 years (range 20-62 years). Nursing experience ranged from one to 25 years, mean 12.6 years. The average time they had known the patients was 42 months (median 30 months), range 3-128 months.

The registered nurses and enrolled nurses were given the questionnaires, which they were to fill in without consulting anyone in close connection with the interviews with the patients. All nurses were given oral information regarding how to fill in the questionnaire. They also had the possibility to direct questions to the interviewer/interviewers if there was something they did not understand or which was unclear in connection with the filling in of the questionnaire, which occurred on some occasions.

## **ETHICAL ASPECTS**

Written and oral information about the studies was given to the participating patients and nurses. The Ethical Committee of the County Council of Örebro, Sweden approved the studies.



# METHODS AND DISCUSSION OF THE METHODS

In paper I, a qualitative, inductive grounded theory approach was used, i.e. interviews with open-ended questions, which influenced the choice of questions designed for the quantitative, deductive approach in papers II-V. The questionnaires, interviews, and observations were used according to the scheme in Table 1.

## THE INTERVIEW AND OBSERVATION PROCESS (I)

The interviews and observations were carried out in a medical-surgical intensive care unit (I). Several of the patients were interviewed on more than one occasion. The interview time varied, mainly depending on the patient's condition. The observation time varied between ten minutes and several hours. The reliability of the data collection method is increased with the use of several methods (Strauss & Corbin, 1990). Themes discussed in the interviews concerned the patients' experiences of pain and distress during the nursing time in the intensive care unit. Verbal and nonverbal reactions were observed. Nonverbal reactions observed were patients' autonomic responses, blood oxygenation, breathing, body language, eye expressions, nonverbal expressions such as moaning, and tone of voice. Notes were made during, or immediately following, the interviews and observations. A tape-recorder could not be used, as the patients had difficulty in speaking sufficiently distinctly and loudly for their speech to be interpreted on the tape.

It was sometimes difficult to conduct the interviews without interruption; the patients were to undergo some treatment or examination, or their families came to visit them. Sometimes the interview had to be terminated due to the patient running out of strength to speak. Often an enrolled nurse was present in the patient's room during the interviews, which in some cases probably had an inhibitory effect. This could probably have been avoided by postponing the interviews until the patient had been discharged from the intensive care unit. The reason the interviews were conducted while the patients were still residing in the intensive care unit was to capture their experiences while these were still fresh. A third of the patients were also interviewed later when residing in the care unit. Several of the patients were then not able to remember different experiences they had narrated while in the intensive care unit. Several studies show that many patients do not later remember what they have experienced (see e.g. Bergbom-Engberg et al., 1988; Jones et al., 1994). Patients may undergo a process of denial, as for some patients the illness and stay in the intensive care unit are an unpleasant experience to think about (Compton, 1990).

## MEASUREMENTS

### Pain and Distress Scales (II, III, IV, V)

The Pain and Distress scales were taken from the model developed in the grounded theory study (see Appendix 1). In all the studies, data was collected using parts of the model. The original model, which consists of four dimensions and 16 categories, has not been fully used in any of the studies. In the second study no questions were asked within the existential dimension to reduce the risk of causing the patients emotional distress, since the patients, at

the time of the interview, were still residing in the intensive care unit. No questions were asked within the categories of resignation and bitterness, because these were difficult to operationalise. In the other studies categories of a more general character were selected, while those judged to be valid only within intensive care were dropped.

The ambition in all studies has been to construct questions derived from the model. The model and the subsequently constructed instruments are developed from a patient perspective and not a personnel perspective. Relevant literature and experienced nurses have, in certain cases, been consulted in connection with the construction of the questionnaires. In order to make the items as comprehensible as possible to patients, the wording was inspired by the interview responses obtained in the grounded theory study. The questionnaires were constructed with a large number of items, which were tested on a small number of patients. Based on the views of the respondents, the items were changed and reduced. Although longer instruments may increase internal consistency, they may be a burden for elderly people who are physically frail (Rasin, 1997). The final versions of the questionnaires in the different studies have, despite the different patient groups, turned out to be relatively similar. The questionnaires included a Likert-type response scale, using three, four, or five response alternatives or a behavioural report (Yes/No) response format. Despite the fact that a visual analogue scale may be more sensitive for measuring pain (Stephenson, 1994), we did not use this because not all patients, especially not elderly people and those with severe pain, are able to use a visual analogue scale (McGuire, 1988). The patients also answered a number of open-ended questions regarding what caused their experiences of pain and distress (not reported in this thesis).

The internal consistency has not been tested on the pain and distress scales, as most of them consist of one item only. It would have been an advantage to develop these instruments further, something which ought to be made in future studies. However, the pain and distress scales are assumed to have high construct validity because they have been derived from a model reflective patient perspective. One should also be critical of transferring a model developed in one context to other contexts.

The patients were interviewed by experienced nurses and the researcher (II, III) as well as by the researcher alone (IV, V). To attain consistency or dialogic intersubjectivity at the interviews (Kvale, 1997), the interviewers went through the questionnaires thoroughly before the start of the studies and had continuous discussions.

In the second study the length of stay could vary from 3 to 31 days. Usually patients were interviewed the day before or on the same day they left the ICU. Experiences related to "earlier" may have varied for both patients and nurses. In all the four studies, in which the pain and distress form has been used, the patients may have had problems other than those covered by the dimensions and categories included in the model. The patients had different medical diagnoses and many of the patients also had additional diagnoses. All the patients were in a condition that allowed mental and physical participation in an interview. Patients who did not meet this criterion may have had other experiences and were not represented in the samples.

## The Sense of Coherence Questionnaire (III, IV, V)

The SOC questionnaire was developed by Antonovsky in 1987 and was designed to test the hypothesis that sense of coherence is causally related to health status (Antonovsky, 1987). Several instruments have been developed for measuring sense of coherence (see e.g. Antonovsky, 1993). Apart from Antonovsky's own construction, Lundberg and Nyström Peck

(1995), among others, have constructed three questions in Swedish, which each encompasses the three dimensions. Also, Setterlind and Larsson (1990) have developed a questionnaire including nine questions.

The original version of the instrument comprises 29 items, which are rated on a seven-point scale, where the end points consist of 'strongly agree' respectively 'strongly disagree' with the statement. The original instrument has been used in studies of different groups (Antonovsky, 1993). A Swedish version of the SOC scale was constructed and tested on five different samples (Langius et al., 1992). The age range for the five groups was 36-48 years. This version of the SOC scale varied between 0.79-0.90 of internal consistency, as measured by Chronbach's alpha.

Two concise versions of the SOC instrument were used in this study (III, IV, V). The first form, containing 13 questions, was recommended by Antonovsky (1987). Since there is high correlation between the longer and the shorter version, the shorter version can also be used (Langius & Björvell, 1993). This instrument has, for example, been used in studies of district nurses (Pålsson et al., 1996), patients with cancer (Forsberg et al., 1996), patients with a renal disease (Klang et al., 1996), and elderly people living in their own homes (Sarvimäki & Ojala, 1994). In these studies, Cronbach's Alpha varied between 0.76 - 0.78. The 13-item scale was used to measure SOC among enrolled nurses (IV). All items have 7-point scales with the anchors defined. A scale score was computed by adding the scores of all individual items. Scores could range from 13 (lowest sense of coherence) to 91 (highest sense of coherence).

The second concise version, containing nine items, corresponds to Antonovsky's instrument (Setterlind & Larsson, 1990, 1995, interscale correlation with Antonovsky's Sense of Coherence Questionnaire: 0.70). This short version is part of a larger questionnaire aimed at measuring psychosocial aspects of stress. The instrument has been tested on approximately 4 000 people. It has also been used in studies of elderly patients with a hip fracture (Larsson et al., 1995; Johansson et al., in press). In the first study SOC was measured twice, Cronbach's Alpha was 0.74 to 0.79. This 9-item scale was used among postoperative patients (III) and chronic pain patients (V). Originally, the scale was a 5-point response scale but a 3-point response scale has also been used. In the study of postoperative patients, a 5-point scale was used and in the chronic pain sample a 3-point scale was used. In the analysis all items were re-coded so that high scores represent a stronger SOC and vice versa. The individual score was obtained by adding the sum of the nine items and dividing that sum by nine.

In the postoperative study, sense of coherence was measured on one occasion only. Therefore we do not know if there was any change between the three interview occasions. However, theoretically sense of coherence is assumed to be consistent in adult life (Antonovsky, 1987) and, empirically, sense of coherence has proved to be a relatively stable characteristic in earlier studies (Langius et al., 1992; Larsson et al., 1995; Forsberg et al., 1996). On the other hand, sense of coherence can quickly change in a negative direction, for example, in connection with a hospital stay (Antonovsky, 1987). Still, in the absence of empirical data, variability can not be ruled out. The Swedish version of Antonovsky's questionnaire has been criticised on grounds of the items possibly being difficult to understand (Tishelman, 1993). This was one of the reasons for choosing the 9-item version to be used on the patients. Unlike the Swedish translation of Antonovsky's instrument, the used scale has a response scale, which may be easier for old people to answer. However, this version has subsequently been subjected to criticism, since the questions were regarded as difficult to interpret by active Pentecostals (Benzein et al., 1997). The investigator's experience of how the elderly people perceived the questions differs; in some cases some of the questions were perceived as difficult to understand while the majority did not think so. In

the studies of elderly patients, the respondents have had the opportunity to ask about, and discuss, the different questions with the interviewer. Nevertheless, the original instrument, above all the 13-item version, can be recommended for use in future, since it may otherwise be difficult to make comparisons between different studies.

## Five-Factor Personality Inventory (IV)

The Five-Factor Personality Inventory (FFPI) was used to measure the personality of enrolled nurses and is based on the so-called BIG-Five model of personality (see e.g. Costa & McCrae, 1985). Within personality theorising, the BIG-Five model currently appears to have a leading position (see e.g. Pervin, 1993). The FFPI was chosen within this tradition for two reasons. First, it appears to reflect current theoretical thinking within the BIG-Five sphere, and, second, there exists a Swedish translation of this instrument. The FFPI consists of 100 items; 20 are designed to measure each of the following five factors: Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Intellect/Autonomy. The respondents were asked to agree or disagree with each of the items on a five-point Likert-type scale labelled "Not at all applicable", "Little applicable", "Moderately applicable", "Largely applicable", and "Entirely applicable". Negative statements were reversed so that an answer in the direction of the more favourable yielded a higher score. To date, only one study using the Swedish version of FFPI has been made (Larsson et al., in press). However, the FFPI scales showed acceptable reliability in this study.

## The ADL-Staircase (V)

This instrument measures activities of daily living (ADL) according to a cumulative scale of four defined instrumental activities, I-ADL (cleaning, shopping, transportation, and cooking), and six defined personal daily activities, P-ADL (bathing/taking a shower, dressing, going to the toilet, transfer, continence, and feeding). Hulter Åsberg and Sonn (1989) developed the instrument. The validity and reliability of the instrument have been tested in several ways with good results (Hulter Åsberg & Sonn, 1989; Sonn & Hulter Åsberg, 1991, Sonn, 1995). The activities can be summarised in a cumulative scale of increasing dependence, where 0 = independent in all activities and 9/10 = dependent in all activities. In this study, none of the patients were independent. Therefore, two levels of dependence were defined: dependence in I-ADL and dependence in I-ADL and P-ADL.

The ten activities were examined through a personal interview but the patients were not actually performing the activities. This may have resulted in reduced validity and reliability. However, these questions were part of a longer interview, which meant that the researcher during this time had the possibility, to some extent, to observe the patients' functional ability. Another factor which may reduce reliability and validity is the assessor's personal bias regarding what tasks actually pertain to an ADL category (Sonn, 1995). However, a manual defining the different activities accompanies this instrument. The fact that it is the same person who carries out the investigation of all patients can also be regarded as an advantage.

## Need for Social Support (III)

This form was developed in order to assess the need for social support. In developing this form, eight items were considered as sufficient (see Appendix 2). The form included yes-no items; the patients were asked 3 questions on the second day after surgery and 5 items on the third interview occasion. In the statistical analysis a 0 - 1 variable was constructed, where 0 = no or weak need for social support (includes patients who answered No to at least 4 of the 8 questions) and 1 = strong need for social support (includes patients who answered Yes to at least 5 of the 8 questions). The form has a limitation in that the items only include need for emotional support and not the other three components of social support.

## DATA ANALYSES

### Grounded theory (I)

"The grounded theory approach is a qualitative research method that uses a set of procedures to develop an inductively derived theory about a phenomenon" (Strauss & Corbin, 1990, p. 24). All theories, consisting of concepts and their relationships to each other, are basically intellectual constructions of reality by abstractions of concrete phenomena (Glaser & Strauss, 1967). Glaser and Strauss (1967) and Glaser (1978) claim that grounded theory is especially useful in order to study social processes or psychological social processes. Grounded theory may also be a useful method generating theory in a practice discipline (Chenitz & Swanson, 1986). Glaser (1978) states that the grounded theory method can be taken in new directions, depending on the research problem. One of the characteristics of grounded theory is the parallel process of collecting and analysing data. In this study, data analysis was conducted after some observations and interviews, and this analysis guided the direction of the following data collection. The data collection continued until no substantially new data was obtained; theoretical saturation had been reached. The analysis started with open coding, using the constant comparison method described by Glaser and Strauss (1967). The data was compared for similarities and differences, and questions were asked about the phenomena. Concepts and categories were identified. The next step in the analysis was axial coding, described by Strauss & Corbin (1990 p. 97) as "making connections between a category and its subcategories." Open coding breaks the data down while axial coding puts the data together in a new way (Strauss & Corbin, 1990). The borderlines between each type of coding are not clearly discernible, and one continuously moves back and forth between the codings.

Glaser and Strauss (1967) hold that the validity of the analysis in grounded theory is embedded in the research process through continuous verification of the reasonableness, credibility and reliability of the results. Several researchers have been involved in the data analysis. All materials used have been read by two of the authors of the paper. These two researchers mainly carried out analyses. Then the interpretations were discussed by all of the researchers until consensus was reached. The fact that several researchers were involved in the data collection and analysis can be regarded as a strength (Denzin, 1989; Knafl & Breitmayer, 1991; Starrin et al., 1991). Pragmatic validation (Brink, 1991) was obtained through verifying the interview procedures through observations, and vice versa. By communicative validity is meant that the researcher communicates his interpretations in a dialogue with others, for example, the informants (Kvale, 1997). Since it was not possible to do so with our elderly patients, discussions have instead been held with different staff categories within intensive care. Literature can be used as supplementary validation (Strauss & Corbin, 1990). We have also, to some extent, used literature, mainly concerning theories

about pain as well as earlier research into patients' experiences within intensive care, for comparison and validation of the results.

## Statistical Analyses (II, III, IV, V)

Parametric and nonparametric methods were used for comparison of independent and dependent groups in various respects. Parametric methods were used when the variables were regarded as approximately normally distributed. Otherwise nonparametric methods were used. The comparisons between different subgroups used Cochran's Q-test (III), Kruskal-Wallis one-way anova (II, V), Mann-Whitney U-test (II, IV, V), paired t-tests (two-tailed probability) (IV), Pearson's chi-square test (III, IV, V), and one way analysis of variance, (ANOVA) (post-hoc multiple comparisons with Scheffé tests) (III), all with significance level at 0.05. Intraindividual differences over time were tested by repeated measures analysis of variance (III). Logistic regression analyses were used to estimate the effect of one or more independent variables on a dependent variable (III). Cluster analysis (nearest centroid sorting, Anderberg, 1973) was performed to form relatively homogeneous groups of patients (III, V). To correct for differences in the rating scales of different items, the responses of each subject were standardised (z-scores) across the items, and the analyses were carried out using the standard-scored response values (V). Chronbach's alpha (1951) was used to test the internal consistency or homogeneity of standardised measuring instruments (III, IV, V).

The character of the instruments used in studies II-V provided data on an ordinal level, which, in a strict sense, favours the use of nonparametric methods. However, the obtained response distributions were regarded as being on an approximative interval level in studies III and IV.

There is an ongoing controversy regarding the use of statistics for ordinal-level variables both between and within different disciplines. The proponents of the strict approach argue that, in statistical inference, only nonparametric procedures can be used for ordinal data, while the more liberal approach uses the same parametric procedures for ordinal and interval scales (Knapp, 1990).

# RESULTS AND DISCUSSION OF THE RESULTS

The results in this thesis will be presented in the order of the papers included (I-V).

## THE MODEL OF PAIN AND DISTRESS (I)

In this study a model was developed of elderly patients' experiences of pain and distress in intensive care, using grounded theory. Eighteen patients were interviewed and observed. According to the model generated from the data, there are various ways of experiencing pain and distress in intensive care. Elderly patients' experiences of pain and distress were described in four dimensions formed by 16 categories. The sensory dimension is formed by four categories: physical pain, physical discomfort, fatigue, and breathing problems. The intellectual dimension is formed by the following categories: not knowing, difficulty in expressing oneself/not being understood, and confused perception of reality. The emotional dimension is formed by the categories worry, fear, resignation, bitterness, anger/irritation, and dependency. Finally, the categories despair, threat to life, and death acceptance form the existential dimension. The model is shown in Figure 1.

DIMENSIONS	SENSORY	INTELLECTUAL	EMOTIONAL	EXISTENTIAL
CATEGORIES	Physical pain Physical discomfort Fatigue Breathing problems	Not knowing Difficulty in expressing oneself - not being understood Confused perception of reality	Worry Fear Resignation Bitterness Anger/irritation Dependency	Despair - hope- lessness/hope Threat to life Death acceptance
Example regarding "Physical pain"				
VERBAL AND NONVERBAL INDICATORS	"The patient wrinkles her forehead, grimaces, groans, and breathes quickly"			
CAUSAL ATTRIBUTIONS OF CATEGORY	"The patient is in pain when the nurse removes the drainage"			
WHAT THE CATEGORY MIGHT LEAD TO	"The oxygenation is decreasing, the patient will be in need of increased oxygen supply"			

Figure 1. Conceptual Model of Elderly ICU Patients' Experiences of Pain and Distress.

A comparison of the developed model with earlier studies made within intensive care shows that, within the sensory dimension, it is primarily pain (Jones et al., 1979; Puntillo, 1990), fatigue, and sleeping problems (Jones et al., 1979; Daffurn et al., 1994) that have been described. The categories within the intellectual dimension are described in the literature as communication difficulties in connection with respirator treatment (Bergbom-Engberg et al., 1988; Hafsteindottir, 1996), alterations in mental status and nightmares (Easton & MacKenzie, 1988; Jones et al., 1994), and not sufficient information (Jones et al., 1979; Elpern et al., 1992). Emotional reactions such as fear, worry, and anxiety have also been described (Jones et al., 1979; Bergbom-Engberg & Haljamäe, 1988; Elpern et al., 1992; Daffurn et al., 1994). Existential distress such as concern about death is only mentioned in a few studies (Compton, 1990; Elpern et al., 1992).

External as well as internal factors were found to influence patients' experiences of different forms of distress. The external factors could be labelled as nursing activities, treatment and untreated. Nursing activities refer to when the caregivers were doing things for the patients, such as making their beds, performing different kinds of checks and turning the patient in the bed. Nursing activities also include other activities, which are not immediately directed towards the patients, and which are carried out by the caregivers in the patient's room, such as talking to each other. Treatment refers to respirator treatment, drug treatment or oxygen treatment. Untreated means that the patients did not receive the treatment they considered that they ought to have been given, for example an operation. Internal factors concern how the patient's previous and present state of health seemed to be influenced by their experiences. Previous state of health refers to different forms of diseases, such as asthma, and complaints, such as level of pain. By present state of health it is meant the patient's current condition.

The categories may be separate, but they often interact, influencing each other in various ways. For example, the categories in the sensory and intellectual dimensions seem to interact with each other. It also emerged that the categories in the sensory and intellectual dimensions can result in different forms of distress within the emotional and existential dimensions. Taken together, the categories within the three dimensions sensory, intellectual, and emotional seem to be able to cause the development of existential stress.

The interrelationships between the categories are not fully developed. It did not emerge whether or how the categories within the existential dimension influence the categories of the other dimensions or how the categories of the emotional dimension influence the others, apart from the existential dimension. This may be due to the limited amount of data collected, which was mainly the result of difficulties arising in conjunction with the data collection. The design of the interviews, their content, length and depth depended on the patient's condition. Several of the patients had obvious difficulties talking for any length of time during the interviews due to their condition. It was not always defensible to put direct questions concerning existential matters or about their feelings. Existential issues were left to the patient to take the initiative to discussing. It also happened that the interviews were interrupted due to the patients having to undergo some examination, treatment, or receiving visitors.

Since the difficulties in connection with the data collection have resulted in a limited amount of data, no main category or categories could be discerned. This, in turn, illustrates the relativism existing in the grounded theory framework with regard to determining when saturation has been reached. None of the categories have been developed based on observational data alone but all have been complemented and strengthened with interview data. On the other hand, some categories have been developed based merely on interview data, e.g. the categories in the existential dimension. This study, as well as the other studies



included in this thesis, shows that elderly patients do perceive problems with pain and distress and, therefore, all these aspects ought to be taken into account in the provision of care.

## PATIENTS' EXPERIENCES AND NURSES' ASSESSMENTS OF PAIN AND DISTRESS IN INTENSIVE CARE (II)

The study compared patients' reported experiences of pain and distress in intensive care and to what extent they regarded that they had been helped and supported with the assessments of nurses and enrolled nurses. Comparison was also made between nurses' and enrolled nurses' assessments. The sample comprised 51 patients, 44 nurses, and 37 enrolled nurses. The patients' self-reported experiences of pain and distress did not agree completely with the nurses' and enrolled nurses' assessments. Nurses overestimated some of the patients' experiences, whereas enrolled nurses tended to underestimate the patients' pain and distress as well as assessed the interventions as more sufficient compared with their patients. Significant differences between the patients, the nurses, and the enrolled nurses are presented in Table 2 and 3.

Compared with the patients, the nurses assessed that the patients to a higher degree had had problems earlier during their stay in the ICU, within the sensory dimension with respiration and within the intellectual dimension with expressing themselves, making themselves understood and having treatments explained to them. Previous studies show not only that, compared to patients, nurses tend to overestimate factors that are stressful to the patients within intensive care but also that a correct assessment of what the patients regard as most stressful is lacking (Cochran & Ganong, 1989; Cornock, 1998). One possible reason for the patients' perceiving their experiences as less stressful compared to the nurses is that they did not remember what had occurred earlier during their ICU-stay. Results regarding what patients remember from their stay in ICU vary between different studies (Bergbom-Engberg et al., 1988; Puntillo, 1990; Turner et al., 1990; Elpern et al., 1992).

The enrolled nurses' assessed that the patients, during their ICU-stay, had slept better and received more information about their condition, compared with the patients' perceptions. The present results contrast with a study where personnel perceived that patients in respirators had more problems than perceived by the patients themselves (Riggio et al., 1982). However, patients' pain has been found to be frequently underestimated (LeVasseur & Calder, 1995).

Compared with the enrolled nurses, the patients considered to a lesser extent that they had received help and support within the sensory dimension with physical pain, physical discomfort and sleep, and within the emotional dimension with fear. Due to enrolled nurses' limited training, they are not allowed to take decisions and perform interventions on their own. Consequently, they do not make own assessments of interventions.

Both nurses and enrolled nurses judged, to a greater extent than the patients, that the patients could help themselves and that they had been given this possibility. There was divergence between nurses and enrolled nurses regarding breathing problems, sleep and information about patients' condition. Compared with the nurses, the enrolled nurses judged that the patients had received more sufficient help and support with sleep, physical discomfort and fear earlier during their stay in the ICU. This discrepancy between nurses' and enrolled nurses' judgement may be due to differences in education. It was primarily the enrolled

Table 2. Comparisons between patients, nurses, and assistant nurses regarding assessment phase.

NURSING PROCESS PHASE									
Dimension Category Item <sup>a</sup>	Patients		Nurses		Assistant nurses		Kruskal-Wallis	Mann-Whitney	A B C
	M	SD	M	SD	M	SD			
<b>ASSESSMENT</b>									
<b>Sensory dimension</b>									
<i>Breathing problems</i>									
Strained breathing earlier <sup>b</sup>	2.12	1.30	2.92	1.09	2.43	1.40	10.28**		A
Shortness of breathing earlier <sup>b</sup>	1.69	1.17	2.48	1.09	1.50	0.92	16.84***		A, C
<i>Fatigue</i>									
Being unable to sleep tonight <sup>b</sup>	2.82	1.56	2.43	1.07	2.02	0.99	6.98*		B, C
Being unable to sleep earlier <sup>b</sup>	3.31	1.52	2.86	1.20	2.12	0.60	8.60**		B, C
<b>Intellectual dimension</b>									
<i>Difficulty in expressing oneself - not being understood</i>									
Being unable to express oneself <sup>b</sup>	1.46	0.80	1.98	0.93	1.67	0.75	11.00**		A
Being unable to make oneself understood earlier <sup>b</sup>	1.37	0.69	1.89	0.83	1.59	0.59	10.98**		A
<i>Not knowing</i>									
No information of condition <sup>c</sup>	1.84	1.05	1.77	0.84	1.29	0.53	7.00*		B, C
No explanation of treatments earlier <sup>b</sup>	1.57	0.95	2.10	0.83	1.82	1.13	10.22**		A
<b>Emotional dimension</b>									
<i>Dependency</i>									
Being unable to help oneself today <sup>c</sup>	2.35	1.04	1.86	0.84	1.89	0.87	7.74*		A, B
Being unable to help oneself earlier <sup>c</sup>	3.07	1.04	2.36	1.06	2.45	0.96	10.83**		A, B
Have not been given the opportunity to do something today <sup>c</sup>	1.72	0.77	1.37	0.49	1.37	0.49	6.78*		A, B
Do not wish to help oneself <sup>c</sup>	1.25	0.44	1.47	0.71	1.72	0.83	9.63**		B

<sup>a</sup> abbreviations of items

<sup>b</sup> scores could range from 1 (most favourable) to 5 (least favourable)

<sup>c</sup> scores could range from 1 (most favourable) to 4 (least favourable)

A = significant difference of means between patients and nurses (p < 0.05)

B = significant difference of means between patients and assistant nurses (p < 0.05)

C = significant difference of means between nurses and assistant nurses (p < 0.05)

\*p < 0.05 \*\*p < 0.01 \*\*\*p < 0.001

Table 3. Comparisons between patients, nurses, and assistant nurses regarding intervention phase.

NURSING PROCESS PHASE									
Dimension Category Item <sup>a</sup>	Patients		Nurses		Assistant nurses		Kruskal-Wallis $\chi^2$	Mann-Whitney	
	M	SD	M	SD	M	SD		A	B
INTERVENTIONS - assistance regarding									
<b>Sensory dimension</b>									
<i>Physical pain</i>									
Physical pain today <sup>b</sup>	1.60	0.74	1.36	0.54	1.18	0.46	6.75*		B
Physical pain earlier <sup>b</sup>	1.80	0.83	1.48	0.63	1.19	0.40	10.12**		B
<i>Physical discomfort</i>									
Discomfort today <sup>b</sup>	2.12	0.78	1.54	0.60	1.31	0.47	16.88***		A, B
Discomfort earlier <sup>b</sup>	2.17	0.78	1.68	0.53	1.37	0.60	13.68***		A, B, C
<i>Breathing problems</i>									
Breathing today <sup>b</sup>	1.10	0.31	1.07	0.26	1.00	0.00	3.16		
Breathing earlier <sup>b</sup>	1.24	0.44	1.16	0.37	1.08	0.40	4.01		
<i>Fatigue</i>									
Sleeping <sup>b</sup>	2.06	0.92	1.87	0.73	1.38	0.49	9.82**		B, C
<b>Emotional dimension</b>									
<i>Worry</i>									
Worry today <sup>b</sup>	2.08	0.67	1.73	0.64	1.60	0.60	4.06		
Worry earlier <sup>b</sup>	1.92	0.67	2.00	0.65	1.45	0.52	4.86		
<i>Fear</i>									
Fear today <sup>b</sup>	2.33	0.58	1.64	0.63	1.20	0.42	7.54*		B
Fear earlier <sup>b</sup>	1.60	0.55	1.78	0.44	1.00	0.00	7.53*		B, C

<sup>a</sup> abbreviations of items

<sup>b</sup> scores could range from 1 (most favourable) to 3 (least favourable)

A = significant difference of means between patients and nurses ( $p < 0.05$ )

B = significant difference of means between patients and assistant nurses ( $p < 0.05$ )

C = significant difference of means between nurses and assistant nurses ( $p < 0.05$ )

\* $p < 0.05$  \*\* $p < 0.01$  \*\*\* $p < 0.001$

nurses who answered "Don't know" to the questions related to the patients' previous experiences. However, the nurses also showed a high frequency of "Don't know"-answers within the emotional dimension, which might indicate that communication and documentation between nursing staff do not include assessments of emotional experiences to the same extent as sensory ones.

## PAIN AND DISTRESS IN POSTOPERATIVE CARE (III)

The study explored postoperative experiences of pain and distress in elderly patients. The sample comprised 100 patients who had undergone elective surgery. The elderly patients' reported experiences varied in some respects between three interview occasions. Compared with the first day after the operation, the intensity of physical pain and fatigue was reduced on the second day but increased again after discharge. On the first and the second day after the operation, 46 respectively 35 per cent of the patients had physical pain for more than three hours and approximately 25 per cent had moderate or severe pain. Previous studies have shown that patients perceive high levels of postoperative pain (e.g. Closs et al., 1993; Sjöström, 1995). Normally, the postoperative pain decreases gradually from the first to the third day after the operation, however, not for all patients (Tittle & McMillan, 1992). Fewer patients reported physical discomfort the second day compared to the first day after the operation. After returning home more patients again reported discomfort. Sleep, rest and the possibility to manage oneself were improved after returning home. Six weeks after joint replacement surgery the patients rated their sleep and wound pain as significantly improved (Chamberlein et al., 1992).

Logistic regression analyses was used to identify factors influencing the pain and distress variables on the day after surgery and at home. The results of the logistic regression analyses are shown in Tables 4 and 5. There was a significant relation between the independent variable sense of coherence and the dependent variables physical pain, fatigue, and worry the day after surgery (Table 4). Patients with a weaker sense of coherence were, compared with patients with a stronger sense of coherence, more likely to report more intense pain, fatigue, and worry. Chamberlein et al. (1992) found that patients undergoing joint replacement, who had a stronger sense of coherence, reported lower levels of distress than patients did with a weaker sense of coherence.

Fatigue and worry showed significant relations with need for social support. For patients with no or a weak need for social support, the likelihood of their not reporting fatigue and worry increased.

The dependent variables physical pain, unable to manage oneself, no belief in recovery, and no belief in managing oneself showed significant associations with the independent variable type of surgery. Patients who had undergone knee arthroplasty were more likely to report intense pain and anger/irritation while patients who had had hip arthroplasty were more likely to report that they were unable to manage themselves. Boström et al. (1997) found no significant differences in pain intensity between orthopaedic and general surgical groups. Patients having undergone hip arthroplasty and patients with higher age increased the likelihood of no belief in managing oneself. Few studies have investigated more than one type of surgery simultaneously. However, O'Hara et al. (1989) found, in their study of psychological consequences in connection with a number of different operations, that type of surgery seemingly had no influence on psychological distress. Nor were any differences found between patients undergoing operations for cancer and those who did not have cancer.

Table 4. Logistic Regression Analyses the first day after surgery.

Scales and independent variables	Parameter estimates		
	Wald	Significance of Wald	<u>R</u>
<b>Pain</b>			
type of surgery <sup>a</sup>	4.11	0.042*	0.14
age	1.38	0.240	0.00
gender <sup>a</sup>	1.40	0.236	0.00
marital status <sup>a</sup>	2.60	0.107	0.07
additional diagnosis <sup>a</sup>	1.55	0.213	0.00
sense of coherence	6.96	0.008*	-0.21
social support <sup>a</sup>	0.04	0.849	0.00
<b>Fatigue</b>			
type of surgery <sup>a</sup>	2.75	0.097	0.08
age	0.26	0.611	0.00
gender <sup>a</sup>	1.36	0.244	0.00
marital status <sup>a</sup>	1.38	0.240	0.00
additional diagnosis <sup>a</sup>	2.23	0.135	0.04
sense of coherence	3.99	0.046*	-0.13
social support <sup>a</sup>	5.94	0.015*	-0.18
<b>Worry</b>			
type of surgery <sup>a</sup>	1.36	0.714	0.00
age	0.78	0.377	0.00
gender <sup>a</sup>	0.01	0.936	0.00
marital status <sup>a</sup>	0.40	0.525	0.00
additional diagnosis <sup>a</sup>	3.16	0.076	0.10
sense of coherence	3.81	0.051*	-0.13
social support <sup>a</sup>	8.49	0.004*	-0.24

<sup>a</sup>Entered into the model as a categorical variable.

The outcome of the analyses pertaining to at home showed a significant relation between sense of coherence and the dependent variables unable to sleep, no belief in full recovery, and no belief in managing oneself (Table 5). Stronger sense of coherence compared with weaker sense of coherence increased the likelihood of patients not reporting unable to sleep and resignation. Chamberlein et al. (1992) found that sense of coherence was a predictor of the positive aspects of recovery. Also, being elderly and being married increased the likelihood of being unable to sleep. Knee arthroplasty and additional diagnosis increased the likelihood of patients reporting fatigue. Being female and having undergone hip arthroplasty increased the likelihood of reporting no belief in full recovery.

Table 5. Logistic Regression Analyses at home.

Scales and independent variables	Parameter estimates		
	Wald	Significance of Wald	<u>R</u>
Unable to sleep			
type of surgery <sup>a</sup>	6.38	0.094	0.06
age	4.80	0.029*	0.16
gender <sup>a</sup>	0.42	0.519	0.00
marital status <sup>a</sup>	12.63	0.000*	0.32
additional diagnosis <sup>a</sup>	0.01	0.920	0.00
sense of coherence	4.04	0.045*	-0.14
social support <sup>a</sup>	1.69	0.194	0.00
No belief in full recovery			
type of surgery <sup>a</sup>	0.63	0.889	0.00
age	3.00	0.083	0.11
gender <sup>a</sup>	1.12	0.290	0.00
marital status <sup>a</sup>	0.04	0.844	0.00
additional diagnosis <sup>a</sup>	1.01	0.316	0.00
sense of coherence	3.69	0.054*	-0.14
social support <sup>a</sup>	0.34	0.559	0.00
No belief in managing oneself			
type of surgery <sup>a</sup>	5.61	0.018*	-0.18
age	2.91	0.088	0.09
gender <sup>a</sup>	5.53	0.019*	-0.18
marital status <sup>a</sup>	2.13	0.145	0.03
additional diagnosis <sup>a</sup>	0.11	0.745	0.00
sense of coherence	4.86	0.028*	-0.16
social support <sup>a</sup>	0.64	0.425	0.00

<sup>a</sup>Entered into the model as a categorical variable.

In a cluster analysis, three meaningful clusters of patients emerged. One profile, with 43 patients, perceived problems to a minor degree on all variables. Another profile, consisting of 12 patients, reported problems to the greatest degree on all variables except one, compared with the other profiles of patients. The third patient profile with 36 patients was positioned between the other clusters.

The profile with 12 patients showed a significantly weaker sense of coherence compared with the patients in the other two profiles. Johansson et al. (in press) found that hip fracture patients with a weaker sense of coherence reported significantly more discomfort and less favourable scores in emotional status than the patients with a stronger sense of coherence. More of the twelve patients and the profile with 36 patients had a stronger wish to receive social support compared with the profile of patients reporting least problems. The profile of patients experiencing most problems perceived the relief and assistance with physical pain on the second day after surgery, physical discomfort on the first and second day after surgery, and not managing oneself at home as less satisfactory compared with the profile of patients reporting the least problems.

# PATIENTS' EXPERIENCES AND ENROLLED NURSES' ASSESSMENTS OF CHRONIC PAIN AND DISTRESS (IV)

The study compared elderly patients' reported experiences of chronic pain and distress as well as to what extent they regarded that they had received help and support with enrolled nurses' assessments. The sample comprised 38 patients and 38 enrolled nurses. In the sensory dimension the enrolled nurses assessed that the patients had less intense experiences compared with the patients' perceptions within the categories physical pain, physical discomfort, and breathing problems. The results are consistent with an earlier study of nurses' assessment of chronic pain in elderly patients (Walker et al., 1990). In the intellectual dimension enrolled nurses assessed, to a greater degree than the patients, that the patients received sufficient information regarding their condition and scheduled events. There were significant differences in the emotional dimension within the categories resignation and dependency. The patients reported, on the one hand, to a lesser degree than the enrolled nurses, that their condition would improve and that they would receive help to get better and, on the other hand, to a greater degree than the enrolled nurses that they were unable to help themselves and had not been given the opportunity to do something on their own.

Only one of the ten help and support variables showed significant differences between patients and enrolled nurses. Within the existential dimension, the patients regarded that they received sufficient help from the staff to a lesser degree compared to enrolled nurses' assessments. The majority of the nurses did not know whether or not the patients received this kind of support from the staff, and most of the patients considered that they did not expect the staff to be able to support them in existential questions. In a study carried out in a rehabilitation clinic, Anderson et al. (1993) found that none of the staff had talked to the patients about existential questions, despite the fact that two thirds of the patients regarded this to be important. Elderly patients in hospital and in the community stated that they would welcome nursing involvement and interventions to meet their spiritual need (Peterson, 1985; Bauer & Barron, 1995).

The enrolled nurses were divided into two groups according to whether they, in their assessments, had underestimated or overestimated the patients' experiences. The two groups were compared with regard to age, education, experiences in nursing, how long they had known the patient, FFPI, and SOC (Table 6). The enrolled nurses underestimating the patients' experiences showed significantly higher scores on three of five personality scales: Agreeableness, Conscientiousness, and Emotional Stability compared to the overestimating enrolled nurses. They also showed a tendency towards higher scores on Extraversion and sense of coherence although the differences were not significant. High scores on the scales Agreeableness and Conscientiousness mean, among other things, that one is helpful, friendly, and kind-hearted respectively ambitious and reliable as well as having stamina, factors important in a caregiver. One explanation for the differences between the two groups' assessments could be that it may be easier for enrolled nurses with high scores on the personality scales to cope with patients' problems and that they therefore do not perceive the patient's condition as particularly painful and distressing, in contrast to the enrolled nurses with low scores who show greater difficulty in coping with patients' pain and distress.

Table 6. Influence of enrolled nurse and patient characteristics.

Variable	Enrolled nurses underestimating (n=24)		Enrolled nurses overestimating (n=10)		z/chi-square <sup>a</sup>
	M	SD	M	SD	
<i>Enrolled nurse characteristics</i>					
Age	40.08	10.66	32.00	10.91	1.87
FFPI					
Extraversion <sup>b</sup>	15.63	7.11	11.10	12.42	1.04
Agreeableness <sup>b</sup>	23.67	5.90	13.50	11.00	2.60**
Conscientiousness <sup>b</sup>	17.25	10.94	10.20	6.20	2.06*
Emotional Stability <sup>b</sup>	15.79	12.46	4.70	14.47	2.53**
Autonomy <sup>b</sup>	9.42	7.30	7.30	8.74	0.70
SOC <sup>c</sup>	66.71	10.26	59.50	11.27	1.55
Experiences in nursing (years)	13.38	6.36	10.60	7.63	1.10
How long known the patient (months)	49.78	39.52	28.40	32.53	1.67
Education					0.17
Enrolled nurse	63%		70%		
Nursing auxiliaries	37%		30%		
<i>Patient characteristics</i>					
Age	82.58	7.10	80.40	8.03	1.08
Gender					0.25
Men	17%		10%		
Women	83%		90%		
Marital status					11.30**
Married	0%		40%		
Divorced	9%		0%		
Widow/widower	62%		40%		
Unmarried	29%		20%		
Type of housing					2.84
Special housing	71%		40%		
Own home	29%		60%		
Amount of assistance received					1.25
At least 3 times/day	58%		60%		
1-2 times/day	33%		20%		
1 time/week or every fortnight	9%		20%		

<sup>a</sup> Mann-Whitney U-test on the variables age, FFPI, SOC, experiences in nursing, how long known the patient, chi-square-tests on remaining variables.

<sup>b</sup> Scores could range from -40 (lowest score) to 40 (highest score).

<sup>c</sup> Scores could range from 13 (least favourable) to 91 (most favourable).

\* $p < .05$ . \*\* $p < .01$ .



## CHRONIC PAIN AND DISTRESS IN THE ELDERLY (V)

The study identified various profiles of pain and distress experiences among elderly patients in the community. The sample comprised 42 patients. A cluster analysis yielded three profiles of patients (Figure 2). The patients in cluster A consisted of 15 patients, who showed favourable scores in most of the categories. In cluster B the patients had favourable scores in all categories. The tendency in cluster C was that the ten patients did not show favourable scores. The patients in cluster A had significantly less favourable mean scores than the patients in cluster B in three of the categories; not knowing, resignation, and dependency. The subjects in cluster C rated themselves as more tired, worried, bitter, and suffering from despair than did the patients in clusters A and B as well as less informed, more resigned and dependent than did the patients in cluster B. Other studies show that elderly patients do not always feel informed about the cause of the pain (Walker et al., 1990) and that they may resign themselves to the pain because they do not believe that it can be alleviated (Yates et al., 1995).

The patients in cluster A were significantly older than the patients in clusters B and C and reported pain relief as less satisfactory compared with the patients in cluster B. Elderly patients in residential care settings felt that the pain management was not effective (Yates et al., 1995). Few elderly people with chronic pain are treated in pain clinics, despite the fact that their problems are at least as severe as those of younger patients (Roy, 1987). Elderly patients received smaller doses of analgesics compared with younger patients (Short et al., 1990; Closs et al., 1993; Watters et al., 1993). The subjects in cluster C showed a significantly weaker sense of coherence than the patients in cluster B. A strong sense of coherence has been shown to have positive associations with elderly people's perceived health and functional ability (Sarvimäki & Ojala, 1994; Johansson et al., in press). People with a strong sense of coherence has the ability to cope with stressful situations successfully (Antonovsky, 1993; Langius et al., 1994). Compared with the other two clusters, the patients in cluster C perceived the assistance received regarding fatigue and within the existential dimension as less satisfactory. The finding that the patients in clusters A and C felt more dependent compared with the patients in cluster B is consistent with their rated functional ability. More patients in clusters A and C were dependent in I-ADL and P-ADL compared with the patients in cluster B. Study V includes three detailed case descriptions, one for each cluster, showing that the three cases are clearly demarcated and that the different patient groups have varying needs of care.

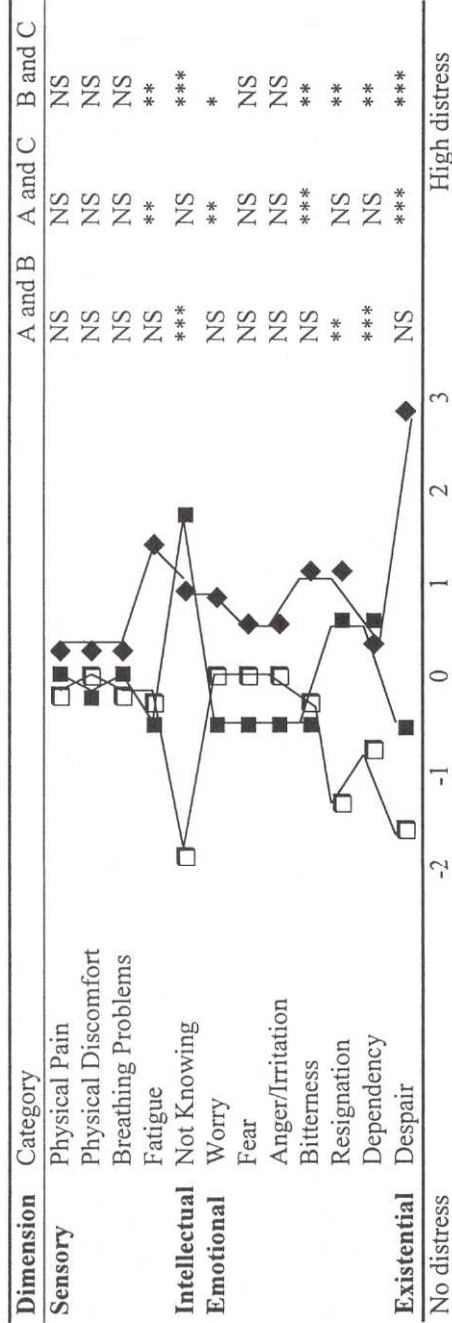


Figure 2. Cluster Analysis of Patients' Experiences of Pain and Distress. Standardised values (z-scores) are marked. Cluster A ■ n=15, Cluster B □ n=17, Cluster C ◆ n=10. \*p<.05. \*\* p<.01. \*\*\*p<.001. NS = not significant, Mann-Whitney U-test.

## GENERAL DISCUSSION

This thesis focuses on pain and distress in various nursing contexts among elderly patients. The most important findings are discussed below. In order to identify areas of pain and distress in intensive care, qualitative interviews and observations were used. The analysis defined qualities within the phenomena pain and distress from a patient perspective and resulted in a theoretical model of elderly patients' experiences of pain and distress. Since the model has been developed within a specific care context, it is rather a substantive model than a formal model (Glaser & Strauss, 1967). A strength of the study is the development of the model, which has been applied within various contexts. A limitation of the study is to not have developed the pain and distress instruments further; something, which ought to be, made in future studies.

Enrolled nurses both within intensive care and in the community tend to underestimate patients' perceptions in their assessments of pain and distress. The enrolled nurses within intensive care overestimated the help/support the patients received, and several of them could not answer the questions regarding patients' previous experiences during their stay in the ICU. On the other hand, there were no considerable differences between the patients and enrolled nurses in the community regarding the help and support the patients received. Unlike the enrolled nurses in the community, who had known the patients for a long time, some of the enrolled nurses in ICU had not met the patients before. In ICU, the enrolled nurses normally stayed with the patient during a whole working period, while in the community the time the nurses spent with the patients varied. Elderly people who receive home help/home nursing perceive that the carers are often hurried and stressed (Tuulik-Larsson, 1992). Under these conditions, it may be difficult for them to make assessments of the patients' health condition.

Different personality factors of importance in a caregiver appear to have an influence on their assessments of patients. Enrolled nurses are one group of caregivers who value empathy and consideration higher than other groups of nursing staff (Gullberg, 1996). This group has a face-to-face interaction with patients and may develop these factors (Gullberg, 1996). Nurses with a high SOC score perceived themselves as having more empathy for their patients compared with nurses with a low SOC (Pålsson et al., 1996). However, in this study enrolled nurses with favourable values on personality factors tended to underestimate the patients' experiences.

In the postoperative group of patients it was primarily type of surgery and sense of coherence that influenced patients' perceptions of pain and distress both on the day after surgery and ten days after discharge from the hospital. In the groups of postoperative patients and patients with chronic pain, three groups of patients with varying pain and distress scores were identified. The groups showing the most favourable scores had a stronger sense of coherence compared to the profiles of patients with the least favourable scores and with a weaker sense of coherence. A strong sense of coherence also means better general resources of resistance and thereby better coping strategies. Walker et al. (1990) found that elderly people with chronic pain reported better pain control and less distress if they used personal pain control strategies. Nurses should therefore support and teach the patients to use individual coping strategies.

None of the chronic pain patients were independent of their functional ability. However, the two groups with less favourable values were more dependent compared with the group with favourable values. Reduced mobility in the elderly, which primarily affected two of the profiles in the chronic pain group, may cause not only worry and fear of, for example, falling

but also for the future, for example, of not receiving the help one may be in need of (Tuulik-Larsson, 1992).

Through the introduction of The Care of the Elderly and Disabled Act (the ÄDEL-reform), the municipality was made responsible for the care to a greater extent compared with the situation just a few years ago. Patients are today discharged earlier from hospitals after, for example, surgery. Elderly people with chronic pain are mainly treated by doctors in the primary care service as well as receive care from nurses within home nursing care. All this requires that the nursing staff possess considerable knowledge of nursing and rehabilitation of patients with different diseases. In a recent study it was found that the majority of district nurses did not make an individual assessment of patients with chronic pain. Further, of those who made such an assessment, very few used any tool for assessing or evaluating patients' pain (Törnkvist et al., 1998).

## NURSING IMPLICATIONS

Assessment of a patient's pain and distress is essential both in intensive and postoperative care as well as in the community. The assessments should include more standardised instruments compared with current non-standardised practices to increase consistency between patients and nurses as well as among nurses. To use such methods may also decrease the risk of a possible bias related to pain and distress assessment. However, assessment tools must be relevant to practice. Many instruments used in research studies are quite detailed and time-consuming. Some patients do not manage to answer all questions or find it too demanding to answer them.

It is also important to be aware that formalised instruments do not always yield the absolute truth and, therefore, they have to be complemented with a professional assessment and analysis. In addition, for some persons there are limits to the degree to which one's personal experience of distress can be communicated and shared with others (Dugan, 1987/88). It is also necessary to take account of factors which are not covered by the content of the questionnaires (Kane, 1993). An example of this is that the organisation of care should optimise the possibilities for caregivers to communicate and co-operate with each other. Nurses should put more effort into documenting their assessments. A sufficient documentation, which includes the steps of the nursing process (Yura & Walsh, 1988), could facilitate the communication, for example, the reporting concerning the patients and co-operation among nursing staff.

There is a need to develop staff training programmes on the assessment and management of pain and distress. The registered nurses responsible for the nursing care should be encouraged to develop their leadership through continuous evaluations of the care provided. As great differences exist between the organisation of care in hospitals and in the community, different solutions may be required. It is also important to include assessment and management of pain and distress in the nursing education. Issues concerning existential problems within different forms of care need to be given greater emphasis (Dugan, 1987/88). Existential questions are inevitable in connection with, for example, life changes, something which caregivers ought to be knowledgeable about (Blomdahl Frej, 1988).

The use of assessment scales could yield structured and reliable data for decisions about relevant care. It is important to assess, at an early stage, the patients' need for help and support with regard to pain and distress, otherwise the extent of pain and distress may increase, making the assessment more difficult to perform (Orlando, 1990). The patients' experiences did somewhat vary in the chronic pain sample as well as among the postoperative

patients. These groups can not be treated as a homogeneous group with the same need of help. This underlies that there is a need to treat patients in different ways in the caring situation. It is important to identify patients who may experience difficulty in coping with situations involving mental and physical strain in order to enhance and strengthen factors counteracting negative experiences.

## FUTURE RESEARCH

Further studies are needed to cover aspects of pain and distress among elderly patients in various nursing contexts. Pain and distress scales appropriate for nursing practice in the care of elderly people should be developed (see section above on methods discussion). Further studies should involve longitudinal designs and larger samples of patients. In postoperative care a greater number of measurement occasions over a longer period of time than was possible in this study are recommended, in order to follow patients during the rehabilitation period. In addition, research is needed on the coping strategies elderly people use, as well as how caregivers can support these strategies.

Potential effects of differences between patients' experiences and nurses' assessments on nurses' interventions deserve further attention. Further studies are needed also to clarify the effect of personality factors on the assessment, as well as on the intervention, in the care of elderly patients, suffering from pain and distress.

## CONCLUSIONS

- Elderly patients' experiences of pain and distress in intensive care may be described in a model including physical, intellectual, emotional, and existential aspects. In the care of the patients all aspects should be taken into consideration.
- Patients' self-reported experiences of pain and distress do not fully agree with nurses' assessments. Nor is there congruence between nurses' and enrolled nurses' perceptions. The assessment of patients' pain and distress must be more systematic, and the use of standardised methods is suggested.
- Personality as a nurse characteristic seems to influence the enrolled nurses' assessment of patients' pain and distress. Nurses need to become aware of possible biases related to pain and distress assessment as a result of personality factors and other variables.
- Patients undergoing surgery differ in their reported experiences between three interview occasions according to physical pain, fatigue, sleep, rest, and dependency. Type of surgery and sense of coherence have a main influence on patients' perceptions of pain and distress on the first day after surgery and after returning home. Patients show individual variations in their perception of pain and distress experiences. The patients with less favourable scores of pain and distress have a weaker sense of coherence compared with patients with more favourable pain and distress scores. It is important to identify patients who may need more support and assistance than other patients.
- There are various profiles of experiences of pain and distress among elderly patients with chronic pain. With the exception of differences concerning distress, there are variations in age, functional ability, sense of coherence, and assistance regarding pain and distress between patients' profiles. This suggests that there is a need to treat the three profiles of patients, demonstrated in this study, in different ways in the caring situation.

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# APPENDIX 1

## PAIN AND DISTRESS SCALES (II, IV, V)

### Study II

#### *Physical pain*

1. Which of the following alternatives best describes your perceived physical pain, if any, today?

- no pain
- some pain
- moderate pain
- severe pain
- excruciating pain

2. Which of the following alternatives best describes your perceived physical pain, if any, that you have had earlier during your stay in the ICU?

- no pain
- some pain
- moderate pain
- severe pain
- excruciating pain
- don't know

#### *Physical discomfort*

3. Which of the following alternatives best describes your perceived physical discomfort, if any, today?

- no discomfort
- some discomfort
- moderate discomfort
- severe discomfort
- very severe discomfort

4. Which of the following alternatives best describes your perceived physical discomfort, if any, earlier during your stay in the ICU?

- no discomfort
- some discomfort
- moderate discomfort
- severe discomfort
- very severe discomfort
- don't know

#### *Breathing problems*

5. Which of the following alternatives best describes your perception of your breathing today?

- no breathing problems
- mild breathing problems
- moderate breathing problems
- severe breathing problems
- very severe breathing problems

6. Which of the following alternatives best describes your perception of your breathing earlier during your stay in the ICU?

- no breathing problems
- mild breathing problems
- moderate breathing problems
- severe breathing problems
- very severe breathing problems
- don't know

7. Is your breathing strained today?

- not at all strained
- somewhat strained
- moderately strained
- severely strained
- very severely strained

8. Was your breathing strained earlier during your stay in the ICU?

- not at all strained
- somewhat strained
- moderately strained
- severely strained
- very severely strained
- don't know

9. Do you have difficulty in breathing today?

- no difficulty in breathing
- some difficulty in breathing
- moderate difficulty in breathing
- severe difficulty in breathing
- very severe difficulty in breathing

10. Did you have difficulty in breathing earlier during your stay in the ICU?

- no difficulty in breathing
- some difficulty in breathing
- moderate difficulty in breathing
- severe difficulty in breathing
- very severe difficulty in breathing
- don't know

11. Do you have a cough today?

- no cough
- moderate cough
- severe cough
- very severe cough

12. Have you had a cough earlier during your stay in the ICU?

- no cough
- moderate cough
- severe cough
- very severe cough
- don't know

13. Do you have a problem with phlegm today?

- no phlegm
- a moderate amount of phlegm
- a fairly large amount of phlegm
- a large amount of phlegm

14. Did you have a problem with phlegm earlier during your stay in the ICU?

- no phlegm
- a moderate amount of phlegm
- a fairly large amount of phlegm
- a large amount of phlegm
- don't know

#### **Fatigue**

15. Which of the following alternatives best describes your perceived fatigue, if any, today?

- no fatigue
- some fatigue
- fairly great fatigue
- great fatigue

16. Which of the following alternatives best describes your perceived fatigue, if any, earlier during your stay in the ICU?

- no fatigue
- some fatigue
- fairly great fatigue
- great fatigue
- don't know

17. How was your sleep last night?

- very satisfactory
- fairly satisfactory
- neither satisfactory nor unsatisfactory
- fairly unsatisfactory
- unsatisfactory

18. How was your sleep at night earlier during your stay in the ICU?

- very satisfactory
- fairly satisfactory
- neither satisfactory nor unsatisfactory
- fairly unsatisfactory
- unsatisfactory
- don't know

19. To what extent have you been able to rest today?

- sufficiently
- to some extent sufficiently
- insufficiently

20. What possibility did you have of resting earlier during your stay in the ICU?

- sufficiently
- to some extent sufficiently
- insufficiently
- don't know

#### **Difficulty in expressing oneself – not being understood**

21. Have you been able to express yourself/communicate during your stay in the ICU?

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all
- don't know

22. Do you find that the nursing staffs understand what you express today?

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all

23. Do you find that the nursing staff understood what you expressed earlier during your stay in the ICU?

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all
- don't know

**Not knowing**

24. Do you know why you are in the ICU?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

25. Have you received sufficient information about your condition?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

26. Do you consider that you receive sufficient information about what will happen during the day (for example about treatments or other activities performed by the nursing staff)?

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all

27. Do you consider that you received sufficient information about what was to happen earlier during your stay in the ICU (for example about treatments or other activities performed by the nursing staff)?

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all
- don't know

28. Do you understand the information you receive today?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

29. Did you understand the information you received earlier during your stay in the ICU?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

30. Do you remember what happened during your stay in the ICU?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- don't know

**Confused perception of reality**

31. Have you had dreams during your stay in the ICU which are difficult to tell whether they are real or not?

- no, not at all
- to a fairly small extent
- to some extent
- to a fairly great extent
- to a very great extent
- don't know

**Worry**

32. Which of the following alternatives best describes your worry, if any, today?

- no worry
- some worry
- moderate worry
- intense worry
- very intense worry

33. Which of the following alternatives best describes your worry, if any, earlier during your stay in the ICU?

- no worry
- some worry
- moderate worry
- intense worry
- very intense worry
- don't know

**Fear**

34. Which of the following alternatives best describes your fear, if any, today?

- no fear
- moderate fear
- intense fear
- very intense fear

35. Which of the following alternatives best describes your fear, if any, earlier during your stay in the ICU?

- no fear
- moderate fear
- intense fear
- very intense fear
- don't know

**Dependency**

36. Can you manage to do something by yourself today (for example, change position in bed, turn on the side, wash yourself)?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

37. Did you manage to do something by yourself earlier during your stay in the ICU (for example, change position in bed, turn on the side, wash yourself)?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- don't know

38. Have you been given the opportunity to do something by yourself today?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable (don't manage to do anything by myself)

39. Were you given the opportunity to do something by yourself earlier during your stay in the ICU?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- don't know
- not applicable (don't manage to do anything by myself)

40. Do you have a wish to be able to manage something by yourself?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

**Anger/irritation**

41. Do you feel irritable/angry today?

- no, not at all irritable/angry
- moderately irritable/angry
- fairly irritable/angry
- very irritable/angry

42. Did you feel irritable (angry) earlier during your stay in the ICU?

- no, not at all irritable/angry
- moderately irritable/angry
- fairly irritable/angry
- very irritable/angry
- don't know

**Intervention**

43. What is your opinion of the help/support you receive today to alleviate your physical pain?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

44. What is your opinion of the help/support you received to alleviate your physical pain earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- don't know
- not applicable

45. What is your opinion about the help/support you receive today to alleviate your physical discomfort?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

46. What is your opinion about the help/support you received to alleviate your physical discomfort earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- don't know
- not applicable

47. What is your opinion about the help/support you receive today with your breathing?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

48. What is your opinion about the help/support you received with your breathing earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

49. What is your opinion about the help/support you received with sleeping earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- don't know
- not applicable

50. What is your opinion about the help/support you receive today to alleviate your worry?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

51. What is your opinion about the help/support you received to alleviate your worry earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- don't know
- not applicable

52. What is your opinion about the help/support you receive today to alleviate your fear?

- sufficient
- to some extent sufficient
- insufficient
- not applicable

53. What is your opinion about the help/support you received to alleviate your fear earlier during your stay in the ICU?

- sufficient
- to some extent sufficient
- insufficient
- don't know
- not applicable

## Study IV and V

### *Physical pain*

1. Which of the following alternatives best describes the physical pain you usually feel?\*

- no pain
- some pain
- moderate pain
- severe pain
- excruciating pain

2. Which of the following alternatives best describes how long the physical pain stated above usually lasts?\*

- less than one hour
- between one and three hours
- more than three hours
- constant pain

### *Physical discomfort*

3. Which of the following alternatives best describes the physical discomfort you usually have?\*

- no discomfort
- some discomfort
- moderate discomfort
- severe discomfort
- very severe discomfort

### *Breathing problems*

4. Which of the following alternatives best describes how you usually perceive your breathing?\*

- no breathing problems
- mild breathing problems
- moderate breathing problems
- severe breathing problems
- very severe breathing problems

### *Fatigue*

5. Which of the following alternatives best describes how you usually perceive your fatigue, if any?\*

- no fatigue
- some fatigue
- fairly great fatigue
- great fatigue

6. How would you describe the way you usually sleep?\*

- very satisfactorily
- fairly satisfactorily
- neither satisfactorily nor unsatisfactorily
- fairly unsatisfactorily
- very unsatisfactorily

7. How do you usually rest during the day?

- sufficiently
- to some extent sufficiently
- insufficiently
- not applicable

**Not knowing**

8. Have you received sufficient information about the cause of your pain?\*

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

9. Have you understood the information you have received about your pain?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable

10. Have you received sufficient information about your condition as a whole?\*

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all

11. Have you understood the information you have received about your condition?

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable

12. Do you usually receive information about what is to happen? (for patients in special housing)

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable

13. Do you usually understand the information you receive? (for patients in special housing)

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable

14. Do you remember what has happened since you came here? (for patients in special housing)

- yes, without doubt
- yes, to some extent
- uncertain
- no, not at all
- not applicable

**Worry**

15. Which of the following alternatives best describes the worry, if any, that you sometimes feel?\*

- no worry
- some worry
- moderate worry
- intense worry
- very intense worry

**Fear**

16. Do you feel fear occasionally?\*

- no, no fear
- yes, some fear
- yes, moderate fear
- yes, fairly intense fear
- yes, very intense fear

**Anger/irritation**

17. Do you feel irritable/angry occasionally?\*

- no, no irritability/anger
- yes, some irritability/anger
- yes, moderate irritability/anger
- yes, fairly strong irritability/anger
- yes, very strong irritability/anger

**Bitterness**

18. Do you feel bitter occasionally?\*

- no, no bitterness
- yes, some bitterness
- yes, moderate bitterness
- yes, fairly strong bitterness
- yes, very strong bitterness

**Resignation**

19. Do you think that your pain condition will be improved?\*

- yes, without doubt
- yes, fairly certain
- uncertain
- no, fairly uncertain
- no, not at all



20. Do you believe that you can get help that will make you better?\*

- yes, without doubt
- yes, fairly certain
- uncertain
- no, fairly uncertain
- no, not at all

#### **Dependency**

21. Do you normally manage to do the things you want to do yourself?\*

- yes, without doubt
- yes, fairly well
- uncertain
- no, fairly badly
- no, not at all

22. Do you usually get the opportunity to do something by yourself?

- yes, to a very great extent
- yes, to a fairly great extent
- neither to a great nor to a small extent
- no, to a fairly small extent
- no, to a very small extent
- not applicable

#### **Despair**

23. Do you feel hopeful for the future?\*

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all

24. Do you feel that you are valuable as a person?\*

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all

25. Do you feel that your life has a meaning?\*

- yes, without doubt
- yes, mostly
- uncertain
- no, mostly not
- no, not at all

#### **Intervention**

26. What is your opinion about the help/support you usually receive to alleviate your pain?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

27. What is your opinion about the help/support you usually receive to alleviate your physical discomfort?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

28. What is your opinion about the help/support you usually receive to alleviate your breathing problems?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

29. What is your opinion about the help/support you usually receive to help you sleep?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

30. What is your opinion about the help/support you usually receive to alleviate your worry?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

31. What is your opinion about the help/support you usually receive to alleviate your fear?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

32. What is your opinion about the help/support you usually receive with the things you can not manage to do yourself?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

33. What is your opinion about the support you usually receive with your spiritual thoughts and concerns?\*

- sufficient
- to some extent sufficient
- insufficient
- not applicable

34. Is there anybody you can talk to about your spiritual concerns?\*

- yes, sufficiently
- yes, to some extent sufficiently
- no, insufficiently
- not applicable

35. Do you consider that the nursing staff can help/support you with your spiritual needs?\*

- yes, sufficiently
- yes, to some extent sufficiently
- no, insufficiently
- not applicable

\* items used in study V

## APPENDIX 2

### NEED FOR SOCIAL SUPPORT (III)

<b>Second interview occasion:</b>	<b>yes</b>	<b>no</b>
1. Do you feel the need for help/support from someone special person on the ward?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you sometimes feel the need for a member of the nursing staff to hug you for support and comfort?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you sometimes feel the need for nursing staff to take the time to be with you and listen to you?	<input type="checkbox"/>	<input type="checkbox"/>
<b>Third interview occasion:</b>		
4. When you were in the ward, did you feel the need for help/support from someone special on the ward?	<input type="checkbox"/>	<input type="checkbox"/>
5. When you were in the ward, did it sometimes happen that you felt the need for a member of the nursing staff to hug you for support and comfort?	<input type="checkbox"/>	<input type="checkbox"/>
6. When you were in the ward, did it sometimes happen that you felt the need for nursing staff taking the time to be with you and listen to you?	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you feel the need for help/support from someone special person in your home?	<input type="checkbox"/>	<input type="checkbox"/>
8. Does it sometimes happen that you feel the need for someone to confide in after returning home?	<input type="checkbox"/>	<input type="checkbox"/>

På grund av upphovsrättsliga skäl kan vissa ingående delarbeten ej publiceras här.  
För en fullständig lista av ingående delarbeten, se avhandlingens början.

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GÖTEBORGS UNIVERSITET

*Frykt & Bunden*  
*Vasastadens Bokbinderi AB*  
1999



