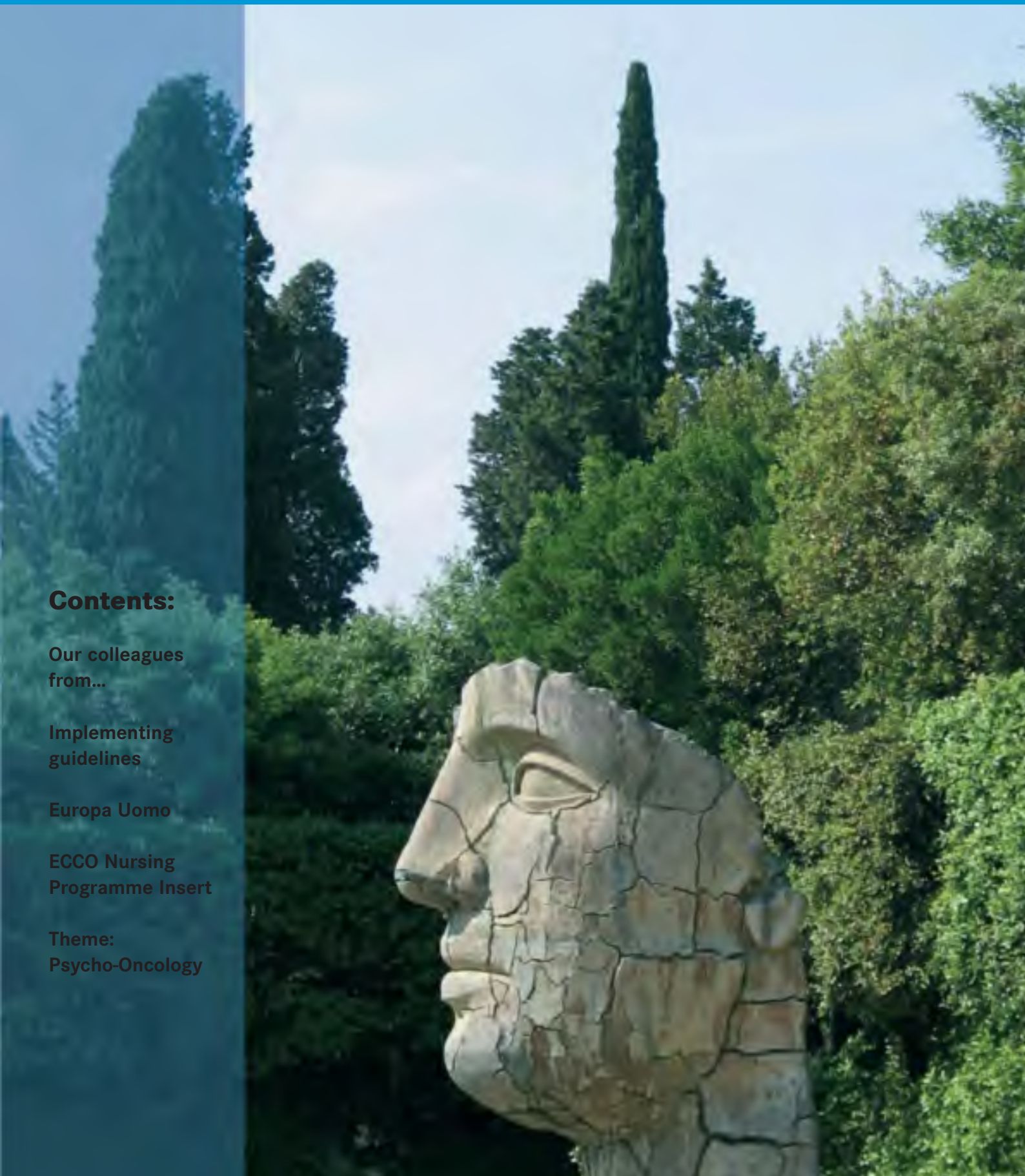
eons newsletter

The Quarterly Newsletter of the European Oncology Nursing Society

Spring 2007



Contents:

The goal of the EONS Newsletter is to inform nurses about EONS and its activities and to provide a forum for cancer nurses throughout Europe to network. The information published in the EONS Newsletter is intended to inspire nurses to improve the care of the cancer patient through improved knowledge.

All correspondence should be addressed to the Editor-in-Chief at:
eons@village.uunet.be

hoto Cover: Lana Lazevnik
www-cvr.ai.uiuc.edu/~slazebni/

EONS Secretariat
Rudi Briké
Avenue E Mounier 83/4
B-1200 Brussels, Belgium
Tel: + 32 (2) 779 9923
Fax: 32 (2) 779 9937
E-mail: eons@village.uunet.be
Web site:
www.cancereurope.org/EONS.html

EONS acknowledges Amgen, Astra Zeneca, Merck, MSD, Novartis and Roche for their continued support of the Society as Sustaining Members.

Print run: 3100 copies
Electronic version accessible to 18000 EONS members

Printed by
Drukkerij Trioprint Nijmegen Bv
The Netherlands

Letter from the Editor

The cancer journey can be divided into three phases. The first of these is when a patient receives the initial diagnosis and goes into active treatment. In this stage most patients receive a lot of information and support. The patient then enters a period of survivorship assuming that treatment results in cure or remission. Here the environment is less supportive as time goes on and patients are expected to return to normal life, to take up their activities and to learn to live with the cancer. If initial or subsequent treatment is not successful, the final phase of cancer shifts to a focus on end of life issues.

This issue of the EONS Newsletter presents psychoeducational interventions that have been found useful during the first phase of cancer. A rationale for the use of such interventions, their basic structure, and nursing sensitive outcomes was written by Nancy W. Fawzy.

Many patients today survive their cancer, but cancer survivors are a vulnerable population. They face long-term effects of their treatment yet are not able to access appropriate services. Cancer nurses can play a key role in the arena of cancer survivorship, as described by Margaret I Fitch, through activity in research, education, practice, and policy. The imperative for nurses to take action comes from the growing number of cancer survivors who continue to struggle because of the effects of the disease and its treatment long after they are finished with active protocols.

The role of the nurse in the care of dying people is probably the longest established role in the health professions. Why is it then, when you ask a nurse what she/he is doing, that a clear, description or definition is so difficult to articulate? Finding words to describe caring, the human response to suffering and the emotional labour that is involved in providing end of life care is difficult. The nursing literature is gradually recognising the exceptional experience of providing nursing care to the dying and their families. More about the role of nursing interventions at the end of life is described in the article by Davina Porock.

In practice, nursing is often known as the profession that holds the contributing health disciplines together; coordinating and communicating care between health professionals. This view of nursing is so strong that when nurses are observed they are seen only to be doing the work of the doctor or the pharmacist or the physiotherapist or the psychologist. In fact, I feel there is an urgent need to address the 'loss of identity' among the nursing community. What a lot of nurses still do goes back to the days of Florence Nightingale: providing basic care and being dependent on doctors to tell them what to do. While there are, of course, many specialized and advanced posts in oncology, there is a danger that the bulk of bedside nursing will remain in an assistant nursing role. Governments will ask, 'Why should we pay so much for registered nurses when one or two can coordinate the care of patients?'

The present day situation is exacerbated by societal changes that have lessened the true value of what nurses do. The uniform and presence once meant you were respected – now society sees nursing as any other job. Nurses often complain about respect and image but it is important for us all to remember that we have to create our own image and earn respect.

In every stage of the disease, cancer patients need support. For nurses it is important to know that we have partners to help us provide support for our patients. I am very happy to announce that EONS has developed a good relationship with a new partner, IPOS (International Psycho-Oncology Society). The vision of IPOS is that all cancer patients and their families throughout the world receive optimal psychosocial care at all stages of disease and survivorship. More about IPOS is described in this issue.

EONS has close relationships with several patient organisations. In this issue, I am honoured to publish an article which describes Europa Uomo. The Summer issue of the Newsletter will follow on the theme of the work of this patient-support organisation and will be dedicated to prostate cancer.

Jan Foubert,
Editor in Chief

Our colleagues from.....

Slovenia

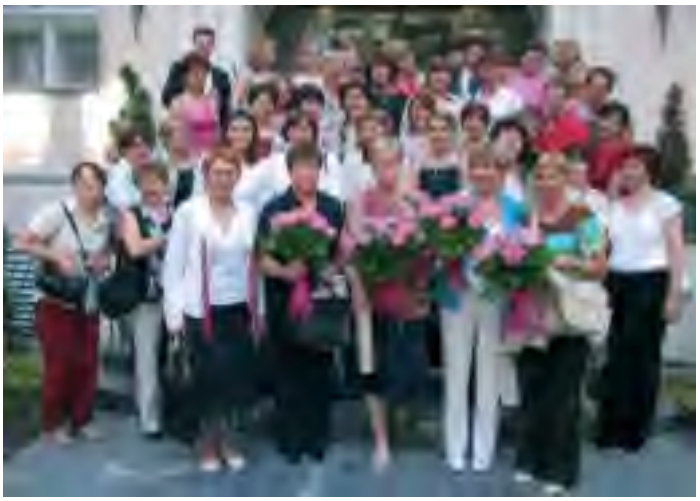
Background/History
The Institute of Oncology Ljubljana is a public health care institution that provides health care services as well as educational and research activities in oncology in Slovenia. Many years ago, the medical profession became aware that clinical management of cancer should be passed into the hands of qualified and experienced specialists. Since 1937 the Institute has steadily grown and expanded and received the title 'University Institute and Hospital of Oncology'. These accomplishments have been accompanied by an on-going expansion of the Institute's physical facilities. With more than 780 employees 350 outpatients and 210 inpatients are examined or treated every day.

Aims/Goals
The vision of the Institute of Oncology Ljubljana is to remain the leading cancer centre in Slovenia and to become one of the leading cancer centres in Europe. In order to realise this vision, the Institute has set clear goals at all levels of medical and nursing activities which include a multidisciplinary approach to comprehensive care. In educational activities, the institute strives to be the reference national institution for Slovenian medical faculties as well as an internationally renowned training institution for all disciplines in oncology.

Nursing is a specialized and independent discipline that collaborates with other disciplines in the comprehensive care of cancer patients. The Nursing Department employs 100 registered nurses and 150 health technicians and is managed by the Director of Nursing. The Director of Nursing is responsible for the improvement of nursing proficiency, the organization of human resources, and for sustaining the position of nursing care as a constituent part of the Institute. The Division of Nursing aims to develop and maintain respect for all employees and the work they perform. Respect for the individual patient and support of activities that help to restore and maintain his/her health are priorities of the nursing staff.

Projects/Initiatives/Activities
Current project work in nursing at our Institute is directed toward nursing consultancy for cancer patients, nutritional support for cancer patients, assessment of pain, prevention of pressure ulcers, and TQM- assessment of quality indicators.

One of our greatest achievements in the year 2006 was the expansion of the program for oncology nursing consultancy. At the Institute of Oncology Ljubljana, oncology nursing consultancy has been operating since 1998. The main reason for its initiation was the vision of further developing nursing thereby supporting the idea that one of the key factors in high quality and comprehensive nursing care of a patient with cancer is a well-planned patient education and counselling program. Why was this needed? In recent years, the strategy of patients' health management has been undergoing rapid changes with shorter hospitalizations and larger numbers of patients being treated at outpatient departments or in day hospital clinics. We were aware that a hasty management of patients could increase the risk that patients, particularly those treated at outpatient departments or in day hospital clinics, would not receive sufficient information. In order to provide these patients with continual and high quality nursing care, we decided to expand the Program for Oncology Nursing Consultancy. Fields of patient education and counselling include: radiation treatment management, surgical treatment management, chemotherapy treatment management, nutrition, palliative nursing care, pain management, stoma and incontinence management, medico-social management, and infection prevention in home care.



Celebration of International Nurses Day

Each year in May we organize a celebration to mark International Nurses Day. On this occasion we award nurses for their achievements in the area of oncology nursing. Last year we opened our celebration to the public as we held an open-door day to present the nursing activities at our Institute.

Affiliation/Collaboration with other Societies
In 1987, the Director of Nursing initiated the establishment of The Section of Oncology Nursing. The Section is headed by a 9-member Executive Committee. Six members from our Institute are also involved providing close contact and cooperation in designing and executing research projects. You can get more information about the Section in the 2006 Summer Issue of the EONS Newsletter.

Interface/Relationship with EONS
The Nursing Division of the Institute of Oncology Ljubljana was a member of EONS from 1989 to 2001. Since 2001 it is affiliated indirectly via the Section of Oncology Nursing. In cooperation with EONS and ESMO we have organised and prepared training courses on safe handling of cytotoxic drugs and proper performance of specific nursing tasks. We have also participated in the TITAN project. The ex-nursing director, Ms. Marina Velepi , was a member of the Board, while Ms. Brigita Skela Savi , current nursing director, is involved in the activities of the EONS Advisory Board.

Future Directions
In the past nursing was oriented toward surgical, radiotherapy, chemotherapy, and palliative nursing care. Today and in the future we are turning toward new directions in oncology nursing practice such as an orientation on patient-centred care, team work, integration of all professional areas, cooperation with patients, evidence-based practice, a multiprofessional approach to care, development of nurse managers, professional development, and postgraduate studies in nursing.

In the future, the Institute will strive to make progress in achieving a multidisciplinary approach to cancer treatment, better team work, conduct more scientific research, fruitful cooperation with local health institutions and effective integration in the network of Slovenian health care services as well as cooperation with similar institutions in Europe and the rest of the world.

Katarina Lokar
Brigita Skela Savi

New on EONS' Website

A Toolkit to Help You Understand and Implement New Guidelines

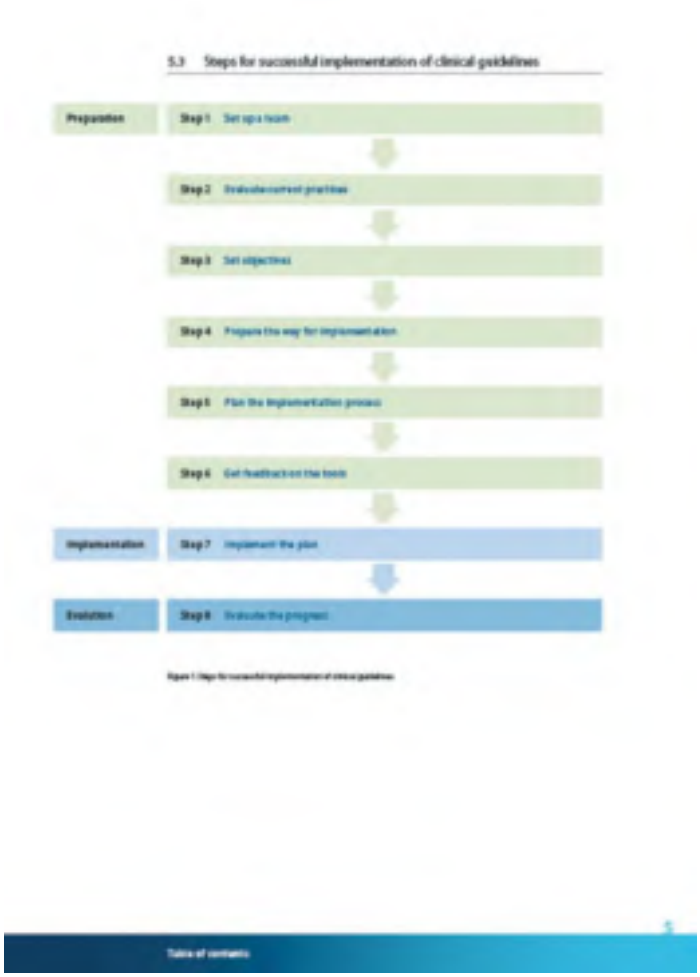
Clinical guidelines are frequently reviewed and amended. In 2006, both the European Organisation for Research and Treatment of Cancer (EORTC) and the Multinational Association of Supportive Care in Cancer/International Society of Oral Oncology (MASCC/ISOO) completed updates of their clinical guidelines for the treatment of chemotherapy-associated complications: anaemia, neutropenia and oral mucositis.
To help understand these new guidelines updates, EONS has developed a comprehensive online Guidelines Implementation Toolkit, which gives a practical guide to the new guidelines and advice on how to implement the new recommendations in your day-to-day practice.

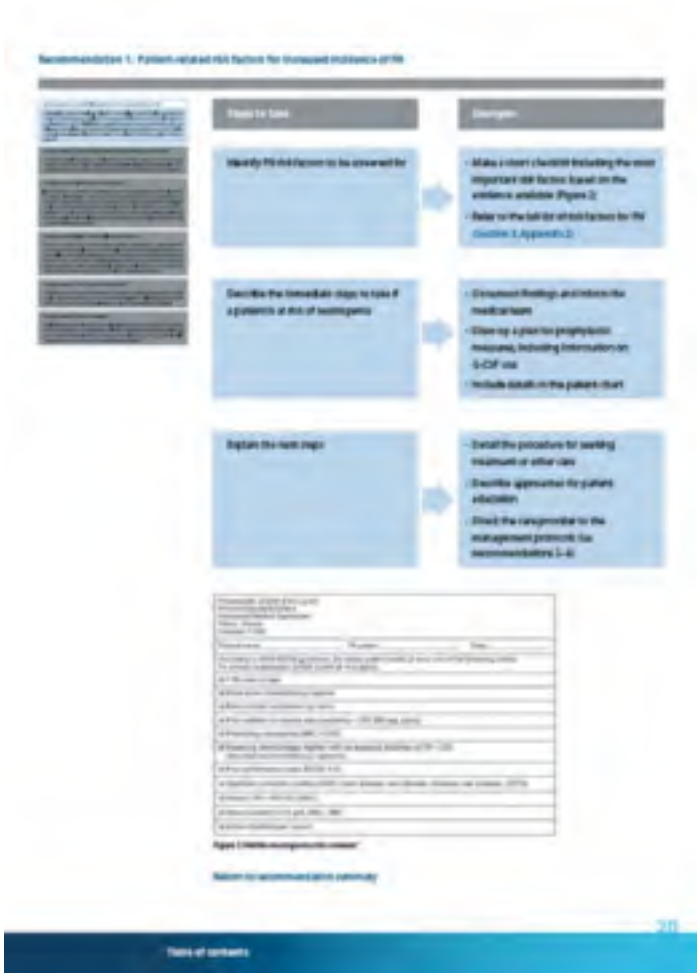
The toolkit has five sections. An introductory section explains clinical guidelines, their development and how they influence clinical practice. The next three sections are devoted to new guidelines (i.e., anaemia, neutropenia and oral mucositis), and contain explanations of the recommendations and a brief description of each condition, diagnosis and treatment. The final section provides an outline of the guideline implementation process, with advice to help you overcome some of the challenges of implementing guidelines in practice.
The Guidelines Implementation Toolkit is available in a flexible and interactive PDF format on the EONS website. To download the kit, simply click on the banner at:

http://www.cancerworld.org/CancerWorld/home.aspx?id_stato=1&id_sito=2

The documents can be reviewed on your computer screen – with interactive links that find the appropriate topic. The documents can be read on screen or printed for your convenience.

The development of the Guidelines Implementation Toolkit was made possible by an unrestricted educational grant from Amgen (Europe) GmbH





Letter from the president

A new working year has begun, a year that for EONS will mean some big and exiting challenges. For the past couple of years the board has put a considerable amount of energy into organisational issues in order to align the activities and financial circumstances of EONS. First of all I am very happy to announce that Jan Foubert has accepted the position of executive director for EONS commencing on April 1st 2007. This means that Jan will leave his duties as a board member at that time to take on this new position to support the president and board in their work.

The scientific nursing program for ECCO 14 in Barcelona was finalised last week and promises to be an interesting conference to learn, share experiences and socialise with colleagues. The program is available on our website and shortly announcements will be made for ECCO 15 in Berlin. On the topic of conferences I would like to remind you of the 1st interconference Breast Cancer Meeting in Sarajevo the 19-22 of April, the meeting has a nursing programme every afternoon that builds on the plenary lectures.

The board is now preparing the elections for president-elect and board of directors, the process will commence in February with the call for nominations sent out to full members and associated members. So it is time to start thinking about nominees, to be a board member promises hard work, fantastic opportunities, creates a network of colleagues in Europe and around the world, sincere dedication is needed!

This years advisory council meeting is planned as a one-day event the 12th of May and a new format for the meeting will be used. This is a very important meeting for the board of directors since this is were we really get to closely interact with members and get advice on what is needed to develop cancer nursing in Europe. I look forward to meeting you there.

In collaboration with European School of Oncology the first masterclass in oncology nursing was held in Malta at the end of February. I think this is a clear example of how EONS is developing the level of educational efforts of nurses in cancer care in Europe and hope that this is the first of many.

Greetings from a very cold and snowy Sweden
Yvonne Wengström

A New and Innovative Postgraduate Programme

at the University of Stirling

Sandra Menzies, Teaching Fellow

The Department of Nursing & Midwifery within the University of Stirling, inclusive of the Cancer Care Research Centre, joined with the Education Department at Strathcarron Hospice in 2005 in an academic collaboration to develop a new and innovative Postgraduate programme. This encapsulates the following distinct and specialist routes for taught Postgraduate MSc/PG Diploma in:

- Enhanced Cancer Care Practice
- Enhanced Palliative Practice
- Enhanced Care practice of Progressive Conditions

In addition, the partnership with clinical experts and other education providers within the University, (in particular Dementia Services and the Division of Academic Innovation and Continuing Education), has provided the opportunity to develop a programme that emphasises the student's ability for the transfer of new knowledge and skill from a theoretical base to practice. It is anticipated that this approach will encourage students to incorporate new learning into their practice both in the present, and for a life long ethos.

An adherence with the Scottish Credit and Qualification Framework (SCQF) Level 11 ensures each module has specified learning outcomes and associated credit that reflect the complexity and depth of knowledge equitable to Master's level study, or a Second Cycle Qualification in a European context. The transparency and integrity of each module to adhere to the SCQF enables the programme to be mapped to the European Credit Transfer and Accumulation System, and thus meets the principles of the Bologna Agreement. Since 2006 Scotland has committed to the Bologna process by reviewing the higher education framework in the context of a European framework. Consequently, students who engage in the Enhanced Care postgraduate programmes are assured of achieving academic qualification that have a currency across the spectrum of Europe.

An awareness of the educational, political and social 'drivers' within Scotland and in Europe has been integral in the planning of each module. Every module within each programme offers flexibility in the learning experience by encouraging student to explore what is meaningful to them. In essence, the intent of the learning experience is to provide a means of improving their knowledge and professional practice, and thereby patient outcomes.

The programme is primarily web based as this enables students from a range of geographical and work place settings to engage with the programme. There is active recruitment, and inclusion, of students from health and social care, pastoral care and voluntary sector workers who have an active role in the planning and delivery of care for people with, or affected by, cancer, palliative care needs or progressive conditions. As a means of ensuring a robust, challenging and supportive learning environment each module requires a maximum of three days on campus.

The next cohort of students will commence on September of 2007 and we are currently welcoming interested potential students to contact us for further information/application packs.
Contact: sandra.menzies@stir.ac.uk or mairead.cody@stir.a.uk
Department of Nursing and Midwifery
University of Stirling
Stirling
FK9 4LA

News from the Board

All Set for the 1st EONS / ESO Masterclass

Stephen O'Connor

As this issue goes to press, final preparations are underway for the 1st EONS / ESO masterclass to be held in Malta on the 24th February to the 2nd March 2007. Held in conjunction with our FECS partner, the European School of Oncology, the event will be chaired by EONS' Executive Director Jan Foubert and Professor Nora Kearney, Director of the Cancer Care Research Centre at the University of Stirling in Scotland.

The week-long Masterclass is designed to fully immerse participants in an intensive, clinically oriented learning environment with the support of a multi-professional team of international experts from no less than fourteen European countries. Lectures will focus on evidence based nursing interventions, nursing research and supportive care for cancer patients; and the event will provide 37.5 hours of continuing professional education which has been approved by EONS.

Successful applicants have already submitted a detailed curriculum vitae and research proposal for the Masterclass which will form the basis of research workshops led by EONS Executive Board Member Professor Davina Porock from the University of Nottingham (UK), EONS' President, Professor Yvonne Wengstrom from the Karolinska Institute (Sweden) and Dr Emma Ream from the Florence Nightingale School of Nursing and Midwifery, King's College London (UK). Other sessions will focus on developments in the management of several site specific cancers including breast, lung, head and neck, colorectal and haematological malignancies; and there will be a joint medical / nursing workshop looking at complexity and multidimensionality in palliative care which will be jointly led by EONS Executive Board Member Stephen O'Connor from Buckinghamshire Chilterns University College (UK) and Dr Florian Strasser from the Kantonsspital, St Gallen, Switzerland. Other activities will include sessions on evidence-based nursing care, symptom clusters, the expert patient and utilizing patient experiences to develop cancer services.

The 41 Masterclass participants have been drawn from a total of 17 countries and will be joined for some sessions by local observers from hospitals and schools of nursing on the island. More news and information about the event will be presented in future editions of EONS news, and details of the application process for next year's Masterclass will be released later this year; so if you are a Masters educated oncology nurse who is keen to engage in clinical research and the implementation of evidence-based nursing interventions in your clinical area you might want to start brushing up on your CV now!

EONS Endorsement for the European Cervical Cancer Association's STOP Campaign

EONS' Executive Board was pleased recently, to support the European Cervical Cancer Prevention Week which took place from the 21st to the 28th January 2007 and endorse a campaign by the European Cervical Cancer Association (ECCA) to raise awareness of cervical cancer and the means by which it can be prevented. The week's activities included an official launch of ECCA's Stop Cervical Cancer campaign at the European Parliament in Brussels on the 23rd of January which was opened with an address by the European Parliament's Commissioner for Health. During the meeting, he was presented with the society's STOP manifesto, developed with the European Parliament Cervical Cancer Interest Group and numerous stakeholder organisations from across the continent. This manifesto is being circulated to organisations across Europe for their endorsement, and EONS is proud to endorse this important campaign.

The vast majority of cervical cancers can be prevented, yet 50,000 women are diagnosed and 25,000 women die from the disease each year in Europe. Effective screening programmes can lead to early detection, treatment and improved outcomes in 80% of cases whilst vaccination against cervical cancer has the potential to reduce its incidence and make the elimination of cervical cancer in Europe a reality in future years. The manifesto calls for the provision of cervical screening programmes for every woman over 25 years of age and greater compliance with existing European guidelines guaranteeing the quality assurance of screening services.

The manifesto urges national governments to offer evidence-based cervical cancer screening and ensure that the benefits of screening are better publicised – especially amongst lower socio-economic groups where a lack of awareness, poor access and competing priorities mean that there is poor take-up of these services. It also calls for better after care for those whose results prove positive, and the sharing of information and expertise amongst member states so that best practice and evidence-based interventions can be made available to all those affected by cervical cancer within Europe.

EONS takes the campaign for recognition of cancer nursing to the European Parliament!

EONS recently took out a full page advertisement in issue 239 of the European Parliament's journal, The Parliament Magazine (12th January, 2007) calling on MEPs to press national governments for full recognition of cancer nursing as a speciality across the whole of Europe. The issue, which had a specific focus on health and cancer issues, contained a special editorial by the European Union's Health Commissioner Markos Kyprianou and comment from leading MEPs in each of the main political groups within the parliament who form part of the assembly's MEPs Against Cancer group. The magazine reaches 20,000 parliamentarians, civil servants, policy makers and analysts each week, and is widely available in Europe's political centre.

The advertisement also called for changes in socioeconomic policy to reduce health inequalities, encourage healthier lifestyles, implement better and more widespread screening programmes and deliver state of the art cancer treatments in order to reduce the continent's huge toll of avoidable cancer deaths and improve the life-chances of those who subsequently go on to develop the disease. The central role played by nurses in each of these crucial areas was highlighted, and calls made for national governments to recognise the full potential and training needs of cancer nurses as Europe's 'secret weapon' in the war against cancer.

EONS member hosts first conference for Lead Cancer Nurses

EONS member, the United Kingdom Oncology Nursing Society (UKONS) recently held its first conference for Lead Cancer Nurses on November 10th 2006. The event, based upon the theme, Authority, Influence and Power, was a great success, and dealt with the challenges of being a Lead Cancer Nurse; an important role within the UK's National Health Service since these senior nurses are responsible for the development of strategic cancer nursing services and the implementation of government policy on cancer nursing in each of the hospitals providing cancer care.

The day's focus on the role of Lead Cancer Nurses provided the opportunity for papers to be pitched at the more advanced, strategic level, and included discussion of health policy directives and consideration of how to promote cancer nursing within the broader provision of clinical cancer services for the benefit of patients and carers alike.

Invitation to the next EONS Advisory Council Meeting
Members of national oncology nursing societies affiliated with EONS are cordially invited, together with individual EONS members, to attend the next meeting of the EONS Advisory Council in Brussels on the 12th May 2007 as observers. Further details about the agenda and location of the meeting, to be held from 10.00 hrs to 17.00 hrs in Brussels, will be available on the EONS website at www.cancerworld.org/eons shortly, or by email from the EONS secretariat at eons@village.uunet.be

EONS regrets that is unable to meet the travel or accommodation costs of members attending the meeting as observers, but would warmly encourage as many individuals as possible to observe, participate and network at this important event in the EONS calendar which will give you more insight into the workings of the society and opportunity to meet members of EONS' Executive Board.

New EONS Associate Members
The European Oncology Nursing Society would like to welcome the Faculty of Health, Sport and Science from the University of Glamorgan (UK), and the Department of Nursing and Midwifery at the University of Stirling (UK) as new associate members of the society. We would like to extend a warm welcome the management and staff in each of these highly regarded academic institutions and trust that they will enjoy the benefits of being part of Europe's largest cancer nursing society. Details about EONS associate membership can be obtained from the society's secretariat at the above email address.

Changes to the Membership of National Oncology Society Boards
Ingrid Lotsberg Noras has succeeded Eli Kjoren as the new President of the Norwegian Society of Nurses in Cancer Care and Mr Alfonso Alvarez has succeeded Mrs Tarsila Ferro as President of the Sociedad Espanola de Enfermeria Oncologica (SEEO). Marie Lavin will be the new President of the Irish Association for Nurses in Oncology (IANO) taking over from Mrs Kay Leonard, and their new representative on EONS' Advisory Council will be Mrs Louise Maher who takes over this role from Paula O' Reilly.

Mr Denis Mlakar Mastnak has succeeded Mrs Maria Logonder as President of the Slovenian Oncology Nursing Society and will also represent the society for the first time at the EONS Advisory Council where he succeeds Mrs Brigitta Skela Savic as its Advisory Council representative.

We would like to welcome each of these new post-holders on behalf of EONS Executive Board and look forward to working with them in the coming months whilst saying good bye and extending our very best wishes to former Presidents and Advisory Council representatives who have made such a string contribution to EONS work and activities in the past.

Images of Hope

'Spring is like a cure from a long-term illness.'

Born again

As in previous years, ESMO (European Society for Medical Oncology), EONS (European Oncology Nurses Society), FECS (Federation of European Cancer Societies), ISNCC (International Society of Nurses in Cancer Care), MASCC (Multinational Association of Supportive Care in Cancer), SIOG (International Society of Geriatric Oncology) and SIOP (International Society of Pediatric Oncology) invited nominations for the second Images of Hope© Photography Award.
Pictures are worth a thousand words and have no language or age barriers. We health care professionals are inspired by the art and stories of individuals who have fought cancer and have come through their experience with a new vision and purpose. This can be dramatically captured through the lens of a camera creating a powerful and emotional art form, which is the inspiration behind the Images of Hope photography award.
EONS is proud to announce that Karolina Kocourkova, from the Czech Republic and whose aunt died from lymphoma, was honored as the 2006 Images of Hope award winner for her sequence of three photographs titled 'Born Again' which features the captivating images of a plant covered in snow. As the snow melts, the plant emerges as a beautiful, delicate spring flower.

Ms. Kocourkova described her feelings behind the image: "We put all our hope into new beginnings. We hope that a new day, a new year, a new relationship will be better. For me a symbol of 'new' is spring. Spring is like a cure from a long-term illness, a new life; and in our children is our continuing, our immortality and our hope!"

Psychosocial Aspects of Cancer Care

The Role of the International Psycho-Oncology Society (IPOS)

Luigi Grassi, Professor of Psychiatry, University of Ferrara, President, International Psycho-Oncology Society (IPOS)

Background and History

The psychosocial dimensions of cancer have been the focus of research, health care and training for the last 35 years. As the number of psycho-oncology programs increase all over the world, the current curricula of institutions of higher learning have begun to include the psychosocial and psychiatric issues of cancer as mandatory topics. With this background, the International Psycho-Oncology Society (IPOS) was created in 1984 to serve as an international, multidisciplinary body and forum for dissemination of information about clinical, educational and research issues that relate to the subspecialty of psycho-oncology, including psychiatric, psychological, social, behavioural, spiritual and ethical aspects.

Aims and Goals

The aims of IPOS are to encourage psychosocial principles and a humanistic approach in cancer care, to stimulate research in this area, and to develop a training curriculum to address these concerns. IPOS encourages the formation of national organizations to further this mission. The mission of IPOS is that all cancer patients and their families throughout the world receive optimal psychosocial care at all stages of disease and survivorship. The vision of IPOS is to become the pre-eminent international resource for the dissemination of information and development of interventions that reduce cancers related to lifestyle and behaviours.

Organizational Structure

IPOS is organized to function with a board of directors which includes a president, a vice-president, a secretary, a treasurer, the past-president and the president of its world congress, plus four other directors. Invited directors, with no voting privileges, are also part of the board.

Three types of memberships exist:

- *Active membership.* Physicians, epidemiologists, psychologists, nurses, social workers and social scientists as well as other professionals at the Masters' or Doctoral level and individuals with professional equivalence who have been actively engaged in the research or clinical aspects of psycho-oncology.
- *Associate membership.* Individuals that demonstrates an interest in psycho-oncology.
- *Member-in-training.* Individuals in training to become physicians, epidemiologists, psychologists, nurses, social workers and social scientists are eligible for this membership category provided they are considered qualified by the Membership Committee.

Projects, Initiatives and Activities

IPOS has developed a number of initiatives and projects which include:

- Core Curriculum in Psycho-Oncology. In cooperation with the European School of Oncology (ESO), IPOS has launched a Multilingual Core Curriculum in Psychosocial Aspects of Cancer Care which is available in six languages (French, English, German, Hungarian, Italian, Spanish) at the IPOS (www.ipos-society.org) and ESO websites (www.cancerworld.org). Five lectures are available at the moment (Communication Skills in Cancer Care; Distress Management; Depression and Depressive Disorders in Cancer Patients; Anxiety and Adjustment Disorders in Cancer Patients; Psychosocial Assessment in Cancer Patients) and six more are in progress to complete the core-curriculum.
- IPOS Press. IPOS founded the IPOS Press with the aim of preparing, publishing and disseminating educational material. In cooperation with the American Society of Psycho-Oncology, IPOS Press has published the Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. The handbook is distributed free of charge to health care professionals from developing countries. A second pocket manual on Palliative Care is in press. Further educational materials (e.g. Advances in Psycho-Oncology Research and Practice Series, CD format educational materials) are under development.
- World Congress. IPOS organizes a world congress on an annual basis. The last congress was held in October 2006. The final report of the congress, data and figures, curiosities and didactic and video material are available at www.ipos2006.it.

Membership Benefits

Membership is open to individuals with a diversity of clinical and research backgrounds, including physicians, psychologists, nurses, social workers, rehabilitation specialists, and educators, among others. Membership benefits include:

- Opportunity to subscribe, for reduced members-only rates, to the journal Psycho-Oncology (12 annual issues), the Journal of Psychosocial Oncology (4 annual issues), and Palliative and Supportive Care (4 annual issues);
- Access to the members-only website, including online membership directory for up-to-date member contact information and participation in online e-mail discussion forum (list server);
- Free membership in the Psycho-Oncology Section of the World Psychiatric Association (see www.wpanet.org);
- Participation in cross-cultural research initiatives and surveys regarding clinical practice and research, and access to a multilingual psychosocial oncology curriculum;
- Reduced rates for conferences and symposia supported by IPOS and those with reciprocity with IPOS (under development).

Affiliation and Collaboration with other Societies

IPOS has more than fifty psycho-oncology and other societies throughout the world affiliated to it and enjoys partnerships with a number of scientific societies and organizations, including EONS, with the specific aim of increasing cooperation between different health care professionals in relation to psychosocial aspects of

The new President of IPOS, Luigi Grassi, a delegate, Jimmie Holland, and Aruna Tole, who received the Award of Distinction for her work in India, at the IPOS 8th World Congress, Vencie, October 2006

cancer. IPOS is cooperating with the International Association for Hospice and Palliative Care on a request by the World Health Organisation (WHO) to update the list of Essential Medicines in Palliative Care. The list will be taken into consideration by countries that are developing national palliative care strategies for cancer, AIDS, chronic illness, geriatrics and paediatrics.

Future Directions

The first important future goal of IPOS is to work in close cooperation with WHO to implement psychosocial programs which are linked to WHO initiatives in cancer (e.g. screening and early detection programs, education in developing countries).
A further objective is to maintain the status of an international society and, at the same time, to become a federation of psycho-oncology societies world-wide.
IPOS is committed to working with its partners to organise a number of programmes which include IPOS World congress and other initiatives:

- 9th IPOS World Congress of Psycho-Oncology (London, September, 16-20, 2007);
- 10th IPOS World Congress of Psycho-Oncology (Madrid, June 9-13, 2008);
- Collaboration with EONS at the ECCO meeting, Barcelona, September, 23-27, 2007;
- Collaboration at the European Congress of Consultation Liaison Psychiatry, Milan, September 27-29, 2007;
- Collaboration at the World Psychiatric Association Congress, Melbourne, November 28-December 2, 2007;
- Collaboration at the UICC Congress, Geneva, August 27-31 2008;
- Collaboration with the European Society of Medical Oncology, Stockholm, September, 12-19, 2008.

More detailed information about IPOS activities and membership is available at the IPOS website www.ipos-society.org.

Being There

Nursing Interventions at the End of Life

Davina Porock, University of Nottingham, Faculty of Medicine and Health Sciences, Nottingham, United Kingdom

The role of the nurse in the care of dying people is probably the longest established role in the health professions. Why is it then, when you ask a nurse what she/he is doing, that a clear, description or definition is so difficult to articulate? Finding words to describe caring, the human response to suffering and the emotional labour that is involved in providing end of life care is difficult. The nursing literature is, however, gradually giving voice to the exceptional experience of providing nursing care to the dying and their families.

In practice, nursing is often known as the profession that holds the contributing health disciplines together, coordinating and communicating care between health professionals and supporting other health professionals, rather than for its independent interventions. This view of nursing is so strong that when nurses are observed they are seen only to be doing the work of the doctor or the pharmacist or the physiotherapist or the psychologist.

Occasionally you will see a nurse apparently just sitting and talking to a patient and when you approach, the conversation automatically stops. Jocelyn Lawler in her book "Behind the Screens" (1) comments on this phenomenon saying that one could conclude that what the nurse and patient are talking about must be trivial because as soon as something or someone more important comes along, the conversation stops. Lawler explains that in fact the content of the conversation is therapeutic and therefore private. Even the act of easy conversation or "chatting" with a patient gives a patient their personhood – they are being treated as a human being worth talking to about ordinary things. This demonstrates that the patient, as an ordinary person, matters even to busy health professionals. It is easy to assume that nurses mustn't be very busy if they have time to just talk. But that talk is providing essential information for understanding the illness experience from the patient's perspective and to preserve personal integrity.

Then there is hand-holding. This is something that nurses do and is an important intervention. Hand-holding is a term used to try and explain the inexplicable parts of the emotional labour of caring, particularly for the dying. There can be, in fact, a lot to this very ordinary action. Nurses have an incredible level of permission in all societies to break the usual rules of personal space between relative strangers, particularly the rules between a professional and a client. The nurse has permission to touch patients, which includes hugging and cradling patients in distress, in a way that is not often available to other health professionals. There is an intimacy in the nurse-patient relationship that is born out of the nurse making him- or her-self available to be therapeutic.

Palliative care is defined by the World Health Organisation (WHO) as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care involves the active total care of patients whose disease may not respond to curative treatment (World Health Organisation 2006).

This definition seems to sum up nursing and many palliative care nurses feel that the specialty offers the opportunity for real nursing. However, we seem to have lost the identification with nursing as palliative care and instead we see nursing as overlapping or even taking over the work of other health professions. Some people think that apart from doing the tasks that are considered too menial for other health professionals to perform, that nurses are not really needed.

At its heart, modern nursing sees the patient as a whole person with a health problem (rather than primarily as a disease requiring treatment). The patient is a person who lives in a family, is part of a community, is someone who works and is socially engaged. This view of the patient is fundamentally different than that of medicine. Nursing work can be defined succinctly as the "diagnosis and treatment of the human response to actual or potential health problems" (American Nurses Association, 1980). The human response to health problems is often notably biological, but is also psychological, social and spiritual/existential. Modern nursing is concerned with the integration of all these dimensions of the human condition and, therefore, in maintaining the integrity of the individual and family during times of illness.

These core values of nursing are never more clearly expressed than

when caring for someone who is dying. When the possibilities of the 'ologies' and sciences have been exhausted and, in terms of prolonging life, or changing behaviour when "nothing more can be done", the ongoing care of the patient and support of the family is the work of nursing. The care of people who are dying is very different to standard health care. The primary goals of health care are the prolongation of life and the maintenance of physical and cognitive function. Comfort is often a last priority in achieving these goals, but when death is imminent, comfort becomes the primary and only goal of care (2). Over the last four decades, starting with the work of Dame Cicely Saunders who founded St Christopher's hospice, greater attention has been placed on the care of the dying and in de-medicalising the experience of dying; placing dying which is a natural event with social rather than just health implications, back in the context of the family.

I am going to focus on the concept of "being there" developed by nurse scholars. It is also called nursing presence. "Being there" is considered here as an intervention based on the fundamentals of nursing philosophy. Elements of "being there" include creating a healing environment, communicating, promoting trust, touching, listening. Providing physical care and symptom management are expressions of "being there" which are familiar to other health professionals but they do not represent the total range of therapeutic intervention that nursing brings. "Being there" requires the nurse to be present and available to build a caring relationship with the patient and family. It takes time to provide this high level of intensive care.

In a study of adolescents with cancer, Woodgate revealed what these patients valued from nurses and their families (3). The consequence of "being there" was described as helping the adolescent feel connected and a part of the world. As the participants stated: "they were there for me".

Pitorak described bereaved families responses to what had been helpful when their loved one was dying (4). Nursing presence was discussed in terms of nurses' actions and attributes:
- Ways of being
- Ways of doing
- Ways of knowing.

This isn't rocket science. But without it, human suffering is left unattended. Both technical skill and understanding the process of dying are essential to providing care at the end of life. The nursing interventions may be simple, but the ability to anticipate needs and provide cogent helpful explanations to the patient and family of the unfamiliar dying process has a particular knowledge base that is honed and improved with experience.

Comfort, bringing physical, psychological, social and spiritual comfort, is a critical element of nursing care and is probably a well-recognized and desired outcome. But it cannot be achieved without the true presence of the nurse. The nurse does not need any special equipment to provide comfort; just friendliness, person-focused care and explanations.

When facing an illness (whether curable or not) patients face potential or actual suffering and will ask: Why is this happening to me and why is it happening right now? Fredriksson suggested two ways to think about those questions (5):

- Firstly, as a question of causation: What is the cause of the suffering? What is the disease or malfunction?
- Secondly, as a question of meaning: What is the meaning of this suffering to me as a human?

The patient needs answers to both. But often the second question is more difficult to address. The patient needs a partner willing to listen and be engaged in the struggle for meaning. This can be achieved through the caring relationship where the motive is to alleviate suffering

Fredriksson deals with these issues in a synthesis of the literature on presence, touch and listening suggesting that there is a difference between just being there (in the room with a patient) and "being with" a patient (5). He makes this differentiation through the ideas of just making contact and making a real connection with the person. Communication is central to making a connection, to being present with a patient (and family) in order to bring comfort during suffering and distress. How we speak and act with our patients is one of the most important nursing interventions at the end of life and indeed at any time that nursing care is needed.

References

1. Lawler, J. (1991). Behind the Screens. Churchill Livingstone, NY City.
2. Gillick, M., Berkman, S. & Cullen, L. (1999). A patient-centered approach to advance medical planning in the nursing home. Journal of the American Geriatric Society 47(2), 227-230.
3. Woodgate, R.L. (2006). The importance of being there: perspectives of social support by adolescents with cancer. Journal of Pediatric Oncology Nursing, 23(3), 122-134.
4. Pitorak, E.F. (2003). Care at the Time of Death. How nurses can make the last hours of life a richer, more comfortable experience. American Journal of Nursing,. 103(7), 42-52.
5. Fredriksson, L. (1999). Modes of relating in a caring conversation: a research synthesis on presence, touch and listening Journal of Advanced Nursing, 30(5), 1167-1176.

Mundipharma International

in Partnership with EONS in 2007

This year EONS will form a new partnership with Mundipharma International to work together on some exciting projects –the first being the European Pain in Cancer survey (EPIC).
Mundipharma is one of the Purdue/Mundipharma/Napp independent associated companies and is dedicated to bringing to patients with severe and debilitating diseases the benefits of novel treatment options in fields such as severe pain, haemato-oncology and respiratory disease.
In 2004 Mundipharma undertook the largest ever survey which set out to explore the prevalence, severity and treatment of chronic pain. The survey undertook interviews with over 46,000 people making it Europe's largest survey of chronic pain sufferers.
Now with the support of EONS and other partners the goal of EPIC will be to identify the impact of pain on cancer patients and the gaps in the provision of effective pain management across Europe.
Results from the study will be used to raise awareness of the need for and importance of effective pain management for cancer patients.
EPIC results are expected to be released in June 2007.

Monday 24 September 2007

09:00 – 09:30 **Opening Speeches**
Chair: J. Smyth (United Kingdom), A. Eggermont (The Netherlands), Y. Wengström (Sweden)

09:30 – 11:30 **Opening Session : Cancer in Europe - sharing the responsibilities (***)**
Chair: Y. Wengström(Sweden)
Introduction
Speaker: Y. Wengström (Sweden)
Nursing on the political agenda
Speaker: P. Rieger (USA)
CARE : managing late and long-term sequelae of cancer and cancer treatment
Speaker: C. Curtiss (USA)
Research : developing collaboration in cancer nursing research in Europe
Speaker: C. Tishelman (Sweden)

11:30 – 12:15 **Special Lecture (***)**
Is patient's information empowering?
Speaker: K. Pollock (United Kingdom)

11:30 – 12:30 **Discussion Forum**
Wound management - do we do a good job?
Moderator: P. Grocott (United Kingdom)
Expert: B. Lund-Nielsen (Denmark)
Expert: S. Faithfull (United Kingdom)
Expert: P. Grocott (United Kingdom)

13:45 – 15:45 **Joint Symposium : EONS/Spanish Oncology Nursing Society (***)**
Developing the advancing cancer nursing practices
Chair: M.L. Munoz (Spain)
Specialist nursing in Europe – issues and concerns
Speaker: W. De Graaf (The Netherlands)
Challenges and current situation in cancer nursing
Speaker: T. Ferro (Spain)
Educational changes on cancer nursing
Speaker: A. Zabalegui (Spain)
The role of the specialist nurse in the team
Speaker: P. Viklund (Sweden)

13:45 – 15:45 **Workshop**
Telling the truth or not - information giving problems in cancer care
Coordinator: L. Hallila (Finland)

(***) Simultaneous Translation

13:45 – 15:45 **Proffered papers**

13:45 – 15:45 **Meet the Manager**
Commercialism in the health sector: pros and cons of bringing private finance into cancer services
Moderator: S. O'Connor (United Kingdom)
Expert: W. Knibb (United Kingdom)
Expert: E. Eke (Hungary)

16:00 – 17:30 **Proffered papers (***)**

16:00 – 17:30 **Joint Symposium : EONS/ISNCC/ONS:**
Hereditary cancer risk assessment: what is missing?
Chair: S. Faithfull (United Kingdom)
Cancer risk assessment in gastrointestinal malignancy: a challenge?
Speaker: L. Lemmens (Belgium)
Psychosocial Issues in Screening for Hereditary Cancers: implications for practice
Speaker: M. Fitch (Canada)
Comprehensive cancer risk assessment and management: the essence of oncology nursing
Speaker: A. Strauss Tranin (USA)

16:00 – 17:30 **Spanish Workshop**
How to evaluate the sensitive indicators of the cancer nursing practice
Coordinator: E. Corrales (Spain)

Tuesday 25 September 2007

08:15 – 09:00 **Teaching Lecture**
Moving forward with evidence base practice
Speaker: B. McCormack (United Kingdom)

09:15 – 11:15 **Proffered papers (***)**

09:15 – 11:15 **Joint Symposium : EONS/ECPC :**
Meeting cancer patients' informational needs: rising to the challenge
Chair: J. Foubert (Belgium)
Chair: L. Faulds Wood (United Kingdom)
Do we know what patients need?
Speaker: J. Foubert (Belgium)
Do we know what patients need?
Speaker: L. Faulds Wood (United Kingdom)
Access to information - the reality for European patients today
Speaker: L. Denis (Belgium)
Meeting patients' informational needs: a practical example
Speaker: A. Mank (The Netherlands)

09:15 – 11:15 **Podium Session**
Future directions in prevention and early detection in prostate, lung and colon cancer
Chair: S. Kav (Turkey)
Future directions in prevention and early detection of prostate cancer
Speaker: C.N. Sternberg (Italy)
Future directions in prevention and early detection of lung cancer
Speaker: T. Le Chevalier (France)
Future directions in prevention and early detection of colon cancer
Speaker: P.G. Johnston (N. Ireland)

09:15 – 11:15 **Meet the Manager**
Choice, equity and access in European health care
Moderator: S. Faithfull (United Kingdom)
Expert: P. Riemer-Hommel (Germany)
Expert: W. Knibb (United Kingdom)

11:30 – 12:15 **Special Session (***)**
Poster Highlights
Chair: S. O'Connor (United Kingdom)

11:30 – 13:00 **Spanish Workshop**
Nursing management on side effects in the new targeted therapies
Coordinator: J. San Francisco (Spain)
Coordinator: M. Martinez Munoz (Spain)

13:45 – 15:45 **Proffered papers (***)**

13:45 – 15:45 **Joint Symposium EONS/EBMT :**
Nursing implications of innovative treatment
Chair: T. Suominen (Finland)
Chair: M. Fliedner (Switzerland)
Oral oncology agents
Speaker: N. Borras (Spain)
Symptom occurrence, intensity and distress in patients during conditioning and early
post-transplant period - implications for nursing
Speaker: J. Larsen (Sweden)
The changing face of GvHD
Speaker: L. Watson (United Kingdom)
Innovations in prevention and treatment of oral mucositis: where to go from here?
Speaker: M. Fliedner (Switzerland)

(***) Simultaneous Translation

13:45 – 15:45 **Discussion Forum**
Psychosexual assessment - do we do a good job?
Moderator: I. White (United Kingdom)
Expert: A.S. Melo (Brazil)
Expert: D. Kelly (United Kingdom)

16:00 – 16:30 **Award (***)**
Excellence in patient education award
Chair: T. Suominen (Finland)

16:30 – 17:00 **Award (***)**
TITAN award : best dissemination award
Chair: J. Foubert (Belgium)

Wednesday 26 September 2007

08:15 – 09:00 **Teaching Lecture**
Your patient completes treatment - what comes next?
Speaker: K. Cox (United Kingdom)

09:15 – 11:15 **Proffered papers (***)**

09:15 - 11:15 **Joint Symposium EONS/SIOP**
Adult survivors of childhood cancers
Chair: Y. Wengstr (Sweden)
Chair: F. Gibson (United Kingdom)
Meeting the ongoing care and support needs of adult survivors of childhood cancer: how might we do it?
Speaker: Anthony Penn (United Kingdom)
The cure from childhood cancer: is it still a mystery?
Speaker: M. Jankovic (Italy)
Topic to be announced
Speaker: L. Wettergren (Sweden)
Post traumatic stress symptoms in adult cancer survivors of childhood cancer - implications for care
Speaker: N. Langeveld (The Netherlands)

09:15 – 10:00 **Teaching Lecture**
Developing clinical guidelines in IV access
Coordinator: E. Johansson (Sweden)

11:30 – 12:15 **Award (***)**
Distinguished Merit Award
Chair: Y. Wengström (Sweden)

13:45 – 15:45 **Proffered papers (***)**
13:45 – 15:45 **oint Symposium EONS/ESO**
The role of breast cancer nurse
Chair: Y. Wengström (Sweden)
Chair: A. Costa (Italy)
The role of the breast care nurse
Speaker: S. Claasen (The Netherlands)
A nurse is a nurse? A systematic review of the effectiveness of specialized nursing in breast cancer.
Speaker: M. Eicher (Germany)
European survey of breast care nurses role
Speaker: Y. Wengström (Sweden)
Accreditation of breast care clinics in Europe
Speaker: A. Costa (Italy)

13:45 – 15:45 **Meet the Manager**
Implementing new technology in health care
Moderator: S. Kav (Turkey)
Expert: P. Wilson (Belgium)
Expert: T. Ferro (Spain)

16:00 – 17:30 **Podium Session**
Managing new treatments and side effects in innovative approaches
Chair: I. Kadmon (Israel)
Hand foot syndrome
Speaker: A. Young (United Kingdom)
Bowel problems
Speaker: A. Cantelo (United Kingdom)
Mucositis
Speaker: R. Stone (United Kingdom)

16:00 – 17:30 **Workshop**
From evidence to research utilization
Coordinator: L. Wallin (Sweden)

16:00 – 17:30 **Debate**
Does education meet the needs of the workforce?
Moderator: S. Faithfull (United Kingdom)
Speaker: A. Topping (United Kingdom)
Speaker: C. Arce (Spain)

(***) Simultaneous Translation

Thursday 27 September 2007

08:00 – 08:45 **Teaching Lecture**
Complementary therapies
Current issues in the delivery of complementary therapies in cancer care-policy, perceptions and expectations: a European overview
Speaker: D. Roberts (United Kingdom)

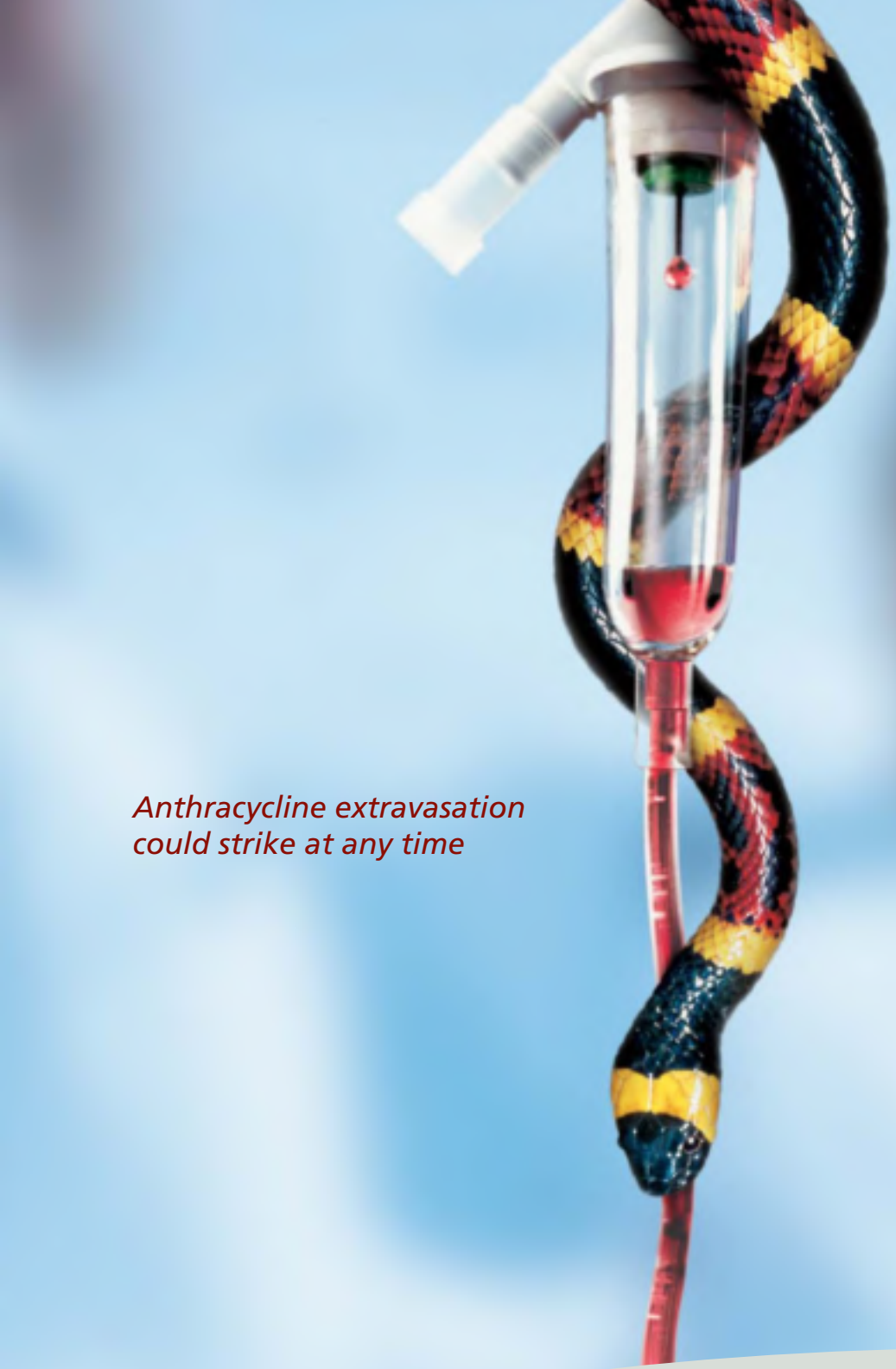
09:00 – 11:00 **Proffered papers (***)**
09:00 – 11:00 **Joint Symposium EONS/IPOS :**
Psychosocial care across the cancer continuum
Chair: S. Faithfull (United Kingdom)
Chair: F. Gil (Spain)
Patient needs and psychosocial interventions in oncology
Speaker: M. Die-Trill (Spain)
Good communications skills as psychosocial care.
Speaker: L. Travado (Portugal)
Uncertainty, optimism and psychological distress: conceptual and communication issues
Speaker: D. Razavi (Belgium)
Clinical practice guidelines for the psychosocial care of adults with cancer
Speaker: S. Aranda (Australia)

09:00 – 11:00 **Discussion Forum**
Respiratory problems: are they well managed?
Moderator: D. Porock (United Kingdom)
Expert: S. Moore (United Kingdom)
Expert: J. Hately (United Kingdom)

09:00 – 11:00 **Meet the Manager**
Nurse migration
Moderator: P. Fernandez-Ortega (Spain)
Expert: D. Cullus (Belgium)
Expert: H. Allan (United Kingdom)
Expert: M. Kingma (Switzerland)

11:15 – 12:15 **Special Lecture (***)**
Innovative methods to support patients' management in health problems
Speaker: M. Välimäki (Finland)

12:30 – 13:45 **ECCO 14 take home messages (***)**



Anthracycline extravasation could strike at any time

Savene™ – Brief prescribing information
(based on the UK Summary of Product Characteristics SPC)
Please refer to the SPC for full prescribing information.
Each Savene™ box contains 10 vials of Savene™ (dexrazoxane) Powder (10 x 500 mg each) and 3 bags of SaveneTM Diluent (3 x 500 ml each) for infusion. **Indications:** Treatment of anthracycline extravasation. **Dosage and administration:** Administration of Savene™ should begin as soon as possible and within 6 hours after the accident. Savene™ should be given as an intravenous infusion once daily for 3 consecutive days according to body surface area: day one, 1000 mg/m2; day two, 1000 mg/m2; day three, 500 mg/m2. For patients with a body surface area of more than 2 m2 the single dose should not exceed 2000 mg. Cooling procedures such as ice packs should have been removed from the affected area at least 15 min before administration. Before infusion, Savene™ Powder must be reconstituted with sterile water before further dilution in Savene™ Diluent. Savene™ is not recommended in children and patients with renal and hepatic impairment. Safety and efficacy have not been evaluated in the elderly. **Contraindications:** Hypersensitivity to the active substance or to any of the excipients, women of childbearing potential not using contraceptive measures, lactation or concomitant vaccination with yellow fever vaccine. Precautions: Local examination should be performed on a regular basis after treatment until resolution and haematological monitoring should be undertaken regularly. Savene™ should be administered only under the supervision of a physician experienced in the use of cancer chemotherapeutic agents. Routine liver function tests are recommended before each administration of Savene™ in patients with known liver function disorders. Patients with renal dysfunction should be monitored for signs of haematological toxicity. Men are advised not to father a child during and up to 3 months after treatment. Women of childbearing potential must use contraceptive measures during treatment. This product is generally not recommended in combination with live attenuated vaccines or with phenytoin. Dimethyl sulfoxide (DMSO) should not be used in patients who are administered Savene™. As the Savene™ diluent contains potassium (98 mg/500 ml) the plasma potassium level of the patient must be closely monitored in patients at risk of hyperkalaemia. It also contains sodium (1.61 g/500 ml) which may be harmful to patients on a low sodium diet. **Interactions:** Interactions common to all cytotoxics, which may also react with oral anticoagulants. Concomitant use of immunosuppressives such as cyclosporine and tacrolimus receive extra consideration due to excessive immunosuppression. **Pregnancy and lactation:** Savene™ should not be administered to pregnant women unless clearly necessary. Women of childbearing potential should use contraceptive measures during treatment. Mothers should discontinue nursing during Savene™ therapy. **Side-effects:** Very common: nausea, injection site pain, postoperative infection. Common: vomiting, diarrhoea, stomatitis, dry mouth, pyrexia, injection site phlebitis, injection site erythema, fatigue, injection site induration, injection site swelling, peripheral oedema, somnolence, infection, neutropenic infection, wound complication, weight decrease, decreased appetite, myalgia, dizziness, sensory loss, syncope, tremor, vaginal haemorrhage, dyspnoea, pneumonia, alopecia, pruritus, phlebitis, thrombophlebitis superficial, limb venous thrombosis. All adverse reactions have been rapidly reversible. More rarely increased concentrations of liver enzymes (ALT/AST) have been reported. Refer to the SPC for additional information. **MA:** EU/1/06/350/001. Date of Preparation: January 2007. TopoTarget A/S Fruebjergvej 3, DK

TOPOTARGET
Practical Answers For Cancer

Be prepared

Anthracycline chemotherapy has long been a cornerstone of cancer therapy. However, it carries a relatively rare but potentially devastating risk: extravasation.

Anthracycline extravasation can result in severe injuries including ulceration, necrosis, slow-healing lesions, serious joint damage and may not only require surgical intervention, but also long-term suspension of cancer chemotherapy[1].

Now there is an Antidote* - Savene™ from TopoTarget.

Savene™ has shown a clinical success rate of > 98% in biopsy proven anthracycline extravasation. It not only avoids the need for surgery but also allows to continue chemotherapy without interruption[2].

Savene™ is available as an 'on-site-ready-to-use' emergency kit – allowing you to always prevent an accident from becoming an emergency.

www.savene.com

savene™
dexrazoxane

The Antidote
to anthracycline extravasation

* Effective against doxorubicin, epirubicin, daunorubicin, idarubicin

1. Mouridsen H.T. et al. Treatment of anthracycline extravasation with Savene (dexrazoxane): results from two prospective clinical multicentre studies. Ann Oncol. 2007; Volume 18 Issue 3:546 - 550. 2. Mouridsen HT, et al. Treatment of anthracycline extravasation with Savene (dexrazoxane). Results from two prospective clinical multicenter studies. ESMO late-breaking Abstract Session: 2 Oct 2006.

Psychoeducational Interventions

Rationale, Structure, and Nursing-Sensitive Patient Outcomes

Nancy W. Fawzy, RN, DNSc, Assistant Clinical Professor, UCLA School of Nursing

The course of cancer can be divided into three phases. The first of these is when a patient receives the initial diagnosis and goes into active treatment. The patient then enters a period of survivorship assuming that this treatment results in cure or remission. If initial or subsequent treatment is not successful the final phase of cancer shifts to focus on end of life issues. This paper will present psychoeducational interventions that have been found useful during the first phase of cancer, diagnosis and initial treatment. A rationale for the use of such interventions, their basic structure, and nursing sensitive outcomes will be provided.

Scope of the Problem

The United States' National Comprehensive Cancer Network (NCCN) has defined the psychosocial scope of cancer problems as distress. "Distress is a multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling such as depression, anxiety, panic, social isolation, and existential and spiritual crisis." It was decided that distress is more acceptable and less stigmatizing than psychiatric, psychosocial, or emotional. Distress sounds more normal and is less embarrassing. In addition, it can be defined and measured by self report. The Distress Thermometer is a simple 10-point scale similar to the pain scale and is a useful clinical tool. It is accompanied by a problem list that helps to identify the specific areas causing distress. (Access the tool at: http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf).

Rationale for Psychoeducational Interventions

Possible manifestations of distress at the time of diagnosis include denial of the disease and refusal of medical care, a prolonged search for other treatment options, giving up and a fatalistic refusal of treatment, acute grief, anger and anxiety, and depression. General manifestations of distress during treatment include anxiety, fear, sadness, depression, loss of control, helplessness, hopelessness, anger, and guilt. There may be additional manifestations of distress that are relative to the type of treatment employed. Patients facing surgery may postpone the procedure or seek non-surgical alternatives. There can be grief reactions to changes in body image, and postoperative reactive depression. Patients scheduled for radiotherapy may experience fear of the machinery, fear of abandonment, and psychotic-like delusions and hallucinations. Chemotherapy can cause fear of side-effects including body image changes, isolation, or drug-induced organic brain syndrome (e.g., psychosis).

Distress can be managed very effectively for most patients with cancer through a combination of psychoeducational interventions. Many of these interventions can be delivered time- and cost-effectively by nurses who are in the forefront of oncology care.

Structure of Psychoeducational Interventions

A wealth of research has supported the evidence base for psychoeducational interventions (Fawzy et al., 1990, 1993, 1994, 1995; Fawzy, N., 1995). This research has elucidated four primary components of psychoeducational interventions: 1) health education, 2) stress management. 3) coping skills, and 4) psychological support.

Health education

The goals of health education are to reduce the sense of helplessness and inadequacy due to uncertainty and lack of knowledge and then to replace feelings of helplessness with a sense of mastery and control.

Stress management

The goals of stress reduction are to help patients cope more effectively with the overall emotional impact of cancer, enhance compliance with medical regimens, and assist in the management of treatment side effects (e.g., pain, nausea, vomiting, and sleep disturbance). Stress management begins with an awareness of stress. This requires the identification of personal sources of stress followed by identification of personal reactions to stress.

There are three effective stress management techniques. First, is the use of problem solving to eliminate or modify the source of stress making it less stressful. Here it is important to identify the problem causing the stress. One may think that their problem is anxiety: the real problem is what is causing the anxiety. Anxiety is a psychological reaction to the problem. Third, brainstorm for possible solutions. This process itself can be relaxing and amusing and foster creativity. Fourth, select one feasible solution and implement it. Fifth, evaluate the result of the selected solution. Finally, if the solution worked, celebrate! If it has not worked, go back to steps 3 or 4 and keep on trying until a solution is reached or the conclusion that this particular problem is not solvable. In this case try one of the following techniques.

The second stress management technique involves changing the attitude toward or perception of a problem. This can be done via cognitive restructuring. This involves asking questions such as, "How really important is the issue?" or "Is it really worth getting upset over?" Such questions help to look at a situation from a different, and hopefully, less stressful, perspective.

The third technique of stress management is to change the physical reaction to a problem or stressor. In times of stress, the body responds by releasing a number of chemicals (e.g., epinephrine and cortisol) whose purpose is to enable the body to respond physically to the stressor (fight or flight). In acute stressful situations this response is healthy and adaptive. In chronic stress situations this response becomes maladaptive leading to many illness conditions such as hypertension and may even become immunosuppressive. This management technique is particularly useful when the two previously mentioned techniques fail but it can also be used as a first line technique in many cancer and non-cancer related situations (e.g., during cancer treatment, going to the dentist, or giving a speech).

Coping skills

There are key ingredients of good coping: optimism, practicality, flexibility, and resourcefulness.

Optimism is the expectation of positive change. Practicality is learning that options and alternatives are seldom exhausted. Flexibility involves changing strategies to reflect the changing nature of perceived problems. Finally, resourcefulness reflects the ability to call upon additional information and support in order to strengthen coping.

Coping skills may be defined as methods that are effective (i.e., what works in a given situation) and ineffective (i.e., what doesn't work in a given situation). Effective methods include active-behavioral and active-cognitive coping.

Active-behavioral coping refers to all of the things that one does (i.e., behaviors or actions) to help solve problems and/or make one feel better. These tend to be effective in both the short and long-term because they are focused on dealing with problems. Examples of active-behavioral coping are exercising, improving diet, forming partnerships with health team, attending support groups, asking questions, and seeking information. Active-cognitive coping refers to all of the thoughts and mental techniques that can help to solve problems and/or make one feel better. These also are problem-focused and tend to be effective in both the short and long-term. Examples of active-cognitive coping include accepting the seriousness of the diagnosis but not automatically accepting a negative outcome, looking for ways in which one is better off than others, assuming that there are options and looking for them, using the situation as a challenge and an opportunity for positive change, and focusing on the positive.

Ineffective coping methods are generally referred to as avoidance coping. These involve both the behaviors and mental activities that may make one feel better in the short-term but are not focused on solving problems. As a result, they do not make one feel better in the long-term. Examples of avoidance coping include abusing drugs (e.g., street drugs, prescription medications, and alcohol), keeping all thoughts and feelings to oneself, oversleeping or overeating, passiveness or waiting until the problem goes away, and denying the existence or seriousness of the problem.

Psychological support
Nurses provide psychological support via establishment of a trusting relationship, therapeutic communication (questioning, listening, teaching), therapeutic touch (holding a hand, touching a shoulder), and providing a safe and healing environment.

Nursing-Sensitive Patient Outcomes
Nursing-Sensitive Patient Outcomes (NSPO) focus on how patients and their healthcare problems are affected by nursing interventions. They are arrived at, or significantly impacted by, nursing interventions which are within the scope of nursing practice and are integral to the processes of nursing care. NSPO are sensitive to independent nursing care or care rendered in collaboration with other healthcare providers. They represent the consequences or effects of nursing interventions and result in changes in patients' symptom experience, functional status, safety, psychological distress, and/or costs (Given & Sherwood, 2005).

The Psychoeducational interventions discussed easily lend themselves to outcome measurement. There already exist numerous research instruments and clinical care assessments and terminology to document NSPO resulting from the delivery of psychoeducational interventions delivered by nursing personnel. Potential NSPOs of psychoeducational interventions at the time of diagnosis are:
- acceptance of the diagnosis;
- establishment of an alliance with the health care team; development and initiation of a treatment plan;
- enhanced coping and adjustment;
- resolved or decreased negative feelings;
- improvement of quality of life.

NSPO during initial treatment are:
- increased compliance with treatment;
- improved coping and adjustment to treatment;
- improved management of side effects;
- improved affective state;
- successful reintegration of patients into their routine life;
- and improved quality of life.

Nursing-Sensitive Patient Outcomes based on interventions that are evidence-based have an important role in current nursing practice. Neither cancer-related assessment processes nor diagnoses are unique to oncology nursing; both may be performed and provided by different health care personnel. In some cases the interventions, such as the psychoeducational interventions described in this article, are also not the sole purview of nursing. However, when any intervention within the scope of nursing practice is delivered by a nurse, then the outcome should be determined and recorded as such. Today's professional nurse must take both responsibility and credit for all nursing actions whether they are collaborative or independent. Measuring and recording Nursing-Sensitive Patient Outcomes resulting from evidenced based practice will enable us to do this.

References

Given, BA and Sherwood, PR. (2005) Nursing Sensitive Patient Outcomes: A White Paper. Oncology Nursing Forum, Vol. 32, No. 4, pp. 773-784.

Fawzy FI, Fawzy NW, Arndt L, Pasnau R. (1995). Critical review of psychosocial interventions in cancer care. Archives of General Psychiatry, 52:100-113.

Fawzy NW. (1995). A psychoeducational nursing intervention to enhance coping and affective state in newly diagnosed malignant melanoma patients. Cancer Nursing, 18(6):427-438.

Fawzy FI, Fawzy, NW. (1994). A structured psychoeducational intervention for cancer patients (manual). General Hospital Psychiatry, 16:149-192.

Fawzy FI, Fawzy NW, Hyun C, Elashoff R, Guthrie D, Fahey JL, Morton DL. (1993). Malignant Melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival. Archives of General Psychiatry, 50:681-689.

Fawzy FI, Cousins N, Fawzy NW, Kemeny ME, Elashoff R, Morton DL. (1990). A structured psychiatric intervention for cancer patients: I. Changes over time in methods of coping and affective disturbance. Archives of General Psychiatry, 47:720-725.

Fawzy FI, Kemeny ME, Fawzy NW, Elashoff R, Morton DL, Cousins N, Fahey JL. (1990). A structured psychiatric intervention for cancer patients: II. Changes over time in immunological measures. Archives of General Psychiatry, 47:729-735.

Living with Cancer

Challenges in being a Survivor

Margaret I Fitch RN PhD, Head Oncology Nursing and Supportive Care
Toronto Sunnybrook Regional Cancer Centre, Immediate Past President ISNCC

Concerns about survivorship and the needs of cancer survivors are surfacing with increasing frequency. Advances in the diagnosis and treatment of cancer have resulted in an ever-growing cadre of individuals who are survivors of the disease. In the US alone there are more than 10 million cancer survivors (ACS, 2005) In Canada, there are almost 800,000 – a comparable number given the country's population (NCIC, 2006). Approximately 60% of adults who are diagnosed with the disease and 78% of the children are alive at 5 years (ACS, 2005). Given the expectation that the number of people diagnosed with cancer will double in the next 40 years, we can expect that the number of survivors will also continue to increase.

Living after a diagnosis of cancer and its subsequent treatment is not without its challenges. We are only now beginning to recognize some of the concerns and issues survivors face and what a vulnerable population these individuals constitute. The growing number of individual in our midst has allowed us to start learning about the challenges survivors can face on a daily basis. Their voices are being heard as advocacy group representatives speak out about their needs and the gaps in cancer service delivery. We are beginning to identify the spectrum of late complications survivors may experience with the potential to compromise quality of life. We are also beginning to recognize that the late and long-term effects are more prevalent, serious, and persistent than was originally expected.

Consequences of Survivorship

In a study by Yabroff et al (2004), which involved 1800 cancer survivors and matched controls in a national population-based sample, the survivors had significantly lower health outcomes on every burden of illness measure. Earle and Neville (2004) also studied cancer survivors (N=14,000) in comparison to matched controls without a cancer history. They reported the cancer survivors were more likely not to receive appropriate care for a broad range of chronic medical conditions (i.e., angina, congestive heart failure, diabetes).

Studies are beginning to emerge in North America describing the common consequences cancer survivors experience over the years following their cancer treatment (Ganz, 2001, Aziz & Rowland, 2003; Denmark et al, 2005). Survivors describe living with uncertainty and fear of recurrent disease; struggling through changes in family roles; coping with alterations in body functions and self-image; and managing challenges in comfort, physiologic functioning, and mobility. Consequences such as alterations in cognitive functioning and fatigue levels can have dramatic influence on returning to work and engaging in formerly enjoyable leisure activities.

In the words of one survivor:
Needless to say I was so happy to hear the cancer was gone. There was no sign of it. But what I didn't realize is that the memory of it was not gone, or all the side effects of the treatments. I am still not really myself and it's been a year. I'm still tired. I'm not able to work at the same pace. I just don't have the energy any more. And I can't concentrate like I used to. I'll read something four times sometimes before it sinks in. It drives me crazy! I keep wondering if I'll ever be myself again. At this rate I don't know if I can do this job anymore – and sometimes I wonder if I want to. (Male, 42 years)

Survivors have also talked about alterations in sexuality and fertility because of cancer treatment. These alterations can, in turn, have consequences for relationships and social support. Many describe the cancer experience as changing their lives in irrevocable ways. Life is no longer what it used to be and many find it is challenging to try to "pick up the pieces and find a new normal" (MaGee & Scalzo, 2006). Life goals, life philosophies, and long held beliefs about the world and one's place in it can be challenged by a life-threatening event. One's spirit can be bruised by the experience or one can find new strength and courage (LAF, 2005). Up to 75% of survivors have health deficits related to their treatment (Aziz & Rowland, 2003), over 50% have chronic pain (LAF, 2004), 70% have experienced depression since their diagnosis (LAF, 2004) and 18%-43% exhibit emotional distress (Vachon, 2006). What is most concerning is that the roles of primary care providers and specialists in the care of cancer survivors is not clearly recognized or defined. As a result, many survivors regularly experience difficulties accessing on-going health care for their concerns.

The Concept of Survivorship

The notion of survivorship unfolding in phases was first described in the cancer literature by Mullan (1985). A physician who underwent treatment for cancer, Mullan described three "seasons of survival", each with its own set of issues and concerns. The season of acute survival included initial diagnosis and treatment and was filled with fear and anxiety. Extended survival included the interval after treatment when the person is in remission or enters a time of watchful waiting, periodic examinations, and consolidation or intermittent therapy. Fear of recurrence dominates, yet it is a time when the person is overcoming the immediate after effects of treatment and re-organizing his or her life. The season of permanent survival, then, is associated with cure. It includes the rest of the person's life or the long term period without recurrent disease.

The notion of survivorship has been debated and defined in a variety of ways. Some will say survivorship starts from the moment a diagnosis is made while others focus on the time initial treatment is finished and there is no more clinical evidence of disease. Others will say that if one is alive 5 years after the diagnosis, one is a survivor. Others will say a person must die of another disease to be a survivor of cancer. Finally, there are others who reject the notion of survivor altogether in favor of the word "thriver". The emphasis these individuals wish to convey is one of not just surviving the cancer but growing through the experience, gaining strength and resolve. For them, the experience has brought new knowledge, skills and personal insight (LAF, 2005).

In 1989, Welch-McCaffrey et al further developed the concept of survivorship for those of us in the cancer practice setting. She and her colleagues described several trajectories of survival and contributed to the notion that, although individuals diagnosed with cancer travel different pathways, all are survivors. The trajectories included:

- live cancer free for many years
- live long cancer free, die quickly of late recurrence
- live cancer free (1st cancer) , develop 2nd primary cancer
- live with intermittent periods of active disease
- live with persistent disease
- live after expected death (family member).

This conceptualization of short and long term consequences of cancer was a new way of thinking about cancer care and the patient

experience. If one embraces this notion of various trajectories or pathways for cancer survivorship, then as practitioners we need to orient our thinking to the future and how we can best assist those with cancer to thrive no matter which pathway they are traveling. How can we best equip them (i.e., provide knowledge and skills) to cope over time with what they will face as consequences of the cancer treatment? Unfortunately, at this time, knowing exactly what is most helpful or how to best equip individuals for the survival journey requires research, testing of interventions, and evaluation of program approaches.

Recognition of Survivorship

In 1996, a significant development occurred in the US to focus attention on cancer survivorship. The Office of Cancer Survivorship was established. The definition of survivor they embraced is: an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life (OCS, 1996). Since family members, friends, and caregivers are also impacted by the cancer experience, they are included in this definition as well

The Office of Cancer Survivorship has a strong research emphasis. They describe cancer survivorship research as encompassing the physical, psychosocial, and economic sequelae of a cancer diagnosis and its treatment among both pediatric and adult survivors of cancer. It also includes in its domain issues related to health care delivery, access, and follow-up care as they relate to survivors. Clearly, the research effort needs to focus on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. Research needs to be conducted in these areas if we are to prevent and control the adverse outcomes of cancer and its treatment. Preventing second cancers, overcoming poor quality of life as well as understanding the best protocols for survivor surveillance and follow-up care are critically important. Additionally, if we know more about what after effects do occur, it may help us to make adjustments in the current treatment protocols and so avoid these outcomes.

Never before have we been in a position with such promise to start this important work. We have a cadre of survivors who have lived the experience and have the wisdom gleaned from it. Many have a passionate drive to help others diagnosed with cancer so that they do not have to experience what the survivors have had to undergo. One of the challenges for cancer researchers and health care providers is to access this survivor expertise and make use of their advice in future program planning and design of interventions.

Several key publications have appeared recently that set the stage for action concerning cancer survivorship:

- Lance Armstrong Foundation – National Strategy for Cancer Survivorship (2004)
- From cancer patient to cancer survivor: Lost in translation (NIH, 2005)
- American Journal of Nursing Vol 106 (Supplement 3) – Managing the Sequelae of Cancer and Cancer Treatment (2006)

Each publication describes cancer survivorship issues and makes recommendations for action. Clearly there are barriers to cancer survivors receiving optimal care. These barriers include, among others: 1) education deficits on the part of health care professionals and the public about survivorship; 2) lack of research to inform practice, education and policy; 3) failure of society to value outcomes other than cure; 4) lack of clarity regarding roles and responsibilities for care of long term survivors; and 5) lack of funding for both survivor care and research.

The Lance Armstrong Foundation (2004) devised a national strategy or action plan for overcoming these barriers. Its key thrusts include:

- surveillance and applied research;
- communication, education, and training;
- programs, policies, and infrastructure; and
- access to quality care and services.

The strategy is aimed at the prevention of secondary cancers and the recurrence of primary tumors; promotion of effective management following diagnosis and treatment; minimizing and preventing pain, disability, and psychosocial distress; supporting people to access resources; and access to quality treatment, pain and symptom management, and end-of-life care. There are clearly implications for database development, design and implementation of navigation systems and guidelines; education; and evaluation and continuous quality improvement.

The Role of Nurses in Cancer Survivorship

Cancer nurses can play a leadership role in the arena of cancer survivorship (Ferral et al, 2003; Curtiss & Haylock, 2006). Often it is cancer nurses who hear about the challenges cancer survivors are facing in their daily lives. The relationship cancer nurses establish during their care of patients provides the avenue for dialogue about a wide range of issues survivors may be facing. Issues of quality of life are central to the practice of cancer nursing. We need to be thinking about our roles in bringing forth, and making visible to others, the needs of survivors as well as how these needs can be met. Cancer nurses have expertise and knowledge to design appropriate interventions and relevant programs for individual, group, and population care levels.

At the very least, nurses need to be conducting comprehensive assessments; developing individualised plans of care with patients and survivors; providing education, symptom management, and referral as needed. Cancer nurses have a key role to ensure continuity of care, and to monitor and evaluate treatment outcomes and quality of life for survivors.

In conclusion, cancer survivors are a vulnerable population. Many face late and long-term effects of their treatment yet are not able to access appropriate services. Cancer nurses can play a key role in the arena of cancer survivorship through intentional activity in research, education, practice, and policy. The imperative to take action comes from the growing number of cancer survivors who continue to struggle because of the effects of the disease and its treatment long after they are finished with active protocols.

References

American Cancer Society (2005). Cancer facts and figures 2005. Atlanta: The American Cancer Society.

Aziz NM & Rowland JH (2003). Trends and advances in cancer survivorship research: challenges and opportunity. Radiation Oncol, 13 (3), 248-66.

Curtiss CP & Haylock PJ (2006). State of the Science on Nursing Approaches to Managing the Late and Long Term Sequelae of Cancer and Cancer Treatment. American Journal of Nursing, 106 (#3 Supplement)

Denmark-Wahnefried W et. al., (2005). Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer. J Clin Oncol, 23 (24), 5814-30

Earle CC & Neville BA (2004). Under-use of necessary care among cancer survivors. Cancer, 101 (8), 1712-9.

Ferral BR et al (2003) The role of oncology nursing to ensure quality of care for cancer survivors: A report commissioned by the National Cancer Policy Board and Institute of Medicine. Oncology Nursing Forum, 30 (1), E1-E11.

Ganz PA (2001) Late effects of cancer and its treatment. Semin Oncol Nurs, 17 (4), 241-8.
Institute of Medicine (2005). From cancer patient to cancer survivor: lost in translation. Washington DC: National Academics Press.

Lance Armstrong Foundation (2004). A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. Austin, Texas: author.

Lance Armstrong Foundation (2005). Livestrong – inspirational stories from cancer survivors. New York: Broadway Books.

Magee S & Scalzo K (2006). Picking Up The Pieces. Vancouver: Raincoast Books.
Mullan, (1985) Seasons of Survival: Reflections of a physician with cancer. New England Journal of Medicine, 313 (4), 270-3.

National Cancer Institute of Canada (2006). Canadian Cancer Statistics – 2006. Toronto: author.
Office of Cancer Survivorship (1996) http//dccps.nci.nih.gov/ocs/ocs_factsheet.phf.

Vachon M (2006). Psychosocial Distress and Coping After Cancer treatment. American Journal of Nursing, 106 (#3 Supplement), 26-31.

Welch-McCaffrey D Hoffman B Leigh SA Loescher LJ Meyskens FL Jr (2989) Surviving adult cancers. Part 2: psychosocial implications. Ann Intern Med 111(6): 517-24.

Yabroff KR et al., (2004). Burden of illness in cancer survivors: Findings from a population-based national sample. J Natl Cancer Inst 96 (17), 1322-30.

Europa Uomo:

The European Prostate Cancer Coalition

Louis Denis, Oncologic Centre Antwerp, Belgium

Europa Uomo, started in Rome in 2002, is the European advocacy movement for the fight against prostate cancer. The objective of the organization is to increase awareness on prostate cancer in Europe. Europa Uomo is a European coalition of support groups for prostate diseases in general and prostate cancer in particular. At present Europa Uomo is represented in Austria, Belgium, Denmark, Finland, France, Germany, Hungary, Ireland, Italy, Norway, Poland, Portugal, Slovak Republic, Spain, Sweden, The Netherlands and the United Kingdom. Europa Uomo is the newest partner to join the www.cancerworld.org website.

Statistics on cancer in Europe reveal quite clearly that prostate cancer is rising quickly to a 'star' position in the European Union. Prostate cancer is now by far the most common men's cancer in developed countries with the mortality rate remaining at a frightening peak despite progress made in early detection and management of this disease. In comparison to breast cancer incidence and mortality, there were 202,100 newly diagnosed patients with prostate cancer and 68,200 deaths versus 275,100 newly diagnosed women with breast cancer and 88,400 deaths in the European Union (Boyle & Fenay 2004).
Alarmed by this trend, Professor Umberto Veronesi summoned Mr. Tom Hudson with extensive European Cancer League (ECL) and International Union against Cancer (UICC) expertise as well as Professor Louis Denis with a lifelong experience of dealing with oncologic urology to a high level political meeting in Rome organized by the European School of Oncology (ESO).
The conclusion of this meeting was the recognition of the burden of prostate cancer as a priority disease in the European Union and the simple fact that the increasing ageing of the population would make 2010-2015 the absolute zenith of prostate cancer and a challenge to European health care systems.
The excellent results of the activities of Europa Donna were seen as an example to follow and influenced the founding of Europa Uomo. Hence, the organization was officially founded in March 2004 with the support of ESO and its director Dr. Alberto Costa with the support of the Oncologic Centre Antwerp and its director, Professor Louis Denis. The concept for the coalition came at the right time and the right place and an immediate enthusiastic response from existing national patient groups led to a joint effort under the leadership of Tom Hudson, Chairman, and Jack Pais, Secretary. However, as the saying goes, men are from Mars and both a mission and organization were put before actions. The mission includes the mobilization and solidarity among men to raise awareness and education and to promote early detection, access to optimal treatment and research in the professional community. The organization recognized as full members patient-led groups who were active in patient support and legally recognized in their respective countries. Each full member is represented by one representative from each European country.

The first action was to write the Manifesto of Europa Uomo. It took almost a year to agree on the final text! It is no surprise that quality of life is the first key point in the Manifesto while peer-to-peer support, provision of information, and advocacy are constants in our policies. The respect for the Manifesto is expressed by the fact that all new members must confirm their agreement to the document to become a full member.
The idea of Europa Uomo caught on and now we represent 18 European countries with more to follow this year. It should be noted that different groups in one country are requested to nominate one representative body or one representative person to the general assembly of Europa Uomo. Emphasis is placed on the autonomy of the national groups and on their national policies respecting the existing social and cultural differences in the European Union. Our website, as part of Cancerworld, provides a link to the sites of the national groups who are members of our organization.

The second policy action, also typical for men, is networking activities. These are intended to provide a broad source of support to form a strong, reliable base to obtain objective scientific information and create a united brand of patient advocacy. The partnerships that we have formed with the European Coalition of Cancer Patients (ECPC) and with the European Association of Urology (EAU) help to provide updates on both clinical and scientific progress on the diagnosis and management of prostate diseases. After presenting our options to the MAC committee of the European Parliament, we plan to join partners in the F7 programme to raise awareness of prostate cancer and to relay new clinical advances directly to relevant populations.
As a strategy policy, we focus on common interest in the EU by providing peer-to-peer patient support in all countries, by equalizing optimal standards of care, and by obtaining support from professional associations of physicians, nurses and other health care workers.

Europa Uomo does not pretend to be a medical authority nor does it claim to have the medical knowledge to provide advice on the diagnosis and treatment of prostate diseases. It is our aim to provide an authoritative and accurate source of information on prostate diseases. Here we highlight the existing open questions in decision-making, the lack of objective, evidence-based information and the specific needs of our fellow men in patient-centred care. We realize that physicians often lack the time for a full engagement in care; however, we expect someone on the team (nurses, data managers and even patient group volunteers) to fill any gaps in providing patient-centred care. Our 'European Prostate Passport' is an example of how we try to provide information which can be understood by all patients in order to foster and facilitate communication with the treating physician.

We realize of course that basic and clinical research is the only way to medical progress and we value the importance of clinical trials. Patients should understand all aspects of participating in such trials and they should be involved in the development of protocols and be able to exercise their basic right of consent. To obtain this right, we are ready to take up our responsibility to submit to the discipline of a scientific trial.

We hope to achieve our ambitious policy by establishing true communication with all involved parties toward the war against cancer in a united effort. Our goals are simple but provide a useful base for our service to patients with prostate cancer. With support, we will be able to obtain optimal treatment and patient-centred holistic care. We are ready to take up our responsibility and we count on your support.

European Actions of Europa Uomo

1. *Expand membership to foster and increase the awareness of prostate diseases for men.*
2. *Provide means and information to educate men based on objective, evidence based holistic care.*
3. *Support all joint efforts to keep patient advocacy a priority in our European health systems based on solidarity and mutual respect.*

Regulation of Biosimilar Medicines

Jo Harkness, International Alliance of Patient's Organizations (IAPO)

In the Fall 2006 issue of the EONS Newsletter, an article appeared on the topic of generic copies of biosimilar drugs. That article discussed the potential risks involved in using generic copies of biological medicines due to differences in composition: differences which could affect the safety and efficacy of these drugs. The article which follows provides information on the regulation of biosimilar medicines which is an important step in ensuring that the mode of action of a biosimilar is similar to the mode of action of a biological medicine.

Manufacturers of biological medicinal products sometimes make changes to such products during their lifecycle, or choose to develop new products which are biologically similar (hence "biosimilar products"). Since the quality, safety and efficacy of these modified or new products may be affected, a series of tests needs to be conducted to ensure the comparability of the new and the old versions.

The EU has a firm legal pathway for approval of biosimilars. This pathway recognizes that practical experience with biologics has demonstrated that they are more complex products when compared to traditional chemical medicines. As a result, additional caution is being applied with regard to demonstrating safety and efficacy of biosimilars with the regulating authority requiring additional data compared to that necessary for traditional chemical generic medicines.
The Biological (Biosimilar) Medicinal Working Party (BMWP) provides recommendations to the CHMP (Centrale Humanitare Médico-Pharmacentique) on the data requirements and conduct of necessary tests, and on any other clinical or non-clinical matter relating directly or indirectly to biosimilar medicines. This may concern products that are already authorised (through either the centralised or mutual-recognition procedure) and those currently in development. The PEG works together with other CHMP working parties and/or scientific advisory groups, and cooperates with the NCAs (National Competent Authorities) of the EU Member States.
The tasks of the BMWP include:

- preparing, reviewing and updating guidelines to ensure that similarity/comparability issues are fully addressed;
- providing scientific advice to the CHMP and appropriate working parties on general and product-specific matters relating to the efficacy and safety of similar biological medicinal products and to the comparability of biological/biotechnological medicinal products;
- contributing to international cooperation with other regulatory authorities;
- liaising with interested parties;
- contributing to comparability-related workshops and training.

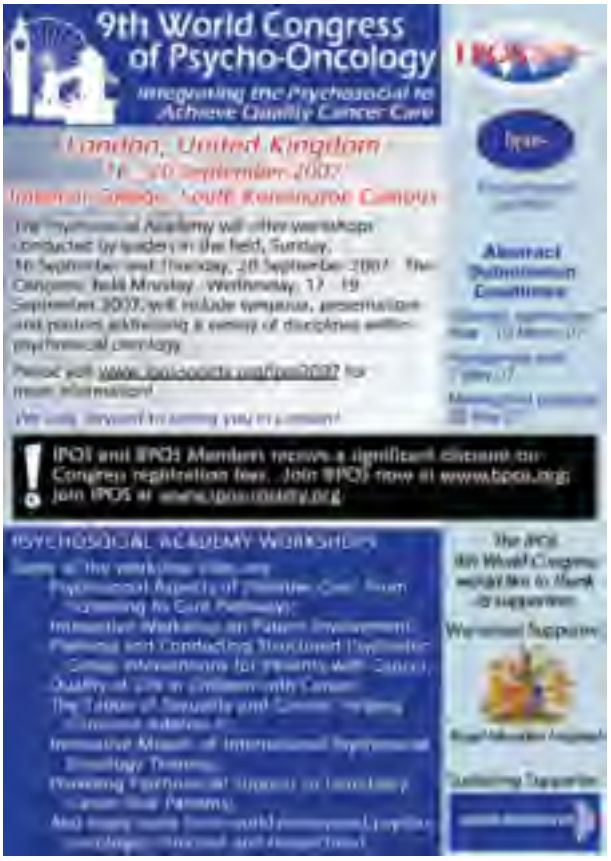
The EMEA (European Medicines Agency) recognizes the potential of biosimilars for boosting the innovation cycle and making these types of medicines available to a wide group of patients. The agency has provided biosimilar manufacturers with guidance on what new studies and clinical trials will be necessary for future applications. This will reduce the burden of clinical trials required to gain approval for a biosimilar product when sufficient experience has been gained from the use of the original biotechnology medicine.

Additional Studies
The requirement to carry out additional studies would depend on various factors including: the complexity of the molecule (more complicated molecules are likely to mean more testing); the previous history of the reference product; the amount of clinical experience with the product; the level of scientific knowledge in the literature; the intended patient population; and the data in the original application. The guidelines make it clear that any differences in the quality attributes of the biosimilar and reference product will have to be justified. The basic structural elements should be identical. However, slight differences may be allowed providing they are justified and do not affect the safety or efficacy of the product. Applicants must show that the biosimilar is as close as possible to the reference product.

Guidelines
During 2006 there were four meetings of the BMWP. The following guidelines related to the approval of biosimilars were produced from these meetings:

- Guideline biosimilar medicinal products containing biotechnology-derived proteins as active substance – non-clinical and clinical issues
- Guidelines on similar biological medicinal products containing:
  - Somatotropins
  - Recombinant erythropoietins
  - Recombinant human insulin
  - Recombinant granulocyte-colony stimulating factor
  - Recombinant -interferons
- Guideline on immunogenicity assessment

More detailed information may be obtained on the EMEA website: http://www.emea.europa.eu/htms/general/contacts/CHMP/CHMP_BMWP.html



Sustained Partners EONS 2007

AMGEN

Working in Collaboration with Oncology Nurses

Amgen recognizes and values the role of the oncology nurse in their commitment to improve outcomes for the person with cancer. Amgen is committed to collaborating with oncology nurses on multiple fronts to advance the science and knowledge in the field of oncology and ultimately improve the care and experiences of persons with cancer. Through the TITAN program and other projects, we have reached thousands of nurses in multiple languages, with the intention to advance knowledge and improve care. We commend and support the mission and objectives of EONS and look forward to working with oncology nurses throughout Europe and abroad.

Amgen discovers, develops and delivers innovative human therapeutics. A biotechnology pioneer since 1980, Amgen was one of the first companies to realize the new science's promise by bringing safe, effective medicines from lab, to manufacturing plant, to patient. Amgen therapeutics have changed the practice of medicine, helping millions of people around the world in the fight against cancer, kidney disease, rheumatoid arthritis, and other serious illnesses. With a deep and broad pipeline of potential new medicines, Amgen remains committed to advancing science to dramatically improve people's lives. To learn more about our pioneering science and our vital medicines, visit www.amgen.com.

Astra Zeneca

Partnering with EONS

AstraZeneca are the second biggest Oncology Company in the world, with major objectives of developing innovative new medicines with aims of benefiting cancer patients in terms of treatment outcome, quality of life and improvement in survival. Treatment of cancer clearly requires a multidisciplinary approach, requiring close collaboration and teamwork between all health case professionals involved with treating the patients, and the pharmaceutical industry. AstraZeneca recognises the great importance of Oncology Nurses in the treatment of cancer and their role in ensuring cancer patients get the best treatment and care that they deserve. AstraZeneca are very pleased to be partnering with the European Oncology Nursing Society (EONS) and look forward to working closely with the organisation in the future, to assist in the advancement of nurse education and the continued growth of the organisation.

MERCK KGaA

Merck KGaA focuses its oncology research on the development of novel therapies that specifically target cancer cells. The monoclonal antibody Erbitux® (cetuximab), Merck's first oncology product, specifically blocks the epidermal growth factor receptor (EGFR). Erbitux enhances the effect of chemotherapy and radiotherapy. Merck has also acquired the rights for the oral cancer treatment UFT® (tegafur-uracil).

Merck's oncology research activities focus on identifying compounds that specifically interfere with one or more of the key cellular processes or pathways which influence the growth and spread of cancer cells. The resulting range of new compounds, including the humanized EGFR targeting monoclonal antibody matuzumab, the cancer vaccine Stimuvax® (formerly referred to as L-BLP25), the angiogenesis inhibitor cilengitide and several immunocytokines, are currently undergoing clinical development.

MERCK MSD

Merck, Sharp & Dohme (MSD) is pleased to be a partner of EONS and promote cancer education and research. MSD shares the mission of EONS and is committed to adding value to the work of oncology nurses as they deliver care to patients with cancer. We look forward to working with EONS on important projects in 2005 and beyond.

MSD is a global research-driven pharmaceutical company dedicated to putting patients first.

MUNDIPHARMA

Mundipharma is one of the Purdue/Mundipharma/Napp independent associated companies and is dedicated to bringing to patients with severe and debilitating diseases the benefits of novel treatment options in fields such as severe pain, haemato-oncology and respiratory disease.

NOVARTIS

Novartis Oncology is committed to developing and advancing the education of nurses engaged in caring for patients with cancer and to co-ordinate top level nursing educational programmes. As such, Novartis considers the concept of sustaining partnerships an optimal vehicle to express our willingness and desire to commit to oncology nursing excellence and to recognize the impact oncology nursing has on the quality of patient care. Novartis envisions our sustaining partnership will enable EONS to develop the projects, education and understanding that will ensure the value of collaborative relationships between industry, nurses and the healthcare community.
Novartis thanks you in advance and looks forward co-operating with you.

NUTRICIA

Nutricia is a company that is dedicated to providing you and your patients with specialised nutritional support products, particularly enteral nutrition. At Nuntricia we recognise the key role nurses play in the treatment and support of cancer patients, and therefore it is a great pleasure for Nutricia to work together with EONS. We are proud that this partnership has resulted in the development of the Nutrition in Oncology Educational Program: NOEP. The NOEP educational program has been developed in close co-operation with EONS members. NOEP is designed to meet educational needs relating to nutrition and oncology, as expressed by nurses during the EONS convention in April 2002. We are looking forward to sustaining this partnership with EONS, and to continue working on joint projects on nutrition to improve nutritional support for oncology patients.

ROCHE

Roche Partnership with EONS

One of Roche's key priorities is the discovery of novel and effective therapeutic agents that provide the best possible treatment for cancer patients. Throughout our range of oncology products, which include Avastin, Herceptin, MabThera, Tarceva, Xeloda, Kytril, Bondronat and NeoRecormon, we are dedicated to improving patient's quality of life. Cancer nurses are a vital component of healthcare services and Roche is committed to supporting further developments in the profession, through sponsoring the research grant to nurses in cancer care. We provide educational materials for use by nurses and complementary information for patients. We are delighted to be partnering with EONS, an organisation that shares our goal of 'improving the care of individuals with cancer by supporting and enhancing cancer nurses throughout Europe.'

SANOFI AVENTIS

Sanofi Aventis is the worlds third largest Pharmaceutical organization and the largest in Europe. We are committed to innovation and a commitment to meet unmet medical needs particularly in Oncology. We seek to build a sustained, enduring partnership with EONS and through this partnership, a continued education of Nurses engaged in the treatment of Cancer patients. We believe that the continuing education is critical to the advancement of Nursing excellence and the eventual quality of patient care. Through our partnership we will jointly identify the education needs of the Nursing community and address these needs through symposia, workshops and other means under the auspices of EONS in Europe and in parallel partner with other Nursing organizations on a global basis. We look forward to working closely with you and in supporting you.

TOPO TARGET

TopoTarget – Practical Answers for Cancer

TopoTarget is a research-based international biopharmaceutical company dedicated to finding practical answers for cancer. TopoTarget is founded and run by clinical cancer specialists and combines years of hands-on clinical experience with in-depth understanding of the molecular mechanisms of cancer.

TopoTarget is committed to ease the burden and improve the efficacy of cancer therapies for both patients and healthcare professionals.

Topotarget is pleased to support the goals of the European Oncology Nursing Society by being a partner of EONS.

TopoTarget recognizes the role of the oncology nurse and look forward to work with EONS on various projects such as development of clinical guidelines, supporting educational programs and provide sponsorships for research.

For chemotherapy-induced anaemia

Aranesp® (darbepoetin alfa) is big on efficacy[1]

Striving to achieve the ultimate goals of anaemia treatment[2]:

– Prevent red blood cell transfusions

– Improve quality of life for your patients

Aranesp®
(darbepoetin alfa)

Aranesp® Brief Prescribing Information

Aranesp® (darbepoetin alfa) SureClick™ Brief Prescribing Information:
Please refer to the Summary of Product Characteristics before prescribing Aranesp®
Pharmaceutical Form: Solution for injection presented in prefilled pens containing 150, 300 and 500 micrograms of darbepoetin alfa, for single-dose use only.
Indication: Treatment of symptomatic anaemia in adult cancer patients with non-myeloid malignancies receiving chemotherapy.
Dosage and Administration: Cancer Patients: Aranesp® should be administered by the subcutaneous route to patients with anaemia (eg. haemoglobin concentration ≤11 g/dl (6.8 mmol/l). The recommended initial dose is 500 µg (6.75 µg/kg body weight) given once every 3 weeks. If the clinical response (fatigue, haemoglobin response) is inadequate after 9 weeks, further therapy may not be effective. Alternatively, once weekly dosing can be given at 2.25 µg/kg body weight. Aranesp® therapy should be discontinued approximately 4 weeks after the end of chemotherapy. Haemoglobin level should not exceed 13 g/dl (8.1 mmol/l). Once the therapeutic objective for an individual patient has been achieved, the dose should be reduced by 25 to 50% in order to maintain haemoglobin at that level. If required, further dose reduction may be instituted to ensure that haemoglobin level does not exceed 13 g/dl. If the rise in haemoglobin is greater than 2 g/dl (1.3 mmol/l) in 4 weeks, the dose should be reduced by 25 to 50%.
Contraindications: Hypersensitivity to darbepoetin alfa, r-HuEPO or excipients. Poorly controlled hypertension.
Special Warnings and Precautions: Iron status should be evaluated for all patients prior to and during treatment and supplementary iron therapy may be necessary. Non-response to therapy with Aranesp® should prompt a search for causative factors. Deficiencies of iron, folic acid or vitamin B12 reduce the effectiveness of erythropoietic stimulating agents and should therefore be corrected. Intercurrent infections, inflammatory or traumatic episodes, occult blood loss, haemolysis, severe aluminium toxicity, underlying hematologic diseases, or bone marrow fibrosis may also compromise the erythropoietic response. A reticulocyte count should be considered as part of the evaluation. If typical causes of non-response are excluded, and the patient has reticulocytopenia, an examination of the bone marrow should be considered. If the bone marrow is consistent with PRCA, testing for anti-erythropoietin antibodies should be performed. Pure red cell aplasia caused by neutralising anti-erythropoietin antibodies has been reported in association with recombinant erythropoietic proteins, including darbepoetin alfa. These antibodies have been shown to cross-react with all erythropoietic proteins, and patients suspected or confirmed to have neutralising antibodies to erythropoietin should not be switched to darbepoetin alfa. Active liver disease was an exclusion criteria in all studies of Aranesp®, therefore no data are available from patients with impaired liver function. Since the liver is thought to be the principal route of elimination of Aranesp® and r-HuEPO, Aranesp® should be used with caution in patients with liver disease. Aranesp® should also be used with caution in those patients with sickle cell anaemia or epilepsy. Misuse of Aranesp® by healthy persons may lead to an excessive increase in packed cell volume. This may be associated with life-threatening complications of the cardiovascular system. The needle cover of the pre-filled syringe contains dry natural rubber (a derivative of latex), which may cause allergic reactions. Cancer patients: Effect on tumour growth. Epoetins are growth factors that primarily stimulate red blood cell production. Erythropoietin receptors may be expressed on the surface of a variety of tumour cells. As with all growth factors, there is a concern that epoetins could stimulate the growth of any type of malignancy. Two controlled clinical studies in which epoetins were administered to patients with various cancers including head and neck cancer, and breast cancer, have shown an unexplained excess mortality. In patients with solid tumours or lymphoproliferative malignancies, if the haemoglobin value exceeds 13 g/dl, the dosage adaptation described in section "dosage and administration" should be closely respected, in order to minimise the potential risk of thromboembolic events. Platelet counts and haemoglobin level should also be monitored at regular intervals.
Interactions: If darbepoetin alfa is given concomitantly with drugs highly bound to red blood cells, eg cyclosporin & tacrolimus, monitor blood levels and adjust the dose of these drugs as haemoglobin rises.
Pregnancy and Lactation: No adequate experience in human pregnancy and lactation. Exercise caution when prescribing Aranesp® to pregnant women. Do not administer to women who are breastfeeding. When Aranesp® therapy is absolutely indicated, breast-feeding must be discontinued.
Undesirable Effects: General: There have been rare reports of potentially serious allergic reactions including dyspnoea, skin rash and urticaria associated with darbepoetin alfa. Cancer Patients: In clinical studies with subcutaneously administered Aranesp®, the incidence of hypertension and cardiovascular events were comparable in cancer patients receiving placebo, r-HuEPO or Aranesp®. Furthermore, these adverse events were not associated with either haemoglobin concentration (< 13 versus > 13 g/dl) or a rapid rise in haemoglobin (> 2.0 g/dl in four weeks). Clinical studies have shown a higher frequency of thromboembolic reactions including deep vein thrombosis and pulmonary embolism in cancer patients receiving Aranesp® therapy compared to patients receiving placebo.
In general, adverse events reported in clinical trials with Aranesp® in cancer patients receiving concomitant chemotherapy were consistent with the underlying disease and its treatment with chemotherapy. Undesirable effects considered related to treatment with Aranesp® from controlled clinical studies with incidence of > 1% to ≤ 10% are arthralgia, peripheral oedema, injection site pain, and thromboembolic reactions. Injection site pain was the most frequently reported adverse event considered related to treatment with Aranesp® (< 5%). The injection site discomfort was generally mild and transient in nature.
Overdose: Wide therapeutic margin. In the event of polycythaemia, Aranesp® should be temporarily withheld. If clinically indicated, phlebotomy may be performed.
Pharmaceutical Precautions: Aranesp® should not be mixed or administered as an infusion with other medicinal products. Store at 2°C to 8°C (in a refrigerator). Do not freeze. Keep container in outer carton to protect from light. For ambulatory use, Aranesp® may be removed from storage once for a maximum single period of 7 days at room temperature (up to 25°C).
The Aranesp® SureClick™ pre-filled pen delivers the complete dose of each presentation.
Legal Category: Medicinal product subject to restricted medical prescription.
Presentation and Marketing Authorisation Numbers:
Aranesp® 150 µg: 1 prefilled pen: EU/1/01/185/054;
Aranesp® 300 µg: 1 prefilled pen: EU/1/01/185/055;
Aranesp® 500 µg: 1 prefilled pen: EU/1/01/185/056;
Availability of presentations may vary in national regions.
Marketing Authorisation Holder: Amgen Europe B.V., Minervum 7061, NL-4817 ZK Breda, The Netherlands.
Further information is available from Amgen (Europe) GmbH, Dammstrasse 23, P.O. Box 1557, Zug, Switzerland CH-6301.
Additional information may be obtained from your local Amgen office.
Date of preparation: December 2006.

AMGEN®
Oncology

References: 1. Canon JL, et al. *J Natl Cancer Inst.* 2006;98:273-284. **2.** Bokemeyer C, et al. *Eur J Cancer.* 2004;40:2201-2216.

Amgen (Europe) GmbH
Zug, Switzerland