



Oncology nursing awards

UK cancer nurse Maureen Gill received the palliative care nurse of the year award at the 1st International Journal of Palliative Nursing (IJPN) Awards.

She received the award for establishing and developing palliative care in Siberia in the face of huge challenges. On giving the award the judges said Maureen was a true inspiration and that she demonstrated courage and determination in adversity.

Other categories awarded at the ceremony in London in March this year were educationalist of the year, development award, non-cancer symptom management award, multi-disciplinary teamwork award and lifetime achievement award.

The majority of applicants for this first ceremony were from the UK, but many of the presentations had an international theme. Applicants from abroad included Natalia Bodiou from Moldova who was highly commended in both the development of services and non-cancer categories for her work in heart disease and palliative care.

Sister Leanarda from New Delhi, India was highly commended in the palliative



care nurse of the year category for her outstanding work in setting up and working within a home care team.

The lifetime achievement award went to Jo Hockley, clinical nurse specialist at St Columba's Hospice, Edinburgh, Scotland who is currently working on a project looking at palliative care knowledge within nursing homes.

Jo was a popular choice of award winner as she is always involved when new and innovative developments occur within palliative care. She is totally focused on clini-

cal care but has a research, education and publication record which demonstrates that her interest lies in both her personal practice and the dissemination of best practice to all.

Candy Cooley, Secretary/Treasurer of ISNCC, Consultant Editor for IJPN, and Macmillan Palliative Development Manager at South Worcestershire Primary Care Trust, UK commented in her closing remarks that it takes very brave people to put themselves and their practice forward for scrutiny and possible criticism.

The awards were developed in collaboration with Cancer Relief Macmillan (CRM).

Don't miss out

The 14th International Conference on Cancer Nursing is to be held in Toronto, Canada from 27th September to the 1st October 2006. Don't miss the chance to present at the largest international meeting of cancer nurses. Information inside about conference themes and abstract submission.

Speak up.

Faisons entendre notre voix.
 BE AN ADVOCATE.
 SOYONS DES PORTE-PAROLE.



Canadian Oncology Nursing Day

2nd Annual
 Canadian Oncology Nursing Day
 Tuesday, April 19, 2005

2^e Journée annuelle
 des soins infirmiers en
 oncologie du Canada
 Mardi le 19 avril 2005

Oncology nurses in Canada celebrated the 2nd Annual Canadian Oncology Nursing Day on April 19th. The day focused on the theme *Speak Up! Be An Advocate* and was organised by the Canadian Association of Nurses in Oncology (CANO) which was established in 1984. Events and promotions planned around Canadian Oncology Nursing Day provided a prime opportunity to raise public awareness of the work of oncology nurses and about issues affecting cancer care in Canada.

Nursing challenges ahead

I am writing this president's message on the eve of leaving Canada to attend the 23rd Quadrennial Congress of the International Council of Nurses and the Council of National Representatives taking place in Taipei, Taiwan. ICN, its 126 national nursing associations, and an expected 4,000 nurses will convene within the overall conference theme of "Nursing on the Move: Innovation and Vitality."

As I read through the materials in preparation for the meeting, I was struck by the significant challenges nurses face around the world. I cannot help but think that we need strong nursing leadership and innovation. Nurses have a history of being creative, finding solutions in seemingly overwhelming situations, and making a difference in the lives of their patients and families. However, current trends and events are interfering with nursing's capacity to continue to provide such care.

Nursing and midwifery form the backbone of health systems around the globe and often provide the platform for efforts to tackle the diseases that cause poverty and ill health. According to Dr. Gro Harlem Brundtland, WHO, urgent action is needed to overcome the problems that interfere with nurses making their contribution. These problems include the overwhelming burden of diseases such as HIV/AIDS, tuberculosis and malaria; migration of health workers; inadequate working conditions, and inappropriate use of practitioners.

An environmental scan by the International Council of Nurses identified several major trends and issues affecting nursing care delivery: working conditions (including safety, burnout, shift work), shortages of nurses, poor remuneration, migration of nurses, difficulty accessing education, poor national economies and the increasing burden related to communi-

cable diseases. Additionally, many countries struggle to find ways to give necessary health care in light of ever increasing financial constraints.

Nurses in cancer care are facing additional challenges emerging from cancer-specific trends. There is a rising incidence of cancer as well as increased prevalence. Advances in science and technology have led to increased complexity in treatment and new side effect profiles. Yet very basic issues such as uncontrolled pain and lack of access to palliative care remain unresolved in many parts of the globe. Cancer nursing is not considered a speciality in many countries, making access to cancer education by nurses difficult.

Key factors affecting nursing's ability to be involved and participate in health policy have been identified as education (lack of speciality preparation), an ageing workforce (demographics of nursing population), the role of nursing, care delivery models and cultural and gender perspectives (role of women in various societies). Solutions to these matters demand long-term investment. Working collaboratively, working in partnerships, striking new alliances, and strengthening interdisciplinary teamwork are all cited as avenues to find creative solutions. But these avenues demand new behaviours from us.

Nurses require key skills to be effective in the future. These include, flexibility in roles/functions, systems thinkers, orientation to continuous learning, critical thinking/decision-making, leadership and team building. As we move further into the 21st century, patients will continue to need nurses. Our challenge is to create the avenues to ensure we are able to be present for patients and to make a difference in their lives.

Margaret Fitch
President ISNCC

UK poaching African healthcare staff

The UK is weakening sub-Saharan Africa's healthcare system by poaching staff, UK doctors have warned. The UK takes over the chair of G8 in July and should seize the opportunity to stop the drain of qualified health professionals from poor to rich countries, they say in *The Lancet*.

In 2003, 5,880 UK work permits were approved for health and medical personnel from South Africa, 2,825 from Zimbabwe, 1,510 from Nigeria and 850 from Ghana.

The doctors are lobbying for the World Health Organisation, to establish a basis in developed countries for minimum annual numbers of health professionals in training. This would help to reduce developed country reliance on the investment in training made by developing countries.

The Lancet 2005; 365: 1893-1900

South-African nurses excluded from pay rise

Nurses in South Africa have been excluded from a public sector pay increase. Police, teachers and social workers have been awarded significant salary increases but nurses will not receive a pay raise. There is a current estimated nursing vacancy rate of almost 40% which represents a shortage of more than 50,000 nurses. An estimated 200 nurses migrate abroad every month.

SEW News January 2005

Elderly cancer patients face discrimination

Terminally ill younger people get much better care than the elderly at the end of life. A study found age discrimination in palliative care services prevented many older people from having a dignified death. Older people were found to be more often denied the opportunity to go into a hospice.

<http://www.helptheaged.org.uk>

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Published on behalf of the International Society of Nurses in Cancer Care by:

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ISSN 09565175



The impact of cancer on the family

The Robert Tiffany lecture was given at the 13th International Conference on Cancer Nursing held in Sydney, Australia last year by Dr Frances Marcus Lewis. Here is an edited version of the stimulating lecture she gave on the impact of cancer on the whole family

When a patient is diagnosed with cancer it has an impact on the whole family. The challenge for the family is to integrate the cancer diagnosis and treatment into their everyday lives while still maintaining their family life. During this work, the disease is interpreted and worked through at multiple levels: at the level of the individual members, at the level of subgroups within the family, at the level of the total household, and at the level of the extended family.

Working through the illness is more than a cognitive-emotional process; it involves the development and refinement of often complex new behaviours, skills, and competencies by family members, including the development of new ways of working and interacting with each other. Each new piece of work brings its own challenges to individual members and the family as a whole as they attempt to integrate the cancer in ways that are least disruptive to their ongoing life, while still helping the member who has the disease.

In the past 15 years there has been an increasing awareness of cancer as a family experience, as opposed to viewing cancer as personal to an individual patient. This perspective was heralded in early theoretical papers by Barckley (1967), Litman (Litman, 1974, Litman & Venters, 1979) and Parkes (1975) and continues to this day in the research programmes of about 10 clinicians and scientists. In looking at this subject I intend to exclude literature on the child as the diagnosed cancer patient, caregiver research, and research with persons with late-stage disease; these areas have extensive literatures and deserve of their own analyses.

Family-level research in cancer evolved through four discernible phases (Lewis & Hammond, 1992). The first phase of research was represented by clinical papers written primarily by physicians. These papers raised concerns about the potential psycho-social morbidity in the diagnosed patient and its potential ramifications for family members.

These included recommendations from physicians about ways to minimise distress for the couple (Ervin, 1973); the value of including the spouse/partner in the preoperative phase of treatment for breast cancer (Kent, 1975); and the importance of encouraging the husband's participation in

decisions about cancer treatment (Ervin, 1973, Wellisch et al, 1978). Although these were important consciousness-raising papers, they did not provide objective data to back up the recommendations, which were instead based on clinical wisdom.

A second phase of research studies which went beyond the anecdotal information reflected in the early clinical papers, emerged in the 1970s and 1980s. Relying primarily on cross-sectional descriptive designs and standardised measures of psycho-social functioning, these data-based studies documented the impact of cancer on individual family members, including the husband. Breast cancer was the clinical prototype that received the greatest amount of attention. Research by Wellisch and Northouse was exemplary within this second phase (Northouse, 1988, Northouse & Swain, 1987, Wellisch et al, 1978). Both Northouse (Northouse & Swain, 1987) and Oberst & James (1985) were among the first to use longitudinal designs and their results revealed a pattern of responses that further heightened our awareness of the spouse's dilemma.

The impact on the spouse was not only a function of the impact on the wife, but often the spouse's distress increased, not decreased, over time, while the diagnosed person's concerns decreased. Baider & De-Nour (1984) were the first to follow spouses of women with breast cancer for more than a few months and documented that husbands had higher levels of distress over time and lower levels of adjustment than did the diagnosed women. Furthermore, this disturbance existed up to 3 years post-surgically (Baider & De-Nour 1984).

Zahlis & Shands (1991), using case-intensive interviews and interpretative methods, not standardised measures, found that the partners of women with breast cancer experienced substantial concerns and difficulties in a number of areas. These included dealing with physicians, obtaining information needed to make informed treatment decisions, adapting their lifestyle to meet the pressures of the illness, and being sensitive to the diagnosed woman's emotional and physical needs. The spouses also talked about the uncertainty of the future, their fear of disease recurrence, and the difficulties they experienced in their relationship with the women, including



Frances Marcus Lewis delivering the Robert Tiffany lecture in Sydney

their struggle to communicate as couples about what was happening because of the breast cancer (Zahlis & Shands, 1991).

The third phase of studies went beyond the prior studies by using statistical modelling techniques to test a set of interrelated hypotheses about the impact of the breast cancer on the family (Lewis & Hammond, 1996, Lewis et al, 1989, Lewis et al, 1993, Woods & Lewis, 1995). These studies had the advantage of modelling the complexity of family life. They considered multiple variables impacting the family; specified the mediating variables that potentially explained differential outcome in families (Moyer & Salovay, 1996); focused on divergent processes used by family members as they tried to function with the cancer; and included multiple outcomes of the household family's adjustment.

Analyses from this third generation of studies were based on data from families with breast cancer in a child-rearing mother. *The Relational Model of Family Functioning with Cancer*, to be described next, derives from lessons learned from these empirical studies and is offered as a framework for oncology nursing practice.

Relational model of the family's functioning with cancer

To understand the family's work in functioning with cancer it is necessary to understand the family as a relational, interacting system working on being responsive to the illness-related demands as well as moderating the cancer's intrusion into the family's life. In the process of moderating the

cancer's intrusion and maintaining the household the family is engaged in cancer-related work as a family.

The Relational Model of Functioning with Cancer depicts cancer as a psycho-social transition in which family members are attempting to balance their on-going life as a family and their life with cancer. Seven concepts form the basis for this model: the family members' perceived illness-related demands, the child's frame of reference for understanding the cancer, the parent's mood and affect, parenting quality, social support available to the family, marital adjustment, and family member coping and management strategies. Within the Relational Model, cancer is viewed as a psycho-social transition and the family as balancing two lives: their family life and their cancer life.

Psycho-social transitions are characterised by deep personal reflection, cognitive-emotional searching, and by existential questions like, Why me? Why now? Why this? Why us? It is through these reflective and searching processes that family members attempt to maintain some sense of control and predictability over what is happening to them (Lewis, 1987, Lewis & Daltroy, 1990). Even when things are not under the control of the family members, the hope is that things are in control (Lewis, 1987, Lewis & Daltroy, 1990).

Families are assumed to consist of intimate, interacting and interdependent members. A family has the potential to be an active manager of its own resources, ways of working and interacting with each other, and negotiations with the community. Illness in a parent requires that the family operate to maintain stability in its routine internal arrangements and activities as well as restructure its interactions and activities in order to manage the ongoing demands of cancer (Broderick & Smith, 1979, Buckley, 1967, Hough et al, 1991, Lewis et al, 1989).

The life of the family involves maintaining members' and household's non-illness-related routines, activities, interactions, rituals, fun, and nurturing. Successful functioning of the family involves the members rearranging their routines and daily work in ways that accommodate the demands of the illness while maintaining time and energy for family life that is not illness-related.

The family's life linked to the cancer involves reconfiguring around the ill member in ways that assist in the healing of that member. Problems will occur for members of the household when there is an insufficient balance between these two lives. If the cancer consumes the family's life, there will be tension and problems. If the family fails to attend to the illness-related demands of the cancer, there will be tension and problems.

The challenge for the family is to give up their old ways of thinking, doing, or interacting as a family and to rebuild themselves around their new way; in a real sense the family evolves a new self-identity as a family as a result of this cancer-related work (Feldman, 1974). Successful resolution of the destructuring and restructuring processes involves the family's relinquishing past ways of functioning and working that are resistant or non-responsive to the ill person. Successful resolution also maintains the essential or core functions of the household. New ways of functioning that evolve from the family members have the potential to help them be the most effective managers of the cancer's intrusion into the family's life. Holding onto old ways of working or interacting which are non-responsive to the illness-related demands create difficulties for the household. In a real sense, the successful family learns to "put the illness on the table, not under it" (Lewis et al, 1989).

Illness-related pressures or demands are subjective, not objective, events (Haberman et al, 1990). It is the perception of the family member, not the objective characteristics of some aspect of the cancer that affects how the family member responds and is affected by the cancer (Compas et al, 1994, Lewis et al, 1989, Lewis & Hammond, 1993, 1996). The family members are affected by the emotional pressures the diagnosis causes. There are also interruptions or changes in life-plans, priorities, and goals (Stetz et al, 1994, Stetz et al, 1986).

Cancer also puts pressures on family members because they are affected by the negative mood, symptom state, and diminished activity level of the diagnosed member. In related studies with both recent and long-term diagnoses, these illness-related demands have deleterious consequences for the quality of the marital relationship. Heightened tension in the marital relationship that is brought on or accentuated by the cancer's illness-related demands has documented deleterious consequences for the household family.

Concluding remarks

The challenge for nurses and nursing services is to respond to the family as a family, not merely as caretaker or source of social support. In doing so, we link our technology of caring with services that heal, not just the patient, but the whole family.

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References

Barckley V (1967) The crisis in cancer. *American Journal of Nursing Research*, 67(2), 278-280
 Litman T J (1974) The family as a basic unit in health and medical care: a social-behavioural overview. *Social Science Medicine*, 8, 495-519

Litman TJ & Venters M (1979) Research on health care and the family: A methodological overview. *Social Science Medicine*, 13A, 379-385
 Parkes CM (1975). The emotional impact of cancer on patients and their families. *Journal of Laryngology and Otolaryngology*, 89, 1271-1279
 Lewis FM & Hammond MA (1992) Psycho-social adjustment of the family to breast cancer: A longitudinal analysis. *Journal of the American Medical Women's Association*, 47, 194-200
 Ervin Jr C (1973) Psychologic adjustment to mastectomy. *Medical Aspects in Human Sexuality*, 7, 42-65
 Kent S (1975) Coping with sexual identity crises after mastectomy. *Geriatrics*, 30, 145-146
 Wellisch DK, Jamison KR & Pasnau RO (1978) Psycho-social aspects of mastectomy II: The man's perspective. *American Journal of Psychiatry*, 135, 543-546
 Northouse L (1988) Social support in patients' and husbands' adjustment to breast cancer. *Nursing Research*, 37, 91-95
 Northouse L & Swain MA (1987) Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research*, 36, 221-225
 Oberst MT & James RH (1985) Going home: Patient and spouse adjustment following cancer surgery. *Topics in Clinical Nursing*, 7, 46-57
 Baider L & De-Nour AK (1984) Couples' reactions and adjustment to mastectomy: A preliminary report. *International Journal of Psychiatry in Medicine*, 14, 265-276
 Zahlis EH & Shands ME (1991) Breast cancer: Demands of illness on the patient's partner. *Journal of Psycho-social Oncology*, 9, 75-93
 Lewis FM & Hammond MA (1996) The father's, mother's and adolescent's adjustment to a mother's breast cancer. *Family Relations*, 45, 456-465
 Lewis FM, Woods NF, Hough EE & Bensley LS (1989) The family's functioning with chronic illness in the mother: The spouse's perspective. *Social Science and Medicine*, 29, 1261-1269
 Lewis FM, Hammond MA & Woods NF (1993) The family's functioning with newly diagnosed breast cancer in the mother: The development of an explanatory model. *Journal of Behavioural Medicine*, 16, 351-370
 Woods NF & Lewis FM (1995) Living with chronic illness: Women's perspectives on their families' adaptation. *Health Care for Women International*, 16, 135-148
 Moyer A & Salovey P (1996) Psycho-social sequelae of breast cancer and its treatment. *Annals of Behavioural Medicine*, 18(2), 110-125
 Lewis FM (1987) The concept of control: A typology and health-related variables. *Advances in Health Education and Promotion*, 2, 277-309
 Lewis FM & Daltroy L (1990) How causal explanations influence health behaviour: Attribution theory. In K Glanz FM Lewis & Rimer B (Eds.), *Health behaviour and health education: Theory, research and practice*. San Francisco: Jossey-Bass
 Broderick C & Smith J (1979) The general systems approach to the family. In W.R. Burr, R. Hill, F. I. Nye, & I. L. Reiss (Eds.), *Contemporary theories about the family* (pp. 112-129). New York: The Free Press
 Buckley WF (1967) *Sociology and modern systems theory*. Englewood Cliffs, NJ: Prentice-Hall
 Hough EE, Lewis FM & Woods NF (1991) Family response to mother's chronic illness: Case studies of well- and poorly-adjusted families. *Western Journal of Nursing Research*, 13(5), 568-596
 Feldman DJ (1974) Chronic disabling illness: A holistic view. *Journal of Chronic Disease*, 27, 287-291
 Haberman MR, Woods NF & Packard NJ (1990) Demands of chronic illness: Reliability and validity assessment of a demands of illness inventory. *Holistic Nursing Practice*, 5(1), 25-35
 Compas BE, Worsham NL, Epping-Jordan JE, Grant KE, Mireault G, Howell DC & Malcarne VL (1994) When Mom or Dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology*, 13(6), 507-515
 Stetz KM, Lewis FM & Houck GM (1994) Family goals as indicators of adaptation during chronic illness. *Public Health Nursing*, 11, 385-391
 Stetz KM, Lewis FM & Primomo J (1986) Family coping strategies and chronic illness in the mother. *Family Relations*, 35, 515-522

Exercise improves breast cancer survival chances

Physical activity may improve survival after a breast cancer diagnosis. Previous research suggests that exercise may stave off breast cancer, but the benefits after diagnosis of the disease have been unclear.

The benefits of physical activity were strongest for women with hormone-responsive tumours who took part in nine or more metabolic equivalent tasks (MET) hours per week.

Three MET hours is equivalent to walking at an average pace for an hour. These women had a 50 per cent lower risk of breast cancer death compared with those with hormone-responsive tumours who had lower levels of activity.

JAMA 2005;293:2479-2486

MRI plus mammography best

Magnetic resonance imaging (MRI) combined with mammography is the best way to detect breast cancer in high-risk women. Women with mutations in BRCA1 and BRCA2 have a higher risk of developing breast cancer at a younger age. This group of women are offered mammography routinely but, because of their age, have denser breasts which make the screening less accurate. MRI was found to be significantly more sensitive than mammography in detecting breast cancer in this high-risk group of younger women. UK researchers conclude that the combined annual screening, MRI and mammography, would be the best option for detecting most tumours in this high-risk group.

Lancet; 365 published online May 16,
DOI: 10.1016/S0140-6736(05)66481-1

Partners help prostate cancer outcomes

Married men or those in a long-term relationship have better outcomes after treatment for prostate cancer than single men. Researchers found that men with prostate cancer who had a partner had better mental health, were less distressed by urinary problems, and coped better with the side-effects of cancer treatment such as nausea, fatigue and pain.

Men without partners appeared to have worse mental health as well as suffering chronic, debilitating illnesses such as diabetes and heart failure. Men with partners may have built-in support systems that help them cope with the psychological and physical stress of dealing with prostate cancer.

Cancer published online: 23 May 2005

VIRTUAL CANCER CARE

The arts and humanities

The use of creative art as a means of helping patients, families and health professionals understand cancer and major illness is becoming much more widespread and accepted. This edition of Virtual Cancer Care takes a look at some of the more interesting websites that help to promote this important area.

The MAP foundation

<http://www.mapfoundation.org>

The MAP Foundation is a registered charity which is the brainchild of Michele Angelo Petrone, an artist and former cancer patient who committed to canvas a whole series of pictures depicting his emotional reaction to his diagnosis and treatment. The result is an exhibition of explicit and bold paintings called the Emotional Cancer Journey that can be viewed on the web site (follow the "exhibitions" link) and indeed booked as a travelling exhibition. Also available to view is an equally striking exhibition of paintings and stories from patients and carers from St Peter and St James Hospice in the UK called Touching the Rainbow.

This site is very easy to find your way around with a simple menu, excellent graphics and an uncluttered feel. The educational work of the foundation is expanding continually as evidenced by the events page. Having viewed the original Emotional Cancer Journey paintings myself I can assure you that they are well worth the effort.

Art for recovery

<http://cc.ucsf.edu/afr/>

This fascinating and well presented web site offers the viewer a gallery of pictures and poetry contributed by cancer patients about their experiences. The site is a branch of the University of California cancer centre and contains details about a wide range of creative projects instigated to help people of all ages deal with cancer through the healing arts. Whilst American oriented, there are some interesting ideas that can be taken and adapted for use in different environments. If you click on the "previous issues/archive" link there are plenty more to pictures and poems to inspire you.

Confronting cancer through art

<http://www.upenn.edu/ARG/archive/ccta/intro.html>

This site is effectively an on line catalogue of paintings and art work related to cancer and terminal illness from a variety of mostly American sources collated in alphabetical order of the artist and accessible by a simple click. It's fabulous in its simplicity and the sheer quality of what is presented. Each picture contains a brief commentary and many are very poignant to read. There are no complex menus to navigate and the pictures are presented on a neutral background for maximum effect. It is possible to spend an hour or more just browsing this site as it is so compelling, so add it to your favourites list and go back again. You will not be disappointed.

Worth a look

Art therapy, dance therapy, music therapy, and imagery

<http://cancer.stanfordhospital.com/healthInfo/alternativeTherapy/senses/>

This page from the Stanford Hospital web site in America gives a very clear overview of a range of therapies in the humanities field and their applicability to cancer care.

Diversions, creativity and coping

<http://www.cancersupportivecare.com/diversions.html>

This page from the cancer supportive care web site is written for patients and families primarily, and talks in a non-patronising manner about attitude to illness, and the creative use of art when coping with illness.

British association of art therapists

http://baat.org/art_therapy.html

This site offers up to date information and useful contacts on the subject of art therapy in the UK.

American art therapy association

<http://arttherapy.org/>

The American equivalent of the UK Art Therapists site, with comprehensive links to a wide variety of related organisations. *Robert Becker, Macmillan Senior Lecturer in Palliative Care, Staffordshire University Faculty of Health and Sciences and Severn Hospice*

Patient experience crucial in cancer education

The European Association for Cancer Education Conference took place in April 2005 in Birmingham, UK.

This was the 18th Scientific Meeting and attracted an audience from across Europe and also from the sister organisation, the American Association of Cancer Education.

Concurrent sessions in the morning enabled researchers from Sweden, Netherlands, the UK and Australia to share their practice of using patient experiences as a learning tool.

The importance of linking the patient experience to service developments and educational courses was key to the round table debate. It stimulated a lively discussion about how to improve the relationships between education and practice.

Dame Gill Oliver, from Macmillan Cancer Relief UK and previous first vice

president of ISNCC, continued this theme in her keynote address on day two. She cited *Cancer Voices* as an example of how important it is to ensure that cancer patients' needs were used as the basis for education. If we want to have health care practitioners who are fit for practice the expertise of patients needs to be harnessed to develop and deliver education.

Looking at new ways of delivering education within the context of competency based learning, IT, e-learning and the changes in clinical roles and professional boundaries was maintained throughout each day and was a key theme in the excellent poster display.

As an individual who has a number of years in education but who is now working within primary/community care, I questioned whether I would gain from attending

the conference.

In fact I was stimulated and delighted by the positive approach that education wishes to take to ensure it supports the health-care practitioner to feel confident to deliver care for this group of patients.

I feel that clinical staff need to reflect on how they are working with their local cancer education departments to ensure that the courses being developed suit the needs of the service but more importantly, reflect the patients' needs.

EACE is a multi-professional organisation which enables cancer educators from medical and healthcare training departments across Europe to come together and share ideas, developments and concerns.

*Candy Cooley, ISNCC Secretary/
Treasurer, Palliative Care Development
Manager, Worcestershire, UK*

EDUCATION COLUMN

The Program of Experience in the Palliative Approach (PEPA)

People with cancer are typically cared for by a range of health care professionals in primary and specialist settings. Education for nurses who work in non-specialist or primary care settings about the fundamental principles and practice of cancer care is therefore an important area for development to ensure patients receive quality care throughout all phases of their cancer journey.

The Program of Experience in the Palliative Approach (PEPA) began in 2003 as an initiative of the Australian Government Department of Health and Ageing National Palliative Care Program. PEPA aims to enhance the capacity of primary health providers to deliver a palliative approach for people with life-limiting illness such as cancer. It does this by providing a clinical placement with a palliative care specialist and by forming supportive relationships between the settings to assist in the assimilation of palliative care skills and knowledge into work practices.

The programme is based on a mentorship model and provides up to two weeks clinical placement in a palliative facility for generalist health practitioners. It incorporates a range of learning strategies to allow the transfer of learning back into the participant's workplace, and promote sustainable outcomes from the experi-

ence. Participants complete a workbook that encourages them to define their learning objectives and identify strategies to assist the transfer of learning into the workplace.

These strategies often include identification of practice improvement projects to implement in the workplace following the placement. Participants are also assisted to identify local palliative care services and strategies for developing supportive links with these services.

Each state and territory in Australia has an appointed PEPA manager who is responsible for arranging suitable clinical placements, supporting host site mentors, and disseminating information about palliative care educational opportunities. A national co-ordinator has also been appointed to provide a source of reference and support for programme implementation and the application of best practice learning strategies. The co-ordinator also facilitates communication amongst the PEPA management team in order to promote the sharing of resources, achievements and challenges.

To date, over 100 weeks of placement have been provided within the state of Queensland alone, and the programme has recently been extended to allow for another 40 weeks of placement. A comprehensive evaluation of the programme is being

undertaken, through pre- and post- programme surveys of participants, mentors and employers.

In addition, participant workbooks are analysed to examine the nature, scope and outcomes of learning activities undertaken as part of the programme. Reports to date suggest that many of the PEPA participants have incorporated key knowledge and skills in palliative care into their practice, and have initiated a range of activities to support the delivery of palliative support in their workplace.

For example, some participants have reported giving educational tutorials to their colleagues while others have provided guidelines in various aspects of the palliative approach for their employing organisation. These have included pain assessment guidelines and guidelines for referral to palliative organisations within the community. Other participants have presented their report in a case study format, outlining some of the nursing problems patients have encountered, and strategies taken to overcome the problems from a palliative viewpoint.

For more information go to the Centre for Palliative Care Website: www.cpcrc.com email the manager of PEPA Queensland Gordon_Poulton@health.qld.gov.au, or the PEPA National Coordinator, Linda_Barrett@health.qld.gov.au

Cross-national views of communication and cancer care

At the 2004 ISNCC conference, the authors presented four papers from three different societies exploring cross-national perspectives in cancer nursing practice. A synopsis of each of the papers is given below.

The United States: use of email communication

In economically developed nations with high rates of computer use, email is thought to be a promising method for clinical communication. To date there has been little study of patient and family preferences regarding email use in clinical contexts. We conducted a study aimed to describe patients' and family members' interest in and use of email with their surgeons and nurses after head and neck cancer surgery.

We designed the survey to assess demographic characteristics, computer use, and experience in and desire to use email for clinical communication. The survey was distributed to patients and family members attending post-operative head and neck surgery clinic visits — 74 patients and 35 caregivers completed surveys.

One third of patients responding noted their interest in emailing their clinicians; however, only 9.5% of them reported actually using email with nurses or surgeons. Symptom management and prescription refills were the most common topics reported addressed in email communications. Almost no family members had any interest in using email to communicate with nurses and surgeons. Our findings suggest that email communication between head and neck cancer patients or family members with surgeons and nurses is not common and that patients, more than family members, are interested in using it for clinical concerns.

Sarah Kagan, Associate Professor of Gerontological Nursing, University of Pennsylvania School of Nursing, USA

Sweden: care diaries in cancer care

Cancer patients and their families have to learn and manage a great deal of complex information and unfamiliar language in order to communicate with a team of clinicians. Findings from earlier research inspired me and my colleagues from three departments, all treating a population of head and neck cancer patients, to develop a care diary. We studied care diaries from other cancer centres and performed a literature search before producing our own care diary for head and neck cancer patients.

The diary was presented to patient and family members at their first visit to the radiotherapy unit, usually the day after

diagnosis. The patient and family were encouraged to use it at home and during visits. A questionnaire was developed to collect evaluative information from patients, family members and clinicians.

The questionnaire included a mix of open and closed questions. A number of representative comments were chosen and translated into English to illustrate the impact of the care diaries. Questionnaire data was collected from 42 patients, 28 family members and 47 clinicians. Eighty-five percent of the patients, family members and clinicians stated that their overall impressions of the care diary were good or very good, and that the diaries improved communication and information.

Most of the patients and their family members used the diaries for both collecting information and keeping notes. Our conclusion is that care diaries can improve communication and patient involvement for cancer patients but a more sophisticated evaluation is needed.

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Hong Kong: brachytherapy telephone follow-up service

Women receiving brachytherapy for uterine cervical cancer treatment experience various physical changes and psychological distress. Lack of information about their disease, brachytherapy treatment, and self-care after treatment may influence the experience of treatment side effects.

For women who receive brachytherapy, knowledge that helps them to prepare themselves for treatment and post-treatment self-care with vaginal douching may help prevent complications. Therefore, we developed a patient education programme and telephone follow-up service for women discharged after brachytherapy for uterine cervical cancer. Our study used a two group pre-test and post-test experimental design. We recruited 27 patients between July 2003 and May 2004, and 20 of these completed the study. We assessed participants' level of knowledge and attitudes towards self-care during hospitalisation at baseline, then randomly assigned them to an intervention or a control group.

In the intervention group, participants received a telephone follow-up call at the first and sixth week after discharge. The call included health assessment questions, provision of health education, clarification of any misconceptions that arose on the part of participants, answers to questions about vaginal douching and dilation, and reinforcement of regular vaginal douching and dilation performance. The control group

received usual care. We assessed both intervention and control groups again at the 6th week after discharge.

Although preliminary findings reveal no significant difference between the groups in knowledge and attitudes towards self-care, participants noted that they were very satisfied with the telephone follow-up call. Future studies using larger samples are necessary to identify whether there are statistically significantly different effects as a result of the intervention.

Winnie So, Lecturer, Department of Nursing Studies, University of Hong Kong, China

The United States: enhancing multi-ethnic cancer care

Nurses provide patient education and support so seamlessly while providing care that it is often taken for granted. Multicultural cancer care challenges nurses to examine how they interact with patients. Where communication barriers exist, nurses cannot easily integrate education and support into the provision of care.

Until they encounter a barrier, nurses often fail to recognise the impact communication has upon patient outcomes. Lack of cultural proficiency can leave nurses frustrated by patient requests. Language differences are a common barrier, but unfamiliar health beliefs and rituals can be equally challenging. How a cultural group understands cancer and what disease and dying rituals exist within that culture directly affects how patients from that cultural group will behave when ill.

Acknowledging the differences inherent in a multicultural setting is the first step to overcoming cultural barriers. Recognition of the culture of healthcare and one's own ethnic background can provide nurses with insight into practice traditions and communication styles. Through understanding the culture of nursing as well as of their own culture, nurses may have increased tolerance for the challenges of multicultural care.

Awareness of cultural norms provides nurses with a context into which they can incorporate a patient's beliefs and practices. This allows them to tailor their care to meet patient's needs. Incorporating culture into practice can improve patient outcomes by decreasing staff frustration and enhancing patient satisfaction with care. With globalisation, multicultural practice will be increasingly common. It is only through striving to become culturally proficient that nurses can achieve holistic care.

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