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RESEARCH ARTICLE

THE ROLE OF CANCER REGISTRIES.

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Abstract

Cancer registration is important for epidemiology, planning, cancer policy and research. The network of cancer registry across India is widened and a process began in 1960's. The cancer registration in India is expanded day by day including many Hospital Based Cancer Registries and Population Based Cancer Registries. Projection of cancer incidence is essential for planning cancer control actions, health care and allocation of resources. The incidence or the projection of cancer is made from the cancer registry. The cancer registry is an organization for the systematic collection storage, analysis, interpretation and reporting data on subjects with cancer. The main objective of these registries is to produce statistics on the occurrence and to provide a framework for assessing and controlling the impact of cancer in community. The emphasis will be an epidemiology and public health. The data will be used for obtaining information on burden and patterns of cancer. It can also provide a focus for research into etiology and prevention (primary and secondary) and patient care. The main role of cancer registry is to capturing a clear and complete picture of cancer in India.

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Introduction:-

Cancer is the major cause of morbidity and mortality around the world. Cancer is the second leading cause of death after cardiovascular diseases (CVDs). As per the latest GLOBOCAN 2018 there will be an estimated 18.1 million new cancer cases and 9.6 million deaths in 2018. Overall Lung cancer is the most commonly diagnosed cancer followed by female breast cancer. So for incidence of cancer in India is concerned, it is also experiencing a simultaneous increase in cancer. In India, in 2018 over 1.1 million new cancer cases patients were registered and 0.78 million people died due to cancer. As of now, there are 33 PBCR and hundred HBCR in India functional currently.

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The cancer registries are an essential part of any rational programme of cancer control (Muir et al., 1985). Its data can be used in a wide variety of areas of cancer control ranging from etiological research, through primary and secondary prevention to health-care planning and patient care, so benefiting both the individual and society. Although most cancer registries are not obliged to do more than provide the basis for such uses of the data. Cancer registries possess the potential for developing and supporting important research programmes using the information which they collect. The emphasis will differ from registry to registry according to local circumstances and interests. In general terms, the data become useful for more and more purposes as they are accumulated over longer periods of time.

Cancer epidemiologists use their knowledge of the distribution of cancer in human populations to search for determinants of the disease. Evidently, the cancer registries provide a crucial basis for epidemiology since it holds information on the distribution of cancer, including non-fatal cases. The cancer registries provide statistical information on the number of cases in the population. This may be used for the planning and establishment of cancer treatment and care facilities directed towards various types of cancer. Geographical differences in cancer occurrence may be taken into account, and so may time trends in the incidence of cancer. Knowledge of trends may then be used for the projection of future incidence rates, case loads, and needs for treatment facilities.

Cancer registry is the systematic collection, storage, analysis, interpretation and reporting of data related with cancer. Cancer registries may be the only way of obtaining information on the burden and pattern of cancer in developing countries as well as providing a focus for research into etiology and prevention. There are two types of cancer registries which is available namely Hospital Based Cancer Registry (HBCR) and Population Based Cancer Registry (PBCR). The purposes of a hospital-based cancer registry are by definition different from those of a population-based registry.

Hospital based cancer registries are concerned with the recording of information of cancer patients seen in a particular hospital. The main purpose is to contribute to patient care by providing readily accessible information on the cancer patients, treatment and its results. The data is mainly used for administrative purposes and for reviewing clinical performance and to some extent for epidemiological purposes. HBCR cannot provide measures of the occurrence of cancer in defined population because it is not possible to define their catchment population that is the population from which all the cases rise. The purpose of the hospital-based registry is to serve the needs of the hospital administration, the hospital's cancer programme, and above all, the individual patient. The establishment of individual hospital cancer registries is historically rooted in the belief that individual patients are better served through the presence of a registry, since the registry will serve to ensure that patients return for follow-up examinations on a regular basis.

Population based cancer registry seek to collect data on all new cases of cancer occurring in a well defined population. PBCR can also be used for evaluating cancer control programs by helping to establish priorities and forecast future needs, by monitoring cancer occurrence in relation to the prevalence of important risk factors, by helping to assess and monitor the effectiveness of screening programs and by evaluating cancer care through survival statistics. Most cancer registries follow up each patient for death, and collect information on date and cause of death. An important indirect contribution to patient care and to health-care planning is the monitoring of population-based survival rates some of the important Objectives of PBCR are mentioned below:

1. To determine the incidence and prevalence of cancer.
2. To monitor trends and patterns of cancer
3. To identify the high risk population, if any
4. To use the data acquired for planning prevention and therapeutic measures at the hospital and state levels.

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. They may be used as a source of material for etiological studies.
3. They help in monitoring and assessing the effectiveness of cancer control activities.

The aim of any cancer registry is to make aggregate and individual data accessible for medical, research and statistical purposes. To be of value, data recorded must be accurate, reliable and as complete as possible. Both the procedures of registration and the maximal use of the data make it essential that individuals can be identified.

Accuracy and completeness can be achieved only if the public and the treating physician are confident that the data required are necessary for the aims and objectives of the registry and that the data will be safeguarded. Safeguarding the data in the cancer registry implies not only that they are sufficiently secured against unauthorized access, but also that they are not used for purposes other than those for which they were collected. The aims of confidentiality measures in cancer registration are thus to ensure

1. The preservation of anonymity for individuals reported to the registry and if necessary also for those making such notifications;
2. That cancer registry data are of the best quality possible,
3. That the best possible usage of cancer registry data is made for the benefit of the cancer patient, for cancer control and for medical research.

Operational tasks of the cancer registry

In some way or other, every registry must carry out the tasks outlined below.

Data collection

No registry can operate without some mechanism for data-gathering.

Record linkage

Frequently the registry will receive records relating to an individual patient from more than one source—for example a hospital, a pathology laboratory and an office of vital statistics. These records must all be linked to the same patient so that the details of each patient are complete and there are no duplicate registrations for the same tumor. The linkage is a crucial operation, the importance of which cannot be overemphasized.

Data organization

Data for scientific study must be held in an orderly manner. Information arrives at the registry in a more or less structured format—partly on well-designed forms created specifically for the purpose and partly on other reports of a more descriptive nature and designed primarily for other purposes. Computerized data will come to the registry in an already processed, or partly processed, form but it is likely that further organization of the data will still be required in the registry.

Medium conversion

Even in a manual registry, it is unlikely that the information will be retained entirely on the original documents. In the computerized registry, information on paper will have to be transferred onto a machine-readable medium, punched cards, magnetic tape or disk. The computerized registry may hold its data on more than one medium.

Enquiry generation and follow-up

Frequently, the acquisition of an item of information alerts the registry to the fact that information it already has may be incomplete or incorrect. For example, the arrival of a death certificate carrying a diagnosis of malignant disease relating to a recently deceased patient who is not already registered indicates the possibility that the registry has failed to acquire information at an earlier stage. The registry must then make further enquiries in an attempt to obtain full details or to resolve any inconsistencies. Many registries regard the follow-up of their patients as one of their most important functions, and this may take an active or passive form. Active follow up involves routine periodic requests for further data about registered patients

Data analysis

Data will be analyzed by using Excel and SPSS software. Quantitative Data will be expressed using Range, Mean and Standard Deviation, while qualitative data will be expressed in the form of percentage, frequency and diagrammatically. Qualitative data will be analyzed using Chi-square test, Fishers exact test, and also these methods are used for comparison. Also survival rate will be found by Kaplan Mier Survival Method, and simple linear regression analysis will be used to find out trend values. Further epidemiological measures will be used to ascertain the burden of disease.

Conclusion:-

Cancer registries are very useful for cancer control program and also used for making policies regarding cancer.

Conflict of interest:

No

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