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International collaborations in cancer control and the Third International Cancer Control Congress

Andrea Micheli¹, Natalia Sanz¹, Faith Mwangi-Powell², Michel P Coleman³, Claire Neal⁴, Andreas Ullrich⁵, Luzia Travado⁶, Luiz Antonio Santini⁷, Luigi Grassi⁸, Francesco De Lorenzo⁹, Alberto Costa¹⁰, Jean-Marie Dangou¹¹, Luigi Bisanti¹², Adele Seniori Costantini¹³, Niveen Abu-Rmeileh¹⁴, Mostafa Kamal¹⁵, Massimo Federico¹⁶, Rodolfo Saracci¹⁷, Gad Rennert¹⁸, Angelo Stefanini¹⁹, Franco Cavalli²⁰, Eduardo Cazap²¹, Kathy Redmond²², Susan O'Reilly²³, Paola Muti²⁴, Paolo Casali²⁵, Gemma Gatta²⁶, Andrea Ferrari²⁷, Sergio Koifman²⁸, Ebrima Bah²⁹, Guido Pastore³⁰, Ronald Barr³¹, Claudio Lombardo³², Cristina Frazzington¹, Roberta Ciampichini¹, Paolo Baili¹, and the ICCC-3 Session B group³³

¹Descriptive studies and health planning unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", Milan, Italy; ²African Palliative Care Association (APCA), Kampala, Uganda; ³London School of Hygiene and Tropical Medicine, London, United Kingdom; ⁴Lance Armstrong Foundation, Texas, USA; ⁵Diseases and Health Promotion, World Health Organization (WHO), Geneva, Switzerland; ⁶National Coordination for Oncology Diseases, High Commission for Health, Lisbon, Portugal; ⁷National Cancer Institute of Brazil (INCA), Rio de Janeiro, Brazil; ⁸Section of Psychiatry, University of Ferrara, Italy; ⁹Italian Federation of the Volunteer Associations in Oncology, Rome, Italy; ¹⁰European School of Oncology, Milan, Italy; ¹¹WHO Regional Office for Africa, Brazzaville, Congo Republic; ¹²Epidemiology Unit, Local Health Authority of Milan, Milan, Italy; ¹³Occupational and Environmental Epidemiology Unit, ISPO Cancer Prevention and Research Institute, Florence, Italy; ¹⁴Institute of Community and Public Health, Birzeit University West Bank, Palestinian Authority; ¹⁵Egyptian Smoking Prevention Research Institute, Cairo, Egypt; ¹⁶Modena Cancer Registry, Modena, Italy; ¹⁷IFC-National Research Council, Pisa, Italy; ¹⁸National Israeli Breast and Colorectal Cancer Detection Programs Ministry of Health and Israel Cancer Association, Department of Community Medicine and Epidemiology Carmel Medical Center and B. Rappaport Faculty of Medicine, Technion, Israel; ¹⁹Office of Development Cooperation, Consulate General of Italy, Jerusalem (on leave from the University of Bologna, Italy), Jerusalem, Israel; ²⁰International Union Against Cancer (UICC), Geneva, Switzerland; ²¹Latino American and Caribbean Society of Medical Oncology (SLACOM), Buenos Aires, Argentina; ²²Cancer World Magazine and Media Program, European School of Oncology, Milan, Italy; ²³British Columbia Cancer Agency, Division of Medical Oncology Department of Medicine at the University of British Columbia, Vancouver, Canada; ²⁴Italian National Cancer Institute "Regina Elena", Rome, Italy; ²⁵Oncology Medicine Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", Milan, Italy; ²⁶Evaluation Epidemiology Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", Milan, Italy; ²⁷Paediatric Oncology Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", Milan, Italy; ²⁸National School of Public Health, Fiocruz, Brazil; ²⁹International Agency for Cancer Research (IARC), Banjul, Gambia; ³⁰Childhood Cancer Registry of Piedmont, Turin, Italy; ³¹Mc Master University, Hamilton, Canada; ³²National Institute for Cancer Research of Genoa, Genoa, and Alleanza Contro il Cancro, Rome; ³³listed in the Acknowledgments

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Key words: ICCC-3, cancer control, international collaboration.

Correspondence to: Andrea Micheli, Descriptive studies and health planning unit, Fondazione IRCCS "Istituto Nazionale dei Tumori", Via Venezian 1, 20133 Milan, Italy.
Tel +39 02 2390 2867;
fax +39 02 2390 3528;
e-mail
andrea.micheli@istitutotumori.mi.it

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Abstract

Over the past few decades, there has been growing support for the idea that cancer needs an interdisciplinary approach. Therefore, the international cancer community has developed several strategies as outlined in the WHO non-communicable diseases Action Plan (which includes cancer control) as the World Health Assembly and the UICC World Cancer Declaration, which both include primary prevention, early diagnosis, treatment, and palliative care. This paper highlights experiences/ideas in cancer control for international collaborations between low, middle, and high income countries, including collaborations between the European Union (EU) and African Union (AU) Member States, the Latin-American and Caribbean countries, and the Eastern Mediterranean countries. These proposals are presented within the context of the global vision on cancer control set forth by WHO in partnership with the International Union Against Cancer (UICC), in addition to issues that should be considered for collaborations at the

global level: cancer survival (similar to the project CONCORD), cancer control for youth and adaptation of Clinical Practice Guidelines. Since cancer control is given lower priority on the health agenda of low and middle income countries and is less represented in global health efforts in those countries, EU and AU cancer stakeholders are working to put cancer control on the agenda of the EU-AU treaty for collaborations, and are proposing to consider palliative care, population-based cancer registration, and training and education focusing on primary prevention as core tools. A Community of Practice, such as the Third International Cancer Control Congress (ICCC-3), is an ideal place to share new proposals, learn from other experiences, and formulate new ideas. The aim of the ICCC-3 is to foster new international collaborations to promote cancer control actions in low and middle income countries. The development of supranational collaborations has been hindered by the fact that cancer control is not part of the objectives of the Millennium Development Goals (MG-Gs). As a consequence, less resources of development aids are allocated to control NCDs including cancer.

1. Introduction

According to WHO's estimates global cancer deaths will increase from 7.6 million in 2004, with 70 percent of these cases occurring in low and middle income countries¹. In 2007, the estimated 7.9 million deaths contribute by 13% to the total death world wide².

While the total cancer burden remains at high level in resource-rich countries, it is increasing rapidly in resource-poor countries³. These trends reflect the prevalence and growth of cancer risk factors, and increasing life expectancy at birth. Life expectancy at birth in countries undergoing rapid economic development (China, India, Brazil, etc.) has increased dramatically, and these countries are now experiencing a cancer epidemic, as has already happened in the industrialized world³.

Cancer is considered one of the main health problems in the richest countries around the world. The impact of the disease in most of these countries is demonstrated by the strong relationship between cancer statistics and socioeconomic indicators, such as per capita Gross Domestic Product^{4,5}. As a consequence, cancer is now one of the most common health problems globally. The total number of deaths from cancer globally is comparable to the combined mortality from HIV/AIDS, tuberculosis and malaria⁶.

Over the past few decades, there has been growing support for the idea that cancer needs an interdisciplinary approach and a global strategic vision, including primary prevention, early diagnosis, treatment, and palliative care, an approach universally known as "Cancer Control"^{7,8}. There is already international promotion

and guidance of cancer control⁹ exchange through the organization of Communities of Practice (CoP)¹⁰. CoP are defined as groups of people who share a concern, a set of problems, or a passion about a topic and who deepen their knowledge and expertise in this area by interacting on an ongoing basis¹⁰. Whether they are called networks, alliances or communities, these groups exist because there are individuals who appreciate the benefits of collaboration on shared concerns. People involved in CoP meet when they find value in their interactions. They get to know one another, share information, insights and advice, help each other to solve problems, discuss their situations, their aspirations and their needs. They consider common issues, explore ideas, and act in consequence. They create tools, standards, generic designs, manuals and other documents and work towards a common understanding of the issues. CoP participants are motivated by the value they find in communicating, learning and working together.

The third International Cancer Control Congress (ICCC-3)¹¹ scheduled for November 2009 in Cernobbio, Italy, will continue the work initiated at ICCC-1 in Vancouver, Canada, in 2005 and furthered at the second ICCC in Rio de Janeiro, Brazil, in 2007, in building communities of practice. The principal goals of the ICCC-3 are to reinforce global communities of practice through extensive participation and dialogue between countries and societies with different experiences in cancer control, by building on and supporting ongoing work by governments, civil society, Non-Governmental Organizations (NGO), and international organizations, and to make sustainable cancer control an important global priority. The theme of the third Congress is "International Collaboration between High Income and Low/Middle Income Countries to achieve Population-based Cancer Control".

The present paper was prepared for the congress to showcase some experiences of current international collaborations around cancer control and proposals for future international collaborations in specific regions of the world, including the European Union and African Union Member States, Latin American and Caribbean countries, and Eastern Mediterranean countries. These regional proposals are presented within the context of the global cancer control strategies proposed by WHO in partnership with the International Union Against Cancer (UICC), as well as some new themes that should be targeted in international collaborations at a global level, including cancer control among youth and Clinical Practice Guidelines. A discussion will also be presented around efforts to promote and develop supranational collaborations, which are hampered by low priority given to cancer control by international development agencies as well as within national health planning and resource allocation in low and middle income countries.

2. Building the collaboration between the European Union and African Union

The goal of the Africa Health Strategy (2007-2015), which was signed by all Members of the African Union in Addis Ababa in 2007, is to contribute to Africa's socio-economic development by improving the health of its people and by ensuring access to essential health care for all Africans, especially the poorest and most marginalized, by 2015¹². Many countries in Africa are confronting particular challenges in meeting the targets of the Millennium Development Goals (MDGs)* by 2015¹³, and will require a broad range of strengthened efforts to meet those targets. Such efforts must include effective action to tackle the shortfalls in policy, predictable financing, data collection and implementation capacities.

Worsening protein energy and micronutrient malnutrition in many countries continues to contribute to elevated mortality. About 60% of under-five mortality in some parts of Africa is attributable to malnutrition, which remains a major challenge to development and child survival in Africa¹². HIV/AIDS, tuberculosis and malaria pose the greatest challenges in the African Health Strategy 2007-2015¹².

The African Union (AU) is committed to quality healthcare delivery strategies for the continent that promote universal access for every African no matter the geographical location or stage in life. The AU will continue to work with Member States to ensure that every African receives the best quality and timely health services.

In 2008, the AU Commission and the EU Commission adopted a declaration to intensify continent-to-continent policy dialogue, cooperation and joint action at all levels, with the goal of achieving the MDGs in all African countries¹⁴.

By 2020, more than 1 million of the cancer cases in resource-poor countries will come from Sub-Saharan Africa¹⁵. Determining health priorities and allocating resources are national decisions. In Africa, as in other low and middle income countries (LMCs), these decisions are deeply influenced by the priorities of the "Global Health Community".

Cancer control is given lower priority on the health agendas of LMCs and less represented in global health efforts in those countries. African countries, of all the resource-poor countries, are the least able to cope with the coming cancer epidemic. To address these challenges there is a need to¹⁶: a) ensure equitable access to

*The United Nations Millennium Development Goals (MDG), signed in September 2000, are goals that all 191 member states have agreed to try to achieve by the year 2015. The Eight MDGs are: to eradicate extreme poverty and hunger; to achieve universal primary education; to promote gender equality and empower women; to reduce child mortality; to improve maternal health; to combat HIV/AIDS, malaria, and other diseases; to ensure environmental sustainability; and to develop a global partnership for development.

health and education services; b) provide encouragement to and assistance with adopting and ratifying the WHO Framework Convention on Tobacco Control; c) provide resources to implement cancer surveillance, prevention, detection, diagnosis, treatment and palliative care; d) ensure low-cost access to essential drugs and life-saving interventions; e) support education and training for existing and new healthcare workers; f) undertake awareness raising campaigns about cancer; g) invest extensively to support improvements in infrastructure and equipment; h) support access to up-to-date medical literature from a range of top peer-reviewed journals; and i) support research collaborations with resource-rich countries.

There are few cancer intelligence units in Africa at the moment and those that do exist invariably suffer from lack of funds and do not cover enough of the population to allow reliable extrapolation of data for the whole country. Cancer registries also form a useful framework for evidence-based cancer research and, therefore, the lack of such resources is undermining research capacity within African nations¹⁵.

There is a need to promote a series of collaborations between the EU and AU, following the adopted declaration¹⁴ to intensify continent-to-continent policy dialogue, cooperation and joint action at all levels, with the goal of achieving the MDGs in all African countries. Collaborative programs addressing the present and future needs in cancer control should be fostered, in line with the recommendations of the MDG (Goal number 8), which encourage re-commitment to the ODA (Official Developed Assistance) pledge of 0.15-0.20 percent of the Gross National Income (GNI) to Less Developed Countries (LDCs) included in the Action Plan for LDCs¹⁷, and the 2005 G8 Gleneagles summit commitment to double aid to Africa from \$25 billion in 2004 to \$50 billion by 2010¹⁷.

This EU-AU collaboration should be based on the European experience in collaborating on efforts to control cancer and on the state of situation in Africa. Four domains should be taken into consideration: for the present needs, palliative care; for present and future needs, training and education (focusing on primary prevention); cancer research; and promoting control and cancer surveillance by developing cancer registries.

Within these domains connections should be made with the main experts and stakeholders: collaborations should be fostered with cancer patients and volunteer associations to better understand the importance of palliative care; there should be constant cooperation with the European School of Oncology¹⁸ to build training projects across Europe; research should be conducted to generate new knowledge about the basic nature of cancer, and about new and more effective approaches to primary prevention, diagnosis and therapy, and the European cancer registries should be actively involved in projects.

2.1. On domains where the AU-EU collaboration might be implemented

Faith Mwangi-Powell

Palliative care should be a critical component of overall national cancer control programs in Africa – both as a vehicle for delivering health promotion messages, and as a means of alleviating pain and other troubling symptoms – and should be integrated into other cancer prevention, early detection and treatment strategies. However, palliative care has been neglected on the continent, overshadowed by donor funding prioritization and compartmentalization of communicable diseases, especially HIV/AIDS. The challenges associated with palliative care service provision for cancer patients in Africa are considerable and are evident at four levels of the health care system: the socio-cultural context level; the governmental, legalistic and national context level; the service provider level; and the service user level. Nevertheless, practitioners on the continent have demonstrated an ability to advance palliative care under favorable conditions, and we expect similar advances to be made in the field of cancer.

Cancer is a national health priority in the European Union and in general in the West. In Africa, cancer is as prevalent as in the West, but goes largely untreated, as other diseases are currently prioritized by governments and donors where funds are limited. In resource-rich countries: 1) people with cancer are recognized by professionals to be in need of treatment, 2) patients perceive their need for care, and 3) services are generally available. People with cancer occupy the overlapping intersection of these three domains. In sub-Saharan Africa, professionals are only now starting to identify cancer as a public health issue; there is still little patient demand for cancer treatment in rural areas and medical services are severely limited. Health priorities in Africa in the last 25 years have understandably focused around maternal and child health, TB, leprosy, malaria and more recently HIV/AIDS. Measures to prevent and early detect cancer, which are emphasized in the industrialized world – such as smoking cessation and screening – are not yet nationally adopted, although the WHO regional office has recently adopted a regional cancer control strategy¹⁹.

National Cancer registries are the only means to provide valid data on cancer incidence, which is essential for cancer control planning. However, there are only very few cancer registries in the African region covering approximately 11% of the population²⁰.

The gap of services for cancer patients in particular in rural African is critical and depends much on the medical infrastructure, referral systems to secondary and tertiary cancer and reimbursement policies.

Africa would like to engage in international collaborations. In order to promote collaboration with the European Union, the experiences and suggestions for inter-

national collaboration, such as those that follow, should be considered under the umbrella of the EU-AU treaty. This collaboration should emphasize and address the fact that cancer is a growing and considerable threat on the African continent. Consequently, palliative care should be a critical component of overall national cancer control programs and should be integrated into other cancer control strategies.

However, the reality of finite national budgets and the myriad social, political, legislative and other challenges to effective service provision mean that individual sub-Saharan nations cannot address cancer in isolation. The EU-AU collaboration is a new cooperative approach that is advocating for the prevention, treatment and palliation of cancer in countries of the AU, and is a means to bridge the gap between resource-rich and resource-poor nations. In this regard, EU countries should work in partnership with resource-poor African countries, encouraging governments to develop cancer control programs and helping them to address the challenges that hinder the implementation of palliative care services for cancer patients.

2.2. Pap smear diagnosis via satellite for Africa

APOF board (Rosario Tumino, Vincenzo Stracca Pansa, Agostino Faravelli, Paolo Giovenali, Laura Viberti, Tiziano Zanino), Paolo Marelli

The Italian NGO "APOF" (Associazione Patologi Oltre Frontiera) was established in the year 2000 for the creation or the improvement of histopathology departments in low income countries. Western countries benefit from thousands of specialists who work in the field of anatomical pathology. On the other hand in sub-Saharan Africa, for instance, this service is absent or relies on a very small number of pathologists. This is why in Cuba, Egypt, Djibouti, Kosovo, Madagascar, Palestine, Tanzania, Uganda and Zambia, APOF is involved in projects that use a tele-pathology system to address the lack of pathologists.

APOF is aware that one of the crucial problems is the prevention of cervical cancer, one of the primary causes of death from cancer for women in south-western Africa²¹, a large region heavily affected by the lack of personnel qualified to read pap-tests.

In 2005, with a pilot project in the village of Chirundu, in southern Zambia, a histo-lab was built and two young local technicians were trained by Italian volunteers who travelled to Chirundu. After the training, the two technicians were able to screen Pap's smears, separating the negative cases from positive ones. In addition, they learnt to prepare samples embedded in paraffin blocks and histological sections both from biopsies and surgical specimens. Digital photographs were taken of the suspicious or positive cases and sent to a group of

nearly 100 volunteer reviewers, one of whom is on monthly rotation and responsible for final diagnosis. For the histological diagnoses a digital scanner was used with a satellite connection. An organized group of volunteer pathologists confirmed the histological diagnosis within four days after scanning the case. Every six months all the histological and cytological slides were sent to Italy and verified. Preliminary results of this experience, including cost evaluation, are satisfactory.

2.3. Psychosocial morbidity and quality of life in cancer patients: the Southern European psycho-oncology study - an international collaboration at the EU level

Luigi Grassi, Luzia Travado, Francisco Gil

Psycho-oncology literature has demonstrated 25-35% prevalence of emotional disorders among cancer patients, but only a minority of patients correctly identified by oncologists. Training models have shown to increase doctors' confidence in their skills to address patient's needs. In Southern European countries (e.g., Italy, Spain, Portugal) data are lacking and a study conducted in these 3 countries aimed to: (i) examine psychosocial problems secondary to cancer; (ii) rate the extent of its recognition by oncologists; (iii) develop and apply a training model to improve doctors' ability in detecting psychological disorders in their patients. A series of cancer outpatients were evaluated as regards to their mental status (WHO-ICD-10), psychological morbidity (HADS), coping strategies (Mini-MAC), concerns about illness (CWI), and ability to talk with their family (Openness scale). Doctors and a subgroup of patients completed also, independently, a VAS relative to quality of life issues. Doctors were asked to complete questionnaires (Self-Confidence in Communication Skills and Expected Outcome of Communication) about their confidence in communicating and dealing with emotions of cancer patients. A specifically designed training model was developed and applied to doctors participating in patients' assessment phase. 277 patients participated in the study. One third (33.08%) had pathological scores ("borderline cases" plus "true cases") on HAD-Anxiety and 24.81% on HAD-Depression. "Caseness" related to high scores on CWI, low scores on Openness, high scores on Hopelessness and Anxious Preoccupations of Mini-MAC²². Concordance between doctors (n = 39) and patients on quality of life domains was within 27-43% range. Levels of doctors' confidence in their ability to deal with emotions in cancer patients were in mild range²³. The training model was applied to doctors (n = 30), satisfaction was high and confidence in their skills significantly improved²⁴. This International multicentre study proved to be a successful way to network and conduct research in countries with similar cultural backgrounds²⁵⁻²⁷.

2.4. A community work model for a cancer survivor driven support network in South Africa

Linda Estelle Greeff, Strydom Eldre

In order to assess the need for service and set up a support service for newly diagnosed cancer patients with different kinds of cancer we began a pilot project in Cape Town, South Africa. This program was developed with the full support and assistance of Ann Steyn, the current National Chairperson of Reach for Recovery Internationally. During the implementation process issues with logistics were encountered, and strategies for getting such a project started and functional needed to be devised. We established screening criteria for choosing cancer survivors that would be suitable for receiving supportive counseling and information about newly diagnosed patients. We developed a training program for the Cancer Buddies to prepare them for the task of supporting newly diagnosed cancer patients, and set up a system to provide continuous supervision, training and support for these cancer buddies as they rendered support services to the new patients they visit.

The model for this pilot project provides a workable model for setting up a peer-to-peer counseling and support network that can be used in many different communities. It is especially applicable in resource-poor regions where trained professional support services are lacking and expensive and exclusive modalities of care are not feasible. This is not a new model but an adaption based on the very successful peer support model "Reach for Recovery" which is supported by the UICC and has been implemented for breast cancer all over the world. The sharing of best practice models of care in the field of psycho-oncology is of great importance as we seek to develop more effective ways of providing support not only to breast cancer survivors but also to patients diagnosed with other cancers. Further evaluation of this project will determine its effectiveness and its value in the cancer community for application in other contexts of care.

2.5. Cancer survival in Eastern Libya: preliminary data from the Benghazi Cancer Registry

Mufid El Mistiri, Nadia El Sahli, Mohamed El Mangush, Adel Attia, Rehab Shembesh, Hanna El Araf, Amina El Faidi

Background So far, few and scattered data are available on cancer incidence and mortality in Northern Africa. The Benghazi Cancer Registry (BCR) was established in 2002 under the auspices of the National Research Centre; in the year 2004 a twinning with Modena Cancer Registry (MCR), Modena, Italy, was activated, and the staff of MCR contributed to the training of clerks in coding techniques and software use. So far the BCR has already collected data for cases registered in

the years 2003-2004, thus allowing the assessment of cancer survival in Benghazi municipality.

Methods All incident cases of invasive cancer registered by the Benghazi Cancer Registry during 2003-2004 in the Benghazi area were selected for survival analysis. The information abstracted from the registry includes: id code, date of birth, residence, date of diagnosis, cancer sites classified according to the ICDO-3, date of last contact and status at last contact. A check of records on vital status is performed by active follow-up procedure, including collecting information from all death registration offices and a search of hospital records. Relative survival, an estimator of the excess risk of death, or the excess mortality ratio, will be calculated by dividing the survival observed in cancer patients by the survival that would be expected in the general population of the same age and gender (the probability of death by age and gender will be taken from Libya life tables published by WHO).

Results A total of 1,082 cases of invasive cancers were recorded among residents in the Benghazi municipality for the 2-year period 2003-2004. The most frequently diagnosed malignancies in males were lung (23.3%) and colorectal cancer (10.2%), followed by bladder cancer (9.3%). In women, breast cancer was the leading cancer site (27.2%), followed by cancer of the colon and rectum (9.9%), uterus (6.0%) and non-Hodgkin lymphoma (5.6%). Of the cases, 581 (53.8%) were known to have died. The top cause of cancer death was lung cancer in males and breast cancer in women.

3. Cancer control collaboration in Latin American and Caribbean countries

Following the 1st ICCC in Vancouver, Canada in 2005, efforts to foster the formation of a global community of practice included a proposal to establish the organization of a regional process within the next two years, with defined goals and actions for a Latin American and Caribbean Alliance for Comprehensive Cancer Control, through which collaboration and synergy could enhance cancer prevention and cancer care interventions for individuals and populations.

In order to achieve its central aims, the Alliance had expected to establish collaborative efforts among the countries in order to share ideas and experiences of common interest, including projects, studies, research and national experiences in improving evidence-based management, accreditation strategies, and assessment and incorporation of new treatment breakthroughs and technology for cancer control.

The Latin American and Caribbean Alliance for Comprehensive Cancer Control was developed in consultation with representatives from the WHO, the Pan-American Health Organization (PAHO) and leading national and international organizations for cancer control, in-

cluding access to political leaders and financial resources essential to its goals and actions.

Signatories to the Rio de Janeiro Declaration in 2007²⁸ committed themselves to mobilizing their colleagues and governments to support the Latin American and Caribbean Alliance for Comprehensive Cancer Control and as initial priorities, support the work plan of the Ibero-American Network on Tobacco Control and the adoption of an action plan for cervical cancer control.

In the past two years, the Latin American-Caribbean regional, bilateral, multi-national and cross-regional collaboration has made progress and has had many accomplishments as well as many challenges. Further discussions will determine how best to promote cancer control in Latin American and Caribbean countries and move forward with the next phase of the Alliance.

3.1. Breast cancer control in Brazil

Carla Andréia Vilanova Marques, Maria Gaby Rivero de Gutiérrez, Elisabeth Niglio de Figueiredo

In comparison to other cancer malignancies, breast cancer has the highest incidence rates among women in Brazil both in terms of morbidity and mortality. The impact of the disease has required Governmental Control Interventions by Public Programs^{28,29}. These programs are described in several documents that need to be evaluated in order to understand the strategy. We investigated, in a chronological order, which strategies were used during the development of National Breast Cancer Control Program. The National Health System database was searched for documents from a narrative review perspective, using the keywords: cancer control, cancer programs and women's health. Ten documents were retrieved and analyzed. The National Institute of Cancer was created in 1957, and the first National Program in Breast Cancer started in 1998^{30,31}. The strategies implemented before 2004 focused on breast self-examination, education, cancer treatment, and reconstructive breast surgery. After 2004, the Breast Cancer Control Consensus began, with goals directed towards primary care through education in health promotion and early detection, identification of target groups, opportunistic screening, and qualification of mammography services³². In 2005, the National High Complexity Oncology Structure for treatment was developed by the National Oncology Politic³³. Currently, the network system in breast cancer is beginning a pilot project to implement a systematic breast cancer screening program. The project was developed with help and advice from other resource-challenged countries. Although previous strategies have focused on treatment and education, this initiative will focus on early detection. The long road to this point has been influenced by the economic situation in Brazil and the geographic constraints of implementing strategies over such a large area. Despite the

different strategies implemented in the past 10 years, the Brazilian Breast Cancer Strategies has improved and is moving forward.

3.2. Medicine consumption and spending for chemotherapy of the most prevalent tumors in Brazil

Tereza Maria Piccinini Feitosa, Reinhard Braun, Isis Tomasini

Background In Brazil, cancer is a public health problem and the Brazilian Universal Health System (SUS) is the main financier of the National Cancer Control Program. The National Cancer Institute (INCA) of the Health Ministry implements the National Oncology Health Care Policy³³⁻³⁵ and monitors the cancer treatment costs in order to plan the appropriate allocation of resources by the government³⁶. In this context, the investigation of chemotherapy spending is a key element for decision-making costs.

Objective To present the spending on chemotherapy medicines per patient in INCA, for the most prevalent tumors (lung, prostate, breast cancer, cervical cancer, colon/rectum).

Methods We identified the operational data system containing information on the acquisition, prescription, manipulation and administration of chemotherapy. We developed a management tool to capture the existing operational data for continuous monitoring and analysis of the spending, in order to assist SUS in managing the consumption of chemotherapy medicines. We investigated spending from a sample of 3,163 patients for the year 2008.

Result The total spending for chemotherapy medicines and the average cost per patient for the following tumors were, respectively: Lung (US\$ 152,860.61; US\$ 499.54); Prostate (US\$ 95,686.10; US\$ 885.98); Breast (US\$ 3,838,303.08; US\$ 1,937.56); Cervical (US\$ 61,976.96; US\$ 180.69); and Colon/rectum (US\$ 159,829.63; US\$ 376.07).

Discussion The development and use of the management tool permitted a global visualization of the spending per patient for each type of cancer. Moreover, the tool facilitated the monitoring of expenditure on chemotherapy medicines for the following areas: Planning; Supplies; Clinical Oncology; and Pharmacy. However, there is a possibility for improvement in this management tool in order to obtain more data on the following expenditure allocations: hospital support materials; out-sourced services; and Human Resources.

4. Cancer control experiences and collaborations in the Eastern Mediterranean area

In the Eastern Mediterranean (EM) region, cancer is the fourth most common cause of death and is increas-

ingly recognized as a major health concern. According to WHO projections, cancer incidence in the EM area is expected to increase from 0.5 million cases in 2008 to 0.9 million cases in 2030³. In the EM region, most countries still lack reliable population based data and cancer is not covered by regular surveillance, so identification of intervention priorities for cancer prevention is extremely difficult. As noted by some scientists in the region, where data do exist, poor reporting regulations and practices affect their quality and reduce their usefulness. Furthermore, good data are often poorly used due to the poor connection between the production of knowledge (academia) and its consumption (policy makers and the general public). The failure of investment in preventive and primary care programs and actions has led to health care being taken over by market forces with a curative, rather than preventive, orientation. This has led to disparities in access to health care and the widespread distribution of risk factors for disease. The most frequent tumor types in the Eastern Mediterranean area are breast carcinoma in women and lung and bladder cancers in men¹. The WHO Regional Office, in association with the Princess Lalla Salma Association against Cancer (HRH Princess Lalla Salma), non-governmental organizations and other relevant international organizations in the Region, agreed to establish an alliance against cancer to join forces in order to generate an appropriate and concerted effort to prevent and control cancer. The alliance was created in Marrakech in 2007, under the patronage of HRH Princess Lalla Salma, and a secretariat based in Morocco was established. Membership in the alliance will be open to all organizations active in the field of cancer in the Region and also for prominent individuals³⁷. Another alliance, the Middle East Cancer Consortium (MECC)^{38,39} was established through an official agreement between the Ministries of Health of Cyprus, Egypt, Israel, Jordan, and the Palestinian Authority. The agreement was signed in Geneva in 1996. Turkey officially joined the Consortium in 2004. The objective of the MECC is to reduce the incidence and impact of cancer in the Middle East through the solicitation and support of collaborative research. Since its inception, MECC's major activities have focused on the Cancer Registry Project (CRP), which supports population-based cancer registries within MECC members and develops linkages between them, and the Small Grants Program, which provides funding for clinicians and scientists within MECC signatories. All proposals for funding are peer-reviewed for their scientific merit and must involve collaboration between more than one participating MECC member. In addition to its flagship activities, MECC is involved in efforts to enhance cancer communications, control cancer, and improve palliative care and end-of life services for patients with cancer.

4.1. A model for international and regional scientific collaborations in the King Hussein Cancer Center

Jamal Khader

The King Hussein Cancer Center (KHCC) is known to be a leading comprehensive Cancer Center in the Middle East region. KHCC has been working extensively on realizing its mission of providing state-of-the art comprehensive cancer care to the citizens of Jordan and the region. In order to do so, KHCC has relied heavily on creating, maintaining and strengthening its bilateral International Scientific Collaboration with some of the best cancer centers in the world⁴⁰.

KHCC has built a strong and functional relationship with the University of Texas, MD Anderson Cancer Center and with the National Cancer Institute in Cairo, Egypt over the past few years. Activities, such as faculty visits, staff training, medical professional observer workshops and participation in International Symposia, have all opened the doors for even bigger and better opportunities for each centre. As part of M.D. Anderson's Cancer Center (MDACC) Global Academic Programs, KHCC now plays a significant role in Jordan and the region. Inviting professionals from MDACC to conduct intensive workshops for local physicians and technicians has also proven to have a great impact on the level and quality of services provided at the centers⁴¹.

Similar to the activities with MDACC, the relationship with NCI-Cairo is vital in connecting the pillars of cancer care in the region. Areas of collaboration between the centers are complimentary to each institution's mission and vision, especially in oncology nursing, pediatric oncology, palliative and hospice care, and cancer registries.

4.2. Initiating a psychosocial treatment program for cancer patient's in Turkey

Patricia Fobair, Haldun Soygur, Derya Akbiyik

Physicians from Turkey and a Fulbright Social Work Senior Specialist (2007-2012) from California collaborated in 2008 to develop a psychosocial treatment program for cancer patients at the Ankara Oncology Education and Research Hospital. The team met in 2006 at an international oncology meeting in Venice, Italy. Drs. Haldun Soygur and Derya Akbiyik invited Patricia Fobair to speak at a successful 180 participant workshop for Turkish oncology health professionals in Capadocia in 2007. Enthusiasm for the concept of developing a psychosocial treatment program for cancer patients in Turkey led to further collaboration resulting in Grant ID 88413989, Project ID 3263 by Fulbright 2008: Develop the Psychosocial Treatment Program for Cancer Patients at the Ankara Oncology Research and Training Hospital, Turkey in 2008.

Using a public health planning process we developed goals for the program, after learning from the patients

and staff about patient needs and concerns; we reviewed the ideas presented for practical implementation; chose several 'best ideas' for presentation to the administration for implementation; gained the assistance needed (time, budget, personnel) and organized for implementation of a pilot program, testing the ideas' usefulness. Evaluating results of the pilot test, alterations were made for the new program.

Goals were accomplished: two weeks for the survey; two weeks initiating group interventions; and two weeks evaluation and discussion of future plans.

During the six weeks between November 10-December 22, the Soygur, Akbiyik and Fobair team-mates succeeded in demonstrating that cancer patients needed additional services, that staff was available and interested in providing group support and occupational therapy services, and that medical faculty, the Director of the Hospital, and Health Minister were supportive of initiating a Supportive Care Program at the Ankara Oncology hospital as a model for the country.

The work of initiating a Supportive Care Program in Ankara continues. A proposal will be written to the Health Ministry applying for continuing funds for a Social Work staff position. Additional grants will be submitted to the World Health Organization and the European Union for funds allowing collaboration for the program's growth throughout the country. In the meantime, the psycho-education groups started for the breast cancer patients and men with testicular cancer continue with Turkish health professionals leading the groups. The Occupational therapy, art classes began in February 2009, a program for group singing is the most recent addition to the program.

Collaboration between health faculties in countries of diverse ethnic and religious origins were effective in this US-Turkish collaboration. It is increasingly possible for such collaborations to occur, depending only on affinity and commonality of purpose and need. As an international organization, Fulbright can take credit for setting the stage where new friendships among health professionals concerned with cancer can meet, confer and begin relationships that can lead to improved health care programs for cancer patients.

The authors are grateful for the assistance from the Fulbright Senior Specialist Program (US State Department) which underwrote the consultant's expenses during the six weeks in Ankara, Turkey. The Ankara Oncology Research and Training Hospital in Ankara, Turkey provided the housing and maintenance expenses.

This model of collaboration between health faculties, between countries of diverse ethnic and religious origins can be effective. It is possible for collaborations to occur, when affinity and commonality of purpose are discovered. As an international organization, IPOS can take credit for setting the stage where new friendships among health professionals concerned with cancer meet, and begin relationships that lead to improved

health care programs for cancer patients throughout the world.

We demonstrated that by using a planning process, we could involve the patients and staff in supporting the development of a new program. With continuous meetings with the staff and patients, we were able to counter resistances and provide successful group interventions for the patients. In the future, as the program grows patients will participate in providing clinical research information that will allow for more sophisticated program evaluation. At the moment, increasing patient participation and staff enthusiasm speak to the program's success.

5. Cancer control: the World Cancer Declaration promoted by UICC

The UICC⁸ is an international non-governmental organization dedicated exclusively to the global control of cancer. It is a dynamic global community of connected cancer control organizations, professionals and volunteers working together to eliminate cancer as a major life-threatening disease for future generations. Their mission is to connect, mobilize and support cancer organizations and individuals with knowledge and skills to increase their effectiveness. The main objectives of the UICC are to develop, maintain and continuously improve knowledge and transfer platforms for communication and mutual support; establish/enhance the authority of UICC through key knowledge transfer "flagship" activities; build international capacity for cancer control, by promoting collaboration and partnerships across sectors and geographical divides; use the collective voice of UICC to advocate globally for cancer control as a public health priority and for achieving the achievable; provide resources and "umbrella" support for coordinated activities that complement activities of member organizations for the populations they serve.

Since 2005, the UICC has promoted yearly world cancer campaigns focused principally on prevention (primary and secondary) and improving childhood habits, and since 2006, UICC has coordinated World Cancer Day activities. The global vision promoted in 2009 by the UICC is synthesized in the World Cancer Declaration⁴² signed the 26th of August 2009 by 649 institutions and 9082 individuals, which outlines a plan of action to reduce the global cancer burden by 2020 and increase cancer's visibility on the international political agenda.

In Geneva, the 58th World Health Assembly accepted a resolution urging Member States among other things:

- "to collaborate with the Organization in developing and reinforcing comprehensive cancer control programs tailored to the socioeconomic context...";
- "to set priorities based on national burden of cancer, resource availability and health system capacity for

cancer prevention, control and palliative-care programs”;

- “to integrate national cancer-control programs in existing health systems...”.

Although this resolution is of historical importance, this by no means will ensure that governments will comply with what was adopted by their representatives on the 25th of May 2005 in Geneva.

In this respect, the example of the WHO Framework Convention on Tobacco Control has been somewhat sobering: it has recently been shown that tobacco lobbies have succeeded in blocking the requested national legislation in most resource-poor countries. One of the main approaches for putting pressure on governments to act according to the WHO resolution is to mount public pressure in each country. In order to achieve this task, NGOs and the UICC in particular, are probably the most important resource for mobilizing civil society.

UICC now encompasses 330 member organizations in 103 countries and is therefore the most important global NGO in the field to fight against cancer. At the 2008 World Cancer Congress (WCC) in Geneva, an updated World Cancer Declaration was approved, which requests urgent action on the following issues:

- availability of cancer-control plans in all countries;
- substantial improvement in the measurement of the global cancer burden;
- substantial decrease in tobacco consumption, obesity, and alcohol intake;
- universal vaccination in areas affected by Human Papilloma Virus and hepatitis B virus;
- misconceptions about cancer dispelled;
- substantial improvements in early detection programs;
- diagnosis and access to cancer treatment, including palliative care, improved worldwide;
- effective pain control universally available;
- greatly improved training opportunities in oncology;
- substantial decrease in migration of health workers;
- major improvement in cancer survival in all countries.

The followings projects illustrate the strategies that are being used to realize these targets in regions with differing levels of available resources.

5.1. Results of a comparison between 10 national cancer plans (NCPs) in Europe

Renée Otter, Jean Francois Doré, Josep Maria Borrás, José Expósito Hernandez, John Fitzpatrick, Brigitte Guillemette, Niels Hermann, Tony Holohan, Jozsef Lövely, Teresa Moss, Reto Obrist

Background NCPs are essential in prioritizing the key actions necessary in the country to reduce cancer inci-

dence and mortality. To identify whether a coordination of NCPs on a European level might reinforce the EU goal of reducing the burden of cancer, a comparison of the NCPs was done in the European+Plus Project in 2007.

Objectives Through analysis of similarities, differences in goals, contents, and priorities, the leaders of the NCPs can weigh the additional relevance of a coordination (of some aspects) of NCPs at the EU level in order to more rapidly achieve the national goals of the NCP.

Methods The study was carried out by identifying the existing NCPs at the end of 2006; determining their willingness to participate; preparing a general questionnaire, based on the NCCP and policies (managerial guidelines of WHO and UICC publication on NCCPs); and organizing meetings to validate the results/conclusions.

Results Ten regional-national plans from 8 different EU countries were analyzed. The plans included domains of primary prevention, screening, and care (medical, supportive, psychosocial and palliative). Research, training of professionals, patient education, and information were not covered by all plans. Concerning screening, there was a diversity regarding the methods used, the age range of invited persons and the interval period chosen. Not all countries focused on national/regional treatment guidelines, implementation of clinical pathways, multidisciplinary teams or rehabilitation programs, although all participants reported that they would like to incorporate these aspects into their plans. A coordinating group at the EU level should support and advise the development and implementation of a NCP, and supervise the integration of domains and scientific evidence within the NCPs. At the EU level, a monitoring instrument for a NCP should be available to make consistent and comparable monitoring and evaluation possible.

Conclusions A coordinating group at the EU level would improve the implementation of NCPs and speed up the realization of the main goal of the NCP: to reduce the burden of cancer. A framework for information exchange according to different domains, which should be part of a NCP, will be part of such an EU program.

5.2. The 1st international tele-health palliative care symposium

Judith Salmon Kaur, Christine DeCourtney, Melanie Merriman

As the incidence and prevalence of chronic diseases and cancer increase worldwide, there is a critical need to develop resources for palliative care^{43,44}. The Mayo Clinic and the Alaska Native Tribal Health Consortium piloted a “virtual” symposium on palliative care. The symposium involved the US, Canada, Australia, New Zealand and American Samoa. Social Networking tools such as Facebook, Twitter, LinkedIn and Flickr allowed registrants from around the world to connect to lectures and to post questions for speakers in real-time and to

“discuss” issues with other participants. Over 390 participants logged in to hear speakers address a wide range of palliative care topics, from cultural perspectives to pain and other symptom management. Many sites held face to face sessions in their locale or discussion groups to complement the formal presentations. We are creating an ongoing “virtual” palliative care community so that teams can share the latest information and resources, discuss their local palliative care needs, submit questions to experts on the Web and support each other beyond the formal conference. At Mayo Clinic, Rochester, MN, 10 teams of professionals from across the Indian Health Service participated in experiential training in the Medical Simulation Center and made hospital rounds with hospice and palliative care professionals each morning and participated with the teleconference in the afternoons. This intensive case-based palliative care training involved both “hands on” and didactic sessions.

This symposium was unique for the breadth of nations and locations represented and the use of cutting-edge technology to bring people together. The results of the online evaluation of this conference will help to plan for our 2010 conference and may help to identify opportunities for participation from other countries.

5.3. Survivors: living through and beyond cancer: an Italian study on rehabilitation for cancer patients

Lucia Mangone, Massimo Vicentini, Carlotta Pellegrini, Sonia Cilia, Maria Antonietta Orengo, Paolo Crosignani, Mario Budroni, Fulvio Aurora, Francesco de Lorenzo, Giovanni Fattore, Milena Sant, Gemma Gatta, Francesca Di Salvo, Paolo Baili, Andrea Micheli

Background The proportion of prevalent cases (persons alive on a given date with a past or current cancer experience) in Europe is estimated to be 1-3% of the general population and >10% of the population 65+ years of age. Therefore the role of rehabilitation services in cancer control is expected to increase. According to our estimates, prevalent cases should total about 2 million in Italy in 2010. CaReMoRe (Cancer Registry Model on Rehabilitation) is a three-year Italian project that examines physical, psychological, nutritional and social aspects of rehabilitation in order to provide indicators useful for rehabilitation planning.

Methods Information on 1,800 cases (breast, colon, rectum and lymphoma) provided by five Cancer Registries, representing three different socio-demographic areas in Italy, will be collected and analyzed. Two approaches are planned: a cohort approach (cases diagnosed in 2002 and followed up until 2007) and a period approach (cases diagnosed in 1997-2001 and studied in 2007).

Results In the first year, the Joint Community, consisting of oncologists, epidemiologists, and cancer patient organizations, identified indicators of current rehabili-

tation services, including physical (physiotherapy, reconstruction and complications for breast cancer; stoma, urinary and sexual dysfunction for colorectal cancer); nutritional (information and assistance); psychological (type and duration of assistance); and social (disability benefits and home care) indicators. For breast cancer, indicators of direct (diagnostic and therapeutic tests) and indirect (job loss, demotion and decreased/lost wages) costs were also identified.

Conclusions This will be the first time this kind of information is collected in Italy. Subsequently, we hope to expand this project to other countries by seeking further international collaboration so that we can build a world-wide map of rehabilitation service use and requirement. The results, disaggregated by disease severity and geographical area, may help policymakers plan a budget to develop national rehabilitation services that ensure that cancer survivorship requirements are met adequately and equally.

6. World-wide study of cancer survival (CONCORD); an example of international collaboration

Michel P Coleman

The CONCORD study was originally intended to update the first trans-atlantic comparison of cancer survival (published in 1964) to the 1990s. Other countries rapidly joined and it has become the first study to provide comparable estimates of cancer survival from many countries⁴⁵. It revealed wide international variation in survival, and confirmed the wide gap in survival between blacks and whites across the USA. CONCORD brings together data from 101 population-based registries in 31 countries. For 16 countries, the data covered the entire national population. For other countries, one or more regional cancer registries provided data with national coverage from around 1% to 60%⁴⁵. In all, the base population was almost 300 million. CONCORD presents 5-year relative survival estimates for cancers of the breast (women), colon, rectum and prostate based on almost 2 million cancer patients from around the world. The patients were diagnosed between 1990 and 1994 and followed until 1999. Survival estimates were adjusted for the wide international differences in background mortality and for age. Comparability of the estimates was maximized by centralized quality control with standard criteria, correction of faulty records and a single, centralized analysis⁴⁵. Some 2,800 complete (single-year-of-age) life tables by sex, country/region, year and (in the USA) race were constructed to control for background mortality^{45,46}. Estimates were age-standardized with the International Cancer Survival Standard weights⁴⁷. The highest survival was seen in the USA (breast and prostate cancer), Japan (colon and rectal cancers in men) and France (colon and rectal cancers in women). The lowest survival for each

cancer in both sexes was seen in Algeria. In Australia and Canada, survival was high and regional variations were very small, suggesting widespread access to high standards of health care. In stark contrast, variation between European countries and US states was apparent⁴⁵. Plans are in hand to update CONCORD to 2007, and extend it to additional cancers and other countries. Problems of funding, co-ordination and dissemination in such studies should be considered.

7. Cancer control experiences and collaborations on the epidemiology of cancer in young adults

Although less than 1% of all cancers are diagnosed in the age class 15-24 years, they have a number of characteristics that increase their impact on society: a) the prevalence of adults diagnosed with cancer before the age of 25 is increasing due to improving survival, and to a lesser extent, increasing cancer incidence; b) the risk of second cancers is high in adults surviving cancer diagnosed before the age of 25; c) many cancer survivors diagnosed before the age of 25 experience sequelae in later life that require medical treatment; d) populations differ markedly in cancer survival, implying inequality of access to treatment for diseases in young people which are typically highly curable; e) survival in adolescents/young adults (AYA) is worse than in children with biologically similar cancers, probably because intensive treatment protocols have been mainly developed for children⁴⁸⁻⁵⁷.

The organization of care in AYA is of major interest, because this group of patients is in between childhood and adulthood. Without specific protocols available for AYA, a closer collaboration between pediatric and general oncologists is required for the tumors occurring in AYA.

7.1. Cancer survival differences between European adolescents (15-19 years) and young adults (20-24 years)

Giulia Zigon, Gemma Gatta, Guido Pastore, Andrea Ferrari, Annalisa Trama

Objectives To compare the survival rates between adolescents (15-19 years) and young adults (20-24 years) with cancer diagnosed in Europe during 1995-2002.

Materials and methods Data from 83 population-based cancer registries in 23 European countries involved in EUROCARE-4 were analyzed. 30,187 AYA with cancer diagnosed during 1995-2002 and followed-up to December, 2003 were included in the analysis. Cancers in AYA were classified using both ICCC (International Childhood Cancer Classification) and ICDO-3 (International Classification of Disease for Oncology, 3rd version). Five-year survival rates and 95% confidence intervals were calculated and are shown in Table 1.

Conclusions Survival rates in young adults are worse than in adolescents in most of the cancer sites, particularly for leukemia and central nervous system tumors. The disparities between AYA and children⁵² are also large, likely due to the lack of specific protocols for AYA, while the observed differences between adolescents and young adults are likely due to the more frequent use of the children's intensive treatment protocols in the adolescent group.

7.2. Adolescent cancer in El Salvador

Roberto Franklin Vasquez, Miguel Edgardo Bonilla, Francesca Favini

The incidence and outcome of childhood cancer in high income countries (HIC) is well documented, and there is emerging information from low income countries (LIC). Among adolescents, equivalent incidence and outcome data continue to show distinctive variations between different world regions and ethnic groups. Based on the 2007 national census, which included patients registered in the Pediatric Oncology Network Data Base (POND), and the Surveillance Epidemiology and End Results (SEER) Program incidence estimates for this age group⁵⁸, we estimated the adolescent cancer incidence for that year. One hundred seventy-six new patients with cancer aged 0-14 years were diagnosed in 2007 (96 Acute Leukemias, 19 Central Nervous System Tumors, 11 Hodgkins Lymphoma, 9 Non-Hodgkins Lymphomas, 5 Wilms' Tumors, 3 Neuroblastomas, 5 Retinoblastomas, 7 Soft Tissue Sarcomas, 8 Bone Tumors, 13 other diagnosis); representing 76.5 % (176/230) of the expected cases for a population of 1,946,967. Additionally, during the same period, only 2 new patients between the ages of 15 and 19 years, of 121 cases expected in a population of 600,565, were admitted in the pediatric cancer program.

In El Salvador, children aged 0-14 years, but not those aged 15-19 years, are experiencing the benefits of being treated for cancer in a pediatric setting. Although two thirds of adolescents with cancer usually have a pediatric type of disease, only a limited number of adolescents are treated in the referral pediatric oncology unit; most of them are treated by adult oncologists with no adequate expertise in treating pediatric cancer. These data confirm the necessity of cooperative action between adult and pediatric oncologists to implement a referral system to offer the best treatment for this group of patients.

7.3. Adolescent cancer in Guatemala

Federico Guillermo Antillon-Klussman, Mauricio Castellanos, Patricia Valverde, Claudia Garrido, Francesca Favini, Ronald Barr, Andrea Ferrari

Background Adolescents with cancer in resource-rich countries are in a "gray zone" between Pediatric Oncol-

Table 1 - Five-year survival (%) of European adolescents (15-19 years) and young adults (20-24 years) diagnosed during 1995-2002 with cancers characteristics of this age group

Diagnostic group		Five-year survival (95% CI) 15-19 years		Five-year survival (95% CI) 20-24 years	
ICCC II(a)	Hodgkin lymphomas	93.6	92.0 - 95.1	94.5	93.1 - 95.8
ICCC II(b)	Non-Hodgkin lymphomas	70.9	66.3 - 75.5	75.1	71.3 - 78.8
ICCC I(a)	Lymphoid leukaemias	55.6	50.2 - 61.0	44.8	38.5 - 51.2
ICCC I(b)	Acute myeloid leukaemias	52.7	45.7 - 59.7	47.2	39.8 - 54.6
ICCC X(c)	Germ cell: ovary	94.3	89.5 - 99.0	93.4	88.3 - 98.6
ICCC X(c)	Germ cell: testis	91.9	89.3 - 94.5	95.0	93.8 - 96.1
ICDO-3 C440-C449*	Melanoma of Skin	93.9	91.5 - 96.3	91.9	89.9 - 94.0
ICDO-3 C71*	Brain	65.0	60.2 - 69.8	58.6	54.1 - 63.1
ICCC III(b)	Astrocytomas	62.7	56.0 - 69.5	51.7	45.4 - 58.0
ICDO-3 C40-C41*	Bone	59.1	54.7 - 63.6	62.2	55.6 - 68.7
ICCC VIII(a)	Osteosarcomas	61.1	54.9 - 67.3	58.1 [§]	47.3 - 68.8
ICCC VIII(c)	Ewing tumor	44.0	35.1 - 52.9	41.8	32.3 - 51.4
ICDO-3 C739*	Thyroid carcinomas	99.5	98.8 - 100	99.6	99.3 - 99.9
ICCC IX	Soft tissue sarcomas	64.7	59.6 - 69.8	62.6	57.8 - 67.3
ICDO-3 C53*	Cervix	82.8 [§]	66.5 - 99.0	87.6	82.2 - 93.0
ICCC X(d)	Ovary carcinoma	88.1 [§]	78.9 - 97.4	85.5	79.6 - 91.4
ICDO-3 C18*	Colon	89.8	84.7 - 94.8	82.0 [§]	77.2 - 88.3
ICDO-3 C500-C509*	Breast	84.1 [§]	73.1 - 95.0	80.4	75.2 - 85.7
ICDO-3 C339-C340*	Lung	74.7 [§]	61.0 - 88.3	69.4	59.5 - 79.3

*Morphology-Melanoma of Skin: 8720-8790; brain: excluding 9530-9539 and 9590-9989; bone, thyroid, cervix, colon, breast: excluding 9590-9989; lung: excluding 9590-9989 and 9050-9055.

[§]No cases diagnosed from Eastern Europe (the final survival value is calculated as the weighted sum of Northern Europe, UK and Ireland, Central Europe and Southern Europe).

ICCC, International Childhood Cancer Classification.

ICDO-3, International Classification of Disease for Oncology, 3rd version.

ogy and Adult oncology, and are rarely included in clinical trials. In resource-poor countries the situation might be worse, with most patients lacking access to care; however, little research has been done in this age group.

Methods We analyzed the situation in Guatemala, focusing on the referral pattern at the Unidad Nacional de Oncología Pediátrica (UNOP) in Guatemala City, the only pediatric cancer referral centre in the country, whose mission is to treat patients up to 18 years. In 2008, the population of children (0-14 years) was 5.78 million, and that of adolescents (15-19 years) was 1.5 million (total Guatemalan population 13.7 million).

Results Applying the cancer incidence derived from the North-America Surveillance Epidemiology and End Results (SEER) dataset⁵⁹, we estimated that we would expect 809 cases in the range 0-14 years, and 304 in the range 15-19 years per year. In 2008, we treated 267 children (observed/expected [O/E] ratio: 30%) and only 18 adolescents (O/E: 6%).

Conclusions Though two thirds of adolescents have cancer subtypes typical of pediatric oncology, only 6% of them are treated at UNOP. We believe most are treated by adult oncologists or have no access to care. International collaboration can improve this situation. More active cooperation with adult medical oncologists may be required.

8. Cancer Control: international collaboration on clinical practice guidelines (CPGs)

Susan O'Reilly

Evidence-based clinical practice guidelines are the foundation upon which we build access to high quality cancer control. The scope of guidelines spans prevention, screening, diagnosis, treatment and symptom control.

Guideline development requires, as a minimum, a critical mass of health professionals with enough time and resources to develop guidelines that are not only soundly based on appropriately conducted, well-designed clinical trials, but are also tailored to meet the needs of the population served and the competing goals of provision of various social services, including health care, in the political and fiscal realities in different countries or regions.

In circumstances where health care human resources are insufficient to support buy-in and development of national or local guidelines, cancer systems and staff are well advised to adopt and adapt guidelines developed by respected national or professional bodies in other countries. Examples comprise the National Institute of Clinical Excellence (NICE) guidelines advice in the United Kingdom, the Cochrane Collaboration, the National Comprehensive Cancer Network (NCCN) or the American Society of Clinical Oncology in the USA. A variety of European,

Canadian and Australian practice guidelines are also available. Countries may adopt the guidelines that are best fitted to their means. The adaptation processes, which typically limit access to those therapies or technologies demonstrating the greatest benefit or most cost-effective intervention, are likeliest to be endorsed.

The Guidelines Workshop at the ICC-3 will focus on international collaboration in the adaptation of guidelines and their integration into the broader base of cancer care planning, oncology drug delivery, accessibility and good fiscal management.

8.1. Patient self management for women with breast cancer

Siew-Yim Loh, Cheng Har Yip, Ann Passmore

Patient self management is recognized as a crucial part of medical care for chronic diseases⁶⁰⁻⁶², but it has yet to make an impact in the field of oncology. The aim of this study was to explore, develop and evaluate a 4-week self management program for women with breast cancer.

The study design was guided by the complex intervention framework⁶³ to ensure maximum clinical evidence. Starting from the preclinical phase, a qualitative focus group (n = 39) for needs assessment was conducted, to inform the design of a self management program for women with breast cancer^{64,65}. The program was pilot-tested (n = 6) and refined, and then evaluated using a clinical controlled trial (n = 147). The primary endpoints were quality of life, participation in life, and psychological distress (depression, anxiety and stress). The secondary endpoints were cancer specific self efficacy and proactive coping.

An intent-to-treat analysis using multivariate covariance showed significant differences between the experimental group and control group for limitation in Social-Relationship participation ($P = 0.015$), Stress ($P = 0.001$), Anxiety ($P = 0.003$) and Depression ($P = 0.003$). Significant differences between groups was also found in the Cancer Self-efficacy scales ($P < 0.001$ to $P < 0.002$) as well as in Proactive Coping ($P < 0.001$). Bonferroni corrections were applied on all analyses.

There should be more national as well as international collaboration to develop and promote innovative programs like the 4-week 'SAMA' program (Staying Abreast, Moving Ahead), and to explore their potential for enabling women to self manage their breast cancer and minimizing the range of breast cancer implications on women's quality of life. Strategies to reduce health care utilization should be the focus, as breast cancer is emerging as a new chronic illness, due to earlier detection and better treatment. Patient self management programs may offer a viable option for cancer-care and cancer-control strategies.

8.2. Bridging the gap – linking cancer management with cancer care: the role of the oncology social worker in South Africa

Clare Manicom

Introduction South Africa has several major health care concerns aside from cancer control. Add to this the reality of limited resources, and access to cancer treatment becomes difficult for many. The provision of psychosocial support for patients is therefore almost impossible outside of the private sector.

Objectives This descriptive overview of the contrasting and various roles of Oncology Social Workers in South Africa illustrates the valuable contribution this group of professionals can make to the Psycho-Social care of patients and their families by providing support and respect for the patient as a whole person.

Materials and methods Data was gathered from personal interactions, correspondences and experiences of Oncology Social Workers in various settings. Some of the competition for social workers' energy and attention in various health care settings was examined. This competition can be considered in categories of broader health care concerns, existing social problems, and structural or policy obstacles. The tasks and roles undertaken by Oncology Social Workers were also reviewed, illustrating the need for this group to be flexible, innovative and adaptable in the face of challenges.

Results Interdisciplinary sharing, as well as networking nationally and internationally were beneficial for social workers – all of these linkages can bring together social workers who may feel isolated in their work. The practices and approaches that are helpful and relevant in South Africa were noted.

Conclusion It would be easy to allow daily challenges and frustrations to overwhelm the average practitioner. However, with support, acknowledgement and the respect of clients, colleagues and authorities, it remains within the power of South African oncology social workers to make a meaningful contribution to the overall well-being of cancer patients.

9. Conclusions: ideas for future cancer control international collaborations

A Community of Practice¹⁰, such as the ICC-3, is an ideal place to share new proposals, learn from other experiences, and formulate new ideas. The aim of the ICC-3 is to create the basis for new international collaborations in order to promote cancer control actions in LMCs. We have formulated some ideas for the EU-AU future cancer control collaborations that can be also be considered at the global level.

Palliative care

Late diagnosis of most cancers in LMCs and a lack of treatment options even when diagnosis is early mean

that there are large numbers of patients who can benefit from palliative care in this region. The cornerstone of palliative care is pain control with oral morphine or other strong opioid analgesics. These medications are largely unavailable in LMCs. In addition to medication, palliative care involves a range of other services to relieve and manage symptoms and to provide psychosocial support to patients and families in the communities where they live. The two major obstacles to palliative care in LMCs are (1) legal, societal, and educational barriers to opioid availability; and (2) lack of programs to deliver palliative care at the community level. Because people dying from AIDS require much the same palliative care as do cancer patients, building or adapting organizations to serve both types of patient presents a new set of opportunities.

High Income countries should focus their efforts on international cancer control projects and/or actions with the following goals: (1) to build up a working network in LMCs of training and education programs regarding palliative care; (2) to develop an innovative model applicable in LMCs, which includes training personnel from various backgrounds who can deliver psychosocial services and symptom relief interventions; and (3) to address the issues around palliative care drug availability and national policy for palliative care in LMCs.

Cancer registration

Few LMCs have accurate, recent data about their cancer burden or major risk factors for cancer, consistent with generally poor vital and health statistics. Estimates of cancer incidence and mortality by cancer type, age, and gender have been produced for every country by the International Agency for Research on Cancer (IARC). These estimates are useful for setting initial priorities, but cannot be used to track progress or to define priorities.

LMCs must agree on what areas to monitor and evaluate to assess progress in health; thus common indicators must be agreed upon and developed, based on a realistic minimum package for health interventions. For this to happen, common and standard data sets, disaggregated by gender and age will have to be designed. This will necessitate collection of common datasets across the continents, using the same design and methodologies, in order for scientifically sound analyses and comparisons to be made. Efforts should be concentrated on the improvement of the vital statistics registration systems, epidemiological surveillance, morbidity and mortality registration and resource management information systems. Health workforce monitoring should also be an integral part of the information system¹².

Cancer registries that record cancer cases and outcomes over time — in specific hospitals (clinical registries), or more usefully, in defined geographic areas (population-based registries) — are important for understanding local cancer patterns of those who seek medical attention. Registries require sustained commitments and

trained personnel, which are most feasible in urban areas where diagnosis and treatment are available.

By linking incidence data with vital status databases, population-based cancer registries can also estimate relative survival, an indicator for monitoring countries' performance in cancer control⁵. Moreover, international comparisons of population-based cancer relative survival provide valuable information about cancer outcomes and progress in cancer control for clinicians, patients and policy-makers⁶⁶.

Training and education focusing on primary prevention

It has recently been estimated that in Europe about 50% of the most common cancers could be avoided through interventions directed at reducing smoking, obesity and alcohol use, as well as increasing physical activity and fruit and vegetable intake⁶⁷. In LMCs, where these risk factors are not yet well-known, potentially effective ways of curbing the increasing cancer burden are to take measures to prevent cancer, such as smoking cessation and reducing alcohol consumption, reducing exposure to carcinogens (e.g., asbestos), persuading people to change their eating habits and encouraging physical activity. These prevention strategies are a realistic approach to cancer control plans in those LMCs where other interventional cancer control initiatives are limited or not yet feasible.

Current educational approaches to building interdisciplinary teams to address cancer control tend to be poorly coordinated and not always useful in LMCs. The standard model includes providing support for oncologists from LMCs to attend major cancer meetings in high-income countries, organizing smaller versions of such meetings in LMCs, and providing training in institutions in high-income countries. In each of these situations, the educational content largely addresses the needs of the high-income countries and ignores obstacles blocking progress in LMCs, such as those that arise from a shortage of human and material resources, poverty, illiteracy, and a broad range of cultural issues. Not surprisingly, a substantial fraction of those who undergo formal training in high-income countries do not return home or do so only temporarily. Even when LMCs themselves are able to effectively train health professionals, many of their graduates emigrate to countries able to offer better personal and professional circumstances. Internal disparities compound the problem: urban regions are far better served than rural regions, and the for-profit health-care sector, which tends to expand side-by-side with economic development, serves a small fraction of the population but attracts a high proportion of the available health professionals. In these circumstances, the development of guidelines for best-practice treatment is problematic. Such guidelines tend to be derived largely from evidence obtained in high-income countries, and the presumption of their applicability in low-resource settings might not always be correct.

International efforts should be addressed to better understand the specific needs and focused on defining more concrete projects for providing contextually appropriate cancer training and education in LMCs. This means giving priority to primary prevention, coordinating the project in cooperation with the stakeholders in LMCs. and developing centers of excellence in education and training for ongoing skills development in LMCs.

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