

Cancer Control in Developing Countries: Need for Epidemiological Surveillance based on Health Information Systems and Health Services Research

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Abstract. The purpose of this paper is to present an argument for the need for population level interventions to smoking cessation and tobacco control in the developing countries. Health information systems (HIS) have made a significant role over the years in both the developed and developing countries. In order to provide a comprehensive health risk assessment profile for populations in the developing countries, however, there is an urgent need to develop epidemiological surveillance data to be integrated within HIS. This is principally important for health surveillance data on structure, process, risk factors, and outcome of cancer, given the economic, clinical and public health burden of cancer particularly in low- and middle-income developing countries. A comprehensive approach to cancer prevention and control in the developing countries should involve systematic and timely epidemiological surveillance. Such surveillance systems should be established keeping in mind the unique socio-economic, environmental, and cultural influences on cancer incidence in the developing countries.

Keywords. Health information systems; epidemiological surveillance; tobacco use; diet; physical inactivity; cancer prevention and control; developing countries.

Introduction

Cigarette smoking and other forms of tobacco use inflict a growing global public health burden. Across the World and each year tobacco use is estimated to kill about 5 million people.¹ By 2030, tobacco-related mortality will rise to 10 million given current smoking patterns. The 21st century is likely to see 1 billion tobacco deaths, the majority of which will be in low- and middle-income countries.^{1,2} Tobacco consumption is rising globally, primarily because the industry is targeting young people and women in low- and middle-income countries.^{3,4}

According to Lawrence and colleagues⁵ there is a preponderance of studies into individual smoking cessation therapies which seem out of proportion to the actual people who use such techniques. There is an imbalance and general bias toward funding research by pharmaceutical industries toward individual rather than population-based approaches to smoking intervention strategies. Smoking and how to reduce its consumption remains one of the few health issues that many consider as an individual (not a population) health problem.⁵ This is surprising, however, since tobacco use (smoking) is one of many risk factors for chronic, multi-factorial

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conditions such as obesity, type 2 diabetes, cardiovascular disease (CVD), and the metabolic syndrome (MetS) which require population-based intervention approaches to chronic disease prevention and management as opposed to individual high-risk strategy “therapies”.

The purpose of this paper is to present the current author’s opinion for the need for population-level approaches to smoking cessation and tobacco control in the developing countries in general. The author argues that there is also a need for epidemiological surveillance data to be developed and integrated or “built-in” health information systems (HIS) and electronic medical records (EMRs) -- in order to provide a comprehensive health risk assessment profile for communities and populations in developing countries. There is paucity of information and lack of research related to how to design and implement effective chronic disease epidemiologic data for the monitoring and evaluation of preventable chronic diseases related to tobacco use and other lifestyle behavioural risk factors (physical inactivity; unhealthy eating patterns; alcohol drinking), and how such surveillance systems be integrated into primary care and health services research databases.

Health Information Systems in Developing Countries

There have been a few published studies on the lack of interoperability of health information systems (HIS) in developing countries. For example, Gambo et al.⁶ discuss that computer-based HIS are required to have the ability to exchange medical and health-related information or “talk to each other” if developing countries need to work towards providing efficient primary and healthcare delivery services to their people. Unfortunately, this dream is yet to be achieved since nearly all of the HIS and electronic health record (EHR) systems in use lack database management programs that allow for data linkage and interoperability between the various systems or networks.⁶

Health services research largely concerns itself with the factors affecting the need for health services, access to these services, quality control and economic stability, apart from health outcomes of the individuals and populations involved.⁷ Standards of care for various chronic conditions such as cancer and CVD have been largely defined. However, within the context of simple evidence-based clinical practice guidelines adherence to such guidelines while essential is only one component of the solution towards a chronic disease management model.⁸ While health services research involves training of health care professionals to provide primary and clinical health care services, there are many issues with just depending on this approach for the management of cancer and CVD, since the training process itself concerns itself with the delivery of health care with little consideration to the structure, process, and outcome of quality care.⁸

The Need for Epidemiological Surveillance Data for Cancer Risk Factors

The burden of cancer affects people of the entire world. It is estimated that more than 20 million individuals are living with a cancer diagnosis, and each year another 10 million cases occur.¹³ The global mortality from cancer is profound as cancer is the second most common cause of all-cause mortality. More than 50% of new cancer cases occur in developing countries where cancer has reached epidemic proportions

particularly low-income/poor developing countries where high rates of cancer have been associated with risk factors such as tobacco, less healthy dietary patterns, physical inactivity and obesity.

Collection of health data allows outcome assessment of cancer control programs. This includes changes in trend as reflected by cancer incidence or survival over time, or following geographic variations in incidence of a given cancer.⁷ The great majority of current available data in the area of cancer etiology and prognosis has been drawn from epidemiological studies conducted in the western world or developed countries, with approximately one-third of such studies conducted in North America and Europe.⁹ Without cancer surveillance data on structure, process, risk factors, and outcome, we cannot know if programs and interventions that have been presumably successful in the western world (wealthy) settings will work as well in limited-resource settings in low- or middle income developing countries.^{7,9} This highlights the need for population-based surveillance studies in the developing world. In addition to limitations to monitoring and evaluation of cancer-related health data there are limited human resources in low and middle-income countries to produce efficient health services and policy research.

Common information sources in developing countries are health surveys, birth and death registration data, census data, health facility reporting systems, and health administrative data.¹⁰ Population-based cancer registries collect information on the prevalence of different types of cancer in a population. Cancer registries provide the backbone of information infrastructure required to perform a wide range of oncology health services research. What is missing is the collection of population-based risk factor information which can be linked to primary care cancer cases data and other hospital-based and governmental data sources to provide a comprehensive and rich profile of information on structure, process, and outcome of cancer prevention, screening, and management including palliation and treatment. Hanna and Kangolle⁷ mention common sources of cancer registry information to include hospital inpatient records, pathology records, radiation treatment records, haematology laboratory reports, screening program records, and death certificates.

There are still many developing countries without a cancer registry of sufficient quality. For example the International Agency for Research on Cancer's (IARC) 2007 report on global cancer incidence which was 4% for Asia, 1% for Africa, and 4% for Central and South America in comparison with 80% in North America and 33% in Europe.¹¹ In addition, in developing countries as opposed to developed countries there is partial computerization of vital statistics, medical records, and lack of a unique identification (ID) number for each individual which poses significant problems for record-linkage studies. Househ and others¹² mention that in Saudi Arabia for example a national effort to develop an e-health framework for the country has yet to be discussed. Subsequently, a large number of different HIS that use different data processes and formats were in use in large regional hospitals with no linkage or horizontal (parallel) integration with each other.

Prospects for Future Research

The fundamental prerequisite in epidemiological research is a high quality cancer surveillance system. This program should be capable of providing methodological and statistical data related to patterns and trends of cancer. In most developing countries there are large knowledge gaps in the structure, process, risk factor data, and outcome pertinent to cancer information. The need to build and collect high quality systematic information for the purposes of monitoring and evaluation of cancer prevalence, incidence, and risk factor-related data is warranted. As we engage in expanding the scope of cancer surveillance systems, new tools and methods must be developed to connect all other data sources with cancer surveillance frameworks and resources. The epidemiological research that is much needed for cancer control in the developing countries emphasizes the recognition that human lifestyle behaviour as a major determinant. Therefore, comprehensive tobacco control programs and strategies, healthy eating policies and dietary guidelines, and promotion of physical activity and exercise should be high priority for governments, health officials, and the public. Authorities in developing countries must try to improve the system of cancer and death registration and governments in general should invest more money in the public health infrastructure.

A comprehensive approach to cancer prevention and control in the developing countries should include ongoing systematic and timely epidemiological surveillance which is necessary to provide evidence-based population health and clinical evidence to formulate research priorities, and to monitor the outcomes of preventive interventions, cancer treatment and palliation.¹³ Epidemiologic surveillance studies in developing countries can provide distinct opportunities to examine the etiology of cancers and underlying interrelated mechanisms by which cancer develops. It is important to keep in mind, however, that these countries are influenced by different economic, environmental, socio-cultural, diet, and lifestyles. Their socio-economic backgrounds are quite different from the majority of people in the western world or developing countries. Efforts aimed at successful control and reduction of cancer burden should accept the importance of the unique social and cultural influences on cancer incidence in the developing countries.

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