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Organization of population-based cancer control programs: Europe and the World

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

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Abstract

As cancer is to a large extent avoidable and treatable, a cancer control program should be able to reduce mortality and morbidity and improve the quality of life of cancer patients and their families. However, the extent to which the goals of a cancer control program can be achieved will depend on the resource constraints a country faces. Such population-based cancer control plans should prioritize effective interventions and programs that are beneficial to the largest part of the population, and should include activities devoted to prevention, screening and early detection, treatment, palliation and end-of-life care, and rehabilitation.

In order to develop a successful cancer control program, leadership and the relevant stakeholders, including patient organizations, need to be identified early on in the process so that all partners can take ownership and responsibility for the program. Various tools have been developed to aid them in the planning and implementation process. However, countries developing a national cancer control program would benefit from a discussion of different models for planning and delivery of population-based cancer control in settings with differing levels of resource commitment, in order to determine how best to proceed given their current level of commitment, political engagement and resources. As the priority assigned to different components of cancer control will differ depending on available resources and the burden and pattern of cancer, it is important to consider the relative roles of prevention, early detection, diagnosis, treatment, rehabilitation and palliative care in a cancer control program, as well as how to align available resources to meet prioritized needs.

Experiences from countries with differing levels of resources are presented and serve to illustrate the difficulties in developing and implementing cancer control programs, as well as the innovative strategies that are being used to maximize available resources and enhance the quality of care provided to cancer patients around the world.

1. Introduction

The majority of the 25 million people with cancer live in developing countries. As cancer is to a large extent avoidable and treatable, a cancer control program should be able to reduce mortality and morbidity and improve the quality of life of cancer patients and their families. However, the extent to which the goals of a cancer control program can be achieved depends on the resource constraints a country faces. Such population-based cancer control plans should prioritize effective interventions and programs that are beneficial to the largest part of the population, and should include activities devoted to prevention, screening and early detection, treatment, including psychosocial and palliative care, and rehabilitation.

Independent of resources, a national cancer control program (NCCP) will only be effective if it can be implemented, evaluated, and continuously refined[1]. Creating a national cancer control committee specifically devoted to this task is required if available resources are to be used most efficiently and effectively. In many instances, limited resources are largely consumed by expensive drug treatments provided by hospitals and medical specialists in the absence of a well managed and integrated cancer control plan, with negligible impact on reducing the national cancer burden. Rational allocation of systemic therapy utilization and costs is essential within the broader implementation of the plan.

A well organized and managed plan should not be restricted to one domain, but should take an integrated approach with well defined and formulated goals. Although the initiative for developing a publicly-funded comprehensive cancer control program comes primarily from government, subsequent efforts to establish priorities requires input from all the main stakeholders, who should be identified early and included in the process to ensure successful implementation of the plan. However, without dedicated and broadly supported leadership cancer control is impossible. Identification of a steering group and a leader is not only necessary at the start of the program, but also throughout implementation and evaluation. The leadership team should be able to work closely with governmental and non governmental leaders, as well as patients and public (future cancer patients or families of cancer patients), another key stakeholder group in this process. Resources should be allocated to fund the national committee to enable them to appropriately plan and carry out cancer control activities. The level of funding extended to this process will depend on the amount of political will that exists for cancer control.

Although many different partners should be involved in the development, implementation and evaluation of the cancer control program, all have different agendas. Program leadership should determine how to actively engage these partners in the process, so that they can share in the responsibilities, accountability, and recognition. In this way, they will be more likely to collaborate throughout implementation, evaluation and improvement of the cancer control program.

A framework for comprehensive cancer prevention and control developed for the United States was proposed by Abed *et al.*[2] However, all countries are different in their cultures and health care systems, and one framework may not be adequate to fulfill the needs for programs in these different settings. Good examples of other approaches exist, such as top-down NCCPs in China[3] and France[4] as well as bottom-up approaches in Canada[5] and the Netherlands[6]. The Centers for Disease Control and Prevention has developed a useful tool for assisting countries in developing a cancer control program and identifying potential partners once the goals have been defined[7]. In addition, the World Health Organization[8] and Cancer Control PLANET[9] have developed tools to establish NCCPs, defining the problem, identifying stakeholders and advocating for policy development, and the International Union Against Cancer has developed guidelines around cancer control specifically for non-governmental organizations working on this issue in low and middle income countries[9].

Surprisingly, even with such instruments available, most countries are working independently and are not following guidelines when developing their NCCPs. For example, within the Eurocanplus+ project, a comparison of cancer control programs from countries in the European Union found that the approaches to identifying priorities were different and were defined primarily by the most organized and powerful partners that had influence over the content of the program[10].

In summary, countries that are developing a NCCP would benefit from a discussion of different models for planning and delivery of population-based cancer control in order to determine how best to proceed given their current level of commitment, political engagement and resources. Each NCCP will need to prioritize the various components of cancer control, including prevention, early detection and diagnosis, treatment, rehabilitation and palliative care, depending on available resources as well as the burden and pattern of cancer in the country. In addition, the choice of optimal model employed to deliver cancer control activities will need to be determined according to the context of the country, whether it is through specialized cancer facilities, a primary health care system, or both. Successfully providing cancer control services requires teamwork among a broad range of disciplines and experts, particularly for the rarer cancers, and for those occurring among children and adolescents.

2. Stakeholders and coalitions in cancer control

2.1. Integrated non-communicable diseases control and stakeholder coalitions

Robert Burton

Integrated primary prevention programs that target the common behavioral risk factors of the major non-communicable diseases (NCD) make sense worldwide, and is now the World Health Organization's (WHO) preferred approach[11,12]. Some or all of tobacco use, unhealthy nutrition and physical inactivity leading to obesity, and alcohol abuse are shared between all of the following NCD, which accounted for half of the estimated 58 million deaths worldwide in 2005[11]: cardiovascular diseases (17.5 million), cancer (7.6 million), chronic obstructive pulmonary disease (4.1 million) and diabetes (1.2 million). Many countries at all levels of resources are now planning for national chronic disease control, incorporating integrated primary prevention of NCD, as recommended by the WHO. When successfully pursued, together with immunization against infectious cancers, this has the potential to prevent at least one third of all cancers. While effective primary prevention can impact on diabetes incidence and coronary heart disease mortality in a five year time frame, the impact on cancer incidence and mortality usually takes some decades.

For secondary prevention (early diagnosis and screening) for all these NCD, the conceptual framework is the same. A public informed about the early signs of these NCD and willing to self refer for diagnosis and participate in screening and a competent, available, accountable and affordable primary health care system with the certainty of referral to competent, available and affordable diagnostic, medical and surgical treatment resources are necessary for population NCD control at this level. The early warning signs and screening tests may be different for these NCD, but the systems needed to make secondary prevention work for a population, such as screening registers, are the same. This means, at a minimum, working together in the Government, Non-Government (NGO) and health care professional sectors on public and health care professional education and health promotion, with consistent messages and sharing of cash and in-kind resources. Taken together, about 50% of cancer mortality is currently potentially preventable by population-based primary and secondary prevention. Early detection of asymptomatic, pre-clinical cancer, can impact on cancer mortality in a five year time frame, providing accessible and appropriate interventions are available to treat early disease. Consequently, development of these competencies should be a priority for most countries, along with effective palliative, symptom control, and end-of-life services for the majority of patients with clinical cancer who will die of their disease.

Irrespective of resource-setting , control of NCDs, including cancer, is a global challenge. The commonalities of shared risk factors, and the necessity for collaboration, coherent and integrated disease-control planning, common messaging, and resource-pooling across diseases, professionals and stakeholders, will be a necessary consideration for most, if not all, countries.

2.2. Building a grassroots breast cancer movement in Latin America

Alessandra D Durstine, Cristina Parsons Perez

The objective of this paper is to assess and identify the key strengths and weaknesses of breast cancer patient groups in Latin America, with the goal to make recommendations about how to improve their impact on the advocacy movement as it pertains to cancer. The methods included literature reviews, expert interviews and site visits to Latin American cancer hospitals and NGOs. The overall findings were that patient groups currently do not take a leadership role in cancer control in Latin America. The lack of a grassroots survivorship movement, faulty patient information services and failure of the government to include patient groups in policy creation were identified as areas for further project work and collaboration. The stigma of cancer still remains and a burgeoning patient movement can be created to help de-stigmatize and debunk the myths that surround cancer[13-15].

2.3. Building partnerships and momentum through focus and impact

Leanne Kitchen Clarke, Jessica Hill

The Canadian Partnership Against Cancer was created by the federal government as an independent, arms' length corporation with a five year mandate to implement the Canadian Strategy for Cancer Control (CSCC). The CSCC was the result of more than a decade of work by over 700 cancer control stakeholders. Our shared goals are to prevent the number of Canadians from developing cancer, reducing mortality of those diagnosed with cancer, and improving the quality of life for those affected by cancer. The goals of the strategy are shared by many organizations, governments, NGOs, patients, survivors and their families, and the Partnership. The Partnership brought focus to the strategy and defined strategic initiatives that could be advanced within the first five years of its mandate and where tangible outcomes and impact could be achieved[16]. The work is advanced through pan-Canadian networks representing the numerous stakeholders in cancer control, including the patient voice. Our work spans all priority areas of cancer control and takes a whole population approach. We are also working on foundational aspects to support a system-based approach that leverages existing resources in the cancer and health systems. We are establishing platforms in quality and system performance along with our partners, and have developed targets to 2012 for our initiatives. We have convened and created networks across the country to develop a coherent plan for cancer control implementation within a federated health system but outside government. In less than two years we have advanced numerous initiatives including Canada's largest population health study of risk and protective factors in cancer and chronic disease. We will be launching Canada's first comprehensive online portal that serves as a gateway to cancer control. We work with and through partners to create shared ownership of priorities to accelerate action on cancer control.

2.4. National cancer control planning in Jordan

Fadwa Ali Attiga, Rabab Diab, Sami Khatib, Taghreed Nusairat, Nour Ali Obeidat

Jordan, a middle-income country of 6 million in the Middle East, is facing its cancer-related challenges on a national level. Currently, cancer patients receive care in either public or private general hospitals, or in one comprehensive cancer-treatment center. However, National Cancer Registry estimates indicate that the number of new cases is increasing every year[17], and that cases are mostly presenting at late stages. Healthcare spending has burgeoned as the government continues to cover cancer services for all Jordanian patients, and the country's limited funding resources has led to inequitable access to care. Moreover, the insufficient investment in data information systems has made evidence-based decision-making about the quality, value and projected sustainability of cancer care difficult. To address these challenges, King Hussein Institute for Biotechnology and Cancer (KHIBC) is assisting the Ministry of Health with the development of the first National Cancer Control Plan. Relevant stakeholders in the healthcare sector convened in a workshop along with international partners (American Cancer Society-ACS, International Agency for Research on Cancer-IARC, International Atomic Energy Agency-IAEA, National Cancer Institute-NCI and World Health Organization-WHO) experienced in national cancer control planning. Four working groups were established: primary prevention; screening/early diagnosis; treatment; and palliative care. An overview of the current status of cancer was provided, and the major challenges were identified. The lack of healthcare data management systems about cancer care prohibited the generation of evidence-based and applicable recommendations. Therefore, a gap analysis map was formulated, and a second stakeholder meeting is planned for the second half of 2009, to charge working groups with the tasks needed to bridge the gap. A steering committee will oversee the data analysis to formulate an evidence-based action plan to be included in the national cancer control program. Continued involvement of relevant stakeholders will contribute to buy-in for further planning and implementation. Successful planning to strengthen existing cancer services and increase their efficiency, and to monitor service performance, will contribute to sustainable and outcomes-oriented cancer control activities in Jordan.

3. Supportive and palliative care

Across the nations of the world, approximately one-half to two-thirds of patients with cancer die of their disease. This reflects the reality that the majority of patients in low and middle income countries present with advanced disease with limited access or opportunity to benefit from potentially curative or palliative interventions. The needs for symptom control, support -both individual and for care-givers - and the opportunity to have life end with compassion and dignity are a universal expectation. Accordingly, supportive and palliative care are a fundamental element of a cancer control program, recognizing that such care is most often required and provided within the home or community setting. To this end, a strong network of appropriately trained personnel must exist across the home, community, hospice and hospital setting, and be integrated within the health care system to achieve coordinated care across the trajectory of illness. Such capabilities have the potential to be developed to enable other aspects of cancer control within a family and community setting, e.g., risk factor management, early detection enrollment etc.

4. Primary care systems

Cancer control is an activity that extends from birth to death, and is intended to impact incidence, mortality and quality of life. The majority of activities of cancer control (risk factor management, early detection, diagnosis and investigation of disease extent, follow-up, survivorship, palliation and end of life care) take place within a family and community setting. Indeed, while the management of acute and chronic cancer treatment may involve specialized facilities/centers, the vast majority of care is within the community. The role of primary care health professionals, including the general medical practitioner, as key educators, informants, guides (“navigators”), supports and providers of care, is paramount. Indeed, for population-based cancer control programs to be effective, they must function across health, healthy living and illness, and engage both care and treatment. The integration of primary care into cancer control program design and execution is a key and necessary component. In addition, public and patient engagement as a means of determining priorities, expectations, implementation, and broad stakeholder support (including NGOs and governments) is an increasingly recognized element of population-based health care.

4.1. Intervention in the use smokeless tobacco of rural Indian population as a measure to control oral cancer

Mira Brij Aghi

Objective To reduce the use of chewing tobacco in rural populations in India

Background The use of smokeless tobacco (ST) is very common in India. The most common practice is chewing betel quid or one of its variants. Almost all users of betel quid use it with tobacco.

Method In a house-to-house screening survey conducted in three rural Indian districts, we interviewed tobacco users aged 15 years and above. The interviewees were asked about their tobacco habit(s) and history of use, including how the habit was formed, what made them continue using and what would make them give it up. Investigations revealed that the population had almost no knowledge of the ill effects of tobacco on health. In fact, they believed that it had healing powers. To reduce tobacco use, we educated them using participatory- and user-driven approaches, in a one-to-one as well as a group mode. The information was reinforced with visual aids and we highlighted the association of chewing tobacco with oral pre-cancerous lesions and oral cancer. The advantages and disadvantages of giving up the habit were explained, along with individualized ways of quitting the habit. Information on withdrawal symptoms and their effective management was also provided. Those who gave up the habit were motivated to stay away from it and to act as leaders to help others in giving up the use of tobacco.

Results Two measurements were done to assess complete cessation and reduction for all types of tobacco use - smoking as well as smokeless. Reductions were observed for both types.

Conclusion We found that educating rural populations and providing them with the knowledge and support to cease using tobacco can lead to health benefits[18,19].

4.2. The British Columbia Patient Navigation Model (BC PNM): a health care broker application to the breast cancer treatment decision making process

Allison E Pedersen, Thomas F Hack

The topic of oncology patient navigation has generated a ground swell of activity as many North American health care programs strive to provide efficient, streamlined care[20-23]. The psychosocial impact of a cancer diagnosis is multifaceted for each patient and their family. The BC PNM is a practical model developed from a psychosocial perspective in response to the demands for evidence based literature that supports the navigation role in practice[22]. The model expounds the navigator’s role, while identifying health care system gaps, and patient and family needs[24]. It also illustrates the potential outcomes of navigation including improved patient emotional and informational preparedness for treatment and post treatment coping[24]. The purpose of this study is to demonstrate the application of the BC PNM to the treatment decision making process for patients newly diagnosed with breast cancer. The treatment decision making process occurs during a time that has been scientifically identified as a period of high anxiety and uncertainty for patients and their families[23,25,26]. The BC PNM contains four key concepts: readiness to move from emotional coping to problem solving, confidence and hope, social support, and patient preferences[24]. These concepts elucidate the numerous psychosocial aspects that contribute to the oncology patient navigator’s goal of facilitating patient preparedness. The BC PNM is parsimonious, contributing to its overall ease of use, flexible to the health care context, and generalizable to other domains of health care. This model is a recent development therefore supplementary literature does not exist to support the model's reliability and validity. The BC PNM illustrates the integral components of the oncology patient navigator and identifies targeted phases along the illness trajectory. These phases are referred to as systemic health care gaps where navigation services would be most beneficial.

5. Organization of diagnostic and treatment services

Within the domain of diagnostic and treatment services, the initiatives and best practices that countries are able to implement vary from one context to another. The examples presented here can serve to illustrate different cancer service delivery models and highlight what can be done with different levels of resources, as well as how countries are able to build leadership, motivation, and multidisciplinary collaborations around cancer diagnosis and treatment.

5.1. IAEA/PACT model for building self-sustaining cancer cure and care capacity in developing countries

Massoud Samiei

Background The International Atomic Energy Agency's Program of Action for Cancer Therapy (IAEA/PACT) was created in 2004 to help place cancer on the global health agenda and attract new funding to enable low-resource countries to provide equitable cancer cure and care and improve cancer survival[27-29]. PACT works through public-private partnerships, including WHO, its Regional Offices, (WHO-IAEA Joint Program on Cancer Control was signed in February) and 20 other organizations.

Method PACT is implementing an overlapping three pronged strategy: 1) imPACT Reviews: provides a multi-stakeholder assessment of a country's cancer burden and cancer control capacity, identifies priority needs for targeted assistance, and advises on the national cancer control program. All imPACT Reviews are performed in cooperation with the requesting government, WHO, and PACT partners; 2) PACT Model Demonstration Sites (PMDS): Six countries – Albania, Nicaragua, Sri Lanka, Tanzania, Vietnam and Yemen – are serving as initial sites. Each of the PMDS presents funding opportunities with well-defined projects designed to respond effectively to priority cancer control needs; and 3) Regional Cancer Training Networks: The goal is for each regional center to become a "hub of excellence", helping countries in the region to share mentorship, resources and knowledge. Education and training would be accelerated using distance learning and e-communication tools, augmented by South-South and North-South collaborations.

Results PACT partnership has raised awareness about cancer through 5 policy-level events, mobilized $23 million for PMDS, and advocated for inclusion of cancer in the Millennium Development Goals (MDGs). PACT and partners have facilitated the development of cancer control plans; the establishment of National Cancer Control Steering Committees in all six PMDS; and e-training of over 400 health professionals from low-resource countries. Following assessment of the PMDS, the IAEA/PACT model may be replicated successfully in other low-resource countries.

5.2. Population-based breast cancer screening in Podlaskie Voivodship (Poland)

Katarzyna Maria Maksimowicz

Background Population-based breast cancer screening is one of the objectives of Poland's National Cancer Plan activated in 2006[30]. Screening based on personal invitations for mammography every two years for women aged 50-69, regardless of their health insurance, was implemented. Nation-wide screening is provided by 16 Voivodship Coordination Centers (WOK) acting under the supervision of the Central Coordination Center, and is carried out by health care providers selected by the National Health Fund (NFZ). The project has suffered from low attendance, and therefore the systems of delivering invitations and education campaigns are constantly being modified. In 2009, the system for delivering invitations was transferred from the NFZ to the WOKs at the regional level. In Podlaskie, 67,490, 69,081 and 70,867 women were in the target age groups in 2007, 2008, and 2009, respectively.

Objectives To calculate the attendance rate in the breast cancer screening program by age group in Podlaskie between January 1, 2007 and May 31, 2009.

Methods The number of women that participated in the screening program was calculated from a database designed for monitoring and was summarized by 5-years age groups.

Results In 2007, 28,867 (43%) women were screened, 22% of whom had been invited to participate. In 2008, 28,985 (42%) women were screened, 20% of whom had been invited. In 2009 (January-May), 13,841 (20%) women were screened. The predicted coverage for the year 2009 is 48%. The majority of women participating in the screening program were 50-54 years old (34%). The proportion of women in older age groups was 29%, 20% and 17% among women aged 55-59 years, 60-64 years and 65-69 years, respectively.

Conclusions In the first years of the screening program participation was low. The majority of screening tests were performed for women who attended without invitation. We expect that by modifying the program to provide invitations at the regional level, deliver screening activities by nurses, and improve education campaigns, participation in the program will increase. In particular, actions ought to be intensified in older age groups where participation in screening is lower.

5.3. Communities of Practice (CoPs): what contributes to their effectiveness for implementing cancer control strategies

Barbare Poole, Colene Bentley, George Browman

Background Canadian cancer control faces two ongoing challenges: 1) to coordinate a pan-Canadian approach across complex provincial jurisdictions; and 2) to facilitate the *rapid translation* of knowledge into clinical practice and policy. Kerner hypothesizes models that integrate explicit knowledge from research with tacit (experiential) knowledge may be effective for knowledge translation[31]. Wenger's community of practice (CoP) presents one such model[32].

Purpose Using social network analysis derived from detailed notes, surveys and personal interviews we explored how the structure and functioning of CoPs impacts knowledge translation among health professionals across organizational/geographic frontiers.

Methods Two pan-Canadian CoPs (A and B) were purposefully selected from a project to adapt clinical guidelines in cancer control. The attributes of members included professional designation, organization affiliation, and province. The forums for knowledge translation included both synchronous (face to face meetings, teleconferences, videolinks) and asynchronous (emails, written correspondence) interactions conducted over 12 months.

Results The two groups have distinct structures – notably the composition of the core and periphery – and rely on different types of interaction. Group A interacts mainly through asynchronous means with a small core group. Group B uses considerably more synchronous interaction with a larger and denser core group.

Implications With limited interaction with the periphery, Group A varies from the Wenger model of CoP. This structure and reliance on asynchronous interaction created bottlenecks for knowledge translation. Group B exhibits the more diffuse interactions expected of a CoP, but presented other challenges for knowledge translation.

Conclusion Understanding both the structure and means of interaction can assist in identifying facilitators and barriers to successful knowledge translation and professional learning within collaborative communities.

5.4. The cancer patients' perspective on follow-up in Danish health care

Janne Lehmann Knudsen

Introduction Approximately 38,000 patients participate every year in a follow-up program after treatment for cancer. The clinical outcome and fulfillment of patient needs is not known. These facts, combined with patients' spontaneous reporting to the Cancer Association about problematical issues, was the reason for conducting a patient survey in April 2009.

Objective To identify cancer patients' experiences with the follow-up program and their priorities in relation to specific elements of the program.

Method A questionnaire was developed and distributed through 6 disease specific patient associations. It addressed questions about demographic characteristics (age, gender and disease), experiences with the program (plan of care, intervention modalities, information, and details from the last control), and patient priorities.

Results 924 patients responded; 65% women and 35% men. Patients with breast cancer (n = 290), myelomatosis (n = 168) or prostate cancer (n = 156) represented the biggest groups.

Examinations during the follow-up program were not in agreement with patients' assessment of the importance of cancer recurrence and metastases. Only 30% of patients were examined for side effects and 17% for late sequelae of treatment, but 77% and 85%, respectively, regarded such examinations as important. Gender differences regarding support from the health care system and reaction to symptoms between follow-up consultations, including contact with general practitioners, were noted.

Conclusion The survey indicates discrepancy between patient priorities and what is provided by the health care system. The routines and organization need to be critically revised and adjusted at the national level to ensure that patients with the same needs are offered the same quality of services. The results emphasize the need for clear objectives and patient involvement to ensure fulfillment of patient needs.

5.5. Multidisciplinary Tumor Groups as an organizing paradigm for improving cancer outcomes and promoting translational research

Leigh J Passman, Simon Sutcliffe, Luiz A Maltoni

Most cancer institutions or services are organized according to clinical departments, corresponding to medical specialties, and basic science research departments. Such traditional organizational structures tend to isolate basic scientists from their clinical counterparts and even segregate medical specialists.

Similarly, public health and health care services administrators tend to oversee clinical departments (radiology, surgery, clinical oncology, pharmacy, anatomic pathology, laboratory and molecular biology, radiation oncology) without an integrated perspective as to how patients (and their tissue specimens) transit among various departments, or how their demographic, clinical, pathology, and outcome information, if consolidated, might inform cancer surveillance and treatment response, survival, and cost-effectiveness analyses.

This presentation will describe how two organizations in Canada and Brazil are using Multidisciplinary Tumor Groups (MTGs) as an organizing paradigm for improving cancer outcomes and promoting translational research. The British Columbia Cancer Agency (BCCA) has more than 10 years of experience with MTGs. Brazil's Instituto Nacional de Cancer (INCA) is implementing tumor groups, drawing from BCCA's experience and adapting the model to its own reality.

At BCCA, multidisciplinary Tumor Groups for specific topographic sites (Breast, Lung, Head & Neck) or types of cancer (Lymphoma, Pediatric tumors) draw members from clinical services (radiology, surgical oncology, nursing, anatomic and molecular pathology, clinical oncology, radiation oncology, medical genetics, palliative medicine), researchers (in the areas of cellular and molecular biology, genome sciences, and bioinformatics), epidemiologists, economists, and public health program coordinators responsible for population-based cancer surveillance and registries, prevention and cancer screening programs, health services, health economics and cost-effectiveness research[33].

Within a BCCA-INCA collaboration, BCCA leaders are mentoring INCA colleagues about MTG composition, processes, and products, and are accompanying INCA's fledgling efforts.

5.6. Two years of experience with the national population-based cervical cancer screening program in Poland

Marek Spaczynski, Agata Karowicz-Bilinska, Ewa Nowak-Markwitz

Background The plan for the National Population-Based Cervical Cancer Screening Program (NPCCSP) in Poland was developed between 2005 and 2006 and the program was initiated in 2007. The NPCCSP was designed to target women between 25 and 59 years of age. Women were individually identified and personally invited to undergo screening with Pap tests, as recommended every 3 years. Monitoring and management of the NPCCSP (mailing, attendance rate, Pap test results registration) is conducted by an interactive database – The System of Information Monitoring in Prophylaxis (SIMP), which connects gynecological practices and histopathology labs participating in the NPCCSP, 16 Regional Centers and the main supervising NPCCSP Center located in Poznan. Further diagnostic procedures are recommended in the case of positive Pap test results.

Method The target population consists of 9.5 million women and each year approximately 3.2 million Pap tests are estimated to be performed. We analyzed the NPCCSP participation rate and Pap test results in 2007 and 2008. SIMP database information was used to calculate and perform the statistical analysis. Pap smears were assessed using the Bethesda system.

Results In 2007 and 2008, 686,623 (21.10% of the target population) and 795,891 (24.43%) women participated in the NPCCSP, respectively. An increasing number of gynecological practices took part in the NPCCSP, increasing from 1,226 in 2007 to 2,357 in 2008. Among all women undergoing screening in 2007 and 2008, 2.36% and 2.50% had positive Pap test results.

Conclusions We observed a very low response rate to personal invitations for screening, potentially indicating poor health awareness among Polish women. We also noted a low rate of positive Pap test results, which may indicate that a larger proportion of women with a history of normal Pap tests responded to the invitations for screening.

5.7. Developing an interdisciplinary program to improve integrated care and quality of life of cancer patients

Doris Schopper, Nadia Fucina

One of the objectives of the Swiss NCCP 2005-2010 is to ensure patient-centered high-quality treatment and care[34,35]. This also implies that patients are given the opportunity to participate substantially in decisions regarding their cancer treatment. As health care is highly decentralized in Switzerland (being the prerogative of the cantons), there are no accepted standards for cancer-specific structures and no central decision making body that could mandate implementation of this objective.

Stimulated by the NCCP, one of the five University hospitals (CHUV, Lausanne) decided to implement the recommendation of the NCCP and to launch an interdisciplinary, hospital-wide program to improve integrated care and quality of life of cancer patients. The program was developed in 2006 in a large consensus-building process involving approximately 100 professionals and 40 cancer patients. Four main themes emerged: improving communication with the patient, particularly when breaking bad news; ensuring coherent and appropriate information at all stages of the disease process; expanding psychosocial support; and enhancing physical well-being[36]. Since mid-2007 various actions have been conceptualized (Figure 1), agreed upon by all stakeholders and implemented in a pilot phase. Patients continue to be regarded as experts in all phases of the program. Their involvement has proven crucial to legitimize the need for improved and new services, to ensure the appropriateness of services developed and to gain political support.

The main challenges in the coming years are to integrate this new approach throughout the hospital and to ensure its sustainability in a changing health care environment.

5.8. The use of communication tools to increase the Brazilian Marrow Donor Registry – REDOME

Daniela Cunha Rangel

Background In 2004, INCA began a project to stimulate donor centers to begin mobilizing bone marrow donors in the country. At that time, the Brazilian Marrow Donor Registry (REDOME) had 60,000 donors. In Brazil, the donor centers are public institutions and they have the responsibility of registering the marrow donors. INCA coordinates this work and is responsible for the match between donors and patients.

Methods The project was carried out throughout the country, and was a collaborative effort between INCA, donor centers, health secretaries, non-governmental organizations, laboratories, companies and hospitals. First, it was necessary to mobilize the different partners and get them to work towards the common goal of rapidly increasing the number of the donors. Working in partnership, many campaigns were held in different states of Brazil and it was possible to mobilize the community by disseminating information about the process of becoming a donor. Since 2006, the project entered into a second phase, with the goals of maintaining good relationships with the professionals involved in bone marrow donation and getting in touch with registered donors to ensure continued commitment to bone marrow donation. In order to fulfill these objectives, INCA created many communication tools, such as folders, posters, videos and a donor card.

Results The donor centers are currently carrying out mobilization activities throughout the country. Approximately 15,000 new donors are registered each month and, in May 2008, REDOME reached a total of one million donors. More than 140,000 cards were sent to people who were registered as bone marrow donors between November, 2008 and February, 2009.

6. Organization (priorities) for aligning resource and capacity (including alternate care delivery models)

An important area in developing cancer control programs is how to coordinate and integrate planning to address population needs and the capacity for cancer

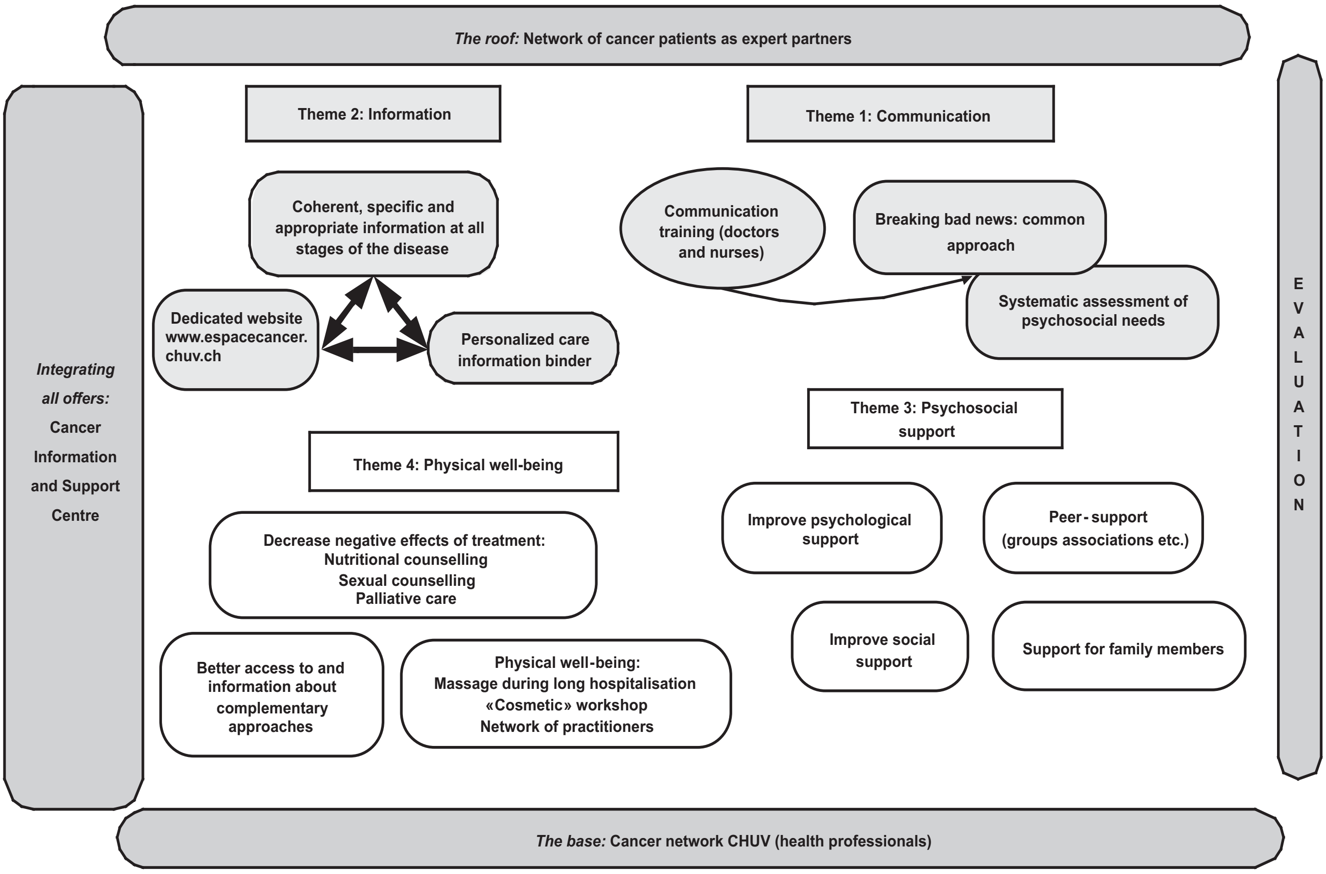

Figure 1 - Interdisciplinary program to improve integrated care and quality of life of cancer patients.

control services, and how this is integrated with capital planning (facilities, equipment, etc), operational planning (human support and operating budgets), and workforce planning (health professionals). The following examples illustrate how contextual pressures within different resource settings can determine which models for cancer control planning are used.

6.1. The Canadian Partnership Against Cancer service delivery models project: optimizing the use of human resources through innovation

Christine Da Prat, Muneerah Kassam

Ensuring an adequate and appropriate complement of human resources (HR) dedicated to cancer is a key issue facing the cancer control system in Canada and around the world. Cancer statistics indicate that as the Canadian population continues to grow and age, the number of new cancer cases and deaths will increase steadily. Advances in research, technology and treatment are improving survival rates of people living with cancer, but also increasing demands placed on the cancer system. In contrast, the supply of healthcare workers needed and available to treat those diagnosed with, living with and dying of cancer is inadequate. Adjusting supply levels to match demand is not enough to address the growing complexity and technological advances imposed on the cancer control system. Rather, innovative methods of service delivery which, for example, optimize available HR and expand HR competencies, are required to build capacity of the cancer control system in Canada and address its HR concerns and crises. This is the focus of the Service Delivery Models (SDM) Project, which is expected to be complete in October, 2009. Its purpose is to better understand and promote the application of leading and innovative SDM that can be shown to be effective in overcoming existing and future HR challenges faced by the cancer control system. Two hundred innovative SDM from Canada and the international domain are being collected and described using a framework that enables comprehensive comparisons between models in areas such as: work team configurations, service delivery effectiveness, implications for future workforce requirements, and viability for adoption across jurisdictions and population groups. Model descriptions will be accessible online through CancerViewCanada. The findings from this research will help to address improving access to primary cancer care in hard-to-access regions and populations, gaps in service delivery, implications for further exploration of SDM, and the potential to expand or adopt models across jurisdictions and countries.

6.2. Training of school teachers to become counselors in cancer prevention in Lima, Peru, 2008-2009

Abel Limache-García, Katia Amaro-Llanos

Cancer is the most important public health problem in Peru and is ranked as the second most common cause of mortality. The most common types of cancer in Peru are cervical, breast, stomach, lung and prostate cancer[37], which can all be prevented and/or detected earlier if the population, especially in the younger age groups, are well-informed.

For this reason, over the last year we have organized 8 workshops for school teachers with the general objective of consolidating and strengthening cancer prevention and promoting healthy lifestyles through the development of a strategic alliance between the Sector Education and the National Institute of Neoplastic Diseases. The specific objectives of the project were:

1. Principals and teachers should raise awareness on issues related to cancer prevention and the promotion of healthy lifestyles, including the health effects of consuming of snuff and the benefits of healthy diets and physical activity[38].
2. Create an active network of teachers and tutors in cancer prevention and provide them with regular updates on issues relating to cancer prevention.

Currently, we have more than 2,000 teachers who are trained as cancer prevention counselors in 9 districts of Peru. They have basic knowledge on cancer prevention and healthy lifestyles, receive regular updates, and can disseminate knowledge on cancer prevention issues to students, children, young people and their coworkers[39].

During the training, counselors are provided with information on the National Plan for Cancer Control in Peru, how to prevent the five most common malignancies in the country, tobacco control, cancer and diet, and physical activity and cancer. With our help, 550 teachers organized and created "The Teachers-Counselors on Cancer Prevention" during the last training workshop.

6.3. The role of cancer information services in cancer control

Monika Preszly, Chris Thomsen

Throughout the world, there is growing interest in people assuming more responsibility for and involvement in their own health and having information that will enable them to understand how to maintain a healthy lifestyle, manage disease, and achieve quality of life during illness. A survey in 10 European Union states identified the need for “accurate, relevant and comprehensive information for patients and their caregivers to help them make informed decisions about treatment.” Cancer Information Services (CIS) provide this information via telephone, e-mail, Internet and media. Despite differences in culture, financing, and resources, CIS programs provide tailored, quality information and counseling free of charge. The International Cancer Information Service Group (ICISG) is a worldwide network that promotes collaborations, assists organizations to develop a CIS, and is a forum for exchange of best practices, thus strengthening the role of CIS in cancer control[40].

In Europe, 27 CIS programs are operating in 25 countries. In 2009, the German CIS surveyed the cancer information and communication needs of Europeans to determine how to meet these needs. Results from more than 250,000 inquiries answered in 2008 show the need for trustworthy, evidence-based, personalized information. ICISG has developed a European action plan to improve cancer knowledge for the European public, cancer patients and their families. This plan is adaptable to other countries and ICISG can provide technical assistance.

CIS programs are important components in cancer control. They disseminate information and can be used to determine users' needs and gaps in prevention, treatment, and care. This information contributes to health care policies, national cancer plans, and public health action. CIS programs can be national reference centers for cancer information and contribute to cancer control plans. An international network fosters collaboration and quality services.

6.4. Importance of voluntary work to an oncology center

Jose Getulio Martins Segalla, Rute Maria Martins Capra, Claudia Luciana de Araújo Veneziano, Donaldo Botelho Veneziano, Ana Lúcia Coradazzi, Paulo Eduardo de Abreu Machado

Objective To determine whether having an active network of volunteers to support cancer patients has an impact on cancer outcomes. Hospital Amaral Carvalho (HAC), in Brazil, has a volunteer network that covers 86 cities and 60% of new registered patients[41]. Volunteers provide information about basic care, prevention and early diagnosis for cancer. They also facilitate patients' access to diagnostic tests and provide transportation for them to the hospital.

Methodology Registered patients[42] from Hospital Amaral Carvalho, diagnosed in 1998, 2003 and 2005, were classified into two groups: patients from cities with volunteers (A) and those from cities without volunteers (B). Patients were classified by clinical stage at diagnosis[43,44].

Results In 1998, patients in group A presented in earlier stages of disease than patients in group B (respectively, 3.9% and 2.6% for stage 0, 27.7% and 19.7% for stage I). In 2003 and 2005, an increased incidence of stages 0, I and II, and a decreased number of advanced disease (stages III and IV) was observed, but differences between group A and group B remained the same. Using five-year survival estimates[45] from patients treated at HAC between 1999 and 2002 (85.7% for stage 0, 72.6% for stage I, 62.3% for stage II, 37.2% for stage III and 11.5% for stage IV), five-year survival according to clinical stage was estimated for patients diagnosed in 2005. The estimated five-year survival was 54.0% for group A and 48.4% for group B, indicating a significant advantage for those patients with access to the network of volunteers.

Conclusion Active volunteer networks may have a significant impact on early diagnosis of cancer, which may result in better long term survival for cancer patients who receive support from voluntary organizations.

7. Pediatric oncology

Within a cancer control program, less frequent cancers or cancers in a particular segment of the population may require specific knowledge, experience, technology and facilities, as well as collaboration between different disciplines and experts. The ability of a program to accommodate special groups and to provide quality care will depend on the availability of both human and technical capacity. Pediatric oncology is one such example. While pediatric cancers represent a small fraction of cancers in all geographic settings, they represent a larger fraction of cancers in low and middle income countries, with an estimated 80% of pediatric cancers occurring in these regions. This difference can be attributed to differing population structures, with low and middle income countries tending to have younger populations, and patterns of cancers. From experiences in high-income countries, an estimated 70-80% of pediatric cancers have the potential to be cured. However, results are poorer in low and middle income countries, where the needs of cancer patients suffering from relatively rare cancers are not often met.

7.1. Attitudes and practices of Canadian pediatric and adult cancer treatment centers regarding care of adolescent and young adult (AYA) patients

Paul Charles Rogers, Raveena Ramphal, Annette Penney, Sonja DePauw, Ronald Barr

The needs of adolescents (ages 15-19) and young adults (ages 20-29), AYA, with cancer are being poorly met by the conventional pediatric and adult health systems. The small number of cancers in AYA does not represent this group's personal and societal costs, as reflected in potential years of life lost[46]. The Canadian Partnership Against Cancer (CPAC) and the consortium of Canadian pediatric oncology centers (C17) have formed a Task Force whose mission is to ensure that AYA with cancer and AYA cancer survivors have prompt, equitable access to the best care, and to establish and support research to identify how health outcomes and quality of life can be optimized for this group. The first of 6 objectives is to document care for approximately 2000 AYA diagnosed with cancer annually, in a survey of all pediatric (n = 16) and adult (n = 51) cancer treatment facilities in Canada. Surveys have been completed by all pediatric centers. The most common AYA collaborative initiative at pediatric and adult facilities is a care transition program. Mean, minimum, and maximum upper age limits at pediatric centers are 18.3, 17.0, and 22.0 years, respectively, and mean, minimum, maximum lower age limits at adult centers are 17.0, 16.0, and 18.0 years, respectively. At the pediatric centers, patients almost always complete active treatment at the pediatric facility even if they reach the upper age limit, and are usually transferred to an adult facility if they relapse "over age". They are usually treated at the pediatric facility in consultation with adult specialists if diagnosed with adult type cancers such as melanoma or carcinomas. At least 30% of adult centers, when treating AYA with "pediatric" cancers, rated the following factors as "very important" or "somewhat important": lack of experience of medical oncologists, pathologists, surgeons, radiologists and pharmacists in dealing with these diseases, and little access to pediatric specialists.

8. Conclusions

The experiences from countries with differing levels of available resources illustrate that it is not an easy task to develop and implement a cancer control program or any of its components. It requires dedicated and accepted leadership for ongoing commitment from all the main stakeholders, who must be willing to change and adapt to new circumstances. As there are many players at different levels of health care, a stepwise and systematic approach to program implementation should be considered. Partnerships, including cancer patient associations, can enhance the effectiveness of the cancer control program, and ownership and mutual recognition and respect can lead to successful integration and implementation of the program into the existing health care system.

Before initiating or evaluating a cancer control program, being well informed about the best practices and methods, as well as the critical factors affecting implementation in different settings, is essential. Throughout the process, all those involved in cancer control programs should never forget their main goals: *reducing the incidence and mortality of cancer and improving the quality of life of all cancer patients.*

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