



## EONS award

The European Oncology Nursing Society presented its 2003 Distinguished Merit Award to Alison Richardson, Chair in Cancer and Palliative Nursing Care, Florence Nightingale School of Nursing and Midwifery, King's College, London, UK.

Receiving the award at ECCO 12 — The European Cancer Conference — in Copenhagen, Professor Richardson said that it was 'a great moment in my professional career'.

During her award lecture she focused on the topic of supportive care which helps the patient maximise the benefits of treatment and to live as well as possible with the effects of cancer.

She identified five areas of focus to further supportive care and improve performance. These were rigorous and regular assessment, team work, integrated cancer care, partnerships with patients and evidence based care.

Professor Richardson advocated continual development of research to bring clinical practice to the next level and urged nurses to be inclusive of other professions. She said: 'We are at the point where collaborative efforts are needed to develop new

methodologies for addressing increasingly complex issues, such as the identification and management of symptom clusters.

'Perhaps for too long we have separated ourselves out from other professionals, trying to find a unique piece that cannot be shared. By holding ourselves out as different we may be actually preventing ourselves from feeling and being perceived as equal. It takes courage to work collaboratively with others.'

Professor Richardson concluded by emphasising the key role that nurses play in supportive care and how they needed to build on the care they offer. She said: 'We should grasp opportunities, however flimsy they at first might appear, confident that together we have the skills and knowledge to move things forward.'



Alison Richardson

## Challenges for new patient coalition

ECCO 12 saw the announcement of the formation of the European Cancer Patient Coalition (ECPC), the first pan-European patient group to represent all major forms of the disease.

Members of the coalition intend to influence European health policymaking, affirm the rights of cancer patients, ensure access to appropriate screening, treatment and care, and promote the advancement of cancer research. To ensure that their voice is both strong and representative, they will work together with the scientific and professional cancer community in lobbying policymakers.

But, according to Kathy Redmond, Editor, Cancer Futures, from Milan, Italy, there are many challenges to be faced in building an effective patient organisation. At a European level it is difficult to define common concerns because of the variability of health care systems, she said. And the European legislative system is extremely complicated, even to Brussels insiders, and ECPC will have to learn how to navigate and influence it.

But one of the largest obstacles to patient collaboration at European level is language. 'Relatively few Europeans have the same mother tongue, with just over 25% speaking German, and 16% speaking English,' Ms Redmond pointed out.

Funding is another problem for patient organisations, and one of the biggest challenges facing ECPC will be to ensure adequate funding to overcome the linguistic divide and to enable the coalition to operate effectively, said Ms Redmond.

## Prostate cancer death rates down

Findings presented at ECCO 12 show that US prostate cancer mortality rates, which had been increasing slowly during the 1970s and 1980s, suddenly started to fall rapidly during the 1990s.

Between 1990 and 2000, US prostate cancer mortality fell by one third at ages 50-74,

and it fell by one quarter at ages 75-84. Definite decreases are also beginning to be seen in the UK, France and some other European countries.

The improvement is thought to be due to early detection, prompt surgery and hormonal treatments.

**Don't miss the 13<sup>th</sup> International Conference on Cancer Nursing  
Sydney, Australia 8-12 August 2004**

# ISNCC gives cancer nurses an international voice

My research unit has a mandate to focus our research efforts on understanding the experiences of women with breast cancer who are not usually part of research studies. These are women we think of as having been marginalised both in the cancer care system and in research studies. We are focusing our work on various communities of women: young, old, living in rural settings, recent immigrants, indigenous peoples, lesbians, women of colour and so on.

We often talk about the research work as an avenue to giving the women 'a voice' — a way for their views and experiences to be shared. We hope their voices will help to make changes in the cancer care system, in the first instance by raising the awareness of health care professionals to the way the women are being treated as people.

## Sharing experience

I cannot help but think that our oncology cancer nursing societies can, and in many instances do, serve the same purposes for cancer nurses. The societies are a way to give cancer nurses an avenue to voice their views and experiences. And there are many topics about which cancer nurses have experiences and have ideas about where improvements can be made.

Cancer care systems around the world are undergoing change. Trends in health care are impacting cancer care delivery: patient-focussed philosophies, focus on cost control and managed systems, integrated delivery models, population-focussed care, focus on accountability, evidence-based practice and transfer of care to ambulatory and community based care delivery. As well, trends in cancer con-

trol are also having an impact on cancer care delivery: advances in science and technology, increased complexities in treatment protocols, and enhanced ability to manage side effects, and changing profile of side effects.

Finally, social trends can influence care delivery: changes in population demographics, changes in family patterns, changes in societal perspectives about health. Oncology nurses clearly have confronted these changes and hold viewpoints about the resulting impact and about where improvements in care are needed.

## Powerful influence

As I speak with nurses from around the world, I am struck by the similarity we share in the issues we face. Examples of issues I have heard about are: access to care, unequal burden of cancer, cancer research funding, use of technology, tobacco, access to end-of-life or palliative care, and shortage of nurses. These are health policy issues that influence patients and nurses alike.

Cancer nurses with our experience and expertise need to speak out about these issues. Cancer nurses can be a powerful influence if we work together and work to have our voice emerge in the interest of better cancer care. Patients need powerful nurses!

Historically, nurses have had tremendous influence on health policy regarding public health, and maternal and child care. Cancer nurses have been instrumental in many of the technological advances in chemotherapy, radiation patient care, access devices, and biotherapy. They have

also contributed to advances in symptom distress management, patient education, supportive care and end-of-life care. This tradition of influence is of paramount importance to continue in our present times.

There are various places where cancer nurses can speak out and influence the decisions about how care is delivered:

- at staff meetings in your unit
- to your head nurse or manager
- to your Director of Nursing
- to your city or municipal government representative
- to your Ministry of Health (state, provincial, national)

We cannot all personally have conversations with governmental representatives. But by working through our professional organisations, our voices can be heard.

ISNCC is your voice in the international arena. ISNCC has the capacity to interact with the World Health Organization and the International Council of Nurses. Our position statements are tools used to influence health policy. These statements are developed to reflect the collective voice of oncology nurses from around the world.

Our capacity to be effective is directly related to our ability to reflect the voices and views of nurses worldwide. And this is why it is so important for the membership of ISNCC to be as inclusive as possible.

I urge you to join ISNCC. Let your voice be added to those of other cancer nurses from around the world.

*Margaret Fitch*  
President, ISNCC

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# Nurses ignore sun exposure advice

Healthcare professionals with high levels of awareness of the risk of skin cancer are not taking heed of preventive measures according to nursing research presented at ECCO 12

Kerry Guile, senior chemotherapy sister at St George's Hospital, London, UK, designed SAMPLE (the Sun Awareness/Melanoma-Prone Lifestyle Enquiry) as a tool to research the epidemiology of melanoma.

Ms Guile gave the questionnaire to oncologists, oncology nurses, non-oncology nurses, medical students and the public. Ms Guile said: 'There was a statistically

significant difference across the five groups in the headings of protection and knowledge with oncology nurses scoring highest on sun protective behaviour and oncologists on knowledge. But, there were no significant differences in behaviour and no correlation between knowledge and behaviour scores.

'These findings are consistent with studies in some other populations: it means that assumptions by public health bodies that improving awareness of the risks of sun exposure will reduce the incidence of melanoma are probably not correct,' said Ms Guile.

## Survivors after-care

Survival rates from childhood cancers have improved but many survivors suffer complications from the disease or treatment.

A study presented to ECCO 12 showed that for children aged 14 and under diagnosed with cancer between 1960 and 1999 the five-year survival for all cancers increased from 23% in the 1960s to 70% in the 1990s.

Professor Jill Mann, Professor of Paediatric Oncology at the University of Birmingham, UK said: 'Research is required to determine the extent of problems in survivors, so that treatment of current patients can be modified to avoid them as far as possible.

'For example, already we have greatly reduced the use of cranial radiotherapy in children with leukaemia and doctors use smaller doses of anthracyclines.'

### EDUCATION COLUMN

## Sharing the responsibility of course evaluation

How do educators know that the educational course they are delivering is meeting its intended outcomes? Most educators rely upon the success of graduates in examinations or other forms of summative student assessment to determine the success of the course. However, in today's world, driven by a focus upon organisational outcomes, educators are challenged to demonstrate the success of their courses in other ways.

It is accepted that monitoring and evaluation of education programmes is important, however this area continues to be inconsistently addressed by educators and organisations alike. Rather, the excitement of a new programme and its associated planning and implementation can take the limelight and associated energy, leaving current programs to continue until enrolments drop off.

In a practice-based discipline, like nursing, education is focussed upon nursing work: improving health outcomes for patients/families and ensuring nurse health and safety. Any programme monitoring in today's environments should focus upon the outcomes of nursing work. With this in mind, the responsibility for monitoring can then be shared with those affected by its outcomes: student, other nurses, patients and families, other health professionals working with the graduates, as well as the managers/policy makers.

Establishing a reference group to support the educator in the monitoring work ensures that the outcomes of the education programme are identified and followed over time. The reference group shares responsibility for planning and implement-

ing monitoring processes and then interpreting the findings, with an advisory role on how the course is meeting its intended outcomes. Terms of reference, determined by the reference group, are required to create an environment of open and authentic collaboration. Terms of reference could:

- establish the shared goals for the reference group. This could include identification and measurement of the expected outcomes of the education course, as well as other areas considered important by the group,
- determine the structure of the group. Identify who else should be included, how long the group should continue to meet to achieve its agreed goal, and identify a date for review of the group,
- generate and accept agreed parameters for the group's work. This may include identification of those areas that are not to be addressed by the group.

The kinds of work that the reference group may pursue include planning of the monitoring process. What kinds of data need to be collected to answer the question: How do we know that the education course is meeting its intended outcomes? The reference group would identify possible sources of data such as the students, the nurses in the areas where the knowledge will be applied by the students/ graduates, other health care professionals working with the students/ graduates, the patients and their families, who will be directly affected by the increased knowledge from the education, and the managers/policy makers who provide the framework for the delivery of

care. The reference group would then generate and agree on how the data might be collected. For example, data can be gained in a range of ways such as the development of monitoring surveys/questionnaires, in-depth interviews, focus group interviews, as well as the collection of the views of members of the reference group.

In making a decision about the kinds of data to be pursued, the reference group would consider the available resources such as human resources to create questionnaires, collect interview data and then transcribe and analyse the data for consideration by the reference group. Like development of new programmes, there are costs associated with monitoring and evaluation of current programmes. Annual education budgets need to acknowledge these costs. Inclusion of managers and policy makers on the reference group has the potential to increase the level of awareness of the relevance of monitoring work, and possibly influence available resources.

In summary, the value of monitoring and the evidence it provides continues to be overlooked. In contemporary practice settings, with a focus on evidence and outcomes, the value of monitoring courses is increasing. Rather than take this on alone, educators should consider a collaborative model that brings together the stakeholders for the course and shares the responsibility of education evaluation amongst those that it affects.

*Laurie Grealish, Board Member ISNCC (Far East and Australasia) Senior Lecturer in Nursing, University of Canberra*

# Conference diary

## It's now less than a year until the society's biannual conference in Sydney. In this second installment of her conference diary, Patsy Yates brings us up to date with preparations for the event

'Beautiful one day — perfect the next'. That's how we like to describe my home state of Queensland. It's especially true at this time of year. As I write this update, it is one of those perfect spring days, and I am starting to count down the days till summer holidays. But there are a couple of important conference deadlines to meet before I head off on vacation. Number one priority is to finalise the conference programme, so it can go to print before the New Year.

The 2004 programme is looking great. We've identified some excellent speakers from many regions of the world. It's been fantastic to see the enthusiasm our speakers have shown when asked if they could share their expertise with cancer nursing colleagues from around the world. I've had some fascinating phone and email conversations with nurses from many different countries about what the conference programme should be like. I have had to become an expert on international time zones.

Even though it doesn't seem very long since our 2002 conference, it's quite remarkable to reflect on the enormous advances that are continuing in cancer care. I've been especially struck by some of the recent developments in areas such as supportive care, cancer prevention, cancer

treatment, and nursing advocacy. These developments are providing the planning committee with a wealth of possibilities for conference sessions.

We've had hundreds of abstract submissions from around the world. Our abstract review team is ranking these submissions as I write. The feedback from the abstract reviewers so far is that there is a lot of excellent work out there. It's fascinating to see the scope of topics addressed in these abstracts. It's going to be an enormous challenge to choose from the overwhelming number of submissions.

The pre-conference workshops are also taking shape. The research workshop has become a tradition at the ICCN, and we are just sorting through the dozens of other ideas that have been submitted for the pre-conference programme. I expect that the workshops will be quite popular as they are going to be presented by experts in the field who will provide updates on some 'core business' topics for cancer nursing practice.

Looking at all there is to be done, it does seem like a bit of a jigsaw at the moment. But all the pieces do seem to be coming together, and it won't be long before we see the final product.

Our other priority over the next few months is to plan the welcome functions,

ceremonies, and social programme. This work has proved too big for one person to handle. We've had to recruit some of our most creative Australian nurses to handle these important tasks.

Keith Cox from Sydney is chairing the Local Arrangements Committee. He has also taken on the job of leading the team that will be arranging our social functions, including the gala dinner. This will be an event not to be missed. Tish Lancaster from Sydney is leading the team responsible for organising the opening and closing ceremonies and other more formal activities associated with the meeting.

Cath Johnson from the Hunter region, just north of Sydney, is leading the team that is planning the delegate welcome activities.

These three nurses are working with another large group of committed volunteers, so delegates to the conference are in some very capable hands. We'll hear more from these team leaders over the coming months.

*Patsy Yates*

*Associate Professor Director of Research, Centre for Palliative Care Research and Education, School of Nursing, Queensland University of Technology, Australia*

## Smoking kills as many in developing world

Recent research has estimated that 4.83 million premature deaths worldwide were attributable to smoking in the year 2000.

Researchers used lung-cancer mortality as an indirect marker for accumulated smoking risk. Mortality was found to be similar in developing and industrialised regions of the world, and was greater in men than in women.

The leading causes of death from smoking were estimated to be cardiovascular diseases (1.69 million deaths), chronic obstructive pulmonary disease (0.97 million deaths), and lung cancer (0.85 million deaths).

Larger variation in mortality attributable to smoking was found in the regions of the developing world than in industrialised regions. For example the fraction of total adult mortality from smoking ranged from

a low of 2-4% in sub-Saharan Africa and parts of Latin America to a high of 9-11% in other parts of Latin America, southeast Asia, and the western Pacific.

The researchers point out that using lung cancer as the marker for accumulated smoking hazard can result in an overestimation of risk where there have been sharp declines in smoking, and underestimation of risk where there has been large increases in smoking. So because smoking has declined in North America and some countries in western Europe there may be some over estimates of mortality. And the hazards of smoking may be underestimated in most developing countries, where smoking has been on the rise over the past few decades.

In developing countries mortality linked to smoking is higher among men (84% of

smoking-attributable deaths). Compared with industrialised countries, developing countries have a higher proportion of deaths due to smoking at a younger age.

The researchers conclude that: 'The results of this analysis suggest a transition to an era in which smoking kills about as many people in developing countries as in industrialised nations.'

They predict that mortality as a result of smoking will rise substantially in developing countries unless effective interventions and policies that reduce smoking among men and prevent increases among women are implemented.

### Reference

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# Positive feedback for the nurse's role in myeloma care

**The role of a clinical nurse specialist for myeloma patients has been developed to provide for the complex and ongoing needs of this group of patients. This article describes the process of establishing a need and responding to it by providing a new patient-led service**

The haematology department at Christie Hospital, Manchester, UK, is a regional centre for the treatment of haematological malignancies including multiple myeloma.

Multiple myeloma is a haematological malignancy affecting bone marrow plasma cells. It is relatively rare with 4/100,000 newly diagnosed cases diagnosed in the United Kingdom per annum (Smith 2001). The median age at diagnosis is 65 years thus affecting a predominantly older age group. Less than 2% of patients will be under 40 years of age at diagnosis. It is more common in men than women and has a higher incidence in Afro-Caribbean populations.

## Outpatient management

Unlike other haematological malignancies such as leukaemia much of the treatment for multiple myeloma is managed on an outpatient basis including initial chemotherapy regimens and treatment for those with relapsed or progressive disease. However there are a growing number of patients who as part of their care are undergoing high dose chemotherapy and peripheral blood stem cell transplant, with a small number of younger patients undergoing allogeneic bone marrow transplantation from a sibling donor. Both of these procedures require admission to hospital for significant periods of time.

## Complex disease

Multiple myeloma is a complex disease, symptoms at presentation can be varied. Occasionally a diagnosis is made after routine investigations for other procedures. However more commonly patients present with a variety of symptoms including bone pain, recurrent infections, fatigue, anaemia, renal impairment and in some cases require emergency treatment for hypercalcaemia or spinal cord compression. Accurate diagnosis of the disease is essential and requires patients to undergo a number of investigations including blood analysis, 24 hour urine collection for Bence Jones Protein, bone marrow aspirate and skeletal survey.

Myeloma cannot be completely eradi-

cated by chemotherapy. It is therefore considered an incurable but treatable condition. The aim of treatment is to slow the progression of the disease, treat symptoms and reverse complications hopefully restoring and maintaining quality of life for these patients. Some types of myeloma can remain stable for long periods of time after diagnosis without any treatment. Treatment is only indicated in the presence of symptomatic or progressive disease. It is therefore essential that the disease is accurately staged and patients regularly monitored for signs of progression (Smith 2001).

## Identifying need

At Christie Hospital patients are referred to the myeloma clinic from across three cancer networks with a population of 6.6 million. There are around three hundred patients regularly attending the clinic with an average of one hundred new referrals each year. Patients attending the clinics are at different stages in their illness and as such have a variety of needs and expectations of the service.

New patients under the age of 65 are generally referred for consideration of intensive chemotherapy followed by high dose chemotherapy and peripheral blood stem cell transplant (PBSCT). Patients attend for routine follow up and monitoring of their disease. Also attending the clinic are patients with relapsed or progressive disease who are receiving oral chemotherapy or treatment with new therapies such as thalidomide or those participating in clinical trials. Many of these patients regardless of the status of their illness have ongoing symptom control issues especially relating to bone pain and fatigue.

As already mentioned most of the care these patients receive is managed on an outpatient basis. Whilst in many ways this is ideal it does present certain problems particularly for newly diagnosed patients and those requiring treatment for the first time. Most outpatient departments are busy hectic places where time and privacy are at a premium. This can mean people who are often afraid and emotionally vulnerable

may not have the time they need to fully discuss their diagnosis and proposed treatment. This can be unsatisfactory for all concerned. Research has clearly shown that how people perceive the initial consultations telling them about their illness and treatment were handled has an impact on how they cope emotionally.

Alongside this people are attending the clinic with ongoing, often chronic problems. Some of these include pain control issues, recurrent infections, and the need for emotional support due to the incurable nature of the illness.

There are often financial concerns for a group of people often retired and facing a drop in income or unable to work. There is also a lack of awareness of myeloma in the community and therefore potential lack of support from peers and health care professionals.

## Teamwork

The role of myeloma clinical nurse specialist was set up partly to help address some of these problems. The medical consultant in charge of the myeloma service first recognised the need for the role. She identified gaps in the service in relation to the information and support people were receiving. After much hard work on her part, funding for the post was secured. The post was initially funded for one year on a part time basis, three days per week.

The key elements of the role identified were to attend outpatient clinics, providing a point of contact for patients between appointments and liaising with other services such as primary health care teams, community palliative care teams and referring hospitals. Coordinating the many aspects of treatment including chemotherapy, blood and bisphosphonate infusions was also seen as an important aspect of the job.

Other aspects of the role include ongoing support for patients with myeloma and their families at any point in their illness including symptom control and palliative care support. Information and support for those patients receiving inpatient care and discharge planning.

## Patient-led

There are several specialist nurses attached to the haematology unit, including transplant co-ordinators, research nurses, a leukaemia liaison nurse and a specialist team of nurses responsible for insertion of central lines and bone marrow aspirates. There is also a specialist social worker attached to the unit and two haematology outpatient nurses who run day care services. Each of these has different degrees of contact and involvement with the myeloma patients.

The first few months in post were spent liaising with other staff on the unit, establishing what part other people played in the care of myeloma patients and gaining insight into where people felt the gaps in the service lay.

## Audit

During this time however, it quickly became clear that the development of the role would be patient led. Having met patients at clinic and given them a contact number people began contacting the service with various queries. These included:

- symptom control concerns,
- help with referral to other community services such as district nurses, palliative care and hospice services,
- co-ordination of various aspects of their care such as organising blood transfusions or bisphosphonate infusions,
- anxieties about disease progression and carers needing support when patients had relapsed and/or had terminal disease.

However despite some clear feedback from both patients and staff it seemed important to try to identify more formally the extent of the current service as well as perceived gaps in the service. The intention being to better prioritise the key developmental needs of the job, prevent overlap of roles and fragmentation of care and to help when presenting a case for permanent funding of the role.

## Service shortfalls

With the help of the hospital clinical audit team questionnaires were designed for both staff and patients. Twenty-seven were sent to staff including medical, ward-based and outpatient nursing staff.

The questions focused on asking staff to identify whom they felt currently carried out certain tasks such as research, clinical procedures for example bone marrow aspirates, information and support for patients and families and discharge planning. They were then asked to say which of these the myeloma CNS should carry out and to prioritise the key tasks.

The overwhelming response indicated that staff felt the key elements of the role should centre around the more pastoral aspects of care including information and support for patients and their families, discharge planning and post discharge support.

Staff also highlighted the need for liaison with referring centres, district nurses, GP's, palliative care teams and education for staff about myeloma.

Fifty questionnaires were sent to patients. We asked patients about the amount of information they received about their illness and treatment, how easy it was to understand and if people felt they got the information at the time they most needed it. We also asked about care and support and whom people would contact if they needed help and if the level of support was adequate.

Seventy two percent of patients returned their questionnaires and the overall results were very positive. Most people felt they did receive enough information when they needed it and that the information was fairly easy to understand. Almost all the patients said they would contact staff at the hospital if they needed support, these included consultant medical staff, the myeloma CNS, research nurses and the chemotherapy hotline.

Shortfalls in the service mainly focused on the busy nature of the clinics, which often run over time, and the difficulty of seeing different doctors at each visit. Patients also asked for more information about new treatments, clinical trials, what they can expect from the future as the disease progresses and timescales for treatments.

Some of the other comments related to co-ordination of care. Patients often found the number of investigations, procedures and treatments they needed confusing. They were keen to have someone co-ordinating these in order to make their experience at the hospital as straightforward as possible.

Overall the comments from both sets of questionnaires were very positive. The key elements of the role identified from the audit in fact reflect how the job has already developed, with emphasis on information support co-ordination of care and discharge planning.

However this is a new post with scope for further development. One frequent comment from the questionnaires was the need for the post to be full time in order to provide better continuity of care. This has now been made possible and for the last nine months the post has been funded full time with two nurses job sharing.

In response to the audit results we have made several changes to the service. We

have developed a series of patient information leaflets about various aspects of treatment and put together some information packs for new patients which include booklets from other organisations such as Cancer Bacup and the International Myeloma Foundation (IMF UK).

The IMF is a charitable organisation set up in 1997 dedicated to informing and supporting those affected by myeloma. They provide written information about all aspects of treatment and have a telephone helpline. Alongside this the IMF run educational seminars for patients and their families several times each year.

They also provide grants for health care professionals undertaking research in the field of myeloma. The IMF have also set up a resource and education programme called MAGIC for nurses to help support those caring for people affected by myeloma. They can be contacted at [www.myeloma.org](http://www.myeloma.org).

## First timers clinic

Perhaps the key change for us has been setting up a new patient clinic. This means those patients attending the clinic for the first time can be seen by the consultant in a relaxed and informal atmosphere away from the main outpatient department. Ideally this allows enough time to begin to explain the diagnosis and potential treatment.

This is also an ideal time for us as specialist nurses to meet patients and their families and hopefully explore any concerns they may have, provide written information about their treatment and answer questions.

As yet we have not repeated the audit, but have had very positive feedback from patients and their families about all the changes made to the service.

Whilst this is still a very new role it feels to have been well used by both staff and patients and has provided a useful and necessary source of contact for a group of patients whose needs are complex and often chronic in nature.

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## Reference

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### Enhancing the benefits of nursing research for people with cancer: some methodological issues (part 2)

In the last ICNN research column, we noted that a substantial body of evidence exists that nursing intervention can improve a wide range of patient outcomes. However the extent to which such interventions actually translate to improved outcomes depends on many factors. Such factors may include the relevance, applicability and feasibility of the tested intervention to real world clinical contexts. In this second part we consider some issues associated with interpreting the clinical importance or significance of research findings.

#### Assumptions

Two key assumptions of the randomised controlled research design are: (1) that we have clearly defined and measurable end points that we hope to affect by our intervention; and (2) that we can determine how much of a change in these end points is important. Both assumptions can present problems for cancer nursing research.

Firstly, despite the importance to nursing intervention of a range of broader psychological, spiritual, and social outcomes, value is typically placed on a limited number of what are considered to be the 'harder' or more measurable outcomes. An example would be the emphasis placed in clinical research on achieving improvements in ratings of symptom severity. In practice, however, a nursing intervention may explain only a small proportion of the variance in multi-dimensional phenomena such as cancer symptoms. Moreover, to individual patients, outcomes such as improvements in functioning or perceived control over one's circumstances may be just as, or perhaps even more important than, an arbitrary change in a rating scale.

Secondly, the relationship between statistically significant and clinically significant findings is not always easy to determine. Statistical tests are tools for analysing data, and as such, they should not be a substitute for knowledgeable interpretation of outcomes (Portney & Watkins

2000). For example, if an educational intervention achieves a mean decrease in pain scores of one point on a ten point severity scale, what does this change actually mean to an individual patient? In reflecting on his seminal work in this field, Cohen (1990) notes that the .05 level for determining statistical significance has played a remarkable role in social sciences and this 'arbitrary unreasonable tyranny' has presented problems for the interpretation of research findings.

#### Additional dimensions

The limitations of outcomes measurement and the interpretation of statistical conclusions have a number of important implications for cancer nurse researchers. Firstly, statistical findings should be a form of input to, but not the sole criterion for clinical decisions outcomes (Portney & Watkins 2000). Continuing theoretical and empirical advances in knowledge of patient needs and experiences is required to more clearly define outcomes from nursing intervention that are the most meaningful. A good example of this is the recent interest of some nurse researchers in theoretical and empirical analyses of symptom clusters.

It is also important to consider research findings in the context of what a particular statistical conclusion means to the person with cancer, and whether that statistical conclusion warrants a change in practice (LeFort 1993). Indeed, it has become a standard requirement that research proposals address the issue of statistical power of a research design, and that effect size and confidence intervals are presented in research reports. Moreover, others have emphasised that the most appropriate way to interpret the relevance of research findings to practice is simply to ask those who are in the best position to make such judgements. In other words, we should ask questions such as how does a quantitative change or statistical conclusion make a qualitative difference to a person's life

(LeFort 1993).

Consistent with this latter view, a number of researchers are now examining issues such as what is the minimum clinically significant difference required for a change score to be meaningful to patients. For example, Kelly (2001) hypothesised that a clinically important change in a pain severity scores was the mean difference between current and preceding scores when the person reported 'a little worse' or 'a little better' pain. Similarly, Farrar et al (2000) defined clinical importance as the proportion of patients who achieved relief in a clinical trial, as measured by whether the patient required an additional rescue medication for episodes of pain.

LeFort (1993) argues that this type of social validation of research findings is critical to nursing, since it acknowledges unreservedly that clinical significance is ultimately a matter of values. As such, what is meaningful or important will depend in part on who is asked. These efforts to determine clinically important referents and their relationships to cut points on a measurement scale may therefore be one way to enhance our understanding of the impact of nursing intervention on patient's lives.

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## CALENDAR OF EVENTS

**The 4th European Breast Cancer Conference** will take place in Hamburg, Germany, 16-20 March 2004. *For information contact:* FECS Conference Unit, Avenue E Mounier 83, B-1200 Brussels, Belgium; fax: 32 2 775 0200; e-mail: EBCC-4@fecb.be

**The 4th EONS Spring Convention** will take place in Edinburgh, UK, 15-17 April

2004. *For information contact:* FECS Conference Unit, Avenue E Mounier 83, B-1200 Brussels, Belgium; fax: 32 2 775 0200; e-mail: info@fecb.be

**The 29th Annual Congress of the Oncology Nursing Society** will take place in Anaheim, CA, USA, 29 April-May 2, 2004. *For information contact:* ONS, 501

Holiday Drive, Pittsburgh, PA 15220, USA; tel: 412-859-6100

**The 13th International Conference on Cancer Nursing** will take place in Sydney, Australia, 8-12th August 2004. *For information contact:* ISNCC conference office, tel: 44 116 270 3309, fax 116 270 3673, email: conference@isncc.org