
RESEARCH COMMUNICATION

An Independent Survey to Assess Completeness of Registration: Population Based Cancer Registry, Chennai, India

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Abstract

Cancer registration in the population based cancer registry (PBCR), Chennai, India, is carried out by active methods. It undertakes re-screening of cases in government hospitals and Cancer Institute (WIA), trace back death certificate notifications and collect information on all the deaths, irrespective of the stated cause on the death certificate, occurring in the registry area routinely to reduce the under-registration of incident cancer cases and associated mortality. The completeness of registration during 1982-95 was assessed by conducting an independent survey in randomly selected areas in Chennai. The total number of households covered in the survey was 7737 and were collected which constituted 1% of the Chennai city population. The response rate to the survey was 96%. A total of 42,502 incident cancer cases were registered in Chennai PBCR during 1982-95. The total number of cancer cases that were already registered in PBCR from the survey area during 1982-95 was 208. Out of 208 cases, 91 (44%) were identified in the survey; the families of the remaining 117 had migrated out of the surveyed area. Two new cancer cases hitherto unregistered in the PBCR during 1982-95 were identified from the survey. Based on the survey, it is estimated that the completeness of cancer registration in Chennai PBCR is 96%, which is comparable to those of other registries in the world.

Key words: Population based cancer registry - completeness of cancer registration - data quality - survey of general population - Chennai

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Background

The population based cancer registry (PBCR) in Chennai (in southern India) was established at the Cancer Institute (W.I.A) in July 1981 and the data collection commenced from 1st January 1982. It is one of the six PBCRs in the network of the National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research (ICMR), Government of India. The PBCR in Chennai covers an area of 170 km² and a population of 4,216,268 (M:2,161,605; F:2,054,663) with a sex ratio of 951 females to 1000 males at present [Census of India, 2001]. A total of 42,502 incident cancer cases were registered during 1982-95 with a male-female (M:F) ratio of 1:1.17. The average annual age adjusted incidence rate of all sites together was 99 per 100,000 among males and 118 per 100,000 among females [Shanta et al., 2000].

Cancer registration is done by active methods in India: this is dependent on the unstinted cooperation of numerous personnel from various medical institutions in and around the city of Chennai and staff of the vital statistics department (VSD). The extent of coverage in the form of number of sources of registration in Chennai PBCR has risen from 92 sources in 1982 to 215 in 2001 due to the advent of new private hospitals in Chennai. The proportion of cases registered from government hospitals as the primary source has shown a decline from 67% in 1983-87 to 51% in 1993-97; there has been a corresponding increase in the cases registered from private institutions as the primary source from 10% in 1983-87 to 28% in 1993-97. This might be a reflection of a change in health seeking behaviour among cancer patients as well as the availability of cancer directed treatment facilities in many private hospitals in Chennai in recent years. The number of cancer cases with microscopic

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verification has increased over the years: from 68% (M:63%; F:71%) in 1983-87 to 78% (M:75%; F:80%) because of the increased cooperation from pathology departments in government and private hospitals over the years.

The registry is always conscious of maintaining a high quality of data collection. Quality control exercises have formed an integral part of the cancer registration procedures. The validity of data collected by the social scientists of the Chennai PBCR are monitored by conducting data quality exercises periodically on abstraction of data from medical records and coding of the diagnosis. Once in 6 months, an independent social scientist was deputed to collect information on all the cancer cases attending the government hospitals from cancer out patient/in patient services, pathology and medical records department. The data collected were linked with the cancer registry data already collected from these sources to identify apparently missed cases from routine registration. This exercise resulted in the decline in the number of cases identified on re-screening over the years: from 4.5% in 1983-87 to 1% in 1993-97 [Swaminathan et al., 1997]. Those cases identified on re-screening were subsequently included in the registry database. However, re-screening exercise is not carried out in private hospitals due to varying extent of accessibility to records and we expect 1% (the same proportion recaptured from government hospitals) of cases being missed from registration in PBCR from private hospitals.

Cases registered on the basis of death certificate only (DCO) give an extent of missing of cases in routine registration practices when they were alive. The proportion of DCOs has decreased from 8% in 1983-87 to 3.5% in 1993-97. This proportion is currently the least among all older PBCRs that are in the National Cancer Registry Programme network in India: Bangalore: 9% in 1983-87, 13% in 1987-91 and 9% in 1992-96; Mumbai: 10%, 8% and 7%; Chennai: 8%, 5% and 4% respectively [National Cancer Registry Programme 1994, 2000(a), 2000(b); Jussawala et al., 1999; Shanta et al., 2000; Yeole et al., 1988].

An independent survey of the general population was carried out in two randomly selected areas in Chennai to evaluate the completeness of coverage in PBCR, Chennai during 1982-95. The results of the survey are reported here.

Materials and Methods

Cancer registration

Cancer is not a notifiable disease in India. Hence, registration of cases is done by active method: the trained social scientists of the registry regularly visit all the government and private hospitals, nursing homes, pathology laboratories, imaging centres and hospices, located in and around the city, to collect the required data on incident cancer cases in a standardized proforma by interviewing the patients and/or the accompanying persons and abstracting the clinical

data from medical records. The residential criterion for inclusion is that the case should have been residing in Chennai for at least a year at the time of first diagnosis of cancer. Only invasive cancers are reported. Chennai PBCR has always accorded a special attention in optimizing the completeness of collection of death information of the registered cancer cases. The main source of mortality information has been the vital statistics department. Till 1991, information on deaths whose cause was mentioned as "cancer" or "tumour" on the death certificate was collected from VSD. From 1992, the registry staff started to abstract the information of all deaths (irrespective of the stated cause of death in the death certificate) that were registered in VSD to diminish the under registration of mortality data. The methods of collecting and processing morbidity and mortality data are described in detail elsewhere (Shanta et al., 1994; Gajalakshmi et al., 1998).

Survey of the general population

Two areas in Chennai were selected by simple random sampling to conduct a survey of the general population during 1997-98 to identify all cancer cases who were residents of that area and were diagnosed during 1982-95. The trained field investigators visited all the residential households in the selected areas to ascertain the data on identification details and history of cancer among the family members (alive or dead) since 1982. The respondents were either the head of the family or any adult person closely related and living with the family. Repeat interviews by one social scientist of the registry was done for about 1% of the total subjects registered from the survey to check the validity of survey data. All the subjects who were reported as having had cancer since 1982 in the survey area were matched with the registration records in PBCR during 1982-95. Matching was done both by computer program and visually perusing alphabetical lists of cancer cases. House visits for cancer cases that were not identified from the survey in 1997-98 but were originally registered from the survey area in PBCR during 1982-95 were undertaken by the social scientists of the registry to find out the reasons for not identified in the survey.

Results

The total number of households covered in the survey was 7737 and the total number of subjects registered was 32,171 constituting 1% of total estimated population of Chennai city in 1998. The response rate was 96% (7450/7737). The head of the household as a respondent constituted 54% followed by spouse (42%), son/daughter (2%), parents/siblings (1%) of the head of family and others (1%) accounted for the rest. The distribution of literacy status among 32,171 individuals in the study revealed 16.6% (Male:11.9%; Female:21.6%) to be illiterates and 12.3% (M:15.3%; F:9.2%) having had more than 12 years of education.

The total number of incident cancer cases registered in

Table 1. Number of Cancer Cases Identified in the Survey (1997-98) and Cancer Cases Registered in PBCR during 1982-95 from the Survey Area by the Classified Registration Period

Registration period: PBCR	Survey 1997-98		Registered in PBCR (1982-95) but not identified from survey (1997-98)	Total cases registered in PBCR from survey area in 1982-95
	Identified from survey and matched with registry records (1982-95)	Identified from survey but not registered in PBCR (1982-95)		
	Number	Number		
1982-86	9	2	39	48
1987-91	31	0	44	75
1992-95	51	0	34	85
Total	91	2	117	208

PBCR: Population Based Cancer Registry

PBCR during 1982-95 was 42,502 and from the survey area was 208. Of these 208 cancer cases registered from the survey area during 1982-95 in PBCR, 91 were identified from the survey and 117 were not identified. However, the survey identified two cancer cases that were not registered in PBCR from survey area during 1982-95. Both these cases were first diagnosed during 1982-86. Among the 208 cancer cases registered in PBCR during 1982-95, the proportion of cases identified in the survey varied between 19% (9 out of 48) for cases diagnosed in 1982-86 to 60% (51 out of 85) in 1992-95 (Table 1).

There were no cancer cases that were missed from registration in PBCR among those who had attended any of the government hospitals (Table 2). Both the cases that were identified from the survey (1997-98) and not been registered in PBCR during 1982-95, had attended private hospitals which were not covered by the registry during that period and were later included in the list of sources of registration of the registry.

Visits to the houses of cancer cases registered in PBCR (1982-95) but not identified from the survey (N=117) were carried out to find out the reasons for not identifying them

in the survey. A majority of the families (N=98; 84%) had shifted their residence elsewhere before or after the death of the cancer case. The houses of 7 (6%) were demolished while no information was available on the rest (10%) of the cases (Table 3). A majority of the latter was registered in PBCR during 1982-86. There is a likelihood of these families having migrated outside the survey area long before the survey was carried out and those currently living here might not be aware of their whereabouts.

Discussion

An independent survey of the general population, conducted to evaluate the completeness of coverage in Chennai PBCR for the period 1982-95, was part of a multi centric study by the National Cancer Registry Programme, Indian Council of Medical Research, Government of India and was the first of its kind in the country. The number of cancer cases registered in Chennai PBCR from the survey area during 1982-95 was 208 or 0.5% of the total cancer cases registered in PBCR during the period. Of these, 91 (44%) were identified from the survey and the rest (n=117) were not. The proportion of cancer cases identified in the survey (1997-98) shows an increasing trend from 19% in

Table 2. Cancer Cases Identified from Survey (1997-98) and those Registered in PBCR from the Survey Area (1982-95) by Classified Sources of Registration

Sources of Registration in PBCR	Survey 1997-98		Total cases identified from survey (1997-98)	Total cases registered in PBCR from survey area in 1982-95
	Identified from survey and matched with registry records (1982-95)	Identified from survey but not registered in PBCR		
	Number	Number		
Government hospitals	37	0	37	103
Private hospitals	54	2	56	105
Total	91	2	93	208

PBCR: Population Based Cancer Registry

Table 3: Reasons for cancer cases registered in PBCR from the survey area during 1982-95 and not identified from the survey (1997-98)

Reason	Number	%
Shifted elsewhere before/after death of cancer case	98	83.2
House sold/ Demolished	7	6.0
No information available about the cancer case	12	10.2
Total	117	100.0

1982-86 to 60% in 1992-95. The chances of the cancer cases registered in PBCR getting identified from the survey depends on the time period between the diagnosis and the conduct of the survey: the closer they are, the higher will be the proportion of cases identified from the survey.

The survey identified 2% (2/93) cancer cases that were not registered in PBCR during 1982-95. Both the cases had been first diagnosed in the earliest five-year period of cancer registration. Their age at diagnosis were between 60-69 years. They had attended private hospitals. The reason for both cases having been missed in routine cancer registration procedures was that the private hospitals attended by them were not under the coverage of the registry at the time of their cancer diagnosis. So we missed 2% (2/93) among cancer cases who were still residing in the survey area and we assume the possibility of missing another 2% among cases with cancer diagnosis during 1982-95 and migrated from the survey area before the conduct of the survey in 1997-98. Thus the completeness of registration for the period 1982-95 in Chennai PBCR was 96% (and 4% were missed). The fact that none of the newly identified cases from the survey were from government hospitals augurs well with the effective re-screening exercises carried out in government hospitals and the Cancer Institute (WIA) as part of cancer registration activity by which the missed cancer cases were included in the registry database soon after detection.

Based on the independent survey results, we conclude that 4% of cancer cases were missed in PBCR during the period 1982-95 and the completeness of registry was 96% which is comparable with the figures reported by registries in other parts of the world [Brenner et al., 1994; Brewster et al., 1997; Parkin et al., 2001; Dickinson et al., 2001].

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