



**18<sup>th</sup> Annual Scientific Meeting**

**Birmingham**

**28<sup>th</sup> - 30<sup>th</sup> April 2005**

# Words of Welcome

## Presidential welcome

Friends and colleagues it is my privilege to welcome you all here to the historic yet very modern city of Birmingham and the 18<sup>th</sup> Annual Scientific Meeting of the European Association for Cancer Education.

The theme of this Scientific meeting is Changing Morbidity; Changing Mortality; Changing Cancer Education, plus the networking opportunities provided by this meeting will be of benefit not only to us but also for the patients and students we seek to support.

I am thrilled that the International Union against Cancer has again supported this meeting, as has the WHO-Collaborating Centre for Cancer Education in Groningen. As a result we have new delegates from countries not previously represented at EACE meetings, including Lithuania, Poland, Egypt and Nigeria.

American colleagues from our sister organisation The American Association for Cancer Education (AACE), and delegates from other continents, have assured that this meeting will have a truly international flavour.

Two years ago when we began the planning for this Scientific Meeting the University of Central England, with the support of Macmillan Cancer Care, committed themselves to fully hosting this meeting. Their commitment, enthusiasm, energy and professionalism have been outstanding and I and the Board are very grateful to them for what I know will be an exciting and very interesting three days.

The theme of this year Changing Morbidity; Changing Mortality; Changing Cancer Education extends the repertoire of the meeting and is very apposite with the move to multi professional cancer education and patient and user involvement

The Board of EACE looks forward to welcoming old and new members at the 18<sup>th</sup> *Annual General Meeting* of the Association on Friday afternoon 29th April 2005.

*Heather Mercer* President, EACE

Due to the ageing of the European population, cancer incidence will increase in the next decades. Timely recognition and treatment, but also prevention and palliative care will be a major challenge respecting the needs and preferences of the individual patient.

I am sure that this 18<sup>th</sup> EACE meeting will help to prepare the coming generation of medical professionals to fulfil this difficult task. I would like to express a special word of welcome to this target group which is hopefully well represented in this scientific meeting. As a famous Dutch proverb says 'those who have the youth have the future'.

I hope this meeting will stimulate them to join the EACE and strengthen our task force against cancer.

*Jakob de Vries* Director WHO-CCCE



## **The European Association For Cancer Education (EACE)**

**Founded in 1987**

### **Aims**

To optimise cancer education across all settings. This is achieved by providing a forum in which individuals, institutions, societies and organisations, with an interest in any aspect of cancer education can share ideas, materials, experience or plan collaborative activities that may be externally funded.

### **Target Group**

Cancer educators, physicians, nurses, dentists, social workers, students, educationalists, psychologists, researchers, other health professionals, staff members of comprehensive cancer centres and/or cancer societies/leagues.

### **Fields of Cancer Education**

Undergraduate and graduate medical, nursing, and dental cancer education; public and patient cancer education.

### **Statement of Purpose**

- To achieve excellence in cancer education by promoting and identifying the highest standards of education for health care professionals and others, thereby improving standards of care.
- To work collaboratively and proactively with other cancer educators to more effectively meet the needs of cancer patients and their carers.
- To strengthen the individual and collective expertise of our members and to ensure dissemination of this expertise by holding an annual scientific meeting
- To promote educational research in partnership with clinical disciplines and practitioners

### **Sister Organisation**

The American Association for Cancer Education: the AACE

### **Activities and Range of Services Available**

- Hold an annual scientific meeting
- Publish with the AACE, the Journal of Cancer Education four times a year
- Have an exchange agreement with the AACE so that members of either association can attend scientific meetings at a reduced registration fee
- Identify members with similar interests and facilitate opportunities for networking

### **Resources**

- An active Executive Board
- Journal for Cancer Education
- Reduction in registration fees for both EACE and AACE annual scientific meetings

### **Action Plans**

- To seek to develop appropriate opportunities for educational research and development proposals for external funding
- To ensure effective working communications between the Executive Board, local planning committees, members and prospective members to support local initiatives under the auspices of EACE.

### **Membership**

Membership of the Association is open to all individuals in any area of cancer education

Applications for membership should be made to the Secretary of the EACE

### **The Journal of Cancer Education**

The Journal of Cancer Education (JCE) is the official journal of the AACE and EACE. Of the many journals devoted to cancer, only JCE deals with the cancer education of students, practitioners, patients, and the community. Its readership includes physicians, dentists, nurses, allied health professionals, educators, students and social workers.

#### *The Journal*

- Reports results of educational research
  - Examines the management of cancer patients
  - Evaluates undergraduate, and postgraduate education programmes.
- Regular features include original reports, commentaries, book and media reviews, and announcements of educational programmes, fellowships and grants.

#### *Selected articles from Journal of Cancer Education*

- Breast self examination amongst Swedish women. A survey of frequency, knowledge and attitudes.
- Topic selection in undergraduate medical cancer education and the relevancy to general practice.
- Problem based learning in Dentistry.
- Psychosocial effects of level of information and severity of disease and head and neck patients.
- A cancer prevention intervention for disadvantaged women: design and implementation.
- Racial/ethnic factors in skin cancer detection
- The UICC/WHO-CCCE cancer education project for medical schools. A different approach.
- Using the hypertext software to develop computer assisted instruction for medical students.
- Cancer education and school teachers in England and Wales.
- Continuing medical Education through the videotex system in Italy.

### **Scientific Meetings**

The EACE holds an annual scientific meeting each spring: the AACE in the Autumn. Members are urged for both associations to present papers/posters on new and innovative techniques in cancer education for health profession students, practicing health professionals, cancer patients, and the general public.

**In Memoriam:**

**Professor Ullabeth Sätterlund Larsson**

**1939 - 2004**

*It is with sincere sorrow that we notify you of the death of Professor Ullabeth Sätterlund Larsson. Ullabeth has passed away at the age of 65 after a year of struggling with cancer disease. Our sympathies go to her husband Lars and their daughters Maria and Kristina with their families.*

*Ullabeth was professor at the Institute of Health Care Pedagogics at the Sahlgrenska Academy, Göteborg University, Sweden, and also assistant dean at the new Faculty of Health and Caring Sciences. She belonged to the first generation of Swedish nurses, who achieved a doctoral degree and made an academic career.*

*She got her nursing degree in 1961 and was educated as a nursing tutor in 1965 in Göteborg at the institute that later became the Institute of Health Care Pedagogics, where she was employed as the head of department during 1979-1983.*

*She finished her doctoral studies in 1989 at Tema Communication Studies, Linköping University and defended her thesis "Being Involved – Patient Participation in Health Care". After her public defence, she was employed as a senior lecturer of communication at Linköping University, where she also became an associate professor in 1994. She has worked as a research assistant at the Swedish Medical Research Council and been a research fellow at Clark University, Worcester, USA, where she started to build up a large international network.*

*In 1994 she was back at the Institute of Health Care Pedagogics in Göteborg and contributed with her enthusiasm and skills in building up the doctoral programme in health care pedagogics as a research supervisor, teacher and also as head of the department.*

*Ullabeth was the president of European Association for Cancer Education between 1995 and 1997. She hosted the first Swedish EACE meeting in Linköping 1993 and she was an active member of EACE and attended EACE and AACE meetings regularly.*

*During 1997-1999 she was the Director of Research at Vänersborg University College of Health Sciences and in 2000 at The University of Trollhättan/Uddevalla*

*In 2000 Ullabeth became a full professor of Health Care Pedagogics at Göteborg University. Her research focused mainly on communication, health and life style. She has supervised a large number of PhD-students who now carry on her research legacy. From 2002 to 2004 she was head of a national research platform at the Swedish Vårdal Institute.*

*Just after the 16<sup>th</sup> annual scientific meeting of the EACE in Trollhättan, Ullabeth got a cancer diagnosis. She tried to fight the disease, and although surgery, chemotherapy and radiation therapy made her last year very difficult, she went on with the work she loved so much. We will remember her as a good friend with great courage, enthusiasm, and determination.*

On behalf of the president and the Board of the European Association for Cancer Education  
Regina Nobis, friend and Vice President EACE

# **Conference Programme**



**Wednesday 27<sup>th</sup> April**

**16.00 – 18.30**      **Registration opens**

**Venue: Copthorne Hotel  
Paradise Circus  
Birmingham**

**Tel + 44 121 200 2727**

**19.00 –21.30**      **Social programme – Birmingham Canal Boat Trip - see  
conference registration form**

Delegates joining this social event should be in the reception of  
the Copthorne Hotel at 19.00

Boat trip includes light buffet foods

## Thursday 28<sup>th</sup> April- Morning Sessions

- 08.00** Registration opens  
Access for posters
- 09.00 - 10.35** **Conference Opening and Welcome**  
**Chairs:** Heather Mercer (UK), President of EACE and Doug Ross (USA), President of AACE
- 09.10 - 09.20 **Welcome by Professor Stewart Buchanan** – Dean of Faculty of Health and Community Care, University of Central England, UK
- 09.20 - 09.50 **Opening Keynote Address: the Hon. Dr Ian Gibson** Chair of the All Parliament Cancer Group for HM Government UK
- 09.50 - 10.30 **Keynote Address: Marie Curie Cancer Care: Learning to Practice**  
**Anita Roberts** Senior Lecturer, Education, Marie Curie Cancer Care, Liverpool
- 10.30 - 10.35 **Tribute to Professor Ullabeth Sätterlund Larsson** Regina Nobis (SE), Vice President of EACE
- 10.35 - 11.00** **Coffee/ tea and poster viewing**
- 11.00 - 12.35** **Session 1: Chairs Sharing Information / Research and Evaluation**  
**Chairs:** Regina Nobis (SE) and Alex Stewart (UK)
- 11.00 - 11.20 **Inger Sandén (SE):** A case study of the experiences of living in a disrupted situation
- 11.20 - 11.40 **Sylvia Vonk-Klaassen (NL):** An inquiry into the construction and implementation of a regional network for Palliative Terminal care
- 11.40 - 12.00 **Ruth Sewell (UK):** The emotional (typo)responses in women with primary breast cancer, treated with radiotherapy following conservative surgery
- 12.00 - 12.20 **Grace Adamson Gawler (AUS):** Breast cancer and supportive care
- 12.20 - 13.40** **Lunch**

## Thursday 28<sup>th</sup> April Afternoon Sessions

- 13.40 – 14.15**      **Poster viewing and judging by all delegates**
- 14.15 - 15.50**      **Round table: Changing Roles: the Implications for Cancer Education**  
**Chairs** Alex Stewart (UK) and Prgina Nobis (SE)  
**Participants:** ***Jean-François Heron (FR), Truus Spijker (NL), Douglas Ross (USA), Candy Cooley (UK) Graham Dark (UK)***
- 15.50 - 16.20**      **Tea / poster viewing and judging by all delegates**
- 16.20 - 18.10**      **Session 2: Education and Training/ Communication with Patients**  
**Chairs:** Charles Kelly (UK) and Jakob de Vries (NL)
- 16.20 - 16.40      ***Sara Faithfull (UK):*** The Role of the European Oncology Nursing Society (EONS): Accreditation and Core Curriculum in the Developing Oncology Nursing in Europe
- 16.40 - 17.00      ***Karen Cook (UK):*** A retrospective case note review of the experiences of carers caring for palliative care patients with primary malignant glioma
- 17.00 - 17.20      ***Murtaza Faizi (IN):*** A survey (Space) of knowledge, attitudes and practices of cancer basics: comparison between specialist and general medical practitioners in urban India
- 17.20 - 17.50      ***Melany Cueva (USA):*** Penetrating the silence of cancer: using theatre in Alaska
- 17.50 - 18.30**      **Poster viewing and judging by all delegates**
- 19.30 - 20.30**      **Lord Mayor's Reception,  
The Banqueting Suite, Birmingham Council House** (map in folder, or meet in Copthorne Hotel reception 19.15)

## Friday 29<sup>th</sup> April Morning sessions

- 09.00 - 09.40**      **Keynote address: Changing Needs of patients and Carers: the Implications**  
**Dame Gill Oliver**, Advisor for Nursing and Allied Health Professionals, Macmillan Cancer Relief, UK  
**Chairs:** Regina Nobis (SE) and Candy Cooley (UK)
- 09.40 - 10.20**      **Session 3: Education and Training**  
**Chairs:** Darren Starmer (Aus) and Brian Nyatanga (UK)
- 09.40 - 10.00      **Douglas Ross (USA)** : Training program in palliative and end-of-life care for internal medicine residents at an American training school
- 10.00 - 10.20      **Cathryn Havard (UK):** Understanding and developing Competence in Specialist practice- A Survey of Post-Qualified nurse undertaking continuing professional development (CPD) modules in cancer and palliative care
- 10.20 - 10.40      **Pat Turton (UK):** Bridging the Gap – the development of a continuing professional education (CPD) programme for complementary therapists working in the cancer field.
- 10.30 - 11.00**      **Coffee and poster judging by all delegates**
- 11.00 - 11.40**      **The Millie Haagedoorn Lecture: Pat Webb Principal lecturer and Editor**  
**Chairs :** Heather Mercer (UK) and Douglas Ross (UK)
- 11.40 - 12.50**      **Session 4: Education and Training**  
**Chairs:** Charles Kelly (UK) and Carolyn Messner (USA)
- 11.40 - 12.00      **Kate Jones & Rev. David Mitchell (UK):** On-line Learning: Innovative assessment at Masters Level in Palliative Care and Applied Education
- 12.00 - 12.20      **Debra Sprague (UK):** Nurse Prescribing: its impact on education and training
- 12.20 - 12.40      **Sarah Heatley (UK):** The importance of integrating understanding of audit within a web-based MSc module on oncology practice development
- 12.40 - 12.50      **Richard Bakermeier (USA):** The Journal of Cancer Education: the Editor speaks
- 12.50 - 13.50**      **Lunch**

## Friday 29<sup>th</sup> April Afternoon Sessions

- 13.50 - 14.15**      **Poster viewing and judging by all delegates**
- 14.15 - 15.45**      **Session 5: IT Workshop**  
**Chairs:** Jean-François Heron (Fr) and Richard Bakemeier (USA)
- Darren Starmer (AUS):*** Virtual Nursing Education- Web-based continuing education
- Graham Dark (UK):*** The development of just-in-time learning applications: Creation of an on-line medical dictionary service.
- Nigel Wynne (UK):*** Developing a Virtual Ward
- Paul Batholomew (UK):*** Moodle
- 15.45 - 16.00**      **Coffee and tea**
- 15.45 - 16.00**      **Session 6: Research and Evaluation**  
**Chairs:** Jakob de Vries (NL) and Brian Nyatanga (UK)
- 16.00 - 16.20**      ***Hilde de Vocht (NL):*** Using an instrument to tailor palliative care to the needs of cancer patients and their relatives: a feasibility study
- 16.20 - 16.40**      ***Maria Vincent (UK):*** Developing services for Thyroid Cancer patients who require radioactive iodine ablation (I131): The impact of user involvement
- 16.40 - 17.00**      ***Jo Hanson (USA):*** Cancer End of Life Care Evaluation: Using Chart Audit and Case Analysis Reports
- 17.00 - 17.20**      ***Catherine Jörn (SE):*** Narratives: A road to knowledge and understanding oncology nursing
- 17.20 - 18.00**      **EACE AGM – conference suite**
- 19.30**              **EACE dinner – Copthorne Hotel – see conference registration form**

## Saturday 30<sup>th</sup> April Morning sessions

- 9.30 - 10.45**      **Session 7: Sharing Information/ Education and Training**  
**Chairs:** Regina Nobis (SE) and Joy Notter (UK/NL)
- 09.30 - 09.50      **Carolyn Messner (USA):** The Efficacy of teleconferencing to disseminate cancer education to patients
- 09.50 - 10.10      **Ralph Spijker (NL):** Depression in Oncology; spaceA patient just being gloomy or a special field of attention within caring processes?
- 10.10 - 10.30      **Sabine Muschovitz (AT):** International Summer School on Experimental and Clinical Oncology for Medical Students:space  
The 4 years experience of an Austrian Cancer Education project
- 10.30 - 10.50      **Jakob de Vries (NL):** Designing an oncology course in a competency based curriculum
- 10.50 - 11.10**      **Coffee and tea**
- 11.10 - 12.00**      **Session 8: Education and Training**  
**Chairs:** Charles Kelly (UK) and Truus Spijker (NL)
- 11.10 - 11.20      **Liz Travers (UK) :** Work based learning in Cancer and Palliative Care Education
- 11.20 - 11.40      **Jean-François Heron (FR):** When a website conceived for students becomes an information tool about cancer for the general public
- 11.40 - 12.00      **Graham Dark (UK):** Interface of technology developments and educational pedagogy in cancer education
- 12.00-13.00**      **Closing session**  
12.00-12.40      **Closing Keynote address: Does Teaching on Patients Harm Them?**  
**Professor the Baroness Finlay of Llandaff, Wales**  
**Chairs** Heather Mercer (UK) and Doug Ross (USA)
- 12.40-14.45      **EACE 2006**
- 12.45-12.50      **AACE 2005**
- 12.50              **Closure of Conference: Heather Mercer**  
**President of EACE**
- Afternoon/  
evening**              **Social programme – Swan Theatre at Stratford upon Avon –  
Play Sir Thomas Moore – see conference registration form**

## **Biographies of keynote Speakers**

## **The hon. Dr Ian Gibson**

Ian was born in Dumfries and educated at Dumfries Academy, followed by Edinburgh University where he gained his PhD. He has experience researching and teaching in the USA, New Zealand, Portugal and has been involved in many symposia and lecture tours across the world.

His major interest was biomedical research and genetics with a particular interest in the molecular biology of cancer. He was Dean of Science at the University of East Anglia in Norwich, where he led a research team investigating various forms of cancer, including leukaemia, breast and prostate cancer. He then became MP for Norwich North in 1997

In the UK Parliament he has specialised in medical science and related areas, serving on a range of committees including the Chairing the Select Committee on Science and Technology, and is currently Chair of the All Parliamentary Group on Cancer

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## **Anita Roberts**

Qualifications: MSc, BSc (Hons), Dip HE, RGN, RSCN.

Anita Roberts is Senior Lecturer with responsibility for National Projects within the Education Service of Marie Curie Cancer Care, and is based at the Education department at the Marie Curie Hospice in Liverpool.

Current projects she is involved with include the Liverpool Care Pathway Project and Advanced Communication Skills Training Project. She has worked for Marie Curie Cancer Care for almost 20 years and before joining the Education Department worked as a Ward Manager at the Hospice.

Over the past 11 years she has been involved in research studies which look at the process of communication in palliative care as well as teaching communication skills to health care professionals. She has always been interested in end of life issues and the role communication plays within healthcare in general and this has led to a developing interest in the ways in which communication is used and particularly in the palliative care setting. She is about to start a 2 year secondment with the Cheshire and Merseyside Strategic Health Authority as Programme Lead for the End of Life Initiative



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## **Dame Gill Oliver**

Gill Oliver trained as a nurse at the Middlesex Hospital in London, and has worked both as a night sister and ward sister in a regional oncology centre in the North West of England.

In 1987 Gill was seconded to the Royal College of Nursing where she held a national role as Acting Advisor in Oncology Nursing and in 1989 she returned to a Macmillan funded post at the Mersey Regional Health Authority with a cancer and palliative care remit. When Clatterbridge Centre for Oncology became a National Health Service Trust in 1992 she joined the Trust Board, becoming Director of Patient Services.

Gill has been involved with planning and strategy groups at local and national level and was a member of the Department of Health group that produced "*A Policy Framework for Commissioning Cancer Services for England and Wales*".

Gill joined Macmillan Cancer Relief, one of UK's two largest cancer care charities, in April 2000 in the new position of Director of Service Development and was responsible for expanding and developing Macmillan services for people affected by cancer. She continued to contribute to policy and strategy development both within Macmillan and in partnership with the Department of Health. In October 2004 Gill retired from her full time post but continues to work for Macmillan Cancer Relief in a part time consultancy capacity as *Advisor for Nursing and Allied Health Professionals*.

## **Professor the Baroness Finlay of Llandaff**

Ilorá Finlay has been Vice Dean in the School of Medicine, Cardiff University since August 2000. She is Professor of Palliative Medicine and has worked with Marie Curie Cancer Care since 1987. She was a member of the Expert Advisory Committee on Cancers to the Chief Medical Officers of England and Wales, producing the 'Calman Hine' report in 1995.

Since her elevation to a Peerage in 2001, she has been actively involved in debates on health issues, particularly the Tobacco Advertising Act. She is a Member of the Select Committees on Science and Technology, enquiries include: 'Fighting infection' and "Aging", and on the Assisted Dying for the Terminally Ill Bill.

She is a member of the international scientific expert panel of the Cicely Saunders Foundation.

She is President of the Association of Chartered Physiotherapists, MS Cymru and Patron of Shalom Hospice, Wales. She was Welsh Woman of the Year 1996-97 and has held Visiting Professorships at Groningen University (Johanna Bijtel Chair), and University of Melbourne.

She has published and lectured widely on palliative care, and researched into aspects of cancer palliative care. She established the internationally renowned Certificate Diploma/MSc distance learning courses in palliative medicine at Cardiff University, from which over 800 senior clinicians worldwide have graduated.

## **The Millie Haagedoorn Lecture**

Dr E. Milly L. Haagedoorn MD after working as a GP and a surgical resident, has been a full time cancer educator for over 20 years, first at Leiden University, then at the Netherlands Cancer Institute in Amsterdam. She presented her PhD thesis about the 'Aspects of Cancer Education for Professionals' at Groningen University Faculty of Medical Sciences. She then moved on to be assistant professor for cancer education at the department of Surgical Oncology of Groningen University until her retirement in 1997. She is still, however, very active in the UICC/WHO-CCCE project, with Dr Jakob de Vries and remains the heart and soul of the EACE. She is the author of many articles, and several books about cancer education, both in Dutch and English.

In 1987 Dr Haagedoorn was one of the founders of the European Association for Cancer Education (EACE). In 1997, in consideration for her tremendous work for cancer education, she was invited by the Board of this Association to give her name to an Annual EACE lecture. The condition was that the speaker could be from any health profession, and should be a young professional who is doing outstanding work in cancer education.

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## **Pat Webb**

Pat has worked in the cancer field for most of her professional life and, in the last 10 years has developed also into palliative care. Her current post involves working with medical, nursing, midwifery and radiography *students* and with those same groups as they pursue their continuing professional development or post-graduate studies.

Research interests include healthcare ethics, older people and cancer and patient information and education.

Amongst other publications she is Editor of 'Ethical Issues in Palliative Care'(Radcliffe Medical) and the multiprofessional, peer-reviewed journal, 'European Journal of Cancer Care'(Blackwell Publishing).

**Abstracts**  
**For Podium Presentations**  
**Thursday 28<sup>th</sup> April**

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**A Case Study Of The Experiences Of Living In A Disrupted Situation**

New knowledge has been gained during the last years about how close relatives re-orient themselves and handle their life situation when facing close relatives' illness. In this case study, a young woman's experiences of living along side with her loved one, a man with testicular cancer are revealed. The case was scrutinised in a narrative analysis.

**Aim**

The aim of this study was to describe the lived experiences of living in a disrupted situation.

**Method**

The method was a conversational interview using a semi-structured guide with open ended questions.

**Results**

The results revealed four major themes, namely: the shared self care, the restricted space, the saving of energy, and the shortness of time. The developing of self care was gained through implementing different activities related to the care of the diseased man. The young woman's existence was heavily changed and framed in a treatment trajectory that became identical with her own needs to be with her fiancée.

**Conclusion**

A single case cannot be representative for all relatives' experiences, but this analysis has essential characteristics related to the four existential conditions; communality, spaciality, commonality and temporality, for how a young woman understands her disrupted situation by which future cases can be defined. This will deepen the knowledge about the awareness of meeting relatives in a disrupted situation

Key words; cancer, case study, disruption of life, existential conditions, narrative

## **An Inquiry Into The Construction And Implementation Of A Regional Network For Palliative Terminal Care**

Following the establishment of a regional alliance for palliative care, it was agreed that there needed to be a regional network to improve palliative terminal care. Establishing networks in palliative care is a comparatively new development in the Netherlands. Therefore prior to developing the network, preliminary investigations were necessary. Literature searches were made. Firstly, to explore the theoretical frameworks regarding the origin and meaning of networks as a remedy for improving palliative terminal care. Secondly to identify the factors impacting on the success or failure of networks. To test these out the preliminary findings a pilot/case study approach was carried out.

The outcomes from the searches and the case study were used to design a feasibility study to ascertain the views of healthcare providers and users in the region.

As participation is a key element in the success of a network, the feasibility study was based on an action research approach. Using focus group interviews, the study focused on identifying which of the factors (as seen by the participants) would influence the success and/or failure of the establishment of a network specifically designed for this region. The outcomes from these consultation based interviews have been used to develop a model for the optimum construction of a network which is now in the process of implementation. This paper presents the research process used, the main results and describes the model now in use.



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## The Emotional Responses In Women, With Primary Early Breast Cancer, Treated With Radiotherapy Following Conservative Surgery

Breast cancer is the most common cancer in England and Wales, 1 in 9 women will develop the disease in her lifetime. In 2000 there were 36,000 new cases diagnosed which represents 30% of all cancer in women at a rate of 114 per 100,00 women, with up to 13,000 women dying each year as a direct consequence of breast cancer. The current directive of the Department of Health sets a target standard within the National Health Service of 31 days between the times a woman receives her diagnosis to the commencement of treatment.

This presentation is a reflection of the findings from a prospective qualitative study of nineteen women and their experiences of receiving a diagnosis of primary early breast cancer subsequently treated with two forms of radiotherapy, external and interstitial following breast conservation surgery. The primary aim of the study sought to explore the function of information specifically related to the participating informants understanding of and actual experiences of treatment. However in the process of qualitative inquiry and in the asking of personally relevant and sensitive questions of research participants there was a natural yielding of answers and insights into other aspects of the participants lives.

The presentation will therefore reveal not only the function and impact of treatment sensitive information but will also illuminate those other aspects that were individually and collectively highly integral and significant as each woman encountered a life threatening diagnosis. There will be specific reference made to the stress and traumatic impact of diagnosis and role of hope and faith in restoring some sense of coping and adjustment. However what is highly significant is that despite all treatment and the individual means of coping and adjusting life for each woman in this study was for ever changed, life was 'never the same again'. For some women coping and adjustment was positive while for others it summoned a time of great and perpetual suffering and distress.

It is evident that the means of coping and adjustment at the time of and on from diagnosis may have an impact on the individual's changes of survival.

This presentation will conclude with recommendations for current clinical management and psychological care of women at the time of diagnosis and treatment with particular reference to cancer induced post traumatic stress disorder along with recommendations for ongoing research.

### References:

- Adamson G. (2003) *Women of Silence: Reconnecting with the emotional healing of breast cancer*. UK. Highclere Ltd.,  
Cordova M.J., Cunningham L.C., Carlson C.R., Andrykowski M.A. (2001) Post traumatic growth following breast cancer: a controlled comparison study. *Health Psychology* 20 (3): 176-185.  
Cunningham A.J., Watson K. (2004) How psychological therapy may prolong survival in cancer patients: new evidence and a simple theory. *Integrative Cancer Therapies* 3 (3): 214-229.

## Breast Cancer and Supportive Care

### Motivation

Observations were gathered over a thirty year period in a cancer support environment with more than 10,000 patients; in particular women with breast cancer that attended gender specific support groups and residential support programs.

### Problem statement

The current *systems* of medicine still have difficulty integrating the holistic-support concept into mainstream. There are many 'gaps' that require bridging. How can we affect change?

### Approach

Using a feedback model from support groups and questionnaires, the aim was to discover what women with breast cancer needed, what was available to them, what was not, and what new life skills helped them.

### Results

The supportive care approach resulted in demonstrable affects on life quality, quantity and healing environments. The result of my *Women of Silence: Reconnecting with The Emotional Healing of Breast Cancer* (Pub. UK 2003), discusses the importance of the supportive approach to women with breast cancer.

### Conclusions

Motivated by results of supportive interventions, The College of Supportive Care Medicine was founded. If we are to *effectively support* patients, we must provide knowledge and train health care providers in how to implement supportive care methods. This will have significant and far-reaching consequences



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## The Role of the European Oncology Nursing Society (EONS): Accreditation and Core Curriculum in the Developing Oncology Nursing in Europe

The European Oncology Nursing Society was set up in 1984 as "the Fellowship of European Oncology Nursing Societies". One of the Society's most important educational activities is the accreditation of continuing education courses. The ultimate aim of accreditation is to improve the quality of continuing education courses offered to cancer nurses throughout Europe. In 1991 the core curriculum in oncology nursing was developed to provide a framework to enable the development of cancer courses within Europe which would prepare nurses to care for patients with cancer and their families across a range of different settings. This was revised in 1998.

This framework outlined the minimum standards for a post-registration course in cancer nursing. It was not intended for use in the development of courses in cancer nursing at an advanced level, but to provide an initial training for the specialty. Since 2000 there have been 22 professional accreditations given by EONS, 7 of these are attached to long courses, 7 short courses and 8 accreditations have been given for study days and conferences.

The core curriculum provides a guide for developing long courses with learning outcomes attached to the whole programme rather than specific content or areas. This creates problems in evaluating short programmes and educational study days. The level of this education is not defined in any competencies for professional practice or in the academic assessments that are used to provide evaluation of knowledge.

A recent review of annual cancer course programmes accredited with EONS highlights that assessment of practice is uncommon and that competencies are not routinely assessed as part of professional courses in many countries. Part of the initial brief for the core curriculum was to facilitate the development of cancer nursing professional programmes to influence practice.

Future developments are now focusing on providing information for educators and professionals wanting to apply education into practice and a revision of the core curriculum has been undertaken to reflect this changing focus. EONS strives to develop educational materials and provide resources for educational initiatives that will support member societies and the changing nature of cancer nursing as a speciality within Europe.



## **A Retrospective Casenote Review Of The Experiences Of Carers Caring For Palliative Care Patients With Primary Malignant Glioma**

This abstract presents the findings from a retrospective casenote review of patients with primary malignant glioma (PMG) referred to a hospice service over the period of one year.

Survival for people with PMG is limited, with treatments palliative rather than curative. Patients with PMG may suffer multiple and complex symptoms making this group of patients unique. Responsibility for care provision at home lies, primarily, with those close to the patient. The provision of supportive hospice services for these families is largely unreported.

This retrospective casenote review arises out of a need to consider the specific needs of PMG patients and their carers within a palliative care service. It found that rapid illness trajectory and extent of disabling symptoms reflects other studies. The lack of rehabilitation services and the limited use of day care and respite beds reflects the limitations of healthcare provision.

The review highlights the high level of acute admissions and outpatient appointments for this patient group. This may reflect the level of carer burden and unique patient symptoms. Caregivers may undergo severe stress, which can affect the carers ability to care and offer emotional support. Brain tumour diagnosis can have a devastating effect on the family, leaving them in a state of crisis and feeling helpless, often attempting to shelter the patient from the enormity of their situation. When questioned, carers often relay the patients' experiences, rather than identifying their own needs. Little is known about the service requirements of these carers, and further study is needed to map carer experience, satisfaction and need, prompting the development of a study designed to discover the lived experience of the carers of PMG patients.



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## Developing Services For Thyroid Cancer Patients Who Require Radioactive Iodine Ablation (I131): The Impact Of User Involvement

**Aim:** To provide an insight into how service user involvement can be used to successfully facilitate service modifications

Thyroid cancer is the most common endocrine malignancy in the UK with 0.7 per 100,000 males and 1.9 per 100,000 females diagnosed every year. Thyroid cancer in the young is associated with an excellent prognosis and only 9% of patients die as a result of their disease. The most common treatment is surgery (thyroidectomy) with a high proportion of patients requiring I131 to reduce the risk of local recurrence and improve survival (NCN 2000). The disease is associated with significant physical and psychological morbidity exacerbated by short term radiation protection issues associated with the administration of I131. A specific area of concern for patients revolves around the requirement to be nursed in a lead lined room for several days with minimal contact with staff or visitors (Stajduhar et al 2000). In the past this has been referred to as 'nursing patients by neglect'. The central theme underpinning the reform of health care services has been the emphasis on consulting patients, involving them in the shaping and redesigning of local services (DoH 2000 a & b) (Cancer Services Collaborative 2004). It is acknowledged that because patients have 'been there' they are able to suggest things that others may not think of and this sharing of experiences can be used to benefit others (DoH 2003)

### Key milestones

Audited access to patient information and support - pre and post diagnosis and pre I131 treatment.

Undertook a service review and in collaboration with ALL key stakeholders and considered options for service improvement included:-

Improved the treatment environment - décor and access to resources

- Improved visiting arrangements – time and visiting area
- Addressed areas of potential risk for patients nursed by 'neglect'
- Review of medical, nursing & medical physics documentation
- Ongoing review of education / training for all staff groups
- Improved access to support for patients – Inception of first UK support group for thyroid cancer patients and successfully negotiated a Macmillan CNS post for the Northern Cancer Network (NCN)
- Improved access to patient information across the NCN

### Learning outcomes

- To have a basic understanding of the management of thyroid cancer
- To be aware of some of the problems and challenges associated with I131 treatment
- To demonstrate how service users can facilitate the development of services focusing primarily on environment, processes and education.
- To demonstrate the benefits of multi-professional, multi centre involvement / working.

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Stajduhar KI, et al (2000) Thyroid cancer: patients' experiences of receiving iodine-131 therapy. *Oncology Nursing Forum*, vol. 27, (8):1213-8

## Penetrating the Silence of Cancer: Using Theatre in Alaska

*Understanding*, a 45-minute play was developed to begin a dialogue about cancer among Alaska Natives (AN). Cancer, currently the leading cause of mortality among AN was considered a rare disease in the 1950s. *Understanding* explores the challenging themes of cancer diagnosis, treatment, pain management, and loss and grief. Healthy life style choices and cancer screening exams are emphasized. Between March 2002 and September 2004, *Understanding* was performed 23 times. On written evaluations completed following the play, 92% of people reported feeling more comfortable talking about cancer, 68% shared they had learned about cancer and 65% wrote healthy ways they intended to change their behavior.

Based upon this positive response, the play was adapted for television in August 2004, to expand cancer knowledge and understanding to a wider rural Alaska audience. *Understanding: Stepping into the Light*, a 27-minute movie, is performed by an all-Alaska Native cast. Evaluation comments from six audiences who have previewed the movie since September 2004 will be presented. Preliminary data analysis revealed that 100% of audience participants liked the format of a theatre piece adapted for a movie, and 98% recommended the movie. 93% of people reported they felt more comfortable talking about cancer. Select evaluation comments: "The terrible part is not talking about it because of fear, shame, etc." "My sister died of denial of cancer. I wish she could have seen this 10 years ago." "I will never again be timid about talking about these issues with my family and friends."



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**Abstracts**  
**For Podium Presentations**  
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## Training Program In Palliative And End-Of-Life Care For Internal Medicine Residents At An American Medical School.

The practice of palliative and end-of-life care in the United States has been noted to have deficiencies, particularly in the areas of pain and symptom management and communication. To address these deficiencies, we are implementing comprehensive instruction in palliative and end-of-life care for our internal medicine residents. The first phase of this effort is a web-based learning program to establish a knowledge base from which clinical training exercises during the residency program will build skills. The web program contains six modules dealing with:

- 1) pain management;
- 2) management of symptoms other than pain;
- 3) communication;
- 4) psychosocial, cultural and spiritual issues;
- 5) ethical and legal issues; and
- 6) hospice care.

Each module contains a pre- and post-test based on content of the module. Upon completion of the course, each participant is asked to fill out a course evaluation on-line. Data regarding demographics, prior palliative care training, pre- and post-test scores, time spent using the course, and evaluation results are recorded in a database. At this writing (academic year 2004-05), all of our internal medicine residents have completed the course. In subsequent academic years, all interns will be required to complete the course in the first 6 months of their training. Evaluation data of this first cohort of residents to complete the course will be presented. Despite being time intensive – many residents spent 4 to 6 hours completing the course – the course was received very favorably, with nearly all participants agreeing or strongly agreeing that the information was applicable to their clinical practice, and valuable to their education/training as a physician. We conclude that mandatory training in end-of-life care for internal medicine residents is feasible, and perceived as valuable by the trainees.

Understanding and Developing Competence in Specialist Practice – A Survey of the Experiences of Post-Qualified Nurses Undertaking Continuing Professional Development (CPD) Modules in Cancer and Palliative Care.

Following on from the publication of the Calman Hine report (1995) and the National Cancer Plan (DoH 2000) there have been major changes and developments in the structure and organisation of services for the treatment of cancer in England. In order to deliver effective care and services against a range of national cancer standards, an educated and competent workforce is required. Both locally and nationally, work is being undertaken to develop and agree competencies in cancer care and practice for practitioners at all levels.

At the institution where this study was conducted, the achievement of a range of work-based competencies is a feature of professional practice modules in cancer and palliative care. These modules have evolved over a period of time and in their current format, have been undertaken by three cohorts of post-qualifying nurses. It was therefore opportune to conduct a review of the student experience of these modules, in order to inform future module and programme design and ensure their relevance to service developments in cancer care.

The study utilised a survey design to carry out an audit of three cohorts of post-qualified students (n=92) who had undertaken a professional practice module in either adult cancer care, child cancer care or palliative care. A questionnaire was used to elicit information about the experience of using a competency-based assessment tool and a portfolio of learning as part of the assessment of professional practice. Data were analysed using the Statistical Package for Social Sciences (SPSS) and a thematic analysis of qualitative data was conducted.

Although not statistically significant, the responses overall indicated a positive approach to the usefulness of the tool in helping students identify and develop a range of competencies relevant to their specialist practice. The role of the work-based mentor was identified as being central to this process and students also recognised the usefulness of support from academic staff and designated study days. It was further identified that the development of a portfolio and a range of evidence to support the achievement of competencies represented a significant amount of work which needed to be valued and supported. This is consistent with issues identified in the preliminary literature review which highlighted the importance of effective facilitation by work-based mentors and academic staff and the need for a strong personal commitment on behalf of the student.

Although this study is limited due to a low response rate (32%), the findings have provided a useful insight into the experience of practitioners to inform a further phase of the study. This will focus on selected interviews with students and mentors and documentary analysis of portfolios and the supporting evidence. In this way it is hoped to further explore the support needs for both students and mentors and incorporate these elements into future modules and programmes. A further issue is the need for rigour and consistency in the assessment process and clarification about the amount and quality of evidence that is presented. This represents a challenge and an opportunity for both educationalists and service-based colleagues to develop effective documentation systems and to explore the possibility of new roles and programmes to support learning in practice.



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**Bridging the Gap – the development of a continuing professional education (CPD) programme for complementary therapists working in the cancer field.**

This presentation describes the development of the 'Certificate in Working with People with Cancer', a continuing professional development (CPD) programme for complementary therapists working in the cancer field. It was developed in response to a perceived need arising from the growth in use of complementary therapies by people with cancer, coupled with the national policy drive to promote the regulation of complementary therapies and the development of the NICE Guidelines for Supportive and Palliative Care in Cancer

Mainstream healthcare professionals are rightly concerned regarding the level of training and awareness of complementary practitioners, and their concerns can pose a barrier to the integration of complementary therapies within programmes of supportive care. In addition, therapists can lack confidence in how to set about providing a service, and can be unaware of many of the issues, both personal and professional, which confront those providing care for people with serious and possibly life-threatening illness.

This certificate course addresses both of these issues. It comprises 6 taught days, and the submission of a Reflective Portfolio relating to the topics of the taught days. The Certificate can be taken either as a Bristol Cancer Help Certificate, or, with an additional assignment, be taken as a work-based module accredited by the University of the West of England.

The presentation will outline the development process, and report on the uptake and results of the first two years. It will conclude with some reflection on possible future developments, needs for the provision of truly integrated support and areas of potential research.

## On-line Learning: Innovative assessment at Masters Level in Palliative Care and Applied Education

This session introduces the development of a palliative care pathway on an existing Masters Programme. It includes an analysis of the market research suggesting a blended learning approach, the development of content materials and the essential support of on-line learning advisors for platform design and on-line activities.

The innovative assessment design, based on a Reflective Learning Journal, integrates the on-line activities and evidence of student development within the module assessment. The session includes an overview and evaluation of the student and lecturer experiences, and makes recommendations for developing integrated forms of assessment and encouraging student participation within on-line learning.

### Reflective Learning Journal

A portfolio style journal which includes the evidence/activities engaged in on-line throughout the module. Presented in an individual format the assessment follows the sequence of the module units building up the evidence of reflection and learning.



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### **Nurse Prescribing: the impact on education and training**

'Nurse Prescribing has contributed to transformation in nursing practice in cancer care in the UK and, with further legislation afoot set to expand nurse prescribing, the scope for role development remains exponential'.

This paper focuses on the highly dynamic development of Nurse Prescribing within cancer care, in the fields of both oncology and palliative care. The development and history of non-medical prescribing in the UK will be described, as will the educational process of Nurse Prescribing, from both the university and clinical perspectives.

The concepts of Independent and Supplementary Prescribing and of Patient Group Directions will be explained and contrasted in the context of oncology and palliative care and clinical examples of Prescribing Nurses' use of their prescribing skills in enhancing patient care and quality outcomes in cancer will be given.'

## **The Importance Of Integrating Understanding Of Audit Within A Web-Based MSc Module On Oncology Practice Development.**

Clinical governance is the process by which clinical management decisions are quality assured. Therefore, any development in oncology practice must be evaluated as part of this quality assurance process. Consequently, audit is essential for determining the impact and benefits of the development initiative. We have developed a web-based MSc module to teach oncology practice development, and clearly an understanding of audit is a key element. Not only can audit be used to ensure that new practice initiatives are meeting established standards, but audit also identifies the need for new practice.

This module was developed around the model of the audit cycle, focussing on the key stages of; setting standards, observing current practice, comparison between current practice and standards, implementation of change and evaluation of change through re-audit. The learning activities utilised the context of audit and the multi-professional status of the students and assessment focussed on their ability to design a proposal for practice development, and an audit plan to assess the practice development.

This paper describes the methodology and evaluation of integrating audit into a web-based Masters module on practice development within oncology.



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## **Virtual Nursing Education – Web-Based Continuing Education**

### **Introduction**

Continuing professional education has become an essential component of modern nursing. In addition to core competencies requiring continual refreshing, advances in knowledge and treatments have emphasised the importance of keeping abreast of the latest developments.

### **Why Virtual Education?**

Traditional nurse study days are often inflexible in their delivery, provide significant financial burden to the hospital and require repetition to ensure that all staff are catered for. Full and half day sessions require the nurse to abandon the bedside for the classroom, leaving the clinical area short staffed, or the hospital out of pocket in having to provide extra staff.

The Virtual Medical Centre.com is developing several suites of online educational modules for nurses to provide an alternative to current practices. Web-based delivery allows the nurse to access modules from any computer with internet capabilities and the flexibility to complete the modules at any time. Up to date information is accompanied by audiovisual aids and links to additional information. Pre and post testing provides evaluation of each nurse's progress and case studies allow application of knowledge to a clinical scenario

### **Conclusion**

Web-based educational modules provide a flexible, interactive and cost effective alternative to traditional continuing education sessions.

## **The Development Of Just-In-Time Learning Applications: Creation Of An On-Line Medical Dictionary Service.**

Busy healthcare professionals often encounter situations where they identify a gap in their knowledge, but do not have sufficient time to address this deficiency before the moment that they need the information. As a result there is considerable interest in developing e-learning resources, or access to information that can provide support in these situations.

There are essentially 2 approaches to this problem; provision of a specific learning application that provides the information in a structured manner, specific to the nature of the problems encountered, or alternatively provide a search engine that has previously indexed the available information. The second approach can result in an overwhelming number of links to possible solutions and may provide the intended outcome but not in the timeframe available.

We have developed a proof-of concept project to explore the first option in the creation and delivery of an on-line medical dictionary (OMD).

The OMD is available at <http://cancerweb.ncl.ac.uk/omd/> and currently delivers 12-14 million requests per month to a global audience. This paper will describe the development process, the management of intellectual property, administration of the service and evaluation of the utility of the service



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## The Virtual Ward: Real World Learning in Real World Contexts.

This workshop will provide delegates with an opportunity to experience a *Visual Learning Environment* known as the **Virtual Ward**. This web based multimedia application is being blended with traditional teaching methods in adult pre-registration nursing modules within the Faculty of Health and Community Care, University of Central England. The Virtual Ward aims better to prepare student nurses to assess, record and understand the significance of client information. Evaluation indicates that the context rich, practice focused environment it simulates increases students' intrinsic motivation and promotes a deeper approach to learning.

Key features of the virtual ward include:

- Video handovers of clients
- An assessment simulation
- The opportunity to access nursing and medical notes and charts
- Online discussion forums
- Self assessment multiple choice quizzes
- A student profile of progression within the virtual ward
- Access to module resources.

Students work and learn collaboratively through a combination of classroom, computer laboratory and plenary session activities. Because the virtual ward is delivered entirely online students have more flexible access e.g. from home and placement, to the learning opportunities presented.

The Virtual Ward was designed so that it could develop with and adapt to the frequently changing needs of practice. For example, the assessment parameters and values, MCQ questions and answers, and the charts can all be changed by academic staff without recourse to technical expertise.

Through an innovative collaboration with the Technology Innovation Centre at UCE, a software engineering student was able to provide the technical skills required to develop this work. This student is currently employed by the Faculty and is further developing this application with a wide variety of module teams. We hope in the near future to incorporate an oncology specific scenario within the virtual ward.

## Reclaiming the Classroom: A Blended learning Approach

### Aim

The aim of this project was to reclaim the classroom for the facilitation of sessions that would focus on knowledge application rather than knowledge acquisition.

Many educational programmes have significant amounts of core content that require communication to students. Student demand is such that this material is often delivered within the classroom via didactic means. The volume of such material may leave little space within a programme for the application and discussion of course content. Self-study time, when undertaken, is often used to reinforce this surface knowledge.

This project uses information technology to radically change the learning and teaching process. 'Information delivery' has been shifted from the classroom to the students' self study time using multimedia video lecture technology. Using this approach, students can study at their own pace, and the classroom contact time was thus freed up to facilitate a more interactive learning environment.

To further enhance the learning process, resources can be embedded within virtual learning environments or distributed to students on a CD ROM.



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## Using An Instrument To Tailor Palliative Care To The Needs Of Cancer Patients And Their Relative: A Feasibility Study

Although there are validated measures to assess various aspects of health and quality of life in the Netherlands there are still few validated measures that assess palliative care needs and wants from the patient's perspective. The Provincie Gelderland have therefore commissioned this study as a first step in the development of a standardised approach to assessing patient needs and wants in palliative terminal care.

### Aim

The aim of this study is to pilot a newly validated questionnaire for needs assessment in palliative care (Osse 2004)

### Method

The needs and wants assessment is based on the completion of comprehensive questionnaires, one for the patient, and one for the relatives. Already trialled in the community it is hoped that its use can be transferred to nursing homes and hospices.

Once completed the questionnaires are used to help healthcare professionals work with patients and relatives to identify unmet needs and to tailor care to the needs of the individual patient. To assess the effectiveness of this tool, a cohort 10 patients and their families have been selected, 5 in a nursing home (with a palliative care unit) and 5 in a hospice. Once they have completed the questionnaires, a series of semi-structured interviews are conducted with the patients, carers and care providers. These are designed to explore the practicality and appropriateness of the tool in each care setting.

### Results

This paper presents the first results of the study, together with some of the ethical issues that arose in planning and operationalisation.

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## **A Survey Of Knowledge, Attitude And Practices Of Cancer Basics: Comparison Between Specialist And General Medical Practitioners In Urban India**

The rising incidence of cancer has become an important factor in the global burden of diseases. The estimated number of new cases in the world each year is expected to rise from 10 million in 2005 to 15 million by 2020. Some 60% of all these new cases will occur in the less developed part of the world, India being one of them. To face this challenge newer medical educational and training strategies have to be formulated. This needs an initial assessment of knowledge, attitude and practices about cancer basics in specialist and general medical practitioners working in urban India dealing with patients having cancers.

A questionnaire based on random survey of two hundred doctors practicing cytopathology and histopathology in various hospitals in India was taken. This was compared with another random survey done on an equal number of doctors of those specialities who came in contact with cancer patients, although not as specialist oncologists viz. General surgeons, gynaecologists etc.

The survey brought out interesting similarities and differences in knowledge and facts and perceptions between the two groups. The results of this survey and its analysis will be presented with an indication about which way the medical education policy of developing countries should be directed to combat the problem of cancer.



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## Cancer End-Of-Life Care Evaluation: Using Chart Audit And Case Analysis Reports

Disseminating End-of-Life Education to Cancer Centers (DELEtCC), an interdisciplinary staff cancer educational project, is supported by the National Cancer Institute and presented by City of Hope National Medical Center. Two person teams participate in an intensive three-day course addressing palliative/end-of-life (EOL) care issues. Annual courses (2002-2004) averaged 48 insitutional teams per course.

### Methods

Prior to course attendance, teams completed a chart audit and case analysis of a cancer patient who has died within the last six months. Content includes patient and interdisciplinary staff description, symptom management, and EOL psychological items.

### Results

Attendance at case analysis averaged 4.7 interdisciplinary staff members. The typical patient was 58 years old and 56% were female. The average patient was in hospice 10.5 days and self-report of pain was 4.8 on a 0-10 scale (no pain =0). Data revealed that 17% of the patients were not identified as terminally ill, 18% of patients were unaware that they were terminally ill, while only 10% of the families were unaware. Besides pain the most common symptom at 96% was fatigue. 83% of the patients had DNR orders, but only 55% had advanced directives.

### Conclusions

Case analysis and chart audits provide valuable information in identifying EOL care issues as well as the baseline data for educational courses addressing the problem areas.

## **Narratives: A Road to Knowledge and Understanding for the Nurse in Oncology Nursing**

The significance of narratives in nursing is obvious. Narrative understanding is required for the appreciation of how experiences of illness and suffering, as well as of caring and nursing, affects the individual. However, the role of narratives in the nursing discipline is still in its infancy.

### **Aim**

The aim of this study was to elucidate the importance of narratives in oncology nursing.

### **Method**

The method used was literature review.

### **Results**

Five themes emerged as important for the understanding and knowledge of the patient's life-situation and experience of illness: content and delivery of the narrative, the patient's narrative, various carer's narratives, fiction and autobiographies, and the perspective of the narrative in nursing. Experiencing cancer and cancer therapy is a painful process. The need to narrate becomes urgent. The narrative is probably the most important road to knowledge of suffering and alleviated suffering. We need to develop methods for analysis of what the patient narrates, to be able to understand and interpret the narrative in an appropriate way. My contention is that 'narrative nursing' could be used as a concept, describing nursing that emanates from the patient's narrative and emphasizes the total narrative. I believe that narratives are important in the education of nurses and other professional caregivers. Narratives make the foundation in the nurse/patient relationship.



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**Abstracts**  
**For Podium Presentations**  
**Saturday 30<sup>th</sup> April**



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## Work based learning in Cancer and Palliative Care Education

This paper will explore the rationale behind the introduction of a work based learning module into an undergraduate cancer and palliative care programme of study. The module aim is to enable students to identify, implement and evaluate a relevant practice based initiative.

Work based learning approaches allow learning to be integrated into practice and provide opportunities for professional development (Flanagan et al 2000). The paper will include information on the learning and teaching approach and the assessment strategy which incorporates a portfolio of evidence and an executive summary of the initiative.

The paper will also provide an overview and evaluation of the student and lecturer experiences and offer an insight into the impact on clinical practice.

### References

Flanagan J. et al (2000) Work based learning as a means of developing and assessing nursing competence. *Journal of Clinical Nursing*. 9 (3) 360-368

## International Summer School On Experimental And Clinical Oncology For Medical Students: The 4 Year Experience Of An Austrian Cancer Education Project



### Introduction

Beginning in 1999, the 'International Summer School on Experimental and Clinical Oncology for Medical Students' was organised for four times (1999-2001, 2003) at the Medical University of Vienna by the Departments of Radiotherapy and Oncology in collaboration with the WHO-Collaborating Centre for Cancer Education in Groningen. The fifth summer school in Vienna will take place in July 2005 ([www.univie.ac.at/vsso](http://www.univie.ac.at/vsso)). The target group are medical students in the final phase of their studies.

### Methods

In the four courses, 106 students from about 18 countries participated. The programme included fundamental aspects of cancer biology, diagnostic work-up and clinical oncology. Lectures were given by medical oncologists, radiotherapists and oncological surgeons to outline the multidisciplinary management of cancer treatment. Teaching also included case reports prepared by students and role-plays. The teachers were members from the Medical University of Vienna. Additionally a guest professor from the University of Groningen was invited. A social programme was organised by Austrian students who were part of the organising committee.

### Evaluation

All courses were evaluated by the students. High scores concerning global usefulness, scientific content and range of subjects were attained. Criticism contained the tightness of the programme, long lectures (>45 min.) and too little interactive education

### Conclusion

Taking the results of the evaluation into account, the teaching programme is regularly re-evaluated and restructured: More interaction by increasing the case presentations and role-plays is being provided. The 2005 course will be extended to have more time for an interactive teaching programme and more space for learning, to maintain a high quality of teaching and a high acceptance.

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## Depression in Oncology;

### A patient just being gloomy or a special field of attention within caring processes?

Hearing the message that one is burdened with a diagnosis of cancer makes it completely understandable that a process of grieving will be part of one's present and possible future. All kinds of thoughts will go through one's mind and a process of 'healing and fighting' will start. In most cases the patient will become part of a strict therapeutically regime, in which the cancer need to be 'fought' at. The therapeutically options and measurements in combating the cancer process are not mild and will damage healthy tissues as well.

In only these four sentences several stressors which all belong to the therapeutically regime where a patient will become part of in oncology treatment illustrate the heaviness of this disease. And then the cancer itself and what it does to the body, is hardly mentioned. This presentation will not discuss the options and diversities of the disease and therapeutically measurements itself but will focus on one of the mental problems where at least 25% of all oncological patients have to deal with, a depression<sup>1</sup>.

Cancer, its treatment and factors within the patient himself can be seen as risk full factors which are related for developing a depression. Defining a depression seems to be an clear art in which one will follow, for example, the criteria of the Diagnostical and Statistical Manual of Mental Disorders 4<sup>th</sup> edition. But the actual situation will tell otherwise. The symptoms that belong to a depressive disorder are overlapping symptoms that belong to a disease like cancer. This will ask for another focus in signaling depressive symptoms within patient with cancer. The importance that nurses operating in the field of oncology have knowledge of the signs and symptoms of a depression and can identify some risk full factors will hopefully lead to a positive change in preventing patients from more suffering and hospitalization.

Also in signaling and solving problems within care giving, nursing interventions need to be differentiated on the bases of etiology. A patient suffering of pain is an example of a problem in which cancer is related to, but a depression can have great influence on the meaning and behavior of patients suffering from pain as well. Knowing what related factors are the foundation of care giving problems will mean that the interventions to be taken have a different focus within patient care. And that this has to be seen not only as a task but also as a challenge means that the complexity of this topic is high, and calls for more knowledge and strategies within the nursing process. Hopefully this all will lead to improvement of patient care and quality of life.

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## Designing An Oncology Course In A Competency Based Curriculum

The new Curriculum for undergraduate medical students in Groningen is based on 7 competencies :

1. Communication
2. Problem solving
3. Using knowledge and Science
4. Patient Investigation
5. Patient Management
6. Using the Social and Community context
7. Reflection

The oncology course for bachelor students has been designed in a three week training block and as usual there originally was a huge perceived discrepancy between *available* and *deemed necessary* training hours.

The decision process of selecting and allocating topics in conjunction with editing a textbook will be presented and is open for discussion with the audience

<http://www.rug.nl/med/onderwijs/g2010/index?lang=en>



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### When A Website Conceived For Students Becomes An Information Tool About Cancer For The General Public

Oncoprof.net is a French teaching website for medical students about general medical oncology. It is structured as a regular course with many explanation pages and picture or scheme illustrations, multi-choice questions and a downloadable text. However, most of the visitors are from the general public. We have used a statistical tool (E-Stat.com) since the beginning of the website publication.

From Jan 23<sup>rd</sup> to Dec 31<sup>st</sup> 2004, 108,000 different visitors consulted around 500,000 web pages. Visitors mainly originate from French speaking countries (85%). Most visitors read one page found using key words.

The study of visited pages permits a mirroring demonstration of the general public's need for information. The fields of interest are very diverse: from new technologies (PetScan, new drugs) to general descriptions of cancer (tongue cancer), from methods of prevention (PSA, alcoholism) or palliative care (mourning, clinical aspects of death). Compared to the high number of daily visits (around 1,000), the messages to the author are rare (4 per week), mainly requests for counselling. The impact of such a website in French is an invitation to study the possibility of translating it into English or Spanish, although the cultural differences would also have to be considered. A precise description of the Website visitors will be presented at the meeting



## **The Efficacy of Teleconferencing to Disseminate Cancer Education to Patients.**

This oral presentation will describe the efficacy of a fifteen-year project at CancerCare using free Telephone Education Programs to disseminate cancer education to 45,000 patients, families and healthcare professionals yearly.

Currently, cancer research is progressing more rapidly than its knowledge transfer to patients and their clinicians. The conceptual underpinning of CancerCare's Teleconference Project recognizes that cognitive mastery of cancer treatment, supportive care and latest research discoveries improve the ability of patients and their families to make informed decisions about their care. These public programs provide rapid access to current and novel research outcomes with the overall goal of reducing morbidity. The telephone is a ubiquitous and user-friendly tool for intervention.

The author will present qualitative and quantitative data, as well as a typology of consumer responses to these programs. The benefits and challenges of weekly cancer education programs to thousands of patients and their caregivers will be discussed. Utilizations of global communication technologies, including internet archive of these programs, can serve to decrease the isolation and suffering from cancer.



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## Interface Of Technology Developments And Educational Pedagogy In Cancer Education.

E-learning has been through a 'boom and bust', driven by exuberant predictions of e-learning impact and anticipated results. From the stages of early excitement, inflated expectations, and gradual disappointment into the trough of disillusionment that was experienced in 2002, we are now entering the period of quality applications that have refocused on good educational methodology.

What has been learnt is that the technology had been driving the learning applications and not the educational pedagogy. Fundamental principles for good teaching were being ignored and the participants soon tired of the approach and lost interest in the learning material. Quality was often overlooked and materials have lacked support and appropriate assessment of understanding and learning.

Early e-learning expectations did not correlate with outcomes and this has left a barrier to uptake of current e-learning offerings. The experience of designing, developing and bringing to market, the worlds first MSc in Oncology and Palliative Care, which despite the described climate is now a market leading product, has been a pioneering experience.

This paper will discuss the interaction between education and technology and illustrate the developments that have been driven by education and technology and suggest future directions for successful e-learning.

**Abstracts**  
**For Poster Presentations**

## Alphabetical List of Posters

1. Andersson, U., Nysten, M., Gatel, M. (Uddevalla hospital/ University of Trollhättan / Uddevalla, SE)  
***Cancer-Related Fatigue – A Nursing Problem For Both The Patient And The Nurse.***
2. Bukhari, D., (Sandwell and West Birmingham NHS Trust, Birmingham UK)  
***Hypercalcaemia.***
3. Dark, D., Earl, H.M. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Development Of An Outcome-Based Curriculum For Specialist Registrar Training In Medical Oncology In The UK.***
4. Dark, D., Heatley, S.J., Harbinson, S. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***The Development Of A Multi-Professional Web-Based Msc Module To Teach Skills To Undertake Research Within Oncology Practice.***
5. Dark, D., Earl, H.M. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Development of competency-based assessment methods for specialist registrars training in Medical Oncology.***
6. Dark, D. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Use of discussion board technology for cancer education within a managed e-learning environment***
7. Furphy, E. ( Oxford Radcliffe NHS Trust, UK)  
***The Research Into Prevention And Treatment Of Mucositis In Cancer Care Patients***
8. Grant, M., Hanson, J. (City of Hope National Medical Center, USA)  
***Evaluating Dissemination Of Education On End-Of-Life Care To Cancer Centres (DELEtCC).***
9. Heatley, S., Dark, D. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Clinical trials for cancer: Addressing patient information needs with the development of an assessment tool.***
10. Heatley, S., Harbinson, S., Dark, D. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Enhancement Of Learning And Understanding By Use Of Reflection During A Web-Based MSc Module On Oncology Practice Development.***
11. Heatley, S., Dark, D. (Centre for Cancer Education University of Newcastle upon Tyne UK)  
***Raising Awareness Of Oncology Clinical Trials Through Education: Extending The Role Of A Research Nurse.***

12. Kelly, C., Dobrowsky, K.W. (Northern Centre for Cancer Treatment, Newcastle General Hospital UK)  
***Patient Information And Education And Their Effects On Trade-Offs And Decision-Making In Head And Neck Cancer***
13. Kelly, C., Zahoor, T., Roberts, J.T. (Northern Centre for Cancer Treatment, Newcastle General Hospital UK)  
***Patient Preference in Patient Decision Making for Cancer Management : Are other factors as important as patient information and education?***
14. Korp, K., Sörensen,C., Gatel,M. (Department of Oncology, Lidköpings Hospital SE)  
***Childrens Experiences From Living With A Parent Diagnosed With Cancer – A Literary Study***
15. Lane, S, (Q.E. Hospital, Oxford Radcliffe NHS Trust, UK)  
***Management Of Tumour Lysis Syndrome***
16. Mahoney, M. (Timeline Services, Warrington UK)  
***The Use Of The Therapeutic Audio CD Program: An Aid To Emotional Recovery After Breast Cancer In Mitigating Post-Surgical Fears And Emotional Presentations In Female Breast Cancer Survivors***
17. Rezgiene, L.R., Ziziene, J., Van Elk, W. (Siauliai Hospital Lithuania LT)  
***Education in Breast Cancer Prevention***
18. Starmer, D., Dean, A., Underwood, R., Maher, T., Ewen, J., Giandzi, S., De Bruyn, J. (Virtual Medical Centre, Subiaco AUS)  
***MyQuest – An Online Patient Managed Record System***
19. Vincent, M. . (Northern Centre for Cancer Treatment, Newcastle General Hospital UK)  
***Communicating The Results Of A ‘Normal’ Follow Up Mammogram To Women With A Personal History Of Breast Cancer. A Cancer Services Collaborative Approach To Service Re-Design.***
20. Vincent, M. (Northern Centre for Cancer Treatment, Newcastle General Hospital UK)  
***Chemotherapy Induced Alopecia – Improving Access To Information And Resources.***



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## Cancer-Related Fatigue – A Nursing Problem For Both The Patient And The Nurse.

Cancer-related fatigue is the most common and frequently reported symptom related to cancer and cancer treatment. Although a great deal of research has been conducted to describe the symptom experience of patients with cancer and its treatment, information on how to best manage symptoms has lagged far behind.

### Aim

The aim of this literature review was to illustrate which factors nurses and patients describe as relevant for the nursing care of cancer-related fatigue.

### Results

The result showed that fatigue was a big problem for both patients and nurses. Seven factors within nursing care were identified as relevant from both patients and nurses perspective. One of the most important factors was the lack of awareness of fatigue's impact on daily life, by cancer care providers. Patients wanted more information and education, for both themselves and their families, about how fatigue can affect them and how to manage the symptom. Further more nurses consider the management of fatigue as an important issue, but they need more education and tools for measurement and guidelines for effective strategies to manage fatigue.

## Hypercalcaemia

The poster is designed to be viewed within an acute medical admissions unit.

### **Aim**

To increase the knowledge, awareness, and pro-active response of qualified nurses to the signs and symptoms of patients presenting with possible hypercalcaemia.

Hypercalcaemia needs prompt treatment if complications are to be avoided, as members of the multi-disciplinary team, nurse have a key role in early identification and treatment.

A key element of diagnosis is the blood calcium level. If nurses are aware of high blood calcium level being one of the primary factors in the diagnosis of Hypercalcaemia, they may view other symptoms differently. Rather than assuming that the symptoms may be due to the sudden deterioration of the patient from a primary oncological condition they may be able to alert doctors at an earlier stage. Nurses therefore need to be able to read and assess the results of tests, rather than having to wait for the availability of doctors to view results. This provides the possibility of earlier intervention, to help alleviate symptoms and minimise patient suffering.



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## Development Of An Outcome-Based Curriculum For Specialist Registrar Training In Medical Oncology In The UK.

Outcome-based education is neither new nor a passing phase in adult education and is applicable throughout the educational continuum from primary school to postgraduate training. The principle is that it focuses on the end-product and defines what the learner is accountable for and able to undertake in a responsible manner.

A learning outcomes curriculum determines what is taught and not the method of the tuition. Outcome-based education is not about telling teachers how to teach nor learners how to learn, more that it can identify what is and is not essential.

The Specialist Advisory Committee for Medical Oncology has been re-writing the curriculum Medical Oncology and includes the required skills, knowledge and attitudes with a definition of the minimum standard required to obtain a certificate of completion of specialist training. This new curriculum must reflect the manpower requirements of the future NHS, and training programmes must produce trainees that are omni potential and can adapt to changes in their future practice.

A change in training also raises issues about training the trainers in the portfolio of teaching methods outlined in the document. This paper will discuss the issues encountered in the development of the curriculum and barriers to its integration into existing training programmes within the UK.



## **The Development Of A Multi-Professional Web-Based MSc Module To Teach Skills To Undertake Research Within Oncology Practice.**

E-learning offers the opportunity to provide training that overcomes the geographical and temporal boundaries that professionals face when considering their own professional development needs. We have developed a 10 credit Masters level module delivered via a web-based managed learning environment, that provides training in research methodology. The module runs over a 15-week period with 2 formative and 1 summative assessment.

The learning activities cover evidence-based practice, research methodology and placing the research into context of clinical practice and incorporate a multi-disciplinary and multi-professional perspective, reflecting the spectrum of students on the course. Further issues relating to the scalability of the module were encountered and required consideration in the revision of the module.

Issues with the largest influence, perceived by students, on the quality of the module included; availability of support, ease of access to module leader and programme director, access to library resources, temporal arrangement of the learning activities, underestimation of the time to complete activities resulting in students developing time conflicts.

A number of requirements for success in e-learning were identified as a result of a pilot of this module and they will be included in the presentation of this paper.



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### **Development of competency-based assessment methods for specialist registrars training in Medical Oncology.**

Assessment consists of tests and observations that are used to determine how well a trainee has achieved the objectives defined in a curriculum and whether the required standards of performance have been achieved. Performance assessment and the corresponding evidence of competence is increasingly required to quality assure the clinical service provided by the NHS in the UK. Working as part of the Specialist Advisory Committee at the Royal College of Physicians, we have been developing and refining methods of assessment to determine the competency of trainees.

For any assessment it is vital that it is linked with feedback to the individual trainee and this is incorporated into the assessment process.

The choice of how best to evaluate the knowledge and performance of trainees is of vital importance and most critical is the realisation that there is more than one way to do it. It is important to recognise the various methods available as the coverage of the curriculum may vary from trainee to trainee, depending on factors such as; the clinical setting, the random flow of patients, and that the educational experiences will vary amongst trainees.

This paper will discuss the development of the competency-based assessment tools including; direct observation of procedural skills, 360° appraisal and a modified mini-CEX (clinical evaluation exercise).

## **Use of discussion board technology for cancer education within a managed e-learning environment.**

E-learning has a lot of advantages for students and emphasis is placed on the removal of temporal and geographical boundaries in the delivery of education. However, this also creates problems in these same domains. Students cannot always relate to their fellow students on the course and as a result feel isolated from the other students. Furthermore, real-time learning activities not only exclude some students but also discriminate against those not in the same time zone, which is an issue when considering the course in a global perspective.

Following a pilot programme we have conducted a comparison study to evaluate the use of synchronous and asynchronous technologies to facilitate discussion during learning activities. This indicated the use of asynchronous technology to be more versatile in application to learning activities, and critical review of the educational pedagogy is also more sound. There are specific instances when real-time activities are useful and these will be discussed, but in the delivery of our web-based MSc, all synchronous facilities have been discouraged.

These findings have implications for the design of future programmes and technology developments, moreover, this evaluation emphasises that e-learning provisions must develop through a foundation in education pedagogy and not the capability of the technology.



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## The Research Into Prevention And Treatment Of Mucositis In Cancer Care Patients

Mucositis is a common side-effect of chemotherapy and radiotherapy. Severe complications can occur due to the symptoms, such as pain and sepsis.

### Process Inquiry

Databases used included CINAHL and Medline as these databases are most commonly used in nursing. Search terms included, Mucositis, Mouthwash, Bone Marrow Transplant, Cancer, Oral Care and Symptom Control. Resulting in fifty papers which were narrowed down to five. Five comparative articles were chosen that examines solutions which are currently used in our practice. Each were critiqued using a framework by Bennett (2003).

### Research Findings

Two separate double-blind clinical trials found that antibiotic pastilles and salt and soda were effective in treatment of mucositis. However three separate double – blinded studies demonstrated that Allopurinol, Sucralfate Suspension and Chamomile are not effective in prevention and treatment of mucositis.

### Conclusion

The evidence suggests that Allopurinol, Sucralfate Suspension and Chamomile have no effect in preventing and treating mucositis in cancer care patients. However it is clearly seen that antibiotic pastilles and salt and soda are effective.

### Implications for Practice

Improving treatment and prevention of mucositis for patients by implementation of antibiotic pastilles and salt and soda to our current practice.

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## Evaluating Dissemination Of Education On End-Of-Life Care To Cancer Centres (DELEtCC)

DELEtCC is a National Cancer Institute funded project focused on providing clinical leaders with resources to improve end-of-life (EOL) care for cancer patients.

### Methods

Interdisciplinary two-person teams from nationwide cancer centers are competitively selected for annual three-day courses. Evaluation begins pre course with institutional surveys and projected goals, then continues up to 18 months post course.

### Results

Teams from 140 institutions (61% nurses, 17% social workers, 11% physicians, 4% psychologists, 4% pastoral care, 3% other) representing 39 states, completed courses in 2002-2004. Institutional surveys revealed 12 and 18 month increases in the effectiveness of EOL, increased comfort of staff in caring for patients, positive receptiveness of staff in improving EOL care, and vacillation support from administration. Goal analysis revealed 17% structure, 74% process and 9% outcomes. Staff education was the most common goal accomplished.

### Conclusions

The evaluation plan provided quantitative data via institutional surveys, and qualitative data via goals/analysis. Goal analysis revealed that many participants accomplished their original goals. The DELEtCC program is effective in initiating changes needed to improve EOL care in cancer centers.



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### **Clinical trials for cancer: Addressing patient information needs with the development of an assessment tool.**

Historically, healthcare professionals have adopted a paternalistic attitude when providing the patient with cancer information, deciding not only when and where to deliver information, but also in what format. Frequently presumptions are made regarding from whom the patient would most like to receive their information. For instance, bad news is often delivered by a clinician and subsequent reinforcement provided by a clinical nurse. In recent years there has been a swell in the volume of written information available and an increasing number of websites covering all aspects of cancer care. Unfortunately, this often results in information overload and confusion rather than improved understanding.

In our quest to improve the patients understanding of oncology clinical trials, we have developed a questionnaire with which we intend to identify patient's opinion and understanding of clinical trials in oncology. Using this tool we will determine their information needs in order to target future educational interventions.

This paper describes the process through which a questionnaire was developed to identify patient's perceptions and possible misconceptions regarding clinical trials, in order to target the provision of information appropriately. Furthermore, it will explore the method by which patients prefer to access such information.

## Enhancement Of Learning And Understanding By Use Of Reflection During A Web-Based Msc Module On Oncology Practice Development.

Reflection has been recognised as one of the defining characteristics of continuous learning in professional practice. Furthermore, it has been acknowledged that true reflection requires a second person, or a mentor, who can ask pertinent questions so that the reflection has some direction. Reflective learning activities were incorporated into this web-based MSc module, but instead of utilising a mentor, the students became the mentor for both their own work, and also for that of other students through the use of an on-line discussion board.

Throughout the module, students are called upon to reflect back on their own workplace environment, and to consider situations through reflection from the perspective of the service user, as well as the service provider. This was facilitated through interviews with the various personnel and patient groups and then voiced through an on-line discussion board for students to share experiences and knowledge, and encourage reflection. As the whole principle of reflection relates to the student being able to relate their own learning to their personal experience, it has to be presumed that the student will have some experience to relate to. Where this is not the case, the use of the on-line discussion board has proved to be extremely valuable for the students to share experiences and outcomes.

This paper describes how the practice of reflection has benefited students participating in a multi-professional web-based MSc practice development module, and enabled students to benefit from each others contribution to the discussion activities.



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### **Raising Awareness Of Oncology Clinical Trials Through Education: Extending The Role Of A Research Nurse.**

Educating cancer patients about specific clinical trials is a fundamental role of the oncology research nurse and is often incorporated into the informed consent process. However, for many patients offered the opportunity to participate in a clinical trial, it will be the first time they have ever considered any aspect of clinical research. In view of this, the basic principles of clinical research have to be explained, in addition to the specific details of the study for which the patient is eligible. This is in addition to information regarding the patients diagnosis, disease progress and other treatment strategies. Clearly, this can result in significant information overload and may result in refusal to enter a trial. It would seem logical, therefore, to educate people before they become patients. The traditional research nurse is employed to manage a patient case load, and often has no provision in their job plan to widen their role into a greater educational remit.

We have developed a senior research nurse post which is dedicated to developing evidence-based cancer research education for patients, the public and the broad range of healthcare professionals.

In this paper we describe how this post has evolved, and how the post holder has collaborated with external agencies, including the media, in order to successfully raise awareness of cancer clinical trials.



## Patient Information And Education And Their Effects On Trade-Offs And Decision-Making In Head And Neck Cancer

Head and neck patients, in general constitute a socially deprived group of oncology patients, and are often relatively information poor, when first presenting with a head and neck tumour. They are usually unaware how such tumours progress, what treatment with surgery, radiotherapy or chemotherapy entails, nor the potential morbidity from such treatments.

These patients often, because of their more deprived social circumstances, co-morbidity, and limited access to digital information can become more dependent on their professional carers for all of the information related to the tumour, when compared to other oncology patients. This may impact on the patient's decision making and perception of the trade-offs in the potential benefits and morbidity of treatment options.

We have investigated, using questionnaires dealing with cancer information sources and patient preferences and priorities, where and how, initially a pilot group of forty head and neck patients, have obtained their cancer information, their access and ability to use digital information sources, and how this may have affected their decision making and their perception of trade-offs in terms of benefit and morbidity in the management of their own head and neck tumour. This pilot study was also used to assess how difficult it would be to obtain this information from all head and neck patients presenting to our centre and include this information as a standard part of our history taking.

In this process, head and neck cancer patients can be seen as a model for other socially deprived cancer patients.

***This poster was displayed at AACE 2004, and won a prize and we therefore asked for it to be presented at EACE***



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## Patient Preference in Patient Decision Making for Cancer Management : Are other factors as important as patient information and education?

The UK Cancer Plan of 2000 states that "users and carers should have choice, voice and control over what happens to them at each step in their care". The Cancer Plan also suggests that patients should be treated as close to home as possible.

However, decision-making for both medical professionals and patients and their carers is often a complex procedure, against a background of incomplete evidence. In recent years, patients and their carers have been given more and more information about their cancer, the prognosis, and its possible outcomes and the acute and long-term associated morbidities, in the hope of improving patient input into the decisionmaking process.

Despite this increase in patient information and educating the patient about the risks, outcomes and morbidity, decision making is still a complex procedure and can be influenced by external features not related directly to the information given to the patient about their tumour type, stage and treatment options.

We have surveyed two differing groups of cancer patients, with head and neck and testicular cancer to see if these external factors can potentially affect the decision. These factors include travelling time and distance; inconvenience and discomfort; and whether patients wished to be treated at cancer units closer to home or at "Specialist Cancer Centres" further from home, but perceived as centres of excellence.

The results from this survey, show that not all patients do wish to be treated as close to home as possible, and that some patients prefer to travel to what they perceive as a centre of excellence. Head and neck cancer patients, who are generally older, less fit and have less access to transport than testicular cancer patients, have a higher but not majority preference for been treated closer to home. The reasons given for the patients` choices are discussed, as is the limited literature on patient preference in this particular clinical cancer presentation.

## Childrens Experiences From Living With A Parent Diagnosed With Cancer – A Literary Study

When a familymember is suffering from cancer the whole family will be affected. In order to clarify all familymembers´need the theory regarding the Family System Nursing could be useful. Children will live for a long time with the experiences of a parent’s cancerous disease, and it is essential that they are considered to be important family members.

### Aim

The aim with this literary study was to describe childrens´ (6-18 years) experiences of living with a parent diagnosed with cancer.

### Results

The results showed that children lived in two different worlds. In the home environment the disease was evident and the children took on an increased burden of responsibility. Outside the home the children often experienced a free zone where they could disclose the disease for a while. Children were conscious of the fact that cancer is a fatal disease, and noticeable signs of the disease increased the fear the children experienced. The children had the need of knowledge that was adapted to their cognitive level of learning in order to avoid any misunderstandings.

### Conclusion

To conclude, oncology nurses that can be of important support for children and parents need knowledge of childrens´ needs and cognitive development.



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**Management Of Tumour Lysis Syndrome****Aim**

This poster aims to raise awareness amongst nursing staff of the symptoms and treatments available

Tumour Lysis Syndrome is a life threatening complication for cancer patients undergoing chemotherapy and other drug treatments.

A review of information available in the ward setting revealed that there was little literature available and no formal education on Tumour Lysis Syndrome.

Early recognition of at risk patients is vital if treatment is to be offered early enough to maximise its effectiveness, and nurses have a key role in the process of recognition of symptoms.

Therefore as a first step to raise awareness of all nursing staff, it was decided that this poster should be developed and displayed within the haematology ward.

The Use Of The Therapeutic Audio CD Program: *An Aid To Emotional Recovery After Breast Cancer* In Mitigating Post-Surgical Fears And Emotional Presentations In Female Breast Cancer Survivors.



**Purpose:** To determine if on-going posttraumatic and emotional presentations following traditional surgical treatment and emotional support provided for female breast cancer survivor patients could be successfully addressed via specific clinical hypnotherapeutic processes.

**Objective:** This private study set out to evaluate a simple means of introducing cost effective mind body processes aimed to mitigate emotional presentations and to increase female breast cancer survivors' participation in their own emotional recovery.

**Background Methods:** Twenty-four female breast cancer survivors aged 41 – 58 years were recruited to the study, inclusion criteria were they had all had breast cancer. A mixed treatment group was used. All presented with posttraumatic emotional issues including anxiety, fear of re-occurrence and vulnerability over a period of 29 months (07/00 –10/02). End of treatment time lapse varied between 3 months to 8 years 2 months. An initial counselling session explained the mind body connection. Specific guided imagery and relaxation processes were used intended to mitigate presenting symptoms and frequency of presentation. Audio recordings of each session given to each participant used the same process, content and delivery methods. An additional ambient music session provided patient self-relaxation. After each session, subjects continued listening in the home environment according to a required session. All patients completed a questionnaire at 4 monthly intervals; numbers were variable as patients joined the group at various times.

**Background Results:** Reduced anxiety was reported in 23 of the 24 participants. One participant who reported increased emotional distress also reported a life-changing event occurring in the significant other. Also reported were reduced fears of reoccurrence, increased optimism along with a sense of taking part in their own healing, easier relaxation and increased confidence and self esteem. Commencing March 2003, the above processes were migrated onto compact disc. Included with the CD is a 45-day listening schedule. Commencing May 2003, the CD was given to a total of 15 breast cancer survivors over a period of 6 months (aged 38 – 63 years). Time lapse from treatment ending was between 11 months – 6 years 1 month. Each patient was asked to submit an evaluation form that included QOL issues, perceived benefit of recording in confidence, mood, significant other relationship, along with interpersonal confidence. Questionnaires were submitted bi-monthly until May 2004.

**Results:** All patients recorded beneficial feedback in QOL, relations with significant other, and mood. Twelve patients offered additional information including: enhanced future perspectives, better sleep, reduced 'free floating anxiety', reduced vulnerability and appreciation of their own self help involvement.

**Conclusion:** Significant cost effective benefit appears possible by structured self help recordings. These preliminary trials indicate a patient need and a solution method in this area of emotional recovery. Patients appear willing to participate in additional self help methods. Significant other participation also appeared to aid in reducing anxieties, and enhanced personal bonding.

**Additional:** The CD program has been purchased by several NHS Hospitals and informational leaflets are being made available to patients and professionals in over 30 NHS hospitals. Feedback from patients, medical professionals and breast cancer care providers indicates that the use of structured recordings of this kind has a place in emotional recovery after breast cancer.

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## Education in Breast Cancer Prevention

Every year thousands of new cases of breast cancer have been detected all over the world, and in Lithuania too. Breast cancer occupies the leading position among female oncological diseases and is the reason of the largest female mortality from cancer. Though contemporary medicine is capable to detect cancer in early stages and cure the disease without painful consequences, almost half of the affected women search for help too late when the chances to save their lives are nearly equal to zero. Morbidity and mortality from breast cancer in Lithuania increases from year to year, and death rate from breast cancer in Siauliai region is rather high. Breast cancer cases diagnosed in late stages (III – IV stages) cause great anxiety and they make up about 60 % from all diagnosed cancer cases.

### The main goal

To inform the community about breast cancer, its early diagnostics, importance of prophylactic care in order to decrease the death rate from breast cancer.

### Specific goals

They cover the organization and implementation of educational courses in breast cancer prevention for community nurses using original models of continued professional education. The goals also cover implementation of educational courses in breast cancer prevention for women who had had or are having breast cancer, and at the same time give them opportunity to integrate into society.

### Results

According to the approved study plan 72-hour educational courses were conducted for 60 community nurses and 30 women with breast cancer. Before and after the courses questionnaires were carried out in order to evaluate the level of their knowledge about breast cancer.

- 31 % of respondents having breast cancer asserted that their knowledge about the disease is sufficient, while 69 % stated it being insufficient.
- One third respondents from cancer affected group pointed out that the information they have about the disease was from doctors oncologists and Women Breast Cancer.

The survey of answers of community nurses showed that their knowledge about breast cancer is not sufficient either :

- 32 % of respondents do not have enough knowledge about prophylaxis of breast cancer;
- 33 % of community nurses do not teach women breast self - detection and do not urge them for check - ups,
- When the courses were finished, 97 % of respondents stressed that they had been informative and useful. Only 22 % of respondents mentioned that some lecture material had not been new for them as they had been introduced to it during other educational courses.
- 73 % said that the acquired knowledge was purposeful and would be used at work.

### Conclusions

Neither community women nor community nurses have sufficient knowledge about breast cancer prophylaxis. Insufficient attention is shown in teaching breast self detection and doing mammography.

Increase in community literacy in breast cancer prophylaxis would help to solve breast cancer delay problems. Women's Association can and must take an active part in encouragement of oncological awareness.

## MyQuest – An Online Patient Managed Record System

### Introduction

MyQuest is an on-line patient managed record system developed by a consortium of healthcare organisations. As a computer-based record system the patient is able to store easily a substantial amount of health-related information and generate reports which can be forwarded on-line to the relevant health practitioner prior to the scheduled consultation.

### Pilot Study

Several features incorporated into MyQuest have been favourably received by patients and practitioners:

- Patient control of the data entered and accessed.
- Patients are able to include questions, or concerns about their condition in the MyQuest medical report.
- More efficient use of consultation time.
- Patient access to the latest information regarding their condition, the current best methods of treatment and a library of drug-related information.
- Improved patient education
- Accurate list of response to treatment allows the treating doctor to easily identify effective drugs
- Improved communication between patient and doctor

Finally, a Continuing Professional Development learning module on patient-led records is available to health practitioners through the Virtual Medical Education Centre.

### Conclusion

Patient managed records are a valuable addition to patient care with advantages being expressed by both patients and clinicians



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## **Communicating The Results Of A 'Normal' Follow Up Mammogram To Women With A Personal History Of Breast Cancer. A Cancer Services Collaborative Approach To Service Re-Design.**

**Aim** To provide a practical insight into how a Cancer Services Collaborative approach can be used to optimise service delivery.

Women with a personal history of breast cancer are at increased risk of developing a new primary lesion (Dixon 1995) and require structured surveillance. This incorporates annual mammography (Kaas et al 2001) and regular short term follow-up, with history taking and physical examination (NCN 2001, NICE 2002). Follow-up can be associated with a transient increase in anxiety (Allen 2002) as there is the potential for diagnosis of metastatic disease, local recurrence or a new primary breast cancer. This can be compounded by the feelings of powerless, isolation, and vulnerability that surround a diagnosis of breast cancer (Colyer 1996). A significant number of women can be classified as anxious or clinically depressed a year after diagnosis (Fallowfield et al 1990). There is however no quality standard that governs the speed at which women attending follow up receive the results of their routine surveillance mammogram (DoH 1995). The Cancer Plan has made Cancer Networks responsible for improving care (NHS Executive 2000) and the Cancer Service Collaborative programme was developed to improve the patient's experience of cancer services. Key objectives focus on optimising service delivery from a patient perspective, to reduce unnecessary delays, provide a consistent service, and improve patient satisfaction. (DoH 2004).

### **Key Milestones**

Mapped the mammogram pathway

Audited the current service including

- No. of patient telephone enquiries regarding screening results
- No. of patient telephone inquiries regarding screening results
- Time taken for results to be sent out (62% sent within 14 days)

Together with Key Stakeholders options for service improvement were considered and a pilot commenced for a period of 3 months.

Audited the pilot. (100% of letters sent within 14 days)

### **Implications for practice**

- The breast clinician identifies individuals as per protocol and marks the mammogram
- if the result is 'normal' a routine letter is sent directly from the breast assessment unit.
- An additional process has been added to check the status of the patient prior to dispensing the mammogram request form to the breast assessment unit.
- A patient satisfaction survey is to be undertaken.

### **Learning objectives**

To identify key factors that facilitate sustainable service re-design.

To gain an insight into one Cancer Centre's experience of using a Cancer Services Collaborative approach to optimise service delivery.

To establish how audit can be used to support service re-design.

### **References**

See poster



## Chemotherapy Induced Alopecia – Improving Access To Information And Resources.

Hair is an appendage, which has particular social, cultural and religious significance. Hair loss (alopecia) is a common side effect of chemotherapy and it can be associated with loss of attractiveness, sexuality, individuality, a state of disgrace, illness and death (Batchelor 2001). Health care professionals acknowledge that 'service users' are instrumental in developing and shaping services that are responsive to the needs of local people (Department of Health 2000). It has been suggested that information giving can be associated with a reduction in physical and psychological discomfort (Fallowfield et al 1990) and often enhances feelings of personal control. A group of like-minded individuals were identified and commandeered from the secondary and voluntary sector. They identified the following problems.

- Patients expressed difficulty in accessing appropriate alternative head wear at a reasonable price.
- Written information did not address local practices.

### The group aim was to

- Produce written information that reflected local practices – focusing on practical issues.
- Provide a range of appropriate, modestly priced alternative head wear within the Cancer Centre.

### Process

- A member of the group visited a well established alopecia service at the Christie Hospital, Manchester.
- The manager of the Cancer Centre's charitable outlet expressed an interest in providing financial and practical support
- The Trust's 'supplies department' were approached to establish appropriate wholesale sources.
- The group liaised with a number of key individuals responsible for the delivery of alopecia services.

### Results

- Turbans and headscarves are now available for sale via the 'Charlie Bear' charity at the Cancer Centre and these volunteers and staff from the 'Room for you' Arts Project team provide some informal individualised assistance / support to patients.
- An patient information leaflet is available locally and regionally.
- We are working in collaboration with Breast Cancer Care to expand the range of services available to patients within the Cancer Centre as a weekly service is now accessible to patients within the local Marie Curie Centre.
- A private hat maker provides free consultations to patients attending the Cancer Centre on alternate weeks.
- The project continues to grow and there are plans to increase user involvement in future developments

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