



## New president for the ISNCC

Professor Sanchia Aranda has taken over as president of the International Society of Nurses in Cancer Care. Sanchia took up the four-year presidency of the society at the Toronto conference in September following a two-year term as president-elect.

She holds a joint appointment as Head of the School of Nursing, University of Melbourne and Director of Cancer Nursing Research at Peter MacCallum Cancer Centre, Melbourne, Australia.

### Research and teaching

Sanchia has worked in cancer and palliative care for nearly thirty years, predominantly in research and teaching roles since 1989. Her current research is in the area of supportive care and in the development of innovative nursing interventions to address problems such as pain and psychosocial distress.

Methodologically her research covers



ISNCC president Professor Sanchia Aranda

both quantitative and qualitative approaches and evidence-based practice, and focuses particularly on implementing evidence within clinical practice.

### Publications

She has more than 70 publications in the form of refereed journal articles, book chapters and conference proceedings and has been joint editor on two significant Australian palliative care texts, one in its second edition. Sanchia was until recently co-consulting editor of the International Journal of Palliative Nursing. In 2001, she received the Oncology Nursing Society (USA) International Award for Contributions to Cancer Care.

### Representation

In Australia Sanchia has represented cancer nursing at all levels of hospital and university administration and in government forums. She is the only nurse member of the Victorian Ministerial Taskforce on Cancer, where she has been instrumental in ensuring the advancement of supportive care initiatives in the state cancer plan. She was recently appointed to the Advisory Council of the newly formed Cancer Australia.

Sanchia has been involved with the ISNCC for many years. She served on the ISNCC board of directors for 8 years from 1992 to 2000 and is delighted to be taking on the leadership of the society. She said: 'This as an opportunity to contribute to the global development of the specialisation of cancer nursing'

### Future of the ISNCC

In particular, she believes that the ISNCC's role will increasingly focus on forming partnerships between well-resourced and poorly resourced countries to reduce inequities in cancer control. She said: 'There are many exciting developments in cancer nursing around the world that, with coordination and partnerships, could be made more widely accessible.'

In addition, Sanchia sees her role in the ISNCC as promoting the contribution of nurses to cancer control with bodies such as the WHO and the UICC (International Union Against Cancer) of which the ISNCC is a member organisation.

### Date for your diary

Planning is now underway for the 15<sup>th</sup> International Conference on Cancer Nursing which will be held in Singapore on August 17-21, 2008

For more information about the conference contact Malachite Management Inc, 375 West 5th Ave, Suite 201 Vancouver, BC, V5Y 1J6, Canada. Email: 15iccn@malachite-mgmt.com.

## Forging ahead in 2007

Greetings from Australia and I wish you all well for 2007. As this is my first president's message since taking over the role from Margaret Fitch in Toronto I want to begin by acknowledging the incredible work she has done in her four years as president. While much of this work is invisible to most of you, behind the scenes Margaret has worked tirelessly to develop the business systems for the society, to set a clear strategic direction for the board of directors to work from and critically, to develop our important relationships with other international bodies such as the International Council of Nurses and the International Union Against Cancer (UICC).

I hope you will join with me in thanking Margaret for this contribution, although of course she continues on as immediate past president and as founding president of ISNCC Ltd, the new company that holds responsibility for running our international conference every second year.

The International Conference on Cancer Nursing (ICCN) held in Toronto last September is now behind us. The conference was a wonderful success, showcasing cancer nursing from around the world and providing opportunities for all of us to network with many old and new colleagues.

The next ICCN will be held in September 2008 and planning is underway for this meeting. Watch out for more information over the coming months and start thinking now about potential abstracts you might want to submit.

You should also consider your travel plans. Singapore is in the heart of Asian holiday destinations so a planned break would be a good idea. Alternatively take the opportunity for a study tour in this part of the world. If you have any good ideas for the conference, Margaret Fitch and her team will be happy to hear from you.

The ISNCC is at an important stage in its

development. We have become large enough to be a major force in cancer control internationally and yet lack the financial base and systems support that allow us to wield our influence effectively. Over the coming year the board of directors will be working to develop our systems to make the society more effective.

The creation of ISNCC Ltd has been an important part of this as much of the board's energy has traditionally focused on the ICCN. Several changes are thus in train. The first of these is to seek to increase the level of administrative support the society receives.

For several years now ISNCC has used the secretarial services of Mediate Health Consulting Ltd in the UK and have received dedicated and loyal support from its staff, particularly director, Christine Armstrong. Mediate have also provided conference management services for several of our international conferences on cancer nursing. Recently the board considered the changing needs of the society in relation to secretarial services and determined a need to put these services out to tender in 2007.

I wish to take this opportunity to thank Christine for her wonderful service to the society and wish her well in her future business ventures. As an interim arrangement the services will be provided by Malachite Management Inc in Vancouver, Canada. Interim contact details can be found in this edition of the newsletter.

Finally can I ask that all of you consider ways in which you would like to be involved in the ISNCC and to pass these ideas on to our secretariat. The ISNCC will only ever reach its potential if we are all united in furthering the contribution of nurses to global cancer control efforts.

*Sanchia Aranda*  
President, ISNCC

## Marking World Cancer Day

A partnership of international institutions marked this year's World Cancer Day on February 4<sup>th</sup> by launching an initiative to fight the growing cancer crisis in Nicaragua. Many in the country have little access to screening and treatment facilities. The 7 million population is currently served by one radiotherapy centre.

The new partnership, coordinated by the Programme of Action for Cancer Therapy (PACT), aims to dramatically reduce cancer deaths in Nicaragua and improve conditions for people living with cancer by mobilising experts from across the cancer care community.

## Nurse politicians can join together

A new network launched by the International Council of Nurses (ICN) offers nurses from all regions who are active in politics the opportunity to meet, share expertise and strengthen the nursing contribution to policy.

The ICN Nurse Politician Network can be found at [www.icn.ch/npnnet.htm](http://www.icn.ch/npnnet.htm) and is open to nurses who have been elected or appointed at national, provincial/state and supranational levels currently or in the past.

## Correction

The winner of the poster award in the research category at the 14<sup>th</sup> International Conference on Cancer Nursing in Toronto, Canada was Tom Donovan from the University of Liverpool for the poster *Psychological distress following referral to a rapid access lung clinic*. Apologies as this award was wrongly attributed in the last issue of ICNN.

### EDITORIAL BOARD

#### President, International Society of Nurses in Cancer Care

Sanchia Aranda  
tel: +61 3 9656 3783, fax: +61 3 9656 1337  
email: [sanchia.aranda@petermac.org](mailto:sanchia.aranda@petermac.org)

#### Chair of the Editorial Committee

Candy Cooley  
tel: +44 (0)1905 733173  
email: [Candy.Cooley@sworcs-pct.nhs.uk](mailto:Candy.Cooley@sworcs-pct.nhs.uk)

#### Central and South America

Cibele Pimenta  
tel: +55 11 3066 7544, fax: +55 11 3066 7546  
email: [parpca@usp.br](mailto:parpca@usp.br)

#### North America

Catherine Glennon  
tel: +1 919 724 3678, fax: +1 919 681 8247  
email: [cglennon@nc.rr.com](mailto:cglennon@nc.rr.com)

#### Far East and Australasia

Patsy Yates  
tel: +61 7 3864 3835, fax: +61 7 3864 3814  
email: [p.yates@qut.edu.au](mailto:p.yates@qut.edu.au)

#### Europe

Candy Cooley  
tel: +44 (0)1905 733173  
email: [Candy.Cooley@sworcs-pct.nhs.uk](mailto:Candy.Cooley@sworcs-pct.nhs.uk)

#### Africa and the Middle East

Petra Fordelman  
tel: +27 21 843 1323, fax: +27 21 843 3382  
email: [petra@tlabs.ac.za](mailto:petra@tlabs.ac.za)

#### ISNCC Secretariat

email: [ISNCC@malachite-mgmt.com](mailto:ISNCC@malachite-mgmt.com)  
tel: +1 604 630 5516, fax: +1 604 874 4378

#### Editor

Kathryn Godfrey  
11 Chesholm Road,  
London N16 0DP, United Kingdom  
email: [kathryngodfrey@blueyonder.co.uk](mailto:kathryngodfrey@blueyonder.co.uk)  
All correspondence should be addressed to the editor.

<http://www.isncc.org>

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Mediate Health Consulting Ltd,  
108 Chestergate, Macclesfield,  
Cheshire SK11 6DU, United Kingdom.  
email: [christine@mediate-health.co.uk](mailto:christine@mediate-health.co.uk)

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# Intervening with self-care

The Robert Tiffany Memorial Lecture was given at the 14<sup>th</sup> ICCN by Professor Marylin Dodd from the School of Nursing, University of California, US. It focused on the development of the PRO-SELF Program. This is an abridged version

Self-care research in the oncology population included early work without intervention conducted by myself and others (1978-88). At this time patients had little knowledge of self-care. The modest self-care behaviours they used were mostly developed from trial and error which was costly in time and energy. They waited until side effects were severe and persistent and there were virtually no preventive self-care behaviours.

Changes in clinical practice were reflected in our study of 100 outpatients and their family members (Dodd et al, 1993). We learned that cancer treatment was aggressive and complex with remarkable treatment-related morbidity. Furthermore in the 1980's and early 90s cancer care had shifted from inpatient to outpatient settings with managed care. What was clearly evident to us was the need to develop effective approaches for teaching patients and their families. We focused our work on the developing, testing, and refining of a self-care intervention to decrease symptoms associated with cancer and cancer treatment.

A group of us met to determine "ideal creative and realistic nursing interventions to decrease treatment-related symptom morbidity." We determined that patients and their families needed information about their disease, treatment and side effects; instruction in essential self-care skills; and ongoing supportive nursing care. This information needed to be presented in a appropriate and consistent manner.

As a result the PRO-SELF Program has been designed to provide adult patients receiving cancer treatment with the information, skills and support they need to engage effectively and consistently in prescribed self-care symptom management. It serves as our intervention framework.

Orem's theory of self-care deficit in nursing (Orem, 1995) provides the theoretical framework for our series of studies. Specifically, we use four relevant concepts from her theory:

- *Self-care*: the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, well being,
- *Therapeutic self-care demand*: factors that affect human functioning, eg chemotherapy side effects, which produce a therapeutic self-care demand,
- *Self care agency*: the individual's self-care ability,

- *Need for nursing*: when there is a deficit between therapeutic self-care demand and self-care agency.

Self-care builds on what patients already know, and are doing for themselves. The content of the PRO-SELF Program depends on the symptom or symptoms being targeted. The dimensions of skill enhancement, proficiency, accuracy, consistency and timeliness are emphasised.

The last component of the PRO-SELF Program includes supportive, interactive nursing care or coaching. Here the research nurse listens to the individuals' experiences, positively reinforces their self-care activities, and provides encouragement. If self-care activities are not being performed, the research nurse tries to find out why.

### The series of studies

The series of studies listed below use outpatient samples as over 90% of cancer care is now provided in an outpatient setting. The studies are longitudinal (each patient is followed for 3 to 12 months with repeated assessments). The research teams are interdisciplinary, eg dentist, pharmacist, medical oncologist, radiation oncologist, exercise physiologist, physical therapist, statistician, and core nursing oncology faculty. All completed PRO-SELF Program studies are published with either me or my colleague Christine Miaskowski, Professor, Physiological Nursing, School of Nursing, University of California, San Francisco as the lead author.

The goal of the first large randomised control trial of the PRO-SELF Program (1988-1992) (Dodd & Dibble, 1993) was to decrease chemotherapy morbidity, targeting multiple side effects (nausea and vomiting, mucositis, fever and infection). The sample included 127 patients who were receiving selected chemotherapy agents that could produce at least one of the four targeted side effects. The sample included 85 of the patients' primary family caregivers.

The PRO-SELF Program contained schemas as a visual aid, written information on the four side effects and individual information cards. The self-care exercises included the patients recording their side effects and the self-care behaviours they performed. They used assessment equipment, eg, a digital thermometer and a small flashlight/penlight. The assistive support included coaching in the use of the PRO-SELF

Program, audio taping interactions between patient and nurse, relaxation and visualisation audiotapes for use at home, and a follow-up phone call 24 hours later.

The findings were statistically non-significant for the four side effects (quantitative data), but the patients and family members appreciated the intervention. We observed an important difference in our qualitative data with patients reporting that the PRO-SELF "helped manage the side effects and I did not become as sick." It helped people "get through the experience," and they felt "empowered."

### Too much information

In targeting four side effects we provided too much information, yet this is a modest number for the patients to be experiencing. We observed the "floor effect" with the side effect of infection, unplanned hospital admissions, and emergency department visits, being too few. The tolerance of the patients to their chemotherapy protocol as measured by treatment delays and downward dosing also occurred too infrequently to determine a difference by study groups. This outpatient sample experienced remarkable treatment-related morbidity with 30% attrition due to severe illness and death. However, adherence to the PRO-SELF Program was high at 85% as self-reported.

We regrouped our team in the next PRO-SELF study, targeting only one side effect that clinicians said caused considerable patient morbidity. Our goal was to develop a more intense intervention for oral mucositis.

The second generation of the PRO-SELF Program intervention study (Dodd et al 1996) was the PRO-SELF Mouth Aware (1992-1996). The design included two randomised control trials, the first aimed to prevent chemotherapy-induced mucositis (n=222), and the second aimed to treat or manage the mucositis once it occurred (n=204). Patients were randomised into the prevention groups using either chlorhexidine, "magic mouth-wash" (Benadryl, Maalox, Xylocaine viscous), or sterile water, then re-randomised later into treatment groups, using either chlorhexidine or salt and soda. These mouth-washes were selected because they were frequently used in clinical practice and had different underlying mechanisms of action.

The PRO-SELF: Mouth Aware project included information (knowledge), self-care exercises (activities or skills), and sup-

portive, interactive nursing care. The nurse provided:

- Information on how to thoroughly assess the oral cavity, and what constitutes excellent oral hygiene. We know from the literature that oral care is important – we needed to standardise this oral care.
- Self-care skills – performing excellent oral hygiene (penlight, toothbrush, floss, oral assessment and mouthwash) twice daily before mucositis, and four times daily during mucositis.
- Positive reinforcement and support for performing oral hygiene consistently and problem-solving any difficulties.

There were statistically non-significant differences between the mouthwashes used to prevent or to treat the chemotherapy-induced mucositis. There was however, an important reduction in the overall incidence of mucositis in the entire sample with the use of good oral hygiene. Our hypothesised estimate of occurrence was 40%, our actual occurrence was 23%. Clearly, there was no value added with the mouthwashes tested beyond that provided by good oral hygiene.

We learned that targeting one side effect was manageable for the patients, and adherence to the study protocol was not a problem at 95%. Subsequent studies testing different mouthwashes were:

The PRO-SELF: Candidiasis project which targeted persons with HIV or AIDS who were very susceptible to recurrence of oral candidiasis. A statistically significant effect of the PRO-SELF Program on recurrence of candidiasis was observed in this sample (Hilton, 2004).

Another study (Dodd et al, 2003) targeted prevention and management of radiation-induced oral mucositis in head and neck cancer patients. The intervention tested micronized sucralfate (carafate) mouthwash versus salt and soda mouthwash. Again, no statistically significant differences were observed between the mouthwashes, ie, there was no value added with the mouthwashes tested beyond that provided by good oral hygiene.

## Pain control intervention

The fifth generation of the PRO-SELF Program intervention study is the PRO-SELF: Pain Control (PSPC) (1995-2001). The principle investigator is Christine Miaskowski. In this randomised controlled trial patients who were experiencing metastatic bone pain were recruited. The design stratified on whether or not patients had a family caregiver who agreed to participate in the study. Patients who were randomised to the PRO-SELF: Pain Control group received from the research nurse:

- Information (knowledge) “academic detailing” which was tailored to each individual patient. Information was

provided on how to effectively take prescribed analgesics for metastatic bone pain, and correcting myths about taking opioids.

- Self-care exercises (activities and skills). Individual tailoring of self-care skills/exercises (based on the academic detailing), adjusting dosages and combinations of drugs.
- Supportive, interactive nursing care included coaching by the nurse, providing patients with a script to talk to their physicians about unrelieved pain and supporting them in these behaviours. Here is a sample of the script a patient was to use when contacting his/her physician about inadequate pain relief: “My pain is 7 on a 0-10 scale. I have been taking x drug dose, x times. I cannot do light chores around the house. The pain medications are not working. I need your help with my pain.”

The PSPC intervention obtained statistically significantly decreases in patients' pain scores, and significantly increased opioid intake by 50 mgs/day. The family caregivers' qualitative data has been analysed and published with Karen Schumacher as the lead author (Schumacher et al, 2002).

## More time needed

We learnt that the six-week trial should have been longer, 12 weeks was needed for behaviour change. The usefulness of pill-boxes was demonstrated, giving patients a visual reminder that they needed to reorder some of their medications ahead of time. The family members liked to participate in the study and intervention. Although the intervention was successful, it had no effect on 30% of patients. Learning this, we hypothesise that the dose may not have been high enough to affect these patients – we are about to test the 8th generation of the PSPC with a low and high dose intervention.

Our 6th intervention the PRO-SELF Fatigue Control (1999-2005) targeted chemotherapy-related fatigue and tested an individualised home-based exercise intervention. An exercise prescription was written (by an exercise physiologist) from cardiopulmonary fitness data of each patient. 101 women who were being treated for their breast cancer were randomised into three groups, the early exercise group (EE) during their chemotherapy with or without radiation therapy; the later exercise group (CE) after completion of their chemotherapy with or without radiation therapy; and the control group (CC).

Data analyses are ongoing, and will be presented at the Oncology Nursing Society Cancer Nursing Research Conference in Hollywood, California, February 2007. This study will contribute to our knowledge about when patients should exercise.

Women who are diagnosed with breast cancer are enthusiastic and motivated. Some women were already exercising before entering the study, this was not an exclusionary criteria as we did not instruct women to stop exercising.

## Future studies

Our next large study which looks at symptom management after breast cancer surgery, targets women who receive surgery for breast cancer, both subjective (eg pain, paresthesia) and objective (eg shoulder mobility, oedema) measures (prevalence phase 12 months). Subsequently, women who develop neuropathic pain are initiated in the RCT phase and treated with lidocaine patch or placebo for 2 months. This PRO-SELF Pain Control (Lidocaine Patch) is our 7th intervention (2003-2008), and is ongoing.

Returning to the persistent problem of mucositis, we learned in the intervening years of work being done which increased our understanding of the complex pathogenesis of mucositis. As a consequence of this knowledge, the 8th study in this series is our ongoing RCT (PRO-SELF: Mouth Aware: Management of Radiation Therapy-induced Oral Mucositis with GM-CSF Mouthwash 2003-2008).

We are using a more biologically active agent, GM-CSF (Granulocyte Macrophage Colony Stimulating Factor), a hematopoietic growth factor that influences proliferation and differentiation of stem cells and regulates several functions in mature leukocytes, macrophages, and dendritic cells of the dermis and submucosa. Clearly GM-CSF has pleiotropic activity. This study includes patients who have head and neck cancer who are being treated with radiation therapy alone, or concurrent chemotherapy with either GM-CSF (Sargramostim) mouthwash or salt and soda mouthwash.

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# Margaret Fitch

## ISNCC President 2002-2006

Margaret Fitch has handed on the presidency of the ISNCC after four successful years in office. Margaret took over the presidency four years ago at the ISNCC London conference and completed her presidency at the society's Toronto conference in October last year.

Margaret, who is Head of Oncology Nursing and Supportive Care at the Toronto-Sunnybrook Regional Cancer Centre, Canada first became involved with the ISNCC when she presented her research at the society's international conference on cancer nursing in London in 1988.



Margaret Fitch, immediate past president

### Voice of cancer nursing

Elected as a board member representing North America in 1992, she served in this role for ten years. In 1994 Canada was invited to host the biannual conference and Margaret co-chaired the successful event.

She has always been a firm believer in professional associations and was involved in forming the oncology nursing organisation in Canada which became the Canadian Association of Nurses in Oncology (CANO).

When she was elected as president in 2002, Margaret emphasised the importance of the ISNCC for oncology nurses around the world and proclaimed her intention to help the society to become 'the voice of cancer nursing'.

### Profile raising

During her presidency Margaret has worked hard to raise the profile of the ISNCC and its role in cancer care and control.

She has been a great ambassador for the society, networking and representing the ISNCC at international conferences, mak-

ing the society more visible to nursing groups and institutions around the world.

Margaret has been instrumental in forging and strengthening links with international organisations. She has worked closely with the WHO to ensure that the ISNCC is an essential player within the planning of National Cancer Control strategies.

### Forging relationships

She has raised the profile of the ISNCC within WHO, and established contacts and a presence that did not exist previously. Similarly she has strengthened and raised the profile of ISNCC with the International Council of Nurses (ICN) and with the International Union against Cancer (UICC).

During her presidency Margaret has developed a relationship between the ISNCC and the Multinational Association Supportive Care in Cancer (MASCC). This has led to the establishment of joint educa-

tional sessions during each organisation's conference.

She has also overseen the establishment of a collaborative agreement with the European Oncology Nursing Society (EONS), the only regional cancer nursing society.

She has represented the ISNCC within the Global Breast Cancer Initiative which develops guidelines for breast health and cancer control to improve breast health outcomes.

### Leadership programme

One of the pillars of Margaret's presidency has been the establishment and development of the ISNCC leadership programme. The programme was developed to bring cancer nurses together to learn about leadership and to develop their skills in influential change. Thirty cancer nurses took part in the first programme which took place over three days in Toronto, Canada in June 2005.

The second programme was held in Cape Town, South Africa in April 2006. This was an historic event in the life of the ISNCC as it was the first time the society had held an educational activity on the African continent.

### Continuing contribution

Although Margaret's term as president has come to an end, she will continue to serve as immediate past president, continuing to share her knowledge, experience and skills, in moving the society to the next stage of its development. Margaret also takes up the role of founding president of ISNCC Ltd, a body established to run the biennial International Conference on Cancer Nursing.

## RESEARCH ROUNDUP

### Experience helps nurse confidence

A study of 410 nurses working in paediatric palliative care found that a greater number of years in nursing practice and more hours of palliative care education resulted in the nurses feeling more comfortable working with dying children and their families. It also produced lower levels of difficulty talking about death and dying, and higher levels of palliative care competency.

Feudtner C et al (2007) Hopeful thinking and level of comfort regarding providing pediatric palliative care: a survey of hospital nurses. *Pediatrics*, 119:1, 186-192

### Prompt list eases patient interview

Giving terminally ill patients a prompt list of questions to use in a physician consultation encourages them to ask more questions. A study of 174 patients found that the prompt list resulted in more patients asking question about prognostic and end of life issues without creating anxiety or impairing satisfaction.

Clayton JM et al (2007) Randomised controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, 25:6, 715-723

### Telemedicine improves QoL

Telemedicine improves the quality of life of cancer patients, according to the results of a study of patients with cancer involving the head and neck. The patients were given access to an electronic health information support system for six weeks after being discharged from hospital.

van den Brink JL et al (2007). Impact of quality of life of a telemedicine system supporting head and neck cancer patients: a controlled trial during the postoperative period at home. *J Am Med Inform Assoc*, 14, 198-205

## VIRTUAL CANCER CARE

**Quitting smoking**

Smoking related cancers are one of the biggest causes of preventable illness and death across the world and the statistics continue to get worse rather than better.

Whilst legislation against tobacco advertising and smoking in public has made some difference in western society, the situation in developing countries is nothing short of catastrophic. The tobacco companies are targeting increasingly affluent populations with few restrictions in place.

It is useful therefore to look at what the internet has available for health professionals who may wish to offer advice and support to their patients or their colleagues on quitting smoking. The web reviews in this column are independent of the manufacturers of smoking cessation products and are in no way endorsing these products.

**Giving up Smoking**

<http://www.givingupsmoking.co.uk/>

This UK site is part of the National Health Service and the attention to detail makes it one of the best. It has everything you would expect and a number of features that other sites don't have, such as advice regarding second hand smoke, pregnancy issues, cultural issues and an "ask the expert facility".

**Click to Quit**

<http://www.click2quit.co.uk/>

This Niquitin company web site has a wealth of useful information. It offers a range of practical strategies and has a good evidence base to the information, albeit biased towards their products. Health professionals can sign in – which does not entail leaving your email address. Once signed in there are useful guides for consultations.

**British Heart Foundation**

<http://www.bhf.org.uk/smoking/>

This very simple web site has lots of easily accessible, useful advice and uses the internet to good advantage by offering email and text support, a message board, and a stop smoking blog. There is even a downloadable calendar screensaver, to help the person keep track of how long it is since they gave up, and how much money they are saving.

**Why Quit**

<http://whyquit.com/>

This independent US web site uses a very direct and hard hitting approach to its message, which is to its credit. Some of the statistics need updating, but there is some excellent material here.

**Worth a look****Action on Smoking and Health**

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

This UK web site has a range of resources available including fact sheets, links and details of support services. ASH are a public health charity who lobby for legislation.

**CDC – Tobacco information and prevention source**

<http://www.cdc.gov/TOBACCO/how2quit.htm>

If you just want a large database of resources that are printable and downloadable in one place then this is the site for you. It effectively pulls together all interested parties throughout North America in smoking cessation.

**Quit Smoking Reviews**

<http://www.quit-smoking-inspector.com/>

This independent site has a strong evidence base to its content and systematically reviews all the products currently available in this area on the internet and ranks them according to their effectiveness.

*Robert Becker, Macmillan Senior Lecturer in Palliative Care, Staffordshire University Faculty of Health and Sciences and Severn Hospice, UK*

## EDUCATION COLUMN

**Education in cancer nutrition**

Despite the well-documented adverse effects of malnutrition in cancer care, it remains unrecognised in routine clinical practice. Nutrition status education should be one of the priority subjects in cancer nursing education as malnutrition is often preventable.

RS Cunningham states in her article, *Measuring oncology nursing – sensitive patient outcomes* (Cunningham, 2005) that: "Oncology nurses should receive formal and continuing education that includes information on nutrition status in cancer. This should include information on screening and assessment tools, the need to provide anticipatory care and proactive interventions, current guidelines for developing nutrition care plans, and the need for specialised nutrition support.

"New research findings on nutrition status as an outcome variable need to be incorporated rapidly into educational strategies so that they can be translated into clinical practice."

She also says: "Clinical screening and assessment are essential for early identification of cancer-related nutrition problems. Screening should occur at baseline (the point of initial patient contact). Patients who are identified as malnour-

ished will need to have nutrition care plans developed. Patients who are identified as not being at risk should continue to be screened throughout the care process."

The European Oncology Nursing Society (EONS) commissioned a study into the nutrition education needs amongst cancer nurses. The topics of most interest to nurses identified from that study were ethical issues, improving the patients' nutritional intake and helping control their symptoms.

In the same study, nurses said that they would like to know more about nutritional management in various stages of cancer, metabolic changes in cancer patients, nutritional advice to patients/relatives, evidence-based information (particularly for discussing nutrition issues with the medical profession), information on the composition and use of oral supplements and tube feeds and complementary therapies including vitamins and minerals. (Foubert, 2004)

It has become evident that nutrition is crucial throughout illness and treatment, and affects response to treatment, quality of life, length of hospital stay and survival.

For example during active cancer treatment, maintaining energy balance or pre-

venting weight loss is the most important nutritional goal for patients at risk for weight loss – eg those who are already undernourished or those who receive treatment to the alimentary tract. Nutritional assessment and planning for these patients should begin while treatment is being planned and should focus on current nutritional status and anticipated nutritional problems related to treatment. Often the nurse is the health care worker mostly in contact with this person, and therefore the most obvious person to identify the needs and address the problems.

Therefore, although courses in cancer nutrition are starting to emerge, there is a real need to further establish nutrition education as a core element in cancer nurse training.

*Petra Fordelmann, Nursing Service Manager and Part Time Lecturer for the Oncology Nursing Course, iThemba LABS, Cape Town, South Africa*

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### Recruitment of ethnically diverse populations

It is essential to recruit ethnically diverse populations for cancer nursing research in order to generate the knowledge required to provide culturally competent care and increase our understanding of factors that contribute to cancer disparities among minority populations.

Descriptive research is needed to address the changing demographic profile of our patient populations worldwide and there is a need for intervention research that is culturally sensitive and aimed at improving disparate cancer outcomes.

#### Barriers to recruiting diverse populations

Economic, social and cultural factors contribute to cancer disparities (Ward et al, 2004) and these same factors explain the common barriers researchers face in recruitment of minority populations.

Low socioeconomic status has been associated with lower educational levels and literacy, misperceptions about health and illness, limited cancer knowledge, lack of resources and negative attitudes about research, specifically fear and mistrust (Giuliano et al, 2000).

The demands of everyday life and concerns that research will interfere with work and family life may mean that persons from lower socioeconomic backgrounds are reluctant to participate in studies.

Finally, language is a significant barrier in recruitment of minority populations if it is different from the dominant language spoken. This has significant implications for development of recruitment materials, informed consent procedures (written and verbal), composition of the research team (we need team members fluent in the language of the target group), the need to translate instruments for data collection and interpretation of translated qualitative data.

#### Challenges for researchers

Time is a major factor in the conduct of research with diverse populations and the time required is frequently underestimated in the planning and timetabling of the proposed study. Getting to know the community and engaging their support is recognised as essential to successful recruitment and

retention (Julion et al, 2000).

Community engagement is time and labour intensive and requires funding support to adequately compensate the study recruitment staff before and during the conduct of the study.

Heterogeneity within ethnic groups, regional variations, levels of acculturation and estimating the available target population are challenges to defining the sample (Oncology Nursing Society, 2000). The availability of culturally relevant materials and the limited number of ethnically diverse cancer nurse researchers are further challenges to the research process.

#### Strategies to recruit diverse populations

Multiple strategic approaches are recommended for research with ethnically diverse populations (Ashing-Giwa et al, 2004). The ideal research team is diverse and includes members who have a shared sociocultural background with the target population ("insiders") and members who are not part of the culture ("outsiders"). Access, trust, insight and language are advantages associated with "insider" team members, but because of the shared culture, they may have inherent biases or fail to make important observations.

The reality of the shortage of ethnic researchers supports the need for "outsiders" who have research experience, resources and the potential for insight into less explicit findings. Prior to study implementation, the research team needs to establish trust and respect through community networking ("doing time in the community") and needs to gain an understanding of the culture within that community in order to specifically tailor recruitment strategies, materials and incentives for the specific target population.

Successful recruitment techniques that have been identified for diverse populations include community outreach, targeted mass mailings, personal referrals, media, community endorsement and face to face contact (Gilliss et al, 2001).

These techniques however must be tailored to the culture of the specific ethnic population(s). For example, face to face or

personal contact strategies may have advantages over media approaches in the recruitment of Latino and Asian populations and community networking has been shown to be a successful approach to recruiting African Americans for cancer nursing research (Knobf et al, 2005, in review).

#### Summary

Recruitment of ethnically diverse populations for cancer nursing research is essential to provide culturally competent care. Strategies have been identified to overcome common barriers to recruitment of diverse populations and special attention is required in recruiting minority populations of lower socioeconomic status.

Time, resources and training and support of recruitment staff must be carefully integrated into the research proposal for successful recruitment and retention of multi-ethnic populations. Finally, it is critical to recruit and mentor ethnically diverse men and women into the profession of nursing as oncology practitioners and researchers.

*M Tish Knobf, American Cancer Society Professor of Oncology Nursing, Yale University School of Nursing, New Haven, United States*

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## CALENDAR OF EVENTS

- **The World Cancer Congress 2008** will be held by the UICC in Geneva, Switzerland on 27-31 August, 2008. For information go to [www.uicc-congress08.org](http://www.uicc-congress08.org) email: [secretariat08@uicc.org](mailto:secretariat08@uicc.org)
- **The 15<sup>th</sup> International Conference on**

**Cancer Nursing** will be held by the International Society of Nurses in Cancer Care in Singapore on August 17-21, 2008. For more information contact Malachite Management Inc, 375 West 5th Ave, Suite 201, Vancouver, BC, V5Y 1J6 Canada.

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- **The 14<sup>th</sup> European Cancer Conference** will be held by the Federation of European Cancer Societies in Barcelona, Spain on 23-27 September, 2007. For information go to [www.fecs.be](http://www.fecs.be) email: [ecco14@fecs.be](mailto:ecco14@fecs.be)