

## Monday, 31 October 2005

### Teaching Lecture

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INVITED

#### Learning to live with cancer® – from Sweden to Europe in 10 years

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Learning to Live With Cancer® is an education and support programme for cancer patients and their significant others. Developed and implemented in Sweden since 1992, it is based on a research project by Professor Gertrud Grahn from Lund University. The programme consist of 8 two hours sessions with themes such as the human body, cancer treatment, side effects but also talking about cancer, relaxation, support and resources in the community or expressive art. Inspired by the Chinese proverb "Tell me and I forget, show me and I remember, let me take part and I understand" it has strong pedagogical basis to allow cancer patients but also families and friends to understand more about the meaning of learning to live with cancer. Generally led by nurses, doctor, physiotherapist, dietician and social worker are involved according to the different topics. After Sweden, where the programme is available in 33 locations, it has been translated into Norwegian and is running in Norway. The European Union's Europe against cancer programme allocated money in 1995 and 1996 for "Training the Trainers European workshop" starting in Lund (1995). Supported by an educational grant from Bristol-Myers Squibb Oncology Division Europe (BMS-ODE) and in collaboration with the European Oncology Nursing Society (EONS), three other workshops took place in Athens twice (1996) and Dublin (1997). 66 persons from 21 countries all over Europe and Israel have been trained. The learning material from the programme has been translated into English, German, French, Spanish and Dutch by BMS-ODE. Participants from Italy, The Czech Republic, Iceland, Finland and Serbia have made their own translation, supported by their national cancer societies or institutions. The programme could start in several countries and also organise local "Training the trainers" workshop. Results from a questionnaire, send to the participants of the four workshops, will enable a survey of the situation of the programme in 2005 in Europe, ten years after its implementation as a European project. A particular focus will be given to Switzerland where trained nurses have chosen to create an association and been able to implement the programme all over the country and to update the learning material with the support from Amgen Switzerland.

### Proffered papers

#### Symptoms and improvement in clinical practice

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ORAL

#### Clinical practice improvement methodology leads to a sustained decrease in the incidence of chemotherapy induced nausea and vomiting in the chemotherapy day unit

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**Introduction:** Chemotherapy induced nausea and vomiting (CINV) remains the most common chemotherapy related side effect. Its frequency is often underestimated [1] and in the majority of patients can be controlled or prevented [2]. We utilised clinical practice improvement (CPI) methodology to assess and improve CINV in our chemotherapy day unit (CDU).

**Methods:** A multidisciplinary team analysed the systems and processes supporting prevention and treatment of CINV for patients attending the CDU. Methods included mapping current processes and grouping highlighted problems into common themes. Themes were then ranked and prioritised. Intervention brainstorming centred around identified priorities of: standardisation of antiemetic prescribing according to evidence based guidelines and facilitation of accessible, 'real time', amendments to antiemetic treatment protocols. Repeated Plan-Do-Study-Act (PDSA) cycles were undertaken over a 12-week period to trial interventions. Data collected included a continuous prospective audit of 231 patients receiving chemotherapy in CDU. The audit captured incidence and severity of CINV and the presence or absence of side effects likely to be attributed to commonly prescribed anti-emetic drugs. Changes in prescribing practice were monitored by expenditure on antiemetics. A repeat snapshot audit of 95 patients at 6 months post completion of the project was conducted to ascertain to what extent improvements were sustained.

**Results:** Baseline audit of 100 patients showed that 52% of patients experienced nausea, 13% at grade 2 or above and 12% of patients

experienced vomiting, 4% at grade 2 or above. By the end of the study period, less than 30% of patients reported any nausea or vomiting (>22% reduction in incidence). CINV severity remained stable with 12% of nausea at grade 2 or above and 4% of vomiting at grade 2 or above. Follow up data at 6 months revealed that 36% of patients experienced nausea, 10% at grade 2 or above, and 8.4% of patients experienced vomiting, 1% at grade 2 or above. There were no significant changes to the incidence of antiemetic related side effects and a trend towards decreased expenditure was demonstrated.

**Conclusion:** Through utilisation of a Clinical Practice Improvement project we were able to demonstrate sustainable gains in decreasing the incidence of CINV for patients receiving chemotherapy in our clinical setting. Results were achieved without causing significant changes to antiemetic side effects and showed a potential for cost savings.

### References

- [1] Grunberg S, Deuson RR, Mavros P. et al. Incidence of chemotherapy-induced nausea and emesis after modern antiemetics. *Cancer* 2004; 100(10): 2261–2268.
- [2] Gralla RJ, Osoba D, Kris MJ. et al. Recommendations for the use of antiemetics: evidence-based, clinical practice guidelines. *J Clin Oncol* 1999; 17(9, September): 2971–2994.

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ORAL

#### Managing chemotherapy-related nausea and vomiting in breast cancer patients using acupressure wristbands

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The aim of the current study was to evaluate the effectiveness of using acupressure in Pericardium 6 (Neiguan) acu-point in managing chemotherapy-induced nausea and vomiting. The study was a randomised controlled trial. Acupressure was applied using wristbands (Sea-Band™) which patients in the experimental group had to wear for the 5 days following the chemotherapy administration. Assessments of nausea, retching and vomiting were obtained from all patients daily for five days. Thirty-six patients completed the study from two centres in the UK, with 19 patients allocated to the control arm and 17 to the experimental arm. It was found that nausea and retching *experience*, and nausea, vomiting and retching *occurrence* and *distress* were all significantly lower in the experimental group compared to the control group ( $P < 0.05$ ). The only exception was with the vomiting experience, which was close to significance ( $P = 0.06$ ). Results highlight the important role of safe and convenient complementary therapies such as acupressure in the management of the complex symptoms of chemotherapy-related nausea and vomiting.

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ORAL

#### Post-cancer fatigue: has your patient visited the osteopath?

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**Background:** Post-Cancer fatigue (PCF) has a lot of specific characteristics and the loss of energy that comes with this condition has a negative impact on a patients daily living. The purpose of this study was to describe the sign and symptoms of PCF with the view of osteopathy on mobility and motility of organs and tissue. The second purpose of this study was to investigate the effect of osteopathic treatment of the dysfunctions found at initial examination on the gain of daily energy. The third purpose was to show that the liver may play a pivotal role in the signs and symptoms of PCF and that treatment of liver dysfunctions will be necessary in the total management of PCF.

**Materials and Methods:** In total 13 patients entered the study. All patients were examined prior to treatment and all found lesions were treated according to osteopathic standards. Specific attention was paid to the liver and its neurological segmentation. All patients underwent 3 treatment sessions with an interval of 2 weeks. Evaluation of treatment was done by the FACT-An quality of life questionnaires before and after treatment.

**Results:** 12/13 patients (92%) showed liver dysfunctions at initial examination. This was diagnosed as loss of liver mobility and a ptotic liver due to congestion. In addition, according to the neurological segmentation of the liver, somatic dysfunctions were found in the region TH6 – TH10 and on the OAA complex.

After the osteopathic treatment, an improvement of the Visual Analogue Score (def: an increase of 10 points on the 100 point VAS scale for patients with an initial score of <50) on the question on the level of energy during the past week was found for 10/11 (91%) patients ( $p=0.02$ ). An equal improvement of the VAS score was found for the question on the ability to perform the daily work for 9/11 (88%) ( $p=0.035$ ) and for the question on quality of life for 8/9 (80%) ( $p=0.04$ ). Four typical "fatigue" questions gave a mean score of 9.3 points (range 0–15) prior to treatment. After the osteopathic intervention, the mean score decreased to 5.8 ( $p \leq 0.05$ ). Two other specific fatigue questions gave a mean total score of 5 points prior to treatment. This score dropped to a mean score of 3 ( $p=0.34$ ). On the questions concerning the direct effects of fatigue, there were 6/13 patients that indicated an extreme need for help in daily activities prior to treatment. After treatment this was reported for only 2 patients. The need for bedrest during the day improved due to treatment. There was also an increase in the social activities.

**Conclusion:** Patients with PCF have signs of liver congestion and loss of liver mobility at initial diagnosis. Osteopathic treatment of these liver dysfunction results in a significant improvement of PCF. Normalisation of other dysfunctions in the parietal, visceral or craniocervical system has also a significant positive effect on the fatigue complaints. Osteopathy has a worthy place in the total treatment of Post Cancer Fatigue.

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ORAL

#### Knowledge and experience of Greek family caregivers on cancer pain management: a pilot study

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**Background:** Greek family possesses a major role on cancer care provision, decision making, and patient's support. This pilot study was designed to explore knowledge and experiences of cancer pain management from the family caregiver's perspective.

**Material & Methods:** Researchers visited all patients admitted on Monday, Wednesday and Friday for a two month period (March-April 2005) at "St. Savvas" Oncology Hospital in Athens. Patients with a cancer diagnosis, who reported pain, were asked to name their primary caregiver. A Demographic Form and the Family Pain Questionnaire (FPQ-Ferrell BR, 2000, City of Hope) were used for data collection. FPQ is a sixteen item ordinal scale, including a subscale measuring knowledge (9 items) and a subscale measuring experience (7 items).

**Results:** Only 30 caregivers, from a total of 57 patients experiencing pain, accepted to participate. The greatest percentage of them were women ( $n=22$ , 73.3%). Their mean age was 47.97 years (S.D.: 16.59). Among them, 16 were partners, 12 children, and 2 siblings. 23 participants (76.6%) were of primary and secondary education. A knowledge deficiency was detected in several aspects of pain management; particularly, 63.3% ( $n=19$ ) of participants stated that patients would become addicted to analgesic treatment and believed that analgesics should be administered only when pain was severe. 14 participants (48.3%) strongly agreed to give the lowest possible amount of medication in order to save larger doses for worse pain, whereas 13 caregivers (44.8%) strongly believed that analgesics would affect patient's breathing. Furthermore, 23 subjects (76.7%) comprehended pain deterioration as deterioration of cancer. However, the majority of caregivers ( $n=23$ ) claimed that cancer pain could be effectively relieved, and more than half ( $n=17$ ) were fond of a scheduled administration. Meanwhile, responses varied on the effectiveness of complementary therapies on pain relief. Spearman's correlation analysis indicated statistic significance between future perspectives and present level of pain ( $p=0.005$ ,  $r_s=0.512$ ), and pain relief ( $p=0.002$ ,  $r_s=0.559$ ). Comparing caregivers' estimation of pain as a distressing feeling both for themselves and for their patient, they found pain significantly more distressing for them ( $p=0.016$ ). No significant difference was found either between gender and knowledge, or educational level and knowledge.

**Conclusions:** Family caregivers hold limited knowledge about pain and pain management. Further research is needed to confirm these findings, before planning the most appropriate educational interventions.

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ORAL

#### High prevalence of psychosocial distress in cancer patients treated in the outpatient clinic

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**Background:** In the Oosterschelde Hospital a psychosocial support program is being developed for patients treated in the medical oncology department. This program encompasses accurate screening of all patients at different stages of the treatment process and definition of the psychosocial support needed.

**Purpose of the study:** In order to estimate the need for psychosocial support, we screened all cancer patients who visited our outpatient clinic on 2 consecutive days. The Distress Thermometer (DT, [www.nccn.org](http://www.nccn.org)) was used as screening tool. A DT-score of at least 4 positive items was considered as an indication for psychosocial support.

**Results:** All patients asked ( $n=26$ ) filled in the DT-questionnaire; 16 were female and 10 male. The patients were treated for breast ( $n=6$ ), colorectal ( $n=8$ ), ovarian ( $n=2$ ), gastric ( $n=1$ ), renal ( $n=2$ ) and lung ( $n=1$ ) cancer or a hematological malignancy ( $n=6$ ). The treatment setting was palliative in 22 and curative in 4 patients. Twenty two patients had a DT-score of at least 4 (range 4–20). Out of these 22 patients, 10 wished to receive help if indicated, 12 did not. Two out of 4 patients treated with curative intention had a DT-score of at least 4.

**Conclusions:** In 85% of the cancer patients screened in our outpatient clinic psychosocial support appeared to be indicated. The greater part of these patients however preferred to remain untreated. Psychosocial distress appears to be a significant problem, not only in the palliative setting, but also in the curative setting.

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#### What do newly-diagnosed patients with lung cancer report as most distressing during the first year post diagnosis?

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The patient perspective on distress associated with lung cancer is important, yet understudied. The study reported here was part of a large-scale project to help clarify distinctions between symptom intensity and symptom distress in patients with lung cancer. The aim of this study was to explore what patients diagnosed with inoperable lung cancer spontaneously report as most distressing during the first year post diagnosis. Inductive, structured data has been collected from 400 men and women consecutively diagnosed with primary lung cancer through two university hospitals in the Stockholm area of Sweden, using a 'free-listing and ranking' method. The patients were asked to respond to an open question "What do you find most distressing at present"? This data was collected close to diagnosis (median 23 days) and prior to treatment (T1), and after two weeks (T2), one month (T3), three months (T4), six months (T5) and one year (T6). The responses were categorized by two members of the research team, based on content.

Fifteen categories of distress were identified, which were structured under the three dimensions: bodily distress; distress related to living with lung cancer, and iatrogenic distress, defined as distress described as triggered by contact with the health care system. Patients reported, on average, approximately two distressing problems per person and time point. Distress associated with the body comprised between 57% and 72% of the issues reported, and increased steadily during the first year. Difficulties with breathing, pain and fatigue were responsible for nearly half the bodily distress reported, although even symptoms not generally assessed were reported. Distress related to living with cancer decreased steadily from 34% at T1 to 23% at T6. Iatrogenic distress accounted for approximately 8% of the reports during the first six months and decreased to <5% after one year.

Implications for care of this group of patients, with numerous and complex problems will be discussed. Strengths and weaknesses of this inductive approach versus structured questionnaires as means of collecting data on distress will also be addressed.

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ORAL

#### Train-the-trainer method for a prospective oral mucositis audit (POMA): a report from the collaborative EBMT nurse/physician mucositis advisory group

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**Background:** Oral mucositis (OM) is a frequent and debilitating consequence of cancer treatment (Eilers 2004). The true incidence and duration of OM are largely unknown due to inaccurate assessment and underreporting. Unlike assessment of neutropenia or anaemia, the presence and severity of OM requires routine physical assessment by an individual. In addition, multiple OM scoring systems exist, with no current standard of care (Rubenstein et al, 2004). Experts have shown that proper training can lead to substantial improvement in consistency and accuracy of OM assessment. Accurate assessment is important for the conduct of