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Tiffany lectureship awarded

Frances Marcus Lewis, an oncology nurse whose work has focused on the effect that cancer has on the family, has been awarded the Robert Tiffany Lectureship.

Dr Lewis, Elizabeth Sterling Soule Distinguished Professor of Health Promotion and Nursing, University of Washington, Seattle, US, said she was overjoyed to receive the award.

She told ICNN: 'I was already thrilled that I had been nominated by the Oncology Nursing Society and then shocked when I heard that I had won the award.'

Dr Lewis's contributions to cancer nursing have been extensive and include her pioneering work in the realm of the psychosocial issues of cancer and its multi-dimensional effects on the family.

Her theory of promoting nurses as coaches to families during and after the cancer experience has given voice to a new and dynamic role for nurses. This seminal research gave rise to the 'nurse as coach' role that is being taught to nurses and other practitioners in multiple types of provider settings.

Her research about the impact of cancer on the family has revealed how the effects of depression and marital tension, quality of parenting, and the use of social support systems shape a family's mechanism of coping with cancer.

Looking back over her career Dr Lewis identified a number of significant turning points that directed her.

One was her training as a nurse at Loretto Heights College in Denver, Colorado where she qualified in 1967. She recalls: 'My teachers, who it turned out were ahead of their time, taught me to focus on holistic care. They also instilled in me a deep respect for everyone in the community. And that we need to help communities to grow their own strength — which is the essence of what I have been trying to do in my international work.'

It was while at Loretto Heights that Dr Lewis came across two authors whose work has stuck with her across the years. The first is Virginia Barckley who wrote about family-focused cancer care. The second was a British oncologist Dr Parkes who talked about cancer 'invading the family in the same way as it invades the patient'.

Dr Lewis says: 'I thought at the time that there must be a way to stop the invasion of cancer in a family and in fact that is what I have been trying to do in much of my research.'

Another turning point for Dr Lewis was when she went to Stanford University to study for a doctoral degree in applied sociology. She said: 'I realised that I needed more skills in research methods. What I learnt at Stanford was transforming as it taught me to think as a scientist — although it didn't change my heart which remains that of a nurse.'

Frances Marcus Lewis

Later in her career, in 1996, Dr Lewis took on international work on a programme working with the high-risk for cancer population in Ukraine on a four-year project with US Assistance for International Development.

As one of four technical lead consultants she developed a national breast screening programme as well as an educational programme for medical workers, including doctors, in counselling breast cancer patients pre and post-operatively. She is hoping to return to work in both Ukraine and Russia in the near future to train medical and nursing staff working in terminal care.

Dr Lewis' work has been widely published in books and peer-reviewed journals. Despite her significant national and international role in the world of cancer nursing, she has not forgotten her roots as she continues to work with regional and local oncology nursing communities.

She welcomes the chance to take part in the international conference on cancer nursing as she says: 'Cancer is a world wide health problem, affecting millions of peoples. ISNCC creates a critical mass of colleagues all of whom are dedicated to helping, preventing and assisting those affected by or at risk of cancer.

Their vision and activities are essential to advancing hopes for cancer control across the globe. We are all one family, despite geographic boundaries.'

Don't miss our report on the 13th International Conference on Cancer Nursing in the next issue

Middle East meets Far East

A report on the continuing collaboration between Tianjin Cancer Institute and Hospital, Tianjin, China and Hadassah Medical Center, Jerusalem, Israel

In the year 2001, a project on the subject of oncology nursing, and specifically in breast cancer care, was launched between two big institutions in China and Israel. During that year, a seminar on breast care nursing was held in the cancer center in Tianjin, monitored by Dr Ilana Kadmon, a breast care nurse specialist from Israel (*ICNN* 2001, vol 13, 4).

More than two years have passed since then, and there are many more results from our collaboration that we would like to report on. Tianjin Cancer Institute and Hospital has expanded and modernised. It is becoming a leading cancer centre in China, tackling all types of tumours and providing a service for patients from all over the country. The hospital specialises in cancer therapy both by conventional as well as Chinese traditional medicine.

It has four breast cancer departments, treating over 160 in-patients on a regular basis. Approximately 1600 women are diagnosed with breast cancer at this institution each year. It is for this reason that significant attention has been given to breast care nursing in this hospital. Moreover, the increasing incidence of breast cancer in China, and growing awareness of the disease has created a demand for Chinese oncology nurses to increase their expertise.

In Israel, breast cancer nursing has made steady progress and developed. There is now a network of over 20 nurses dedicated to the provision of support and care for women with breast cancer countrywide. This network and the professional development in this domain have inspired the continuation of our project and made the exchange of knowledge and ideas possible.

Our joint cooperation covers many aspects of breast cancer care, including nursing research, practice, administration and education. As far as research is concerned, a comparative study, looking into the psychosocial experiences of partners of women with the disease in the context of the two different cultures, has been completed.

This study shows that there is a great need for further professional development regarding the emotional and social support provided by cancer nurses, both in China and in Israel. It also demonstrates that it is important to take into account cultural differences when planning psychosocial care.

In September 2003 we met again in Tianjin. A number of ideas and professional activities were included in the agenda for this meeting. The study on partners of women with breast cancer is now going to be extended to add a qualitative aspect.

Qualitative research methods will provide the opportunity for Chinese and Israeli nurses to examine this issue from an additional angle. In this study, personal interviews with men and a collective focus group session will be held.

The mutual work also provided for seminars to be given to oncology nurses in Tianjin, meeting their specific needs and concerns. Lectures were given on the topics of developments in oncology nursing and breast cancer care, as well as on psycho-oncology and its significance for oncology nursing practice. The newly established cancer center in Tianjin is being used as the venue for academic activities, discussions and the sharing of experiences.

Another element of our programme includes the translation into Chinese of material about breast cancer care, both for professionals and for women diagnosed with the disease. The material chosen is adapted to the Chinese culture and health care system.

Dr Ilana Kadmon (centre) with the nursing education programme leaders in Tianjin

In the future, possible continuation of the project may include research into other areas of care, such as the use of traditional Chinese medicine in this field, or other cultural factors that may influence oncology nursing. It is also our aim to provide Chinese nurses with more possibilities for practice and an enriched experience in breast cancer nursing in foreign countries and in different cultural contexts.

Dr Ilana Kadmon, Breast care clinical nurse specialist, Hadassah Medical Center, Jerusalem, Israel
Jiang Yong Qin, Vice Director of Nursing Dept, Tianjin Cancer Institute and Hospital, Tianjin, China

All change on the ISNNC board

Recent elections have resulted in new members joining the ISNCC board. We would like to welcome the following to the board.

New executive officers

Sanchia Aranda (Australia) President Elect
Candy Cooley (UK) Secretary/Treasurer

New board members

Luciane Kalakun (Brazil)
Shelley Dolan (UK)
Carol Tishelman (UK)
Virginia Gumley (Pakistan)
Patsy Yates (Australia)
Wang Qi (China)

At the same time a number of board members are leaving us, including two outgoing executive members, Connie Henke Yarbro and Wim Dellepoort.

Connie Henke Yarbro, who first joined the board in 1992, was president of the society from 1996 until 2002.

Wim Dellepoort, a board member since 1990, has been secretary/treasurer for the past four years (see report on page six).

ISNCC would like to say a very big thank you to the outgoing board members for all their hard work. Contributing to the society as well as having a busy job is not easy and is much appreciated.

Outgoing executive officers:

Wim Dellepoort (Secretary/Treasurer)
Connie Henke Yarbro (Immediate Past President)

Outgoing board members:

Anne Murphy (Switzerland)
Tore Schjolberg (Norway)
Jiang Yong Qin (China)
Kazuko Ishihara (Japan)
Laurie Grealish (Australia)
Clara Granda Cameron (Columbia)
Myrna McLaughlin Anderson (Panama)
Helen Porter (UK)

New beginnings in Sydney

I am very excited about the 2004 International Cancer Nursing Conference in Sydney, Australia. I am so looking forward to meeting the cancer nurses who attend the conference, hearing the presentations and seeing the posters.

There has been such a keen interest in the conference (we had almost 500 abstracts submitted) I know there will be lots of interesting ideas and opportunities for learning and networking. At the time I am writing this President's Message, already there are over 750 registrants and more than 30 countries represented by those nurses.

Cancer nursing, as a specialty, has been developing steadily around the world, over the past several decades. The body of knowledge on which we base our practice is growing and the skills necessary to practice oncology nursing are expanding. Providing cancer nursing is a complex process. Maintaining the sensitivity and compassion for patients while providing highly complex, and often technical care is challenging.

One of the avenues for cancer nurses to meet this challenge is to join regularly with other colleagues. Sharing ideas and perspectives about challenges and solutions is supportive and energising.

A conference like the one in Sydney provides an excellent opportunity to meet cancer nurses from around the world, to network and learn from them, and to renew one's energy for returning to the challenges at home. I have seen these outcomes result from many international conferences I have had the privilege of attending.

However, the 2004 ISNCC Conference, marks several new beginnings for our international cancer nursing community. The 2004 conference is the result of a new business model for conference planning where ISNCC and the national cancer nursing association in the host country work in partnership.

The two organisations work collaboratively throughout the planning and delivery of the conference. Both share equally in the risks and benefits of the enterprise. I think this will be the most effective approach for the future and will allow the international conference to be held in different venues. I anticipate this will allow a greater number of cancer nurses from various countries to participate in the conference as it moves location.

There are also other 'new beginnings' for ISNCC. About half of the board members change in 2004 (see opposite). This is the result of regional elections held this past spring in Europe, Central and South America, and Australasia. We also have two new officers in the President Elect (Sanchia Aranda) and Secretary Treasurer (Candy Cooley). At our board meetings after the Sydney conference we will be renewing our strategic plan and selecting priority actions for the next two years.

Three other aspects of 'new beginnings' have a direct application to cancer nurses reading this message. Three directions adopted by ISNCC will facilitate your personal involvement in ISNCC activities:

- individuals can join ISNCC as individual members,
- ISNCC wants non-Board members to participate on committees/task groups, and
- ISNCC wants to see regional activities developed that incorporate an international focus.

You can be involved in each of these activities. All you have to do is contact the ISNCC Secretariat and let us know of your interest. I look forward to hearing from you!

Margaret Fitch
President ISNCC

Oncology nurses day

The Canadian Association of Nurses in Oncology (CANO) held its first annual Canadian Oncology Nurses Day this year on April 20, 2004.

Held around the theme *A compassionate vision. A knowing voice.* the day provided an opportunity for oncology nurses in Canada to be recognised through special educational events and celebrations of accomplishments, and to raise public awareness of oncology nursing. The event will now be held annually.

Global poll

A poll of the global representatives of nursing, medicine and pharmacy from more than 60 countries has revealed that heart disease, obesity and cancer are expected to be the top health problems in both developing and developed countries over the next five to ten years. The informal poll was taken at the first conference of the World Health Professions Alliance (WHPA) in Geneva prior to the WHO's World Health Assembly.

A heavy workload, stressful work environment and insufficient staff topped the list of trends and concerns for health professionals themselves. Full results of the poll can be accessed at **www.whpa.org**

Smokers lose a decade of life

On average cigarette smokers die ten years younger than non-smokers, according to a 50-year-long study of smoking and mortality rates.

The study of UK doctors found that stopping smoking at age 50 halves the risk, and stopping at 30 avoids almost all of it. Stopping smoking at ages 60, 50, 40 or 30 gains, respectively, about 3, 6, 9 or 10 years of life expectancy.

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EDITORIAL BOARD

President, International Society of Nurses in Cancer Care
Margaret Fitch
tel: +1 416 480 5891
fax: +1 416 217 1321
e-mail: marg.fitch@tsrcc.on.ca

Central and South America
Stella Aguinaga Bialous
tel: +1 415 476 8276
fax: +1 415 476 0705
e-mail: AQUINAGA@CARDIO.UCSF.EDU

North America
Margaret Fitch
tel: +1 416 480 5891
fax: +1 416 217 1321
e-mail: marg.fitch@sw.ca

Far East and Australasia
Kazuko Ishihara
tel: +81 958 83 4994
fax: +81 958 49 7944
e-mail: kazuko@net.nagasaki-u.ac.jp

Europe
Helen Porter
tel: +44 (0) 151 604 7489
e-mail: helenp@ccotrust.co.uk

Africa and the Middle East
Sarah Ben-Ami
tel: +972 3 558 0666
fax: +972 3 558 0777
e-mail: sbenami1@netvision.net.il

ISNCC Secretariat
email: secretariat@isncc.org
tel +44 (0) 1625 669588
fax +44 (0) 1625 610152

Editor
Kathryn Godfrey
11 Chesholm Road,
London N16 0DP, United Kingdom
e-mail: kathryn@vangod.u-net.com
All correspondence should be addressed to the editor.

http://www.isncc.org

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Mediate Health Consulting Ltd,
108 Chestergate, Macclesfield,
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WHO tobacco treaty leads the way

The WHO Framework Convention on Tobacco Control launched last year was the first international legal instrument designed to reduce smoking and tobacco-related deaths. As the ratification deadline passes the challenge is to encourage countries to incorporate it into national law. This article discusses the main points of the treaty and the part that oncology nurses across the world have to play

The World Health Organization (WHO) declared cancer prevention and control as one of the most important scientific and public health challenges. In the past five decades, thousands of studies have demonstrated that tobacco use and exposure to secondhand smoke causes a variety of cardiovascular, respiratory and other illnesses, as well as several types of cancer. Given the lag time between smoking and the development of cancer, it is estimated that the cancer toll in developing countries will increase in the next few decades.

The present and future burden of tobacco-related cancers makes tobacco control a high priority for all nurses and a key component of nursing practice. Tobacco use has been declared the single most important preventable cause of death and disease and epidemiological data should place tobacco control at the highest level on the political and healthcare agendas.

On the other hand, the tobacco industry wields powerful influence in the political process and is a significant barrier to tobacco control. For decades, the tobacco industry has known about the carcinogenic effects of cigarettes smoking but had not disclosed the relevant data or publicly admitted that tobacco causes cancer. Although some tobacco companies now admit the link between smoking and cancer, in general the tobacco industry continues to deny both the harmful effects of secondhand smoke and the addictive properties of tobacco. The tobacco industry has waged massive public and political campaigns to influence the development of tobacco control policies, including attempts to influence the work of the WHO and the International Agency for Research on Cancer (IARC).

The essential elements of a tobacco control programme are: taxation, regulation of products, restrictions on advertisement/ promotions and sponsorships, bans on smoking in workplaces and public spaces, protection of non-smokers, support for cessation, youth access restriction and firm action against cigarette smuggling.

In May 1999 the World Health Assembly, the governing body of the WHO, voted in favour of the development of an international treaty to address the global epidemic of tobacco-related diseases and deaths. This step recognised the global burden of tobacco-related diseases and death, and that tobacco control is a cost-effective measure that helps to alleviate the burden.

This was to be a comprehensive treaty, addressing all of the main components of tobacco policy making. ISNCC and several of its members were amongst the groups that submitted written support for the treaty during the public hearings phase in the earlier stages of treaty negotiation. After four years of intense negotiations by diplomats from around the world, and with the participation of several non-governmental organisations, a final text of the treaty, WHO Framework Convention on Tobacco Control (FCTC), was unanimously approved by all United Nations members on May 21st 2003 at the World Health Assembly in Geneva.

The overall text recognises the devastating health impact that both tobacco use and exposure to tobacco smoke has on the health of people and on the welfare and economy of countries. It also recognises the need for collaborative, international measures to address the problem and calls for political commitment to achieve the goals of the treaty. Some of the main points of the treaty are summarised on Table 1 and described below.

Table 1: Key aspects of the framework convention on tobacco control

Pricing: encourages price increases through taxation or other means as per the country's policies.

Second-hand smoke: non-smokers must be protected from exposure to tobacco smoke in workplaces, public transport and indoor public places.

Packaging: large health warning labels are required. Health warning labels with rotating messages should cover preferably 50% or more, and at a minimum 30%, of the principle display areas of each cigarette packet within three years of ratifying the treaty.

Labelling: ban misleading or deceptive descriptors and the examples provided include 'light' and 'low tar' within three years of ratifying the treaty.

Advertising: comprehensive ban, or a restriction as extensive as constitutionally allowed, on direct and indirect tobacco advertising, promotion and sponsorship within five years of ratifying the treaty. It includes cross-border advertising.

Smuggling: requires collaborative measures to eliminate cigarette smuggling.

Product regulation and ingredient disclosure: countries that signed the treaty agreed to establish guidelines to regulate the content of tobacco products and required manufacturers to disclose product ingredients to the government of each country.

Price and taxation measures

Increasing taxation and prices of tobacco products have been proven as an effective mechanism to reduce consumption and has been recommended by the World Bank. The FCTC calls participating countries to establish taxation and in some cases, price policies that are compatible with the goals of tobacco control.

The FCTC is not specific about percentages and amounts, and in the case of taxation, as in the case of many other articles of the treaty, language was crafted with diplomatic concerns about sovereignty in mind. Additional price-related measures include a suggested restriction on the availability of duty-free tobacco products.

Protection from exposure to tobacco smoke

It was progress that the FCTC included protection against second-hand smoke throughout the text, as well as a final recommendation of adoption of protective measures in 'indoor workplaces, public transport, indoor public places and, as appropriate, other public places'.

Packaging and labelling of tobacco products

In order to eliminate any false impressions the industry might convey through labelling of tobacco products, as had been the case with 'lights' cigarettes, the FCTC urges participating countries to adopt measures to eliminate misleading claims by tobacco companies.

The FCTC did not go as far as demand-

ing that warning labels should take up at least 50% of the packaging, instead it recommends a minimum of 30%. It also did not require pictorial warnings, as have been used in Canada and Brazil. This is one of the measures opposed by the US, claiming infringement of trade mark legislation.

Tobacco advertising, promotion and sponsorship

It is widely accepted that a complete ban on tobacco product marketing, advertising, sponsorship of events is a very important step in the reduction of tobacco consumption, mainly among young people. This was one of the most controversial measures of the FCTC and one which the US opposed and continues to oppose.

The final text recognises that a comprehensive ban is an effective way to reduce consumption, but it makes exceptions for countries with constitutional impediments to implement total bans. However, it is still recommends that to the extent possible, all countries should restrict 'advertising, promotion and sponsorship' and when possible, also ban cross-border advertising. At a minimum, the FCTC bans misleading and deceptive advertising and restricts marketing and promotion on 'radio, television, print media and, as appropriate, other media, such as the internet'. The FCTC requires reporting of advertising and promotion expenditures.

Smuggling or illicit trade in tobacco products

The importance of cigarette contraband in consumption and the economic and social issues associated with this problem have been amply described. Also previously described has been the tobacco companies' involvement and profit from the contraband of cigarettes. The FCTC recognises the need to eliminate cigarette smuggling as well as counterfeiting as essential for tobacco control. To achieve that, there is a need for the 'development and implementation of related national law, in addition to sub-regional, regional and global agreements'.

Youth access

The tobacco industry has been, for years, developing and promoting ineffective youth smoking prevention programmes worldwide, in an attempt to avoid legislative as regulatory measures. As with the industry's voluntary marketing restriction codes, these programmes have not had an impact on tobacco consumption. The FCTC requires participating countries to enact measures to limit access to tobacco products, making them available only to those who are 18 years older, or older if national law goes beyond 18. Among other access measures, the FCTC also requires sellers to make tobacco products less available to minors, and bans the distribution of free samples to the public.

In addition the FCTC calls for each country to establish regulatory measures for the contents of tobacco products, for the establishment of measures to promote and support cessation and to consider taking legislative action to 'deal with criminal and civil liability' of tobacco companies. It also calls for the participation of civil society as 'essential in achieving the objective of the Convention and its protocols'.

Countries that are members of the United Nations then go through their own legal process to sign and ratify the treaty. Signature of the treaty is not a legal binding document, but it is a commitment of goodwill by the country to work towards ratification. Ratification is basically the process through which a country incorporates the articles of the FCTC in its own legislation.

So far the FCTC has been signed by 138 countries and ratified by 21 countries. The treaty was open for signature until 29 June 2004. After that date countries can still become parties of the FCTC by means of accession. Once 40 countries ratify, the treaty assumes its legal binding status. For more details and up to date information about the signature and ratification status, please go to the WHO Tobacco Free Initiative page: **http://www.who.int/tobacco/en/**

Table 2: Examples of opportunities for nurse involvement

- Write letters to the editor or policy makers on — control policy proposals at the local, state or federal level.
- Write/call/e-mail legislators and policy makers at all levels to express support for tobacco control proposals
- Get involved with a local tobacco control group or organisation
- Create a committee at your workplace to enhance nurses' awareness about tobacco control issues, such as integrating smoking cessation in nursing practice
- Advocating for access to and reimbursement for tobacco cessation treatment (behavioural and pharmaceutical)
- Adoption of smoking status as a vital sign on all patient records
- Improving the quality of tobacco cessation treatment through adoption of clinical practice guidelines for tobacco use cessation
- Push for government regulation of nicotine as a drug
- Advocate for tobacco tax increases and dedication of funds for tobacco control programmes and research
- Advocating for bans on smoking in workplaces and public spaces
- Support and participate in lawsuits against the industry

Implications for nursing practice

Effective tobacco control requires individual and societal change. Behaviour modification presents many challenges and is more successful when individual intervention is part of a broader social and political intervention that promotes the healthy behaviour as the acceptable social norm. For example, smoke free environments promote non-smoking as the social norm and facilitate smoking cessation interventions. Populations based methods, such as increasing cigarette taxes and banning smoking in public places, reach more people and are more effective than programmes aimed at changing personal behaviours person-by-person.

It remains a challenge for oncology nurses to promote tobacco use cessation and prevention behaviours. Some of the ways nurses could be involved are to: join smoke-free coalitions and non-governmental organisations; organise Nurses Against Tobacco groups as has been done in Sweden, the United Kingdom, and more recently, the Tobacco Free Nurses initiative in the United States (**www.tobaccofreenurses.org**); develop letters to editors and policymakers; testify at policy bodies and as expert witnesses in lawsuits against the industry; educating the public (see Table 2).

Nurses play an important role in reducing the devastation caused by tobacco use and addiction. Policy approaches decrease tobacco consumption. Nurses, as the most numerous segments of the health professions, have many opportunities to lead tobacco control. Tobacco control issues that nurses might lead include: advocating for access to and reimbursement for tobacco cessation treatment (behavioural and pharmaceutical), adoption of smoking status as a vital sign on all patient records, improving the quality of tobacco cessation treatment through adoption of clinical practice guidelines, pushing for government regulation of nicotine as a drug, and advocating for tax increases and bans on smoking in workplaces and public spaces. And last, but not least, nurses can ensure that their countries sign ratify and implement the FCTC. Support for the FCTC saves lives!

This article is taken from Aguinaga Bialous S, Kaufman N, Sarna L (2003) Tobacco control policies. *Seminars in Oncology Nursing*, 2003; 19; 4, 291-9

Loyal ISNCC officer takes his leave

Wim Dellepoort is leaving the ISNCC board after fourteen years of commitment and hard work. Mr Dellepoort, Director of Clinical Care/Chief Nursing Officer at Slingeland Hospital in Holland, first formed an association with the society twenty years ago when he became involved in organising the international conference in cancer nursing held in Amsterdam in 1990.

From then he was elected onto the board serving as a representative for Europe as well as a four-year term as Vice President and then latterly as secretary/treasurer.

He has always been very involved in the international conference held every other year by the society. Having organised the event in Amsterdam, he was very involved in the Vienna conference, gave a presentation at the Vancouver conference and was on the organising committee of the Brighton, UK, conference.

He told ICNN that he would miss his role at ISNCC but is going to try and stay involved. He said: 'I shall miss the international contacts as I have learnt so much from all the people that I have met. But I would like to stay involved, particularly in the conferences which for me have always been the highlight.'

He commented on the exchange of learning that occurs between developed and less developed countries. He said; 'We can bring knowledge to developing countries with translating books and educational materials. But we can learn from how ingenious and inventive nurses are in countries where they don't have all the facilities that we have.'

VIRTUAL CANCER CARE

Finding help on the web with management of lymphoedema

With the incidence of cancer increasing worldwide, lymphoedema is a symptom that is being met much more often in specialist centres, the acute hospital setting and in the community. It is vital therefore that nurses working with cancer patients know how to deal with the management of this distressing condition and to keep themselves up to date with developments in treatment approaches.

British Lymphology Society

http://www.lymphoedema.org/

This UK site promotes itself as a major information resource for both patients and professionals concerned with care in this area, and it is fair to say that it generally succeeds in this aim. It is easy to navigate and the relevant sections are quick to load with no complex graphics. There is a useful and simply laid out area containing an explanation of just what lymphoedema is, and the terms used in treatment, which for the newly diagnosed patient or raw professional is very helpful.

There are some useful contact links via the international directory and for the professional, several full text articles that can be easily printed off for future reference. The children's section gives an interesting case study, but the conference section is at least two years out of date. All in all this site is well worth a visit, despite its lack of development. Its simplicity can actually be viewed as an advantage for many internet users and there is no need to register to access the information.

The National Lymphoedema Network (NLN)

http://www.lymphnet.org/

This American site is professionally constructed and although the sections listing doctors, therapists and support groups are somewhat irrelevant to countries other than the US, a lot of the information available is highly relevant. The presentation is simple and clearly laid out, with pages quick to load. I particularly liked the opening section on 'what is lymphoedema', which is very detailed and gives an excellent overview of causes, symptoms, stages, treatment and contraindications. The 'Lyphlink' area has two interesting full text articles available to read or print out, although you do have to pay for any more, and the 'Net pals and Penpals' area offers offers patients an opportunity to contact fellow patients.

The section on prevention is quite good with an 18 step guide offered. 'Question corner' is perhaps the most interesting part of this site and contains a large range of patient questions dating back to 1996 that have been responded to with concise and pragmatic advice.

The Lymphoedema website

http://www.lymphoedema.co.uk/welcome.htm

This very simple UK site, written by a consultant vascular surgeon, is a good starting point for those wanting basic information about lymphoedema. It is very quick to scroll through the pages via the links on the left side of the home page. It is an unpretentious site, with no complexities. It simply informs in a straightforward and professional manner, from an expert in the field.

Cancerbacup

http://www.cancerbacup.org.uk/Resourcessupport/Controllingsymptoms/Lymphoedema

This excellent web site which is justifiably regarded as one of the best for cancer information, contains a very comprehensive section on lymphoedema. As with all their material it is easy to read and understand and is presented in a user-friendly format. Topics covered include the physiology of lymphoedema, extensive treatment options, prevention, diet, symptoms and it is the only site I came across which discusses the psychological impact on the patient. It is also possible to order the excellent booklets they produce, including one on lymphoedema, from the site itself. For patients, there is no charge, but for health professionals the cost is a reasonable £1.95. Because of the size of the site the pages take a little while to load, but it is worth the effort. The web site is to be recommended to all patients and professionals alike.

An Arm and a Leg

http://www.anarmandaleg.co.uk/default.htm

This imaginatively named site promotes the work of a private clinic in the UK which specialises in residential treatment for lymphoedema and related conditions. It may prove useful for those patients who wish to access such a service and for health professionals as a contact point. The reference list is particularly good.

Cancer Help UK

http://www.cancerhelp.org.uk/help/default.asp?page=2614

This excellent cancer information site has been reviewed before, and has a well laid out and informative page specifically on lypmhoedema.

Robert Becker, Macmillan Senior Lecturer in Palliative Care, Staffordshire University School of Health and Shropshire and Mid Wales Hospice

Conference diary

Conference organiser Patsy Yates looks back over the last few weeks of preparation leading up to the international conference in Sydney

Where has the time gone? With all major planning decisions locked in, we are now in the comfortable position of being able to put just a few last finishing touches to our scientific and social programmes.

We've had some very good news in recent weeks. Dr Karl Kruszelnicki, a well known media medic in Australia, has confirmed he will provide the keynote address on the first morning of the conference. Our local Australian contingent, especially Radio Triple J listeners, are very pleased to have secured Dr Karl. He has a unique and very entertaining style, and his passion and enthusiasm for science and technology should set a fabulous tone for our meeting.

One last teleconference with local members of the Scientific Planning Committee was held this week to check programme details. We feel confident that the busy programme covers some very important topics to cancer nurses today, and that we have some of the best speakers to deliver the latest information in the field. We all agree, we are ready to sit back, learn and enjoy.

There has been lots of behind the scenes work going on over the past few months to ensure everything associated with the conference runs smoothly. Our local arrangements committee is calling together a large army of volunteers to help with the more practical but essential jobs associated with a large conference such as this (for example satchel stuffers, room monitors, registration desk staff).

The more creative types have been working on what we hope will be a memorable opening ceremony, something that reflects the very best of Australian lifestyle and culture. Discussions have provided some interesting insights into the music tastes of some of my most respected colleagues!

From the beginning we've been nervously watching the number of registrations as the reports have come in from our local conference organisers. We can now relax on this front. Attendance is well above projected targets. Around 30 countries are represented in the delegate list so far.

There is still a bit to do in these last few weeks, if the number of emails I am getting everyday from our conference organisers, delegates from around the world, sponsors and other interested parties is any indication.

But what seemed like such a huge task, back two years ago when we started to talk about hosting the International Conference here in Sydney, is now all falling into place. A number of wise and more experienced folk told me this would happen, even if there were days when I was not sure that it would.

So now I am looking forward to meeting up with everyone who has contributed to planning this conference, so that we can celebrate our efforts.

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

EDUCATION COLUMN

How can higher degrees contribute to practising nurses?

Catherine Jones tells us how taking a higher degree has had a impact on her day-to-day work as a clinical manager

There are many nurses with graduate diplomas in advanced nursing and Masters degrees in practice in Australia. Indeed, the recent trend has been for universities to offer Masters degrees to prepare people for the advanced practitioner role, and for Clinical Masters courses. So I would imagine that the answer to the question posed is that nurses do value the contribution higher degrees make to their own practice. That is certainly my own personal experience.

I undertook my Masters degree in order to study a specific area that was of interest to me. It was also the area that I felt I needed to know more about in order to be able to better support people undergoing the treatment of autologous bone marrow/peripheral blood cell transplant.

I have been a clinical nurse manager for many years. During that time I have had many conversations with people about their cancer experiences and they treated me as if I truly did understand. Yet, I was aware that my knowledge was limited and this awareness provided the impetus to undertake a PhD into people's experiences of living with recurrent cancer.

I certainly gained a great deal personally from my higher degree studies. The insights and knowledge I gained inform my practice daily. In addition, I have been able to share this knowledge with nursing, medical and allied health colleagues. To some extent I have been able to influence practice and change some of the processes involved with treatment.

My experience of studying whilst continuing to work full time was stressful at times and fraught with the uncertainties that plague almost every student. As a distance education student with only fortnightly contact with my supervisor via telephone, the uncertainties seemed to be compounded by the isolation. Perhaps because of these feelings I have endeavoured to support other nurses in practice who are studying too.

Sometimes this support may be to take time to discuss their study, literature, read and discuss their research proposals, discuss methodological approaches or lend books or articles. Other forms of support are to put nurses in touch with other people who are studying, or people who have completed their study and used a similar methodology to the one they are contemplating.

There are many nurses struggling with the competing demands of home life, work and study. I believe we can help and support one another to make the journey a little less daunting.

Finally, it is my belief that nurses in practice can and do contribute greatly to the body of knowledge that is nursing, especially when combined with experience. Furthermore, they can positively influence the practice of others, including medical and allied health colleagues. So if you are thinking of undertaking further study, no matter where you are, go on, do it!

Dr Catherine Jones
Clinical Nurse Manager
Royal Hobart Hospital
Tasmania, Australia

RESEARCH COLUMN

Family perspectives on caring for a relative with advanced cancer in the Western Isles of Scotland

This piece of qualitative research was conducted to complete my MSc in Palliative Care. I was grateful to receive the 2001 Small Research Grant Award from ISNCC to support its completion. A longitudinal case study research design from an ethnographic perspective was adopted. Two families participated, involving twelve individuals. Statistical and demographic data were added to offer triangulation to the subjective accounts offered by participants.

Palliative care philosophy advocates that the family, rather than the patient alone, should be regarded as the unit of care. This is supported by UK government policy (Department of Health, 1995) which recommends that care should focus not only on clinical treatment, but take account of the practical, emotional, psychological and spiritual needs of patients, their families and carers. Yet palliative care health professionals largely interact within the 'dying triad' (Gilley, 1998) formed by professional, patient and main carer: research reflects a similarly narrow focus. Whilst family caring does tend to fall disproportionately on one individual, at present the experience of other family members is often hidden, or only partly known, outside the family network.

Isolated community

The geographical isolation of the Western Isles of Scotland has tended to preserve traditional cultural attributes of crofting (small-scale farming) for longer and in more complete form than are found in most of contemporary mainland Britain. However, economic decline (average household income in the Western Isles region is currently the lowest in Scotland, third lowest in the UK) has resulted in economic emigration and, therefore, most communities are fragile (Western Isles Structure Plan, 2002).

The participants were drawn from this culture and whilst describing this as hard physical work and not lucrative, described crofting as being a happy, healthy, contented way of life. Traditional gender roles of men and women were evident: men as providers; women nurturing and caring for the family. Participants recognised that the culture of the Western Isles was continuing to change rapidly. Approximately 30% of patients currently die at home in the Western Isles (compared with 24% nationally). Death is still treated simply and as a natural event, involving widespread community participation.

Kinship

Female life expectancy in the Western Isles is the fourth highest in Scotland: conversely, male life expectancy remains third lowest (George, 2001). The effect of this was that participants had had significant prior experience of premature death of a close family member. This was significant on three counts. Untimely deaths within families contract the family network, intensifying the importance of the remaining kinship relationships. It also manifested as anxiety concerning their own health and was also an important determinant in guiding the philosophy, actions and coping strategies demonstrated in caring for their relatives.

The study followed patients until death, involving several periods in hospital. As the patient's condition deteriorated, families felt that further home care was perhaps beyond their capability. Cultural pressure was exerted to accommodate the wishes of patients to die at home, and both patients did, in the event, do so. The researcher observed how this was achieved through intensive practical support from family and the wider community, supported by health/social carers. The key supportive factors from professionals were identified as: good symptom control; a caring and supportive attitude; sufficient practical and emotional support; and repetitive information-giving.

Traditional roles

Predictably in this context, the research found that caring was strongly gendered, with women providing the majority of direct care. Men had supporting roles and all were involved in 'watching and waiting', often perceived as one of the most stressful areas of caring. However, routines of men were not fundamentally disrupted, although as caring demands intensified, men assumed additional domestic tasks and had the dominant role in arranging the funeral. 'Care as a burden' for women was clearly apparent in this study, resulting in tiredness, anxiety and a restriction in normal activity and work patterns. It was fascinating to observe the main carers accommodating the increasing demands of caring by re-negotiating other commitments. In the family context, the stress caused by this was apparent, as, in order to maintain homeostasis, other family members adapted to accommodate the changing roles of others. Humour was used frequently as a tool to diffuse tension. Open dispute was purposefully avoided where possible and family coherence was rapidly and purposefully reinstated rapidly should disputes occur. As death approached, however, there was more sustained open awareness (Glaser and Strauss, 1965).

Such seemingly unhelpful family behaviours as avoidance, over-protectiveness and denial (Bull, 1997) were evident. However, it was clear that these reflected the complexity of maintaining hope, control and a sense of coherence (Antonovski, 1987) within the family context, in very uncertain and, therefore, stressful circumstances. Carers with previous experience of death were more skilled in managing the tensions of the situation and taught others their strategies. The main coping strategies emerging as themes from this research in facing approaching death were: the use of uncertainty to maintain hope; protectiveness; pacing themselves; rationalising the situation. These strategies appeared important in creating the conditions for a culturally acceptable or 'good' death to occur.

Family caring

Conducting this study was an interesting experience. Firstly, I gained insight into the practical and ethical issues arising in qualitative research. 'The researcher' received deeper expression of feelings and fears than 'the nurse', which may reflect the focused time provided during the interviews. All family members wanted repeated information. This suggests that there are unmet needs for information and reassurance even within very functional families.

Both families involved in this study coped well with their experience of home-palliative care, still normal in this culture and generally considered a beneficial experience in coping with bereavement. The study, however, also demonstrated how demanding family caring is, even with support. The haemorrhaging population of the Western Isles, in reducing community support and the pool of experienced carers, both professional and lay, is challenging our ability to maintain palliative home care provision at current levels.

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