

# Care by District Nurses

Management of patients with chronic-pain conditions,  
patient satisfaction and effects of pain advisers

Lena Törnkvist



Department of Clinical Sciences  
and  
Department of Nursing

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## **Care by District Nurses**

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*“Framtiden kommer av sig själv men framstegen måste vi göra själva”  
(Klokboken Gunnel och Kjell Svärd)*

To my mother and in memory of my father

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## Abstract

This thesis focuses on some aspects of primary health care in Sweden before and after the introduction of “pain advisers”: the district nurses’ opinions regarding their knowledge, management and documentation of patients with chronic-pain conditions, the review of the district nurses’ documentation of these patients and these patients’ opinions of the care and their own well-being. Moreover, it focuses on patients’ satisfaction with the primary health care given by the district nurses (not only patients with chronic-pain conditions). In order to make a controlled study design for the four studies with the focus on chronic-pain conditions, a study area (SA, 5 PHCCs = primary-health-care centres) and a control area (CA, 7 PHCCs) were selected within the South-western Health-care Region in Stockholm.

In the first study, before starting the education and introduction of the “pain advisers” in the SA, all 72 district nurses at the 12 PHCCs included were asked to fill in a questionnaire. The questionnaire was answered by 70 (97%) of the district nurses. The results showed that 85% of the district nurses met patients with chronic pain at least once a week and that no PHCC had any written information or policy on pain control. Many district nurses (27-69%) were dissatisfied with the present management of patients with chronic pain at their PHCCs, their own knowledge of pain control and their own documentation. Furthermore, their opinions regarding pain management varied depending on their satisfaction with their own management of the patients’ pain problems.

In the second study, 32 (94%) district nurses in the SA answered a questionnaire before and 36 (97%) after the introduction of the “pain advisers”. The corresponding figures for the CA were 38 (100%) and 27 (75%), respectively. According to the district nurses, several improvements were made after the training and introduction of five of them as “pain advisers” in the SA: e.g. more district nurses reported that pain policies now existed at the PHCCs, and they also reported an increased satisfaction with the routines regarding pain management at their PHCCs and an increased, individual, pain assessment of the patients.

In the third study, the district nurses’ documentation of patients with chronic-pain conditions was reviewed. A total of 144 (56 SA, 88 CA) patients’ records were reviewed before and 104 (76 SA, 28 CA) after the introduction and support of “pain advisers”. At the follow-up in 1998, a more detailed description of the chronic pain was found in the SA.

In the fourth study, a total of 84 (34 SA, 50 CA, answering rate 67%) patients answered a study-specific questionnaire in 1996 and 60 (43 SA, 17 CA, answering rate 77%) patients in 1998. It revealed that the patients with chronic-pain conditions considered that the pain influenced their well-being to a rather great extent. However, the patients felt confirmed at the meeting with the district nurse, e.g. they felt believed, taken seriously and understood. The advice and recommendations and/or information and education received were also found to be of great value to these patients. After the introduction of “pain advisers” into the SA, the patients reported less pain as a result of the advice and recommendations. The patients also reported more knowledge with which to understand the pain as a result of the information and education.

The fifth study investigated the patients’ satisfaction with the care given by the district nurses at home and at the PHCCs (not only patients with chronic-pain conditions). In order to collect the data, the questionnaire entitled “Quality of care from the patient’s perspective” (QPP) was used and answered by 168 (62%) home-care (HC) patients and 264 (72%) out-clinic (OC) patients. High satisfaction was in general reported although some areas were identified as being in need of improvements. HC and OC patients with poor, self-rated, physical health were identified as being likely to be dissatisfied with the care.

**Keywords:** district nurse, primary health care, chronic pain, educational program, pain advisers, confirmation, patient satisfaction, well-being, pain assessment, pain management, home care, outpatient clinic, nursing documentation.

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## Sammanfattning

Denna avhandling fokuserar på vårdaspekter före och efter införande av "smärtombud" i primärvården: distriktssköterskornas uppfattning om sin egen kunskap, omhändertagande och dokumentation avseende patienter med långvariga smärttillstånd, granskning av distriktssköterskornas dokumentation vad gäller dessa patienter och patienternas uppfattning om vården och sitt eget välbefinnande relaterat till smärttillståndet. Patienters tillfredsställelse med den vård som de erhållit av distriktssköterskan har också undersökts (ej enbart patienter med långvariga smärttillstånd). I syfte att skapa en kontrollerad studiedesign för de fyra smärtstudierna, valdes ett studieområde (5 vårdcentraler) och ett kontrollområde (7 vårdcentraler) ut i Sydvästra sjukvårdsområdet i Stockholm.

I den första studien innan "smärtombuden" introducerades i studieområdet ombads samtliga distriktssköterskor på de 12 inkluderade vårdcentralerna att besvara en enkät. Den besvarades av 70 (97%) distriktssköterskor. Undersökningen visade att 85% av distriktssköterskorna träffade patienter med långvarig smärta minst en gång i veckan. Inte vid någon vårdcentral fanns skriftlig information eller policy som stöd för omhändertagandet av patienterna. Många distriktssköterskor (27-69%) var missnöjda med det nuvarande omhändertagandet av patienterna vid vårdcentralen, sin egen kunskap om smärthantering, sin egen handlingsberedskap för att möta dessa patienter, egen uppföljning av patienternas smärtproblematik och egen dokumentation. Studien visade också att distriktssköterskornas åsikter avseende smärthantering varierade beroende på egen tillfredsställelse med omhändertagandet av dessa patienter.

I den andra studien, besvarade 32 (94%) distriktssköterskor i studieområdet en enkät före införandet av smärtombud och 36 (97%) efter. Motsvarande siffror i kontrollområdet var 38 (100%) och 27 (75%). Uppföljningen efter introduktionen av "smärtombuden" i studieområdet, visade på ett flertal förbättringar t ex en större andel distriktssköterskor ansåg att de hade smärtpolicy på respektive vårdcentral, en ökad tillfredsställelse med rutinerna avseende smärthantering på vårdcentralen samt en ökad individuell smärtbedömning av patienterna.

I den tredje studien granskades totalt 144 (56 i studieområdet, 88 i kontrollområdet) patientjournaler före och 104 (76 i studieområdet, 28 i kontrollområdet) efter införande av "smärtombuden". Vid uppföljningen 1998 beskrev distriktssköterskorna patienternas smärttillstånd mer i detalj i journalerna.

I den fjärde studien 1996 erhöll totalt 84 patienter med långvariga smärttillstånd (34 SA, 50 CA, svarsfrekvens 67%) och 60 patienter 1998 (43 SA, 17 CA, svarsfrekvens 77%) en enkät inriktad på smärta. Studien visade att patienterna ansåg att smärtan till ganska stor del påverkade välbefinnandet. Patienterna upplevde sig bekräftade i mötet med distriktssköterskorna t ex upplevde sig trodda, tagna på allvar och förstådda. Råd och rekommendationer och/eller information och undervisning visade sig vara värdefulla för patienterna. Uppföljningen efter införandet av "smärtombuden" i SA visade att patienterna rapporterade mindre smärta som ett resultat av råd och rekommendationer. Patienterna rapporterade också mer kunskap för att förstå smärtan som ett resultat av information och undervisning.

I den femte studien undersöktes patienters tillfredsställelse med den vård de erhållit av distriktssköterskan, dels på mottagningen, dels i hemmet (ej enbart patienter med långvariga smärttillstånd). Frågeformuläret "Kvalitet ur Patientens Perspektiv" (KUPP) användes för att samla in data. Enkäten besvarades av 168 (62%) patienter som besökts av distriktssköterskan i hemmet och 264 (72%) patienter som besökt distriktssköterskan på mottagningen. Patienterna rapporterade generellt hög tillfredsställelse, med vården, dock identifierades några förbättringsområden. Patienter som rapporterade ett dåligt fysiskt hälsotillstånd identifierades som sannolika att vara mer missnöjda med vården.

## List of Publications

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

- I Törnkvist L., Gardulf A., Strender L-E. The opinions of district nurses regarding the knowledge, management and documentation of patients with chronic pain. Scandinavian Journal of Caring Sciences 1998;12:146-153.
- II Törnkvist L., Gardulf A., Strender L-E. Effects of “pain-advisers”: District nurses’ opinions regarding their own knowledge, management and documentation of patients in chronic pain. Submitted.
- III Törnkvist L., Gardulf A., Strender L-E. District nurses’ documentation of patients with chronic-pain conditions before and after the introduction of “pain advisers”. Submitted.
- IV Törnkvist L., Strender L-E., Gardulf A. Patients’ opinions of the care and their own well-being before and after the introduction of “pain advisers” in the primary-health-care system. Accepted for publication in Primary Health Care Research & Development. In the press.
- V Törnkvist L., Gardulf A., Strender L-E. The patients’ satisfaction with the care given by district nurses at home and at primary-health-care centres. Scandinavian Journal of Caring Sciences 2000;14:67-74.

Studies I, IV, and V are reprinted with the permission of the publisher.

## **Abbreviations**

PHCC	Primary-health-care centre
VIPS	Well-being, Integrity, Prevention, Safety (a nursing-documentation model)
SA	Study area
CA	Control area
HC	Home care
OC	Outpatient clinic
QPP	Quality of care from the patients' perspective



## **Background of the study**

### **The role of the district nurse**

The district nurses are well integrated and well known in the Swedish primary-health-care system (1). During the last decade, this system has been exposed to increased demands (2, 3). It has been decided that it should be the first line of the health care and that it should be organised in such a way that it decreases people's need for hospital care (2). The numbers of beds at the hospitals have been reduced (4) and patients are often cared for for shorter periods of time at the hospitals today. Another reason for the increased demands on the primary-health-care system is the changing demographic pattern, i.e. the increasing proportion of elderly persons in society (4). This category of persons is often met by the district nurses (5-7). Although elderly people's health and functional ability have improved, the medical developments may result in the elderly living longer with chronic illnesses (4, 8).

The work of the district nurses is guided by the Health and Medical Services Act (9). The overall goal, according to this Act, is promoting health on equal conditions for the whole population. Furthermore, it stipulates that the care and treatment of the patients should be available, safe, appropriate, of high quality, based on thoughtfulness and respect for the patients' autonomy and integrity and, as far as possible, be planned and performed in co-operation with the patient. The patient should also be informed about his or her health care and about the available methods of treatment. According to the Swedish General Advisory on Nursing, the aim of the nursing care is "to strengthen health, prevent sickness and illness, restore and retain health seen from the patients' individual possibilities and needs, diminish suffering and give the possibility of a death in dignity" (10, p. 151). Furthermore, nursing care includes relieving pain and other discomfort (10).

The district nurse's main responsibility is to prevent illnesses in the population and to plan, give and evaluate the nursing care of children, adults and the elderly. The district nurse also examines, treats, informs and educates the patients, both independently and in co-operation with others in the health-care team (11).

In the South-western Health-care Region in Stockholm, activities have been organised and support provided to improve the care given by the district nurses. One aim of the activities has also been to improve the nursing documentation. The VIPS nursing-documentation model was introduced into the region in October 1995. A year later, another project was initiated to meet the demands for further education from the district nurses and to try to give a high quality of care for patients with chronic-pain conditions. This project included the training of district nurses at some PHCCs to become so-called pain advisers.

Although the district nurses are important in the Swedish health-care system, their work seems to have been relatively little investigated. This thesis focuses on the conditions at the PHCCs in the South-western Health-care Region before and after the introduction of the pain advisers: the district nurses' opinions regarding their knowledge, management and documentation of patients with chronic-pain conditions, the district nurses' actual documentation regarding this group of patients and the opinions of patients with chronic-pain conditions of the care and their own well-being. Furthermore, it focuses on the patients' satisfaction in general with the care given by the district nurses at home and at the primary-health-care centres.

### **Pain - chronic pain**

#### *The concept and definition*

It is important to improve pain management in order to achieve a high quality of care (12). Pain is a complex, multidimensional phenomenon which requires a holistic approach (13, 14). The International Association for the Study of Pain has presented the following definition: "Pain is an unpleasant sensory and emotional experience associated with actual or potential

tissue damage or is described in terms of such damage” (15, p.217). Another definition is that “pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does” (13, p. 26). In her book, McCaffery uses the following “working definition” of chronic, non-malignant pain: “Pain that has lasted 3 months or longer, is ongoing on a daily basis or recurs on a regular basis, is due to non-threatening causes, has not responded to currently available treatment methods, and may continue for the remainder of the patient’s life” (13, p. 198). Ferrell (16) states that chronic pain is pain with a duration of more than 3 months. However, time limits of up to 6 months have been mentioned in the literature (17). Another definition of chronic pain is pain which has lasted for longer than the normal time for healing (17).

#### *Chronic pain in the general population and in the elderly*

Chronic-pain conditions are a common problem in the general population (17, 18). The results of a postal survey among 1,009 persons aged 18–84 years in a Swedish county showed a prevalence rate of 40% of pain which had lasted more than 6 months (18). Chronic-pain problems were most common among individuals between 45 and 64 years of age (50%) and less common in the group over 65 years of age (36%). Other studies have shown that complaints of persistent pain may increase with age (19) and be common among the elderly (20). American population studies have indicated that for individuals aged 60 or older, the prevalence of pain is twice as great (25%), compared with younger adults (12%) (21). Among the elderly in institutions, the prevalence of pain has been found to be as great as 71% (22).

Although inconsistent results are found regarding age differences in pain prevalence, it has been found that a significant proportion of elderly people do experience pain problems (14). In a study in which individuals aged 65 and older were interviewed, 86% reported some kind of pain and 59% reported multiple pain problems. Joint pain was most common, followed by leg and back pain (23). Joint pain was also found to be the most common pain problem among elderly people receiving home-nursing services, where 75% of the responders suffered from pain (24). An English survey of people aged 85 and older living at home showed that 70% reported aches, pain or stiffness in muscles or joints (25).

Elderly people are also an age-group in which leg ulcers predominantly occur and the majority are treated in the primary-health-care system (26). In measuring the quality of life in chronic-leg-ulcer patients, high scores for pain were obtained, especially among men (27). In another study, the health-care professionals reported pain in 47% of all the patients with venous leg ulcers and that only 29% of these patients received pain relief (26). It has also been found that 70% of those with advanced cancer have pain as a major symptom (17, 28). In a study among the oldest old (77 and older), it was reported that total pain among women decreased with age but among men there was an increase of severe pain with age (20). Musculoskeletal pain was more common among old women than old men but for chest pain and abdominal pain there were no differences (20). There are several chronic-pain conditions that affect women more than men, e.g., rheumatoid arthritis, fibromyalgia, migraine headache and multiple sclerosis (13).

#### *Consequences of pain and chronic pain*

In a sample of chronic-pain patients attending a pain clinic it was found that 85% of them were never free from their pain (29). In a review article, it was reported that many elderly people experience pain which may interfere with their normal functioning and that many of them do not receive adequate pain management (14). Ferrell (30) developed a conceptual model of the impact of pain on the quality of life in the domains of physical, psychological, social and spiritual well-being (30). Pain was in one study found to influence the patients’ well-being more or less in all the above-mentioned domains (31). Other studies (32-35) have also stated that chronic-pain conditions may lead to undesirable consequences, which may affect the patients’ quality of life (16, 24, 32, 35). Chronic-pain conditions can be associated

with depression (14, 24, 34, 35), sleep disturbances (24, 29, 34), fatigue (34), decreased socialisation, impaired mobility (34, 35) and decreased satisfaction with life (24).

Several authors have tried to explore the understanding of the quality of life for persons living with chronic pain (24, 35, 36). Three themes arose from the analysis in one study: the anguish of living with the pain; the isolating retreats but also the new, comforting engagements; and the hope for some relief (36). In one study, elderly patients with chronic pain living in the community reported that the worst aspect of feeling pain was its impact on the ability to perform activities (32).

#### *Control and alleviation of chronic pain*

For patients with chronic-pain conditions, pain management is a struggle for control (37). A patient's ability to control a situation is influenced by the available information and by pain-controlling skills or actions (32, 37, 38). Walker *et. al.* found that one of the predictors of negative moods among the elderly in the community was lack of information about their painful condition (32). In a study among patients with chronic pain attending a pain clinic, it was found that nearly half of them wanted to have more information about their condition and pain treatment (29).

Patients have been found to regard the alleviation of the physical symptoms of disease, such as pain, as an important task for the district nurses (39). The patients' possibilities of being confirmed at the meeting with the nurse is regarded as a prerequisite for good care and the patients' self-esteem is affected if he or she is not believed, taken seriously or understood (40, 41). Patients with chronic-pain conditions living at home reported that the human support given by the district nurses was the most important factor in coping with the pain (32). However, although the patients regarded the "caring" aspects as most important, the nurses were found to focus more on "curing" or relieving the pain with the help of drugs (32). Factors such as understanding, sympathy, reassurance, confidence, the possibilities of talking about the pain, social contacts, advice about available therapies, information and encouragement were also found to be important to the patients (32). Other studies have also found that talking about what the pain means to the patient in chronic pain is crucial in helping them (35, 36). However, even though the nurses have a responsibility to listen to the patients, if they want to speak, they also have to respect those who do not wish to speak (36). This may be a strategy for some patients for continuing with their lives (36).

It is important that the nurse should respond to patients in pain with sensitivity, non-judgemental listening and openness (12). In two studies aimed at investigating what it meant to people to experience chronic pain, it was found that it was crucial for many of them that others should do believe that the pain existed (35, 36) as was the presence of hope of relief (36). Struggling for relief from pain was also a theme which arose in the analysis of data obtained from interviews with nurses and physicians regarding their experiences of men living with chronic pain (41). Confirmation in the meeting with the patient were also found to be of utmost importance in this study. According to the interviewed nurses and physicians, the men dared to disclose their pain experience more honestly when they felt confirmed. Furthermore, according to Gustavsson, confirmation "strengthens persons' positive self-assessment" (42, p 10).

Some studies have investigated the patients' own pain-controlling strategies (pain-reducing drugs not included) (31-33, 35). Examples of such strategies are exercise, heat and topical applications, dressings, massage and physiotherapy (32). The most commonly used psychological therapies are relaxation and distraction (i.e. activities that need concentration, listening to music, humour or company) (33). In one study, it was found that relaxation gave some patients more control over their chronic pain while others were not confident that relaxation would help (35). Furthermore, it is suggested that transcutaneous electrical nerve stimulation (TENS), acupuncture or therapeutic touch can be used for pain alleviation (33).

Nurses can learn from patients with chronic-pain conditions how to provide the nursing care (36).

#### *Factors influencing pain management*

Knowledge itself among nurses is not enough to guarantee improvement in patient care. However, it is the first step (43). Several authors have pointed out the important role that nurses have regarding pain management (30, 43-48). Some studies have also identified strategies and advices regarding the pain management to be used by the nurses (16, 32, 37, 49-51). Despite this, lack of knowledge regarding pain management has been found among students (45), in a sample of a nursing faculty (52), in hospital nurses (45, 48, 53-57) and in home-care nurses (12, 31).

Knowledge deficits among nurses have been found regarding pain assessment, (45, 53) and pharmacological pain treatment (12, 43, 45, 53, 58-60). One common problem which may also be caused by lack of knowledge is when the patient's chronic-pain condition is treated as if it were acute (35, 53). According to the patients in one study, it was common for their chronic pain not to be believed by the health-care professionals (35). Furthermore, they felt a lack of understanding and interest, and their chronic pain was not taken seriously (35).

In several studies, nurses themselves have been asked to rate barriers of importance in order to obtain optimal pain management for their patients. The following ratings have been found to be common: patients' reluctance to report pain, inadequate assessment of pain and pain relief, inadequate staff knowledge of pain management and patients' reluctance to take opiates (53, 54, 58, 61). In a review article, three reasons for inadequate pain management in elderly people were found: lack of proper pain assessment, potential risks of pharmacotherapy in the elderly and misconceptions regarding both the efficacy of non-pharmacological pain-management strategies and the attitudes of the elderly towards such treatment (14).

Even though the knowledge of pain management seems to have improved among hospital nurses, knowledge deficits continue (43, 60, 61). Nurses have also admitted feeling inadequate in managing pain relief for patients (45, 46). In a home-care setting it was found that the nurses needed education, support and also further continuing education (12, 31). McCaffery stated in reviewing the literature both in 1990 and in 1997 that, although progress had been made, there was still much to be done to improve nurses' pain management (43, 46).

#### *Educational programmes to improve pain management*

In 1996 O'Brien stated that research among nurses is needed in order to fully understand the effect of pain education and experience on practice (61). In order to try to improve the nurses' pain-management practice, home-care nurses working with cancer patients were offered an educational programme on one day a week for 6 weeks to become "pain management consultants" (62). The education included increased understanding of pain assessment, the importance of documentation, drugs and non-pharmacological methods. Data were collected from the nurses by a questionnaire but also from patient records before and after the educational programme. The authors concluded that no statistically significant increase of the nurses' knowledge was found, although the nurses reported feelings of improvement. In general, the cancer-pain management was infrequently documented and did not improve until 6 months after the education. The authors concluded that the pain-management programmes had made a difference, even though it was slow to occur (62).

In two other studies intended to evaluate educational programmes, the 5-day-long "Pain-resource nurse-training program" (63) and a 3-hour-long "Pain-monitoring program for nurses" (57), more knowledge was found regarding pain assessment. Finally, in a study among oncology nurses intended to evaluate the effect of a "Continuing education program" by extracting pain assessments from records, no significant differences in the documentation were found (64). However, the follow-up evaluation was performed after only two months.

None of the above-mentioned studies used a study design with both an intervention and a control group and they mainly focused on nurses' working with cancer patients.

In the study by O'Brien, predictors of pain knowledge for nurses were found to be the number of patients with cancer cared for in the last six months, the level of education among the nurses, the hours of pain-management education in the past five years, and willingness to attend a pain-management class (61). In another recently performed study, it was found that age and also additional pain courses were predictors of pain knowledge (57). Dalton found that older nurses and more years of experience were associated with more frequently performed, pain assessments (65). However, in a literature review, Sullivan found no evidence that the age of the nurses, educational preparation, years of experience and/or clinical subspecialty had any effect on the frequency of pain assessments (48).

#### *Assessment of pain*

Even though several authors have stated that thorough pain assessments are essential for good pain management (14, 33, 47, 50, 66, 67), few district nurses perform this (32). In assessing the pain, multidimensional approach is required (16, 35). An essential starting-point for the pain assessment is the patient's own pain reports (33, 36, 43, 48). Furthermore, pain assessment should include knowledge of physical health, cognitive functions and the outcome, which may be measured with assessment instruments (33). The visual analogue scale (VAS) is a common measuring instrument used to assess the intensity of the pain or the results of pain-management strategies (34). The VAS is a 10-cm line, on which the patient marks his or her pain (0 = "No pain" and 10 = "Worst possible pain"). However, if district nurses wish to help the patient, they also need to assess factors such as past regrets, occupation, the presence of other stressful problems and how well informed the patient feels about the painful condition (32). The patients' personal strategies for relieving their pain, as well as their "hopes and dreams for living", should also be assessed and recorded in the plans of care (36, p. 1247). Furthermore, it is necessary to consider factors such as personality, age, previous experiences and culture when evaluating the results of the pain assessment (68) and other well-known consequences of pain for the patients' well-being (31). It is recommended that nurses who meet elderly patients routinely should assess them for the presence of chronic pain (69, 70).

It is important to be aware of attitudes and beliefs among the health-care personnel that may influence the pain assessment. Closs, for instance, claims that perception of pain has long been assumed to diminish with ageing, although there is no clear evidence of this (33). She concludes that it should not be assumed that elderly people experience less pain than younger, unless research evidence is produced (33). In a review article, it was also stated that insufficient data are available to determine whether chronic-pain problems have a greater negative impact on the well-being of the elderly, compared with the younger patients (71). Lately, in another review article, some evidence was found that elderly patients, compared with younger ones with chronic pain, rate lower scores on the sensory dimension of pain, but there is little evidence of whether depression and anxiety are different across the age-groups (14). According to several authors, pain is definitely not a normal consequence of the ageing process (14, 66, 69-72).

It has been found that nurses spend little time in assessing the effect of pain on quality-of-life factors, such as sleeping, eating, working and activity (65). Research findings have also shown inconsistencies in nurses' ratings and patients' ratings of pain (48). For example, it has been found that the district nurses underestimate the patients' levels of greatest pain and overestimate their levels of least pain (32). Furthermore, even though the most reliable indicator of pain is the patient's self-report (43, 48) this was understood by only less than one half of the surveyed nurses in a study (43). In another study, 44% of the nurses thought that the estimation of pain by a physician or a nurse was more valid than the patient's self-report

(53). Furthermore, it was found that the nurses believed that 22% of the patients over-reported pain (58).

There may also be factors among the patients which can lead to inadequate pain control. For example, many elderly patients may not report pain because they do not want to bother anyone (16, 22, 66) or do not want to be labelled as “bad patients” (72). Even though they are willing to talk about their pain, they may avoid this in order not to “take up” the professionals’ time (72). Elderly people may not request pain relief, which means that the older generation may suffer more in silence than younger people do (33, 66). Another problem which may lead to inadequate pain relief for patients may be that the nurses expect the patients to ask for pain relief if they need it, but, on the other hand, the patients expect the nurse to know when they are in pain and need pain relief (73). Furthermore, in some cultures it is socially unacceptable to complain about pain (12). Pain management could be improved if nurses assessed the elderly patients’ beliefs regarding themselves and their attitudes to the ageing process (72).

Finally, it has to be noted that pain management is a multidisciplinary responsibility. Nurses alone cannot achieve optimal pain management. As nurses become better educated and more conscious of pain issues, insights must be shared with the health-care team (48).

### **Nursing documentation**

The district nurse is obliged by the law to document essential information about the patient and the care in the patient’s record (74). This is important for several reasons; to deliver good and safe care (10), to create a tool for the everyday clinical work, for the continuity of the care, as a source of information for the patients and their relatives, for supervision and control, and as a source for nursing research (75).

The nursing process is a goal-oriented, systematic, problem-solving model (76) which can be used in education, clinical practice and research (77) and as a support for the nursing documentation (68). It is suggested in the Swedish General Advisory on Nursing that this systematic approach should be used in the nursing documentation (10). Although the nursing process has been criticised (78, 79) it has been suggested that the model can be used to assess, treat and follow-up chronic-pain conditions in patients (12, 13, 80, 81). The nursing process must, however, be guided and supported by professional knowledge and skills (82).

The VIPS nursing-documentation model is based on the nursing process and the four key concepts of well-being, integrity, prevention and safety (68). These four concepts may be seen as indicators of the outcome of the health-care service (83). A suggested quality goal for the nursing documentation is a “nursing documentation which can be retrospectively monitored, is available for each patient, designed to meet the conditions for safe and satisfactory individualised care, and characterised by optimal continuity” (84, p. 123).

In a study recently performed in the South-western Health-care Region, it was shown that the majority of the district nurses regarded their own knowledge of nursing documentation as insufficient (85). The lack of a model for the nursing documentation was found in this study to be the greatest problem, followed by lack of time (85).

#### *Nursing documentation regarding patients with chronic-pain conditions*

Independently of the cause of the pain, pain management also includes accurate nursing documentation in the patients’ records (47, 86). In one study, it was confirmed that the patients’ individual strategies to obtain relief for their pain and their hopes and dreams for living should be recorded in the care plan (36). In a review of the records in a hospital setting, it was found that 76% of the records lacked documentation of the use of a patient-self-rating tool by nurses to assess pain, despite a high reported use (76%) of such a tool (54). Furthermore, it was found that 90% of the records had no documentation of the use of non-pharmacological interventions to relieve pain (54).

After an educational programme in nursing documentation, improvements were found regarding the nurse's documentation of pain-intensity ratings, location of pain, number of sites of pain, presence of confusions, anxious or depressed moods, sleep, vomiting, constipation and general activity (62). However, according to McCaffery, the nurses may record what the patient says, although they do not necessarily feel obliged to act upon it (43). In a study performed in a home-care setting, it was stated that research was needed regarding nurses' pain documentation as an integral part of the nursing process (12).

## **Patient satisfaction**

### *The concept*

Patient satisfaction is considered to be a multidimensional concept (87). The meaning of the concept differs according to (a) "the epoch and culture or the society to which reference is being made", (b) "the intended level, for example the individual, organisational or social level", and (c) "who defines the concepts, for example the patients, the relatives or the staff" (87). Mahon found in a recent review of the literature that there was no common definition of the concept of "patient satisfaction" (88). However, Mahon states that it is a subjective measure and represents perceived needs, expectations and experiences of care (88). The patient satisfaction has also been described as the degree of relationship between a patient's expectations of the nursing care and his or her perception of the care received (89). Another model suggests looking at the relationship between the subjective importance of the care and the perceived reality (90).

### *Reasons for measuring patient satisfaction*

Patient satisfaction has become an important indicator of the quality of care (91-94). Patient satisfaction, or dissatisfaction, is the patient's view of the quality of the care and can contribute to the evaluation of the outcome, process and structure of the health-care service (95). It has also been stated that only when the patient is satisfied can the health care be considered to be of high quality (96) and to have achieved its goal (93).

Satisfied patients seem to be more willing to follow treatment regimes and to return to the same provider when they need care in the future (88, 92, 93, 95, 97). For the patients, it may also be important to know that their opinions count (5). In a democratic society, the patients must have the right to give their opinions about factors that influence them (93). They also seem to be the best judges of some aspects of care, e.g., interpersonal relations (93). Furthermore, the investigation of patient satisfaction is an opportunity for nurses to learn from the patients and to improve the nursing care (98).

### *Measuring patient satisfaction*

As Mahon (88) concluded, it is important to determine what patients regard as important and what they expect from the nursing care, before attempting to measure their satisfaction with it. It may also be important to discuss with patients what they can expect from the nurse (88).

Two commonly used methods of measuring patient satisfaction are questionnaires or interviews (97). It is important to make clear the purpose of the investigation, as the choice of method depends on that. Interviews have been said to be preferable (97), although there are some negative issues to consider, e.g., they are more time-consuming and more costly, the effect of the interviewer cannot be excluded and only a small sample can usually be reached (99). The opposite is applicable to questionnaires. However, many patients cannot be given a questionnaire because of medical and/or cognitive impairments or language difficulties (100). Furthermore, to perform an investigation using a questionnaire may increase the number of non-responders (99). If questionnaires are used, it is important to choose carefully the point in time when the measurement is to be made and also to consider the wording of the items (97, 99).

### *Factors of importance for patient satisfaction*

Patient satisfaction with the quality of nursing care has been found to be the most important predictor of the patients' overall satisfaction with their hospital care (88, 91). Weiss found that the patients' satisfaction with the care they had received increased as they gained more confidence in the community medical-care system (101). Age, sex, race, education and income seemed not to be as important as confidence, meeting the same health-care professional and being satisfied with life in general. Clearly and McNeil found when reviewing the literature that the more individual care a patient received, the greater was the level of satisfaction (91). Variables found to influence patient satisfaction are age (older patients often more satisfied), sex (female patients often more satisfied) (95), perceived health status (95, 102), physical function and social activities (102).

### *Factors influencing patient satisfaction with primary health care*

In studies performed to measure the patients' satisfaction with primary health care or home health-care, the following dimensions have been found to be important: technical quality of the care, communication, personal relationship between patient and provider, delivery of services (103), organisation of work, clinical skills, approaches to care, images of the good nurse (39), professional care, depth of relationship, perceived time spent with the primary-health-care professionals (104), availability, continuity, knowledge/professionalism, personal qualities, the relationship between the patient and the district nurse, participation and responsibility (105). It has also been concluded that the district nurses' technical competence and management of time are important to the patients (39).

## **Summary**

The district nurses are important, well known and integrated in the Swedish primary-health-care system. To be able to deliver a high quality of nursing care, great competence is necessary among the district nurses in a variety of areas. The management of chronic-pain conditions among patients in need seems to be an area of great importance, as these conditions may lead to undesirable consequences which may influence the patients' well-being. Chronic-pain conditions are common among the general population and among the elderly, a category of patients often met by the district nurses. Patients have been found to regard the alleviation of pain as an important task for the district nurses. However, pain management is a multidisciplinary responsibility and nurses alone cannot achieve optimal pain management. According to the literature, there seem to be many barriers against patients obtaining adequate pain management. Although many authors have pointed out the important role that nurses play in relieving pain, it has been found that one of the barriers to adequate pain management is that nurses are often inadequately prepared in this area. The results of several studies support the need for both basic and continuing pain-management education for nurses. However, there also seems to be a lack of controlled intervention studies regarding the possible effects of educational pain-management programmes among nurses, especially among district nurses. It has been found that research among nurses is needed to fully understand the effect of education and experience on practice. To obtain satisfactory pain management, the nurses' documentation is an important means. Several authors suggest that the nursing process can be used to document the care and pain management for patients in pain. Patient satisfaction, or dissatisfaction, is the patients' view of the quality of care. To ask for the patients' opinions is important and they also have the right to give their opinions about the care.

## **Aims**



**General aims**

The general aims of this thesis were to investigate some aspects of the district nurses' work with a focus on chronic-pain conditions and to investigate the patients' satisfaction with the primary health care.

**Specific aims**

To investigate the opinions of district nurses regarding their own knowledge, management and documentation of patients with chronic-pain conditions (*Study I*).

To investigate whether the district nurses' opinions regarding their own knowledge, management and nursing documentation of patients with chronic-pain conditions changed after the introduction of the "pain advisers" (*Study II*).

To review the nursing documentation related to chronic pain in the records of patients with chronic-pain conditions (*Study III*).

To investigate whether the nursing documentation regarding the patients' chronic-pain conditions changed after the introduction of "pain advisers" (*Study III*).

To investigate the opinions of patients with chronic-pain conditions regarding the confirmation in the meeting with the district nurse, the satisfaction with the received treatment, their own knowledge and understanding of the pain and their own well-being (*Study IV*).

To investigate whether the opinions of patients with chronic-pain conditions changed after the introduction of the "pain advisers" at primary-health-care centres (*Study IV*).

To investigate the patients' satisfaction with the care given by the district nurses at home and at the primary-health-care centres (*Study V*).

To identify the characteristics of patients dissatisfied with the nursing care (*Study V*).

## Material and methods

### Ethical approvals

Ethical approvals for the five studies included in this thesis were obtained from the Ethical Committee at the Huddinge University Hospital (Dnr: 227/96, *Studies I-IV*; Dnr: 273/95, *Study V*).

### Research setting, participants and records

#### *Study and control areas (Studies I-IV)*

The material was gathered from the South-western Health-care Region of Stockholm County Council. This region consists of 22 primary-health-care centres (PHCCs). In order to obtain a controlled study design, a study area (SA) and a control area (CA) were selected from the 22 PHCCs. The selection of the two areas was based on geographical considerations, with the requirement that there should not be any regular meetings between the district nurses in the two areas. One of the selected areas consisted of five and the other of seven PHCCs. The area with five PHCCs was selected by lot to be the SA and the other consequently became the CA.

#### *Pain advisers (Studies II-IV)*

The Swedish Nurses' Association (SSF) organised training for nurses to become "pain advisers". The 4-day course (3 days + 1 day after six months) included education given by both physicians and nurses in how to write a pain history, how to assess and analyse the patient's pain and how to implement, evaluate and document the pain control. The education also included pain physiology, pharmacology, non-pharmacological methods, possible effects of chronic-pain conditions on the patients' well-being and attitudes, and how to communicate with patients. Other important aims of the training were to prepare the pain advisers to participate in the evaluation of the quality of the pain control at their PHCCs. Furthermore, to be able to help colleagues to increase their knowledge and thereby give the patients with chronic-pain conditions an individual, high quality of care, in order that they might have the best possible well-being (106).

In summary, the pain advisers' role was to be an educational resource to their colleagues at their own PHCCs. After completing the course, the "pain advisers" continued to work as district nurses, which included both caring for patients at home and having an outpatient clinic of their own. They individually had to arrange how to perform their tasks with regard to the present conditions and possibilities at their own PHCCs within their usual working hours. No extra resources were given to the "pain advisers". However, to support the five (one per PHCC), designated, "pain advisers" after the completed course, one of the authors (L.T.) arranged regular meetings (2-4 hours each) during the study period (see below). These meetings (ten in all) comprised discussions between the "pain advisers" regarding the literature on and strategies for improving pain management and pain documentation at each PHCC. They also included visits to two different pain clinics. Information regarding how each "pain adviser" in detail arranged her work at the PHCC was not systematically collected. The "pain advisers" worked to improve the nursing care and the nursing documentation from 15 October 1996 onwards.

We found it interesting to investigate whether the concept described above was useful in achieving changes regarding some aspects of the district nurses' work and opinions with a focus on chronic-pain conditions.

#### *District nurses (Studies I and II)*

Before starting the education of the "pain advisers" in the SA, all the 72 district nurses at the 12 PHCCs (5 SA, 7 CA) were asked to fill in a questionnaire. The questionnaire was answered by 70 (97%) female district nurses with a mean age of 49 years (range 25-62). A

total of 65 (96%) of the district nurses had received their basic, professional education before 1986 (i.e. when the nursing process was introduced in the nurses' basic education (76)). The nurses had worked for 20 years (md = median, range 4-38) and had worked as district nurses for 8 years (md, range 1-25) (*Study I*).

In order to investigate whether the district nurses' opinions changed, the questionnaire was distributed once more (i.e. 15.5 months after the introduction of the pain advisers) to all the 73 district nurses employed at the time at the 12 PHCCs (5 SA, 7 CA). In the SA, 32 (94%) district nurses answered the questionnaire before the introduction of the pain advisers and 36 (97%) after. The corresponding numbers for the CA were 38 (100%) and 27 (75%), respectively. In the SA, 28 and in the CA, 25 district nurses answered the questionnaire both in 1996 and in 1998 (*Study II*).

The district nurses' ages, professional experiences and educational backgrounds are shown in Table 1.

Table 1. The district nurses' ages, professional experiences and educational backgrounds.

	1. SA96 <i>n</i> = 32	2. SA98 <i>n</i> = 36	3. CA96 <i>n</i> = 38	4. CA98 <i>n</i> = 27
Age (median)	52	51	50	46
Registered nurse before 1986 (%)	97	91	96	89
Number of years as nurse (median)	18	20	21	19
Number of years as district nurse (median)	12 <sup>a</sup>	11	5 <sup>a</sup>	8
University education in nursing documentation (%)	22 <sup>b</sup>	47 <sup>b</sup>	38	50
University education in pharmacology and drug prescription (%)	69	81	47	65
Education in pain and pain control (district nurses trained to become pain advisers included) (%)	16	35 <sup>c</sup>	8	8 <sup>c</sup>

<sup>a</sup>  $p < 0.01$  (1 vs. 3), <sup>b</sup>  $p < 0.05$  (1 vs. 2), <sup>c</sup>  $p < 0.05$  (2 vs. 4).

#### *Selection of records and patients with chronic-pain conditions (Studies III and IV)*

All the district nurses in the SA and the CA were in September 1996 and in January 1998 asked to register on a study-specific protocol, all patients older than 16 years with chronic-pain conditions with whom they were in contact. Chronic pain was defined as pain which had lasted for more than 3 months. A total of 145 (57 SA, 88 CA) patients were registered in 1996 and 104 (76 SA, 28 CA) patients in 1998 ([Table 2](#)). The district nurses were also asked to state the reason why the patients were having chronic pain.

The nursing records of all the registered patients (except for one in the SA in 1996 who was registered only by age and sex) were collected and reviewed for two periods, each about 8.5 months long and with 7 months in between (1 February to 14 October 1996 and 14 May 1997 to 2 February 1998, respectively). The assistant nurse's documentation was included in the review of the documentation (*Study III*).

The registration of the patients also formed the basis for an investigation of the patients' opinions of the care and their own well-being. However, before asking the patients to answer the questionnaire, the district nurses were asked to mark in the study-specific protocol which of the patients they considered unable to answer the questionnaire and also to state the reason why. For the reasons shown in Table 2, many patients did not receive the questionnaire (*Study IV*).

The questionnaire was answered by 84 (34 SA, 50 CA, 67%) patients in 1996 and 60 (43 SA, 17 CA, 77%) patients in 1998. A description of the patients who answered is given in Table 3. One significant difference was found on comparing the patients who answered the questionnaire and the patients considered unable to answer the questionnaire, the latter being older ( $p < 0.001$ ) in the SA in 1998.

Table 2. Overview of the registered patients with chronic-pain conditions and these who finally answered

	SA96	SA98	CA96	CA98
Registered patients	57	76	88	28
No. of patients considered unable to answer the questionnaire (excluded owing to medical and/or cognitive impairments) or considered unable to answer the questionnaire by the district nurses without them writing down any specific reason	-7	-26	-10	-0
No. of patients given oral information about the questionnaire by the district nurses and asked if they were willing to answer it	50	50	78	28
No. of patients who declined to participate	-1	-1	-1	-0
No. of patients who agreed to participate and were sent the questionnaire	49	49	77	28
No. of non-responding patients	-15	-6	-17	-11
No. of patients who answered the questionnaire	34	43	50	17

Table 3. Description of the patients with chronic pain conditions. Data are given as the number and percentage of patients answering the questionnaire.

	1. SA96 <i>n</i> = 34		2. SA98 <i>n</i> = 43		3. CA96 <i>n</i> = 50		4. CA98 <i>n</i> = 17	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Sex								
Women	30	(88)	34	(79)	37	(74)	12	(71)
Men	4	(12)	9	(21)	13	(26)	5	(29)
Age								
24-50	7	(21)	9	(21)	6	(12)	2	(12)
51-65	6	(18)	14	(33)	9	(18)	6	(35)
66-80	12	(35)	13	(30)	23	(46)	6	(35)
81-	9	(26)	7	(16)	12	(24)	3	(18)

#### *Selection of patients for investigation of patient satisfaction (Study V)*

All the district nurses at all the 22 PHCCs were asked during one week in 1995 to register all the patients seeking care at the district nurses' out-patient clinic and also the patients whom they visited at home. The patients were noted in a study-specific protocol. The patients had to be older than 16 years and considered to be in need of treatment or care by the district nurses for more than 2 weeks. A total of 593 home-care (HC) and 492 out-clinic (OC) patients were registered. For the reasons shown in Table 4, many patients did not receive the questionnaire that asked about the patients' satisfaction with the care given by the district nurses. The questionnaire was answered by 168 (62%) HC and 264 (72%) OC patients. A description of the answering patients is shown in Table 5.

Table 4. Overview of the registered patients and those who finally answered.

	HC	OC
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• Registered patients	<b>593</b>	<b>492</b>
• No. of patients considered unable to answer the questionnaire by the district nurses (excluded owing to medical and/or cognitive impairments)	-258	-74
• No. of patients considered unable to answer the questionnaire by the district nurses without the district nurses writing down any specific reason	-39	-5
• No. of patients given oral information and shown the questionnaire by the district nurses	<b>296</b>	<b>413</b>
• No. of patients who declined to participate	-12	-8
• No. of patients who agreed to participate	<b>284</b>	<b>405</b>
• No. of patients excluded owing to set limit of 60 patients per PHCC	-12	-40
• No. of patients finally sent the questionnaire	<b>272</b>	<b>365</b>
• No. of non-responding patients	-104	-101
• No. of patients who answered the questionnaire	<b>168</b>	<b>264</b>

Table 5. Description of patients who answered the questionnaire. Data are given as the numbers (*n*) and percentages (%) of patients.

	HC		OC	
	<i>n</i>	(%)	<i>n</i>	(%)
<b>Sex</b>				
Women	102	(61)	142	(54)
Men	55	(33)	115	(43)
Not registered	11	(6)	7	(3)
<b>Age, years</b>				
21-50	4	(2)	26	(10)
51-65	21	(13)	73	(27)
66-80	82	(49)	126	(48)
81-	58	(34)	39	(15)
Not registered	3	(2)	0	(0)
<b>Education</b>				
Compulsory school	129	(77)	161	(61)
Upper secondary school	21	(12)	72	(27)
University	10	(6)	21	(8)
Not registered	8	(5)	10	(4)
<b>Living conditions</b>				
Living alone	96	(57)	97	(37)
Cohabiting	70	(42)	161	(61)
Not registered	2	(1)	6	(2)

## **Instruments**

### *The questionnaire to the district nurses (Studies I and II)*

The questionnaire consisted of a total of 51 questions and was developed in order to find out the district nurses' educational backgrounds including education in nursing documentation, professional experience and knowledge of pain and pain control. Furthermore, questions were included to find out the nurses' satisfaction with their own pain management (including pain assessment and nursing documentation) and to ask for the routines regarding pain management at the PHCCs. In the questionnaire, chronic pain was defined as pain which had lasted for more than 3 months. Mainly verbal rating scales were used as answering formats for the questionnaire. These ordinal-data scales consisted of four to six answering alternatives ranging from "very satisfied" to "Very dissatisfied" or from "Very good" to "Very bad". The questions regarding to what extent the district nurses documented data about their patients' chronic-pain conditions were answered by using five answering alternatives. For example: To what extent do you today document pain assessment? Answering alternatives: for none of my patients, for a few of my patients, for half of my patients, for most of my patients or for all of my patients. Visual analogue scale (VAS) was also used, ranging from 0 mm = "No, not at all" to 100 mm = "Yes, fully satisfied". The alternatives "Yes" or "No" were also used for some questions. The study-specific questionnaire was pilot-tested and discussed with eight nurses. No significant changes were made in the questionnaire after this.

### *The protocol for reviewing the patients' records (Study III)*

A protocol for both an overall and a detailed review of the nurses' documentation related to chronic pain was developed, using a combination of an existing protocol for documentation review (NoGa<sup>®</sup>) (107), the VIPS nursing documentation-model (68) and knowledge derived from the literature regarding pain assessment documentation and patients' well-being in relation to pain (30, 64, 68, 84). The protocol used for the review is shown in Appendix 1.

### *The questionnaire to the patients with chronic-pain conditions (Study IV)*

For the study, 17 questions were selected from three already existing instruments: the Patient Questionnaire on Confirmation (10/15 questions) (40), the Treatment-satisfaction Questionnaire (2/8 questions) (108) and the Health-index Questionnaire (5/11 questions) (84, 109). The questions were slightly modified in order to focus them on pain and the meetings with the district nurses. Seven additional questions were added by the authors of the study. The study-specific questionnaire was pilot-tested on and discussed with eight nurses. No significant changes were made in the questionnaire after this. The questionnaire consisted of 24 questions in total.

### *The QPP questionnaire to measure patient satisfaction (Study V)*

To collect the data regarding the patients' satisfaction with the care, the QPP questionnaire was used (Quality of Care from the Patient's Perspective) (90, 110, 111). The theoretical model describes the patients' perceptions of the quality of care in the following four dimensions: the medical-technical competence of the caregivers; the physical-technical conditions of the care organisation; the degree of identity orientation in the attitudes and actions of the caregivers; and the socio-cultural atmosphere of the care organisation (90). Each item in the QPP questionnaire is answered by the patients in two ways: "perceived reality" (A) and "subjective importance" (B). The scales used are shown in Figure 1.

	(A) I have had...		(B) This is how important it was for me...	
...the best possible advice and directions from the district nurse about my self-care	Fully agree	4	Of very great importance	4
	Mostly agree	3	Of great importance	3
	Partly agree	2	Of some importance	2
	Do not agree at all	1	Of no importance	1
	Of no current interest	x	Of no current interest	x
...effective pain alleviation when necessary	Fully agree	4	Of very great importance	4
	Mostly agree	3	Of great importance	3
	Partly agree	2	Of some importance	2
	Do not agree at all	1	Of no importance	1
	Of no current interest	x	Of no current interest	x

Figure 1. Examples of questions and the answering alternatives in the QPP questionnaire.

A quality-of-care index (QPP index) can be calculated, using the formula *subjective-importance score*  $\times$  ( $2 \times$  *perceived-reality score* - *subjective-importance score*) (90). The QPP index may range from -8 (lowest quality) to 16 (highest quality). Example: I have received effective pain alleviation when necessary:  $4 \times (2 \times 3 - 4) = 8$  QPP index

## Analyses

Non-parametric tests were used for the analysis of ordinal data. The Wilcoxon summary ranking test (comparison between two groups) was applied in the statistical analysis (*Studies I, II, IV and V*). When the Kruskal-Wallis test (comparison between several groups) showed a significant difference ( $p < 0.05$ ), the Wilcoxon summary-ranking test comparison between two groups (Mann Whitney U-test) was applied in order to identify the groups between which significance existed (*Study V*). The Wilcoxon signed-ranks test was applied for individual comparisons (*Studies II and IV*). The limit of statistical significance was  $p < 0.05$ . However, owing to the problem of multiple significance testing, the limit of statistical significance was arbitrarily chosen to be  $p < 0.01$  when appropriate (*Study V*). Nominal data were tested by the chi-square test and Fisher's exact test.

## Results

### District nurses' opinions regarding the knowledge and management of patients with chronic-pain conditions (*Studies I and II*)

*Study I* showed that no written information or policies regarding pain management were available at the PHCCs before the introduction of "pain advisers". In *Study II*, 26% of the district nurses in the SA98 stated that written information or policies were available at their PHCCs. This improvement was statistically significant ( $p < 0.01$ ) and was found only in the SA (Table 6).

About one-fourth of the district nurses, both in the SA98 (29%) and in the CA98 (28%), stated that it was not possible for them to get any support when they cared for people with chronic-pain conditions. The corresponding figures were 37% in the SA96 and 27% in the CA96. These differences were not statistically significant. Support from the "pain advisers" was not asked for in the questionnaire (*Study II*).

In the SA98, after the introduction of the "pain advisers", the district nurses stated that they cared for a larger proportion of patients with chronic-pain conditions, as compared with the nurses in the CA98 ( $p < 0.05$ ) (*Study II*).

In 1996, 37 of the district nurses at the 12 PHCCs stated that they were satisfied or quite satisfied with their own management of patients with chronic-pain conditions (group A) and 32 that they were not (group B). When compared statistically significant differences were found. Group A were found to be more satisfied with the co-operation between colleagues ( $p=0.001$ ) and other health-care professionals at the PHCC ( $p<0.001$ ), the present pain management routines at their PHCC ( $p<0.001$ ), knowledge of non-pharmacological methods ( $p<0.01$ ), their own preparedness in meeting patients with chronic-pain conditions ( $p<0.001$ ) and their own follow-ups of the patients ( $p<0.01$ ). However, group B were more positive to the idea of a colleague in the future being designated as a “pain adviser” ( $p<0.05$ ) (*Study I*).

The district nurses in *Study I* perceived their knowledge of alternative methods of reducing pain as less than their knowledge of the pain aetiology ( $p=0.0001$ ) and pharmacological pain treatment ( $p=0.0001$ ). Furthermore, the district nurses perceived the pain control for patients with leg ulcers as worse than that for patients with arthrosis of the knee and/or hip joints ( $p<0.05$ ) and/or the patients with cancer-related pain ( $p=0.001$ ) (*Study I*).

All the district nurses in the SA98 (100%) found the idea of a district nurse being designated as a “pain adviser” to be very good, good or quite good. The district nurses’ opinions regarding their knowledge and management of patients with chronic-pain conditions are shown in Table 6 (*Study II*). The district nurses’ opinions within and between the SA and the CA in 1996 and 1998 were compared and the statistically significant differences found are shown in Table 6.

With two exceptions, the statistically significant improvements presented in Table 6 did not differ, when the “pain advisers” were excluded from the sample of district nurses in the SA96 and the SA98. The individual pain assessments of the patients and the documentation regarding the nursing pain history were then not improved.

The district nurses opinions among those who answered the questionnaire in both 1996 and 1998 were also compared. In the SA, the statistically significant differences presented in Table 6 did not differ except for one question: the documentation regarding the nursing pain history was then found not to be statistically significantly improved. In the CA the statistically significant differences presented in Table 6 were no longer found, i.e. the district nurses’ opinions regarding the better pain control for patients with leg ulcers and the better documentation of pain status.



Table 6. The district nurses' opinions regarding their knowledge and management of patients with chronic-pain conditions. The results are presented in percentages (very satisfied, satisfied and/or quite satisfied **or alternatively** very good, good and/or quite good **or alternatively** yes) of the total number of answers (*Study II*).

	1. SA 1996	2. SA 1998	Comparison 1 vs. 2	3. CA 1996	4. CA 1998	Comparison 3 vs. 4	Comparison 1 vs. 3	Comparison 2 vs. 4
	<i>n</i> = 32 %	<i>n</i> = 36 %	<i>p</i> -value	<i>n</i> = 38 %	<i>n</i> = 27 %	<i>p</i> -value	<i>p</i> -value	<i>p</i> -value
• Available written information or policy (yes)	0	26	< 0.01	0	0	n.s.	n.s.	< 0.01
• Co-operation between colleagues at the PHCC	75	91	n.s.	71	65	n.s.	n.s.	n.s.
• Co-operation with other health-care professionals at the PHCC	50	41	n.s.	63	61	n.s.	n.s.	n.s.
• Co-operation with others outside the PHCC	29	3	< 0.01	19	23	n.s.	n.s.	< 0.05
• Own knowledge of pain aetiology	53	69	n.s.	79	58	n.s.	n.s.	n.s.
• Own knowledge of pharmacology	59	71	n.s.	71	81	n.s.	n.s.	n.s.
• Own knowledge of non-pharmacological methods	31	53	n.s.	32	52	n.s.	n.s.	n.s.
• Own preparedness in meeting patients in chronic pain	34	56	n.s.	61	71	n.s.	< 0.05	n.s.
• Own perceptions of the overall pain control at their PHCCs regarding patients with:								
Pain from leg ulcers	22	53	< 0.05	42	73	< 0.05	n.s.	n.s.
Pain from arthrosis of the knee and/or hip joint	39	36	n.s.	41	65	n.s.	n.s.	< 0.01
Pain from cancer	33	22	n.s.	21	50	n.s.	n.s.	n.s.
• Satisfaction regarding the pain-management routines at their PHCC	20	44	< 0.001	54	50	n.s.	n.s.	n.s.
• Interest at their PHCC in questions regarding management and treatment of patients with chronic-pain conditions	83	94	n.s.	68	54	n.s.	n.s.	< 0.001
• Satisfaction with their own management of patients suffering from chronic-pain conditions	37	58	n.s.	68	74	n.s.	< 0.05	n.s.
• Performing individual pain assessments on at least half of the patients.	9	23	< 0.05	6	22	n.s.	n.s.	n.s.
• Using visual analogue scale (VAS) to measure the patients' pain (yes)	6	66	< 0.001	8	19	n.s.	n.s.	< 0.001
• Using visual analogue scale (VAS) to evaluate the patients' pain (yes)	6	41	< 0.01	11	8	n.s.	n.s.	< 0.01

### Pain assessment and nursing documentation (*Studies I and II*)

In *Study I*, 47 (70%) of the district nurses stated that they never performed individual pain assessments on their patients. Five district nurses (7%) stated that they used VAS as a tool to measure the patients' pain, and six (9%) that they used it to evaluate and follow up the patients' pain. The district nurses rated low scores when asked if they were satisfied with their own follow-ups (md 22 on VAS with 100 mm = "Yes, fully satisfied") (*Study I*).

In *Study II*, in both areas in 1996 and 1998, the district nurses stated that they performed individual pain assessments to a small extent. However, in the SA98, it was found that individual pain assessments were performed by the district nurses to a greater extent, compared with the nurses in the SA96 ( $p < 0.05$ ) (Table 6). Furthermore, a larger proportion of the district nurses in the SA98 stated that they used VAS to perform the assessment ( $p < 0.001$ ) and to evaluate the effects of pain treatment ( $p < 0.01$ ), as compared with the nurses both in the SA96 and in the CA98 (Table 6).

The district nurses' opinions in both areas in 1996 and 1998 regarding the question whether they were satisfied with their own follow-ups of the management of patients with chronic pain are shown in Figure 2 (*Study II*). In the Figures 2 and 3, the box size represents the middle 50% (interquartile range Q1 to Q3) of the data, and the lines (or "whiskers") extending to either side, indicate the general extent of the data (lower limit Q1 -1.5 (Q3 -Q1) upper limit Q3 +1.5 (Q3 -Q1)). The median value is marked at the box. Outliers are points outside the "whiskers" and are plotted with asterisks (\*) (only Figure 3). No statistically significant differences were found regarding this question within or between the SA or the CA in 1996 or 1998 (Figure 2).

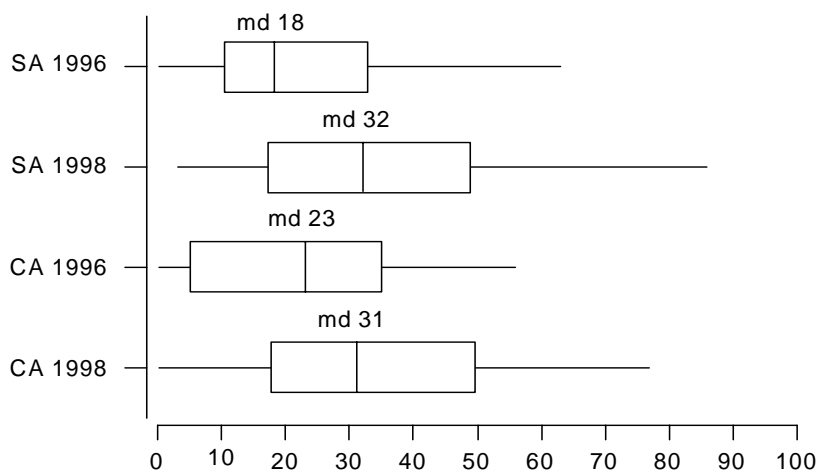


Figure 2. The district nurses' satisfaction regarding their own follow-ups of the pain management (on VAS 100 mm = "yes, fully satisfied") (n.s).

**District nurses' opinions regarding their own documentation before and after the introduction of "pain advisers" in relation to the review of it (Studies I-III)**

When asked, the district nurses reported that they documented "nursing history" for 24% of at least half of their patients with chronic-pain conditions. The corresponding figures for "nursing status" and "nursing treatments/interventions" were 27% and 33%, respectively. "Nursing diagnosis", "goals", "results" and "epicrisis/nursing-care message" were said to be rarely used for the documentation (3-15%) (*Study I*) (Table 7).

Table 7. District nurses' reported documentation, according to the steps of the nursing process with regard to patients with chronic-pain conditions. The results are presented as the numbers and percentages of district nurses.

	For all/most of my patients		For half of my patients		For none/a few of my patients	
	<i>n</i>	(%)	<i>n</i>	(%)	<i>n</i>	(%)
Nursing history ( <i>n</i> = 67)	16	(24)	1	(1)	50	(75)
Nursing status ( <i>n</i> = 67)	18	(27)	5	(7)	44	(66)
Nursing diagnosis ( <i>n</i> = 66)	3	(5)	1	(1)	62	(94)
Nursing goal ( <i>n</i> = 67)	3	(4)	0	(0)	64	(96)
Planned treatment ( <i>n</i> = 66)	10	(15)	2	(3)	54	(82)
Nursing treatments/interventions ( <i>n</i> = 67)	22	(33)	6	(9)	39	(58)
Results ( <i>n</i> = 67)	5	(7)	6	(9)	56	(84)
Epicrisis or nursing-care message ( <i>n</i> = 65)	2	(3)	1	(2)	62	(95)

In *Study II*, at the follow-up in 1998, the district nurses in the SA and the CA reported that they documented "nursing history" for 32-52% of at least half of their patients with chronic-pain conditions. The corresponding figures for "nursing status" and "nursing treatments/interventions" were 39-50% and 32-57%, respectively. "Nursing diagnosis", "goals", "results" and "epicrisis/nursing-care message" were said to be rarely used for the documentation (0-21%).

On reviewing the district nurses' documentation (*Study III*), it was found that the district nurses in the SA and the CA in 1996 and 1998 documented "nursing history" for 2-6% (totally obtained scores of maximum possible score) of their patients with chronic-pain conditions, "nursing status" for 45-55% and "nursing interventions" for 29-35%, but that the other parts of the main keywords/nursing process (Appendix I) could be found in the records only to a small extent (0-9%).

In *Study II*, no statistically significant differences were found between the district nurses' opinions in the SA and the CA in 1996 or 1998 regarding the nursing documentation related to chronic pain. However, within the SA, the district nurses considered that they documented nursing history to a greater extent after the introduction of the "pain advisers" ( $p < 0.05$ ) and in the CA the district nurses considered that they documented nursing status related to chronic pain to a greater extent in 1998 ( $p < 0.05$ ). These improvements could not be found when reviewing the patients' records (i.e. that, for example, the main keyword "nursing status" was found at least once in each patient's record within the study period) (*Study III*).

The district nurses in both the SA and the CA who answered the questionnaire on both occasions stated that they to a statistically significant, higher degree documented nursing goals, and planned nursing interventions ( $p < 0.05$ ), but to a lower degree nursing results ( $p < 0.05$ ) in 1998, as compared with 1996. The district nurses in the CA also stated that they documented nursing interventions to a lower degree in 1998, as compared with 1996 ( $p < 0.01$ ) (*Study II*). These differences could not be found when reviewing the patients' records (*Study III*).

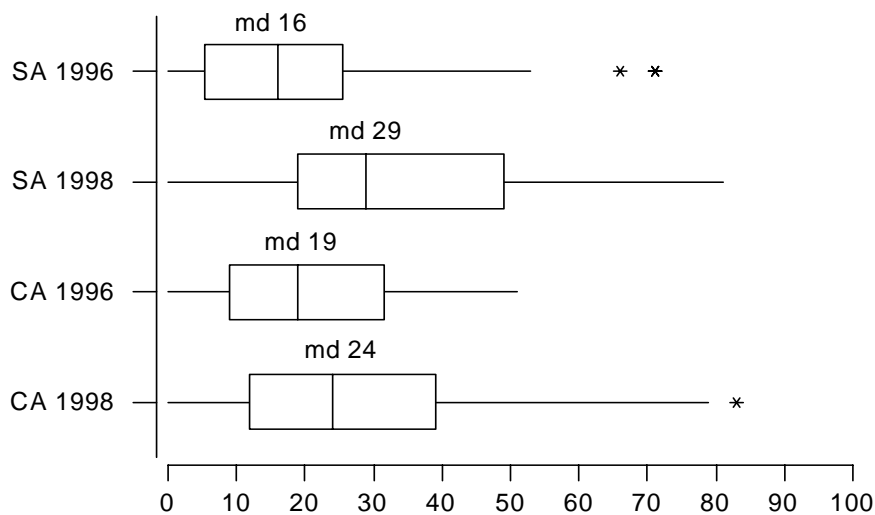


Figure 3. The district nurses' satisfaction with their own nursing documentation (VAS 100 mm = "Yes, fully satisfied"). The difference between SA 1996 and SA 1998 was statistically significant ( $p < 0.01$ ).

The district nurses rated low scores when asked if they were satisfied with their own nursing documentation regarding the patients with chronic-pain conditions (md 17, on VAS with 100 mm = "yes, fully satisfied") (*Study I*). The district nurses' opinions in both areas in 1996 and 1998 regarding this question are shown in Figure 3 (*Study II*). In the SA98, the district nurses were found to be more satisfied with their nursing documentation regarding the patients with chronic-pain conditions, as compared with the nurses in the SA96 ( $p < 0.01$ ).

#### **The documentation after the introduction of "pain advisers" (*Study III*)**

After the introduction of the "pain advisers" in the SA, the review of the nursing records showed some improvements: a more detailed documentation was found regarding the aspects of pain status ( $p < 0.05$ ), increased use of the eight descriptions of the patients' chronic pain ( $p < 0.001$ ) and of the five different descriptions of the patients' well-being ( $p < 0.01$ ). Furthermore, the proportion of records containing documentation as to whether the patient felt or did not feel well-informed about his or her chronic-pain condition increased from 0 to 11% of the total number of reviewed records ( $n = 76$ ) ( $p < 0.05$ ).

The proportion of documentation regarding direct and indirect "nursing care and communication" had increased in both the SA and the CA ( $p < 0.01$ ) at the follow-up in 1998. The most commonly documented intervention in the SA both in 1996 and in 1998 was indirect "drug management" (e.g, distribution of drugs into a pill dispenser). The proportion of documentation of "independent" nursing interventions increased in the CA ( $p < 0.01$ ) at the follow-up.

In the CA only, it was found that the distributed proportion changed with the result that the number of main keywords increased ( $p < 0.01$ ), but very few nurses used more than two keywords (Table 8).

Table 8. District nurses' documentation according to main keywords related to chronic pain. The results are given as the number of records (*n*) and the percentage (%) of all reviewed records.

Number of main keywords found	1. SA96		2. SA98		3. CA96		4. CA98	
	<i>n</i> <sup>a</sup>	(%)	<i>n</i>	(%)	<i>n</i> <sup>a,b</sup>	(%)	<i>n</i> <sup>b</sup>	(%)
0	9	(16)	9	(12)	38	(43)	3	(11)
1	15	(27)	21	(28)	23	(26)	12	(43)
2	20	(36)	24	(31)	21	(24)	10	(36)
>2	12	(21)	22	(28)	6	(7)	3	(10)
Total	56	(100)	76	(100)	88	(100)	28	(100)

Fisher's test regarding distribution, <sup>a</sup>  $p < 0.01$  (1 vs. 3), <sup>b</sup>  $p < 0.01$  (3 vs. 4).

### **Patients' opinions of the care and their own well-being before and after the introduction of "pain advisers" and in relation to the district nurses' documentation (*Studies III, IV*)**

Among the patients in both the SA and the CA, in 1996 as well as in 1998, median scores of 5-6 (maximum 6) were obtained in 5 out of 6 questions asking whether the patients felt confirmed at the meetings with the district nurses. Lower median scores (4) were obtained from the patients in both areas (1996 and 1998) when they were asked if they had experienced increased capacity to manage their life situations after the contacts with the district nurses (*Study IV*).

The patients in both areas, in 1996 and 1998, rated median scores of 3-4.5 (maximum 6) regarding satisfaction with the present treatment or knowledge and understanding of the pain. No statistically significant differences were found within or between the different areas in 1996 or 1998. Neither were any statistically significant differences found regarding patients who answered "Yes" to the question whether they had received advice and recommendations (55-76%) and/or information/education (25-53%) from the district nurses (*Study IV*). However, as mentioned above, the information regarding whether the patient felt or did not feel well-informed was found to be documented to a greater extent by the district nurses after the introduction of the "pain advisers" in the SA (SA96 0%, SA98 11%,  $p < 0.05$ ) (*Study III*). Furthermore, in *Study IV*, after the introduction of the "pain advisers", the patients in the SA who stated that they had received advice and recommendations from the district nurses considered that this had resulted in less pain ( $p < 0.05$ ) and that the information/education received had resulted in more knowledge with which to understand their chronic pain, compared with 1996 ( $p < 0.05$ ). These statistically significant differences were found only in the SA. However, in both the SA and the CA in 1998, it was found that the patients who had received advice and recommendations and/or information/education to a higher degree were more satisfied with some aspects of the nursing care, compared with the patients who stated that they had not (Table 9).

In general, the patients stated that their chronic-pain condition influenced their well-being (*Study IV*) but no statistically significant improvements of the different aspects of the patients' well-being could be found in the SA after the introduction of the "pain advisers" (*Study IV*). However, in the SA, a higher score was found compared with the maximum possible score regarding the nursing documentation of the patients' well-being ( $p < 0.01$ ) (*Study III*). According to the patients in the CA at the follow-up, the chronic pain influenced their energy less ( $p < 0.05$ ) (*Study IV*). It was also found that the documentation regarding the patients' well-being increased ( $p < 0.01$ ) (*Study III*).

Table 9. Statistically significant differences found when patients who replied “Yes” were compared with patients who replied “No” to the questions whether they had received advice and recommendations and/or information/education regarding their chronic pain.

	SA98	CA98
<i>Received advice and recommendations</i>		
Patients who replied “Yes” (SA $n = 26$ , CA $n = 13$ ) stated to a greater extent that they:		
• Were given the opportunity to bring up questions and problems regarding their pain as they desired.	**	-
• Received professional and competent caring regarding their pain.	**	-
• Felt satisfied with the present treatment of their pain.	**	**
<i>Received information/education</i>		
Patients who replied “Yes” (SA $n = 17$ , CA $n = 9$ ) stated to a greater extent that they:		
• Received professional and competent caring regarding their pain.	-	**
• Experienced a better capacity to manage their life situation since they made contact with the district nurse.	**	-

\*\* =  $p < 0.01$ .

### Patient satisfaction (Study V)

The study showed that the patients were very satisfied with the care received at home or at the district nurses’ outpatient clinics. A median QPP index of 16 (highest quality) was found on 22/31 items (HC) and 22/34 items (OC). The items that received lower median QPP indexes than 16 are shown in Table 10.

Table 10. Patients’ satisfaction with the care given by the district nurses. Items with median QPP index  $< 16$ . Patients in home-care (HC) and at outpatient clinic (OC).

Item	HC md	OC md
• Effective pain alleviation when necessary	15	
• The safety of the care situation at the outpatient clinic <sup>a</sup>		15
• Safety of the living environment <sup>b</sup>	9	
• Feeling of interest from district nurses in the patients’ outlook on life	9	9
• The patients’ possibility of participating (medical care)	15	9
• The patients’ possibility of participating (personal care)		15
• Information regarding, e.g. treatments	15	15
• Information regarding drugs	15	15
• Feeling that desires and needs were considered	15	9
• Meaningful recreation during waiting time <sup>a</sup>		8
• Comfortable waiting-room <sup>a</sup>		9
• Help regarding meaningful activity during the day	9	
• Well-functioning organisation		15
• Possibility of meeting the same district nurse		9
• Possibility of reaching the district nurse on the phone	9	15

<sup>a</sup> Only OC patients were asked. <sup>b</sup> Only HC patients were asked.

The HC patients were found to be older ( $p < 0.001$ ) and were more often living alone ( $p < 0.001$ ). They rated their physical health ( $p < 0.001$ ) and psychological well-being ( $p < 0.001$ ) as worse compared with the OC patients. The HC patients were more satisfied with regard to the clarity about which of the district nurses was responsible for their nursing care ( $p < 0.01$ ).

The younger OC patients (21-65 years) were less satisfied with the access to magazines or papers in the waiting-room ( $p < 0.001$ ), the comfort of the waiting-room ( $p < 0.01$ ) and the possibility of having access to a telephone at the outpatient clinic ( $p < 0.01$ ).

### Dissatisfied patients (*Study V*)

The five items most frequently marked by the identified “dissatisfied” patients (arbitrarily defined as patients who reported a QPP index of 0 or less in at least one item) are shown in Table 11.

Table 11. Items most frequently marked by the “dissatisfied” patients (QPP index  $\leq 0$ ).

Item	HC	OC
• Possibility of reaching the district nurse on the phone	x	
• Effective pain alleviation when necessary	x	
• Possibility of having home visits by the same district nurse (HC) or meeting the same district nurse at the outpatient clinic (OC)	x	x
• Clarity about which of the district nurses was responsible for the nursing care		x
• Possibility of participating (medical care)		x

The 41 “dissatisfied” HC (24%) and 56 OC (21%) patients rated their physical health as poorer, compared with that of the remaining HC and OC patients ( $p < 0.01$ ). Moreover, the “dissatisfied” HC patients rated lower scores regarding both physical health and psychological well-being, as compared with the “dissatisfied” OC patients ( $p < 0.01$ ).

## Discussion

Despite the fact that chronic-pain conditions are common among the general population (18, 19) and among the elderly (23-25), several studies show that one barrier to adequate pain management among nurses is that they are not equipped or prepared regarding pain management for patients in pain (12, 31, 45, 52-57). Even though they do not focus on district nurses, several studies support the need for both basic and continuing pain-management education for nurses (12, 31, 45, 52-57). There also seems to be a lack of controlled intervention studies regarding the possible effects of educational pain-management programmes among nurses (57), especially among district nurses.

The general aims of this thesis were to investigate some aspects of the district nurses’ work with a focus on chronic-pain conditions and also to investigate the patients’ satisfaction with the primary health care. Before these studies were undertaken, many district nurses in the South-western Health-care Region had indicated their need for education in pain and pain management. The first three studies also confirmed the district nurses’ need for support and education (*Studies I-III*). Although many district nurses often met patients with chronic-pain conditions, it was found that they had no guidelines for support. More than half of the district nurses were not satisfied with the pain-controlling routines at their PHCCs and did not feel prepared to meet patients with chronic-pain conditions. This is disquieting, as it has been stated that considerable support is needed from all health-care staff to help the patients to gain control over their pain (17). Furthermore, nursing care includes relieving pain and other discomfort (10). The patients also have the right to be informed about their conditions and about available methods of treatment (9).

District nurses have to treat, inform and educate the patients with chronic-pain conditions, as well as the patients with, e.g., diabetes or asthma. This can be done partly by the district nurse herself or in co-operation with others in the health-care team. However, our study showed that many district nurses felt that improvements in the communication and co-operation with the other professionals at the PHCCs are needed (*Studies I and II*). Multiprofessional co-operation has also been stated to be important for effective pain control in home care (28, 37). In our study, the district nurses’ views on co-operation, the present

pain-management routines at their PHCCs, their own follow-ups and their own knowledge of non-pharmacological methods seemed to influence their satisfaction with their own management of the patients with chronic-pain conditions (*Study I*). Furthermore, knowledge of non-pharmacological methods and the problems regarding patients in pain from leg ulcers seemed to be areas especially in need of improvements. High scores for pain regarding patients with chronic leg ulcers have also been found in several studies (26, 27) which further support the need for high competence in this area among the district nurses.

Before the introduction of “pain advisers”, few district nurses stated that they performed any individual pain assessments of their patients with chronic-pain conditions (*Study I*). This has to be noted, as it has been stated that effective pain assessment and documentation are essential procedures for the effective and optimal management of pain (14, 33, 47, 50, 66, 67). However, according to the district nurses in the SA, several improvements had been obtained at the follow-up in 1998 (*Study II*). More district nurses stated that they had pain policies at their PHCCs, an increased satisfaction with the present, overall, pain routines at their PHCCs and a better pain control for patients with leg ulcers. They reported an increased, individual, pain assessment of the patients, an increased use of pain VAS to assess the patients’ pain and to evaluate the pain treatment, an improved nursing documentation and also an increased satisfaction with their own nursing documentation. With one exception (the pain control for patients with leg ulcers), these improvements were obtained only in the SA. Furthermore, with one exception (the nursing documentation), these improvements were also obtained when individual comparisons among the district nurses participating in both 1996 and 1998 were performed over time in the SA. In accordance with our study, more knowledge regarding pain assessment was also found in two other studies intended to evaluate educational pain programmes (57, 63). In the SA, the improved pain assessment and satisfaction with their own nursing documentation (*Study II*) and the improved nursing documentation regarding the description of the patients’ pain (*Study III*) may indicate that the district nurses have started to carry out pain assessments of their patients to a greater extent.

The screening of the documentation in both 1996 and 1998 regarding the different main keywords (nursing process) showed that most keywords were lacking or very scarcely documented (i.e. nursing history, nursing diagnosis, goals, planned nursing interventions, the outcome of the care and nursing discharge) (*Study III*). Even though the results obtained regarding the district nurses’ opinions of their own nursing documentation (*Studies I and II*) and the nursing documentation actually found in the patients’ records (*Study III*) are not directly comparable, it seems that the district nurses reported that they documented “nursing history” to a greater extent than was actually found on reviewing the patients’ records. This may have been due to the fact that the registered patients’ records were reviewed within certain time periods and may not always have included a documentation of the beginning or the end of the patients’ problems. A full documentation with all the different main keywords could therefore not be expected to be found in all records. Especially “nursing history” and “nursing discharge” documentation were expected to be lacking. However, even with regard to these extenuating circumstances, the documentation was still scarce. With such documentation it becomes hard to follow-up and evaluate the patients’ care or to use the record for different purposes. According to the district nurses themselves they seem to be aware of this and they also reported low satisfaction with their own documentation (*Studies I and II*).

Also hospital-based studies reviewing the nursing documentation related to pain have shown deficiencies (54, 81). One of the studies showed that none of the documented goals for pain management were measurable, that the documented nursing interventions were focused on analgesia and that no psycho-social interventions were mentioned, e.g. patient information (81). In the study by Clarke *et al.* 90% of the records did not contain any documentation regarding the use of non-pharmacological methods (54). It was also found that, despite a high,



nurse-reported use of a patient-self-rating tool, a high percentage of the records (76%) lacked the results of the use of these measurements (54).

It has been found that “drug management” is a commonly documented nursing intervention (81, 107, 112, 113). In our review of the patient records (*Study III*) it was found that the proportion of direct and indirect “nursing care and communication” increased in both the SA and the CA (e.g. support, information, training given to the patient or to “others” in order to help the patient). This finding may indicate an increasing awareness on the part of the district nurses of the importance of documenting other nursing-intervention data than only “drug management”.

More knowledge among nurses regarding pain management could lead to better pain assessment and care-planning, which in turn could lead to improved well-being for the patients in chronic pain (60). Despite the fact that the documentation regarding the patients’ well-being increased in both areas, it was still scarce (*Study III*). Furthermore, the patients’ self-reported well-being related to their chronic-pain condition must be regarded as rather poor and no statistically significant improvements of the different aspects of the patients’ well-being could be found in the SA after the introduction of the “pain advisers” (*Study IV*). However, in the CA at the follow-up the chronic pain influenced the patients’ energy less (*Study IV*). Many of the patients in both areas rated high scores on the scales regarding their pain at the time when they were answering the questionnaire and when the level of pain was “at its worst”. Even though it is important to measure the level of pain and to evaluate pain management strategies and treatment, it is also of the utmost importance to investigate whether the patient feels that the pain is under control or not (32). Since many patients considered that their chronic-pain condition influenced their well-being, this may indicate that they did not feel that it was under control.

In order to help patients in chronic pain to come to terms with their pain, it is important to talk about what the pain means to them (35, 36, 114). Patients have stated that factors such as understanding, sympathy, reassurance, confidence, social contacts, advice about available therapies, information and encouragement are important factors to them (32). To feel confirmed and having others to believe the pain are also crucial to many patients (35, 36, 41, 114). In both the SA and the CA, it seems that the district nurses to a large extent fulfilled the patients’ desire to feel confirmed in the meeting with them (*Study IV*).

The proportion of records containing documentation as to whether the patient felt or did not feel well-informed about his or her chronic-pain condition increased in the SA at the follow-up (*Study III*). However, no increase was found regarding the proportions of patients who replied “Yes” to the question whether they had received information/education from the district nurses regarding the pain in the different areas in 1996 and 1998 (*Study IV*). In *Study IV*, after the introduction of the “pain advisers” into the SA, the patients stated that the district nurses’ advice and recommendations had led to less pain and that the information/education received had led to more knowledge that made it possible to understand the pain. This was the only aspect of improvement that was found in the SA. However, our study also shows that those who had received advice and recommendations and/or information/education were more satisfied regarding some aspects of the care, for example, the opportunity to bring up questions and problems regarding their pain as they desired.

A finding in the SA98 was that the patients who had received information/education stated that they had an increased capacity to manage their life situations. Interpretations of these results may be that the district nurses’ information/education were of a high quality and/or that these patients really felt confirmed in the meeting with the district nurses and therefore also assimilated the information/education given. When patients feel confirmed they dare to disclose their pain experience more honestly (41), which may facilitate to preferment of an accurate pain assessment for the nurse and thereby produce suitable individual care. Furthermore, the results also indicate that when they were received, these nursing interventions (advice and recommendations and/or information/education) were highly valued

by the patients. However, these patients did not rate their well-being as better, compared with those patients who reported that they did not receive this care.

The investigation of the patients' satisfaction with the primary health care given by the district nurses at home and at PHCCs showed high satisfaction in most areas, although some areas were identified as being in need of improvements. Not surprisingly, the HC patients were found to be older and more often living alone and reporting poorer physical health and psychological well-being, as compared with the OC patients. Poorer physical health was also found to be reported by the dissatisfied patients in both the HC and the OC. Hall *et al.* found in their study a causal link between health and satisfaction (115) and patients with better, self-reported, health status have often been shown to be more satisfied with medical care (95, 102). One possible interpretation, and perhaps the most natural explanation of the dissatisfaction among the patients with poorer physical and psychological health, may be that they really have a greater need of care and therefore are in a situation in which there is an increased risk of these needs not being satisfied. This suggestion has also been put forward by Ehnfors (100).

### **Clinical implications**

It has been found that the patients' own strategies are important for them if they are to maintain control over their chronic pain (32). This implies that the nurses should support patients and inform them about possible strategies (32). The nurses also need to become more aware of their own role in pain management and acquire knowledge of the consequences of chronic-pain conditions and the interventions which may help the patients. To support the nurses, several studies have identified strategies and advice on pain management that could be used (16, 32, 37, 49-51).

All the district nurses in the SA98 found the idea of a district nurse being trained as a "pain adviser" to be a good one. The results of *Studies II-IV* also indicate that our concept of introducing the "pain adviser" was useful in order to achieve changes regarding some aspects of the district nurses' work and opinions with a focus on chronic-pain conditions. However, there was no change regarding e.g. the district nurses' satisfaction regarding their own pain management regarding patients with chronic-pain conditions. It is important to continue to work with improvements to support the district nurses to develop their knowledge and skills in this area.

In order to meet the identified needs found in our studies, one or two district nurses at all the 22 PHCCs were offered after the conclusion of the studies, university education for five weeks in pain management. The university education included the education given to the first five "pain advisers". A district nurse has also recently been designated a manager within the Health-care-Region with a focus on pain and pain management. Important tasks for her are to create a network of all the "pain advisers" and to support them in their work of improved care regarding patients with chronic-pain conditions. Areas in need of further improvements are; to develop the routines and the co-operation between the different professionals, to co-ordinate and develop the written information given to the patients, and their relatives, to develop basic educational programmes for patients and district nurses and to improve the documentation of patients with chronic-pain conditions. There is a need for more knowledge among the district nurses in several areas regarding pain management, especially regarding non-pharmacological methods of pain relief and pain management for patients with leg ulcers. Since it was found in our study that e.g. advice and information was highly valued by patients who had received them, these interventions should be further investigated, developed and used.

Activities should be undertaken in order to improve the care in those areas where the patients were not fully satisfied, for example, their opportunities to participate in decisions regarding their care and meeting the same district nurse. As it was found that the dissatisfied

patients rated their physical health as poorer, it may be useful to teach the district nurses how to measure the patients' self-rated, physical health, in order to identify early those in need of more support.

### Methodological considerations

The selection of the 12 PHCCs included (*Studies I-IV*) was not performed at random. We endeavoured to obtain a controlled, study design with both a study and a control area. However, it cannot be excluded that the introduction of the "pain adviser" in the SA also affected the district nurses in the CA. We could not be sure that the district nurses did not have any contacts between the SA and the CA, e.g., when attending courses arranged outside the region. We knew that the district nurses had regular meetings as usual within the SA and the CA but not between the areas. However, the improvement that was found in the CA may also reflect the fact that the subject of pain has received increased attention in Swedish society within the last few years.

The selection of patients with chronic-pain conditions was performed by the district nurses at the PHCCs. Another method of selecting the patients with chronic-pain conditions, e.g. by interviewing the patients, was considered to be too time-consuming. However, with regard to lack of knowledge, time and resources, it cannot be excluded that some of the patients with chronic-pain conditions were not registered by the district nurses and were thereby not included in the study. The majority of the patients in both areas registered by the district nurses were women (*Study IV*). This is not surprising since several chronic-pain conditions are more common among women than men (13).

When the district nurses in the CA were asked in 1998 to register the patients with chronic pain with whom they were in contact, they did so at only four out of the seven PHCCs (*Studies III-IV*). The reason for this was stated to be lack of time and resources. It was found that the results in the CA differed on some questions when the three non-participating PHCCs were excluded from the CA96. The improvements found regarding the district nurses' documentation in the CA then no longer appeared (*Study III*). Furthermore, in *Study IV* in the CA, two further improvements but also one decrease were found regarding the patients' opinions.

The questionnaire to the district nurses and the patients with chronic-pain conditions was specifically developed for these studies and has not been validated (*Studies I, II and IV*). The QPP questionnaire (*Study III*) is established and has been tested for reliability and validity (90, 111, 116). One reason for choosing the QPP was that it to a great extent covered all the dimensions that it was considered important to measure in investigating the patients' satisfaction with district nursing and primary health care (39, 103-105). Despite this, there were quite a few patients who regarded some questions as being of "no current interest" to them. There were also a number of non-responders to each question. Even though patients who were regarded as being unable to fill in the questionnaire were excluded, the response rate for the HC patients was 62%, and for the OC patients 72%. The reasons for the relatively low response rate may have been that the district nurses could have overestimated the patients' ability to answer the questionnaire or that the nurses did not have enough time to explain how to fill in the questionnaire.

The majority of patients were found to be very satisfied with the primary health care. A question that can always be raised is whether the patients had a sense of dependence that might have influenced the expression of satisfaction (7). Consideration must be given to the special relationship that may exist between the patient and the district nurse. Owens argued that elderly persons in particular, on account of their dependence, are unwilling to criticize the care (7). Also, it should be noted that only 168 out of 593 HC and 264 out of 492 OC patients answered the questionnaire. Consequently, we do not know whether the patients who, for a number of reasons, could not answer the questionnaire were satisfied or dissatisfied.

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## Conclusions

- The district nurses considered their knowledge, management and documentation of patients with chronic-pain conditions to be in need of improvements. According to the district nurses in the SA at the follow-up, some improvements were made.
- With the exception of the main keywords “nursing status” and “nursing interventions”, the nursing documentation in the patients’ records was found to be scarce in both areas in 1996 and 1998. At the follow-up, some improvements were found in both the SA and the CA. Our results indicate that the introduction of “pain advisers” improved the documentation in the SA with regard to both the extent and the more detailed description of the patients’ chronic-pain conditions.
- The patients with chronic-pain conditions felt confirmed at the meeting with the district nurse. In general, the patients stated that their chronic-pain condition influenced their well-being. At the follow-up, some improvements were found in both areas. However, in the SA only, the patients reported having less pain and receiving more knowledge to enable them to understand the pain as a result of advice and recommendations and/or information/education.
- Both the HC and the OC patients were satisfied with the care, although some areas were identified as being in need of improvements. Furthermore, the HC patients were found to be older, more often living alone and reporting poorer, physical health and psychological well-being as compared with the OC patients. Another finding was that dissatisfied patients rated their physical health as poorer, compared with the rest of the patients.

## I. Overall review

<p><b>Main keywords</b> (<i>main keywords in the nursing process relating to chronic-pain conditions</i>) (1 score for each identified keyword/record, max. 8 scores/record)</p>
<p><b>1. Nursing history</b> (“Patients or significant other’s description of reason for admission or care. Expectations as to care and treatment. Health situation and living conditions before current care and contact as a basis for continuous assessment and nursing care planning”)</p>
<p><b>2. Nursing status</b> (“Patient’s health situation and conditions influencing present nursing care, at the time of contact and continuing during the care episode”)</p>
<p><b>3. Nursing diagnosis</b> (“Identified and prioritised needs, problems or risks, possible causes and symptoms influencing functioning in daily life. Needs to maintain or strengthen resources and functions”)</p>
<p><b>4. Nursing goal</b> (“Goal and expected outcome in measurable terms. Prognosis. Expectations and priorities agreed with patient or significant other. Goals can be related to functional ability and health status, management of health promotion, self-care and disease, lifestyle alterations, patient’s satisfaction and well-being. Long and short term”)</p>
<p><b>5. Planned nursing interventions</b> (Includes documentation regarding the planning of forthcoming nursing interventions)</p>
<p><b>6. Nursing interventions (performed)</b> (“Specify what, when, where, how and by whom. The intention behind interventions is to promote health and prevent illness. Maintain or retain health and well-being. Promote a peaceful death. This can be done by different approaches, such as facilitating, limiting or protecting, motivation or distraction, support or assistance, doing things for the patient, awaiting or withdrawing”)</p>
<p><b>7. Nursing outcomes</b> (“Outcome and evaluation from a nursing perspective. Signs and symptoms of changes, stability or achieved goals, short and long term. The effect of nursing care on the patient’s functional ability and health status, management of health promotion, self-care and disease, lifestyle alterations, patient’s satisfaction and well-being. Continuously during care episode and at discharge, related to nursing diagnoses, goals and interventions”)</p>
<p><b>8. Nursing discharge</b> (Discharge note or note in connection with transfer. Summary of the nursing care and the patient’s progress during the care episode. Patient’s health situation, nursing diagnosis and nursing-care plan when relevant, including communication problem if any. Information and contacts made prior to discharge. Information about to whom the nursing discharge note has been given)</p>

## II. Detailed review - of the two main keywords “nursing status” and “nursing interventions”

<p><b>a. Nursing status</b></p>
<p>Description of chronic-pain conditions (1 score for each identified aspect/record, max. 8 scores/record)</p>
<p>1. Whether the patient suffers from chronic pain (a medical diagnosis was not regarded as enough)</p>
<p>2. Location of pain</p>
<p>3. Character/pattern/intensity of pain</p>
<p>4. Assessment with a scale (visual analogue scale, VAS)</p>
<p>5. Complaints and expressions</p>
<p>6. Behaviour in connection with pain (e.g. crying)</p>
<p>7. What causes onset or relief</p>
<p>8. How the patient manages the pain (including drugs)</p>
<p>Well-being relating to chronic-pain conditions (1 score for each identified aspect/record, max. 5 scores/record)</p>
<p>1. Mobility</p>
<p>2. Isolation</p>
<p>3. Mood</p>
<p>4. Sleep</p>
<p>5. Energy</p>
<p>Patients’ control and information relating to their chronic-pain condition (No. and percentage. This part was not scored)</p>
<p>1. Pain was/was not under control</p>
<p>2. Patient felt/did not feel well informed about the painful condition</p>

Protocol continued

<p><b>b. Nursing interventions</b>                  Direct and indirect nursing interventions relating to chronic pain  <i>(Distribution in percentage of total no. of documented interventions)</i></p>
<p>A. Direct nursing interventions (i.e. direct contact with the patient)                  A.1 Nursing care and communication (e.g. support, information, training given to the patient)                  A.2 Medical and/or technical interventions (e.g. different kinds of treatment, transcutaneous, electrical nerve stimulation (TENS), massage)                  A.3 Drug management (e.g. the delivery of drugs to the patients for direct intake, injections)                  B. Indirect nursing interventions (i.e. indirect contact with the patient)                  B.1 Nursing care and communication (e.g. support, information, training given to “others” in order to help and support the patient)                  B.2 Drug management (e.g. distribution of drugs into a pill dispenser)                  B.3 Administrative interventions (e.g. different kinds of written applications, prescription of technical equipment)                  B.4 Administrative drug management (e.g. prescription of drugs by the district nurses)</p>
<p>Dependent/independent nursing interventions relating to chronic pain  <i>(Distribution in percentages of total no. of documented interventions)</i></p>
<p>1. Dependent nursing interventions                  2. Independent nursing interventions</p>

Figure 1. The protocol for review of the district nurses’ documentation relating to chronic pain. The definitions of the main keywords have been taken from (82, pp. 865-867).

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## References

1. Emanuelsson A, Wendt R. I folkhälsans tjänst. Sju decennier med den svenska distriktssköterskan. FoU Rapport 43. Vårdförbundet. Stockholm, Fälths Tryckeri, Värnamo, 1994. In Swedish.
2. Stockholms läns landsting. Hälso- och Sjukvårdsnämnden HSN. Riktlinjer för primärvården. 1996. In Swedish.
3. Stockholms läns landsting. Hälso- och Sjukvårdsnämnden HSN. Hur mår primärvården i Stockholms län? Parlamentarisk utvärdering av primärvården 1998. Stockholm, 1998. In Swedish.
4. Socialstyrelsen. Statistik. Hälso- och sjukvård 1998:1. Hälso- och sjukvårdsstatistisk årsbok. Stockholm, 1998. In Swedish.
5. Reeder P, Chen S. A client satisfaction survey in home health care. *Journal of Nursing Quality Assurance* 1990;5(1):16-24.
6. Grundy E. Population review: The population aged 60 and over. *Population Trends* 1996(84):14-20.
7. Owens DJ, Batchelor C. Patient satisfaction and the elderly. *Social Science Medicine* 1996;42(11):1483-1491.
8. Statens offentliga utredningar (SOU 1996:163). Behov och resurser i vården - en analys. Del A. Socialdepartementet, Delbetänkande av kommittén om hälso- och sjukvårdens finansiering och organisation (HSU 2000). Stockholm, 1996. In Swedish.
9. Svensk författningssamling. Hälso- och sjukvårdslagen (SFS 1982:763). Stockholm, 1982. In Swedish.
10. Socialstyrelsen. Socialstyrelsens allmänna råd: Omvårdnad inom hälso- och sjukvården (SOSFS 1993:17). Stockholm, Sverige, 1993. In Swedish.
11. Socialstyrelsen. Allmänna råd från Socialstyrelsen 1995:5. Kompetensbeskrivningar för sjuksköterskor och barnmorskor. Stockholm, 1995.
12. Laborde EB, Texidor M. Knowledge and attitudes towards chronic pain management among home health care nurses. *Home Health Care Management Practice* 1996;9(1):73-77.
13. McCaffery M, Beebe A. Pain. *Clinical manual for nursing practice*. Eds. Latham J, Ball D. Mosby, London, 1994.
14. Gagliese L, Melzack R. Chronic pain in elderly people. *International Association for the Study of Pain* 1997;70:3-14.
15. Classification of chronic pain. 2nd ed. International Association for the Study of Pain, IASP. Seattle, 1986.



16. Ferrell B. Pain management in elderly people. *Journal of the American Geriatrics Society* 1991;39:64-73.
17. Socialstyrelsen. *Behandling vid långvarig smärta. SoS-rapport 1994:4*. Jönköping: Tryckeri AB Småland, Sweden, 1995. In Swedish, parts in English.
18. Brattberg G, Thorslund M, Wikman A. The prevalence of pain in a general population. The results of a postal survey in a county of Sweden. *Pain* 1989;37:215-222.
19. Crook J, Rideout E, Browne G. The prevalence of pain complaints in a general population. *Pain* 1984;18:299-314.
20. Brattberg G, Parker MG, Thorslund M. The prevalence of pain among the oldest old in Sweden. *Pain* 1996;67:29-34.
21. Kane RL, Ouslander JG, Abrass IB. *Essentials of Clinical Geriatrics*. McGraw-Hill, New York, 1989.
22. Ferrell BA, Ferrell BR, Ostweil D. Pain in nursing home. *Journal of the American Geriatric Society* 1990;38:409-414.
23. Mobility P, Herr K, Clark K, Wallace R. An epidemiological analysis of pain in the elderly. *Journal of Ageing and Health* 1994;6(2):139-154.
24. Ross M, Crook J. Elderly recipients of home-nursing services: Pain, disability and functional competence. *Journal of Advanced Nursing* 1998;27:1117-1126.
25. Bowling A, Browne PD. Social networks, health, and emotional well-being among the oldest old in London. *Journal of Gerontology* 1991;46(1):20-32.
26. Ebbeskog B, Lindholm C, Öhman S. Epidemiology and nursing care in an urban population in South Stockholm, *Scandinavian Journal of Primary Health Care* 1996;14:238-243.
27. Lindholm C, Bjellerup M, Christensen O, Zederfeldt B. Quality of life in chronic leg ulcer patients. An assessment according to the Nottingham Health profile. *Acta Dermato Venereologica* 1993;73:440-443.
28. World Health Organisation. *Cancer pain relief*. Geneva: World Health Organisation, Geneva, Switzerland, 1986.
29. Soafer B, Walker J. Mood assessment in chronic pain patients. *Disability and Rehabilitation* 1994;16(1):35-38.
30. Ferrell BR. The impact of pain on quality of life. A decade of research. *Nursing Clinics of North America* 1995;30(4):609-624.
31. Ferrell BR, Borneman T, Juarez G. Integration of pain education in home care. *Journal of Palliative Care* 1998;14(3):62-68.

32. Walker JM, Akinsaya JA, Davis BD, Marcer D. The nursing management of elderly patients with pain in the community: Study and recommendations. *Journal of Advanced Nursing* 1990;15(10):1154-1161.
33. Closs SJ. Pain in elderly patients: A neglected phenomenon? *Journal of Advanced Nursing* 1994;19:1072-1081.
34. Brattberg G. Att möta patienter med långvarig smärta. Almqvist & Wiksell Medicin, Liber utbildning. Stockholm, 1995.
35. Seers K, Friedli K. The patients' experiences of their chronic non-malignant pain. *Journal of Advanced Nursing* 1996;24:1160-1168.
36. Carson G, Mitchell GJ. The experience of living with persistent pain. *Journal of Advanced Nursing* 1998;28(6):1242-1248.
37. Ferrell BR, Johnston Taylor E, Grant M, Fowler M, Corbisiero RM. Pain management at home. Struggle, comfort and mission. *Cancer Nursing* 1993;16(3):169-178.
38. Marcer D, Murphy EJJ, Pounder D, Rogers P. The pain relief clinic: how should we define success? *Journal of Intractable Pain Society of Great Britain and Ireland*. 1990;7(2):9-13.
39. Ong BN. Researching needs in district nursing. *Journal of Advanced Nursing* 1991;16:638-647.
40. Gustafsson B, Pörn I. A motivational approach to confirmation: An interpretation of some dysphagic patients' experiences. *Theoretical Medicine* 1994;15:409-430.
41. Paulsson M, Danielson E, Norberg A. Nurses' and physicians' narratives about long-term non-malignant pain among men. *Journal of Advanced Nursing* 1999;30(5):1097-1105.
42. Gustavsson B. The SAUC Model for confirmation nursing: An action-theoretic approach to theory building and nursing practice. *Journal of Nursing Theory* 2000;9(1):6-21.
43. McCaffery M, Ferrell BR. Nurses' knowledge of pain assessment and management: How much progress have we made? *Journal of Pain and Symptom Management* 1997;14(3):175-188.
44. Akinsaya CY. The use of knowledge in the management of pain: The nurse's role. *Nurse Education Today* 1985;5:41-46.
45. Watt-Watson JH. Nurses' knowledge of pain issues: A survey. *Journal of Pain and Symptom Management* 1987;2(4):207-211.
46. McCaffery M. Nurses lead the way to new priorities. *American Journal of Nursing* 1990;10:45-49.
47. Ferrell BR, Wisdom C, Rhiner M, Alletto J. Pain management as a quality of care outcome. *Journal of Nursing Quality Assurance* 1991;5(2):50-58.

48. Sullivan LM. Factors influencing pain management: A nursing perspective. *Journal of Post Anesthesia Nursing* 1994;9(2):83-90.
49. Walker JM, Akinsaya JA, Davis BD, Marcer D. The nursing management of pain in the community: A theoretical framework. *Journal of Advanced Nursing* 1989;14:240-247.
50. Latham J. Treatment we can all believe in. Pain and its management in later life. *Professional Nurse* 1993;8(4):212-220.
51. Walker JM. Caring for elderly patients with persistent pain in the community: A qualitative perspective on the attitudes of patients and nurses. *Health and Social Care* 1994;2:221-228.
52. Ferrell BR, Mcguire DB, Donovan MI. Knowledge and beliefs regarding pain in a sample of nursing faculty. *Journal of Professional Nursing* 1993;9(2):79-88.
53. Brunier G, Carson G, Harrison D. What do nurses know and believe about patients with pain? Results of a hospital survey. *Journal of Pain and Symptom Management* 1995;10(6):436-445.
54. Clarke E, French B, Bilodeau M, L., Capasso V, Edwards A, Empoliti J. Pain management knowledge, attitudes and clinical practice: The impact of nurses characteristics and education. *Journal of Pain and Symptom Management* 1996;11(1):18-31.
55. Coyne ML, Reinert B, Cater K, et al. Nurses' knowledge of pain assessment, pharmacologic and non-pharmacologic interventions. *Clinical Nursing Research* 1999;8(2):153-165.
56. Brown S, Bowman J, Eason F. Assessment of nurses' attitudes and knowledge regarding pain management. *Journal of Continuing Education in Nursing* 1999;30(3):132-139.
57. de Rond MEJ, de Wit R, van Dam FSAM, van Campen BTM, den Hartog YM, Klievink RMA. A pain-monitoring program for nurses: Effect on nurses' pain knowledge and attitude. *Journal of Pain and Symptom Management* 2000;19(6):457-467.
58. Vortherms R, Ryan P, Ward S. Knowledge of, attitudes toward, and barriers to pharmacologic management of cancer pain in a state wide random sample of nurses. *Journal of Post Anesthesia Nursing* 1992;15:459-466.
59. Hamilton J, Edgar L. A survey examining nurses' knowledge of pain control. *Journal of Pain and Symptom Management* 1992;7(1):18-26.
60. Closs SJ. Pain in the elderly patients: A survey of nurses' knowledge and experiences. *Journal of Advanced Nursing* 1996;23:237-242.
61. O'Brien S, Dalton JA, Konsler G, Carlson J. The knowledge and attitudes of experienced oncology nurses regarding the management of cancer-related pain. *Oncology Nurses Forum* 1996;23(3):515-521.

62. Dalton JA, Blau W, Carlson J, et al. Changing the relationship among nurses' knowledge, self-reported behaviour, and documented behaviour in pain management: Does education make a difference? *Journal of Pain and Symptom Management* 1996;12(5):308-319.
63. Ferrell BR, Grant M, Ritchey K, Ropchan R, Rivera L. The pain resource nurse training program: A unique approach to pain management. *Journal of Pain and Symptom Management* 1993;8(8):549-556.
64. Camp-Sorrell D, O'Sullivan P. Effect of continuing education. Pain assessment and documentation. *Cancer Nursing* 1991;14(1):49-54.
65. Dalton JA. Nurses' perception of their pain assessment skills, pain management practices, and attitudes toward pain. *Oncology Nursing Forum* 1989;16(2):225-231.
66. Ferrell BR, Ferrell BA. Easing the pain. *Geriatric Nursing* 1990.
67. Janman L. Assessment brings its own relief: nursing care of individuals suffering from ischaemic leg pain. *Professional Nurse* 1993;8(8):524-529.
68. Ehnfors M, Thorell-Ekstrand I, Ehrenberg A. Towards basic nursing information in patient records. *Vård i Norden* 1991;21:12-31.
69. Klinger L, Spaulding S. Chronic pain in the elderly: is silence really golden. *Physical & Occupational Therapy in Geriatrics* 1998;15(3):1-17.
70. Ebener K. Older adults living with chronic pain: an opportunity for improvement. *Journal of Nursing Care Quality* 1999;13(4):1-7.
71. Harkins SW. Pain in the elderly. *Proceeding of the vth world congress on pain*. Amsterdam: Elsevier Science Publisher B. V. 1988:355-367. vol 3.
72. Hofland SL. Elder Beliefs: Blocks to pain management. *Journal of Gerontological Nursing* 1992;10:19-23.
73. Seers K. Perception of pain. *Nursing Times* 1987;83(48):37-39.
74. Svensk författningssamling. Patientjournalag. SOSFS 1985:562. Socialstyrelsen. Stockholm, 1985. In Swedish.
75. Socialstyrelsen. Socialstyrelsens föreskrifter och allmänna råd (SOSFS 1993:20) om patientjournalagen, Stockholm, 1993. In Swedish
76. Yura H, Walsh MB. *The Nursing Process: Assessing, Planning, Implementing, Evaluating*. (5th ed) Appleton & Lange, New York, 1988.
77. Mason G, Attree M. The relationship between research and the nursing process. *Journal of Advanced Nursing* 1997;26:1043-1049.
78. Henderson V. Nursing process - A critique. *Holistic Nursing Practice* 1987;1(3):7-18.

79. Fonteyn M, Flaig Cooper L. The written nursing process: Is it still useful to nursing education? *Journal of Advanced Nursing* 1994;19:315-319.
80. Walker J, Campbell S. Pain assessment and the nursing process. *Senior Nurse* 1988;8(5):28-31.
81. Carr E. Evaluating the use of pain-assessment tool and care plan: A pilot study. *Journal of Advanced Nursing* 1997;26:1073-1079.
82. Ehrenberg A, Ehnfors M, Thorell-Ekstrand I. Nursing documentation in patient records: Experience of the use of the VIPS model. *Journal of Advanced Nursing* 1996;24:853-867.
83. Statens beredning för utvärdering av medicinsk metodik (SBU). Behov av utvärdering inom sjuksköterskans arbetsområde. Nordstedts Tryckeri AB, Stockholm, 1994. In Swedish.
84. The Swedish Nurses Association (SSF) and The Swedish institute for health services development (Spri). Quality indicators in nursing. Spri Publications, Stockholm, 1996.
85. Törnkvist L, Gardulf A, Strender LE. The opinions of nursing documentation held by district nurses and by nurses at primary-health-care centres. *Vård i Norden* 1997;17(4):18-25.
86. Fordham M, Dunn V. *Alongside the person in pain. Holistic care and nursing practice.* Baillière Tindall, London, 1994.
87. Larsson G, Wilde B, Udén G. Patients' view on the care: A review of the literature. Patienters syn på vård. SoS-rapport 1996:21. En litteratursammanfattning. Socialstyrelsen, Stockholm, 1997. In Swedish.
88. Mahon PY. An analysis of the concept "patient satisfaction" as it relates to contemporary nursing care. *Journal of Advanced Nursing* 1996;24:1241-1248.
89. Risser N. Development of an instrument to measure patient satisfaction with nurses and nursing care in primary care settings. *Nursing Research* 1975;24(1):24-52.
90. Wilde B, Larsson G, Larsson M, Starrin B. Quality of care. Development of a patient-centred questionnaire based on a grounded theory model. *Scandinavian Journal of Caring Science* 1994;8(1):39-48.
91. Clearly PD, McNeal BJ. Patient satisfaction as an indicator of quality of care. *Inquiry* 1988;25(1):25-36.
92. Donabedian A. The quality of care: How can it be assessed? *JAMA* 1988;260(12):1743-1748.
93. Vuori H. Patient satisfaction: Does it matter? *Quality Assurance in Health Care* 1991;3(3):183-189.

94. van Campen C, Sixma H, Friele RD, Kerssens JJ, Peters L. Quality of care and patient satisfaction: A review of measuring instruments. *Medical Care Research and Review* 1995;52(1):109-133.
95. Pascoe GC. Patient satisfaction in primary health care: A literature review and analysis. *Evaluation and Program Planning* 1983;6:185-210.
96. Vuori H. Patient satisfaction: An attribute or indicator of the quality of health? *Quality Review Bulletin* 1987;13(3):106-108.
97. Bond S, Thomas LH. Measuring patients' satisfaction with nursing care. *Journal of Advanced Nursing* 1992;17:52-63.
98. Hohl D. Patient satisfaction in home care. *Nursing Management* 1994;25(1):52-54.
99. Polit DH, Hungler BP. *Nursing research. Principles and methods.* (6th ed.) J.B. Lippincott Company. Philadelphia, 1995.
100. Ehnfors M, Smedby B. Patient-satisfaction surveys subsequent to hospital care: Problems of sampling, non-response and other losses. *Quality Assurance in Health Care* 1993;5(1):19-32.
101. Weiss GL. Patient satisfaction with primary medical care. Evaluation of sociodemographic and predispositional factors. *Medical Care* 1988;26(4):383-392.
102. Hall JA, Feldstein MD, Fretwell M, Rowe JW, Epstein AM. Older patients' health status and satisfaction with medical care in an HMO population. *Medical Care* 1990;28(3):261-270.
103. Laferriere R. Client satisfaction with home health care. *Journal of Community Health Nursing* 1993;10(2):67-76.
104. Poulton BC. Use of the consultation-satisfaction questionnaire to examine patients' satisfaction with general practitioners and community nurses: Reliability, replicability and discriminant validity. *British Journal of General Practice* 1996;46(402):26-31.
105. Gäfert A, Ek AC. Home-nursing patients' expectations and satisfaction. *Vård i Norden* 1996;16(2):19-24.
106. Östlinder G. Smärta ett område för omvårdnad. *Vård* 1996;2:47-52. In Swedish.
107. Nordström G, Gardulf A. Nursing documentation in patient records. *Scandinavian Journal of Caring Science* 1996;10:27-33.
108. Bradley C. *Handbook of psychology and diabetes.* Harwood Academic Publishers, Hardcover, Singapore, 1994.
109. Nordström G, Nyman GR, Theorell T. Psychosocial adjustment and general state of health in patients with ileal conduit urinary diversion. *Scandinavian Journal of Urology and Nephrology* 1992;26:139-147.

110. Wilde B, Larsson G, Larsson M, Starrin B. Patients' perceptions regarding quality of care in an orthopaedic clinic at the hospital in Karlstad. *Centre for Public Health Research* 1995;6:1-34.
111. Larsson G, Wilde B, Munck IME. Refinement of the questionnaire "Quality of care from the patient's perspective" using structural equation modelling. *Scandinavian Journal of Caring Science* 1998;12:111-118.
112. Hansebo G, Kihlgren M, Ljungren G. Review of nursing documentation in nursing-home wards: Changes after interventions for individualized care. *Journal of Advanced Nursing* 1999;29(6):1462-1473.
113. Ehrenberg A, Ehnfors M. Patient records in nursing homes. Effects of training on content and comprehensiveness. *Scandinavian Journal of Caring Sciences* 1999;13:72-82.
114. Thunberg K, Carlsson S, Hallberg LR-M. Health care professionals' understanding of chronic pain: A grounded theory study. *Scandinavian Journal of Caring Sciences* 2001;15:99-105.
115. Hall JA, Milburn MA, Epstein M. A causal model of health status and satisfaction with medical care. *Medical Care* 1993;31(1):84-94.
116. Wilde B, Larsson G, Larsson M, Starrin B. Quality of care from the elderly person's perspective: Subjective importance and perceived reality. *Ageing Clinical Experience Research* 1995;7(2):140-149.

## **Original papers**