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#### A study to examine staff stress in a children's hospice

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**Purpose:** With the growth of the hospice movement, there has been a growing recognition that staff working in this area of health care may be particularly susceptible to developing occupational stress. This study took place at a children's hospice to examine stress amongst staff.

**Method:** Forty staff at the hospice were invited to complete a questionnaire to evaluate the degree of stress-related symptoms experienced, the possible causes of stress and the factors that enabled the staff to cope with work-induced stress. The questionnaire contained both qualitative and quantitative questions. Seventeen members of staff returned the questionnaire (response rate 43%).

Results: Nine members of staff (53%) agreed to experiencing at least four of the stress-related symptoms in the preceding year. A number of distinguishing factors were noticed about this group. They generally appeared to be younger, had spent less time working in palliative care, had higher absenteeism rates, were commonly experiencing unresolved grief and had undertaken training of less than two years or no traing at all. Anxiety and physical exhaustion were the symptoms experienced most frequently.

The most common causes of stress were the inability to relieve the distress a child may be experiencing; conflicts within the staff group and communication difficulties between staff. Amongst the community staff, over identification with a family was a common cause of stress.

The sources of support considered to be the most valuable were the informal support derived from work colleagues; having family, a partner or friends outside the hospice and being able to pursue interests outside the workplace. The majority of staff did not use or value the staff support group. The staff with less than two years or no formal training did not value professional support outside the hospice and generally considered the hospice counsellor unhelpful or not relevant to them.

Conclusions: Providing care for the terminally ill child presents the caregiver with many challenges and in certain members of staff, may lead to the development of stress. By drawing attention to the various factors that may precipitate stress, the potential for its occurrence can be more easily recognised and the use of effective support systems encouraged to minimise the opportunity for its development.

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## Palliative care consultations: the experience of a new service in the Netherlands

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**Introduction:** In the Netherlands palliative care teams (PCTs) offer consultation services to support professionals working in primary health care since the late nineties. In our region the service is offered by one Regional Palliation Team (RPT), set up by the cancer institute and a specialised nursing home, and four Local Palliation Teams (LPTs), two set up from nursing homes, one from a home care service and one from a hospice. These LPTs differ in historical background and social environment.

**Purpose:** To provide a detailed description of the professions which referred to the PCTs, the reasons for referral to the PCTs and the advises given, the data from all consecutive referrals to the PCTs in the period of March 2000-April 2001 were evaluated.

**Methods:** All referrals were registered on a standard form. After the period of registration the forms were collected and analysed.

Results: 246 referrals were registered, 67 from the RPT and 179 from the LPTs. Due to the working method, referrals to the RPT could only be handled by telephone, whereas for the LPTs it was possible to make a bedside visit. The latter was done in 122 cases (70%). One LPT with the most bedside visits (88%) was predominantly contacted by nurses (51%). The other LPTs were especially consulted by GPs (38-64%); the RPT was consulted as well by GPs (39%) as by nurses (45%). The most frequent reasons for consulting the PCTs were questions concerning physical signs and symptoms (35%). The RPT was also asked for advice in non-patient related questions (30%). The two LPTs connected with a hospice received many questions regarding admission to the palliative care unit (PCU), 35 and 71% respectively. The advises given by telephone by the PCTs included a change in medication (27%), explanation about the possibilities of care

at home or elsewhere (19%), and admission to the PCU (14%). Important aspects in bedside consultation were guidance in coping with the disease and in psychosocial problems (52%).

Conclusion: There is a significant need for consultation in palliative care especially by GPs and nurses. The character of the questions were influenced by the historical background and social environment of the PCT.

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### Pain and its control in Taiwanese cancer patients: A multicenter patient-oriented survey

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**Purpose:** To investigate the occurrence of pain in cancer patients and its management pattern in Taiwanese cancer patients.

Patients and methods: Patient-oriented questionnaire was given to unselected out-patients in cancer clinic in 15 hospitals across Taiwan in Feb, 2001. Four Questions are asked: 1) Are you having pain from your disease? 2) How severe is the pain? 3) Does your doctor give you medicines for your pain? 4) How is the pain controlled?

Results: There are 17 oncologists in 15 hospitals across Taiwan joined this survey. Totally there are 486 cancer patients surveyed. Patients characteristics: 263 Males(54.1%), Primary lesion: Lung(13.4%), Breast(20%), Head & Neck(11.9%), GI tract(25.1%). 306 patients had no metastasis. There are 257(52.9%) patients claimed to have pain from their cancer. There are no difference between patients with and without pain in sex, age, and primary lesions except more patients with head and neck cancer reported to have pain. The level of pain was mild in 29.2%, moderate in 35.4% and severe in 35.4% of patients. Only 149(58%) of these patients received medications for their pain. NSAIDs was used in 38.9% of patients, weak opioids 32.2%, strong opioids 42.3% and adjuvant analgesics 23.5%. For patients with severe pain (n=63), combination medication was used in 36(57.1%) while 10(16%) had NSAIDs and 11(17.4%) had strong opioids only. Combinations were used in 28% of patients with moderate and 25% of patients with mild degree of pain. The most commonly used weak opioid was tramadol(66.7%) and codeine(16.7%). The most commonly used strong opioids were MS-contin(33.3%) and fentanyl patch(27.0%). Regular morphine was still used in 14.3%. Adjuvant medicines including steroids, anti-depressant, anticonvulsants and laxatives, was used in 35(23.5%) patients. 29(19.5%) patients are very satisfied and 66(44.3%) are satisfied about their pain control. 43(28.9%) patients claimed to have improvement but unsatisfied about their pain control and 11(7.4%) patients felt no improvement.

Conclusions: Pain is still under-treated in Taiwanese patients with cancer pain in oncology clinic. Only 58% of patients with pain are treated. Long-acting opioids are used more commonly than regular morphine tablets. 63.7% patients treated got satisfactory pain control.

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## Educational value of radiation oncology palliative care rounds in the multidisciplinary cancer centre

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**Background:** Radiation Therapy (RT) plays a significant role in the palliation of cancer patients. A Rapid Response RT Program was developed to meet patients' needs and a continuing education (CE) program was developed to meet the educational needs of the multidisciplinary team members.

Purpose: To describe the development and evaluation of this CE program.

Methods: An interdisciplinary planning committee consisting of Radiation Oncologists, Radiation Therapists, Radiation Nurses, Pharmacists and trainees' identified topics, speakers, learning objectives and formats. Monthly interdisciplinary Palliative Radiation Oncology rounds were instituted in September 1998. Since January 2000, attendees, using a standard 5-point rating scale addressing areas of content and practice relevance, have carried out formal evaluations.

Results: Between September 1998 and March 2001, 25 1-hour sessions have been conducted covering a wide range of palliative radiotherapy and other topics. Learning formats consisted of short presentations and interactive discussions, and comprised at least 25% of each session. The median number of participants was 23 (range from 15-35). Preliminary results suggest that participants perceive these rounds to have high educational value.

**Conclusion:** Our experience confirms interest in and supports the need for multidisciplinary palliative care education at the comprehensive cancer centre.

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## Continuous intrathecal application of morphine in cancer pain

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**Purpose:** The main purpose of this study was to investigate the success of the intrathecal application of morphine in cancer pain via implantable pumps.

Patients and Methods: From 1988 to October 1998 the intrathecal oploid therapy via implantable pumps was administered to 101 patients. 42 patients were controlled by an independent anaesthetist, who was not involved in the therapy. The follow-up was 13 months. Evaluation was based on VAS (0–10), the use of drugs (0–10) and quality of life (0–10).

Results: The mean VAS value preoperatively was 9.6, after intrathecal opioid therapy 2.0 after a period of 13 months. Preoperatively all patients had received pain medication according to the WHO stage III. The mean value was 9.7 after intrathecal therapy 4.4. The quality of life (level of activity, emotional state, drug-related side effects and sleep behavior) showed a considerable improvement as far as 50% of our patients were concerned. Prior to pump implantation the mean value was 7.3 after intrathecal therapy 3.0. While preoperatively the severe side effects amounted to 81% in spite of comedication, postoperatively, these were only relevant in 14%. 21% of the patients had no side effects. The lowest dosage was 1 mg morphine/day, the highest 55 mg/day. In most patients a dosage increase or dosage adjustment was necessary.

**Conclusion:** Due to the improvement of the VAS, side effects and quality of life as well as the reduction in drug intake with a low incidence of complications, intrathecal opioid therapy has proven to be an efficient method for the treatment of cancer pain.

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### The luck of the draw - who gets admitted to palliative care?

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Purpose: In the context of limited resources in health care it is imperative that access to services is appropriate to both patient need and the health care being provided. A survey of the criteria used to access palliative care services was used to evaluate how well these could be said to respond to the differing needs of patients.

**Methods:** A questionnaire was sent to all service providers listed in the UK Hospice Directory. Service providers were asked to state what criteria they used to enable access to their facility. Thematic word analysis was used to identify the access criteria used.

Results: 288 responses were received from a mailing of 557. These were representative of the range of services identified from the directory. None of the respondents had fixed criteria but access was specified as being for patients who were in the palliative or terminal phase of disease or having a life-limiting illness. Actual admission criteria were difficult to classify from the replies. Common themes which would make a patient eligible for admission were identified as a patient being in need of 1) pain control 2) other physical symptom management 3) psychological, emotional and spiritual support 4) respite care 5) rehabilitation 6) care and support during or after cancer treatment. In addition information and advice were available for health care professionals and the general public. There were no discernible distinctions between the criteria used by specialist palliative care service providers as opposed to other service providers. Differences in criteria appeared to be related to the type of facility and care available rather than differences in the level of expertise.

Conclusions: Access to palliative care services is not clearly defined. The criteria identify the symptoms that can be treated by a particular unit but give little indication of any means of prioritising patients with different care needs. Distinctions in the level of service provision are not obvious from this survey. If specialist palliative care providers are to meet the needs of patients with complex care needs access criteria need to be more clearly defined.

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## Results of a quality improving pilot project for dyspnea management at a palliative care unit

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Purpose: Being confronted with the problems in managing dyspnea in terminally ill patients at the palliative care unit "Gasthuis St. Camillus", the need of a consensus on an appropriate approach and follow up of dyspneic patients has risen.

Methods: Based on a quality improving model -"The Quality cycle"-a consensus procedure for daily management and follow-up of dyspnea in terminal patients has been worked out and evaluated. Literature was reviewed and a consensus procedure was worked out. The procedure was implemented during a test period in the daily care at the unit. During this test period, the intensity (using visual analogue scale) and the effects (using the specific STAS item of symptom control) of dyspnea were registered and evaluated in a descriptive prospective setup. Problems in implementation of the procedure were evaluated using a questionnaire, filled in by the nursing staff

Results: 21 patients were included: 10 men; 11women, 19 patients had cancer, 15 of which with distant metastasis. Mean age was 72.4 year. Dyspnea diminishes during stay at the unit in most patients who are admitted with dyspnea or who develop dyspnea complaints during stay. In some patients dyspnea complaints increase in the last days before death. Despite new procedure these breathing problems, always accompanied by rales, seem to remain uncontrolable.

All nurses evaluated the procedure as clear, easy to use and covering all topics concerning breathing problems in terminal patients. Remarks were made that some topics should be more nuancated and that psychological factors -other than anxiety- should be included. Disadvantages reported were that the procedure was to laborious and that there was no place for the nurse's own contribution. According to the results of the nurses survey, it is usefull to integrate the procedure, with some adaptations, in the general nursing practice for terminal patients, especially for those with breathing problems.

Conclusions: Despite the small number of patients and the many interfering factors, results of this first evaluation of the new procedure seem promising, especially in terminal patients developing dyspnea

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# Lessons from setting up a multi-centre study to evaluate management of constipation in palliative care settings

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Purpose: The prevention and relief of constipation is a problem in palliative care. About 50% of patients admitted to British hospices cite constipation as a major concern. There has been little evaluation of the effectiveness of constipation management or assessment of the effect of constipation on the quality of life of patients with palliative care needs. A multi-centre study is underway to evaluate:- 1) how effectively constipation is managed in different palliative care settings; 2) any differences in perceptions of the effect constipation has on quality of life between the patient and his/her carers. This is the first study in which all of the Marie Curie Cancer Care palliative services are participating.

Methods: Self-administered questionnaires incorporating the Patient Assessment of Constipation (Frank, 1999), the Palliative Care Outcome Scale (Higginson 1998) and study-specific questions are completed by patients, their main family carer, and named nurse during a designated two week visit in each setting. Questionnaires are completed on day 1 and a week to ten days later. Patients are recruited from the Marie Curie Cancer Care specialist palliative care centres and palliative care community nursing services across the UK.

Results: Data collection is continuing.

Conclusions: Many of the lessons learnt in setting up this study are applicable to future multi-centre research in varied palliative care settings, and will be discussed. Although a strength of the study is that assessments are made in in-patient, day care, and community settings this has required complex administrative arrangements. The challenges of recruitment across the different care settings and of family carers and health care professionals in addition to patients will be presented. Ethical and practical difficulties of designing rigorous multi-cenre research in this setting will be detailed.