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Technological changes and cancer registries: an opportunity?

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Cancer registration has come a long way in the last 70 years. The basic function of a population based cancer registry is to record all new cases (of cancer) in a defined population (most frequently a geographical area) [1] and the core activity of a cancer registry is to generate statistics on the incidence of cancer, classified according to their site of origin and histology.

From the 1960's to current times, the cancer registries have gradually developed the ability to provide information on other aspects of cancer occurrence and on the control of the disease such as stage at diagnosis and the nature of the treatment received, responding to the needs of healthcare organizations interested in other aspects relevant to planning and evaluation of cancer control activities.

This evolution was initially due to the need for information about survival rates from cancer at the population level, and later for studying the effects of various services such as prevention strategies, early diagnosis, treatment and care [2]. In fact, a cancer registry is an information system designed for the collection, management, and analysis of data about persons diagnosed with a malignant or neoplastic disease.

Cancer registries are recognized as being essential components of national cancer control programs [3], and they have a role in the monitoring and evaluation of health services so that local, state and national cancer agencies can use registry data in defined areas to make important public health decisions that maximize the effectiveness of limited public health funds.

Registries are also playing a role in the evaluation of the efficacy of treatment interventions. A wide range of performance measures of the processes of clinical care [4] are available and provide information on cancer disparities and disease burden [5]. Cancer Registries seek information from multiple sources. The idea is to collect a set of variables for every case of cancer diagnosed in the target population, ideally from all those in which the cancer case may be diagnosed or treated. The list of variables recorded in each case depends on the feasibility of capturing the required information in a large proportion of cases and on the resources available for doing so. The various national and international registry groups prescribe data sets for their members that are subdivided into essential variables and those considered very desirable.

The expanding roles of registries in monitoring factors that influence outcome (survival and quality of life), and the nature and quality of the care received by cancer patients, demand a dataset that includes many more variables than have traditionally been collected. The increasing availability of computerized databases that can be linked with cancer registries has enabled the capture of information about cancer patients including, for example, details of treatment and clinical status through health insurance records or hospital information systems.

Another frequently used technique to extend the dataset is geocoding [6] that permits the linkage of census information from the same smallest geographic unit as the patient with reported age/gender and population data. This practice has been widely used to derive indicators of social status or deprivation and environmental factors [7].

Cancer registries are underused if we consider that there is a tremendous amount of valuable information that cancer registrars collect, but all too often, this information isn't used to the full extent possible in many organizations. Nevertheless the pace in which science, clinical medicine, and the environment is changing is pushing cancer registrars to their limits and beyond.

Furthermore, the information expected by the various stakeholders often produces competition or even conflict between each other.

Cancer registrars are at a turning point because health care reform legislation, and the increasingly rapid deployment of electronic health records, have made cancer registries more valuable than ever. These carefully collected data need to be transformed into useable knowledge.

The primary responsibility of the cancer registrar is to ensure that timely, accurate, and complete data is incorporated and maintained on all types of cancer diagnosed and/or treated within an institution or other defined population. Priorities and targets in the short and long term must be defined and related to the environment in which a cancer registry exists and operates, as well as charting the needs of the surrounding area with an enhanced mission and a new vision.

It is a new way to look at how we are gathering and using our data, taking advantage of all the opportunities that technological progress makes available.

The electronic health records, even if in fragmented hybrid records located in fractured healthcare systems, can allow researchers to meet the information needs when the registry database is complete, even several years after the incident data of the cases when individuals might be hard to trace (or may have even died).

Cancer registrars have skills and abilities in setting up and managing databases and in quality assurance systems, wherein one can find a balance between the comprehensiveness and the quality, between the completeness and timeliness that the information provides. From registries, we are able to select the "right" information from numerous sources and transform it into useful knowledge.

The next step is to provide leadership by collaborating with informatics and information management professionals so as to ensure that cancer registry requirements are considered during electronic health records selection, planning and implementation.

A proactive, anticipatory, change-oriented and self-initiated behaviour should be invoked rather than just merely reacting.

Scientific progress requires the exchange and discussion of data and ideas, and the sharing of cancer data is an area of paramount importance. However, it is a time spending activity where Information Technology may be helpful. The online communication of science is evermore an ethical need, and the inevitability of the process must now be accepted, establishing clearer policies and procedures.

Cancer grid metadata registries and web based toolsets which use maps, charts and data tables to display the information for the area of interest as well as the download of the related statistics are becoming more popular. The NCI's approach to cancer data is one such example of standardized data which is easy to interact with, and other data sets are available too (e.g. E-atlas) [8].

The health communication strategies for a cancer registry should ensure valid and reliable information, without running the risk of data being misinterpreted. It could also provide all policymaking in health care with a meaningful analysis and become a tool for the clear interpretation of the data, as well as aid in the development of educational programs for health care providers, patients and the general public.

The value of cancer registrars in collecting and managing cancer data remains unquestionable, and will continue to be an asset to organizations at all levels. Cancer registries are valuable research tools for those interested in the etiology, diagnosis and treatment of cancer.

Change is not new to cancer registrars. Continual learning from and enhancement of the data collected to keep pace with modern medicine and science is driving the need for cancer registrars to develop new ways of thinking and doing their work. It is intended to provide a bridge between the world of research and the world of decision-making and, ultimately, the general public.

Cancer registration has come a long way in the last 60 years and future expansion in the coverage and scope of this work seem like a reasonable prediction, unless registries fall victim to objection to their work from informed - consent ethicists.

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