



Society has new president

Margaret Fitch, Head of Oncology Nursing and Supportive Care, Toronto-Sunnybrook Regional Cancer Centre, Canada has taken over the ISNCC presidency. Ms Fitch was initiated at the recent London conference and will serve as president for the next four years.

Ms Fitch's first involvement with the ISNCC began with an invitation to present her research at the society's international conference on cancer nursing in London in 1988. 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 Ms Fitch co-chaired the successful event.

Ms Fitch qualified as a registered nurse twenty years ago and has a full career to date. Her primary focus has been on research and her work has been widely published. At graduate school she achieved qualifications at both masters and doctoral level.

She became involved in research when, as a staff nurse and team leader, she realised how important it was to know what interventions worked and which did not. Ms Fitch told ICNN: 'Research studies help us understand what is effective and beneficial for patients. It gives us a way to improve care and know whether what we are doing really makes a difference to patients.'

Her research interests concentrate on the areas of coping and adaptation. She explains: 'My studies focus on trying to



Margaret Fitch becomes society president

understand better what patients experience when they have cancer and what would be most helpful to them. I have conducted studies on topics such as patients' perceptions, supportive care needs, fatigue, information needs and psychosocial distress.

'Much of my work is qualitative, although I also enjoy using quantitative methods. The topic of research utilisation and how to use findings from research in clinical practice, has been a focus of mine since I finished my doctorate studies.'

Her specialisation in oncology nursing developed as many of the patients that nurses asked for help with had cancer. 'I realised how much of an impact cancer can

have on a person and his or her family. I also realised what a tremendous difference a nurse could make in helping the patients and their family members if the nurse had specialised knowledge and skill regarding the care of cancer patients.'

Ms Fitch is a firm believer in professional associations and was involved in forming an oncology nursing organisation in Canada. She sees the ISNCC as an important organisation for oncology nurses around the world. She says: 'The ISNCC provides an international focal point for cancer nursing. We are able to look at cancer nursing issues around the world and identify concerns or areas where help could be provided.'

'The society provides a communication system to share ideas and teach one another. It also allows us to find ways of supporting one another with conferences, workshops, position papers, education tools and research grants. Patients and family members will be better cared for if nurses have the specialised knowledge and skills embodied in cancer nursing. ISNCC can help to share that body of knowledge and develop cancer nursing as a specialty.'

Ms Fitch is looking forward to her term as president: 'As president of the ISNCC I am planning to provide leadership and move the organisation forwards. We have a number of goals that must be accomplished if we are to be seen as the voice for cancer nursing.'

Conference information and abstract form inside

Research directory

The ISNCC Directory of Oncology Nurse Researchers was created by the ISNCC Research Committee. Its primary purpose is to enhance networking and communication among cancer nurses interested in, or engaged in, research concerning nursing care of cancer patients and their families.

The directory contains a listing of almost 150 nurses from around the world who are engaged in oncology nursing research. Each nurse's contact information, area of research focus, keyword descriptors for their work, and information about their research projects including title and purpose of each project, co-investigators, study design and status of study are listed. The contact information for each nurse is provided to facilitate communication among nurses around the world.

Members interested in obtaining a copy of the research directory can do so by:

- ordering a copy of the directory. You can use the order form on the ISNCC

website www.isncc.org or send your request to the ISNCC Secretariat (see address on page 3). A copy of the directory will be mailed to interested individuals upon receipt of the order form/request and the fee to cover production and mailing of £5.99 (UK) plus postage.

- downloading a pdf version
- downloading a zipped file version

If you would like your name and information added to the next issue of the directory, you can either complete the information form on the website and email or mail it to Dr. Ann Hilton, Chair of the Research Committee ISNCC, or write to Dr. Hilton or to the ISNCC Secretariat (see address on page 3) for a copy of the information form. After completion, send it to:

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Palliative care curriculum launched

The ISNCC has launched a Palliative Care Curriculum to help cancer nurses across the world plan and deliver educational programmes about palliative care.

Written by nurse experts in the specialty, it represents the recommendations of clinical and education experts in palliative cancer nursing.

The curriculum provides an educational standard for cancer nurses. The content has been endorsed by the ISNCC, the International Council of Nurses (ICN) and the World Health Organisation (WHO).

Palliative care is a form of comfort-giving care that recognises cure or long-term control of disease is not possible. The primary aim of palliative care is quality of life. Individuals who are dying from their disease can be helped to maintain the best possible level of physical, emotional, spiritual and social life during their remaining time, no matter how much limitation may exist because of their disease.

In recent years, palliative care has emerged as a speciality, having evolved from the modern hospice movement. Palliative care encompasses a distinct body of knowledge that embraces many disciplines.

The World Health Organisation (WHO) defines palliative care as: 'The active total care of patients at a time when their disease is no longer responsive to curative measures and when control of pain and other symptoms and of psychological, social and

spiritual problems is paramount. The goal of palliative care is the highest possible quality of life for the patient and family.'

Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team of which the nurse is a vital and essential member. Nurses practising in the field of palliative care require a distinct and essential knowledge base in order to deliver high quality palliative nursing care.

Education needs to include a range of topic areas and focus on skill development in communication, clinical assessment, ethical decision-making, and teamwork.

The curriculum has been designed to meet educational and professional standards for palliative nursing across the world. The essential modules and components of each of the content areas are distinct from national or institutional policies or standards.

The modules aim to prepare students across multiple care settings such as the home, hospital or day care. Each module has been developed in such a way that it can be taught either as a separate module or as part of the entire core curriculum.

The depth of the knowledge cancer nurses require will vary from setting to setting. For example, the nurse working in a cancer screening clinic may need to know what palliative care is as a philosophy of care while a nurse on a palliative care unit must

know a great deal about managing pain and other symptoms, talking about death and dying, and providing emotional support. While the former nurse can learn about palliative care through several lectures, the latter requires a more in-depth, structured programme or course of study.

It is anticipated this curriculum document will be used in various ways, either in part or in its entirety. The content for each topic is presented, but the educator is expected to tailor the actual presentation to the needs of the learners. Educators might select a particular content area or topic from the curriculum and use an range of formats including lectures, workshop, short or long courses and discussion groups.

The degree of detail offered in each session will vary depending on the format and whether the educator has the objective of increasing awareness, enlarging knowledge, or enhancing skills in a particular topic.

In addition to continuing education or professional development purposes, the curriculum document could be used to guide the planning for undergraduate or graduate coursework. The depth of the discussion regarding specific topics with the learners will need to be adjusted or adapted to the expectations of the learners and their practice roles.

story continues on page 4

New beginnings, new challenges

When I sat down to write this first message as the new president of the International Society of Nurses in Cancer Care, I found myself experiencing a number of emotions. I was excited about assuming the role of president and embarking on a new phase with my involvement in the society. It felt like I was starting out on a new journey with great opportunity for learning and meeting colleagues. I felt again the sense of honour that I felt in London when, at the end of the closing ceremony at the 12th International Cancer Nursing Conference, Connie Henke Yarbrow placed the presidential chain of office around my neck. I remember feeling the physical weight of the chain and medallion and thinking that it would be a good reminder, each time I wear it, of the trust you have placed in me when you elected me. I felt that sense of responsibility to provide the kind of leadership that will help us move forward with confidence into the future.

I also felt a sense of challenge. The ISNCC is at a crossroads in its growth and development. In the few short years since the first International Cancer Nursing Conference, 23 years ago, ISNCC has grown from an embryonic, fledgling organisation. We have national oncology nursing full-member organisations that represent more than 40,000 cancer nurses from around the world. When our associate members, both organisational and individual, are added, the ranks swell to almost 60,000. ISNCC is linked with both the World Health Organisation and the International Council of Nurses where we can be an influence for quality cancer nursing care. We have the capacity to be an effective voice for cancer nursing at the international level.

And this is where I see the challenges emerging and the crossroad ahead of us. If

we are to be truly an effective voice, if we are to participate in the processes of debate and influence the decision-making about cancer care policy, we need to focus on specific activities over the next few years.

To achieve the vision of being recognised as the voice for cancer nursing in the international arena, there are three goals we need to accomplish. Firstly, we need a stable financial base for the society. Secondly, we need to actively work to be known as a credible leader in cancer nursing matters. And thirdly, we need to develop effective working relationships or partnerships.

The Board of Trustees of the ISNCC engaged in a strategic planning exercise and set out five objectives that would help us move toward achieving the goals. These objectives include:

- to enhance the revenue base of ISNCC
- to enhance the visibility of the society
- to become more efficient in how we do our business (work)
- to strengthen the links or connections with members, and
- to increase the availability of educational and research opportunities in cancer nursing.

A task group or committee has been established to work on each of the objectives. However, the participation and involvement of the member organisations and individual nurses will be very important in determining whether the activities are successful. To date, the activities of the ISNCC have been undertaken by a relatively small number of individuals. We must change that level of involvement if we are to become a sustained, credible voice for cancer nursing. It will take all of us working together to achieve our vision.

Involving cancer nurses from around the

world will have its challenges. We live in a time of change and technological growth; yet a time of challenge to the very core of our values and livelihoods. It is a time that challenges our very lives.

The future will demand that we take risks, try new ways of working, and develop collaborative relationships. There is a wealth of expertise in cancer nursing around the world and we need to find ways of sharing that expertise with one another so that patients and their families, no matter where they live, can benefit from the wisdom and skill of cancer nurses.

I invite you to communicate with me about what you think ISNCC needs to be doing and about how you want to be involved. Please do not hesitate. I look forward to working with you over the next four years.

Margaret I Fitch
President, ISNCC

The ISNCC board

The board of the ISNCC is made up of the following members.

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continued from page 2

The core curriculum describes the knowledge that should be part of the preparation of every nurse involved in caring for palliative cancer patients and their families. However, it can also be used to focus on the preparation of nurses working at a specific level of practice.

Recommendations for the preparation of palliative nurses across three levels of practice, namely entry level (introductory), specialist level and advanced level, are allowed for in the curriculum. Modules can be presented in greater or lesser depth depending on the level at which the nurse will be working.

Together, the modules identified as part

of the core curriculum represent the essential foundational knowledge for palliative nursing care. It is essential that the curriculum should be realistic and capable of preparing nurses to practice in their existing health care setting, while at the same time enabling them to identify and facilitate change where necessary.

A core planning team consisting of clinicians, service managers and educators should be formed locally. A key role of this team will be the identification of people with appropriate expertise to assist in the delivery of course content. The team should plan, implement, evaluate, monitor and revise the course as necessary. Most importantly, the planning team must

adapt the core curriculum to ensure its relevance to the cultural setting and health care structures in which nursing care is delivered.

The goal of the core curriculum is to identify the distinct and essential body of knowledge required for palliative nursing. The curriculum has been prepared by the ISNCC and so focuses on the palliative needs of people with cancer. It can, however, be adapted for the care of people with diseases other than cancer.

Every ISNCC member will receive a complimentary copy of the Palliative Care Curriculum. Additional copies are available from the Secretariat office, priced £5.99 (UK), plus postage.

EDUCATION COLUMN

Competence: multiple meanings in cancer nursing

Competence is defined as the condition of being able; ability. It is the state of being legally competent or qualified (Concise Collins Dictionary 1985). Contemporary, or postmodern, views suggest that 'true competence' does not exist. Rather competence is judged in relation to social effectiveness. There are multiple discourses around the notion of competence in nursing culture and literature.

Traditional notions of competence, particularly as they appear in the North American literature, suggest that competence can be clearly articulated, through standards, and therefore assessed (either competent or not competent). However, the definition of competence as a set of standards, is contestable when the standards are applied outside of their socially constructed purpose.

Multiple definitions of competence co-exist in clinical nursing practice. Standards of competence are published by a range of organisations including:

- nurse regulatory authorities,
- national and international cancer nursing groups,
- employers and educational institutions.

Each of these standards achieves one or more social functions such as protection of the public, consumer education, reduction of error/litigation, and educational measurement. There are also definitions of competence in relation to clinical skills and technical procedures such as central line dressings. Individual nurses are generally aware of each of these standards for competence.

There are also standards of competence that are shared by groups of people who work together as a team. These standards are not explicitly stated and are learned by working in the group/team.

Adopting a post-modern approach to

competence is helpful for nurse educators who assist nurses to learn more about cancer nursing. Recognition of the importance of group-developed definitions of competence as equal to state and employer definitions is an important first step. Educators can work with teams of cancer nurses to begin to identify what they value in practice — what kinds of nursing work is considered important by the group? Once this is clearly stated, professional development for the nurses as a group and individually would involve an analysis of the group-developed standards of competence to standards published by the state, relevant professional bodies, and employers. This work could be done in workshops, usually away from the workplace. Possible benefits include improved understanding of the theory/evidence underpinning practice and development of collegial relationships among team members.

Nurse educators should know how the competency standards of states, professional bodies, and employers are developed. Who is on the committees to review these standards? Are these committees representative of the nursing or client community who will be affected by the final product ie competency standards? Are the purposes for the standards clearly stated? Are the purposes reasonable given the role of the responsible organisation?

Nurse educators, as leaders, can position themselves within their communities to contribute to the development of competency standards by the state, the professional body, and the employer. Working with these organisations through membership on management boards, committees, nurse educators actively shape the profession in ways that ultimately benefit patients or clients. As leaders, nurse educators should encourage and support nurses whose prac-

tice will be 'measured' by the standards to also contribute to review and development.

Finally, nurse educators also bear responsibility to research the value of competency standards in relation to nursing work and patient care outcomes. Questions that could guide research include:

- what is the process in developing competency standards? Who benefits from the process as it is established? Would competency standards be different if other people were involved in the development?
- what is the meaning of competence for the individual nurse? How do nurses new to the area of cancer nursing develop personal meanings of competence in the field? How can nursing education help in the development of personal meanings of competence?
- how do educators and managers, who are charged with the role of assessing nurses for competence, usually on behalf of the employing organisation, measure competence? What indicators are used? Have these indicators been subject to a rigorous evaluation?

Competence is unquestioned when nursing practice is discussed. What is less clear is what competence means and how it is determined. Cancer nurse educators have a major role to play in developing understanding and knowledge around competence in cancer nursing practice specifically and nursing generally.

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

Reference

Wilkes G A & Krebs W A (Ed) (1985) *Collins Concise Dictionary of the English Language*, Australian Edition Collins: Sydney

Connie Henke Yarbro

ISNCC President 1996-2002

The 12th International Conference on Cancer Nursing held in London in 2002 was remarkable in many ways. However there is one particular event that marked a significant milestone in the society's history. The end of the conference was also the end of Connie Henke Yarbro's presidency of the society.

Connie Henke Yarbro was president of the society for six years during which time she gave freely of her energy, her enthusiasm and her considerable knowledge and experience to oversee fundamental development and change. She handed on to the incoming president the responsibility for a society greatly changed in scale and scope, and a society poised to move to the next stage of its growth and development, supporting cancer nurses and developing cancer nursing in all parts of the world.

Cutting edge

During her long and distinguished nursing career Connie has had a commitment to expanding and developing nursing roles, responsibilities and opportunities. Often at the cutting edge of developments, she took bold steps, sometimes into the unknown.

The 1971 Cancer Act in the USA was the impetus needed to kick start many far reaching initiatives one of which was a proposal to coordinate chemotherapy across the state of Alabama. Connie was appointed to contribute to this programme and became the programme's first oncology nurse.

Thus began her lifelong commitment to oncology nurses, nursing and patients. Back in the 1970s openness and involvement of patients and carers in care was not taken for granted as it is today. But Connie, ahead of her time, developed a group for patients where they could find help and support.

In the late 1970s Connie again ventured into new territory and embarked with a colleague on her first research project. The result of that work was one of the earliest tools for assessing quality of life in cancer patients.

Oncology nursing in the USA was developing fast and there was a clear need for a framework to enable nurses to meet together, to share experiences and to learn from each other. In 1975 the Oncology Nursing Society was founded with Connie as treasurer. She became its president four years later.

Her involvement with the ISNCC was from its beginning. She attended all the international conferences becoming a member in 1984 and joining the board in 1992. She brought a wealth of experience both as an oncology nurse and as a former leader of a big cancer nursing organisation.

Her fellow board members and the society as a whole benefited from her enthusiasm and energy.

At the UK conference in 1996 Connie was elected president of ISNCC. Under the guiding hands and with the experience and inspiration of its earlier presidents, Bob Tiffany and Vernice Ferguson, ISNCC had become the voice of cancer nursing worldwide. The society was poised to take the next step in its evolution. Connie's commitment, her personality and her fundamental belief in the value of ISNCC provided the leadership to build on the achievements of the past and create a new vision for the future.

Communication

Connie recognised that a growing society needed a robust infrastructure. In the early stages of her presidency she led a review and renewal of the constitution and byelaws. This work ensured there was clarity and understanding about the aims, objectives and function of the society, about the membership processes and the communication channels that would best serve the needs of members around the world.

Sharing knowledge is a key element of ISNCC activity and Connie was instrumental in moving the society into the 21st century with the launching of its website. This provides an increasingly important mechanism for members to keep in touch and for the society to contact its members.

Research and education are the bedrock of nursing developments and ISNCC was not to be left behind. Research and education committees were established. Under Connie's leadership, International Cancer Nursing News was redesigned incorporating a modern logo demonstrating yet again that the society was moving with the times.

Sponsorship

The biennial conferences have been the high points in the ISNCC calendar and each has had its own unique character. Successive boards have struggled with the conflicting needs of bringing the conference to developing countries and ensuring that it was held within budget. Difficult decisions sometimes had to be made. Securing sponsorship and funding is becoming increasingly difficult but through her many existing contacts and some new ones, Connie has helped to ensure that the society has a much sounder financial base on which to build for the future. Members have been able to benefit from travel scholarships, research grants



have enabled new projects to be undertaken and industry support for conference activities has given added impetus to the programme.

As ISNCC comes of age it is increasingly recognised as an important player in the world-wide battle against cancer. In seeking partnerships across a variety of interfaces ISNCC has worked internationally with WHO, with PAHO, ICN, UICC and many others.

Collaboration

Connie has been a great ambassador for the society in all corners of the globe, promoting and advancing cancer nursing and helping to develop collaboration between member societies and individuals. ISNCC publications, position statements and other materials are being translated for use in an increasing number of countries to change policy and practice and to enhance learning.

Connie has steered the society through some difficult times. She has done this always with the best interests of the society at heart and without compromising her own principles. Although her 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, supporting her successor and her colleagues in moving the society to the next stage of its development.

ISNCC has taken over much of Connie's life over the past six years. Now it is time for Connie to have some time for herself and for her husband. She has presided over a period of intense activity and change for the society against a backdrop of even bigger changes in the healthcare environments around the world. Her legacy to the society is immeasurable. We wish her well.

Dame Gill Oliver

*Director of Service Development
Macmillan Cancer Relief, London, UK*

Challenges of palliative care and training in Uganda

Palliative care is developing slowly in this African state. Julia Downing looks at the challenges to providing care and how they are being overcome

Cancer in Uganda is rarely cured. This may be due to the cost, the lack of affordable curative treatments and the fact that most patients present too late.

There are an estimated 20,000 new cancer patients per year in Uganda (Kiyonga 2000) and less than 5% of these have access to curative treatment (Merriman 2000). This situation provides many challenges for those involved in palliative care and training in Uganda.

Uganda is in Eastern Africa and is bordered by Kenya, Sudan, Democratic Republic of Congo, Rwanda and Tanzania. In Uganda, the problem of cancer is inextricably linked to the problem of HIV/AIDS with there being a high incidence of AIDS related malignancies such as Kaposi's sarcoma, lymphoma and cancer of the cervix.

There has been some success in Uganda in reducing the prevalence of HIV infection. In Kampala, the major urban area, HIV prevalence among antenatal clinic attendees tested increased from 11% in 1985 to 25% in 1990 and then up to 29% in 1992. However from 1993, HIV prevalence among antenatal clinic attendees began to decline in Kampala dropping to 14% in 1998 and 11% in 2000. This figure is now thought to have dropped to around 6%. Median HIV prevalence among antenatal clinic attendees outside of the major urban area has declined from 13% in 1992 to 6% in 2000 (Ministry of Health 2002).

There has been some controversy (Parkhurst 2002) about the extent of Uganda's success story but the fact remains that whatever the exact figures are, there has been a large reduction in the prevalence rate of HIV and tremendous progress has been made.

The Ministry of Health and the Uganda AIDS Control Programme have been very active and have encouraged initiatives to improve the care available to people living with HIV/AIDS including the promotion of voluntary counselling and testing, and palliative care.

The need for AIDS palliative care is evident from recent statistics published by UNAIDS which note that in 2001 there were an estimated 600,000 people living with HIV/AIDS with 110,000 of those being under the age of 15 (UNAIDS 2002). For a country of just over 24 million this

represents an enormous problem that places considerable pressure on the health services and social support services.

Palliative care

Palliative care is a new yet vital speciality in Uganda and there are many challenges facing us in the provision of care and training. At present there are two main organisations providing care and training in palliative care. They are Hospice Uganda and the Mildmay Centre.

Hospice Uganda provide a home care service both in Kampala and up-country in Mbarara and Hoima. Along with this they provide support at Mulago hospital and the Uganda Cancer Institute. They also provide training for health care and non-health care professionals and have recently started a distance learning diploma in palliative care with the local university in Makerere.

The Mildmay Centre, where I work, is a specialist care and training centre for HIV/AIDS. It was opened in September 1998 and offers services in three main areas. There is a specialist outpatient palliative care and rehabilitation service, a range of training in all aspects of HIV/AIDS care and a specialist children's day care centre.

Because of the link between HIV/AIDS and cancer there has been an increase in the incidence of cancer, especially in those cancers associated with AIDS. So while the Mildmay Centre is an HIV/AIDS Centre, care of adults and children with AIDS related malignancies is an important part of its work. Chemotherapy and radiotherapy are only available to a small proportion of people with cancer either on a curative or palliative basis and the Mildmay Centre works closely with the Uganda Cancer Institute in the provision of such care.

Lack of resources

Medications used in palliative care can be found in Uganda, but the supply is erratic and not spread throughout the country. The cost may be prohibitive for many people. Along with this is the problem of having suitably trained health care professionals to deliver the care. In Uganda there is one doctor to 35,000 people and one nurse to 3,571 (UNDP 2000). Many doctors work in urban areas so access to doctors is even worse in rural areas.

One example of how organisations are trying to meet this challenge is in the provision of oral morphine. Since 2000, when palliative care was included for the first time in the country's Strategic Health Plan, Hospice Uganda, the Mildmay Centre and TASO (The AIDS Support Organisation) have been working closely with the Ministry of Health to improve access to palliative care. The Ministry has made oral morphine available to those districts which have been sensitised to its use so that it can be provided free of charge. There is also an education programme to support this and changes in the law to allow specialist palliative care nurses to prescribe oral morphine have been introduced.

Stigma and beliefs

Uganda has come a long way in the reduction of stigma over HIV/AIDS over the last decade but it still persists. Women can be afraid to tell their husbands that they are positive in case they are thrown out of the house. In some cases they have been killed. Parents are afraid to tell their children in case they are bullied or teased at school.

In rural areas, in particular, there is still a strong belief in witchcraft and in traditional medicine/healers. The belief that someone can get AIDS by being bewitched is still held by many, thus affecting how they might access or accept care.

Poverty

Poverty is a big issue for many people, with Uganda being the fifth poorest country in the world. Many people are unable to provide food, clothing and shelter for their family. It is often the child with HIV who is neglected as it is seen to be a waste of money buying food or medicines for a child who is terminally ill.

AIDS and the health care professional

Health care professional may themselves be infected and/or be caring for family members or friends. Every village and every family in Uganda has experienced the death of a loved one from AIDS. Many of these have died at home and many of them will also have had cancer.

To demonstrate the extent of the problem we asked 15 students training at the Mildmay Centre about their experiences.

We discovered that between them they had 123 family members who had died of AIDS or cancer, 246 close friends who had died of AIDS or cancer and 223 colleagues who had died of AIDS or cancer. As a group they knew over 600 people who had died of AIDS or cancer.

The needs of HIV positive health workers are complex, largely overlooked and a challenge for those of us providing both care and training in palliative care (O'Keeffe et al 02). A longitudinal qualitative study is currently being undertaken at the Mildmay Centre in Uganda to explore areas around training HIV positive health care professionals working in palliative care in grief, loss and bereavement and how can they best be supported. Issues raised by positive health workers include:

- fears around 'will this happen to me?'
- expressing resentment towards patients who are receiving medical care that they cannot afford eg chemotherapy
- depression due to the strain of multiple losses and caring for orphans.

Poor prognosis

The resources in Uganda are poor and money that is available is often not spent on those whose prognosis is poor when it could be better used for other people. This is a horrendous decision for families to take — to decide not to treat or care for their loved ones as the money could be better used elsewhere. Whilst medications for palliative care are available and are affordable, 60% of patients cannot afford anything as they have spent all their money on 'curative' or 'other' treatment before accessing services (Merriman 2002).

In villages in Uganda 57% of people (UNDP 2000), do not have access to health care, palliative care services are currently available to even less. Local communities need to develop referral routes suitable to the village, health centres and district hospitals.

Careful planning and tailoring of service which takes into account palliative and economic needs is required. Any element of an African palliative care service must be affordable and able to be applied to even poorer situations. We are very conscious of this in Uganda. If a model for palliative care is seen to be unobtainable or not sustainable, then the initiators loose heart. Sustainability is a real challenge to palliative care services offered to the most vulnerable and poor members of society.

Meeting the challenges

These are just some of the challenges that face us in the provision of palliative care services in Uganda. Training has an important part to play within the provision of pal-

liative care and in trying to overcome some of these challenges. This training is not just for health care professionals but for all those concerned with the palliative care of people with HIV/AIDS whether they be school teachers, doctors, nurses, religious leaders, carers or the clients themselves.

Training programmes in different aspects of palliative care are currently being delivered by both Hospice Uganda and the Mildmay Centre. These range from one-day programmes to 18-month diplomas in palliative care or HIV/AIDS care and management. Organisations within Uganda are working together to implement training programmes not only to those who are already qualified but also to those still undertaking their training eg medical students, nurses and pastors.

Update meetings on palliative care are held quarterly through the Palliative Care Association of Uganda. The association has been set up to fulfil five main objectives. They are:

- to further the education of health care professionals in palliative care
- to bring together in a professional body, health professionals interested in palliative care, thereby enabling them to share knowledge, experience and provide support for each other.
- to promote palliative care throughout Uganda
- to set standards for palliative care in Uganda
- to promote networking between organisations related to palliative care.

The provision of palliative care is also being developed and supported by the WHO. Country teams on palliative care have been set up by WHO in five African countries including Uganda in order to try and achieve the best possible quality of life for all palliative HIV/AIDS and or cancer patients, their families and caregivers, through an effective palliative care programme.

It is envisaged that a joint proposal of WHO/AFRO countries will be developed,

to introduce and/or consolidate a palliative care programme in the governments health agenda, using the available information from local situation analysis and needs assessments that have been undertaken. Uganda has a head start in this as the government is already committed to the provision of palliative care and training but there is still a long way to go to make it more accessible.

Conclusion

The concept of palliative care is relatively new within Uganda. Many people have no understanding of what palliative care is or how to deliver it. Yet palliative care is an important part of the majority of health care professionals work with over 60% of hospital admissions being for palliative care. Whilst the challenges are great, quality palliative care and training can be given in Uganda and indeed needs to be in order to meet the needs of individuals and of the health services.

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AIDS attacks the body: Prejudice attacks the spirit. One is caused by a virus. One is caused by ignorance. Both can kill. (New Zealand AIDS Foundation).

Some people with AIDS are being denied basic rights such as food and shelter, and dismissed from jobs they are perfectly fit to perform. They may be shunned by their community, or most tragic of all by their own family.

Nurses lead the way in breaking down the walls of stigma and silence. This year International Nurses Day on 12th May is dedicated to fighting the stigma and discrimination experienced by patients with HIV/AIDS.



Quality of life in older cancer survivors: impact of age & culture

Progress report of a study supported by ISNCC Small Research Grant

Cancer is a disease that knows no boundaries. Although many variables are associated with cancer risk 'population age' is the primary risk factor. The vast majority of cancers affect older adults. For example, in the USA, more than 50% of all cancers occur in people 65 and older. Furthermore, more elderly people are living as cancer survivors because cancer incidence and mortality rates have declined slightly in the USA and Europe between 1992-1997 (Robinson, 1998). With five year relative survival rates for all cancers combined at 60%, more older adults are living with cancer.

QOL has been identified as a top priority among cancer nurses in the USA (Stetz, Haberman, Holcombe, & Jones, 1995), Canada (Bakker & Fitch, 1998), Norway (Rustoen & Schjøberg, 2000), Australia (Chang & Daly, 1996), and the Netherlands (Rustoen & Schjøberg, 2000). However, current knowledge is based primarily on empirical data gathered from white, middle-aged and middle-class society. QOL research that investigates the cancer experience from the perspective of older adults and ethnic minorities has received little attention.

Portuguese

The purpose of this research is to describe and understand the survivorship experience of older adults from two cultural groups, non-Portuguese Caucasians and Portuguese. The Portuguese were selected because they are the largest ethnic minority in the principal investigator's region and the local College of Nursing presently has collaborative relationships with several Portuguese higher educational institutions.

The current study uses The Quality of Life Conceptual Model for Cancer Survivors (Ferrell & Dow, 1997) as its framework. This model has been described in many research studies over the last 40 years, but its applicability to older adults and ethnic minority survivors has not been specifically explored.

Using a focus group interview design, in-depth descriptions on survivorship and QOL experiences are being collected by the

principal investigator and research assistant (Krueger, 1994). Trigger questions such as the following are included: We are interested in learning about what it is like to be a cancer survivor. Have you ever heard of the expression quality of life? What does the expression quality of life mean to you? When you think about quality of life, what are some of the areas in your life that are important to you? Interviews are audio taped and field notes are taken. To ensure that the data reflect the views of older adults with various backgrounds and different age-related stages of development, Non-Portuguese Caucasians and Portuguese, 65 years and older, are included.

Method

The focus groups are stratified by ethnicity, gender, and age with approximately four participants in each strata. Four sets of interviews have been done with eighteen survivors. The transcribed interviews are being analysed by gender, culture, and age using Boyatzis's plan for thematic analysis and code development (Boyatzis, 1998). This analytical plan uses specific techniques for reducing data, identifying themes, comparing themes across subgroups and developing codes. The QOL model will be modified or re-configured based on age and cultural findings.

Some preliminary findings for each domain are as follows. In the Physical Well-Being and Symptoms domain participants report changes in cognitive function, body image, sleep patterns and activity levels. In the Psychological Well-Being domain participants experience emotions ranging from a 'sense of gratefulness' that they are survivors, to 'feeling guilty about their positive outcomes.' Participants also described 'worrying' about future health care needs. In the third domain, Social Well-Being, participants reported that social support was obtained from many different sources and some sources were more effective than others. In addition, participants described how they 'managed' their social life and carefully selected their activities. In the Spiritual

Well-Being domain, participants described the meaning that faith and religious activities had for them. They also described how 'having faith' positively influenced their survivorship experience.

This is the first phase in a programme of research that ultimately aims to implement and test educational and psychosocial interventions specifically designed for older cancer survivors, including ethnic minorities. Age appropriate and culturally sensitive models of QOL will inform practice. This research will provide data on which to base culturally sensitive clinical interventions and ensure excellent oncology nursing and quality care for older adults and ethnic minority survivors. Investigating specific cultural groups will increase our understanding of how culture influences the survivorship experience. The current study begins to identify the impact of age and culture on cancer survivors' QOL. The QOL model will be revised as needed. Qualitative data will provide the basis for development of outcome measures that are sensitive to age and culture.

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CALENDAR OF EVENTS

The 12th European Cancer Conference will take place in Copenhagen, Denmark, 21-25 September 2003. *For information contact:* ECCO 12, FECS Conference Unit, Avenue E Mounier 83, B-1200 Brussels, Belgium; fax: 32 2 775 0200; e-mail: info@fecsc.be

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@fecsc.be

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