

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.

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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.

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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.

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ORAL

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

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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.

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ORAL

Spiritual support for terminally ill patients

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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

took part in the study. The data were analysed by SPSS statistical software.

Results: Half of the nurses were poorly equipped to provide spiritual support to the terminally ill patients. The most common form of spiritual support were to take the patient to spiritual events arranged on the ward. Several factors were found which were associated with the provision of spiritual support.

Conclusion: The results indicate that spiritual support is part of the terminal care. Further education and literature on the topic are necessary to improve the nurses' qualifications.

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ORAL

ARC breast cancer partners support programme

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The ARC Breast Cancer Partners Support Programme is the first of its kind in Ireland which offers educational and emotional support for men whose female partners have been diagnosed with breast cancer. Following a pilot programme in July 1998, a national omnibus survey was conducted to explore men's awareness and attitudes about breast cancer. A questionnaire was administered to a nationally representative sample of 589 males. The findings of this study have served to drive the content of the present support programme, especially in relation to the needs identified for educational and emotional support by this group of men. Each group is designed to accommodate a maximum of eight men who are invited to attend an educational class followed by a support group meeting. The four week course includes lectures on anatomy and physiology of the breast as well as the physical, psychological and social aspects of breast cancer. The support group is facilitated each week by a male counsellor. The topics covered in the support group include communication and the marital dyad.

For many years the need for this course has been recognised by women with breast cancer. At a time in their lives when they need so much support, they are aware of the lack of support for their partners. For men, supporting the woman they love and cherish may become easier if they themselves had additional emotional support through a network of men in similar circumstances.

Having completed seven courses to date, this paper explores the effectiveness of the ARC Breast Cancer Partners Programme.

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ORAL

Rehabilitation in the Netherlands: Herstel & Balans, a promising program for cancer patients

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Purpose: Cancer is considered more and more as a chronic disease and survivors need appropriate support at their rehabilitation. The Comprehensive Cancer Centres at Maastricht (1), Enschede (2), Amsterdam (3), Utrecht (4), Nijmegen (5) recognised this need and developed and implemented a health-oriented rehabilitation program 'Herstel & Balans' (recovery & stability), including physical training and psycho-education during three months. The aim of this study was to identify the improvement of quality of life and symptom status of the patients during the program.

Methods: In November 1996 the first pilot of the program has started and by now (2001) over 500 patients have participated. The participants have been tested on variables as quality of life (EORTC-QOL scale), fatigue (FACT scale) and kinesiophobia (Tampa scale) at the beginning and the end of the program. A subjective evaluation was also included. Up to now the data of 350 patients have been analysed.

Results: The results show a significant increase of patients' quality of life during the program and a significant decrease of fatigue and physical complaints. The subjective evaluation shows participants' satisfaction and enthusiasm regarding the program.

Conclusion: The results in this study show that the aim of the rehabilitation program, i.e. improving the quality of life and symptom status of cancer patients after treatment, was achieved. The patients' review regarding the program was positive. These promising results indicate that this rehabilitation program meets the actual needs of cancer patients and can be regarded as a successful intervention in oncology nowadays. The implementation strategy for the program in the Netherlands has been successful. The Comprehensive Cancer Centres in cooperation with rehabilitation centres and hospitals established a nation-wide network for rehabilitation in oncology.

Interactive Symposium

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Fostering partnership in research and development between academic and clinical settings

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Traditionally, nurses in clinical settings have contributed to research endeavours often in the capacity of being 'researched on' rather than 'researching with' academic colleagues. Recognition of the benefits of collaboration between academic and clinical settings has spread. Benefits include improvements to the quality of research, increased research capacity and enabling a shift in culture to that of an evidence based profession. Partnership at all stages of the research process can be cultivated including the development of research priorities and research questions, data gathering and the dissemination and utilisation of findings. Examples of how this can occur in practice will be provided through reference to different models of collaboration both within and out with cancer nursing. Some of the advantages and disadvantages of the different models will be presented. Variables most likely to influence interaction between individuals and institutions, and as such the success or failure of partners' working relationships will be examined (i.e. formal and informal processes, professional and personal dimensions, complementarity, reciprocity). If we are serious about developing and delivering a responsive research and development agenda we must involve all those who plan, deliver, evaluate and experience cancer nursing care. In the end, co-operation and collegiality are a state of mind, and we must make sure that cancer nursing's is a positive one.

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Working together: the process of developing and implementing research

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Nurses who work clinically in cancer and palliative care are deterred from developing and undertaking their own research projects for reasons which include: a lack of time, the sensitive nature of researching people with cancer, the difficulty of measuring outcome in people whose condition is deteriorating and a perceived lack of relevance to immediate patient care. However, if nurses are facilitated to undertake research which is meaningful to them within a supportive structure they may experience research as an exciting and powerful part of their practice. Nurses who took part in a multi-centre study of a randomised controlled trial of a nursing intervention for breathlessness co-ordinated by the Macmillan Practice Development Unit, London were interviewed about issues concerning the conduct of this research and implementing the intervention. These nurses were novices in research and the interviews revealed how they worked together to overcome resistance to innovative nursing practice, collaborated to establish a uniformity of practice and addressed the tensions between their own nursing role and the necessity of an ethically demanding research design. This paper will also address how nurses working at a cancer centre may be supported to think creatively about research in their day-to-day work.