4th INTERNATIONAL CANCER CONTROL CONGRESS

Knowledge Exchange -Translating Research into Practice and Policy

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Abstract

    Substantial differences in population-based cancer control outcomes exist within and between nations. Optimal outcomes derive from 'what we know', 'what we apply in practice', and 'how complete and compliant is the population uptake of public health and clinical practice change'. This continuum of research (scientific discovery) to practice (application and uptake) to policy impacts the speed and completeness of practice change and is greatly influenced by the ability, opportunity and readiness of countries to implement evidence informed practices and policies through innovative change. Session 4 of the 4th International Cancer Control Congress focused on knowledge exchange through three plenary presentations and five interactive workshop discussions: 1) the role of epidemiological data as a basis for policy formulation; 2) existing global frameworks for cancer control; 3) knowledge exchange as it relates to public health practice and policy; 4) knowledge exchange in relation to primary, community, and specialist cancer care; and 5) the role of public engagement and advocacy in influencing cancer control policy. Common themes emerging from workshop discussions included the recognition of the importance of knowledge exchange processes, constituents and forums as key aspects of preparedness, awareness and readiness to implement public health and clinical practice change. The importance of cultural and contextual differences between nations was identified as a challenge requiring development of tools for generating relevant population/societal data (e.g., projection methodologies applied to population demographics, outcomes and resources, both societal, human and fiscal) and capacity building for facilitating knowledge transfer and exchange between the constituencies engaged in population-based public health practice and clinically based primary care and disease specialty practice exchange (researchers, health practitioners, health administrators, politicians, patients and families, and the private and public sectors). Understanding patient and public engagement advocacy and its role in influencing health and public policy investment priorities emerged as a critical and fundamental aspect of successful implementation of evidence-informed cancer control change.

Keywords: Cancer control - knowledge transfer - knowledge exchange - knowledge dissemination - implementation (science) public health - health policy - public engagement and advocacy

Introduction

    Comprehensive cancer control is defined as an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality across the cancer control continuum from primary prevention to end-of life care (Kerner, Cazap et al. 2009). The stakeholders in comprehensive cancer control include:

    1) Basic and epidemiological researchers who look to identify risk factors and study the circumstances that alter the risk of developing and dying from cancer;

    2) Public health, clinical, and health services researchers who study how to reduce the risks of developing and dying from cancer and the systems that influence the costs of and opportunities for cancer prevention, early detection, diagnosis and treatment;

    3) Clinical and social scientists who study how to limit the side effects of the disease, its diagnosis and treatment, and how to improve the quality of life of patients and their families;

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4) Public health practitioners developing, implementing and evaluating health promotion, cancer prevention, and screening promotion program activities targeted to the population;

5) Primary care and oncology-specialty clinicians who focus on identifying high risk patients, and implementing clinical prevention, early detection, diagnostic and treatment interventions within the clinical care settings in which they see patients and deliver care;

6) Public and clinical policy specialists who work within the political arena to develop and implement healthy public policies;

7) The public, patients, and families who both benefit from and work to engage with the research, practice, and policy stakeholders above to insure that emergent solutions from science, implemented in practice and policy, are socially, culturally, and economically relevant to their needs.

Cancer control progress depends on many factors. One factor that is very important, but often unrecognized, is meaningful communication and engagement with patients and the public. Accelerating our progress relies heavily on supportive policy environments, adequate human and fiscal resources, and timely access to knowledge and information, all of which must be leveraged by strong leadership with the will and passion to inspire and mobilize action using the powerful tool of advocacy as the fulcrum.

Cancer is a global problem that is growing in low and middle-income countries (LMICs). Between 2005 and 2015, it is anticipated that 84 million people will die of cancer (John and Ross, 2010). Currently the incidence of cancer remains relatively low in LMICs compared to the high-income countries due in part to competing causes of death and more recent changes in tobacco use, high fat and low fiber diets, and reduced physical activity. Although the cancer incidence is lower, cancer mortality is higher, likely due to differences in stage of disease at diagnosis and differential access to high quality care. In 2008, approximately 72% of cancer deaths were in LMICs (John and Ross, 2010).

As tobacco use in LMICs increases, as is happening in India and China, and LMIC populations adopt a more western diet filled with saturated fats and lower in fiber, cancer incidence and mortality are expected to rise. The global economic loss in 2008 resulting from disability or death from cancer, and not counting the costs of cancer control (the reduction of morbidity and mortality of cancer) was US $895 billion for the 17 types of cancer examined - higher than the cost of heart disease (John and Ross, 2010).

While infectious diseases continue to be more prevalent and compete for limited public health and clinical resources in LMICs, governments in these countries will be hard pressed to ignore the growing burden of cancer and other chronic diseases and to deal with it in the future. LMICs face challenges such as endemic poverty, limited government funds for health expenditures, lack of human resources to provide health care, and more specifically, lack of health care

professionals with expertise in cancer control (WHO 2006). This is why cooperative and collaborative efforts are needed from the global health community, which includes private and public sector organizations and non-governmental organizations. How can these organizations help? WHO has encouraged all countries to establish a national cancer control program (Stewart and Kleihues 2003) and the aforementioned organizations can help initiate its successful implementation.

Knowledge translation and implementation in community, public health, and clinical practice settings holds great promise for widespread improvements in population health by closing the gap between scientific evidence and practice and policy action (Stamatakis, Vinson et al. In Press). Settings for public health and clinical practice are as diverse as the contexts in which public health and clinically-related actions occur. With respect to public health, the Institute of Medicine report The Future of Public Health defined the concept of a public health system as "what we as a society do collectively to assure the conditions in which people can be healthy" (Institute of Medicine, 1988). This definition expands the notion of public health outside of government agencies, to encompass other sectors and settings including the community at large, mass media, and worksites, as well as more traditional public health agencies (Aday, 2005; Scriven, 2007). These systems and the resources to support them clearly vary across high, middle, and low-income countries.

In addition, the transfer and integration of evidence-based interventions to communities occurs both through policy institutions and practice organizations as well as directly to community members, defining the two main groups of audiences. Given that both types of audiences may be found in community, clinical and public health practice settings, knowledge translation and implementation strategies may range from those that target "implementers" (e.g., public health and clinical practitioners and policy makers) to interventions aimed at improving dissemination directly to "end-users" (e.g., patients, family members, and the general public).

Knowledge translation efforts are needed to implement a national cancer control program. The Canadian Institute for Health Research (CIHR) defines Knowledge Translation (KT) as the exchange, synthesis, and ethically-sound application of knowledge—within a complex set of interactions among researchers and users—to accelerate the capture of the benefits of research for improved health, more effective services and products, and a strengthened health care system (CIHR 2004). The importance of KT in cancer control is substantial because much of what is needed for cancer control is already known, especially in prevention and screening (Grunfeld, Zitzelsberger et al. 2004).

The most feasible methods of improving cancer control in LMICs are often through prevention and palliative care and to a lesser extent screening, diagnosis, and treatment due in part to the latter's higher implementation costs. There continues to be many challenges in translating research evidence into public health programs and clinical practice, including primary care and oncology specialty

care. Implementation continues to lag behind discovery, particularly in low resource settings. Evidence from research can lead to evidence-informed and evidence-based practice; however there is a dearth of research in implementation science in LMICs. The definition of implementation science is the scientific study of methods to promote the uptake of research findings into routine settings in clinical, community and policy contexts. Implementation science also creates knowledge that can be adapted and applied across different public health and clinical care settings. The question about to what extent evidence-based practice in high-income settings can be translated to low and middle-income settings remains largely unanswered.

Methodology and Objectives

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

The objectives of this session were to explore the challenges and opportunities for integrating the lessons learned from science with the lessons learned from practice and policy through knowledge translation and exchange in public health, primary care, and oncology specialty care settings, particularly in low and middle-income countries (LMICs). The following five issues were selected for in-depth discussion in the workshops:

1. How do we translate the lessons learned from epidemiological and surveillance research into practice and policy? Examining the interpretation problems of epidemiological research and approaches to knowledge translation of modelling surveillance and epidemiological data.
2. Explore existing frameworks, declarations, and United Nations non-communicable disease (NCD) summit goals by which best practices and policies can be implemented to improve cancer outcomes according to established knowledge, experience, and context.
3. Examine strategies to develop, implement, evaluate and adapt evidence-based public health programs in different settings and for different populations.
4. Examine barriers to evidence-based clinical and oncology care and identify practical solutions and effective knowledge translation/exchange interventions in primary and speciality care in low resource settings.
5. Explore the meaning of patient/public engagement and advocacy in different contexts and discuss the value of engaging constituents and civil society organizations in cancer control policy.

Plenary Presentations

1. Knowledge Translation and Implementation Research and Practice: Overview and Implications for Public Health Practice and Policy: **Jon Kerner**

Knowledge translation and implementation (KT&I) in community and public health settings holds great promise for widespread improvements in population health by closing the gap between scientific evidence and public health action. Settings for public health are as diverse as the contexts in which public health-related action occurs. The U.S. Institute of Medicine report The Future of Public Health defined the concept of a public health system as "what we as a society do collectively to assure the conditions in which people can be healthy". These systems and the resources supporting them clearly vary across high, middle, and low-income countries.

The transfer and integration of evidence-based interventions to communities occurs both through institutions and organizations and directly to community members, defining the two main groups of audiences. KT&I strategies may range from those that target "implementers" (e.g., public health practitioners and policy makers) to interventions aimed at improving dissemination directly to "end-users" (e.g., members of the community). This mix of settings and levels offers opportunities not only to strengthen the translation of scientific discoveries into practice settings, but equally important, for research to be informed by the needs and priorities of practitioners and policy makers.

To make significant change each sector involved in public health will need to examine their priorities and decide what proportion of their investments will be focused on what they can do on their own versus what they should do in partnership with other sectors. While it is much easier to network (i.e., to share information) than to coordinate, cooperate, and collaborate on programs and policies (Himmelman 2001), absent a significant effort at redesigning and increasing investments in collaborative KT&I research and practice on the part of science, service, and policy agencies with academic institutions, the ideal of research influencing practice and policy and vice versa will remain a side show to our seemingly unquenchable thirst for making new discoveries.

2. Knowledge Translation in Primary Care: **Onil Bhattacharyya**

Over the last century, clinical care has gone from being of marginal benefit to a major contributor to the well-being of populations. Consistent use of what is known to work could reduce perinatal and infectious causes of mortality, while blunting the rise in premature mortality due to non-communicable diseases. The most cost-effective of these interventions are almost all delivered in primary care settings, and the quality of primary care is closely linked to health outcomes.

How do we ensure that primary care is doing its best? The traditionally long lag time between research discovery and routine service delivery is sometimes

quickly overcome. There is a gradual trend towards higher quality in many health systems, but the variation in quality within regions, and the rapid pace of medical advances show that much more could be done. The science of delivery lags behind that of discovery, but the knowledge base is growing. The knowledge to action cycle organizes knowledge translation activities into a series of discrete steps. Within these, understanding the context of implementation and pragmatic evaluations that produce broadly applicable knowledge are challenging but tractable problems.

Strategies to improve the quality of primary care can be extrinsic (targeting the context of practice or health care providers) or intrinsic (targeting the guidelines themselves). Extrinsic strategies vary widely in impact cost and applicability. They include financial incentives, organizational change, and provider education. Intrinsic strategies are inexpensive and adaptable, such as making guidelines more actionable and more consistent with the constraints of the primary care setting. These strategies are often effective, but it is still unclear what works best for whom under what circumstances. The next century should be devoted to improving the ability of systems to deliver the benefits of medical science to all populations.

3. Knowledge Translation and Implementation in Oncology Care: **Cheng-Har Yip**

Knowledge translation in oncology care is a dynamic process whereby knowledge gained from evidence-based cancer research is utilized to improve the practice of oncology with the ultimate aim of improving cancer outcomes. However, there is always a gap between "what is known" and "what is currently practiced" due to barriers with implementation especially in countries with limited resources.

In oncology care, with advances in research in genomics, mechanism of cancer etiology, and new treatment methods, the concept of "personalized" treatment based on individual characteristics emerged. However the pace and volume of new discoveries, especially in drug treatment, require the development of new evidence in comparative effectiveness, safety and outcomes, with consequent considerable public investment in time and money. Eventually translation of new research discoveries into practice may only benefit relatively few cancer patients in the high-income countries or the wealthiest of patients in low and middle-income countries.

Research into cancer treatment utilizing relatively inexpensive regimes and use of generics can easily be translated into practice if outcomes are similar to more expensive regimes. Research into pragmatic, rather than evidence-based treatment developed in high-income settings, in areas of need could be used to define acceptable benefits for optimal use where resources are constrained. Overall, knowledge translation and implementation requires a two-way flow of information between the researcher and the practitioner for knowledge exchange, with input from the practitioner regarding clinical issues and implementation considerations that exist in the practice setting.

Challenges to implementation and sustainability of evidence-informed care persist especially in low-income countries, due to a lack of infrastructure and manpower, limited opportunities for collaboration between researchers and practitioners, and lack of accountability and efficiency. The question of how best to overcome these challenges and translate knowledge into action remains unanswered, and hence the gap between research and implementation remains a challenge for cancer control.

Workshops

1. Translating Epidemiological Evidence into Policy and Practice: Leads: **Ed Trapido** and **Kazuo Tajima**

Etiologic epidemiological studies often obtain information on risk factors, such as those related to specific dietary components or tobacco, or studies of the effectiveness of various screening methods. Translating evidence into clinical practice, such as whether a woman should be screened using mammography, or translating it into policy, such as the recent Danish policy on taxing saturated foods, are two examples where epidemiologic data have been used to inform practice and policy decisions. Applied epidemiologic research includes surveillance and studies of health services, outcomes research, and monitoring of risk factors. Results of research in each of these areas also provide evidence for translation into practices and polices. Consideration of translation from epidemioloic research into practice and policy has been well summarized by Wilson et al. (2011) from the US Centers for Disease Control and Prevention, Best et al. (2008), on behalf of the National Cancer Institute of Canada Joint Working Group on Translational Research and Knowledge Integration of the Advisory Committee for Research and the Joint Advisory Committee for Cancer Control, and Khoury et al. (2010), from the CDC and the US National Cancer Institute.

In interpreting epidemiologic research for translation to policy and practice, there are five levels of translation and knowledge synthesis, as described by the Institute of Medicine's Clinical Research Roundtable (Sung, Crowley et al. 2003), and summarized by Khoury. These focus on the contribution that epidemiology has made to science and to translation.

- T0: scientific discovery research (for example, the studies which established tobacco as a major risk factor for lung cancer, leading to tobacco control policies)
- T1: translational research from discovery to candidate application - "the transfer of new understandings of disease mechanisms gained in the laboratory into the development of new methods for diagnosis, therapy, and prevention and their first testing in humans"
- T2: translational research from candidate application to evidence-based recommendation or policy
- T3: translational research from recommendation to practice and control programs
- T4: translational research from practice to population health impact

Problems with interpretation of epidemiologic data are also important when considering development of practices and policies.

These include (1) the population being recruited, (2) the study design, (3) the consistency of the results (3) the context in which the study was conducted, and (5) the study limitations, including confounding and potential biases.

Abstract 1: The Canadian Partnership Against Cancer: Translating Research into Policy and Practice through the Cancer Risk Management Model and Cancer Surveillance and Epidemiology Networks Initiatives
Janey Shin, Bernard Candas, Alyssa Cloth, Fei Fei Liu, Gina Lockwood

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

2. Existing Global Frameworks to Support Implementation
Leads: **Eduardo Cazap** and **Andreas Ullrich**

In today's world, cancer is one of the major causes of mortality, morbidity and disease burden and was recognized as a worldwide public health problem by the World Health Organization (WHO) at the General Assembly in May 25th, 2005. Advances in prevention, early detection, diagnosis, treatment and follow-up have improved our understanding of cancer care. However, these advances must be followed by dissemination and the adaptation of new knowledge to different contexts and resource settings in order to have an impact. The current strategy applied to improving cancer control, lowering cancer incidence and improving curability is based on several steps: first, improving our scientific knowledge with basic research studies and then moving forward to clinical application; second, conducting randomized clinical trials for all new interventions with promising results to define standard of care; third, obtaining approval by the scientific bodies and regulatory authorities for all new knowledge that demonstrates a health benefit; and lastly, disseminating the new intervention to the relevant populations and further evaluation to define impact and value.

While we have much experience with the first three steps of the process, it is this last step, involving the dissemination of information that is the weakest. Regrettably, the current available scientific knowledge is only accessible to approximately 10% of the world's population. In this regard, implementation science is a valid tool for the proper evaluation of results of pilot projects and interventions with the objective of improving the applicability of new interventions (primary or secondary prevention strategies, new diagnostics, therapeutic or palliative care interventions, etc.) to target populations.

The innovation-specific framework for transfer of an innovation from 'discovery' to 'population application' described above needs to be considered within larger contexts – the fit within frameworks (strategies) for disease control, and the fit within larger frameworks that relate to health policy and social well-being. Currently we have two main global frameworks to support implementation for cancer control: the World Cancer Declaration from the Union for International Cancer Control (UICC) (UICC 2011) and the Political Declaration from the United Nations General Assembly Special Session (UNGASS) on the prevention and control of non-communicable diseases (UNGASS 2011).

The World Cancer Declaration from UICC calls on world leaders to develop and implement National Cancer Control Plans, to build and use population-based cancer registries, implement policies to reduce the burden of cancer risk factors and prevent those cancers which can be prevented, enhance screening and early detection

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Recommendations from Workshop 1

• Epidemiologic studies are useful for developing policies and changing practice but must consider the context in which the study was conducted and the design and analytical approaches that were used. Epidemiologic evidence should be used to advocate for policy change.

• Modeling tools for integrating epidemiologic and surveillance data from different countries are available and should be used for practice and policy change.

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capabilities, improve access to diagnosis and treatment, improve training and support for cancer health workers, and ensure that palliative care and pain relief is made available to all patients in need, but especially in the last days of life.

The Political Declaration from the United Nations recognizes that non-communicable diseases, including cancer, represent a major burden to the world's population and a growing threat to social and economic development. The Member States agreed to address the prevention and control of non-communicable diseases worldwide and recognized the role of governments and the international community, and the need to engage all sectors of societies, in responding to the challenge. Both of these frameworks are useful and powerful instruments to support global, regional and local cancer control implementation actions.

Abstract 1: Inequalities in Cancer Care Over Europe: Can We Understand Why? *Renee Otter, Sabine Sieslling, Annemiek Kwast, Paolo Baili, Anna Gavin*

Objectives: Objective: Population-based Cancer Registries (CRs) show large differences across Europe in cancer survival statistics. To get insight into inequalities in cancer care, EUROCHIP (European Cancer Health Indicators Projects) defined the most important indicators to be collected. Concerning care, three indicators, strictly related to cancer survival differences are: "stage at diagnosis", "cancer treatment delay", and "compliance to cancer guidelines". EUROCHIP-3 studies whether these indicators are actually collected by the EU-CRs. Methods: A structured qualitative questionnaire, set up in collaboration with the ENCR (European network of CRs) and EURCOCOURSE, was sent to all EU-CRs (N= 206). It focuses on the availability of items necessary to evaluate the three indicators. Results: The response rate was 50% from 35 different countries covering 28% of the EU- population. 80% of the CRs collected "stage at diagnosis", 37% collected "cancer treatment delay", and 15% collected "compliance to cancer guidelines", but only half of the CRs mentioned the availability of guidelines. Only 15% of the CRs collected variables for all 3 indicators and 25% of the CRs were not interested in collecting this information. Limited access to data sources and lack of staff were the reasons mentioned most frequently for not collecting items. For national CRs there is a relationship between the available budget per cancer case and the available number of indicators, however this is not the case for regional CRs. Conclusion: Only a minority of CRs in Europe deliver comparative cancer care outcome indicators, besides survival. CRs should undertake this additional task in order to provide policy makers adequate tools to understand better the reasons for inequalities and fight against them.

Abstract 2: Accelerating Evidence-based Action in Cancer Control and Facilitating Virtual Collaboration in Canada through Cancerview.ca *Michelle Chong, Anna Greenberg, Lee Fairclough, Wayne Roberts*

The Canadian Partnership Against Cancer's mandate is to accelerate the use of evidence-based knowledge in cancer control. A major impetus for a national cancer control strategy was the potential to reduce unnecessary duplication of effort and resources across provincial cancer systems in Canada through identifying common approaches to cancer control and more effective knowledge management. This case study describes the impact of one of the Partnership's major initiatives - Cancerview.ca. Launched in 2009, Cancerview.ca is a pan-Canadian knowledge hub providing high-quality tools and resources, including seven pan-Canadian searchable knowledge bases, such as a directory of Canadian policies related to cancer prevention. Content on the portal is driven from over 30 health and cancer partners across Canada and internationally. Results from the first annual survey demonstrated that respondents were impressed by the credibility, quality, and reliability of the information on the portal. Seventy-two percent of respondents would recommend the portal to their colleagues and 76% of respondents would recommend the portal to their family and friends experiencing cancer. Cancerview.ca also supports the ability to collaborate virtually across geographic and organizational boundaries. One hundred and fifty groups are using the Collaborative Group Spaces tool to collaborate online at no cost. Tools used include document sharing, discussions, calendars, and wikis. Rather than focusing on technology development, groups are using an existing collaboration tool to work on projects across the cancer control spectrum from cancer research to clinical and palliative care to system planning. One cancer agency, Cancer Care Nova Scotia, has adopted the tool for their extranet made up of over 25 groups representing multi-disciplinary cancer site and administrative teams.

Recommendations from Workshop 2

• We need more country and context specific tools to adapt existing and new frameworks for implementing comprehensive cancer control programs.

• It is recommended that cancer control plans and frameworks should look to other disease frameworks to find synergies and leverage resources to address common risk factors and health care system challenges.

Results from a feedback survey showed that 64% of users agreed that Collaborative Group Spaces is a useful tool for professionals in the cancer control community to connect and collaborate on projects and initiatives.

3. Dissemination and Practical Support for Implementation in Public Health Leads: **Jon Kerner, Maria Fernandez** and **You Lin Qiao**

While cancer prevention and control are important priorities in public health, they are by no means the only priorities, and cancer control programs compete for resources and attention with communicable disease programs as well as programs to reduce risk factors for other chronic diseases. This is particularly challenging in jurisdictions where poverty and cultural diversity are

prevalent and where resources for public health to address the many risk factors and excess disease burdens are limited. In this workshop two presentations examined:

1. How food and nutrition recommendations for cancer prevention are often constructed based exclusively on technical-scientific definitions, ignoring social constructive processes that involve values, perceptions and experiences. Thus, important barriers may impair the advancement of policies that aim to implement these recommendations. Multidisciplinary contributions to the construction of socio-culturally appropriate food and nutrition recommendations and goals are described, especially concerning the recognition of cancer as preventable and of the role of food and nutrition in preventing cancer; and

2. Intervention mapping, as a planning framework for the development and implementation of evidence- and theory-based health promotion programs, was described. Intervention mapping offers a way to adapt programs to different settings and populations, and also to adapt moderately effective programs to increase their effectiveness in diverse populations and settings.

Abstract 1: From Nutritional Recommendations to Real Life: Sociological and Philosophical Contributions for Food Policy Making: *Fabio Gomes*

Food and nutrition recommendations for cancer prevention are often constructed based exclusively on technical or scientific definitions, and ignore social constructive processes that involve values, perceptions and experiences. Thus, important barriers may impair the advancement of policies that aim to implement these recommendations. This paper presented multidisciplinary contributions to the construction of food and nutrition recommendations and goals, especially concerning the recognition of cancer as preventable and the role of food and nutrition in preventing cancer. It discussed some psychosocial determinants and philosophical barriers to this recognition and their implications for population-based interventions. Recommendations and prescriptions of goals were analyzed considering the risk, its social determinants, components, and related concepts (e.g., danger, threat, trust, protection) as multi-dimensional factors. Antique philosophy, Neo-Platonism and Absurdism schools served as the basis for the philosophical analyses. Lessons and considerations on establishing and communicating the recommendations included: 1) to incorporate popular contributions to the definition, content, strategies of communication and implementation of the cancer prevention agenda; 2) to conceive communication strategies that take into account the credit of the information source, and the robustness of popular knowledge; 3) to consider that the worldview of several populations are driven by provision and not pre-vision, which is essential to the effectiveness of prevention recommendations; 4) to consider the gap between the order from self-desire to want and the obedience to this order; and 5) the mitigation of beliefs around prevention by the competing interests of the food industry, which

disorder desires and affections. A long way still separates the established risk from the recognized risk when it comes to food, nutrition and cancer prevention, especially among low- and middle-income countries, which remain essentially more concerned with provision than with prevention. There is also a gap between the recognition and the change, which is especially limited by policy and actions focused on personal changes.

Abstract 2: A Systematic Approach to Program Adaptation using Intervention Mapping: *Maria Fernandez, L Kay Bartholomew, Patricia Mullen*

Intervention Mapping, a planning framework for the development and implementation of evidence- and theory-based health promotion programs offers a way to adapt programs to different settings and populations, and also to adapt moderately effective programs to increase their effectiveness. Some argue that fidelity to the original program is more important than adapting a program to fit a new setting and population. However, in practice adaptation happens. Even when higher fidelity is shown to be associated with improved outcomes, adaptation may add to the programs' effectiveness. This presentation proposed the use of a systematic process for program adaptation that describes steps including: conducting a needs assessment and determining program fit; comparing the change model for the original program with the logic model for new problem or population; examining the original program's theoretical methods and practical applications and making changes where necessary, and testing original materials with the new population to determine any needed changes. The development of an implementation protocol and timeline taking into account limitations of the new setting and performance objectives for implementers was discussed. Finally the importance of evaluation of the effectiveness of the new program was discussed, as well as the process, including how well the new program was accepted in the new setting.

Recommendations from Workshop 3

• There is a great need for broader engagement of multi-sector stakeholders in community-based cancer prevention and control program and policy development implementation and evaluation.

• Civil society organizations should be appropriately resourced, staffed, and authorized to review and disseminate all relevant cancer control (science, practice, and policy-based) evidence to confront the status quo.

• Increase the knowledge, skills, and ability of community-based organizations concerned with cancer control and NCDs to access and adapt evidence-based programs for cancer control.

• Recognizing that scientific evidence is not always available to inform practice and policy, it is recommended that other sources of evidence from experience and best community practices are provided equal weight when science has nothing to say.

4. Dissemination and Practical Support for Implementation in Clinical Practice (Primary Care and Oncology Specialty Care): Leads: **Cheng-Har Yip** and **Onil Bhattacharyya**

The aim of this workshop was to identify the barriers to evidence-based clinical practice and to offer practical solutions to effective interventions, the ultimate aim of which is to improve outcomes in cancer. The emphasis was on clinical practice in LMICs. Each of the three abstracts presented during this workshop introduced an important aspect of KT. For knowledge to be disseminated to clinical practice, there first needs to be a solid foundation of up-to-date knowledge.

The abstract titled "DataLINFO Project: Establishment and Management of Lymphoma Database for Clinical and Translational Research" is a great example of how information can be collected and organized so that important conclusions can be made with solid background evidence. Once this knowledge is obtained, dissemination strategies are necessary to make sure the evidence is being incorporated in practice, so as to have positive outcomes.

The abstract entitled "Physician Detailing to Encourage Cancer Screening" demonstrated how even a simple task, such as colorectal cancer screening is being underutilized despite its proven efficacy. But with organized efforts on educating physicians and patients, improvements can be seen. One of the purposes of KT is to promote consistent use of effective clinical practices. The third abstract titled "Creating Competencies for Hospice and Palliative Care Professionals in Korea" showed the efforts taken to create a universal paradigm for all health professionals to make cancer care more efficient.

Abstract 1: DataLINFO Project: Establishment and Management of a Lymphoma Database for Clinical and Translational Research: *Adriana Scheliga, Isabela Goncalves Antunes Pereira, Isabelle Small, Carlos Gil Ferreira, Claudio Gustavo Stefanoff*

International initiatives have demonstrated the great importance of "mapping" of non-Hodgkin lymphomas (NHL) in different regions of the world. Integrating clinical, pathological and molecular information of lymphoma patients provides a platform for understanding the biological variability in presentation and treatment response and may contribute to the development of novel therapies. Currently there are no official data on the incidence, evolution and prognosis of patients with lymphoma in Brazil. This initiative aimed to consolidate a computerized structure, named dataLINFO, for recording and analysis of demographic, clinical, pathological and therapeutic data of lymphoma patients enrolled in the Brazilian National Cancer Institute (INCA)/Ministry of Health. Management areas of the dataLINFO Project include: voluntary informed consent process, clinical data collection, quality control information, and data processing and analysis. Since its idealization, several retrospective and prospective studies have been linked to the dataLINFO Project, such as the clinical and epidemiological profile of lymphoma patients (including post-transplant lymphoproliferative disorders/PTLD, follicular, diffuse large B-cell, extranodal and peripheral T-cell lymphomas), predictive biomarkers of therapeutic response to monoclonal antibodies, and the occupational hazards and development of NHL. It is expected that the dataLINFO Project will allow: a) standardization of collection and analysis of clinical, pathological, epidemiological and molecular data of lymphoma patients b) access to clinical information and technologies designed to improve diagnosis and treatment of lymphoma; and c) planning of clinical and epidemiological lymphoma studies using the follow-up information. Databases are essential to clinical and translational research, especially for developing novel diagnostic and therapeutic tools for cancer. The dataLINFO Project constitutes a model of clinical data management that can be replicated in other regional institutions contributing to knowledge about the incidence, evolution and prognosis of patients with lymphoma in Brazil. Furthermore, the information in the integrated database may contribute to hospital-based cancer registries, improving the national cancer prevention policy and the adoption of appropriate surveillance strategies for lymphomas.

Abstract 2: Physician Detailing to Encourage Cancer Screening: *Donna Williams, Henry Nuss, Colleen Huard*
Objective: Colorectal cancer (CRC) is the third most diagnosed cancer in the United States and the third leading cause of adult cancer deaths in the U.S. Among U.S. women, breast cancer is the most common cancer and the second leading cause of cancer deaths. Early detection of both cancer types through proper screening mechanisms vastly improves treatment outcomes. Screening rates in the U.S. are low; roughly half of adults are in compliance with CRC screening recommendations. Research shows that individuals are more likely to engage in screening behavior based on a physician's recommendation. However, many physicians fail to advise patients due to a lack of awareness of current guidelines. Methods: To address this issue in Louisiana, The Louisiana Comprehensive Cancer Control Program began a physician detailing program in 2008. Modeled after the pharmaceutical company approach, staff promoted the American Cancer Society screening guidelines through the delivery of brief, targeted messages to doctors and other health care providers at their practice sites. Providers also received patient education materials to promote evidence-based best practices. Since inception, nine regional coordinators throughout the state have detailed more than 180 unique health care providers. Medicare data were obtained to measure the number of enrollees receiving CRC screening and mammography. Results: In the period from July 1, 2008 to June 30, 2010, CRC screening rates were consistently higher in intervention areas of the state as compared to control areas (df=1, F=4.0, p=0.05). This was also true of mammography rates in the same areas (df=1, F=4.3, p=0.043). Conclusions: These preliminary results indicate that physician detailing may be a promising way of encouraging physicians and their staff to recommend cancer screening procedures.

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

Objective: Competency-based assessment of professional development can help to provide standardized content for cancer and palliative care education programs. We develop and describe the process and results of identifying the advanced competencies required by physicians, nurses, social workers and spiritual care providers in hospice and palliative care (HPC) practices. Methods: To develop HPC competencies, 'the Hospice & Palliative Care Professionals Competency Development Task Force Team (TFT)' was put together with experts in HPC from multiple disciplines, consisting of 7 physicians, 4 nurses, 2 social workers, and 2 clergies. TFT identified domains of competency for each professional. To develop consensus regarding competencies in HPC, we performed two round e-mail Delphi surveys. Each Delphi round assessed the validity of competency domains and important ratings of each competency using a 5-point Likert scale. After conducting the Delphi surveys, the opinions which exceeded the criterion (consent mean score above 4.0) were taken into consideration and adapted by TFT. Results: The statement of the competencies was described as knowledge, skills, and attitudes. In round 1, 32 Delphi panels (76%) responded and in round 2, 22 panels (69%) responded. At the end, 11 domains and 16 sub-domains for physicians, 11 domains for nurses, 5 domains and 15 sub-domains for social workers, and 3 domains and 2 sub-domains for spiritual care providers were identified. Conclusions: It is important to examine the role of a multidisciplinary team in HPC and determine what they have to contribute to the care of the patient. The National Cancer Center and the Korean Society of Hospice & Palliative Care created competencies for HPC professionals and these competencies will be very useful in developing and evaluating advanced courses for each professional.

5. *Patient and Public Engagement and Advocacy*: Leads: **Paula Kim** and **Juhee Cho**

Comprehensive cancer control in its simplest form includes prevention, early detection, treatment and palliative care and involves multiple stakeholders representing constituencies that seek to reduce cancer incidence, morbidity, and mortality someplace along the cancer control continuum of primary prevention to end-of-life care. Cancer is personally known to almost everyone; and generally feared by all. Despite occasional bright spots in cancer control, there remains the frustration of knowing that as many as 30% of cancer deaths can be prevented, and in 2008, cancer accounted for about 13% of all deaths with 60% occurring in low and middle-income countries (WHO 2011).

Cancer control progress depends on many factors, none of which is more important than meaningful communication and engagement with patients and

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Recommendations from Workshop 4

• Opportunities should be provided for networking and building strategic partnerships between high and low-income countries in implementation research in clinical practice.

• Protocols and evaluation criteria should be developed to support a system of continuous quality assurance and quality improvement, and these systems should be linked with the growing field of implementation science.

• Given limited funding for international and within-country implementation science, consideration should be given to supporting these efforts through health services budgets.

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the public. Accelerating our progress relies heavily on supportive policy environments; adequate human and fiscal resources; timely access to knowledge and information; all of which must be leveraged by strong leadership with the will and passion to inspire and mobilize action using the powerful tool of advocacy as the fulcrum. In other words, advocacy and stakeholder engagement help bring balance, perspective, insight, and understanding to create working frameworks for mutual respect, greater congruency, and ultimately progress that saves lives and helps control disease.

Advocacy and communication depend in part on the socio-cultural and political contexts in which people live. Advocacy is more likely to thrive in jurisdictions where free speech is a societal value. In societies where some of the population (e.g., socioeconomically underserved) has no means or mechanisms for free expression or may be constrained from doing so (e.g., women in some countries) such movements may prove more difficult to mount, but are not impossible. Healthcare advocacy and patient and public engagement is not a global phenomena. Investment in and support of advocacy, health communication, and behavioral sciences is largely under-developed and under-utilized in many parts of the world.

Therefore, we must strengthen existing advocacy and stakeholder engagement efforts and invest in creating them where none exist. Engagement strategies and advocacy are not one size fits all. With the will and resources of multiple stakeholders, we can share best practices, build resources, teach technical skills, and mentor future leaders towards replicable advocacy and stakeholder engagement program models that harmonize with the unique needs and cultures of each community. The responsibility of creating effective patient and public engagement and advocacy programs rests on multiple stakeholders across all sectors. Well-balanced cancer advocacy and public and patient engagement programs are vital resources that support and benefit all stakeholders in a civilized society.

Globally, very little is known about the impact, size, and scope of public and patient engagement and advocacy programs. However, there is a growing need and demand in all corners of the world for public and private agencies and organizations to step up and strengthen their knowledge

and competencies in cancer advocacy and public and patient engagement programs. This growing global need for better advocacy and stakeholder engagement resources is driven by:

• Cancer continues to be a global burden affecting 1 in 3 women and 1 in 2 men.
• Increasing patient awareness and demand for supportive care environments.
• Increasing access and amounts of health information via the internet; however there are relatively few qualified and trained resources for filtering, validating, and helping patients and the public to obtain reliable and credible information to navigate their healthcare systems, manage their decisions, and communicate with medical teams and loved ones.
• Better patient access to information about detection, prevention, treatment and management of disease often requiring educating policy makers about the need to update and amend relevant public policy in a timely fashion.

Abstract 1: Developing Advocacy Organizations to Support the Needs of People Confronting Cancer: The Cancer Advocacy Leadership Academy: *Gary Kreps, Paula Kim, Lisa Sparks*

Patient advocacy can make significant contributions to clinical oncology and cancer-related research by ensuring that efforts are patient-focused and help promote cooperation between all relevant sectors of the oncology community and other key stakeholders. Yet, the development of effective patient advocacy organizations demands strong leadership, establishment of active collaborations with key stakeholders, and careful management of fiscal and personnel resources to promote population-based cancer control and enhance the outcomes of cancer (and related non-communicable diseases). This presentation described the development and implementation of an innovative training academy to prepare cancer advocacy leaders, both domestically and internationally, by helping them carefully consider strategic cancer advocacy processes, roles, and responsibilities. The Cancer Advocacy Leadership Academy provides participants with a comprehensive overview of the modern oncology community, identifying critical constituents and stakeholders, and examining interrelationships between key individuals and organizations. Strategies for fostering meaningful communication, cooperation, and coordination between patient advocacy organizations and other stakeholders related to cancer, including consumers, other advocacy groups, clinicians, government officials, researchers, and private industry representatives, are explored. For example, patient advocacy organization leaders learn about communication strategies for working effectively with researchers and clinicians to support prevention, detection, treatment, and survivorship efforts that will benefit patients. Patient advocacy organization leaders also explore strategies for raising funds and increasing funding for cancer research. They learn about clinical research, health regulatory systems, community organizing, as well as drug and technology development and approval processes from basic research to clinical practice. Exemplar models of successful patient advocacy organization leadership were described and evaluated as case studies that illustrate effective cancer advocacy. This advocacy training model also has the potential to be applied to other health concerns beyond cancer.

Abstract 2: When the Hospital Goes to the Shopping Mall! Building Partnerships with Community Institutions in Cancer Control: *David Kinyanjui, Lawrence Ikahu, Elizabeth Abongo*

Objective: The growing burden of breast cancer in low and middle-income countries, compounded by poor access to screening and treatment programs, calls for urgent innovative cancer control interventions. This paper described a low cost model of increasing cancer awareness, and screening for breast cancer using clinical breast examinations by taking these services to shopping malls, churches and colleges. Methods: Clinical breast examinations, breast health education and appraisal of breast health were offered by doctors and nurses to women in randomly chosen partner shopping malls, churches and colleges. Publicity was done through announcements in public gatherings and print and electronic media. All women were taught how to perform a self breast examination during the encounter with a health care provider. Each woman filled out a self-administered questionnaire on her breast health and risk assessment. Interactive talks on cancer prevention, screening and control were given in all campaigns. Results: In this ongoing program, 10,000 women have been screened through clinical breast examinations in retail outlets over the last 36 months. 15% of the women presented with defined breast problems, such as lumps with or without lymph nodes or bloody nipple discharge. 20% have done mammograms which they would not have otherwise done. Other health issues, including pap smears, were also addressed. Conclusions: Breast screening in retails outlets is a sustainable, low cost method of promoting early detection, reaching out to women, and demystifying cancer. Clinical breast examinations are a suitable option for countries in economic transition, where incidence rates

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Summary of Workshop 5

• A common definition of advocacy in cancer control and creation of an advocacy vocabulary of basic terms and nomenclature.

• An inventory of best advocacy practices in cancer control that is catalogued, maintained, and available to all who want to make a difference; the inventory will describe stakeholder engagement interventions, policies and guidelines; program focus areas (public policy, survivorship, patient education, patient support, clinical trials, research, etc.); and acquisition, dissemination and evaluation methods.

• Acknowledgement that health professionals and family members of patients have a role to play in advocacy.

are increasing but limited resources do not permit mass routine screening by mammography.

Conclusions

Greater than 50% of cancer patients survive their diagnosis in high-income countries compared with less than 20% in LMICs; cure rates for childhood cancers exceed 80% in high-income countries compared with less than 20% in LMICs. Access to appropriate care is the challenge of LMICs; sustainability of appropriate care is the challenge of high-income countries. Thus, it is not a lack of knowledge about cancer and its care that distinguishes outcomes between resource settings, rather it is the ability to access, apply and derive the benefits of existing knowledge. The challenge is not about whether or why we need knowledge exchange, even in high-income countries – it is about what can be done, how interventional change can be implemented, who must be engaged, and how they can effect their roles and influence to expedite advances in cancer control.

The collection and synthesis of epidemiologic information is recognized as a fundamental underpinning of health policy formulation. To be relevant to policy considerations, epidemiologic studies must:

• be appropriately designed and analyzed in relation to the questions being asked;
• relate to the context, practical realities and time frames in which they were derived, i.e., they are not readily transferred to differing contexts and realities;
• produce results that are amenable to projection and modeling methodologies that relate priorities, resource allocation, expected results, and value in current and future contexts.

Two current global frameworks apply to strategies to enhance population-based cancer control – the UICC World Cancer Declaration (a framework for national cancer control planning) and the UNGASS political report (September 2011; considerations with regard to the control of non-communicable diseases, including cancer). The need for country and regional context-relevant tools to adapt sound conceptual frameworks into practical, relevant population-based interventions is critical. In addition, the UNGASS statement reinforces the necessity to consider illness-intervention programs across a number of diseases that share common risk factors (e.g., poverty, tobacco, alcohol, etc.) and to incorporate lessons learned from the control of other conditions, such as HIV/AIDS, for which focused attention and funding has yielded significant advances that have relevance to the control of NCDs and cancer (Narayan, Ali et al. 2011).

While there is an intuitive belief that research, practice, policy and population application environments are integrally related, the reality is that they exist as separate solitudes with their own incentives/disincentives for knowledge exchange. A change in cancer control outcomes engages interventions from primary prevention and social determinants of health through early detection and diagnosis, treatment, survivorship, and end of life.

Cancer control is a societal challenge requiring the involvement of all sectors of society. This has practical implications for implementing measures that influence both the public's health and illness, and necessitates cross-sectoral collaboration within and between countries to place evidence-based practice and 'practice-based' evidence into appropriate contextual and practical reality. Patient and public engagement in establishing health priorities and allocation of resources from public or personal funds is fundamental and requires rethinking 'health advocacy' – building on personal or disease-specific agendas and moving to informed engagement about preferred choices, deliberative democracy and the 'greatest benefit for the greatest number of people,' from the use of public and personal funds assigned not only to health and illness but also all aspects of the well-being of an informed society (Goodin and Dryzek 2006).

To make significant change in comprehensive cancer control in any country, each and every sector involved in public health and clinical practice will need to examine their resources and investment priorities in order to decide what proportion of their investments will be focused on what they can do on their own versus what they should consider doing in partnership with other sectors. For example, even as academic organizations recognize the potential for peer-reviewed funding and publications in the nascent field of knowledge translation and implementation, will they be willing to also provide academic credit and career advancement for faculty who choose to invest their time and energy in building coalitions and collaborating with public health and clinical practice and policy partners outside of academia?

Similarly, government research and practice funding agencies face a similar choice: continue to expend most of their resources on their own initiatives, within their mission-specific frameworks and comfort zones, versus make a significant investment in collaborative funding initiatives sharing the credit and the responsibility for working together across departments, ministries, and jurisdictions. While, as noted previously, it is much easier to network and coordinate than to cooperate and collaborate (Himmelman 2001), absent a significant effort at redesigning and increasing investments in knowledge translation and implementation research and practice on the part of science and service funding agencies, and a similar change in the academic rewards for research, practice, and policy partnerships that integrate the lessons learned from research with those learned from practice and policy, the ideal of research influencing practice and policy and vice versa will remain a side show to our seemingly unquenchable thirst for new discoveries.

"You must be the change you wish to see in the world." **Mahatma Gandhi**

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

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