



EONS

eons newsletter

The Quarterly Newsletter of the European Oncology Nursing Society

June 2002

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The Goal of the EONS Newsletter is to inform nurses about EONS and EONS activities and to inspire nurses throughout Europe to improve the care of the cancer patient.

The purpose of this Newsletter is to provide:

- Information on EONS activities
- Practical information of interest for the EONS members
- A networking forum for cancer nurses throughout Europe

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Dear Colleagues,

Welcome to the June issue of the EONS Newsletter!

This issue marks the first time that members can receive and read the Newsletter electronically. To fit the different needs within EONS, we have offered every national society within EONS a choice between receiving the newsletter in a paper version (as before) or to receive it as a PDF file per internet. We really hope that these two options may make the newsletter more easily accessible to the EONS membership throughout Europe. Please feel free to contact us if you have questions or comments about the distribution plans for the Newsletter!

The theme for this issue is cancer-related fatigue (CRF). CRF is a subjectively experienced symptom of multiple dimensions. Patients with cancer identify fatigue as the major troubling symptom and the primary cause for distress in their lives. The literature on cancer-related fatigue has expanded dramatically since 1980, with most of the growth concentrated from 1996-2001 (Nail, F., Fatigue in patients with cancer. *Oncology Nursing Forum*, 2002; Vol 29, No 3: 537-544). In this issue, you will find a short, interesting report from Jan Foubert (EONS President-elect) on the use of the Internet to help patients better manage their fatigue. In 1999, Janssen-Cilag offered a grant to challenge novice researchers to investigate the area of cancer related fatigue. The response to a call for research proposals was overwhelming. The grant recipients were announced at ECCO 10 in Vienna. The nurse researchers who received the grants are Ms J Gledhill, Ms G Knowles, Ms M Miller and Ms E Ream. Short descriptions of the research projects are to be found in the following pages. A more complete scientific review of each project will be published in the *European Journal of Oncology Nursing (EJON)*; the first articles were published in the March 2002 issue.

In the column 'Our colleagues from...' on page 3, you can find a report provided by Ms Helen Ekfors. She is the newly elected President of the Swedish Society for Nurses in Cancer Care. The report provides a good impression on the state of cancer nursing in Sweden. In May of this year, the Swedish society produced their 5th national conference in cancer care. The theme for the conference was "Cancer care as art and science" with the aims to reflect on clinical practice and to critically examine how existing evidence based knowledge can find a better fit with clinical practice. The conference was arranged in Gothenburg and visited by 270 nurses from all over the country. It is of interest to mention that the conference was granted, for the first time, EONS accreditation. Since the last issue of the EONS Newsletter, 476 cancer nurses from throughout the world attended the 3rd EONS Spring Convention that was held in April in Venice, Italy.

The goal of this educational event was to teach cancer nurses how to improve their communication skills. Highlights from the conference as well as other news of interest from EONS is to be found on the following pages. The next Spring Convention (the 4th) will take place in Edinburgh, UK, April 15-17, 2004, and the theme will be: "The nursing contribution to quality cancer care". I suggest that you reserve this event in your calendar already today! EONS is your society, and this is your Newsletter. To contribute to its success - we need you! We need to know your opinions, thoughts, wishes and doubts. Also suggestions on how to better reach out to our non-English speaking colleagues are welcome. Please do not hesitate to contact us with questions or material for the Newsletter! Keep each other up to date with cancer nursing in your country! Today there are 23 national oncology nursing societies (representing around 18 000 nurses) and approximately 330 individual members from 28 countries in full membership of EONS (figures taken from the President's Report, 2002). Take the opportunity to reach them! The next issue of EONS Newsletter is planned to be distributed in September. During the meantime, you can visit the EONS website (<http://www.cancereurope.org>) for updates of information about what is happening within EONS! Enjoy your summer!

On behalf of the EONS News Team /
Karin Magnusson, Editor-in-Chief

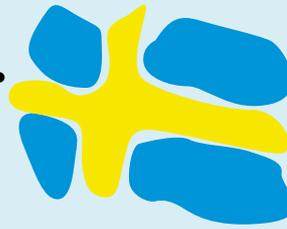
Optimising anti-emetic treatment – nurse survey results

Giel Vaessen, EONS President, The Netherlands

Nausea and vomiting are common and debilitating side effects suffered by patients receiving chemotherapy. Roche has been working with the European Oncology Nursing Society (EONS) to co-sponsor a survey to assist them in the review of the use of anti-emetics within the oncology setting in Europe. The aims of this survey were to establish a greater understanding of the knowledge base of oncology nurses, to identify educational needs of oncology nurses within the anti-emetic therapeutic area and to develop educational tools for the management of chemotherapy-induced nausea and vomiting. Oncology nurses were surveyed randomly by telephone interview in six European countries: France, Germany, Italy, Spain, The Netherlands and the UK. In total, 180 nurses were targeted, corresponding to 30 nurses per country. On average, one-third of nurses were not restricted to treating particular cancers, but nurses in Germany and Italy were least likely to treat a specific cancer type. According to the nurses surveyed, nausea and vomiting are second only to hair-loss as the most common treatment-related concerns as expressed by their patients. From the survey responses obtained, patients are 10 times more distressed about nausea and vomiting than the effectiveness of their chemotherapy treatment. However, in Italy and Spain, nausea was much less of a concern that it was in other countries. A total of 88% of nurses followed anti-emetic guidelines or protocols and there was a high use of 5-HT3-receptor antagonists in highly and moderately emetogenic chemotherapy regimens. Nevertheless, almost one-third of patients still suffered symptoms of nausea, and almost one-third of nurses believed that patients did not receive adequate supportive care. Two-thirds of nurses do not receive formal oncology training and only 12% felt sufficiently prepared to confidently manage chemotherapy-induced nausea and vomiting.

The results of this study have exposed problems associated with the treatment of chemotherapy-induced nausea and vomiting, and demonstrate a clear need to address the educational needs of oncology nurses.

Our Colleagues from...



Sweden is 1574 km long, 499 km wide, has 8,9 million inhabitants and an average life expectancy of 77,4 years for men and 82,3 years for women. Every day about 100 Swedes are diagnosed of cancer, around 45.000 cases every year. About half of the patients are cured.



Most of the patients are at surgical or medical clinics and a row of other clinics with a varying degree of responsibility for cancer care. The oncology clinics are totally aimed at specialised non-surgical cancer therapy, with radiotherapy and chemotherapy in the foreground, but also diagnostics and investigations before or after treatment. The care for patients with advanced, non-curable cancer and nursing at the end of life aims at being situated as near the patients' homes as possible. Advanced home nursing care, often linked to hospitals, has been developed in many regions, also other forms of nursing care at the end of life. Nursing at end of life has for long been focused at cancer patients, palliative care in Sweden encloses all patients at end of life, irrespective of diagnosis.

In Sweden there is about 110 000 enrolled nurses in all areas, the nurses basic education is 3 years at university, then you can specialise to Oncology Nurse after 1 year of clinical practice. The speciality-training course takes 40 weeks full time studying, aims at knowledge and skills in chemotherapy, radiotherapy and palliative care nursing. Each university can differently design parts of the training. Nurses can work at an oncology ward without having undergone the specialist training, it's the employers' responsibility to plan for a mix of nurses at different knowledge degrees and education. If chemotherapy is administered at the unit, it's the employers' responsibility to ensure that the nurses have proper and continuing training.

The nurses administering chemotherapy also inform and intervene when side effects occur. At radiotherapy departments specialist oncology nurses inform, administer therapy and make nursing interventions aimed at enhancing patients' experienced side effects and suffering during the treatment period. Oncology nurses are also working at palliative care units and hospices, in Sweden knowledge among nurses about palliative care is an important and prioritised area. Oncology nurses also work at psychosocial care units and at rehabilitation centres where they play a central role in the different intervention programmes. In Sweden oncology is basically interdisciplinary, the oncology nurse works in teams with an oncology physician, a physicist, an assistant nurse, a physiotherapist, just to mention some.

Just below 400 nurses have reached a PhD, most PhD students are registered at a Department of Nursing at University, the majority of the professors holding the chair of Nursing are nurses. Research in the area of cancer care consists of a wide mosaic of directions e.g. symptom management of cancer related fatigue, pain and side effects during radiotherapy, cancer screening of malignant melanoma and breast cancer, ethics and experiences during palliative care, nursing at special diagnoses and psychosocial nursing.

The Swedish Oncology Nursing Society was established in 1988 after an expressed wish for a forum for nurses working in cancer care. Members of the Society are able to exchange experiences and learn from each other. The Society is a voluntary association for nurses active in cancer care. The aim of

the Society is to contribute to the progress of health services. The Society supports research, development and education within the area. Every second year a national conference for members and non-members is organised, see below. The year in between, the board actively represents the Society at the Swedish National Health Assembly. The Society co-operates with other Swedish Nursing Societies, associations and networks, and international societies such as the NSG, the Scandinavian association for societies in cancer care, EONS and ISNCC.

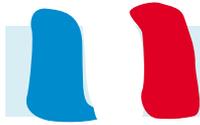
The members and other interested can visit the Society's own website at <http://www.cancervard.org.se> (only in Swedish) or read the periodical *Cancervården* (only in Swedish), four times a year. The board of the Swedish Oncology Nursing Society consists of 9 idealistic members; the tasks are organised after specific areas of responsibility or shorter missions based on own interests and skills. The Society today has just below 1000 members, the increased interest among nurses in cancer care is a strong motivation factor for the work of the board members.

Helene Ekfors

President Swedish Oncology Nursing Society

The strategic plan for 2002-2004 consists of four strategies.

- 1** The first strategy aims at the Society working for further development of education in oncology care at all levels for nurses; from parts in basic nursing training, master courses in oncology care to co-operation with different partners aiming at targeted education.
- 2** The second strategy aims at research, development and clinical work; the Society will stimulate to increased use of research results to develop the nursing profession and to broaden the working area of the oncology nurse.
- 3** Working for a well known and well respected Society among people active in cancer care is the aim of the third strategy; partly through the national conference and the health assembly, partly at other national assemblies and in the periodical *Cancervården* and through the website. Another sign of the well known Society is the annual appointment of the Nurse of the Year in Cancer Care, an appointment of a clinical active nurse that the colleagues experience have done a great effort for the patients, the next of kin and/or the hospital oncology service. Several grants of scholarship in a row of different areas are awarded to members of the society every year.
- 4** The fourth strategy is aimed at further co-operation with the national and international societies within the field of nursing, and to discuss interdisciplinary co-operation with other societies in the area of oncology.



Jane Gledhill, Institut Gustave Roussy, rue Camille Desmoulins, 94805, Villejuif, France.

Fatigue has been shown to be one of the major side effects of cancer and its' treatment (1). Although there is no clear agreement on a scientifically based definition of fatigue in the literature, largely because the exact mechanisms causing fatigue are still in the early stages of investigation, (2, 3) we felt it would be interesting to explore the meaning of fatigue. Especially as fatigue is a French word, used frequently by both patients and healthy persons. It is defined in France (4) as a state resulting from over exertion of the organism or an organ part, resulting in reduced activity and strength, and generally accompanied by a characteristic sensation, 'un sentiment de fatigue'; a slight fatigue, 'lassitude'; an important fatigue. 'Épuisement'; extenuation. The lay public rarely uses 'Asthénie'. No studies to date have been undertaken in France to explore the underlying concepts of fatigue. The specific objectives of this study were therefore:

- to clarify the conceptual definition of fatigue within a French cultural context
- complete a concept analysis of fatigue in patients with cancer and healthy subjects
- examine the strategies used in health and in illness to overcome fatigue
- develop a conceptual model for fatigue.

This study formed part of a larger research programme on fatigue and followed the translation and validation of a French version of Piper's Fatigue Scale (5).

A qualitative research design, using grounded theory methodology was used. 24 cancer patients were recruited within an outpatient or hospital ward setting of a cancer institute and 24 healthy individuals were recruited among the personnel working in the hospital environment or the entourage of the investigator. Data were collected through individual audio-taped, open-ended interviews. The transcripts of the interviews were reviewed, participants' responses analysed thematically and grouped into major categories and sub categories. A second person validated categorisation of the various themes by the investigator.

This study demonstrated differences in the intensity, variability, duration and temporality of fatigue between patients and healthy subjects. Analysis resulted in the categorisation of fatigue into 3 major dimensions, physical, affective and cognitive, common to both patients and healthy subjects, although the importance of themes within these categories differed slightly in the 2 groups. A 4th category, distress, was identified in the patient group. Distress was present in only one of the healthy subjects at the time of interview.

The majority of patients was on active treatment and attributed fatigue to treatment, its side effects and constraints. However some patients in the later stages of the illness trajectory had difficulty in distinguishing side effects of treatment from signs and symptoms of illness progression. CRF (Cancer related fatigue) fatigue was initially essentially physical in nature especially in the pre-trajectory phase of illness and at the start of active treatment. A strong relation between symptoms and reduced physical performance and between symptoms and anxiety was noted. The relationship between symptoms and the cognitive dimension appeared to be less important.

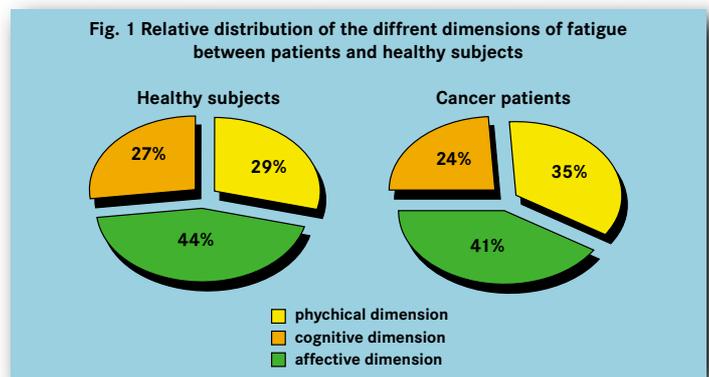
Patients spoke of a feeling of 'mal-être' (ill being) as opposed to 'bien-être' (well being) when speaking of CRF. The distress and suffering caused by CRF were regarded as a threatening experience and although patients had considerable difficulty describing their distress, the different metaphors, images and expressions used by the patients revealed a sense of helplessness, isolation, culpability and dependence. Exhaustion, the sensation of being worn down, resulted in loss of personal identity and loss of life's meaning.

Poor quality or lack of sleep was the most frequently cited cause of fatigue in our sample of healthy subjects. Causes mentioned included difficulty in switching off thoughts from work, family worries, a noisy environment, shift work, intrusive thoughts, seasonal time changes. Stress, induced by life styles, professional overwork, family worries (a sick child, an elderly relative) socio-relational difficulties, transport difficulties, was the second most important cause of fatigue. Professional overwork together with ageing were also important causes of fatigue in both male and female participants.

Short exposes and

Tiredness in healthy subjects was associated with a sensation of heavy limbs, eyelids, a need to lie down, while in patients it was a more generalised feeling of whole body fatigue, both physical and mental, as well as localised tiredness. In healthy respondents tiredness peaked at the end of the day although some subjects noticed a transitory post-prandial fatigue around 13h. Patients however were more tired on waking than prior to illness. A post-prandial peak of fatigue was general around 13h and fatigue sometimes peaked again around 17h. Overall patients were most tired in the evening and earlier than before illness. Fatigue in patients was perceived as an abnormal phenomenon, a source of distress, a threat and a severe handicap in daily living. On the contrary tiredness at the end of a working day was considered a normal phenomenon by healthy subjects and had relatively few repercussions on daily life.

Although we note that the relative importance of the physical, affective and cognitive dimensions was similar between patients and healthy subjects, themes and the relative importance of themes within these dimensions differed slightly between the 2 groups. Mood swings, lack of motivation, decreased concentration, lack of energy, the need to lie down in the evening, and memory problems were the most frequently cited themes in healthy subjects. On the other hand, lack of endurance, an augmentation in the time spent resting during the daytime, lack of motivation, low spirits, lack of energy, anxiety and weakness were the most frequent themes in patients. Weakness, a prominent characteristic feature of physical fatigue in patients was mentioned by only one healthy subject when undertaking prolonged heavy manual work. Decreased energy in healthy subjects was most apparent at the end of the working day and therefore had few repercussions on performance. Weakness, decreased energy and stamina had important repercussions on physical performance in patients. The physical dimension of fatigue was slightly more prominent in the patient group. Low spirits, anxiety, anxio-depressive trait, the need to force oneself to perform an activity, intrusive thoughts, lack of will power and lack of vitality were all more frequent in the patient group. Lack of motivation, and mood swings were similar in the 2 groups. The cognitive dimension was slightly more important in healthy subjects and was characterised by difficulties in concentration and memory, principally confined to the end of the day. In patients we note greater difficulty in reasoning powers, lack of creativity and somnolence during the day as well as difficulties in concentration and memory, all of which had important consequences on quality of life and the initiation of coping strategies. Distress was the most important distinguishing feature between the 2 groups and was present in only one healthy subject at the time of interview. The affective dimension was the most prominent dimension of fatigue in both groups.

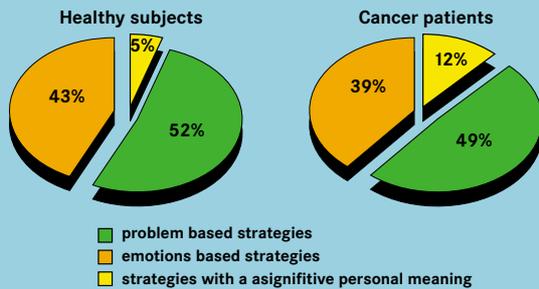


When we compared the different strategies used by patients and healthy subjects we note both patients and healthy subjects used principally problem-focused strategies. (see figure 2)

The regulation of activity and rest and the planning of activities were the most frequently used strategies common to both groups. Rest was seen to be an effective strategy by healthy subjects, but was much less so in patients. Patients, more frequently used information seeking, vigilance, observation, body listening and use of social support for practical help, than healthy subjects did. Seeking clear information in order to understand the causes and pattern of fatigue and together with ways of controlling the symptom was very important for the majority of patients.

reports on fatigue research

Fig. 2 Relative distribution of coping strategies used by healthy subjects and cancer patients



Patients had a more confrontational attitude in their desire to maintain control, and some showed a high degree of fighting spirit. Healthy subjects rarely perceived fatigue as a menace, and just got on with coping, facing up to the situation rather than seeing it as a challenge. Patients, as opposed to healthy subjects, were more likely to become passive in their acceptance of fatigue, to relinquish control to others while healthy subjects tended to withdraw, isolate themselves when tired in order to relax or avoid an explosive situation. Patients used social support for practical help, information, discussing problems, moral support and as a source of motivation. Healthy subjects discussed problems with colleagues and family, but rarely asked for practical help. On the other hand friends were a greater source of distraction, socialisation in this group. The different strategies of coping used by patients and healthy subjects reflected their differing perceptions of the fatigue experience. CRF is very different from 'normal' fatigue and has a major impact on patients' lives modifying their expectations, their motivation and their capacity to initiate coping strategies. The linguistic description of fatigue confirmed the differing perceptions of fatigue between patients and healthy individuals and a heightened concern for the negative aspects of fatigue and suffering among patients. A 4 step conceptual model for fatigue (an inverted pyramid) was developed to explain the different stages in individual responses to fatigue. The four stages, not necessarily consecutive were: Vigilance; Regulation; Submergence and Renaissance. With the exception of regulation, these terms were used by the patients to describe the evolution of fatigue. As we have shown CRF is inextricably linked to the illness trajectory. Patients' capacity to cope also varied with the illness trajectory and changes in situation, mood and physical incapacity. Understanding the phased nature of fatigue, the cancer experience and the coping issues present at each phase is important for clinical practice. We were able to link the above model for fatigue to patients' responses to the different phases of the illness and examine the self-care strategies they used at each phase. We hope the proposed conceptual model will clarify nurses' understanding of the CRF experience and increase awareness of patients' individual and changing needs throughout the illness trajectory. Nurses may then help patients' explore and reframe the meaning of the cancer and fatigue experience, enabling them to accept the limitations of the new self, restore self esteem, and reconstruct a new self with in the limits of the present.



Assessing Fatigue and Self-care Activities in Patients Receiving Radiotherapy for Non-small Cell Lung Cancer

Gillian Knowles, Diana Borthwick, Shanne McNamara, Rita O'Dea

Introduction

The key objectives of this study were to explore the nature of fatigue in patients receiving radiotherapy for non-small cell lung cancer. Lung cancer represents a major public health problem World-wide and is the commonest cancer diagnosed in Scotland (Information and Statistics Division 2000). Prognosis remains poor with 80% of patients presenting with locally advanced or metastatic disease. Given the discouraging survival statistics, treatment is essentially palliative therefore symptom management is crucial. While there is growing research interest in identifying and developing interventions to address specific problems in patients with lung cancer, for

example breathlessness (Corner et al 1995, Bailey 1995, O'Driscoll et al 1999) little is known about the experience of fatigue in this patient population. In order to develop appropriate interventions a thorough understanding of the symptom through careful assessment is necessary. The overall aim of the current study was to gain a greater understanding of fatigue in patients with non-small cell lung cancer undergoing radical or high-dose palliative radiotherapy for stage I, II, and III disease.

The specific objectives were:

- To assess the nature, severity and intensity of fatigue during the treatment period, one week and one month post treatment
- To evaluate the effectiveness of self-care activities utilised by patients to counteract fatigue
- To explore perceptions of fatigue in this patient group undergoing radiotherapy

A consecutive series of 53 newly diagnosed patients with non-small cell lung cancer receiving radical or high dose palliative radiotherapy for stage I, II, and III disease were recruited from the Regional Cancer Centre in Edinburgh. Recruitment was over a 10-month period. A descriptive study was employed using a structured health diary adapted from previous work by Richardson (1994). The diary was completed by patients pre-treatment, weekly during radiotherapy, 1 week and 1 month post-treatment. Semi-structured interviews were conducted with a random sample (n=11) to explore perceptions of fatigue Data was entered onto an ACCESS database and analysed descriptively. Where comparisons were made chi-squared or non-parametric tests were used. Taped interviews were transcribed and analysed using content analysis to identify recurring themes within the transcripts. Fifty-three patients with non-small cell lung cancer were recruited to the study. Demographic details are shown in table 1. Analysis was performed on the 46 complete data sets. The demographic details of the patients who returned the diaries were comparable with the total sample.

Table 1

Total sample:	n=53
High-dose palliative radiotherapy (13#):	n=16
Radical radiotherapy (20#):	n=37
Male:	n=31
Female:	n=22
Mean age:	70 years (range 40-87)

The key findings from the patient diaries and interviews were:

- There was a steady increase in fatigue during the treatment period, peaking one week post treatment followed by a downward trend by one month. This pattern is repeated for both distress and interference with activities
- It appeared that men experienced less fatigue throughout and post radiotherapy whilst for women their levels continued to increase. In addition women were more distressed and fatigue caused greater interference in their life than reported by men.
- By disease stage there was a trend towards higher levels of fatigue in patients with more advanced disease.
- There was a clear trend towards patients becoming more fatigued as the day progressed ($p < 0.0001$).
- Over the whole study period there were significant correlations between mean fatigue scores; and appetite ($p = 0.016$), breathlessness ($p = 0.033$); and sleep loss ($p = 0.005$).
- Interventions most commonly favoured by patients were resting, sleeping during the day, watching television and walking. Sleeping during the day was found to be the most successful intervention. However when analysed other interventions (i.e. resting, watching TV, chores, hobbies, socialising and working) failed to demonstrate effective relief.

This study has enabled us to examine the nature of fatigue in patients with non-small cell lung cancer undergoing radiotherapy. In keeping with current literature (Smets et al 1998, Miaskowski & Lee 1996) the key finding from this study demonstrate the progressive nature of fatigue, starting 2-3 weeks

into radiotherapy, peaking one week post treatment and decreasing by one month. In retrospect it would have been interesting to follow up patients to ascertain the time period for fatigue to return to pre-treatment levels, if at all. Although fatigue is clearly a symptom experienced by this group, in general the levels of distress reported and interference with daily life were not as overwhelming as the literature thus far suggests. Interestingly, the intensity of fatigue and interference with activities was generally greater in women. Further work looking at gender differences and the importance that patients attach to specific symptoms is required.

Furthermore, the findings from the study demonstrate that the strategies used by patients on the whole proved unsuccessful in alleviating fatigue. Similar observations have been made in the literature (Portenoy 1999; Irvine et al 1998; Ream and Richardson 1999). Ream and Richardson (1999) propose that without guidance, patients adopt common sense strategies with limited success. Again further work is needed to evaluate different interventions, specifically in relation to targeting patients more at risk.

In conclusion this research has usefully demonstrated patterns of fatigue in patients receiving radiotherapy for non-small cell lung cancer, perhaps generating more questions and highlighting areas for future research.

A comparison of nurses' knowledge of cancer-related fatigue and its management across primary, secondary and tertiary care settings.

*Morven Miller & Nora Kearney,
Nursing and Midwifery School, University of Glasgow*

This project aimed to describe nurses' knowledge and attitudes of fatigue as well as current institutional management practices across oncology, medical, surgical and community settings. A survey design was used and the questionnaires (the Fatigue Knowledge and Attitude Survey and an Institutional Needs Assessment) were mailed to 470 registered nurses working in these clinical areas. An overall response rate of 43% was achieved and the data were analysed descriptively.

Despite recent attempts to highlight the issue of fatigue, nurses across all specialities consistently under-estimated cancer-related fatigue. Indeed, oncology nurses were not significantly superior in their knowledge and attitudes of cancer-related fatigue when compared to the other nursing specialities. Additionally, while nurses clearly understood the general principles of fatigue assessment and management, they were often unable to translate these into specific nursing actions and interventions. This demonstrates a gap in nurses' knowledge that will ultimately have a direct impact on the patients' cancer experience.

Successful fatigue management requires the commitment of not only nursing staff but also the multidisciplinary team including the clinical management team. However, our results demonstrated that the institutional management of fatigue was consistently poor across all clinical specialities. This would suggest that the most common symptom that patients with cancer are likely to experience is not a priority for healthcare managers. This issue must surely be addressed, and quickly, if successful fatigue management strategies are to be developed.

Improvements in information dissemination are essential to ensure that nurses have access to information about the most common problem that patients with cancer are likely to experience. There is a need to take the information directly to clinical areas through, for example, Fatigue Roadshows. The development of Fatigue Link Nurses in clinical areas would

also promote the issue of fatigue management in practice and would provide nurses with an accessible source of relevant information. However, management support is also imperative and nurses must assume responsibility for alerting management to the problems of fatigue and obtaining their support for innovative fatigue management strategies.



**The www.fatigue.be
Workgroup against Cancer Fatigue Project**

Foubert J, fatigue consultant, Jules Bordet Institute, Brussels, Belgium. Evers G, Catholic University of Leuven, Centre for health services and nursing research, Leuven, Belgium.

Background

Fatigue is the most prevalent complaint in cancer patients. A national survey in Belgium demonstrated that 2 out of 3 cancer patients receiving chemotherapy suffer from fatigue (Evers & Tanghe 2000). Yet the presence of cancer fatigue is systematically underestimated by physicians and nurses and insufficiently reported by patients and their families (Tanghe, Evers and Paridaens 1998).

The aim of the project is to increase awareness and importance of fatigue in cancer patients by helping patients, family members, nurses and physicians to become more successful in the management and control of cancer fatigue by providing high quality, very practical and easy accessible information to them.

The Working Group against Cancer Fatigue in Belgium, founded in 1999, developed a Webpage (www.fatigue.be), which includes a screening and management system for cancer fatigue. In this working group nurses, physicians and representatives of patient organisations collaborate to improve fatigue management in Belgium. It was supported by an educational grant from Ortho Biotech, a division of Janssen-Cilag.

Content

The interactive website presents information on different types of cancer; their treatment, fatigue and cancer related anaemia and its treatment modalities in an easy accessible way. The unit "how to manage your fatigue?" guides the patient through a self-screening page based on the ICD-10 criteria and provides validated fatigue scales which can be used for evaluation and follow up purposes. Included are also a patient fatigue diary, a self-care guide and detection and treatment guidelines for nurses and physicians. Videotaped instructions by nurses, physicians and patients reports illustrate all aspects.

The website also includes a calendar with patient fatigue information sessions in local oncology centres organised by nurses, an address book, greeting cards, commentaries and links to other national and international cancer websites.

This website suggests solutions for patients and relatives, the amount and timing of information can be individualised. This initiative improves self-control by self-assessment and systematic follow up. A correct and structured information reduces uncertainty and anxiety.

Conclusion

This website provides patients, their families, nurses and physicians a powerful instrument to improve the management of cancer fatigue in all aspects. The number of visitors is increasing each month and the number of downloads shows a potential interest for the developed materials.

Recipients of the EONS-Roche Grant 2001-2002 announced

The 3 recipients of the 2001 EONS-Roche Research Grant were honoured at the Spring Convention and were given the opportunity to present preliminary data on their still on-going research projects related to education, research and/or practice in cancer care. The recipients are:

- **Nikolaos Efstathiou**, *Korgialenio Benakio Hospital, Greece*;
Established cancer care priorities in Greece. Cancer patients' and carers' views.
- **Ilana Kadmon**, *Hadassah Medical Center, Israel*;
Israeli and Chinese men's reactions to their wife's diagnosis of breast cancer: a comparative study.
- **Elisabeth Patiraki**, *University of Athens, Greece*;
Barriers in implementing research findings in cancer care. The Hellenic registered nurses' perception.



Resources Available for Patients to Enable them to Cope with Cancer-related Fatigue

Emma Ream BSc (Hons) MSc RN, Lecturer & Research Fellow in Nursing*, Florence Nightingale of School of Nursing and Midwifery, King's College London.

Natasha Browne, BSc (Hons) RN, Research Associate, Florence Nightingale of School of Nursing and Midwifery, King's College London.
Agnes Glaus, MSc PhD RN, Nurse Practitioner and Researcher, Center for Tumor-Prevention and Detection, St. Gallen, Switzerland

Introduction

Patients with cancer in the twenty-first century have increasing numbers of treatments available to them. It is now commonplace for different treatment modalities to be combined within individualised programmes. Whilst this advance impacts directly on patients' survival, it also affects quality of life through the side effects that result. Cancer-related fatigue is one symptom associated with cancer treatments which patients find distressing and which diminishes their quality of life (Sitzia, Hughes et al. 1996; Glaus, Crow et al. 1996; Griffin, Butow et al. 1996; Ream and Richardson 1997; Tanghe, Evers et al. 1998; Stone, Ream et al. 2000).

The impact of fatigue on patients' lives is heightened by their apparent inability to manage this symptom successfully. Studies of the efficacy of strategies employed by patients to relieve fatigue identify patients frequently employing sedentary strategies including sleeping and resting, unsuccessfully (Richardson and Ream 1997). Studies that have researched the management of fatigue allude to the importance of educating and supporting patients in the use of more active and innovative strategies. These have been considered in a previous literature review (Ream and Richardson 1999). There is a growing body of educational resources for patients about cancer-related fatigue. These materials aim to promote actions that will enable individuals to manage the symptom more effectively, and lessen the distress felt by those living with it. However, to date no research has addressed the adequacy of these resources. This study was designed to address this shortfall through providing an overview of European patients' and nurses' views on these resources and provide recommendations on the materials that should be developed in future.

Aims of the research

The study aimed to:

1. Determine need for patient education on cancer-related fatigue in two European countries
2. Describe resources required by patients to enable them to live with, and manage, cancer-related fatigue
3. Ascertain the quality and efficacy of current resources
4. Provide recommendations for future development of educational resources about cancer-related fatigue and its management

Methods Patients' views

Patients' views were attained through conducting focus groups. These were performed as it was envisaged that they would generate rich qualitative data, which would provide a range of suggestions for improving educational materials and enhancing provision of quality nursing care. Focus groups were held in the UK and Switzerland using purposive sampling frames to enable recruitment of individuals with experiential knowledge of fatigue and its management. Nine patients in the UK and 6 in Switzerland participated in the focus groups. All patients were provided with resources that were available in their countries to educate them about cancer-related fatigue. They reviewed these prior to attending the groups.

Nurses' views

Experienced oncology nurses from across Europe were sampled from the EONS database and invited to participate in a Delphi survey with 3 phases. This survey sought their views regarding education of patients about cancer-related fatigue. It aimed to identify common opinions and allow areas of disparity to be determined. Furthermore, the nurses prioritised difficulties associated with educating patients about fatigue and developments needed to enhance patient education in the future.

Results Patient's views

All patients in the study reported receiving insufficient information on cancer-related fatigue; it was a symptom that was not spoken about explicitly in clinical settings. They felt that this may have arisen because fatigue was not of high priority to healthcare professionals, or because members of the cancer team were insecure about their knowledge of the symptom. In

addition, they believed that nurses lacked sufficient time to educate patients about fatigue. They described the educational resources they were provided in positive terms. In the main they were considered easy to read and understand and perceived to include valuable information and advice. It was felt that resources help patients to articulate their experience of fatigue. However, individuals discussed their concerns over their inability to access them. None of the groups' participants had attained information on the symptom previously. Finally, recommendations were made for development of resources to educate patients about cancer-related fatigue in future. Notably, the groups identified a need for materials to detail the management of psychosocial aspects of fatigue including its impact on work and social life, a desire for materials to address the role of complimentary medicine in managing fatigue and a need to understand the contribution of different members of the healthcare team in the management of this symptom. However, whilst these recommendations are helpful, it is clear that access to patient literature on cancer-related fatigue must improve. If patients are unable to obtain currently available educational materials, debate concerning their quality becomes purely academic.

Nurses' views

The first Delphi survey questionnaire (phase 1) was mailed to 101 EONS nurses yielding a response rate of 25%. The second questionnaire (phase 2) was mailed to 100 of those originally circulated and a response rate of 50% was achieved. The third questionnaire (phase 3) was mailed to the 50 nurses that completed the second questionnaire. 31 of these nurses responded, generating a response rate of 62% for the final phase of the study. The nurses in the study reached consensus on a number of issues. They identified cancer-related fatigue as an expected symptom of cancer, yet one that is not addressed sufficiently. They emphasised the importance of integrating the management of fatigue into standard care and advocated greater awareness amongst all healthcare professionals of fatigue and its impact on patients. They promoted interdisciplinary collaboration in the management of fatigue, and need for time dedicated to educate patients about it. The nurses believed that educational resources reassure patients that fatigue is not unusual. The nurses felt it was important for booklets to be revised to include coping with the impact of fatigue on work and social life. They also recommended that disease and treatment specific resources include more information on fatigue and strategies to deal with it, and that there should be a wider range of educational materials. In addition the development of educational programmes about cancer-related fatigue for patients and families was seen to be an important advancement for care.

The nurses prioritised the following difficulties they had identified as being inherent in educating and supporting patients in the management cancer-related fatigue. They saw the most important difficulties as:

- encouraging patients who are fatigued to remain active
- working as a multidisciplinary team, using research findings in practice
- enabling patients to accept fatigue and not feel guilty about their reduced ability
- motivating patients to use the information given to them
- finding a simple, appropriate and useful fatigue assessment tool
- finding sufficient time
- finding the right balance between activity and rest for individuals

Conclusion

At present, education of patients about cancer-related fatigue appears poor. Educational resources to help patients manage fatigue do exist, yet access to them is often inadequate. Patients state that they prefer verbal information to written or other forms of information-giving, but this may contribute to their receiving insufficient information as discussion about fatigue appears lacking. Healthcare professionals rarely assess fatigue or inform patients of ways to manage it. Indeed some patients are unaware of what the symptom is, and thus do not mention it or seek out information about it. Nonetheless, it is clear that fatigue has a great impact on quality of life for these individuals. It is evident that there are many reasons why healthcare professionals do not discuss fatigue with patients. Primarily, the education of patients about fatigue may not be seen as a priority. It appears the symptom is viewed as inevitable yet not life threatening. Lack of time may also prevent adequate patient education regarding fatigue. Even if fatigue is acknowledged by healthcare professionals, it appears that they may not know what to suggest or how to manage it. It is clear that healthcare professionals need to be educated about cancer-related fatigue. Education must be provided to all professional groups to enable them to provide patients with consistent, accurate and up to date information. Patients in both Switzerland and the UK promoted development of specialist nurses, or educationalists, whose role would entail educating patients about the symptom, whilst possessing both the time and knowledge to do so.

Society News Updates

Highlights from EONS 3rd Spring Convention

Despite downpours of rain and unseasonably cool temperatures, participants at the 3rd EONS Spring Convention, held in Venice from 11-13 April, enhanced their knowledge on issues related to improving communication skills and learned of strategies helpful in dealing with information overload.



The international faculty provided insight on issues as diverse as patients and the internet, clinical decision-making and staging plays to explain cancer and its treatment. In the opening session, K. Redmond and C. Krcmar emphasised the benefit of information in aiding patients in becoming active partners in their care and treatment, but both cautioned nurses to be themselves aware of the sources of information which patients utilise, especially the internet. Ms. Redmond pointed out disparities in accessing and understanding available information on the internet which can result in info-exclusion of some populations in Europe. Ms. Krcmar presented tools which can serve as guidelines for patients and health care professionals to assess the quality of information published on the internet. The participants were entertained by an all too real role play of communication patterns between nurse and patient produced by Susie Wilkinson. The play provided the basis for a lively audience discussion on this topic. At the EONS-ONS joint session, Ms. Rieger, current President of ONS, provided theoretical and practical advice on improving decision making skills urging the audience to base decisions on scientific evidence and to make the process of decision making in nursing practice transparent to other health care disciplines. Possessing good communication skills does not necessarily exclude the need to contemplate the ethical and moral implications of the message one is attempting to relate. Stephen Wilkinson elaborated on this theme providing the audience with an ethical framework within which to consider the difficulties in deciding what to tell patients and when. Using the internet to help patients better manage their fatigue (J. Foubert) and producing an interactive play to teach patients and families about the development and treatment of cancer (S.DeCristofaro) were two novel innovations presented in the proffered paper session on 'Knowledge for Practice'. The play, Cell Zappers, (the idea for which was conceived by a cancer patient) resulted in decreased anxiety levels and an 88% improvement in knowledge level (as measured by pre- and post-testing) in the patients who participated.

Participants at the 3rd EONS Spring Convention

Greece	97	Belgium	13
Switzerland	58	Spain	13
UK	54	France	10
Italy	44	Germany	9
Portugal	34	Ireland	7
Sweden	31	Israel	4
The Netherlands	18	Turkey	4
Austria	16	Slovenia	3
USA	15	Czech Republic	2
Denmark	14	Norway	2
Finland	12	Others	16

Total 476

The EONS Spring Convention is intended as an interactive conference where participants enhance their knowledge on a particular topic through sharing knowledge with colleagues. This is mainly achieved through interactive workshops which were held on both days of the conference and were offered in English, German, Italian and Greek. Topics presented for group discussion were 'The art of professional communication' and 'Creating tools for effective patient communication'.

This year, two special EONS symposia preceded the official start of the convention and were held on 11 April. The first symposium was sponsored by Merck Sharp & Dohme and dealt with the important topic of managing chemotherapy induced nausea and vomiting. EONS is currently conducting a multi-centre study on this topic the results of which will be published in full in a future issue of EON. The second symposium was a collaborative educational event with the European School of Oncology (ESO). 'Improving our understanding of the elderly patient with cancer' addressed assessing the elderly patient, the nurse and the elderly patient, and solutions to administering chemotherapy appropriate for the elderly cancer patient.

The Organising Committee extends its gratitude to the following foundations and companies for their generous support of the 3rd Spring Convention: the European School of Oncology, the Susan G. Komen Breast Cancer Foundation, the Robert Bosch Foundation, F. Hoffman-LaRoche, Merck Sharp & Dohme, and Nutricia.

Team from Ljubljana receives Outstanding Poster Award

For the first time, participants at the 3rd Spring Convention were asked to judge the poster presentations and select the best one. From the 47 poster entries, the poster entitled "The relevance of instructing the patients on admission to and discharge from the hospital" was chosen. The presentation, submitted by M. Velepik and B. Skela Savic from the Institute of Oncology Ljubljana, Slovenia, describes the evaluation of written materials provided to patients to better help them cope with a hospital stay. The study reports a significant reduction in anxiety and increased satisfaction in patients who were provided with the learning materials either at the time of or shortly after hospital admission.

The Organising Committee congratulates the authors on their award and on their contribution to extending the scientific base of cancer nursing through their research project.

EONS Young Researcher Award Lecture

Caroline Godino Galvez, recipient of the 2002 Young Researcher Award, presented preliminary results of her research on educational initiatives to decrease fatigue perception in oncology patients at the concluding session of the 3rd Spring Convention. The study, conducted at the Catalan Oncology Institute, involves two groups of patients; the experimental group received structured health education on fatigue and its management. The study investigates if health education provided by nurses decreases the perception of fatigue in patients with digestive cancer. Ms. Galvez has planned two years to conduct her study. The complete results will be published in a future issue of EON.

Nutricia Educational Package

The newest EONS collaborative initiative is a research project with Nutricia. The objectives of the project are to identify the current knowledge and opinion of European oncology nurses in regards to nutrition. The first step of the project was the distribution of a needs questionnaire which was enclosed in the March issue of the EONS newsletter. In addition to the questionnaire, nurses at the Spring Convention were questioned about their knowledge of nutrition and nutritional needs of cancer patients during focus groups. Based on the analysis of these survey results, an educational tool to help nurses understand the role and importance of nutrition in cancer and to improve nurse's contribution to the nutritional well-being of cancer patients in daily practise will be developed.

This multi-country study is slated for completion by summer 2003.



EONS - ROCHE Project Grant 2002-2003

Application Form

Official use only

Important

Date Received: File Number: Date Notified Outcome:	Before completing this form, please read the accompanying Call for proposals Please type your answers.
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I) Details of lead applicant (to whom all correspondence will be addressed)

Title : _____ Surname : _____
Forenames : _____ EONS membership Number : _____
Post held : _____
Department : _____
Organisation : _____
Full postal address for correspondence : _____
Telephone number : _____ Fax number: _____
e-mail : _____ No. of applicants : _____

II) Project Summary

Project Title : _____

Proposed starting date: _____ Proposed duration (Months): _____

Details of joint application

Title : _____ Surname : _____
Forenames : _____ EONS membership Number : _____
Post held : _____
Department : _____
Organisation : _____
Full postal address for correspondence : _____
Telephone number : _____ Fax number : _____
e-mail : _____

Title : _____ Surname : _____
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e-mail : _____

Title : _____ Surname : _____
Forenames : _____ EONS membership Number : _____
Post held : _____
Department : _____
Organisation : _____
Full postal address for correspondence : _____
Telephone number : _____ Fax number : _____
e-mail : _____

IV) Declaration

I declare that the information given on this form is complete and correct.

Signature of lead applicant:

Date : _____

Name : _____
Position : _____
Organisation : _____

V) Details of the proposed investigation

Applicants are expected to provide a description of their research on a separate sheet of paper using not more than 1000 words (app. 2 pages A4) and following the heading guidelines.

- 1. Title
- 2. Problem statement
- 3. Research question(s)
- 4. Aims and objectives of the research
- 5. Methods: sample, selection, data collection method, analysis
- 6. Key references
- 7. Plan of investigation (time frame, institution)
- 8. Factors enabling the applicant(s) to achieve the research objectives (e.g. support through institution, mentor, nurse scientist)

VI) Curriculum Vitae of lead applicant

(Add short biographical sketch, including nursing education, recent posts held, key publications, Presentations)

EONS Welcomes New Sustaining Member

Amgen Europe recently became a sustaining member of EONS. The membership has been approved for the next 2 years. In line with the terms of membership for sustaining members (or patrons), Amgen has provided EONS with an unrestricted grant which will be used to support the 'EONS Task Force Survey Project' and administrative activities of the Society.

Sustaining members are organisations or individuals who do not meet the criteria for other categories of membership but who are willing to support the goals and objectives of the Society. EONS is pleased to welcome Amgen as a sustaining member.

Nora Kearney presents Robert Tiffany Annual Nursing Lecture

The Royal Marsden Hospital honoured Nora Kearney, President of EONS from 1997-1999, in March for her outstanding contribution to cancer nursing in the UK as well as in Europe. Dicken Wier Hughes, Chief Nurse at the Royal Marsden, stated that it was a unanimous decision to select Nora for the award based on her extensive involvement in many aspects of cancer nursing. The title of her honorary lecture, "Cancer Nursing: Practice politics . . . or just pretending?" was described as brilliant and Nora received a standing ovation from the audience, a rarity in Great Britain. Mr. Wier Hughes noted that Nora's remarks in particular on research and nursing provided the audience with some, perhaps contentious, material to stimulate thought on the subject.

The annual lecture is named after Robert Tiffany (a founding member of EONS) who was Chief Nurse at the Royal Marsden from 1976-1993. The award was first presented in 1996 and previous awardees include: Barbara Stillwell, Connie Henke Yarbro, June Clark, Gill Oliver, Sarah Mullally and Sanchia Aranda.

A manuscript of Ms. Kearney's lecture will appear in the June issue of EJON.

Call for Applications: EONS-Roche Research Grant 2002-2003

The European Oncology Nursing Society, in partnership with Roche, is pleased to announce the availability of four EONS-ROCHE Research Grants. Grant recipients will be awarded US \$ 8000; \$6000 to conduct a research project and the remaining sum to apply toward travel expenses to attend the ECCO 12 conference in Copenhagen in September 2003 at which recipients will present their research at a special symposium.

The proposed project should seek to address issues related to symptom management in cancer care and may emphasise research, practice or education. Preference will be given to projects which promote nursing practice and education directed at issues related to anti-emetic care and are supported by a nurse scientist. The proposed project should be implemented no later than 31 September 2002 and completed by September 2003. To be eligible for consideration, project authors must be full members of EONS.

Proposals must be submitted using the official forms available from the EONS Secretariat, the centre-page of this issue, or at www.cancereurope.org/eons. All applicants will be informed of the outcome of the review process by March 31, 2003. The deadline for application submission is 30 September 2002.

Queries about the application procedure or any aspects concerning the EONS-ROCHE Grants may be addressed to the EONS Secretariat.

EONS Strategic Development

The mission of the European Oncology Nursing Society is to improve the care of individuals with cancer by supporting and enhancing cancer nursing throughout Europe. EONS strives through educational and research initiatives to achieve the following 4 goals:

- Quality nursing care is available to patients with cancer in Europe.
- Cancer nursing is recognised as a speciality in Europe.
- Every cancer nurse in Europe is aware of the European Oncology Nursing Society.
- EONS contributes to the accumulation of evidence based cancer nursing knowledge of relevance to European nurses.

President's Report October 2001 – April 2002

An updated President's Report was compiled and available at the Spring Convention. The report in full is available to be downloaded at the EONS web site.

European Journal of Oncology Nursing

The European Journal of Oncology Nursing (EJON) is the official journal of EONS and seeks to address issues of importance to oncology nurses throughout Europe. The journal is a forum which provides information on contemporary practice issues and the latest cancer research. Issues of importance in cancer care are addressed through the exchange of knowledge and experience. Issues are addressed by:

- Original articles
- Critical research commentaries
- Short reports of research work in progress
- Literature reviews
- Reports on service developments
- Research reports
- Practice notes
- Book and media reviews
- A scan of current literature

EJON is listed in the Cumulative Index to Nursing & Allied Health Literature print index, the CINAHL database, VINITI and BDLC.

Subscription information, sample articles, instructions for submitting manuscripts, and advice on preparing manuscripts for publication are available by contacting: www.harcourt-international.com/journals/ejon/. EONS members and member societies are eligible for discounted subscription rates.

Upcoming Events

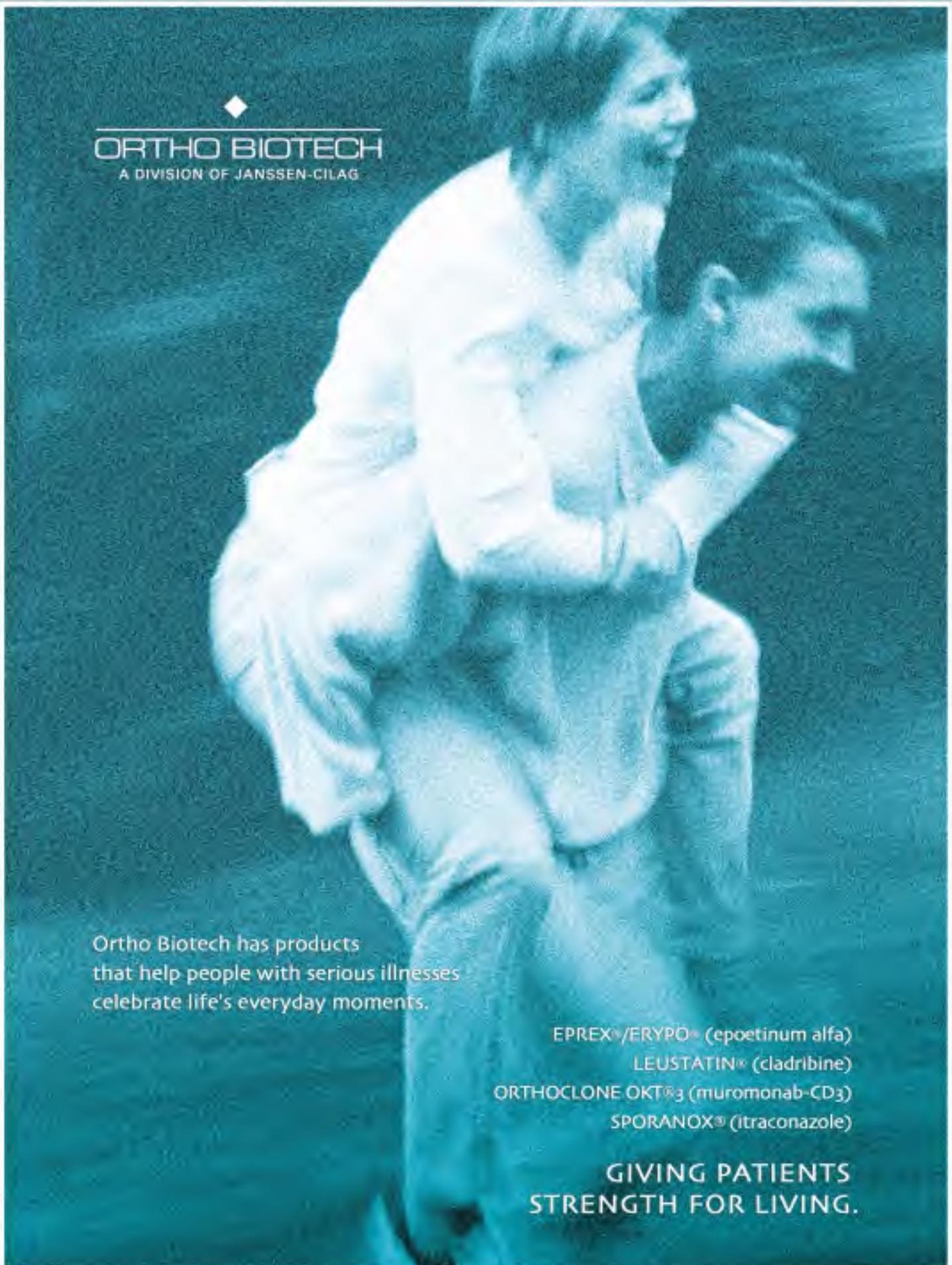
18th UICC International Cancer Congress Nursing, 30 June-5 July 2002, Oslo, Norway. Contact: Congrex Sweden AB, PO Box 5619, S-11486 Stockholm, Sweden. E-mail: canceroslo2002@congrex.se / Web: www.oslo2002.org

6. Internationales Seminar Onkologische Krankenpflege – Fortgeschrittene Praxis, 22-23 August 2002, Universitaet St. Gallen, St. Gallen, Switzerland. (Language is German). Contact: e-mail; eso-d@sg.zetup.ch

12th International Conference on Cancer Nursing, 28 August – 1 September 2002, London, UK. Organised by the International Society of Nurses in Cancer Care (ISNCC). Contact: E-map Healthcare Events, tel: +44 (0) 20 7874 0446, fax: +44 (0) 20 7874 0313. E-mail: Alex.Budgen@emap.com / Web: www.isncc.org

Directory of Oncology Nurse Researcher Information Form

The Research Committee of the International Society of Nurses in Cancer Care (ISNCC) is seeking nurse researchers who would like to have information about themselves and their research included in an Oncology Nurse Researcher Directory. It is planned to publish the directory in hard copy as well as on the ISNCC web site. The information contained in the directory will be updated every two years. Application forms are available by visiting the ISNCC web site (<http://www.isncc.org>) and should be completed and returned by the end of June 2002. For more information, please contact Dr. Ann Hilton, Research Committee Chair, hilton@nursing.ubc.ca.



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