

## Plenary Lecture

1422

### Quality care: Fantasy or reality?

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Quality assurance and control has been developed in the frame work of clinical trials and regards all aspects the process. Protocol development, relevance of the scientific question, statistics, realistic in terms of numbers and time. Control of forms and procedures and actual on site data verification. The main lessons of quality assurance in clinical research has been that there are many flaws at each level compromising the final outcome, unless rigorously controlled. Next to procedures and data checks the actual quality of care given to the patients has been evaluated. In radiotherapy an internationally recognized program has been developed and implemented to control field size, dose calibration etc. For chemotherapy a so called chemotherapy symptom checklist has been developed, implemented and reviewed. For surgery this is less standardized but it is generally accepted that quality of the initial surgery is next to stage a very important prognostic factor. For example the relevance of the number of nodes removed in case of an axillary node dissection in breast cancer and in colonic cancer is an independent prognostic factor for outcome. Furthermore experience of the surgeon and the multi disciplinary team is related to outcome.

If these factors are relevant for clinical research, why should it not be relevant for patient care outside the frame work of clinical trials? We are advocating evidence based medicine and we presume that we can translate the result of clinical trials to daily practice. This requires the same prerequisites as we have identified for clinical research. Do we have the optimal infra structure? Do we have the appropriate training? Do we have a multi disciplinary team to treat certain cancers? Do we see the appropriate numbers to maintain experience? Do we deliver surgery, radiotherapy and chemotherapy according to recognized standards. And last but not least do we have the skills to implement new insights into our practice? The answer on many of these questions is no or at least uncertain. This means there is room for improvement.

It is obvious that the doctor is not the single dominant factor in this process. The support and knowledge provided by the nurses are essential in this process. Recognition of the relevance of quality on all levels of care is the first step for improvement. It is important to select the relevant items for outcome in the process before embarking on program to improve quality of care. In conclusion quality of care is relevant and reality but not sufficiently recognized implemented.

## Proffered Papers

### Supporting patients and families

1423

ORAL

#### Informal carers in cancer contexts: their activities and needs

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**Purpose:** To report a study of the care-giving activities, experiences and needs of informal carers (mainly spouses) of cancer patients, part of a 3 year NHS funded research project on the psychosocial needs of cancer patients and carers.

**Methods:** Data collection involved a descriptive cross-sectional survey of carers (an achieved sample of 262 respondents, with similar numbers of male and female carers) followed by in-depth guided interviews with a sub-sample of surveyed carers (n=32).

**Results:** Care work findings:- additional care work demands were an important feature of informal carers' experiences, although this varied with the stage of the patient's disease and the presence of either co-morbidity in patients or morbidity in carers. Specific groups of carers expressed the need for help with particular practical tasks and with the personal effects of the burden of care work.

Emotion work findings:- carers of either gender worked hard to manage the emotions of the patients as well as their own feeling states; these aspects of emotion work were intimately connected. Carers felt they had

to be strong and positive and to try to maximise the sense of life carrying on as normal. Spousal carers often symbolically shared in the illness and presented the struggle with cancer as a joint one.

**Conclusion:** The roles of informal carers are very significant in the cancer journey, and give rise to carer psychosocial needs. Male carers are less likely than female carers to express these needs. By understanding the roles of informal carers, health professionals can be sensitive to, and supportive of, carers expressed or latent needs.

1424

ORAL

#### Children as relatives, - a challenge for nurses

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**Purpose:** Little empirical evidence exists concerning the impact of a parent's cancer diagnosis on his/her children. The main purpose of this study is to gain knowledge of the situation of children who have a parent suffering from cancer in order to develop adequate strategies for a nursing approach. The specific aims are:

- \* to describe the reactions of children and parents when a parent is suffering from cancer
- \* to describe the children's and the parents need for help and assistance when a parent is suffering from cancer
- \* to develop an intervention program that can meet the recorded/reported needs in order to promote the children's quality of life and help them to cope with serious illness in the family

**Methods:** The design of the study is explorative. The method chosen involves qualitative in depth interviews with children (age 7-11) and their parents (the ill and the healthy parent) in 10 families. The collection and analysis of data follow Kvale's guidelines for qualitative research interviews, which implies a phenomenological-hermeneutical mode of understanding.

**Results:** The study is in progress. However, the preliminary analysis show that parents' cancer affects the children and their daily life strongly and in various ways. The children use a number of different coping strategies, ie denial, positive thinking, sharing feelings and thoughts, seeking information, enjoying themselves, getting angry or moody and wishful thinking. The children seek and receive most of the information about parent's illness from their parents. They seldom get such information from nurses or doctors, but when they do it makes them feel included. The children's overall quality of life can be described as fluctuating. The preliminary findings also show that the parents need help and support in the care of the children. They are concerned about their children's well-being and how they will be able to meet their needs when either of them gets a cancer diagnosis.

**Conclusion:** As a final result this study will give increased knowledge about children's situation and how nurses can meet the needs of children and parents when a parent is suffering from cancer. Strategies for nursing interventions will be presented at the conference.

1425

ORAL

### Nurse-managed follow-up by telephone for patients with brain metastases treated with stereotactic radiotherapy

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**Purpose:** To minimize hospital visits and improve the quality of care in patients with brain metastases (BM) we are currently evaluating alternative strategies such as nurse-managed follow-up by telephone.

A substantial number of these patients is treated with Stereotactic Radiotherapy (SRT) and clinical follow-up is essential for assessment of efficacy and toxicity. However, for these patients with limited life-expectancy (6-12 months), periodic hospital visits can be taxing.

**Methods:** Based on the Barthel Index, a modified questionnaire was developed, which included items like medication and an EFIT-score (Edinburgh Functional Impairment Test). This questionnaire was developed in order to discriminate whether the patient's condition requires consultation by a radiation-oncologist. A pilot study in 15 patients with BM treated with SRT was performed.

In addition, a problem classification scheme and intervention scheme (OMAHA, 1992) was developed and tested in this group of patients. Finally, the nursing competences needed will be evaluated.

**Results:** In the pilotstudy, the extended Barthel questionnaire was validated. Only minor changes were introduced in the questionnaire and completion could be achieved within ten minutes.

**Conclusions:** From the pilotstudy it was concluded that a nurse-managed follow-up clinic by telephone could be a potential future strategy for patients with BM treated with SRT.

The questionnaire and OMAHA scheme are currently implemented in a prospective study comparing the cost-effectiveness, efficacy and quality of care to routine clinical follow-up by a radiation-oncologist.

1426

ORAL

### Telephone support service for patients following surgery for breast cancer

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**Problematic:** With the increasing trend towards early discharge after surgery for breast cancer it is in the home environment that patients are first confronted with the secondary effects of surgery and the psychological impact of diagnosis, both of which may have a negative impact on subsequent coping processes and quality of life. As a result nurses are seeing a significant demand for managing symptoms over the telephone. To meet this demand a structured telephone support service was set up by nurses in the surgical out-patients department for the management of surgical related problems in patients with breast cancer.

**Objectives:** Overall objectives were: to increase the security and well being of the patients in the home environment to provide emotional support and encouragement in the event of psycho-social problems: to reinforce patient education: to detect eventual complications, assess symptoms and

assist with problem solving. More specific objectives were: to assess the nature and urgency of the situation and the capacity of the patient to manage and develop the necessary coping skills: to evaluate family and local resources: to provide concrete information, recommendations for symptom treatment and according to the nature of the problem, referral to an appropriate medical source: free lance domiciliary nurse, general practitioner, consultation at the local hospital, consultation at the surgical outpatients of the Emergency Dept at IGR.

**Method:** After validation of the project by the Dept of Nursing, the concepts of telephone triage and telephone support for symptom management were defined in collaboration with the hospital Department of Nursing Education. Nurses received an appropriate training programme in telephone and communication skills and following this a telephone flow sheet, a telephone protocol (checklist) highlighting key questions, and standard decision algorithms were developed to facilitate assessment and guide nurses in decision making and treatment procedures. These tools include onset, location, duration of the problem, factors associated, treatments used.

**Findings:** In a feasibility study over 1 year, 810 patients received telephone support for symptom management after surgery for breast cancer. An analysis of the frequency of the various symptoms, information collected and the suitability of the information given by the nurses will be presented together with an evaluation of patient and nurse satisfaction.

**Conclusion:** Nurses can successfully manage many patient needs by telephone provided established protocols for assessment and treatment procedures are used to facilitate safe and effective care-giving. With appropriate training nurses can maintain continuity of care for patients in the home environment by telephone support and with appropriate orientation prevent unnecessary visits to clinic or hospital.

1427

ORAL

### Coping patterns of religious and secular parents with their children's cancer

D. Hutt, L. Navon. *School of Health Professions, Sackler Faculty of Medicine, Tel Aviv University, Nursing, Tel Aviv, Israel*

**Purpose:** The professional literature is divided over the extent to which the religiosity/secularism of parents influences the way they interpret, emotionally react to, and actually cope with their children's cancer. The present study examined this issue for the purpose of improving nurses' understanding of the different needs of such religious and secular parents.

**Methods:** The study, conducted in Israel, was based on in-depth interviews with 20 Jewish parents (10 secular, 10 religious) of children with cancer. The data were processed by qualitative content analysis.

**Results:** The study indicates that following the diagnosis both the religious and the secular parents similarly reacted with shock and grief, however the former perceived the disease optimistically whereas the latter viewed it pessimistically. The religious parents attributed it to divine intervention and hence coped with it by such means as prayers, whereas the secular parents ascribed it to chance and felt totally dependent on health professionals. As the disease progressed, the two groups' reactions converged. The religious parents became less hopeful and more secular in their attitude, relying less on miracles and more on modern medical treatment, whereas the secular parents adopted a more optimistic outlook and searched religion in their quest for the disease's reason and cure.

**Conclusion:** The study shows that approaches predicting differences in the reactions of religious and secular parents are more appropriate to the initial phases of their children's disease, whereas those predicting similarities are more relevant to the crisis' more advanced stages. Furthermore, the findings cast doubt on the conventional distinction between coping patterns considered to be "secular" versus "religious". On the basis of these findings it is suggested to supply nurses with a training program aimed at enhancing their awareness of similarities and differences between the needs of religious and secular parents during the various stages of their children's disease.

1428

ORAL

### Spiritual support for terminally ill patients

M. Kuuppelomäki. *Seinäjäoki Polytechnic, School of Health Care Seinäjoki, Finland*

**Purpose:** To describe the provision of spiritual support for terminally ill patients.

**Methods:** The data were collected with a structured questionnaire with multiple choice items and open questions. The study was carried out in 32 community health centres and 328 nurses working on in-patient wards