



How palliative care of cancer patients is organised between a University Hospital and primary care in Finland

Tiina Tasmuth, Tiina Saarto & Eija Kalso

To cite this article: Tiina Tasmuth, Tiina Saarto & Eija Kalso (2006) How palliative care of cancer patients is organised between a University Hospital and primary care in Finland, Acta Oncologica, 45:3, 325-331, DOI: [10.1080/02841860500423898](https://doi.org/10.1080/02841860500423898)

To link to this article: <https://doi.org/10.1080/02841860500423898>



Published online: 26 Aug 2009.



Submit your article to this journal [↗](#)



Article views: 832



View related articles [↗](#)



Citing articles: 1 View citing articles [↗](#)

ORIGINAL ARTICLE

How palliative care of cancer patients is organised between a University Hospital and primary care in Finland

TIINA TASMUTH¹, TIINA SAARTO² & EIJA KALSO³

¹*Cancer Society of Finland*, ²*Helsinki University Central Hospital, Department of Oncology* and ³*Helsinki University Central Hospital, Pain Clinic, Department of Anaesthesia and Intensive Care Medicine*

Abstract

The aim of this study was to find out how palliative care is organised between the Helsinki University Central Hospital (University Hospital) and primary care. The study consisted of 102 patients whose oncological treatment was terminated and the responsibility of palliative care was transferred to primary care. The patients were interviewed by phone using a structured questionnaire. Another questionnaire form was sent to the primary care physicians. Half of the patients were treated in more than one primary care unit. One third of the outpatients were unaware who was responsible for the care. Most of the patients wanted to be at home but this was achieved in less than half of the cases. Most patients were symptomatic while leaving the University Hospital and no improvement was seen thereafter. Every third patient reported of poor quality of palliative care in the primary care. Also the physicians reported a need for training in palliative care.

Palliative medicine refers to the management of patients with an active, far-advanced disease the prognosis of which is limited and the focus of care is in the quality of life [1]. The World Health Organization (WHO) has defined palliative care as being the active total care of patients whose disease is not responsive to curative treatment [2].

The treatment of cancer pain has achieved much attention during the last decades. It has been one of the areas of interest for WHO. In Finland treatment strategies of cancer pain were studied in 1985, 1990 and in 1995 [3–5]. Between these studies significant improvement in cancer pain management took place. However, the doses of analgesics used were still lower than those generally recommended and more than one third of the physicians were not familiar with the WHO analgesic ladder [5]. Symptoms that impair the quality of life of cancer patients are still underestimated [6] with significant differences in the ratings of the symptoms between the physician and the patient [7,8].

Approximately 10 000 cancer patients die annually, but there are only a few specialised palliative care units in Finland. The Finnish health care system is based on a strong primary health care organisa-

tion. University hospitals have had a general trend to reduce treatment periods in hospitals and to transfer the palliative care of the cancer patients from the specialists to GPs. The GPs treat cancer patients in outpatient clinics, inpatient wards and home-hospitals of the health centres, in home care teams and in acute hospitals. In addition, there are hospices maintained by private foundations in Finland. For the palliative care outpatients only the hospices and the home-hospitals provide help with symptom control around-the-clock and seven days a week. The other outpatients in palliative care can use the general public primary health care services, among others the emergency units. The patients in primary care can be referred back to the University Hospital only in very specific problems, for example if palliative radiotherapy or invasive methods of pain management is needed.

Between 1998 and 1999 at the Department of Oncology, Helsinki University Central Hospital, a pilot study of the organisation of palliative care in the area of the Helsinki University Central Hospital was performed (unpublished data). The results of the study indicated that the patients' symptoms were under treated and co-operation between the

Correspondence: Tiina Tasmuth, Department of Oncology, Helsinki University Central Hospital (HUCH), BOX 180, 00029 HUS, Finland. E-mail: tiina.tasmuth@hus.fi

(Received 10 March 2005; accepted 17 October 2005)

University Hospital and primary care was poor. Frequently changing physicians and uncertainty about the future were likely to increase anxiety and insecurity among the patients and their relatives. This work prompted further research.

The aims of the present study were to investigate: (1) how palliative care functions in practice in the University Hospital area; (2) the need and the quality of palliative care in primary care; (3) the problems related to co-operation between the University Hospital and primary care; (4) the need for training in palliative care.

Subjects and methods

Between November 2001 and May 2002 the consecutive patients from the Departments of Oncology, Gynaecology, Pulmonology, Gastroenterological surgery and Urology of the Helsinki University Central Hospital who fulfilled the inclusion criteria were asked to participate in the study. The inclusion criteria were: (1) existence of advanced cancer (local or haematogenous); (2) no further oncological treatment recommended; (3) the main responsibility of palliative care was transferred to primary care; (4) life expectancy was at least one month. A written informed consent was obtained from all patients. In this document the patients named the representative person who could answer the questions in case their health condition did not allow answering themselves.

The study was performed by phone calls using a structured questionnaire. The first call took place at one week after the patient was referred to primary care and then at one, two, three and six months. During the study period the patients were asked about the future care, symptoms, problems in palliative care, and what they would like to change. The general health condition was assessed by a five-point verbal rating scale (very good, good, moderate, weak and very weak). The maximum and the minimum intensities of pain during the last two days were asked by a five-point verbal rating scale (no pain, slight, moderate, considerable, severe). Emotional well-being was assessed by asking the patient to choose one of the following four words that best characterises their mood: "ordinary", "varying", "negative" and "positive". The patients were asked about their satisfaction with the care during each interview on a four-point verbal rating scale (very satisfied, satisfied, discontent, very discontent). Finally, the patients were asked free comments about the palliative care they had.

The communication between the physicians of the University Hospital and the primary care was studied from the primary care's point of view. One month after the patient was referred to primary care

the questionnaire was sent to the primary care physicians. The document included questions about the information they had received from the University Hospital about the patients' case history and about the treatment policy, the possibilities for consultation, and any specific problems in palliative care. The GPs were asked about the problems in palliative care using a five-point verbal rating scale (not at all, a little, some, much, very much). The GP's need for training in palliative care of cancer patients was asked by a five-point verbal rating scale (not at all, a little, some, much, very much).

The Spearman rank correlation test was used to analyse the correlation between the rating of satisfaction with palliative care of the patients and the quantity of problems in palliative care answered by the GPs, as well as the correlation between "receiving information (yes, no) about who is responsible for the home care after the discharge from University Hospital" and the satisfaction with their care. For comparison of non-parametric data in two groups, the Mann-Whitney U-test was applied. Significance was set at $p < 0.05$.

The patient's records were examined for the localisation of the primary cancer and for the physician's decision to discharge the patient from the University Hospital. The treatments the patients had received were not assessed.

The local ethics committee approved the study. The physician who performed the interviews was not involved in patient care.

Results

Palliative care facilities in primary care

During the seven-month recruitment period 110 consecutive patients fulfilled the inclusion criteria. All patients were willing to participate. However, during the first week after signing the consent form, eight patients died. The number of patients or relatives who were interviewed at least once was 102 (Table I). At the time of the first interview a mean of 32 months (range: 2 weeks–164 months) had elapsed from the diagnosis of the cancer. A total of 10 newly diagnosed patients were included. The number of patients who were able to answer the questions was one week later 71 (70%), one month later 45 (65%), two months later 25 (60%), three months later 15 (52%) and six months later six patients out of nine. During the six months' period of observation 93 patients (91%) died (Table II). The median survival time was 49 days (range: 9–180 days).

Forty-five patients (44%) were transferred home from the University Hospital and 57 patients (56%)

Table I. Characteristics of the cancer patients discharged from the Helsinki University Central Hospital after termination of oncological treatment (n = 102).

Sex	
Male	44
Female	58
Age	
Mean age is 67 years (range 39–86 years)	
Primary location of the cancer	
Gastrointestinal tract	31%
Lung	14%
Breast	13%
Gynaecological organs	10%
Prostata	9%
Other urological tract	6%
Lymphoma	4%
Others	13%

to another hospital. Patients preferred to be treated at home (61%) rather than it was realised. As time passed more patients wanted to stay at home. Six months later all nine patients alive wanted to be treated at home, but this was only achieved in six cases. Data of placement of patients are shown in Table III. At some time during the study period 89 patients were treated in a hospital (87%) and 58 patients (57%) were treated in more than one primary care unit (from 2 to 5 units). The average number of primary care units was two.

From the 45 outpatients 29 (64%) were aware of whom they should contact in case they needed help with symptom control, but still 21 patients (47%) planned to go to an emergency outpatient unit. Lack of information was considered as a major problem by every fifth patient or relative.

Symptoms

In about half of the patients the general health condition was weak or very weak throughout the study period. Every third patient characterised his or her mood negative, another third described it as ordinary, one fourth positive and 7% varying. Mood did not change significantly during the study period.

Table II. The number and percentage of cancer patients interviewed at different intervals after the treatment termination and discharge from the Helsinki University Central Hospital.

Time from treatment termination (weeks, months)	Patients	
	n	%
1 week	102	100%
1 month	69	68%
2 months	41	40%
3 months	29	28%
6 months	9	9%

Table III. The distribution of cancer patients treated at some time in different units (1–5 units/patient).

	Patients (n = 102)	
	n	%
Out-patients		
Health centre	36	35%
Home care team	24	24%
Home-hospital	15	15%
Hospice, home care	14	14%
In-patients		
City hospital	54	53%
University hospital	20	20%
Hospice, ward	18	18%
Other hospitals (regional, private)	17	17%

During every interview questions about pain and other symptoms were asked (Figure 1). The following symptoms were reported by the patients at least once: 94% patients reported fatigue, 86% lost of appetite, 72% constipation, 64% pain, 55% dyspnoea, 50% nausea, 36% vomiting, 22% diarrhoea, 15% paraesthesia or paralysis of the lower extremities, 14% confusion, 10% oedema of the lower extremities, 9% cough, 8% dizziness, 7% panic disorder, anxiety, depression or fever, and 6% difficulties to urinate. Dry mouth caused suffering in four patients, dysphagia or ascites in three patients, hiccup, thirst or heartburn in two patients and sexual problems in one patient.

About half of the patients who had pain reported that it was persistent (one week later 57%, one month 40%, two months 50%, three months 33%, and six months later one patient out of four had persistent pain). The majority of the patients had breakthrough pain (after one week 74%, one month 92%, two months 86%, three months 92%, and after six months all the four patients who reported pain suffered from breakthrough pain).

During the previous two days the maximum pain intensity had been considerable or severe during the first interview in 65% of the patients, after one month 57%, two months 83%, three months 25%, and after six months in two out of four patients who had pain (Figure 2).

In the free comments 39% of the patients complained of the poor quality of palliative care in primary care. The shortcomings concerned mainly treatment of pain, quality of care and psychosocial support. Half of the patients (53%) wished to receive more information about their disease and treatment. These communication problems were more common at the University Hospital than in primary care (32% vs. 21%, respectively).

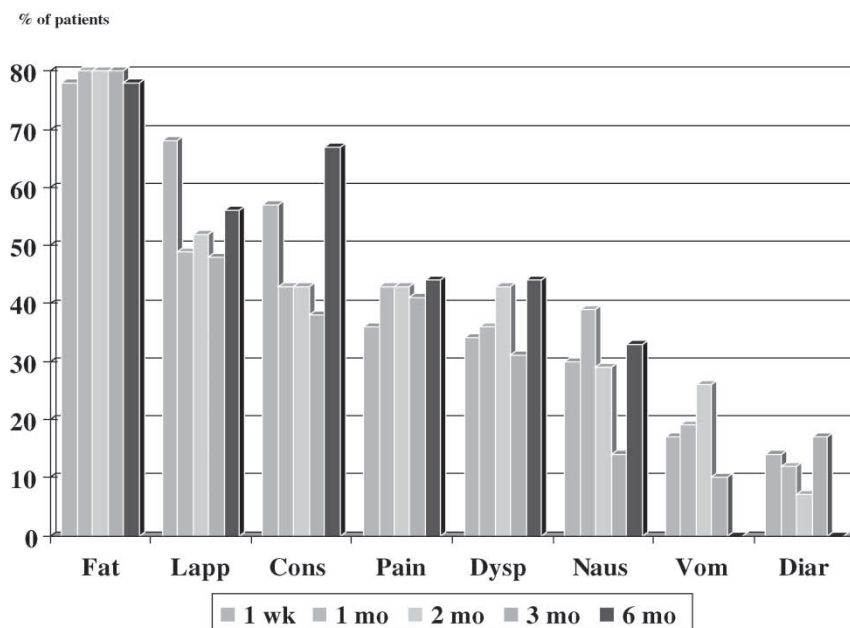


Figure 1. The incidences (% of patients) of symptoms at 1 week (n=102), 1 month (n=69), 2 months (n=41), 3 months (n=29) and 6 months (n=9) after treatment termination and discharge from the Helsinki University Central Hospital (Fat.-fatigue, Lapp.-loss of appetite, Cons.-constipation, Pain, Dysp.-dyspnoe, Naus.-nausea, Vom.-vomiting, Diar.-diarrhoea).

Satisfaction with the care

The patients were generally satisfied with the care. The number of patients who were satisfied or very satisfied with the care was 72% during the first interview, 82% after one month, 78% after two months, 93% after three months, and after six months eight patients out of nine. The ratings did not differ significantly between the patients and the relatives. The outpatients who had the information about who was responsible for their care after the discharge from University Hospital were significantly

more satisfied with their care compared with patients who did not have this information ($p=0,028$, $n=45$). There was no significant correlation between the rating of satisfaction with palliative care of the patients and the quantity of problems in palliative care reported by the GPs.

Questionnaire for general practitioners (GPs)

Forty-three GPs who cared for 61 patients (60%) responded to the questionnaire. To the question about other professionals involved in palliative care

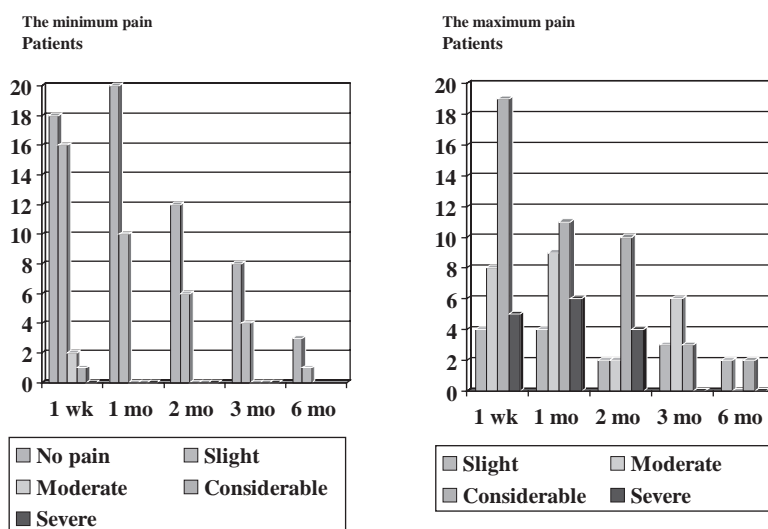


Figure 2. The maximum and the minimum intensities of pain during the last two days by the five-point verbal rating scale (no pain, slight, moderate, considerable, severe) 1 week (37 patients), 1 month (30 patients), 2 months (18 patients), 3 months (12 patients) and 6 months (4 patients) after treatment termination in Helsinki University Central Hospital.

nurses were mentioned by all the physicians, a physiotherapist or an occupational therapist was mentioned by 21 physicians (49%), a hospital attendant by 11 (26%), a social worker, a pastor or a volunteer by 7 (16%), and a psychiatrist or a psychologist was mentioned by two physicians (5%). The physicians had received very good or good information about 47 patients (77%), some information about 9 patients (15%) and little information about five patients (8%). In connection to 11 patients (18%) the physician had to ask for more information.

The GPs had no problems in the palliative care of 15 patients (25%), and a little or some problems with 22 patients (36%). Only with one patient did the physician have either many or very many problems. Approximately every third problem was connected with pain management. There were no significant differences between outpatient care (33%) and inpatient care (35%). The GPs consulted other colleagues about the treatment of 22 patients (36%). In half of the cases the colleague who was consulted worked at the same primary care unit (11 cases), in five cases a physician at the University Hospital was consulted, in three cases a pain unit and in another three cases some other specialised unit was consulted. Lack of information from the University Hospital about a patient's previous case history or treatment strategy was mentioned by 26% of the responders. Only one physician expressed no need for training. Fourteen physicians (33%) needed much or very much training, 19 some (44%), and 9 only a little (21%).

Discussion

We have studied some clinical and organisational problems of the management of cancer patients in palliative care in the Helsinki University Central Hospital area in Finland. Our study revealed major shortcomings in this field of palliative care. Patients were transferred to primary care in a relatively late phase of the disease (about 1.5 months before death) and with an insufficient symptom control. Even though most of the patients wanted to stay at home, this was achieved in less than half of the cases. In the present study this could partially be due to a poor overall health condition of the patients as the study patients were recruited from inpatient units. However, it could also, at least partially, be related to poor resources in primary care to offer home care for very ill patients. A qualitative systematic literature review of patient preferences for place of terminal care indicated that the home death was the most common preference (range 49–100%) [9]. The same conclusion was drawn in a

recent prospective cohort study from USA where nearly 90% of terminally ill cancer patients preferred to die at home and only one-third achieved their preference for place of death [10].

In our study the patients were not properly informed about the future care. Every third outpatient did not know who was responsible for the care after the discharge from the University Hospital and about half of the patients did not know where to go with their problems. Therefore, one third of the patients planned to turn to emergency units with their problems. However, in an emergency department the care of terminally ill patients is often poor and temporary in its character. Without proper management of palliative care these patients overload emergency departments and acute hospitals where there is no time to concentrate in palliative care problems and not enough knowledge either [11,12]. Good continuous collaboration between patients and medical professionals is essential, which is not usually possible in emergency units. In a recently published Swedish prospective randomized study the factors that are related to an increased need for medical services of newly diagnosed cancer patients were studied. The authors concluded that in addition to cancer diagnosis and treatment, comorbidity, physical function, and pain determined use of inpatient care. Also the socioeconomic factors were important in identification of cancer patients with an increased need for healthcare services [13]. The results of the study by Myers and Trotman highlighted the particular difficulties that exist in caring for patients with advanced cancer and their families on busy acute general hospital wards [14]. Clear organisation and course of action of the palliative care are needed to share the responsibility and information between the units in order to ensure a holistic approach to the treatment of the patients. In the present study the organisation of palliative care in primary care did not always work either, since more than half of the patients were treated in more than one primary care unit.

The patients and their relatives wished more information about the disease, treatment plans and support. This was a problem especially at the University Hospital, where physicians are more focused on curative care. However, most cancer treatments even in specialised units are palliative in nature. In addition, health care professionals should be aware that the information needs of patients and family members change throughout the course of care and therefore they should be reassessed periodically.

During the first interview, which took place already a week after the discharge from the University Hospital, most of the patients had

symptoms that considerably decreased their quality of life. This indicates that patients were transferred from the University Hospital to primary care without sufficient symptom control. This could be one reason why so few patients could be treated at home. Even today some of the major Finnish cancer centres lack palliative care units. This can well explain why physicians in primary care consulted the University Hospital surprisingly rarely. Every third patient mentioned that the palliative care in primary care was not sufficiently effective. The majority of the patients were symptomatic without any significant improvement in symptom control during the treatment in primary care. Despite this 61% of the physicians reported no or only little problems with palliative care. This could be due to a lack of knowledge of symptom control or simply because of ignorance of the symptoms' existence. It seems that suffering is still too often taken as a natural part of a terminal phase of cancer.

Nevertheless, the majority of the patients and the relatives were relatively satisfied with the care. The reason for the contradiction between the satisfaction and the multitude of problems was not directly investigated in the present study. However, there is a correlation between the satisfaction with the care and the continuity of the care. Previous studies have indicated that patients often report satisfaction even though they have several problems. In a recent study the patients were satisfied with their pain management even though they had had severe pain during the past three days [15]. Ward and Gordon postulated that expectations about pain pattern, not about pain severity, may be the most important explanatory factor of a patient's satisfaction even though they are in pain [16]. Also, the interpretation or perception of having control over the pain was related to the satisfaction with pain relief [17]. Some studies showed a significant connection between the treatment satisfaction and the patient-provider relationship [15,18]. The results of the study by Sahlberg-Blom *et al.* from Sweden showed that despite having an assessed lower quality of life in many dimensions than people in general, several patients experienced happiness and satisfaction during their last month of life. 'Cognitive functioning' and 'emotional functioning' were the dimensions that differed least from those of the general population, and 'physical functioning', 'role functioning' and 'global health status/quality of life' differed the most [19]. Hence, palliative care provides not only symptom control, but it also integrates psychosocial and spiritual aspects of care, and support for the family to cope during the patients' illness. Thus, the patients' satisfaction does not indicate directly the level of the effectiveness of the treatment.

Almost all general practitioners experienced need for training in palliative care of cancer patients even if only a few of them had reported problems in palliative care. This inquiry was made to physicians in primary care only. However, our understanding is that the need for training is obvious in both specialist and primary care. Each health care professional should be familiar with the basic principles of palliative care. However, too little experience and knowledge accumulates for a single medical professional to be able to take the responsibility for palliative care. In UK, Australia, Canada and USA the hospital-based palliative care teams bring the principles of hospice and palliative care to acute hospitals. They are multiprofessional including nurses, doctors, and often social workers, chaplains, and other staff [20].

Our next step for improving the palliative symptom control of the cancer patients and the communication between the physicians of the University Hospital and the primary care was started in September 2005. It is a project where a specialist palliative care team (physician and nurse) provides a consultation service for more complicated palliative care cases in the University Hospital. This team helps the specialists of the University Hospital to organise the transferral of the responsibility of palliative care to primary care.

Conclusions

This study indicates that the contact between the patient with advanced cancer and the physician who will be responsible for the terminal care in the future must be made as early as possible, not only few months before the death of the patient. However, palliative care should also be part of the treatment of cancer patients in line with oncological and surgical treatment. Most of the terminally ill cancer patients want to stay at home. Thus, good palliative care should be accessible to each patient with no regard to the place of the residence or the medical establishment. More attention should be paid to informing the patients about their disease and the treatment plan. The need for training of medical staff in palliative care is obvious. The GPs must be instructed whom to consult about problems with symptom management. Both, specialist care and primary care need special palliative care units or consulting teams to organise, co-ordinate and educate in palliative care.

Acknowledgements

The authors gratefully acknowledge the Cancer Society of Finland for financial support.

References

- [1] Doyle D, Hanks G, McDonald N. Introduction. In: Doyle D, Hanks G, McDonald N, editors. *Oxford Textbook of Palliative Medicine*, 2nd edition. Oxford: Oxford University Press; 1998. p. 3.
- [2] Cancer Pain Relief and Palliative Care. Technical Report Series 804. Geneva: World Health Organization; 1990.
- [3] Vainio A. Treatment of terminal cancer patient in Finland: A questionnaire survey. *Acta Anaesthesiol Scand* 1988;32: 260–5.
- [4] Vainio A. Treatment of terminal cancer patient in Finland: A second look. *Acta Anaesthesiol Scand* 1992;36:89–95.
- [5] Kaasalainen V, Vainio A, Ali-Melkkilä T. Developments in the treatment of cancer pain in Finland: The third national-wide survey. *Pain* 1997;70:175–83.
- [6] Vuorinen E, Vainio A, Reponen A. Backlash in the treatment of cancer pain: Use of opioid analgesic in a Finnish general hospital in 1987, 1991 and 1994. *J Pain Symptom Manage* 1997;14:289–91.
- [7] Anderson KO, Mendoza TR, Valero V, et al. Minority cancer patients and their providers: Pain management attitudes and practice. *Cancer* 2000;88:1929–38.
- [8] Cascinu S, Giordani P, Agostinelli R, et al. Pain and its treatment in hospitalized patients with metastatic cancer. *Support Care Cancer* 2003;11:587–92.
- [9] Higginson IJ, Sen-Gupta GJ. Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *J Pall Med* 2000;3:287–300.
- [10] Tang ST, McCorkle R. Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. *J Pall Care* 2003;19:230–7.
- [11] Sahlberg-Blom E, Ternstedt B-M, Johansson J-E. The last month of life: Continuity, care site and place of death. *Palliat Med* 1998;12:287–96.
- [12] Llamas KJ, Pickhaver AM, Piller NB. Mainstreaming palliative care for cancer patients in the acute hospital setting. *Palliat Med* 2001;15:207–12.
- [13] Johansson BB, Holmberg L, Berglund IG, Sjoden PO, Glimelius BL. Determinants of cancer patients' utilization of hospital care within two years after diagnosis. *Acta Oncol* 2004;43:536–44.
- [14] Myers KG, Trotman IF. Palliative care needs in a district general hospital: A survey of patients with cancer. *Eur J Cancer Care* 1996;5:116–21.
- [15] Dawson R, Spross JA, Jablonski ES, Hoyer DR, Sellers DE, Solomon MZ. Probing the paradox of patients' satisfaction with inadequate pain management. *J Pain Symptom Manage* 2002;23:211–20.
- [16] Ward SE, Gordon DB. Patient satisfaction and pain severity as outcomes in pain management: A longitudinal view of one setting's experience. *J Pain Symptom Manage* 1996;11:242–51.
- [17] Pellino TA, Ward S. Perceived control mediates the relationship between pain severity and patient satisfaction. *J Pain Symptom Manage* 1998;15:110–6.
- [18] McCracken LM, Klock PA, Mingay DJ, Asbury JK, Sinclair DM. Assessment of satisfaction with treatment for chronic pain. *J Pain Symptom Manage* 1997;14:292–9.
- [19] Sahlberg-Blom E, Ternstedt BM, Johansson JE. Is 'good quality of life' possible at the end of life? An explorative study of the experience of a group of cancer patients in two different care cultures. *J Clin Nurs* 2001;10:550–62.
- [20] Higginson IJ, Finlay I, Doodwin DM, et al. Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002;23:96–106.