

## 4th INTERNATIONAL CANCER CONTROL CONGRESS

### Coordinating Care and Treatment for Cancer Patients

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#### Abstract

Survival following a diagnosis of cancer is contingent upon an interplay of factors, some non-modifiable (e.g., age, sex, genetics) and some modifiable (e.g., volitional choices) but the majority determined by circumstance (personal, social, health system context and capacity, and health policy). Accordingly, mortality and survival rates vary considerably as a function of geography, opportunity, wealth and development. Quality of life is impacted similarly, such that aspects of care related to coordination and integration of care across primary, community and specialist environments; symptom control, palliative and end-of-life care for those who will die of cancer; and survivorship challenges for those who will survive cancer, differs greatly across low, middle and high-income resource settings. Session 3 of the 4th International Cancer Control Congress (ICCC-4) focused on cancer care and treatment through three plenary presentations and five interactive workshop discussions: 1) establishing, implementing, operating and sustaining the capacity for quality cancer care; 2) the role of primary, community, and specialist care in cancer care and treatment; 3) the economics of affordable and sustainable cancer care; 4) issues around symptom control, support, and palliative/end-of-life care; and 5) issues around survivorship. A number of recommendations were proposed relating to capacity-building (standards and guidelines, protocols, new technologies and training and deployment) for safe, appropriate evidence-informed care; mapping and analysis of variations in primary, community and specialist care across countries with identification of models for effective, integrated clinical practice; the importance of considering the introduction, or expansion, of evidence-supported clinical practices from the perspectives of health economic impact, the value for health resources expended, and sustainability; capacity-building for palliative, end-of-life care and symptom control and integration of these services into national cancer control plans; the need for public education to reduce the fear and stigma associated with cancer so that patients are better able to make informed decisions regarding follow-up care and treatment; and the need to recognize the challenges and needs of survivors, their increasing number, the necessity to integrate survivorship into cancer control plans and the economic and societal value of functional survival after cancer. Discussions highlighted that coordinated care and treatment for cancer patients is both a 'systems' challenge and solution, requiring the consideration of patient and family circumstances, societal values and priorities, the functioning of the health system (access, capacity, resources, etc.) and the importance assigned to health and illness management within public policy.

**Keywords:** Cancer control - treatment - capacity-building - primary, community and specialist care - economics of cancer care - sustainability - palliative care - survivorship

*Asian Pacific J Cancer Prev*, **13**, ICCC-4 Supplement, 23-36

#### Introduction

For the cancer patient, the journey begins with a diagnosis of cancer, notwithstanding the social circumstances, risk factor exposures and opportunities for earlier diagnosis, even at a precancerous stage, that

antecedes the diagnosis of cancer (see ICCC-4 Sessions 1 and 2). Ideally, this journey will have a care plan involving health professionals across home, community and specialized hospital settings; will involve evidence-based "best practices"; will involve a coordinated approach to therapeutic interventions across care settings; will

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establish accessibility, availability and compliance with interventions; will address the needs of surviving, with or without continuing disease, to achieve a good quality of life; and will ensure the control of symptoms, especially pain, for a life that should end with appropriate dignity. Even in the most favourable environments, the cancer journey is not ideal, even though the elements to achieve quality care are increasingly universally recognized.

For the cancer/health care system, the ideals for achieving optimal individual patient care are not disputed: the issues are rather one of “who pays”, “for what interventions” and “from what source of funds”. Inherent in these considerations is the cost of care, including treatment, the value of the interventions (the return on the investment of funds), the allocation of funds from private, personal or public sources, and the ethical basis of allocating societal resources for the gains of the individual, for the benefit of those with conditions other than cancer, or for society as a whole for gains other than health (e.g., education, social welfare, etc.).

For healthcare providers, the challenge lies between providing the greatest benefit achievable for the individual (the cancer patient) versus the allocation of available resources for the greatest benefit of the population. The “ideal” is neither cheap nor becoming more affordable. Indeed, the “Western” paradigm of cancer care based in acute, biomedical, facility-based, technology-driven, specialist professional care is inconsistent with the ideals of interdisciplinary, comprehensive, and ambulatory, integrated, community-based care, and challenges the sustainability of healthcare in the highest resource settings. Indeed, the existing paradigm challenges financial viability for patients, families, health systems and society.

## Methodology and Objectives

ICCC-4 Session 3 on “Coordinating Care and Treatment for Cancer Patients” comprised three plenary presentations providing an overview of the subject matter as a means of preparing Congress participants for participating in five, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this Congress.

The objectives of this session were to explore issues of optimal access to cancer care, particularly in the low and middle-income countries (LMICs), and strategies to improve the process and transition of each stage of care from diagnosis and treatment to survivorship and end-of-life care. The following five issues were selected for in-depth discussion in the workshops:

1. What is the current capacity for quality cancer care in terms of diagnostic, radiation therapy, and oncology (surgical and medical) services, and availability of essential oncology drugs?

2. What are the roles of primary and community health care professionals in cancer care and treatment, and how is the transition from specialist to primary care carried out?

3. How can we sustain the cost of cancer care and make it more affordable, and are cancer treatment modalities cost-effective?

4. What are the current issues in palliative and end-of-life care, especially in LMICs?

5. With improvement in survival from cancer, what are the survivorship issues that arise?

## Plenary Presentations

### 1. *Coordinating Care and Treatment for Cancer Patients: Eduardo Cazap*

Coordinating and increasing access to care and treatment is an essential element of cancer control worldwide. This is not only true in LMICs. Many patients have poor access to care in developed countries; as an example, in the US more than 50 million uninsured patients are facing similar situations as individuals in LMICs. Managing cancer requires a strategic approach that combines effective prevention with meaningful and timely access to treatments that can either cure the disease or significantly extend life.

Key elements of a comprehensive response to cancer must always include health systems strengthening and improved provider training; a focus on early diagnosis (which greatly increases the benefits of treatment and reduces treatment costs); access to traditional treatment approaches, including chemotherapy, hormonal therapy, radiotherapy, and surgery, as well as to quality palliative care; access to newer, targeted therapies; and creative strategies to lower treatment costs and increase treatment access (CanTreat International 2010).

A robust, flexible, well-functioning health system is the sine qua non of cancer control. Increased medical training is key. Recommended strategies to improve the availability of medical training programs include the creation of regional cancer training networks to build capacity for the delivery of cancer care in low-income countries and the establishment of cancer “centers of excellence” (Anderson, Cazap et al. 2011).

Institutional ‘twinning’, in which networks of referral, information and support are established between institutions with well-developed cancer capacities and those that do not, has also proved successful in expanding clinical capacity to treat childhood cancer.

Addressing the cancer epidemic in LMICs will require a public health approach that identifies what can be done to diagnose and treat cancers more effectively at each level of the health system (Harford, Otero et al. 2011).

Medical management of most cancers typically requires some combination of surgery and radiotherapy, often complemented by systemic chemotherapy. Cancer therapies represent one of the great “missing links” in cancer control efforts in LMICs. Limited access to radiotherapy and barriers to cancer drugs in LMICs are especially striking in light of the many research advances

of recent years, which have significantly elevated the role of systemic therapy in the management of many priority cancers (Barton, Frommer et al. 2006).

A number of efforts are already underway to increase access to cancer therapies in resource-limited settings. For example, the World Health Organisation (WHO) analyses cancer drugs for inclusion in its essential medicines list, which countries use to prioritize drug procurement and distribution in the health sector. WHO also assists countries in purchasing x-ray equipment and other technologies to diagnose and treat leading cancers. In addition, some countries are taking steps to use the flexibilities allowed in international trade rules to lower the cost of cancer drugs (the examples of Thailand, India or Brazil) following the TRIP flexibilities (Trade-Related Aspects of Intellectual Property Rights).

Access to palliative care and morphine is also emerging as a major issue in providing humane and effective cancer treatment. Initiatives, such as the International Union Against Cancer (UICC) Global Access to Pain Relief Initiative (GAPRI), are working to engage players at the international level, including relevant UN agencies, and to stimulate action at a national level in key countries with the goal of ensuring that effective pain control measures are available universally to all cancer patients in pain (UICC 2011).

The new strategies to develop cancer care and treatment will necessarily need the improvement of health system responses, the expansion of creative strategies to build access to cancer treatment, the improvement of financing, and the development and implementation of targeted initiatives to expedite the introduction and scale-up of therapeutic interventions for priority cancers, guided by milestone-driven health outcome targets.

## 2. Radiation Oncology in Cancer Management: Current and New Technologies: **Eduardo Rosenblatt**

Radiotherapy is one of the main pillars in the curative and palliative treatment of most common cancers in LMICs. Radiotherapy plays a significant role for 45% of cancer patients cured in high-income countries.

Accurate targeting of tumours with maximal sparing of normal tissues has always been the foremost goal of radiotherapy practice. Over the last decades, our ability to achieve this goal has improved greatly. This achievement has been made possible by advances in imaging technology – specifically the development of computerized tomography, Magnetic Resonance Imaging (MRI), Positron Emission Tomography (PET) and Positron Emission Tomography combined with computerized tomography (PET/CT). The developments in imaging technology coupled with advances in computing have fundamentally changed the process of tumour targeting and radiation therapy planning. Our ability to display anatomical information in an infinite selection of views has led to the emergence of three-dimensional conformal radiotherapy (3D-CRT), a modality in which the treated volume conforms closely to the shape of the tumour volume. Interest in 3D-CRT grew from the need to administer higher doses of radiation to control solid

tumours that show a dose-response relationship.

During the last decade the leap in radiotherapy technology has been overwhelming. Improved hybrid imaging techniques using PET/CT and single photon emission tomography combined with CT (SPECT/CT) have taken radiotherapy from 3-D conformal radiation therapy (3D-CRT), to Intensity Modulated Radiation Therapy (IMRT), to 4-D considerations including the effects of organ motion and beyond. Examples include helical tomotherapy, image-guided radiation therapy (IGRT), volumetric arc therapy, stereotactic radiotherapy, robotic radiation therapy and charged particle therapy. Improvements in imaging have allowed a higher level of complexity to be incorporated into computerized treatment planning systems, thus changing the approach regarding how most common neoplasms are treated.

The new techniques provide the capability of more closely aligning the dose delivery within the target volume and reducing the dose to healthy tissues, thereby increasing the probability of tumour control and reducing treatment related morbidity. Simultaneously, robust quality assurance (QA) programs which allow corrections for day-to-day set up variations and target motion become crucial.

The new technologies undoubtedly offer a substantial theoretical advantage in the radiation dose distributions that, if realized in clinical practice, may help many cancer patients live longer and/or better. A more tightly conformal radiation volume associated with a decrease in the toxicity rate may potentially allow dose-escalation. In tumours that exhibit a dose-response relationship, a correlation between increasing the dose and higher rates of local control, may eventually reflect in higher cure rates.

However, the advanced technologies can also result in a greater volume of healthy tissue receiving some radiation compared with the “conventional” techniques, due to the generation of scatter radiation by the machine or the high number of fields employed. Therefore, clinicians and investigators must also consider long-term toxicities, including the risk of radiation-induced cancers.

Image-guided radiation therapy (IGRT) allows assessment of changes in the tumour volume and its location during the course of therapy (interfraction motion) so that daily re-planning can adjust for such changes in an adaptive process. Some target volumes move during treatment due to respiration (intrafraction motion), especially those in the lung, liver and pancreas. Advanced techniques for compensating for such motion are already commercially available and include respiratory gating, active breathing control, and target tracking.

Experts advise caution in the widespread implementation of the new technologies. If the identification of target tissues is uncertain when margins around target volumes are tight, the likelihood of geographic misses or under-dosing of the target increases. Movement of the target with respiration or for any reason during treatment increases the risk of missing or under-dosing the tumour. Since IMRT normally uses more treatment fields from different directions, its use may increase the volume of normal tissue receiving low doses which might lead to a higher risk of secondary cancers. This may be particularly

worrisome in paediatric patients. With the introduction of any advanced technology, such as IMRT and IGRT, data should be collected prospectively, to allow a thorough evaluation of cost-effectiveness and cost-benefit.

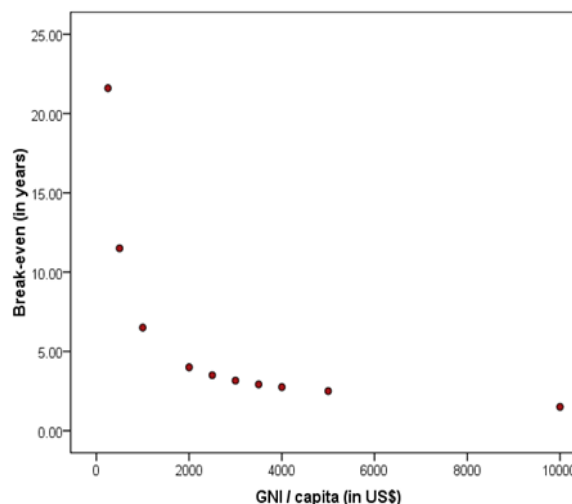
The implementation of advanced radiotherapy technologies tends to distance the physician from the patient, a trend that needs to be consciously counterbalanced by a more personal and holistic approach. In addition, it makes it more difficult to intuitively appreciate the relationship between the radiation fields and the patient's anatomy. Whereas with 3D conformal radiation therapy, the physician can rely on port films to assess the irradiated volume, with IMRT the physician must rely on computer simulations and dose-volume histograms (DVH). Users of advanced technologies should be cautioned not to allow themselves to become too dependent upon the technology itself. It was also recommended that advanced technologies such as IMRT/IGRT should not be acquired until physicians and radiotherapy staffs are fully experienced with advanced treatment planning techniques in 3D conformal therapy. In conclusion, recent technological developments in radiation oncology have brought with them improved dose distributions and reduced toxicity in selected tumour sites. These in turn mean potentially higher chances of local tumour control and improved cure rates. The potential for outcome benefits coupled with the reimbursement incentive may make these techniques attractive to radiation oncologists and hospital administrators. The clinical scientific evidence regarding local tumour control and overall cancer survival are generally inconclusive at this time.

Hypotheses regarding improved patient outcomes based on physical dose-distributions and computer-generated treatment plans require appropriate clinical studies to validate these hypotheses. Clinical trials are necessary to demonstrate the benefits of advanced technologies before they are adopted into widespread use. In general terms, a new and unproven technology should not be universally adopted as a replacement for established proven technologies. Countries should avoid the risk that, by hasty implementation of new technologies, patients would have limited access to established methods of treatment.

The International Atomic Energy Agency (IAEA) has publications providing advice and guidelines on the setting-up or upgrading of radiotherapy programmes, planning national radiotherapy services and transitioning from 2D to 3D and IMRT technologies (IAEA 2004).

### 3. Is Radiation Therapy a Cost-Effective Option for Low and Middle-Income Countries?: Niloy Ranjan Datta

Radiation therapy (RT) is a key component in the multi-modality treatment for cancer. It has been estimated that more than 50% of the cancer patients would need RT in the management of their disease, either as primary, concurrent with chemotherapy, adjuvant to surgery, or as a palliative treatment (IAEA 2004). The proportion could vary depending on the types of cancers seen in a geographical region. However, the availability and



**Figure 1. GNI per Capita (in USD) versus the Time for Break-even Point (in years) for a Basic Radiotherapy Centre**

access to this important modality is a matter of serious concern, especially for LMICs. IAEA estimates that there is presently a short fall of more than 4000 RT treatment units in LMICs (IAEA 2011a). Some 36 LMICs do not even possess any RT facility. One of the major reasons for this scarcity is the considerable capital and infrastructure cost required for establishing a Basic Radiotherapy Centre (BRC) consisting of at least two teletherapy units, one high-dose-rate brachytherapy unit, a simulator, treatment planning system and related dosimetry equipment. In addition, there continues to be a shortage of qualified medical personnel, namely radiation oncologists, medical physicists and radiation therapy technologists, to man these centres.

A number of publications have therefore looked into the various health economic parameters related to RT, namely cost-minimization, cost-effectiveness, cost-utility and cost-benefit (Hayman et al., 1996). However, these publications are usually from high-income countries and hence cannot be expected to mimic the conditions and health economic parameters of LMICs (Sullivan, Peppercorn et al., 2011).

A novel approach using the concept of Gross National Income (GNI) per capita (in USD) and the time (in years) taken for achieving a break-even on the investment for a BRC (around 5 million USD) has been designed in the form of a simple working model. The model assumes that such a BRC could treat a minimum of 1000 new patients per year, of which at least 50% may return back to work for a period of around 2 years following treatment. It was apparent that countries with a higher GNI per capita were likely to achieve the break-even point quicker than those with a low GNI per capita. This could be represented by a power model relation: Break-even point (in years) =  $947.93 (\text{GNI per capita in USD})^{-0.708}$ , (model  $r^2=0.991$ ,  $p<0.0001$ ) (Figure 1). Using the above expression, the mean break-even points for low ( $n=20$ ), low-mid ( $n=34$ ) and upper-mid ( $n=40$ ) countries as listed in the IAEA Directory of Radiotherapy Centres (DIRAC) (IAEA 2011b) were estimated at 12.1, 4.5 and 1.9 years respectively. The application of this model to estimate the cost-effectiveness in terms of GNI per capita

and its long term implication for various countries shows that investment in radiotherapy is both cost-effective and economical. Hence radiotherapy should be an integral part of a Comprehensive Cancer Control Programme (Burkert et al., 2011).

## **Workshops**

### *1. Establishing, Implementing, Operating and Sustaining the Capacity for Quality Cancer Care : Leads: **Massoud Samiei** and **Rolando Camacho***

Quality treatment has an important role in patient survival. Its contribution to cancer mortality reduction, after the implementation of early diagnosis programmes, including cancer screening, is well established (Segnan, Armaroli et al. 2004). Diagnosis at early stages of cancer makes a difference not only to the patients' survival but also to their quality of life. Cancer education at the general population level could reduce the fears and stigma associated with cancer, and this change of attitude, in conjunction with cancer education among health professionals, could increase the proportion of cancer patients diagnosed at early stages. However, all the efforts in that direction could be frustrated if high quality treatment is not offered to patients, or if adequate pathology services are not available to confirm the diagnosis. In addition, a patient's access to cancer diagnostic and treatment facilities, the organization of the services and the health workers handling of patients all play a crucial role in the result of their treatment. When setting up such facilities, WHO and IAEA guidelines are essential references (Sikora et al., 1999; IAEA, 2011c).

Planning cancer care services on a public health platform and within the context of comprehensive cancer control programmes at a national level will increase the chances for their sustainability (WHO, 2006). When establishing/developing a facility for cancer diagnosis and treatment, the selection of appropriate technology according to patients' treatment needs (most common cancer sites and stages), their possibility of access to the service, the resources available for initial investment as well as maintenance, and the number and qualification of required staff should be carefully evaluated (IAEA, 2011a). The existence of adequate training and continuous medical education programmes, combined with teaching approaches tailored to the local environment and offered in partnership with the health professionals working in the local or regional clinical settings, will enhance the success of national educational programmes related to cancer care. The implementation of standardised treatment protocols for common, curable cases in low-income settings, and even in middle-income countries, not only increases the quality and outcome of treatment but also the equity, since the treatment is less dependent on the geographical location of the patient, treating doctor or hospital. Reaching consensus for standardised treatment protocols will facilitate the implementation of the WHO essential medicine list appropriate for the particular conditions of the country (WHO, 2008).

Finally, the origin of scientific/clinical evidence for

cancer treatment is mainly from highly developed centres or countries, which often cannot be translated to low and middle-income settings. Cancer treatment research and specifically clinical trials in low and middle-income settings should be encouraged to have more relevant scientific evidence from where the majority of cancer deaths occur.

### Abstract 1: Building Capacity for Chemotherapy Delivery in Kenya Margaret Fitch, David Makumi, Peter Gachigi Kamau

The worldwide incidence of cancer is anticipated to increase substantially over the next decade. Seventy percent of the new cancer cases will be in countries with middle to low resources. Preparing to deal with this challenge requires access to cancer education. However, this access remains difficult. This project was undertaken to begin building capacity in Kenya for the delivery of chemotherapy through locally tailored education. A five day course was designed as an introduction to administering chemotherapy for nurses. Two courses have been offered (Nairobi, N=70 participants; Eldoret, N=32 participants). The course combined didactic and practical approaches with a variety of learning experiences. Data were gathered before, during, and after the courses to assess attitudes, knowledge, and practice change. Participants evaluated the program positively and indicated they felt an increased level of confidence about their work. Knowledge scores increased by the end of the course. Some students instituted practice changes in their clinical settings following the course, particularly for personal protective equipment use. Some had challenges in sharing the new knowledge with colleagues because of little available time and lack of openness by administration. Success in educational programming is dependent upon tailoring the teaching approaches to the local environment. This tailoring demands a collaborative partnership with health professionals working in the local clinical setting. The lessons learned during the organization and delivery of this course will be of interest to other agencies interested in similar initiatives.

### Abstract 2: Inequities in Access to Radiotherapy: the IAEA Directory of Radiotherapy Centres (DIRAC) Joanna Izewska, Eduardo Rosenblatt, Yaroslav Pynda

The IAEA's Directory of Radiotherapy Centres, or DIRAC, is the world's authoritative source of information on radiation therapy centres. The DIRAC database counts approximately 7,500 radiation therapy centres with about 13,300 teletherapy and 2,600 brachytherapy machines, serving the world's population of 6.6 billion people. These radiotherapy machines are vitally important in the fight against cancer. Currently, the DIRAC database encompasses approximately 90% of the existing radiotherapy facilities with comprehensive up-to-date information for most countries. The present web edition of DIRAC is being continuously updated, based on on-line completion of the electronic questionnaires by radiotherapy centres. At the same time, other sources of information are used, such as national surveys and registries, where available. By offering a global assessment

of the geographical distribution of radiotherapy facilities in correlation to populations, cancer incidence and economic status, DIRAC offers a powerful tool for understanding the current trends in the accessibility of radiotherapy, as well as for planning future radiation oncology services.

DIRAC's global survey shows a dramatic discrepancy in cancer patients' ability to access life-saving radiotherapy around the world: in high-income countries, one radiotherapy machine is available for less than 120,000 people; in middle-income countries, one machine serves over 1 million people; and in low-income countries, about 5 million people rely upon one radiotherapy machine. In 51 countries, independent territories and islands, cancer patients have no access to radiotherapy; of these there are 29 countries with populations over 1 million people. To approach the level of access enjoyed in higher income countries, some developing nations would need to increase radiotherapy availability tenfold or more. There is a clear need for additional radiotherapy facilities. However, strategies for developing new radiotherapy facilities need careful planning at the national level and have to be accompanied by substantial investments in staff training.

Abstract 3: Reasons Why Patients with Clinically Diagnosed Breast Cancer in Vicente Sotto Memorial Medical Center Breast Clinic from July 2008 to June 2010 Were Not Treated: A 2 Year Retrospective Data Analysis  
*Stephen Sixto Siguan, John Andre De Paz*

**Objective:** To determine the reasons why clinically diagnosed breast cancer patients who consulted at the Vicente Sotto Memorial Medical Center (VSMC) Breast Center were not treated. **Methods:** This is a retrospective analytical study involving patients with a clinical diagnosis of breast cancer seen in VSMC Breast Center from July 1, 2008 to June 30, 2010. Pertinent data/events including biopsy, surgery, adjuvant treatments, and the reasons for not undergoing treatment were extracted from the patient files. **Results:** There were 414 patients included in this review. Biopsy was done in 322 patients (77.8%). Among those with no biopsies (92 patients), 77% refused due to fear of the procedure. In 23%, biopsy was not done because the patient was undecided. Among those with biopsy where a definitive breast cancer surgery was indicated, only 39% had the procedure. The most common reason for not undergoing the primary breast cancer surgery was failure to return to the clinic for continuation of work-up and care (lost to follow-up). Among patients needing adjuvant (272 patients) and neo-adjuvant (162 patient) treatments, 88.6% and 85.2%, respectively, had none at all. The most common reason (64.3%) was refusal of these interventions due to fear of potential adverse drug reactions and toxicity. **Conclusions:** Fear of surgery was the main reason why patients did not consent to a biopsy while loss to follow-up was the major reason why patients did not undergo definitive surgery for breast cancer. In adjuvant and neo-adjuvant treatments, fear of potential adverse drug reactions and toxicity was the common deterrent.

2. Primary, Community, and Specialist Care in Cancer Care and Treatment: Lead: **David Weller**

### Summary for Workshop 1

- Clinical research in low and middle-income countries should be encouraged and supported by international organizations in order to provide scientific evidence for what is clinically appropriate and results in positive outcomes while taking into account the level of resources available in different settings.
- Countries, through their national cancer control program (NCCP), should promote implementation of the WHO essential medicine list for cancer treatment as applicable to their resources and health insurance coverage.
- Countries should develop standardized treatment guidelines for the most common curable cancer sites; these should be established through consensus of the medical community and according to the WHO essential cancer medicine list, the IAEA guidelines on setting up radiotherapy programmes, the resources available, and the health insurance coverage.
- International organizations are encouraged to develop recommendations on the choice of cancer diagnostic and treatment infrastructure and technology appropriate for different resource settings, while ensuring that manufacturers provide appropriate technologies at affordable prices without cutting quality.
- Availability of technology and medicines is not enough to ensure adequate cancer treatment and achieve similar outcomes to high-income country settings. Availability of trained personnel, health professional and public education (to reduce the stigma and fear preventing patients diagnosed with cancer from going for treatment or returning for follow-ups), and follow-up of patients by care providers are equally important. There should be a specific focus to study the reasons for lack of patient follow-up.
- The workshop recommends that ICCA set up a mechanism to maintain contact among the interested participants to continue the dialog and collaboration on the above issues and other matters raised during the workshop with a view to developing action plans and hopefully produce some concrete results to be reported in the next ICCC (the example of BHGI guidelines for breast cancer in LMICs was used as a good reference on how clinical practitioners and scientists, together with policy makers, can achieve concrete outcomes of direct benefit to LMIC settings).

With the growing number of cancer survivors

worldwide, it is important to examine how we can best integrate the various health care sectors involved in cancer care and treatment. Further, there is an increasing emphasis on 'survivorship', highlighting the period beyond completion of active cancer treatment. In the UK the Cancer Reform Strategy (2007) has a strong focus on survivorship and the National Cancer Survivorship Initiative (2010) has helped to identify the needs of cancer survivors - with the priority of enabling them to gain access to care and support to participate in an active life as fully as they desire. The Initiative has been driven, most notably, by the scale of the problem in the UK; there were 2 million cancer survivors at the end of 2008 (overall 1 in 8 of those aged over 65), and this number is increasing by approximately 3% each year (Maddams et al., 2009).

There is evidence of unmet need amongst cancer survivors, and this highlights the need for greater coordination of care and treatment; a recent UK-wide study found that almost one-third of patients had more than five unmet needs at the end of treatment - typically psychological needs and fear of recurrence (Armes, Crowe et al. 2009). Traditionally, cancer services have been hospital-based; many cancer treatments are highly technical, and patients have often spent long periods of time in hospital-led cancer treatment and follow-up programmes. There are, however, a growing number of examples in which primary care has linked successfully with specialist services to provide more integrated models of care - a good example is the UPCON network in Manitoba (Sisler and McCormack-Speak, 2009). Primary care is well-placed to provide cancer survivors with the general medical and preventive care they require. Further, in areas such as breast and colorectal cancer, primary care-based follow-up can deliver equal or better cancer outcomes (Grunfeld, 2005).

The issues for cancer control in LMICs are particularly pressing (Hanna and Kangolle, 2010). In low-income settings, primary care and community-based care have the potential to improve outcomes in cancer patients at reduced cost - provided it is high quality care, and there is access to, and integration with, more specialised services when needed.

Of course the concept of 'primary care' differs internationally - while it is well developed in countries such as the UK, Canada and Australia, it is less developed in other regions. In Korea it is emerging as a major contributor in health care, but well-developed roles in areas such as cancer survivorship are still to emerge (Lee, Choi et al. 2007). Hence, models of cancer care which highlight a greater role for primary care must be adapted, in different settings, to the level of development of primary care.

Ideally, integrated models of care, which draw on the best that primary and secondary care have to offer, should be developed and adapted to local contexts (Department of Health, Western Australia 2008). Internationally, there is an emerging trend towards community-based care (Burg, Grant et al. 2005); our challenge is to develop these new models in ways which fully integrate community and specialist services. A great deal more discussion is needed on how these models can be further refined, and,

in particular, how they can be adapted to the constraints and challenges of low-income settings.

Abstract 1: Role of Accredited Social Health Activists (ASHA) in Organized Breast Cancer Detection Programmes of Rural Kerala, India Kalavathy Mathurchennath, Meera Radhakrishnan

**Objectives:** Breast cancer is the leading cancer among women globally and also in the rural district of Trivandrum, Kerala, India. In this area, the incidence of breast cancer is 31 per 100,000 women per year in a female population of 1,107,430). Consequently, an organized cancer control programme for women was undertaken in the district from June 2010 onwards utilizing the ASHA workers in National Rural Health Mission. The objective of the study was to determine the effectiveness of utilizing ASHA (females) workers for identifying high risk women for participating in a local cancer detection campaign. **Methods:** Since rural women with breast lumps are always late in reporting to hospitals, an organized cancer control programme for women was undertaken jointly by Trivandrum Jilla Panchayath and the Regional Cancer Centre. The key persons utilized for motivating women are the ASHA workers, who are given a district level and local level orientation in warning signals and early detection of breast cancer. These ASHA workers in turn visit all the houses in their area to identify women at risk and bring them to the prefixed detection site in PHC. In the camp site, a physical examination of the breast is done by an experienced female Medical Officer. The age and the breast examination findings of these women are recorded. **Results:** A total of 4643 women were examined and 15 breast cancers (13 of which were confirmed), 81 fibroadenosis, 34 fibroadenoma (26 confirmed) and 13 cysts in the breast were identified. **Conclusions:** 0.345% positive cases of breast cancer were found among a population of women motivated by ASHA workers. This program demonstrated that these workers, if trained in a more scientific way and encouraged by all means, can serve as an important instrument for implementing effective early cancer detection programmes among rural women.

Abstract 2: Effectiveness of a Capacity-building Program for Lay Leaders in Cancer Screening: Experience of Community-based Intervention in a Korean Community for 4 years. Bo-young Lee, Heui-sug Jo, HeyJean Lee, Yuri Lee

**Objectives:** This study was performed to evaluate the effectiveness of a capacity-building program for lay leaders that provided education in cancer screening for 4 years. The lay leaders program was designed to improve knowledge of cancer, self-efficacy and communication skills around breast and cervical cancer screening for middle-aged women in Korea. **Methods:** Cancer screening lay leaders were educated to provide information and emotional support about cancer screening in the community. The subjects were 119 women between the ages of 40-69 years and educated for 12 hours through a participatory style education program for 4 years (2008-2011). 740 individuals in the community between the ages

of 30-69 years were contacted by the cancer screening lay leaders. PASW Statistics 17.0 WIN was used for all statistical analyses. **Results:** The contents of the lay leaders education program included cancer and early detection, the benefits of breast cancer screening, the benefits of cervical cancer screening, health care system available for cancer screening, the role of cancer screening lay leaders, communication skills, transtheoretical model and role play. Knowledge of cancer improved significantly, but self-efficacy and communication skills did not show consistent improvement. **Conclusions:** This study showed that the lay leaders program could be applied effectively to communities to improve knowledge of cancer screening. A participant-centered and community-based approach is a useful and appropriate method of public health leadership at the community level and was satisfactory to participants. However, other modified interventions are needed for capacity-building around other skills. Both of these presentations highlight the need for close integration between community-based cancer control programmes, primary care and specialist cancer services. Strategies

#### Summary for Workshop 2

- The role of primary care in cancer screening, treatment, survivorship and follow-up differs around the world.
- While WHO-sponsored declarations such as “Primary Health Care: Now More Than Ever” underline a key role for primary care in non-communicable diseases (NCD’s) including cancer, there needs to be a greater recognition of the contexts in which recommendations such as these might be implemented.
- Ideally, WHO regional offices should be asked to map/identify variations in primary care systems in different countries in order to identify how the role of primary care in cancer control in each setting might be maximised.
- Workshop participants identified only a limited number of models of good practice demonstrating well integrated cancer services.
- Two excellent presentations on community initiatives to promote cancer screening further underlined the need to link community, primary care and hospital-led activities.

based on lay leaders or other non-professional groups have tremendous promise, provided they can work closely with primary and secondary care-based programmes.

### 3. The Economics of Affordable and Sustainable Cancer Care : Leads: **Supasit Pannarunothai** and **Cheng Har Yip**

Cancer has the most devastating economic impact of any cause of death in the world. The total economic impact of premature death and disability from cancer worldwide

was US \$895 billion in 2008. This figure represents 1.5% of the world’s gross domestic product. The economic toll from cancer is nearly 19% higher than from heart disease, the second leading cause of economic loss. This analysis did not include direct medical costs, which would further increase the total economic cost caused by cancer (John and Ross 2010). With the increase in the incidence of cancer, the economic burden of cancer treatments, not only to health systems but to individuals and their households, will inevitably become more pronounced. These impacts will be felt most strongly in low and middle-income countries where social safety nets, such as universal health insurance, are less likely to be present. A consequence of this is that such illness, particularly through the costs associated with its treatment and its impact on people’s ability to work, can be a major cause of poverty. Health financing is a key component of any cancer control program implementation, and encompasses prevention, early detection/screening, diagnosis (including pathology services), treatment (including surgery, radiotherapy, and systemic therapy) and palliative care (symptom management and end-of-life care).

The percentage of GDP spent on health varies from around 2% in low-income countries, to 5% in middle-income countries, and up to 10% in high-income countries. Varying health care financing options are seen, and although some form of universal health coverage provided by the government is ideal, coverage may be patchy or minimal in low and middle-income countries, leading to significant out-of-pocket payments for cancer care, causing households to incur catastrophic expenditures, which in turn can push them into poverty (Xu et al., 2005).

It is important for governments to ensure a basic essential package that will determine the breadth and depth of health benefit coverage, i.e., how many patients are covered and how many services are paid for. It is important also to determine what is an affordable intervention, which can be 1–3 times the GDP per disability adjusted life year. While many cost-effectiveness studies have been conducted in high-income countries, few have been conducted in LMICs.

No single provider payment method is perfect. Public financing would be the most equitable source of funding and is derived from income tax and social security. Private financing can be used to meet certain goals, with some out-of-pocket expenditure and co-payment schemes to allow consumer choice, as well as some voluntary insurance to reduce private catastrophe.

**Abstract 1: Cost-effectiveness Analysis of IMRT – An Evaluation within a Provincial Implementation Strategy: Jean Hai Ein Yong, Jaclyn Beca, Thomas McGowan, Pdraig Warde, Jeffrey Hoch**

**Objective:** Intensity-modulated radiation therapy (IMRT) is an advanced radiation technique that permits the use of escalated doses of radiation while preserving tissue function of neighbouring structures. Previous clinical trials have demonstrated that IMRT is more effective than the conventional radiation techniques for treating prostate cancer and head and neck cancer. The goal of this study was to compare the cost and effectiveness of



IMRT with those of conventional radiation techniques in prostate cancer and head and neck cancer to inform the implementation of IMRT across the province of Ontario, Canada. **Methods:** Two cost-effectiveness analysis models were developed. The costs of IMRT, 3DCRT, and 2DRT were estimated through activity-based costing and incorporating input from radiation oncologists, physicists and treatment planners. The clinical effectiveness estimates were obtained from a systematic review, and quality-adjusted life-years (QALY) gained were calculated using health-related quality of life estimates from the published literature. **Results:** When comparing an equivalent dose of IMRT to 3DCRT in the treatment of prostate cancer, IMRT produced 0.023 more QALYs than 3DCRT, through reduced incidence of gastrointestinal toxicity, at an additional cost of \$738, yielding an incremental cost-effectiveness ratio (ICER) of \$31,842 per QALY gained. Additional analysis comparing a higher dose of IMRT to a lower dose of 3DCRT suggests that IMRT would be cost-saving as a result of greater disease control and cure rates. In the treatment of head and neck cancer, the use of IMRT appears to be less costly and more effective than 2DRT. Despite added resources for planning, IMRT is less costly than 2DRT because the treatment delivery time with IMRT is shorter than for 2DRT. **Conclusions:** For radical radiation treatment of prostate cancer and head and neck cancer, IMRT appears to be good value for money when compared to the conventional radiation techniques (3DCRT and 2DRT).

**Abstract 2: Cancer Cost Analysis in Kerman (IRAN):** *Mohamad Reza Farokhi, Kourosh Holakouie Naieni, Ali akbar Haghdoost, Anahita Emami*

**Objective:** Cancer costs (direct and indirect) and analysis are important in health and should be used in decision making. To determine these costs, some patients with cancer in Kerman (southeast IRAN) were interviewed. **Methods:** Our approach was bottom-up in that expenditures of 233 patients were gathered. Cancer types were divided into eight groups: blood, breast, brain and peripheral nerves, female reproductive organs, gastrointestinal tract, lung, male reproductive organs and prostate. Finally we calculated total cost. **Results:** The overall average cost of cancer was \$3320 per month (SD: 710). Breast cancer, with an average \$4300 per month (SD: 3700) was the most expensive. Cancer of male reproductive organs with average \$2160 per month (SD: 1670) was the cheapest cancer. Hidden costs of cancer were \$2000 per month. In our ranking, breast, lung, blood cancer, and cancers of the female reproductive organs were expensive, while brain and peripheral nerves, gastrointestinal tract and prostate cancer were moderately costly, and cancers of the male reproductive organs were the least costly. **Conclusions:** Within groups cancer expenditures are high. The main costs are invisible, and in health policy, economy and management of disease is notable.

#### 4. Symptom Control, Support and Palliative/End-of-life Care: Leads: **Cynthia Goh and Fraser Black**

Palliative care is a relatively new concept in much of

#### Summary for Workshop 3

- Cost has to be considered from the perspective of the provider as well as the patient and society in general.
- Efficient interventions have to be considered together with the accounting or economic cost (opportunity cost). This should involve non-technical people in assessing cost and proposing policy.
- Cancers are of different disease etiologies and interventions, therefore the plan must be specific to achieve the goals.
- A multidisciplinary approach has to be adopted to achieve economic studies to reach cancer care goals.

the world today. Only recently has it come to the attention of many governments and health policy makers and become a part of only a small proportion of medical and other health professional curricula.

The WHO defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems which may be physical, psychosocial and spiritual” (WHO 2011).

Unfortunately, throughout the world the need for palliative care for people of all ages is great. We know that close to three-quarters of people diagnosed with cancer worldwide present with incurable disease, and, with that, often have significant symptoms, including pain as well as other physical and psychosocial suffering.

It is known that palliative care benefits not only those patients with cancer but also those facing other life-limiting illnesses, such as HIV/AIDS and other chronic life-limiting diseases (e.g., cardiac and respiratory disease). A WHO palliative care project, conducted in five sub-Saharan African countries (Sepulveda et al., 2003) estimated that the number of people needing palliative care each year was at least 0.5% of the total population of these countries.

In addition it has been pointed out that “palliative care has universal value for all patients, whether they are receiving treatments with curative intent or not” (Stjernsward et al. 2007). Palliative care has been shown to improve quality of life, enhance patients’ capacity, be cost-effective and more recently, in a New England Journal of Medicine article (Temel et al. 2010), shown to improve survival in patients with metastatic lung cancer.

Despite the need for and benefits of palliative care, access and availability to quality palliative care has been limited worldwide. The WHO has called on nations to adopt national policies to include palliative care as part of their overall national health plan. In addition, they have advocated for the use of a public health strategy (PHS) to palliative care which addresses appropriate policies,

adequate drug availability, education of policy makers, health care workers, and the public, and implementation of palliative care services at all levels throughout the society (Stjernsward, Foley et al. 2007).

A closer look at the components of this WHO PHS approach as well as the other issues and challenges facing access and availability to palliative care was undertaken at this workshop and through dialogue and discussion, and sharing of experience, recommendations were made to help improve access to palliative care for adults and children worldwide.

**Abstract 1: Suffering in Palliative Care Patients: A Qualitative Study Using Grounded Theory: Seng Beng Tan**

**Objective:** Despite all the advances in medical science and technology of the past century, suffering in medicine remains largely unaddressed. As a whole, the healthcare team has continued to focus on the disease of patients and not the suffering of persons. This study on suffering was done with the main intention of understanding the types of suffering and the clinical presentation of suffering in palliative care patients. **Methods:** Systematic guidelines in grounded theory were used in gathering, synthesizing, analysing and conceptualizing the data to achieve the above purpose. **Results:** With regards to the types of suffering, the study revealed two core categories: (1) attachment-related suffering and (2) aversion-related suffering, in each of the four domains (a) physical domain, (b) psychological domain, (c) social domain and (d) spiritual domain. Regarding the presentation of suffering, we noticed that suffering is a subjective psychosomatic experience with: (1) psychological features and (2) somatic features. **Conclusions:** The former categorization of the types of suffering helps us in the understanding of causes of suffering. The latter finding provides us with insight into the experiences of suffering in patients. These two aspects of suffering enable us to develop a model of suffering that can be generalized to all patients in the field of medicine.

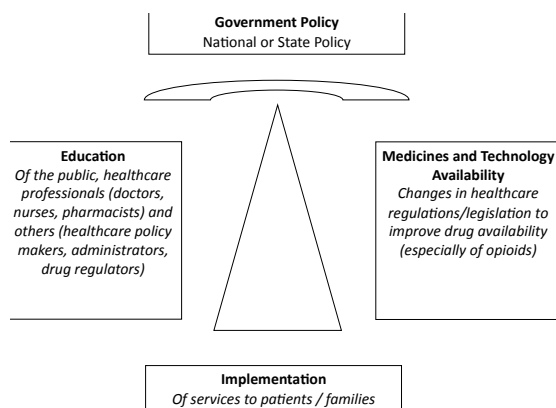
**Abstract 2: Creating Competencies for Hospice and Palliative Care Professionals in Korea: Jina Kang, Yang Suk Yoo, Yeol Kim, Jin Young Choi, Su Jin Koh, Hyun Jung Joh, Youn Seon Choi, Jin No Park, Do Ho Moon, Do Yeun Kim, Dong Wook Shin, Yun Jung, Won Chul Kim, Seung Hee Lim, Seung Joo Hwang**

**Objective:** Objective: Competency-based assessment of professional development can help to provide a standardized content for cancer and palliative care education programs. We develop and describe the process and results of identifying the advanced competencies required by physicians, nurses, social workers and spiritual care providers in hospice and palliative care (HPC) practices. **Methods:** To develop HPC competencies, ‘the Hospice & Palliative Care Professionals Competency Development Task Force Team (TFT)’ was put together with experts in HPC from multiple disciplines, consisting of 7 physicians, 4 nurses, 2 social workers, and 2 clergies. TFT identified domains of competency for each professional. To develop consensus regarding competencies in HPC, we performed two round e-mail

Delphi surveys. Each Delphi round assessed the validity of competency domains and important ratings of each competency using a 5-point Likert scale. After conducting the Delphi surveys, the opinions which exceeded the criterion (consent mean score above 4.0) were taken into consideration and adapted by TFT. **Results:** The statement of the competencies was described as knowledge, skills, and attitudes. In round 1, 32 Delphi panels (76%) responded and in round 2, 22 panels (69%) responded. At the end, 11 domains and 16 subdomains for physicians, 11 domains for nurses, 5 domains and 15 subdomains for social workers, and 3 domains and 2 subdomains for spiritual care providers were identified. **Conclusions:** It is important to examine the role of a multidisciplinary team in HPC and determine what they have to contribute to the care of the patient. The National Cancer Center and the Korean Society of Hospice & Palliative Care created competencies for HPC professionals and these

**Summary of Workshop 4**

- To move palliative care forward and make it an integrated part of health systems in countries around the world, the WHO foundation for implementing pain relief is recommended (Figure 2).



**Figure 2. WHO Foundation Measures for Implementing Cancer Pain Relief Programmes**

- A national policy on palliative care and pain relief is the first step to developing education programmes and policies on making pain medication available.
- Education of the public, health care professionals, policy makers and regulators is important to improve the availability of pain medication, especially opioids.
- Implementation of palliative care/pain relief policies to patients and their families needs to be monitored and audited.

competencies will be very useful in developing and evaluating advanced courses for each professional.

5. *Living Well After Cancer*: Leads: **Ranjit Kaur** and **Margaret Fitch**

The cadre of individuals who are living after a diagnosis of cancer is growing steadily. In high-income countries, where access to diagnostic and treatment capacity is high, as many as 78% of pediatric patients are alive five years following diagnosis, as are 60% of adult patients (Curtiss and Haylock 2006). With the anticipated increase in the incidence of cancer around the world and the success of treatment approaches, it is anticipated this cadre will continue to grow.

Unfortunately cancer survivorship does not come without cost. It is increasingly evident that cancer survivors experience late and long-term effects, both physical and psychosocial, that can compromise quality of life and increase the burden of suffering. Up to 75% of survivors have health deficits related to their treatments (Aziz and Rowland 2003), more than 50% live with chronic pain, 70% have experienced depression (LIVESTRONG/CDC 2004), and between 18% and 43% have reported emotional distress (Vachon 2006). Regardless of tumour type, survivors commonly report challenges that include living with fear and uncertainty; changes in family roles; alterations in self-image and self-esteem; changes in comfort, physiological functioning, and mobility; alterations in cognitive functioning; changes in employment and recreation activities; and alterations in sexuality and fertility. Clearly cancer survivors are a vulnerable population. Innovation is needed to overcome the barriers cancer survivors experience and ensure they receive the appropriate care.

Interest in cancer survivorship had been growing steadily over the past decade. However, there remains a range of conceptualizations for survivorship (e.g., alive more than 5 years following treatment, from the point of diagnosis onward, and dying of another disease than cancer). Additionally, the development of programs in survivorship that are oriented to helping individuals live well after their cancer treatment is primarily a phenomenon in high-income countries. The relevance and applicability of the concept and programming across the world is yet to be fully explored within other contexts. Survivorship programs and service delivery may need to take very different forms in middle and low-income countries from the approaches currently being designed and implemented. Discussion is also needed to explore the role of community based organizations and cancer support agencies in the development of this important topic area.

Abstract 1: Factors Associated With Breast Cancer Survivorship in Malaysia: *Mazanah Muhamad, Nurfaizah Saibul, Nor Mohamed*

**Objective:** The meaning of survivorship continues to evolve as survival times and cure rates improve among patients diagnosed with breast cancer. A cancer survivor is defined as an individual with cancer, current or past, who is still living. According to the U.S. National Cancer

Institute, the survival rate of breast cancer patients increased up to 89.0% in 2008. Despite the survival rate improvement among the population with breast cancer, breast cancer patients in Malaysia still face challenges in survivorship. Breast cancer survivorship is associated with factors including socioeconomic status, cancer stage, reproductive health, psychological distress and social support. This study was conducted to determine the factors associated with length of breast cancer survivorship among Malaysian women. **Methods:** The discussion is based on a research survey conducted among 400 breast cancer survivors in Peninsular Malaysia. **Results:** Based on initial analysis using bivariate correlations, breast cancer survivorship in Malaysia is associated with socioeconomic status, which includes age and ethnicity, cancer stage, cancer treatment, spirituality as well as source of cancer information. **Conclusions:** As survivorship among breast cancer patients is associated with multiple factors, there is a need to design and implement appropriate educational policy and learning programs to prevent and fight against breast cancer. By enhancing knowledge, cancer stakeholders can be guided towards a better understanding of the issues and efforts can be increased in assisting people affected with cancer to improve their physical and emotional well-being.

Abstract 2: Identification of the Screening Item for Predicting Childhood Cancer Survivors' Health Related Quality of Life: *Sul Ki Yang, Kyong-Mee Chung, Myung Ah Rhee, Chuhl Joo Lyu, Sun Chul Won, Yun Jeong Shin*

**Objective:** Due to improvements in medicine, the survival rate of childhood cancer has increased. As a result, medical professionals should focus not only on the improvement of the quantity of life but on the quality of life. Therefore, it is important to incorporate HRQOL assessment into routine medical care. To make this possible, it is necessary to identify a brief screening item. The purpose of this study was to determine the screening item which best predicts the childhood cancer survivors' HRQOL. **Methods:** A total of 111 childhood cancer survivors (66 boys, 45 girls), aged 8 to 18 years ( $M = 13.43$ ,  $SD = 2.98$ ), participated in this study. They were from the Long-Term Follow-Up Clinic at Yonsei Severance Hospital, Korea. They were assessed with the PedsQL (Pediatric Quality of Life Inventory) and rated their school life using a 5-point scale. The item was "I have problems in school life" and children were asked how much they agreed with the statement. Correlation and linear regression analysis were applied. **Results:** The screening item significantly correlated with overall ( $r = -0.420$ ), physical ( $r = -0.349$ ), and psychosocial ( $r = -0.405$ ) scores. Demographic, treatment, and screening items were coded. According to multivariate regression analysis, 3 factors, including the screening item, presence of HSTC, and age at diagnosis, significantly accounted for 33.4% of overall ( $F = 10.84$ ,  $p < .01$ ) and 34.9% of physical HRQOL ( $F = 11.53$ ,  $p < .01$ ). The screening item and the presence of HSTC accounted for 22.6% of psychosocial HRQOL ( $F = 9.61$ ,  $p < .01$ ). **Conclusions:** Among the above variables, the screening item most accounted for survivors' HRQOL. Survivors' perception of how they are doing in school

predicts survivors' HRQOL. This finding suggests that one school life item can be used as the screening item for identifying people who need further HRQOL assessment.

**Abstract 3: Change of QOL over Time among Pediatric Cancer Patients:** *Myungah Lee, Kyongmee Chung, Seulki Yang, Chulju Yoo, Sungchul Won, Yoonjung Shin*

**Objective:** Recently QOL has become a major topic in the field of pediatric cancer. However, not many studies have examined change over time in QOL. It is hard to find studies that have investigated QOL among pediatric cancer patients in Korea. However, increased survivor rates suggest the need for longitudinal studies in QOL. The purpose of this study was to investigate change of QOL among Korean pediatric cancer patients. **Methods:** Participants were 103 pediatric cancer patients who were recruited from the Long-Term Follow-Up Clinic (LTFUC) at a hospital in Korea. LTFUC is run by a multidisciplinary team. Their ages ranged from 8 to 18 years, and they had visited the clinic at least 2 times over the last 5 years. The pediatric Quality of Life Inventory™ 4.0 Generic Core Scales (PedsQL™) were administered. The PedsQL™ is divided into two subscales: physical health and psychosocial health. Paired-T tests were conducted to test the differences between time 1 and time 2. **Results:** Although the QOL increased over time, discrepancies between time 1 and 2 were somewhat different depending on the subscales. The most salient difference between the two time points was found in the social domain; no significant difference was found in the emotion domain. **Conclusions:** It appears that QOL among pediatric cancer patients improves over time. Although it was not directly investigated, it may be that patients regain their strength once painful treatments are over. However, minimum changes over time were noted for emotions, suggesting the need for future studies to investigate whether additional assistance would be helpful for pediatric cancer survivors. Continuous data collection is needed to investigate the changes over time in a more systematic way.

**Abstract 4: Birth Rates Among Female Cancer Survivors: A Population-based Study:** *Mikael Hartman, Jenny Liu, Kamila Czene, Hui Miao, Sven Cnattingius, Kee Seng Chia, Agus Salim, Helena Verkooijen*

**Objective:** Due to improvements in early diagnosis and treatment of cancer, more women of fertile age are long term survivors of cancer. This study evaluated trends in birth rates among female cancer survivors compared to the general population. **Methods:** From the Swedish Multi-generation Register and the Cancer Register we identified 42,691 women ≤ 45 years with a history of cancer, for which we calculated relative birth rates as compared to the background population (Standardized Birth Rates, SBRs). Independent factors associated with reduced birth rates among cancer survivors were estimated with using Poisson modeling. **Results:** Compared to the background population, cancer survivors were 26% less likely to give birth (SBR: 0.74, 95% CI: 0.73-0.76). Large differences in SBRs existed by cancer site, with high SBRs for survivors of melanoma skin, thoracic, head and neck and thyroid cancers and low SBRs for reproductive, breast, brain and

eye and hematopoietic cancer survivors. Parity status at diagnosis affected fertility: women who already had a child at the time of diagnosis were less likely to give birth (SBR: 0.52, 95% CI: 0.50-0.55) than nulliparous women (SBR: 0.87, 95% CI: 0.85-0.89). Multivariate analysis showed that cancer site (reproductive organs), age at onset of cancer (< 12 years) and parity status were significant and independent predictors of a reduced probability of giving birth after diagnosis. **Conclusion:** Cancer survivors are less likely to give birth as compared to the background population. Large variations in the likelihood to give birth after diagnosis were seen according to age at onset, cancer site, and parity status at diagnosis.

#### Recommendations from Workshop 5

- Cancer survivorship is a new and emerging priority. Most developments have been in high-income countries.
- Cancer survivorship needs to be recognised and acknowledged as a distinct phase of cancer care.
- More research is needed to understand and meet the needs of cancer survivors (such as sexuality issues, return to work/school, and cognitive changes).
- The development of programs, guidelines and survivorship care plans need to be organized.
- The experiences of cancer survivors can be used to help develop improvements in cancer care delivery and models of care.
- Health care systems need to be prepared to face the increasing number of survivors and follow-up.

#### Conclusions

ICCC-4, Session 3 engaged the topic “Coordinating Care and Treatment for Cancer Patients” (i.e., after the diagnosis of cancer). The workshops identified that there remain barriers to effective care and treatment for cancer and NCDs in LMICs, where shortages of resources, facilities, technology and manpower prevail. While recommendations have been outlined for each workshop, a number of “cross-cutting” themes arose that present possible routes for further action:

• *Patient and family/personal challenges:* The inability to access care, maintain treatment or sustained follow-up care due to adverse personal circumstances, remoteness, transportation and poverty, and the contributions of lower levels of awareness, education and literacy, are impediments to accessing care earlier in the disease trajectory until late, advanced stage pre-defines a fatal outcome. These considerations are relevant also to Sessions 1 (social determinants of health) and 2 (screening, early detection and health promotion).

•*Societal circumstances*: Important issues in LMICs include the stigma associated with cancer; the lower level of awareness and profile for quality, continuity and integration of care from diagnosis to cure or end-of-life; the relative lack of development of palliative care, symptom control, and end-of-life care; the role of survivorship as a necessary, managed element of personal, social and economic well-being; the necessity to consider policy in relation to health maintenance, health professional education aligned to primary, community and specialist care and models of care to deploy health professionals in care resources in a contextually optimal way; and measurement, reporting and audit of health system performance, quality and safety through processes that optimize health system planning and patient and professional confidence in care.

•*Health system challenges*: Important aspects of access to care in LMICs are rooted in the lack of primary care and effective community health, and poorly developed integration of primary, community, and specialist care. Variability in access to care, as well as the quality and safety of care, could be reduced with the development of contextually appropriate standardized care paths, standards of practice, and clinical management guidelines. Furthermore, treatment advances derived in high-income countries require characterization, management, and operation through contextually relevant research in order to establish their applicability in LMICs. Workshop discussion evolved the value of a global inventory of evidence and “best practices” on integrated systems of care for cancer and NCDs aligned to resource levels and contexts for successful deployment. Elements of an inventory could usefully include geographic/national mapping of the variations in system development and an alignment of global recommendations for access to quality care (e.g., WHO publications) with the realities of health system circumstances and performance in LMICs. In addition to geographic mapping and “best practices” inventories for cancer care and control, the role of communities of practice (national, regional or global networks of patients, health professionals and policy-makers) was identified as a means to educate, mentor, develop contextually appropriate clinical management guidelines, and build system clinical capacity on an ongoing basis between interested parties.

•*Health policy*: The role of health economics was identified as a key element to establishing affordable and sustainable clinical practice, with the necessity to integrate economic assessment as a component of multi-disciplinary definition of impacts of proposed health practices and innovations, priorities, and national allocation of resources to obtain optimal value within affordable and sustainable circumstances. Health human resource policy and planning is recognized as a universal challenge for LMICs, requiring attention to training, recruitment and retention, compensation and professional satisfaction in a manner whereby high-income countries respect, assist and support the requirements of LMICs.

These issues are neither new, nor lacking attention within, and between, nations. Activities at individual, institutional and global organizational levels continue to build capacity for care; however, Session 3 discussions identified the need for more, as well as the necessity to develop capacity and capability at a system-wide level that addresses the elements of cancer control (prevention through end-of-life) within the societal, medical and socio-economic parameters that underlie increasing self-sufficiency and sustainability.

## Acknowledgements

This manuscript is a synthesis of plenary presentations, workshop discussions, including selected abstract presentations, and recommendations for ongoing actions derived from Session 3 of the 4th International Cancer Control Congress (ICCC-4) held in Seoul, Republic of Korea, Nov 3-5, 2011 (for a full listing of abstracts and affiliations from the Congress please refer to <http://icccassociation.com/>). The ICCC-4 working group was made up of Simon Sutcliffe, Kavita Sarwal, Catherine Sutcliffe, and Helen Torrance from the International Cancer Control Association, Jin Soo Lee and Sohee Park from the National Cancer Center in Korea, and Malcolm Moore from the UICC Asian Regional Office. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.

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