Plenary Lectures

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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.

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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

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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 indepen-