COMMENTARY

Role of the Cancer Registries in Determining Cancer Mortality in Asia?

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Abstract

Data on incidence, prevalence, and disease specific mortality are frequently incomplete, not very reliable or are lacking in many countries particularly in Asia and Africa. In the absence of dependable data from the Civil Registration System (CRS), many countries have developed their own Sample Registration System (SRS). Due to several socio-economic constraints cause is not adequately noted in the death certificates. Sample registration system practice in India helps in this but for correlating with cancer registry data this is not the optimal. When cancer morbidity figures from SRS system and cancer registry are compared the SRS figures are low. Reasons for fewer cancer deaths in Municipal Corporation reports may be due to that they only look at primary cause of death and overlook the secondary or underlying causes. There are also a number of reasons for under-registration of cancer deaths in cancer registries but they nevertheless give a more accurate picture. Many registries collect follow-up information for survival studies, which is also helpful to improve cancer mortality data. Tumour registries also represent important resources for rapid identification of cancer survivors for research studies.

Key Words: Mortality data - Sample Registration System - follow-up data - research

Introduction

Burden of disease can be assessed through a number of epidemiological parameters such as incidence, prevalence, mortality and disability caused by the disease. The global burden of disease study conducted by WHO, World Bank and Harvard School of Public in 1990s, further developed sophisticated epidemiological parameters on mortality, morbidity and disability to provide a composite index on burden of disease like – YLD (Years of Life Lived with Disability) and DALY (composite Index of Burden of Disease). However data on incidence, prevalence, and disease specific mortality are frequently incomplete, not very reliable or are lacking in many countries particularly in Asia and Africa.

In the absence of dependable data from the Civil Registration System (CRS), many countries have developed their own Sample Registration System (SRS). Under this scheme in India the SRS collects the information on fertility and mortality indicators at state and national levels. The SRS mechanism involves collection of data through two different procedures. Viz. continuous enumeration and retrospective half yearly survey by a process of matching two records and subsequent field verification of unmatched and partially matched events. The methodology provides a cross check on the correctness of events of birth and deaths listed in both the records (Sample Registration System-Report).

In order to estimate the cancer mortality from other than cancer registries paucity of adequate data on the one hand and complex pathogenesis of disease on the other make for complexity, particularly in rural populations. In India, major death registration sources are neither reliable nor complete. A large percentage of cases go unregistered and out of registered cases only 10% of deaths are medically certified (Ramanakumar and Yeole, 2005). Due to several socio-economic constraints cause is not adequately noted in the death certificates. Sample registration system practice in India helps in this but for correlating with cancer registry data this is not the optimally helpful. When cancer morbidity figures from SRS system and cancer registry were compared the SRS figures are at low level (Ramanakumar and Yeole, 2005).

There are three main sources of cancer deaths to be collected in the registry. Vital statistics departments of municipal corporation, Medical records department of collaborative hospitals and active follow-up through telephone, postal enquiries and house visits.

In cancer registries, completeness of registration, certification of deaths, disease coding practices, cause of

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death, basic information like address and demographic information specially duration of stay and primary cause of death are the main problems to be encountered. There are number of reasons for under registration of cancer deaths in cancer registries. The death certificates are not available at source of information. The death might have occurred out side the area of registration. The deaths may not have registered at vital statistics department of Municipal Corporation. If the cancer has long survival and death was not due to cancer there is high probability that the information that the disease had cancer had been totally forgotten. Migration also play important role. The death registration system may be defective at vital statistics department. Cause of deaths may be erroneously reported like old age, etc.

Mumbai Cancer Registry was established in 1963 for Mumbai Municipal Corporation area. At present this registry covers about 12 million population having 437.7 sq kms area. The death registration system in Mumbai is quite complete i.e. 98.7% (Gupta and Ramarao, 1973). Reporting of cause of death as far as cancer is concerned is quite good – site non specific deaths are less than 1%. About 9500 incidence cases are registered per year at this registry. From the department of Vital Statistics of Municipal Corporation 6200 cancer deaths are collected out of which 5000 are residents, 800 are non residents and 400 are residents not known.

Method of collection of cancer death information in this registry is that staff of the registry visit the Municipal corporation's office to scrutinize all the deaths and copies information on deaths mentioning cancer of tumour has primary or secondary cause of death. Residents deaths to incidence cases gives M/I Ratio. For Mumbai it is 52.6% which is quite comparable with European and developed countries.

The municipal corporation also publishes annual report on vital statistics. When the comparison is made for the year 2000 data for cancer death information by the two sources Municipal report has reported only 4320 cancer deaths as against 6200 cancer deaths collected by the registry. This implies 30% more cancer deaths. Reasons for fewer cancer deaths in the Municipal Corporation report may be due to that they have been looked only at primary cause of death and overlooked the secondary or underlying cause of death.

When the site specific deaths are compared in both the reports deaths due to secondary sites, glands, brain tumours, leukemia, were very minimally reported in the corporation reports. This may be due to lack of training of the coder of vital statistics department. In short all the deaths recorded at Vital statistics should be scrutinized by trained registry staff.

In India other than Mumbai registry, methods have also been applied for improving cancer mortality data in many sites. It is well known that in India except Mumbai, death registration is quite incomplete and cause of death reporting system is not at satisfactory level. When registry started functioning the M/I ratios were for Chennai in 1982 was

23%, for Bangalore in 1982 was 17%, for Bhopal in 1987 was 19% and for Delhi in 1987 was 19%.

Chennai registry was established in 1982 by cancer institute. At present it covers population of 4.3 million having an area of 170 sq kms. Having incomplete reporting of cancer deaths and poor notification of cause of deaths this registry has improved the problem of under registration by following way. This registry records all the deaths regardless of cause of death from the vital statistics department and hospital records. Then all the deaths are computerized. All this mortality data is matched with morbidity data. Matched deaths are then updated in morbidity data. Unmatched cancer deaths are then traced back by house visits. Cases with no other details are registered as "DCO's". By this method the M/I ratio of this registry has been improved from 24% to 54% (Shanta and Swaminathan, 2004).

The Indian Council of Medical Research, New Delhi established a population based registry at Bhopal, in 1986 with the aim to evaluating carcogenic effects of methyl isocynate. This registry covers a 285 sq km area having a population of 1.4 million. Death registration system is far from adequate, resulting in under registration of cancer mortality. This registry has identifying burial grounds and crematoriums for death registration system implementing same methodology as of Chennai PBCR. It has been shown that M/I ratio which was around 19% initially has gone up to 36% (Bharadwaj and Shrivastav, 2005).

Tata Memorial Hospital, Mumbai, in collaboration with Indian Council of Medical Research, New Delhi, established first rural cancer registry at Barshi in Solapur district of Maharashtra in 1987. At present it covers a 0.4 million population with an area 3717 sq kms. Information on deaths is collected from village death records and also from the local community. As death records are not generally medically certified relatives of all diseased are contacted to collect the relevant information to assist in "follow-track" to the medical records in the treating hospital or physician to identify proven cancer cases. In this registry the M/I ratio is 79% (Dinshaw and Nene, 2005).

Many registries collect follow-up information for survival studies. This procedure is also helpful to improve the cancer mortality in registries. Mumbai cancer registry collects the follow-up information for most of the major sites after 5 years for each case To get the follow-up information cancer deaths are first matched with data collected from the vital statistics department (50%). To get a follow-up information from remaining patients by telephone and postal enquiries (15%) and house visits (10%) carried out. Due to this procedure there has been improvements in cancer mortality about 10% (Sankarnarayan et al., 1998).

Special cross sectional surveys in registration areas are also helpful in improving cancer mortality statistics of the registry. Tata Institute of Fundamental Research, Mumbai has carried out a special health survey for Mumbai City population during 1991-94. It was observed that there was been improvement of 4.2% in cancer mortality data.

There is effective use of cancer registries for cancer

survivorship research has been shown (Pakitil et al., 2001). Two hospital cancer registries in USA were used to recruit a large sample of breast cancer survivors for a study examining the late reproductive effects of breast cancer treatments. Although there are some limitations to this approach including non-response of a significant number of breast cancer survivors, tumour registries represent an important resources for the rapid identification of cancer survivors for research studies.

Cancer mortality through cancer registries in Asia, Africa, may be improved as follows : It is well known that usual method of mortality data collection as in the west will not give reliable and complete data. It is absolutely necessary that improvements in the system of registration of deaths include implementation of standard core information mortality form in all hospital-nursing homes in registration area and at birth and death registration units of vital statistics department and at burial grounds and crematoriums. For improvements in the system of certification of cause of death stress on underlying and antecedent cause of death should be given. Medical personnel should be educated on the method of certifying cause of death. Cancer registration topic should be introduced in curriculum of final year MBBS at least one question on this topic in any clinical subject. Verbal autopsies have to be more rigorous and standardized procedures before exact cause of death can be ascertained.

In conclusion, cancer mortality assess is an important function of any cancer control programme. Cancer registries of the sound system for evaluating cancer mortality. Because offer scientific discipline in cancer registration system the mortality rates obtained through cancer registry will be optimally productive. In Asia in general and in India in particular, cancer registries have played a crucial role in providing important improved cancer mortality data.

References

Bharadwaj AK, Shrivastav A (2005). Cancer Incidence and Mortality in Bhopal, Annual Report 2001, Bhopal, India.

Dinshaw KA, Nene BM (2005). Cancer Incidence and Mortality in Barshi –2001, Annual Report, Barshi, India.

Gupta RB, Ramarao G (1973). Effect of elimination of different causes on expectations of life, Mumbai. *Ind J Med Res*, **?**, 950-58.

Kurkure AP, Yeole BB, Lizzy Sunny, Koyande SS (2005). Cancer Incidence and Mortality in Greater Mumbai, 2001, Indian Cancer Society, Mumbai, India.

Municipal Corporation of Greater Mumbai, Annual Report- 2001, Mumbai, India, 2003.

Pakitil AT, Khan BA, Petersen Let al (2001). Making effective use of tumour registries in cancer survivorship. *Cancer*, **92**, 1305-14.

Ramana Kumar AV, Yeole BB (2005). Assessing cancer burden in rural India : An analysis by cause of death statistics. *Asian Pac J Cancer Prev*, **6**, 221-3.

Sample Registration System, Statistical Report – 1998, Registrar General, New Delhi, India, 2000.

Sankarnarayan R, Black RJ, Parkin DM (1998). Cancer Survival in Developing Countries. IARC Scientific Publication No.145, Lyon, France.

Shanta V, Swaminathan R (2004). Cancer Incidence and Mortality in Chennai, 2001, Cancer Institute, Chennai, India.