

The role of a cancer registry in a health care system

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A cancer registry is a list of all individuals diagnosed with cancer in a country or a region, collected directly from hospitals, relevant organizations and healthcare professionals. In England, the cancer registry is managed by the National Cancer Registration and Analysis Service (NCRAS). This is a team that works closely with the National Health Service (NHS). The registry receives details about everyone diagnosed with cancer directly from the hospital or healthcare professionals. The NCRAS works in close liaison with UK Cancer Research which is one of the largest cancer research organization in the world. The UK cancer research fund research applies to all aspects of cancer from its causes to treatment and prevention.

The efficient running of a cancer registry is a mammoth task and needs a group of dedicated professionals, huge financial resources, equality of health care provision- at least at the basic level, constant positive interaction with department of health and a willingness at the highest level to improve patient outcomes.

The five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) which are geographically, historically, culturally and politically related, are a shining beacon for setting up and efficient running of a cancer registry. Each of the Nordic countries has a population-based cancer registry. The Nordic cancer registries collaborate closely, and annual meetings are held to discuss standardization of registration and classification and to plan joint projects. Notification is compulsory in all the Nordic countries. The Danish Registry is the oldest, having been founded in 1942. Notification is compulsory even for private physicians. Almost 100% coverage of incident cases is achieved in all the registries, which rely on reporting from multiple sources, including doctors, hospitals, institutions with hospital beds, and pathological and cytological laboratories. Information is also collected from death certificates. In all the Nordic countries, each inhabitant has a unique personal identification number, which makes identification simple and reliable. The registries collect a minimal set of data on

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each cancer patient, which is used for routine statistical reporting.

The uses of population-based cancer registration data may be summarized as follows:

- (1) They describe the extent and nature of the cancer burden in the community and assist in the establishment of public health priorities.
- (2) Etiological studies are designed in and around the data collected by cancer registries.
- (3) They help in monitoring and assessing the effectiveness of cancer control activities.

The data collected as a result of this phenomenal work goes through an army of statisticians who work out the epidemiology, demographic distribution, causes, screening, prevention, treatment, prognosis and survival figures for cancer. This is dynamic data which is analyzed, presented and compared with current policies to constantly improve cancer related morbidity and mortality. The data is robust and depicts cancer related figures for entire populations in the blink of an eye. This information helps make comparisons between current and previous cancer related investigations, treatments and mortalities. It also helps determine the future direction of cancer treatment policies. The data audits the effect of surgical, oncological, medical and pharmacological cancer treatment. It will clearly highlight if there are units or individuals achieving better results than the others.

Some basic requirements need to be fulfilled before setting up a population-based cancer registry:

- (a) The catchment population need to be clearly defined. Geographical boundaries along with responsible bodies, as far as the provision of health care is concerned, should be made obvious.
- (b) A robust census process should be able to provide reliable population denominators.
- (c) A readily accessible and reliable health care system where majority of cancers are diagnosed, treated and registered.

(d) Easy access to case-finding sources such as hospitals, pathology departments, death certificates and other sources of clinical data within the catchment area and in the surrounding areas.

In developing countries like Pakistan, a cancer registry is virtually non-existent. There are several reasons for this. First and foremost, it is a deficient health care system which is out of reach for majority of population due to socioeconomic and geographical factors. There are not many dedicated cancer centers and often cancer surgery is performed in non-specialist centers to the detriment of the patients. There is a lack of population census denominator data — there are no unique identification numbers/ markers for patients to have a population based registry. The few centers of excellence are completely out of sync with the rest of the health care system. There is no central registration, regulation or monitoring of the health care providers, both individuals and organizations', dipping in and out of cancer treatment.

In my own specialty of colorectal cancer, population based cancer registry has completely overhauled the management of cancer with massive improvements in cancer related morbidity and mortality. In a study from Singapore¹ data was analyzed for 10,000 patients treated

for colorectal cancer between 1968-1992. Huge improvements were seen in survival figures both for colon and rectal cancer over this period. This data was useful in setting up future cancer policies for this region. Lang et al² followed almost 51, 000 patients with colorectal cancer for over 5 years from the SEER Medicare Database in the US. They concluded that the technological advances and changes in patient demographics had the largest impact on improved colorectal cancer survival during their study period.

Patients with cancer and their families suffer irrevocably by the physical and socioeconomic burden of this disease. We owe to our patients to set up a health care system that not only specializes in cancer treatment but is robust enough to set up cancer registries for continual outcome improvements.

References

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