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A comparison of pain and health-related quality of life between two groups of cancer patients with differing average levels of pain

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Summary

• A study was performed to describe and compare pain and Health-Related Quality of Life (HRQOL) in two groups of cancer patients in palliative care as well as to describe the correlation between pain and HRQOL.

• Forty-seven patients with mild average pain [Visual Analogue Scale (VAS) ≤ 3] and 28 patients with moderate to severe average pain (VAS > 3) were included. Medical Outcomes Study Short Form (SF-36) was used to evaluate HRQOL, pain intensity levels were measured with the VAS on Pain-O-Meter.

• Compared to patients with mild pain, patients with moderate to severe pain had statistically significant, higher pain intensity for the items 'pain at time of interview', 'worst pain in the past 24 hours' and 'pain interrupting sleep.' They also had the lowest scores of the SF-36 dimensions: physical functioning, role-physical, and bodily pain. Patients with moderate to severe pain had statistically significant, fewer months of survival. There were statistically significant positive correlations between pain items and negative correlation between pain and SF-36 dimensions.

• The conclusion is that pain has a negative impact on HRQOL, especially on physical health and that pain increases towards the final stages of life. Even if patients have to endure symptoms such as fatigue and anxiety during their short survival time, dealing with pain is an unnecessary burden, which can be prevented.

Keywords: cancer, health-related quality of life, pain, palliative care, SF-36.

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Introduction

Cancer is commonly associated with pain, suffering and death (Vainio & Auvinen, 1996). Once it is understood that the cancer is progressing and that physical, emotional and social symptoms are present, palliative care, which is aimed at controlling or relieving pain, can be provided concurrently with oncology treatment (Addington-Hall & McCarthy, 1995). Although pain control is achievable in most cases today, for many patients the pain relief is still less than optimal (Strang, 1992; Meuser *et al*., 2001). According to Cleeland *et al*. (1994) and Bernabei *et al*. (1998), unrelieved cancer pain persists and seems to increase in the month prior to death (Morita *et al*., 1999). Furthermore, Twycross *et al*. (1996) found that nearly 30% of patients in advanced stages of cancer experienced severe multiple pain. Pain has a negative impact on movement, sleep and concentration besides increasing distress and anxiety levels (Strang, 1992; Cleeland *et al*., 1994; Vainio & Auvinen, 1996). Portenoy *et al*. (1994) also found a negative relationship between pain intensity and duration and its impact on Health-Related Quality of Life (HRQOL). However, without the patient's own perception of illness, treatment and personal expectations, health care professionals often fail to ascertain the patient's 'true' HRQOL (Bowling, 1995). Medical Outcomes Study Short Form 36 (SF-36) is an instrument for the measurement of subjective or perceived well-being, which places a great emphasis on the individual's response and the response variation across individuals (Ware & Sherbourn, 1992). SF-36 could be used as an evaluation tool for measuring HRQOL in order to accomplish a simpler and more cost-effective assessment of the value of interventions for cancer patients (Clohisy *et al*., 1997). Concerning interventions for pain relief, Wang *et al*. (1999) found that cancer patients with moderate to severe pain had lower SF-36 health dimension scores than patients with only mild pain or no pain at all. Although it is intuitive that more severe pain is associated with lower HRQOL, the relationship between pain and HRQOL is complex. A study by Klepstad *et al*. (2000) reported a decrease in pain intensity among patients receiving morphine therapy, without a subsequent increase in HRQOL. A better understanding of the relationship between pain severity and the different health dimensions measured with SF-36 may help patients and health care professionals to discuss individual goals for pain management (Wang *et al*., 1999). According to the American Pain Society Quality of Care Committee (1995), both acute and cancer-related pain should be recognized and treated promptly. Establishing limits of pain intensity as well as individual goals for pain treatment can alleviate the patient's pain (Rawal & Berggren, 1993; Meuser *et al*., 2001; The National Board of Health and Welfare, 2001). It is not enough merely to measure current pain intensity, as a single score may not adequately reflect the patient's satisfaction with pain management. The duration of pain may increase the fear of future pain problems, which in turn may influence the HRQOL (Strang, 1992; Meuser *et al*., 2001). The health dimensions of SF-36 have convergence points with the multidimensionality of pain. In palliative care the focus is on pain management irrespective of the diagnosis of cancer. Therefore, the purpose of this study was to describe and compare pain and HRQOL among cancer patients in palliative care with either mild average pain intensity described as ≤3 on a Visual Analogue Scale (VAS) or moderate to severe average pain intensity described as >3 on VAS, as well as the correlation between HRQOL and pain.

Methods

DESIGN AND SETTING

A descriptive, comparative study design was performed in a county of south-west Sweden with a catchment area of 370 000 inhabitants. The study was approved by the Committees of Ethics in Medical Investigations at the Universities of Lund and Göteborg, Sweden.

STANDARD PALLIATIVE CARE

Two separately organized teams provided palliative care, each associated with a different hospital. The teams provide home-care service to inpatients. Services are also available, on a consultancy basis, to hospital staff and the community. Patients were referred to palliative care either after consultation with the patient's own physician, by a nurse caring for the patient, by the patient herself or by a relative of the patient. The most common reason for requesting palliative care was pain-associated problems. The independent palliative care objectives of the two teams were almost identical: to make an assessment of the patient's problems and needs – with special regard to pain, and to initiate, suggest and perform interventions for pain relief and other symptoms, as well as preventing negative side-effects of medication. The objective also included continually supporting the nurses and physicians in their roles

around the patient, providing a link between the patient, the patient's family and the other care-providers.

SUBJECTS

A sample of 75 consecutive patients from two hospital-based palliative care teams were recruited. The inclusion criteria were: being orientated to person and place, having no major sensorial defects, able to speak Swedish, over 35 years of age – in line with SF-36 Swedish norm data (Sullivan *et al*., 1994), being in need of analgesic treatment and with one of the following diagnoses: lung cancer, colorectal cancer, breast cancer or prostate cancer, and assessed as being at the final stage of life. Furthermore, the patients needed to be aware that they had been diagnosed with cancer and would receive palliative care, as opposed to primarily curative care. Finally, in order to describe and compare patients' HRQOL in terms of their different levels of pain intensity, two stratified samples were constructed: one group rating average pain in the past 24 hours at a mild intensity level of ≤3 on VAS (low pain group) and the other rating average pain in the past 24 hours at a moderate to severe intensity level of >3 on VAS (high pain group). The reason for selecting VAS 3 as the value for dividing the groups was based on recommendations from a Swedish guideline designed under government auspices, stating this value as a quality outcome indicator when treating cancer-related pain (Swedish Medicine 58, 1997; The National Board of Health and Welfare, 2001) as well as the statement from Mantha *et al*. (1993, p.10419) that 'the range 0–3 cm may be thought of as a zone of analgesic success'.

INSTRUMENTATION

Demographic and clinical characteristics

A demographic sheet was used to gather data from the patients regarding the variables gender, age, civil status, education, diagnosis, place of care, duration of care from a palliative care team and prescribed analgesic medication. The patients were also asked the open-ended question: 'What disturbs you most?'

Assessment of HRQOL

The SF-36 is a general health questionnaire evaluating the physical, social and mental aspects of HRQOL, designed for use with both the general population and populations with chronic diseases. SF-36 focuses on a patient's functioning in eight different dimensions of HRQOL: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. SF-36 can be either self-administered or administered by an interviewer with the help of a special interview guide. SF-36 has been validated extensively on general populations as well as on patients with different diseases, demonstrating high reliability and good construct validity (Ware & Sherbourn, 1992; Sullivan *et al*., 1995). When using SF-36 it is possible to reach 80% power and detect a 15–20-point difference between two groups as a postintervention measure, despite a small sample (Sullivan *et al*., 1994). In this study, Cronbach's alpha was 0.70 for the whole questionnaire while the internal consistency coefficients were between 0.76 and 0.88 for each of the dimensions physical functioning, role-physical, bodily pain and role-emotional and between 0.40 and 0.50 for general health, vitality, social functioning and mental health.

Pain assessment

Selected and modified items from the American Pain Society Quality of Care Committee (1995) Patient Outcome Questionnaire were used. This questionnaire was employed in order to evaluate the outcome of patients' pain management after the implementation of quality improvement guidelines. It includes four questions concerning pain intensity at different times. In this study pain intensities were measured with the VAS on Pain-O-Meter (POM). POM provides information about pain intensity, quality, location and duration (Gaston-Johansson, 1996). In order to indicate pain intensity, POM-VAS consists of a 10-cm straight-line continuum at the front of the POM, with anchors at each end, representing no pain at the lower end of the scale and severest possible pain at the upper end of the scale. Pain intensity can be evaluated by asking the patients to indicate the intensity of pain by moving an adjustable marker along the POM scale. A centimetre scale can be found on the reverse side, numbered from 0 to 10. Four items from the American Pain Society questionnaire were used in this study. They were answered with the help of POM-VAS: How much pain are you in right now? Please indicate the worst pain you have had in the past 24 hours. Please indicate the average pain you have had in the past 24 hours, and, please indicate the pain interrupting your sleep.

Reliability and validity have been demonstrated satisfactorily for VAS (Grossman *et al*., 1992; Herr & Mobily, 1993) and for POM (Gaston-Johansson, 1996). In this study, Cronbach's alpha for the four questions selected

from American Pain Society Quality of Care Committee (1995) was found to be 0.84 and content validity was satisfactorily established by recommendations from The National Board of Health and Welfare (2001) in Sweden.

PROCEDURE

Patients who agreed to participate in the study were contacted for an interview. They were informed that participation in the study was voluntary and that their answers would be treated in confidence. They were also informed that they could withdraw from the study at any time without reason. The data were collected by the main author, a nurse teacher with special interest in pain management, and without any connection to the care teams. Firstly, the purpose, content and layout of the SF-36 questionnaire, as well as the POM-VAS instrument, were thoroughly explained to the patients. Then the patients were asked to complete the SF-36 questionnaire. Most of the patients were able to complete the SF-36 questionnaire without assistance and without omitting any items. Sometimes the questionnaire was administered in interview form because the patient was in a weak physical state or expressed a preference for an interview. After completing the SF-36, the patients were interviewed for demographic and clinical data. These questions were dealt with in interview form. Supplementary information about prescribed analgesic medication was obtained from the patients' medical charts. The patients were also asked to describe carefully their pain by using POM-VAS. They indicated their pain intensity by moving an adjustable marker along the 10-cm line between 0 indicating 'no pain' and 10 indicating 'severest possible pain'. Three patients declined to complete the SF-36 questionnaire because of confusing questions. All three were in an extremely weak condition and severe pain. Therefore, in agreement with the Committee of Ethics and after receiving the patients' consent, contact was immediately taken with the ward staff or the palliative care team staff. One year after all data had been collected, a follow-up was made of the patients' medical charts to determine how long the patients survived after the interviews were carried out.

DATA ANALYSES

Descriptive statistics were used to describe the demographic characteristics of the sample and the pain intensity variables ('pain at the time of interview', 'worst pain', 'average pain' and 'pain interrupting sleep'). SF-36 raw scores for each question were transformed to a scale of 0–100, with higher scores representing better levels of functioning and states of health (Sullivan *et al.*, 1994). Mean scores and SDs as well as median scores and ranges were calculated for the SF-36 dimensions for all patients. Due to variables on ordinal scale level and with skewed distributions, non-parametric methods were employed. Mann–Whitney *U*-test and chi-square test were used for testing statistical differences between the two groups of patients as well as differences within the groups. Firstly, Spearman's correlation coefficient was used to assess if there were any relationships among the different pain intensity items. Secondly, the method was used to see if there were any relationships between the different pain intensity items and the different SF-36 dimensions. A P-value <0.05 was considered statistically significant.

Results

DEMOGRAPHICS AND CLINICAL CHARACTERISTICS

Seventy-five patients were included in this study. Forty-seven patients were included in the group of patients with low pain (≤3 on VAS) and 28 in the group of patients with high pain (>3 on VAS). Due to rapid deterioration in pain three patients dropped out of the study before contact was made for the interview. Patients in both groups had received palliative care for a median time of 2 months. As shown in Table 1, the most common cancer diagnosis in the low and high pain groups was prostate and colon cancers, respectively. Seventy-five per cent of the patients in the low pain group and 50% of patients in the high pain group were cared for at home. A statistically significant difference was that the patients in the high pain group survived for fewer months ($P = 0.002$) after inclusion in the study compared with the patients in the low pain group. All patients were prescribed analgesics in accordance with the WHO (1990) guideline, the so-called analgesic ladder. No further statistically significant differences were found between the two groups of patients or between men and women.

Of the patients in the high pain group, 39% stated that pain or fear of increased pain disturbed them most, compared with 36% of the patients in the low pain group. Fatigue or lack of energy was the second most common concern for 36% of the patients in the low pain group and 28% of the patients in the high pain group. The remaining patients were disturbed about different things, such as worry about family and children, financial matters or limitations in performing work or leisure activities.

Table 1 Demographic and clinical characteristics of cancer patients in palliative care with low or high average pain

Characteristics	Low pain group ($n = 47$)		High pain group ($n = 28$)		
	n (%)	*P*-value within group	*n* (%)	*P*-value within group	*P*-value between groups
Gender		n.s.		n.s.	n.s.
Male	32 (68)		20 (71)		
Female	15 (32)		8 (29		
Age (years)					n.s.
Mean/median	71.2/71		68.1/69		
SD/range	10.2/35–88		9.8/44–84		
Diagnosis				n.s.	n.s.
Lung cancer	9 (19)		6 (21)		
Breast cancer	7 (15)		6 (21)		
Prostate cancer	20 (42)	0.038	7 (25)		
Colon cancer	11 (23)		9 (33)		
Place of care				n.s.	n.s.
Home	35 (75)	<0.001	14 (50)		
Hospital	10 (21)		9 (32)		
Combination of hospital and home	2 (4)		5 (18)		
Survival time in months after inclusion in the study					
Mean/median	7.9/5*		3.2/2†		0.002
SD/range	7.5/0.5–31		2.9/0.5–10		

Low pain group = patients with average pain intensity ≤3 rated on VAS.
High pain group = patients with average pain intensity >3 rated on VAS.
*Six still alive; †Two still alive.

PAIN INTENSITY LEVELS (TABLES 2 AND 3)

The patients in the high pain group had statistically significant, higher pain intensity levels, in terms of the items 'pain at the time of the interview', 'worst pain' and 'pain interrupting sleep' compared with the patients in the low pain group. In both groups there was a wide range of pain intensity levels for each pain item. Two patients in the low pain group rated 'worst pain' as 9 on VAS and three patients gave a VAS rating of 7 when evaluating 'pain interrupting sleep'. One patient in the high pain group evaluated 'pain at time of interview' as 8 on VAS, while four patients evaluated 'worst pain' as 9 on VAS.

When seeking a correlation between the four pain intensity items (Table 3), it appeared that, for patients in the low pain group, all pain intensity items correlated with each other to a statistically significant level. For patients in the high pain group, 'pain at time of interview' showed no statistically significant correlations with the other pain intensity items, while 'worst pain', 'average pain' and 'pain interrupting sleep' showed statistically significant

Table 2 Visual analogue scale (VAS) rated levels of pain intensity, evaluated by cancer patients in palliative care with low or high average pain

Pain items	Low pain group ($n = 47$)	High pain group ($n = 28$)	*P*-value
Pain at time of interview			
Mean/SD	1.8/1.3	3.9/1.9	<0.001
Median/range	2/0–5	4/1–8	
Worst pain in the past 24 hours			
Mean/SD	3.3/2.3	6.2/1.6	<0.001
Median/range	3/0–9	6/3–9	
Average pain in the past 24 hours			
Mean/SD	1.8/1	5/1.4	<0.001
Median/range	2/0–3	4/4–8	
Pain interrupting sleep			
Mean/SD	1.9/1.6	3.5/2.3	0.001
Median/range	1/0–7	3/1–9	

Low pain group = patients with average pain intensity ≤3 rated on VAS.
High pain group = patients with average pain intensity >3 rated on VAS.

Table 3 Correlation between pain intensity items rated by cancer patients in palliative care with low or high average pain

Pain items	Pain rated according to the visual analogue scale (VAS)			
	Pain at time of interview	Worst pain in the past 24 hours	Average pain in the past 24 hours	Pain interrupting sleep
Pain at time of interview				
Low pain group		0.652**	0.677**	0.350*
High pain group				
Worst pain in the past 24 hours				
Low pain group	0.652**		0.793**	0.497**
High pain group			0.709**	0.502**
Average pain in the past 24 hours				
Low pain group	0.677**	0.793**		0.332*
High pain group		0.709**		0.665**

Low pain group = patients with average pain intensity ≤3 on VAS ($n = 47$).
High pain group = patients with average pain intensity >3 on VAS ($n = 28$).
Spearman's correlation is significant at the *0.05 and **0.01 level.

correlations between each other. This revealed that it was only for the low pain group that 'pain at time of interview' had a relationship with 'worst pain', 'average pain' and 'pain interrupting sleep.

HEALTH-RELATED QUALITY OF LIFE

Patients in the low pain group reached higher mean and median scores for all SF-36 dimensions compared with patients in the high pain group. As shown in Table 4, statistically significant higher median scores were reached for the dimensions of physical functioning, role-physical and bodily pain for patients in the low pain group compared with patients in the high pain group.

CORRELATIONS BETWEEN PAIN AND HEALTH-RELATED QUALITY OF LIFE

The SF-36 dimensions that showed statistically significant correlations with the items of pain intensity are shown in Table 5. For patients in both the low and the high pain groups, negative correlations were found between bodily pain and all pain intensity items measured with POM-VAS with the exception of 'pain at time of interview' in the high pain group. General health correlated with three pain intensity items for patients in the low pain group compared with one intensity item for patients in the high pain group. Role-physical showed a statistically significant negative correlation with one pain intensity item in each patient group. This revealed that pain affected general health more directly for patients in the low pain group compared with patients in the high pain group.

Table 4 Health-related quality of life dimensions for cancer patients in palliative care with low or high average pain

SF-36 dimensions	Low pain group ($n = 47$)	High pain group* ($n = 25$)	*P*-value
Physical functioning			
Mean (SD)	36.3 (22.3)	25 (20.1)	
Median (range)	35 (0–90)	20 (0–70)	0.027
Role-physical			
Mean (SD)	21.2 (30.3)	8 (22.5)	
Median (range)	0 (0–100)	0 (0–100)	0.027
Bodily pain			
Mean (SD)	65.9 (24.2)	35.7 (12.1)	
Median (range)	62 (21–100)	32 (12–62)	<0.001
General health			
Mean (SD)	44.1 (15.7)	36.9 (9.3)	
Median (range)	40 (20–77)	40 (10–50)	n.s.
Vitality			
Mean (SD)	42.7 (17.9)	34.8 (17.0)	
Median (range)	40 (15–75)	35 (0–80)	n.s.
Social functioning			
Mean (SD)	61.7 (28.3)	56 (27.5)	
Median (range)	62.5 (0–100)	50 (0–100)	n.s.
Role-emotional			
Mean (SD)	62.4 (44.2)	48 (43.1)	
Median (range)	100 (0–100)	33 (0–100)	n.s.
Mental health			
Mean (SD)	63.9 (17.7)	58.7 (17.1)	
Median (range)	64 (20–96)	60 (28–92)	n.s.

Low pain group = patients with average pain intensity ≤3 rated on VAS.
High pain group = patients with average pain intensity >3 rated on VAS.
*Three missing patients.

Table 5 Correlation between pain intensity items and SF-36 dimensions, for cancer patients in palliative care with low or high average pain

SF-36 dimensions	Pain items rated according to the visual analogue scale (VAS)			
	Pain at time of interview	Worst pain in the past 24 hours	Average pain in the past 24 hours	Pain interrupting sleep
Role-physical				
Low pain group	−0.297*			
High pain group				−0.427*
Bodily pain				
Low pain group	−0.488**	−0.564**	−0.468**	−0.312*
High pain group		−0.446*	−0.518**	−0.532**
General health				
Low pain group		−0.317*	−0.312*	−0.358*
High pain group	−0.450*			

Low pain group = patients with average pain intensity ≤3 on VAS ($n = 47$).
High pain group = patients with average pain intensity >3 on VAS ($n = 28$).
Spearman's correlation is significant at the *0.05 and **0.01 level.
For the SF-36 dimensions, a higher score represents a higher level of functioning. For the pain variables (VAS at time of interview, VAS-worst, VAS-average, VAS interrupting sleep), a higher score represents a higher level of pain.

Discussion

This study was performed on selected patients with cancer-related pain admitted to two palliative care teams. The palliative care team staff made the selection of patients for the study and asked for their oral consent. The staff did so at a suitable opportunity, depending on the patients' condition. This could explain the absence of drop-outs when the patients were contacted for the interview. However, three patients in hospital dropped out before contact was made, due to having become too ill to participate. Therefore, the sample may not be representative of all cancer patients with pain, not even of all patients receiving palliative care. However, the study probably provides a good description of the relationship between pain and HRQOL and the differences that occur with increased intensity of pain.

Reliability could also be discussed in terms of the fact that Cronbach's alpha for the SF-36 reached 0.70. This is consistent with the reliability coefficient ranging from a low level of 0.65 to a high level of 0.94, as reported by McHorney *et al.* (1994). Perhaps the SF-36 is not a sensitive enough instrument for cancer patients in palliative care. The low internal consistency coefficients for some dimensions may indicate that some of the questions were difficult for the patients to understand or answer (Cella, 1995). However, the dimensions physical functioning, role-physical, bodily pain and role-emotional showed good internal consistency reliability. Accordingly, the dimensions physical functioning, bodily pain and role-physical are the ones with a statistically significant difference between the groups. The pain items also showed a statistically significant correlation, with role-physical and bodily pain. POM-VAS was an easy-to-use tool for all patients.

The predominance of men in both groups was a reflection of the distribution of patients in the two palliative care teams. This is alarming, as factors such as feeling of helplessness (Tate *et al.*, 1997) and unwillingness to complain (Twycross *et al.*, 1996) may have had a negative influence on the tendency of women to initiate a referral to a palliative care team.

PAIN

Despite the fact that all patients were prescribed analgesics in accordance with the WHO three-step analgesic ladder approach (WHO, 1990), many patients reported high pain intensity. Not only the patients in the high pain group, but also those in the low pain group, reported severe 'worst pain'. Obviously, the analgesic treatment was not optimized, as it should have been (Meuser *et al.*, 2001). The reason for this might have been barriers created by nurses and physicians, although this seems rather unlikely, as they were specially trained in pain treatment. Instead, possible explanations are patient- and family member-related barriers, such as fear of addiction or side-effects, patients' desire to be a 'good' patient or possibly a misconception about the inevitability of pain (Ward *et al.*, 1993; Riddell & Fitch, 1997; Meuser *et al.*, 2001). The fact that two-thirds of the patients were cared for at home could also be a potential risk for failure in pain assessment,

especially if only the current pain was reported (Owen *et al*., 2000).

Even if the patients in the low pain group had an average pain intensity of ≤3 on VAS, many of them reported more intensive pain for the items 'pain at time of interview', 'worst pain' or 'pain interrupting sleep'. With the strongest correlation between 'average pain' and 'worst pain', this may indicate that even if 'average pain' was not yet too high, it could probably have increased if nothing was done to lessen the so-called breakthrough pain (Ferrell *et al*., 1999). However, patients in the high pain group also showed the highest correlations between 'average pain' and 'worst pain', indicating the importance of assessing the intensity of 'worst pain' in order to distinguish breakthrough pain from persistent pain. Notably, for patients in the high pain group, 'pain at time of interview' did not correlate with 'average pain', 'worst pain' or 'pain interrupting sleep' (Table 3). It may indicate that the interview itself provided an intervention for pain relief. Alternatively, patients in the high pain group may have been so used to being in pain that 'worst pain' and 'pain interrupting sleep' were the most disturbing aspects. However only 'pain at time of interview' exhibited a statistically significant correlation with general health, for patients in the high pain group (Table 5). As demonstrated by Ferrell *et al*. (1999), there is a discrepancy between recommendations in guidelines and the actual practice of pain management at home. Ferrell *et al*. (1999) found that 38% of the patients took less than the prescribed routine analgesic and that 96% took less than the available breakthrough analgesic. In this study, half of patients in the high pain group and three quarters of patients in the low pain group were at home, which means that a possible interpretation may be poor patient compliance with the prescribed analgesic. Another aspect worth noting but not included in this study is that problems with constipation and dry mouth are strongly associated with analgesic medication, and especially opioids (Morita *et al*., 1999; Klepstad *et al*., 2000). This stresses both the importance of the nurses' role in patient education and the need for nurses to improve the methods of pain assessment and pain relief, even if they do not meet the patients every day (Bookbinder *et al*., 1996). A further urgent goal is pain relief at night. Not being able to sleep because of pain has a wide impact on daily life and energy levels. 'Pain kept me from sleeping' was a frequently reported concern (Bookbinder *et al*., 1996, p. 345) and is in accordance with the patients in this study, reporting fatigue and lack of energy. This is alarming as for these patients energy is necessary in order to live as good a life as possible, specifically, because of their cancer.

PAIN INTENSITY AND HRQOL

In the high pain group, all SF-36 dimensions showed lower mean and median scores compared with the low pain group (Table 4). The severity of pain appeared to be a significant factor decreasing patients' levels of functioning. This applied particularly to the dimensions of physical functioning, role-physical and bodily pain. physical well-being is disturbed by both pain and fatigue, which are symptoms that increase at the final stage of life (Morita *et al*., 1999). The patients in the high pain group had significantly fewer months left to live, and the severity of pain increased as they reached the final stage. This highlights the importance of not taking for granted a decrease in HRQOL for patients approaching death. Perhaps it is unavoidable that physical functioning decreases as patients approach death, but it should not be due to lack of effective pain management. Pain must be discussed and treated in view of the ability to function in daily life, including emotional, social and physical aspects (Wang *et al*., 1999; Owen *et al*., 2000).

Wang *et al*. (1999) examined a similar sample of patients to those in this study and found almost identical mean scores and SD of SF-36 dimensions. The patients included in the study showed higher physical functioning but lower social functioning and role-functioning compared with the two groups in the present study. An explanation may be that patients in the study were at least 20 years younger compared with participants in this study. For all other dimensions, the mean scores were in between the mean scores for the high pain group and the low pain group in this study. The SF-36 dimensions that correlated significantly with the pain intensity items were role-physical, bodily pain and general health. The lack of relationship between pain and other dimensions of HRQOL was also shown by Klepstad *et al*. (2000) and supports the importance of a wide-ranging pain assessment. VAS assesses pain intensity without discriminating between sensory and affective dimensions of pain while SF-36 covers the patient's general health and the impact of pain on the patient's overall physical functioning, social and mental well-being, and ability to work or perform daily activities.

According to the International Association for the Study of Pain (IASP) (1979), pain is both a sensory and an emotional experience, associated with actual or potential tissue damage or described in terms of such damage. However, if this definition is to be of use in clinical practice, a well-structured and organized pain management programme must be implemented (Cleeland *et al*., 1994). The American Pain Society Quality of Care Committee's (1995) quality assurance standards can be

adopted (Bookbinder *et al*., 1996). The first standard is to recognize and treat pain promptly, including recording, displaying and defining both pain and pain relief levels. In order not only to recognize pain intensity, but also to establish acceptable pain relief levels, appropriate tools must be used. Another standard from American Pain Society Quality of Care Committee (1995) is to promise patients attentive analgesic care. To accomplish this – as opposed to merely promising it – nurses need to improve their knowledge of pain management and be aware of attitudes and perceptions leading to pain management barriers. Bookbinder *et al*. (1996) found that after the implementation of national standards for cancer pain management, patients were very satisfied with the way nurses managed patients' pain. When discussing pain as well as goals for pain relief with patients and their relatives, the questions in the SF-36 questionnaire appeared to be a relevant point of departure.

CLINICAL IMPLICATIONS

Satisfactory pain assessment must not only include the current pain intensity, but also average pain and worst pain over the past 24 hours, as well as pain interrupting sleep. The impact of pain on daily life must also be assessed. Pain should be treated as early as possible during the course of the illness because persistent pain increases the level of pain gradually. Implementation and follow-up of well-structured pain management programmes are required. This should include the optimal use of both pharmacological and non-pharmacological treatments as well as instructions on how to initiate and maintain a discussion with patients and relatives about the importance of pain management.

IMPLICATIONS FOR RESEARCH

Further research is needed in order to explore how symptoms such as fatigue, dyspnoea, nausea and constipation influence the patient's HRQOL as well as patients' own views of failed pain management. Another important research question is patients' evaluation of pain treatment and their view of the relationship between pain and health. The use of the SF-36 questionnaire also needs further validation and norm setting, with regard to patients in palliative care.

Conclusion

Despite being referred to palliative care, too many cancer patients suffered unrelieved pain. Pain had a negative impact on HRQOL, particularly physical functioning, which may reduce the ability to perform daily activities. Pain intensity also increased as patients reached the final stage of life. Pain and anxiety about pain, together with fatigue and lack of energy, were aspects that disturbed most patients. Even if patients with a short survival time exhibit other symptoms, such as tiredness and anxiety, having to deal with pain is an unnecessary burden that can be prevented.

References

Addington-Hall J. & McCarthy M. (1995) Dying from cancer: results of a national population-based investigation. *Palliative Medicine* **9**, 295–305.

American Pain Society Quality of Care Committee (1995) Quality improvement guidelines for the treatment of acute pain and cancer pain. *JAMA* **274**, 1874–1880.

Bernabei R., Gambassi G., Lapane K., Landi F., Gatsonis C., Dunlop R., Lipsitz L., Steel K. & Mor V. (1998) Management of pain in elderly patients with cancer. *JAMA* **279**, 1877–1882.

Bookbinder M., Coyle N., Kiss M., Goldstein M.L., Holritz K., Thaler H., Gianella A., Derby S., Brown M., Racolin A., Ho M.H. & Portenoy R.K. (1996) Implementing national standards for cancer pain management: program model and evaluation. *Journal of Pain and Symptom Management* **12**, 334–347.

Bowling A. (1995) *Measuring Disease: a Review of Disease-Specific Quality of Life Measurement Scales*. Open University Press, Buckingham.

Cella D.F. (1995) Methods and problems in measuring quality of life. *Support Care Cancer* **3**, 11–22.

Cleeland C.S., Gonin R., Hatfield A.K., Edmonson J.H., Blum R.H., Stewert J.A. & Pandya K.J. (1994) Pain and its treatment in outpatients with metastatic cancer. *New England Journal of Medicine* **330**, 592–596.

Clohisy D.R., Le C.T. & Umen A.J. (1997) Measuring health status in patients with skeletal metastases treated by surgery. *American Journal of Clinical Oncology* **20**(4), 424–428.

Ferrell B.R., Juarez G. & Borneman T. (1999) Use of routine and breakthrough analgesia in home care. *Oncology Nursing Forum* **26**(10), 1655–1661.

Gaston-Johansson F. (1996) Measurement of pain: the psychometric properties of the Pain-O-Meter, a simple inexpensive pain assessment tool that could change health care practices. *Journal of Pain and Symptom Management* **12**, 172–181.

Grossman S.A., Sheidler V.R., McGuire D.B., Geer C., Santor D. & Piantadosi S. (1992) A comparison of the Hopkins pain rating instrument with standard visual analogue and verbal descriptor scales in patients with cancer pain. *Journal of Pain and Symptom Mangement* **7**, 196–203.

Herr K.A. & Mobily P.R. (1993) Comparison of selected pain assessment tools for use with the elderly. *Applied Nursing Research* **6**(1), 39–46.

International Association for the Study of Pain (IASP). (1979) Sub-Committee on taxonomy. Pain terms: a list of definitions and notes on usage. *Pain* **6**(3), 249.

Klepstad P., Borchgrevink P.C. & Kaasa S. (2000) Effects on cancer patients' health-related quality of life after the start of

morphine therapy. *Journal of Pain and Symptom Management* **20,** 19–26.

Mantha S., Thisted R., Foss J., Ellis J.E. & Roizen M.F. (1993) A proposal to use confidence intervals for visual analogue scale data for pain measurement to determine clinical significance. *Anesthesia and Analgesics* **77,** 1041–1047.

McHorney C.A., Ware J.E., Lu J.F.R. & Sherbourne C.D. (1994) The MOS 36-item short health survey (SF-36). III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care* **32,** 40–66.

Meuser T., Pietruck C., Radbruch L., Stute P., Lehmann K. & Grond S. (2001) Symptoms during cancer pain treatment following WHO-guidelines: a longitudinal follow-up study of symptom prevalence, severity and etiology. *Pain* **93,** 247–257.

Morita T., Tsunoda J., Inoue S. & Chihara S. (1999) Contributing factors to physical symptoms in terminally-ill cancer patients. *Journal of Pain and Symptom Management* **18,** 338–346.

Owen J.E., Klapow J.C. & Casebeer L. (2000) Evaluating the relationship between pain presentation and health-related quality of life in outpatients with metastatic or recurrent neoplastic disease. *Quality of Life Research* **9,** 855–863.

Portenoy R.K., Kornblith A.B., Wong G., Vlamis V., McCarthy Lepore J., Loseth D.B., Hakes T., Foley K.M. & Hoskin W.J. (1994) Pain in ovarian cancer patients. Prevalence, characteristics, and associated symptoms. *Cancer* **74,** 907–915.

Rawal N. & Berggren L. (1993) Postoperative pain management. There are simple methods for improvement. *Läkartidningen* **90**(5), 369–372. (in Swedish)

Riddell A. & Fitch M. (1997) Patient's knowledge of and attitudes toward the management of cancer pain. *Oncology Nursing* **24,** 1775–1784.

Strang P. (1992) Emotional and social aspects of cancer pain. *Acta Oncolologica* **31**(3), 323–326.

Sullivan M., Karlsson J. & Ware J.E. (1994) *SF-36 Health Survey. Swedish Manual and Interpretation Guide*. Health Care Research Unit, Medical Faculty, Göteborg University and Sahlgrenska University Hospital, Göteborg, Sweden. (in Swedish).

Sullivan M., Karlsson J. & Ware J.E. (1995) The Swedish SF-36 Health Survey I. Evaluation of data quality, scaling assumptions, reliability and construct validity across general populations in Sweden. *Social Science of Medicine* **41**(10), 1349–1358.

Swedish Medicine 58 (1997) *Management of Tumour Related Pain: Quality Improvement Guideline*. Swedish Physician Association for Medical Quality Advice, Stockholm Spri. (in Swedish).

Tate D.G., Riley B.B., Perna R. & Roller S. (1997) Quality of life issues among women with physical disabilities or breast cancer. *Archives of Physical Medicine and Rehabilitation* **78,** 18–25.

The National Board of Health and Welfare (2001) *Pain Management at the End of Life. Guidelines*. Socialstyrelsen, Stockholm. (in Swedish).

Twycross R., Harcourt J. & Bergl S. (1996) A survey of pain in patients with advanced cancer. *Journal of Pain and Symptom Management* **12,** 273–282.

Vainio A. & Auvinen A. (1996) Prevalence of symptoms among patients with advanced cancer: an international collaborative study. *Journal of Pain and Symptom Management* **12,** 3–10.

Wang X.S., Cleeland C.S., Mendoza T.R., Engstrom M.C., Liu S., Xu G., Hau X., Wang Y. & Ren X.S. (1999) The effect of pain severity on health-related quality of life. *Cancer* **86,** 1848–1855.

Ward S.E., Goldberg N., Miller- McCauley V., Mueller C., Nolan A., Pawlik-Plank D., Robbins A., Stormoen D. & Weissman D.E. (1993) Patient-related barriers to management of cancer pain. *Pain* **52,** 319–324.

Ware J.E. & Sherbourn C.D. (1992) The MOS 36-item short-form health survey (SF-36) I. Conceptual framework and item selection. *Medical Care* **30,** 473–483.

World Health Organization. (1990) *Cancer Relief and Palliative Care*. Technical Report Series. WHO, Geneva.