

Use of results of Population-based Registries in Palliative Care Planning

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Abstract

The presentation was an attempt to answer some questions related to the use of registry data for planning of delivery of health care in general and palliative care in particular.

What is the cancer burden? Until very recently it was difficult to get an estimate of the cancer burden in Egypt and most countries in the region. In Egypt, there are eight cancer centers affiliated to the Ministry of Health in addition to the National Cancer Institute of Cairo University and the Cancer Institute of Southern Egypt affiliated to Assiut University. Nonetheless, all statistics were hospital-based and incidence rates were completely absent.

How to get incidence and prevalence rates using MECC data? In 1988, the MECC Joint Registration Project was established in five countries in the region, namely Cyprus, Egypt, Israel, Jordan and Palestine. Turkey was included at a later stage. Incidence rates are now available for the years 1999 – 2002 in all registries. Prevalence could be easily estimated by multiplying incidence x duration of disease. The latter is usually empirically considered = three if the median survival is not exactly known.

What are the characteristics of the population-based Cancer Registry in Egypt? Like all MECC registries except Israel, data collection is done actively. Methodology is standardized using training courses and manuals and quality control is achieved through internal auditing and periodic external auditing. The registry in Egypt covers one Governorate, Gharbia, in the middle of the Nile Delta.

Is it possible to infer from the registry results to the entire country? The Human development Index (HDI) used was used to evaluate how far does Gharbia represent other governorates in Egypt. The HDI is a composite index that takes into consideration a big set of demographic factors, health indicators and socioeconomic characteristics. It was developed by the National Planning Institute in Cairo and used in their reports about Development in Egypt. The HDI of Gharbia was just above the median of all Egyptian Governorates .

What are the estimates for Egypt? Using data of Gharbia registry and the relation between incidence and prevalence; the following estimates could be calculated

- Prevalence = Incidence x Duration
- Incident cases in Gharbia = 3,300
- Median survival = 3 years
- Total # of cancer patients \simeq 10,000
- Patients in need of palliation (SEER stage 7): \simeq 25%
- Number of patients in need of palliation in Gharbia \simeq 2,500/year.
- Gharbia represents 6.5% of Egyptian population \rightarrow approximately 40,000 patients in need of palliation every year in the entire country

Take home message:

- Use Cancer Registries to estimate cancer burden.
- Data on new cases (incidence) could be used to estimate the number of existing cases (prevalence) and need for palliative care.
- Registries could be of great help in coordination of research