# Plenary Lectures

1165

### Quality of life: patients and care-givers view

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It is generally agreed that patients are the best raters of their own quality of life (QL). Where it is not possible to obtain information from the patient e.g. when the patient has insufficient cognitive or communication abilities, experiences severe symptom distress, finds an interview too burdensome, or is too young or immature the use of surrogates to rate patient QL by proxy has been relied on as an alternative. The proxy can be a significant other e.g. a partner or parent or a health care provider e.g. a physician or nurse. The use of a proxy potentially offers a solution to nonresponse, however, whether the information collected is similar to that provided by the subject is not definitive. Whether proxies are able to accurately rate patient QL might be of relevance for adequate patient care. Most typically proxies tend to report more problems and lower levels of functioning than patients themselves. Using the patient rating as the point of reference, this tendency has usually been interpreted as an underestimation of patient QL. The accuracy of proxy reports is most typically determined by examining the extent to which proxy ratings are in agreement with those provided by the patients themselves. Generally, this includes assessing patient-proxy agreement both at the level of the individual patient, most often by means of correlations, and at the group level, by comparing patient and proxy mean scores. The former method provides a direct indication of the extent to which the proxy ratings concur with those of the patients themselves. The latter method allows one to determine the direction and magnitude of any systematic bias that might be introduced in QL investigations when using proxy respondents. Agreement depends on several factors. Methodological limitations may exert an impact on the level of patient-proxy agreement e.g. insufficient sample size, limited score reliability, and limited score variability. Agreement also varies according to the QL domains under study, the highest level of agreement is usually found for concrete domains e.g. physical functioning. In addition, patient and proxy characteristics have been found to be related to agreement. However, when designing QL studies the threat of selection bias due to exclusion of important patient subgroups has to be balanced against the threat of information bias due to proxy ratings.

1166

### Development, implementation and evaluation of a structured nursing intervention to prevent nausea / nutrition deficit experienced by patients undergoing chemotherapy - a randomized controlled clinical trial

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The study mentioned above is a government funded randomized controlled trial in nursing, starting in September 2003. Two German university hospitals (Halle and Munich) are cooperative centres. We want to test a structured nursing intervention for nausea / vomiting / nutrition deficit and deficient knowledge in these areas in patients undergoing chemotherapy. In Germany until now there have been no evidence based nursing standards in oncological care. Therefore the first step is a structured intervention to improve outcomes for patients in terms of quality of life and self care. Information on appropriate interventions and the development of skills in strategies against nausea / nutrition deficit can be used by patients to prevent or reduce nausea, particulary between cycles of chemotherapy. An intervention comprising 4 elements: information / counseling / teaching, medication, relaxation techniques and nutrition will be used in this study. Nurses in participating centres will be trained in the use of the intervention. An assessment instrument will be developed in order to measure the intervention effect. We shall measure the base line status / grade of these patient problems and at intervals following the intervention.

In the longer term our aim is to develop a clinical nursing pathway for chemotherapy patients. The structured intervention will be one tool of an interdisciplinary pathway. Elements of a clinical pathway consist of modules of the intervention strategy. These are systematic nursing interventions for key problems expected by chemotherapy patients, such as nausea, stomatitis, fatigue, pain, knowledge deficit, deficient coping mechanisms etc. Each tool includes an assessment instrument used to identify complications such as nausea, nutrition deficit and criteria to measure the severity or grade of these complications.

The pathway we are developing will be used for not only the period the patient stays in the hospital, but also the periods before and after inpatient treatment. This study is concentrated on the nursing role, but the pathway will be used in a interdisciplinary setting, by multiple health professions.

# Proffered Papers

## Supportive care

1167 ORAL

### Woman with breast cancer suffering from cancer wounds. A prospective, explorative and descriptive study

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**Background:** In Denmark 3.500 women are diagnosed annually, with breast cancer; 2-5% of these will suffer from cancer wounds. Cancer wounds are a frightening and painful problem, which can lead to physiological problems as offensive odour, exudation, bleeding, pain and infection and psychological and social problems, such as depression, shame, altered body image and isolation. In Denmark there are no uniform knowledge about cancer wounds, and there are no guidelines.

The aims are: 1. to achieve understanding of care for women with cancer wounds, 2. to achieve a systematic wound treatment, that nursing care is uniform, evidence based, and achieves quality and continuity, and 3. to develop, test and describe a wound treatment, which meets the needs of the woman with cancer wound.

**Methods:** The trial period was of 1 year (2001-2002), including 12 women with advanced breast cancer, and cancer wounds. The intervention period was 4 weeks. Three wound care nurses undertake the wound treatment in the home of the patient. Relevant uniform wound treatment products, are used for each wound phase. *Quantitative methods*: The cancer wound is photographed, and a wound morphology chart is completed before and after the intervention period. *Qualitative methods:* Semi-structured interviews are carried out before and after the intervention period.

**Results:** Woman with cancer wounds suffer extremely, due to the wound related problems. 83% of the woman did not have a district nurse. Nurses and doctors shows no interest in wound management the responsibility was placed on the woman. *After intervention*: The cancer wound was smaller in size in 75% of the woman. The wound treatment increases patient independence, due to decrease in necessary dressing change in 100%. The wound treatment gives well-being due to comfortable and flexible dressing material in 83%, and wound treatment gives increased quality of life, due to control of exudation problems (100%), and control of odour problems (67%). The wound treatment increases feelings of womanliness and attractiveness. This lead to decreased social isolation.

**Conclusion:** The wound treatment results in smaller cancer wounds, it gives well-being, and increased quality of life, due to continuity, evidence based wound knowledge, modern wound products, and psychosocial support. The woman demand that nurses and doctors takes the responsibility for wound treatment. A greater insight is achieved into management and care of patients with cancer wounds.

1168 ORAL

## The phenomenon of fatigue in young people

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**Background:** Cancer-related fatigue (CRF) is achieving recognition as a common and disturbing symptom for adults with cancer (Richardson, 1995, Stone et al., 1998). CRF has only recently been recognised and reported in children and teenagers (Hockenberry-Eaton and Hinds 2000, Langeveld et al 2000, Davies et al 2002). This paper will present a descriptive study that explores the impact of cancer and its treatment on young people. It draws on a multi-centred collaborative project involving nurses who care for adults, and who have considerable expertise in researching CRF, and nurses who care for children and young people.

**Materials and methods:** The study uses semi-structured interviews, diaries and focus groups to collect narrative data in order to discover the essence of the phenomena of fatigue in young people from their perspective. The sample includes those who are receiving treatment for cancer (n=8), those who are in early remission (n=8) and late remission (n=18), and a group who have not had cancer (n=20). Only the on treatment group will be reported in this paper. Data has been analysed using the phenomenological methods outlined by Moustakas (1994).

**Results:** Fatigue was present in varying degrees depending on the stage and intensity of treatments. Fatigue was experienced as absolute and complete exhaustion. It was unpredictable and varied in intensity and duration. Normal activity was prevented, which left teenagers weak, inactive and unmotivated. A number of strategies were used to relieve fatigue.

**Conclusions:** Fatigue was just one element of the teenagers overall experience, the experience of illness and treatment having altered their perspective on life itself.

1169 ORAL

## Needs of family members of patients receiving palliative care services in Iceland.

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The philosophy of palliative care emphasizes that the patients' family is the unit of care. The integration of families in palliative care has been the standard of care since the movement of organized palliative care began in Iceland in 1986. However, little has been documented about the needs of families of palliative care patients and how they are met by health care professionals.

The aim of this study was to evaluate care needs of families of patients receiving palliative sercives (PCS) on four different sites: palliative care inpatient unit, oncology unit, palliative home care and on general medical/surgical units with consultations from a palliative care consultation team. Family members of 111 patients admitted to these units between December 1999 and May 2001 were invited to participate and agreed to do so, 67 (60%) completed and returned the survey.

The Family Inventory Needs (FIN) questionnaire was given to family members on day 5 from admission to the PCS. The FIN consists of 20 statements about the importance of care needs and whether each need was currenly met, partially met or not met. Most of the family members who participated were the patients'spouse (59%), women (73%), younger than 56 years of age (59%), and worked outside of the home (62%). All 20 needs were perceived as being important or very important by 64-100% of participants. The most important needs were related to the patients' themselves but the less important ones were related to the family members'personal needs. Needs about infomation about symptoms were most seldom met (38-46%), whereas the need to feel that the professionals care about the patients was most often met (86%). On the average, most family members had their needs met by the palliative home care team (73%), and family needs were least met on general inpatient units (44%).

It is evident from these findings that family members of patients receiving palliative care services have multiple needs that they perceive as being important. It is also evident that much work needs to be done to meet those needs, particularily those who concern infomation sharing about the patients condition and that improvements are needed in general units where palliative care is not the area of specialization.

1170 ORAL

## Patient education – a new strategy for prevention of infections due to permanent central venous catheters among patients with hematological malignancies: a randomized clinical trial

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**Objective:** A well-functioning tunneled central venous catheter is a crucial factor for patients with hematological malignancies receiving high-dose intravenous chemotherapy and associated problems during treatment. Despite many advantages, infections associated with CVC's are a major cause of sepsis and excess length of stay in the hospital. The importance of stringent procedures during insertion and care are heavily recommended. Our aim was to investigate the impact of patient-education, where the patients themselves were taught to execute clinical catheter procedures.

**Design:** A prospective randomly designed clinical intervention study.

**Methods:** From May 2000 until September 2002 patients with hematological malignancies receiving high-dose chemotherapy and had a tunneled dobbeltlumen Hickman catheter inserted was consecutively randomized to one of two study-groups. The intervention group was individually trained by the clinical nurse-specialist to support an independent catheter care between admissions. The control group followed the clinics standard CVC-procedures carried out by professionals in and outside the hematological ward.

**Results:** 82 consecutive patients were finally included (respectively 42 and 40 patients). On several statistic tests, we found a significant reduction of catheter-related infections (CRI) due to the intervention group. The mean rates of CRI were decreased by almost three fold. The total incidence of CRI was more than halved for the intervention group (2,55/1000 catheter days) compared with the control group (5,91/1000 catheter days).

**Conclusion:** Rigorous patient-education as a primary clinical intervention can reduce catheter-related infections. The intervention has uncovered an unknown potential source and breaks with traditional thinking in health prevention policy.

1171 ORAL

## Patients suffering from lung cancer. Experiences during radiotherapy.

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Distress experienced by lung cancer patients during RT is covered in quantiative studies concerning prevalence and correlation. Patients' verbal accounts of experiences and distress are not described sufficiently, enhanced knowledge is crucial to give individual nursing care during treatment. The aim of the study was to describe patients' experiences suffering from lung cancer during radiotherapy. An inductive, qualitative study was done on 15 patients at a Radiotherapy department in the southern part of Sweden. Interviews were done during the second week of treatment at one occasion, the transcribed data was analysed with content analysis and interpreted. The findings show that fatigue was a major symptom, expressed in terms of low energy levels and low condition, leading to social isolation. Managing daily life problems during radiotherapy was solved by routinising everyday life and by inner and/or outer resources. Emotional distress such as fear was expressed of the unknown, the future and sudden encounters. Patients go through a shift of accepting or not accepting the fact of letting cancer diagnosis rule their daily life. Informing about and assessing fatigue as well as implementing interventions and nurse-patient interaction, support, information, encourage and focus on patients' own