

Rural cancer registry at Barshi, Maharashtra and its impact on cancer control

KASTURI JAYANT, BHAGWAN M. NENE, RAJENDRA A. BADWE,
NANDKUMAR S. PANSE, RANJIT V. THORAT, FEROS Y. KHAN

ABSTRACT

Background. The relevance of population-based cancer registries for planning and implementing cancer control programmes cannot be overemphasized. There are some urban registries in India but very few rural registries despite India being predominantly rural. There are several obstacles to setting up a rural registry including lack of cancer awareness in the rural population and inaccessibility of modern medical facilities. The first rural cancer registry was set up in 1987 at Barshi (population 0.4 million) in western Maharashtra by adopting a methodology suitable for rural areas.

Methods. The innovative methodology supplemented the usual registry methodology by regular interaction with the community to educate them on warning signals for cancer, raise cancer awareness and motivate suspected individuals to seek medical attention. Cancer detection clinics were held in villages.

Results. The reliability indices show that the registry is of an acceptable standard. The registry activity has increased cancer awareness in this population ($p < 0.01$), increased the frequency of early cervical cancers (stages I and IIa) by more than 2-fold during the past 16 years and significantly decreased the relative risk of death (hazard ratio 0.7 [0.5–0.9]).

Conclusion. The innovative methodology has facilitated the process of cancer registration in rural areas. It has had a positive impact on cancer awareness, stage at presentation and survival of cervical cancers—the predominant cancer in the area. The registry has created a resource for epidemiological studies in a rural area where national and international studies are currently being undertaken.

Natl Med J India 2010;23:274–7

INTRODUCTION

The relevance of population-based cancer registries for planning and evaluation of cancer control programmes cannot be overemphasized. In India, there has been one urban cancer registry (Bombay, now Mumbai) since 1964 and a few other urban

Rural Cancer Registry, Nargis Dutt Memorial Cancer Hospital,
Agalgaon Road, Barshi, Solapur District, Maharashtra, India

KASTURI JAYANT, BHAGWAN M. NENE, NANDKUMAR S. PANSE,
RANJIT V. THORAT, FEROS Y. KHAN

Tata Memorial Centre, Mumbai, Maharashtra

RAJENDRA A. BADWE

Correspondence to KASTURI JAYANT; barshivac@rediffmail.com

© The National Medical Journal of India 2010

registries since the 1980s covering about 7% of the urban population. Cancer registration in the urban registries is done by active case-finding by the registry staff by visiting and abstracting information on incident cancer cases at data sources such as cancer centres, hospitals, pathology laboratories and other facilities where cancer patients are likely to be diagnosed and treated as well as by visiting municipal death registration offices to collect information on cancer deaths. India is a vast country with almost 72% of the population living in rural areas with diverse lifestyles. In the absence of data from rural areas, an accurate estimate of the national cancer burden cannot be obtained. However, there are several obstacles to setting up rural cancer registries and ensuring satisfactory case-finding and completion of cancer registration. This is because the rural population does not have easy access to cancer diagnosis and treatment, they need to travel long distances to access healthcare services, generally belong to the lower socioeconomic strata, lack adequate financial resources to support diagnosis and treatment and lack awareness about cancer. It is plausible that a proportion of cancer patients in rural areas may not even access hospitals and may die before a diagnosis is established. Hence, visiting and collecting data from hospitals, clinics and laboratories alone, as in urban registries, is insufficient to ensure satisfactory cancer registration in rural areas.

The first population-based rural cancer registry (RCR) in India covering a population of about half a million in 346 villages in 3 sub-districts of Barshi in Solapur district and Paranda and Bhum in Osmanabad district in western India was set up at the Nargis Dutt Memorial Cancer Hospital (NDMCH), Barshi under the National Cancer Registry Programme of the Indian Council of Medical Research in collaboration with the Tata Memorial Centre, Mumbai in 1987. It adopted a method suitable for registration of cases in rural areas. We describe our experience with this approach.

METHODS

The registry is physically located at the NDMCH in Barshi and uses active case-finding methods as advocated by the International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries.¹ The registry has 8 cancer registrars and 1 medical officer—a total of 9 staff members. The cancer registrars carry out case-finding, abstracting, coding, data entry, analysis and report preparation under the supervision of an experienced epidemiologist. The cancer registrars were trained in-service on the principles and methods of cancer registration, scrutinizing medical records and abstracting relevant data in the cancer registry abstract, coding the collected information, merging data from different abstracts and data entry. The case-finding methods included regular visits by the registry staff members to

75 data sources comprising cancer centres, major hospitals in government and private sectors, nursing homes, consultants, radiation centres, pathology laboratories and imaging centres in Solapur district and nearby districts to abstract cases as in the urban registries. A standardized form was used for collection of data on personal identification, disease, treatment and outcome. All incident invasive cancers, diagnosed by any means among the residents of the 346 villages were included in the RCR. Although death registration is grossly inadequate and incomplete in these villages, efforts were made to collect information on death certificates mentioning cancer as the cause of death but these were minimal. For every death of a village resident occurring in the village or elsewhere, a verbal autopsy was conducted by the registrar. A cross-check with the deceased's hospital records at the treating hospital, if any, was also done.

To minimize the impact of under-diagnosis and under-treatment of cancer cases on cancer registration, the registry implemented educational activities and provided early detection clinics among the population to create awareness, and facilities for early clinical diagnosis, treatment and follow up care. Recognizing the importance of raising awareness and empowering symptomatic persons to seek diagnostic and treatment services, the registry staff regularly interacted with the rural community in the 346 villages by conducting person-to-person as well as mass health education sessions to publicize the symptoms of common cancers, the methods used for early diagnosis and treatment, favourable outcomes of treatment of early cancers and how and where cancer diagnosis and treatment services can be accessed in the district and neighbouring areas. They delivered messages in the community on early warning signals of cancer and about the importance of early diagnosis and treatment of cancer. From these interactions, people with symptoms were identified by the registry staff and they were motivated and navigated to attend the early detection clinics organized and conducted by the NDMCH in villages or were referred to any cancer hospital of their choice to confirm or rule out invasive cancer. Free treatment and follow up care were provided for socially and economically disadvantaged patients at the NDMCH with the assistance of various charitable institutions/trusts.

The reliability indices for the Barshi cancer registry were estimated in the usual way for 5 yearly periods beginning with 1990. Completeness of registration could not be assessed by estimating 'Death certificate only' cases (DCOs) as deaths are not medically certified in the villages. We took recourse to annual household sample surveys in a random sample (2%–10%) of villages to ascertain whether any case with cancer was missed. Coding for topography and morphology were done using standard International Classification of Diseases (ICD) norms.^{2,3}

To assess whether cancer awareness in the population under the registry had been enhanced due to the registry activity, a

simple random sample of villages, making up about 2% of the population, in each of the 3 registry subdistricts and in a corresponding, neighbouring subdistrict not under the registry (control) was drawn in 1993 and the eldest male and female members in each household were asked whether they were aware of any symptom of cancer. The reported symptom was matched with the 7 cancer warning signals. The proportion of persons not aware of any symptoms in the registry population and the corresponding controls were compared.

All incidence rates were expressed as average annual incidence rates per 100 000 person-years. Age standardized rates (ASR) were computed by direct standardization using the world standard population.⁴ Cancer incidence rates in the Mumbai population-based cancer registry were obtained from published reports.⁵

The impact of the RCR methodology involving health education, increasing awareness and encouraging early clinical diagnosis by providing early detection clinics in the population to compensate for poor health services was assessed in terms of stage distribution, stage-specific crude incidence rates and observed survival of incident cases of cervical cancer in the RCR. Cervical cancer was chosen for this assessment as it constituted one-third of all cancers in the RCR. The survival time was calculated as the duration between incidence date and date of death or loss to follow up or closing date (31 December 2007) whichever was earlier. The observed survival was computed by the actuarial method.⁶

RESULTS

ASR varied from 44.2 to 47.8 per 100 000 among men and from 53.1 to 59.3 per 100 000 among women. The reliability indices in the 5 yearly periods, viz. 'microscopically confirmed cases' varied from 80.9% to 91.4% and the 'mortality to incidence ratio' from 61.3% to 87.3% (Table I). Among 280 000 villagers in 99 villages, who were enumerated over 10 years from 1990, 350 cancer cases were recorded during the survey; 257 of these cases could be matched with the cases that were already registered by the RCR. Others were found to be either non-cancer cases or cancer in non-residents. Thus, it can be said that the RCR has not missed registering any proven cancer case.

A comparison of cancer awareness in the two neighbouring subdistricts not covered by the registry showed cancer awareness in the registry population was enhanced. The proportion of persons unaware of the warning signals of cancer in each of the 3 registry subdistricts was significantly lower ($p < 0.01$) compared with the corresponding control area. In the 3 subdistricts covered by the RCR, 20%, 32% and 13% of men and 21%, 26% and 12% of women were not aware of the early warning signals of cancer compared with 82%, 49% and 49% of men and 80%, 50% and 50% of women, respectively in the neighbouring control subdistricts not covered by the cancer registration activity.⁷

TABLE I. Number of cancer cases registered, reliability indices and the age standardized rates (ASR) for all cancer sites

Item	1990–1994		1995–1999		2000–2004		2005–2006	
	Male	Female	Male	Female	Male	Female	Male	Female
Number of cancer cases	454	550	474	545	547	594	234	263
ASR/100 000	47.8	59.3	44.2	54.1	45.5	53.1	46.4	56.2
Microscopically confirmed (%)	84.4	89.6	88.4	89.3	86.0	91.4	80.9	90.4
Mortality/Incidence (%)	77.8	61.3	87.3	76.5	75.9	73.2	73.5	76.8
Death certificate only (%)	1.3	1.3	0.8	0.4	0.6	0.3	1.3	0.0

The rates for leading cancers for the period 1990–96 in RCR are compared with the Mumbai cancer registry (Table II). Cancer of the cervix accounted for half the cancer burden among women in the RCR. The risk of cancer of the cervix is considerably high in RCR compared with that in the urban Mumbai cancer registry.

The stage distribution and stage-specific incidence rates of cervical cancer during 1990–2006 in the RCR are given in Table III. The frequency of early cancer (stage I and IIa) increased by more than 2-fold during this 16-year period (from 20.3% to 43.1%). The stage-specific crude incidence rate increased over the years for early cancers \leq IIa from 4.2 to 7.1 per 100 000 and decreased for IIb+ cancers (Table IV).

The survival experience of patients with cervical cancer registered during 1988–89, 1990–2001 and 2002–2006 are given in Fig. 1 and Table V. The observed survival increased from 26.2% in 1988–89 to 32.5% during 2002–06 and the hazard ratio is 0.7 (0.5–0.9).

DISCUSSION

The combination of active case-finding by visiting data sources as well as by improving population awareness and access to diagnostic and treatment services have compensated to a large extent for the deficiencies of registration and under-diagnosis in rural settings and has resulted in satisfactory case-finding and completeness of cancer registration in the RCR. The registry has not only raised awareness but also improved access to diagnosis, treatment and follow up care by providing early detection clinics and facilitating those diagnosed with cancer to have their treatment completed by subsidizing treatment services in cooperation with the NDMCH and several voluntary health agencies. Thus, the patient is educated, motivated and empowered to seek medical attention. Therefore, the possibility of the registry having missed cancer cases that did not reach medical centres before death is minimal.

We found that the age standardized cancer incidence rate in 2006–07 in Barshi town (males 51.9/100 000, females 55.4/100 000) were not significantly different from the corresponding incidence rates in the Barshi Cancer Registry for the same period (males 49.1/100 000, females 50.9/100 000). However, the urban–rural ratio of ASR for cancers at all sites compared with the Bombay registry was 2.7 (95% confidence interval [CI] 2.5–2.9) for males and 2.3 (95% CI 2.1–2.4) for females.⁸ The low incidence rates in males in the Barshi registry can be attributed to the lower proportion of smokers in the area (9.9%) compared with that in Mumbai (23.6%). Smoking-dependent cancers in the Barshi registry have been shown to have low rates.⁹ (ASR in males for lung cancer is 1.3 per 100 000, larynx 2.5 per 100 000 and oropharyngeal cancer 0.8 per 100 000.)

Incorporating the Barshi cancer registry incidence rates in the estimation of national cancer burden has brought in some realism to the reported estimates of cancer in India.^{10,11} In a vast and diverse country like India, more data from rural areas from different regions would be required to obtain reliable estimates of the national cancer load. As of now, besides the Barshi registry, there are 2 cancer registries, Ambillikai^{12,13} and Karunagappally¹⁴ in southern India and one in Ahmedabad¹⁵ in western India. The ASR for cancer (all sites) in males in Ambillikai (83.3 per 100 000) and in rural Ahmedabad (67.5 per 100 000) are lower than the corresponding urban rates in Chennai¹⁵ (110.4 per 100 000) and urban Ahmedabad¹⁶ (116.0 per 100 000), respectively. Thus, in all 3 rural registries, the cancer rates for males in rural areas are lower than those in corresponding urban areas. However, the findings for cancer in females shows the ASR for cancer among

TABLE II. Comparison of age standardized rates (ASR) at the rural cancer registry with those in the Mumbai cancer registry (1990–96)

Site	Male		Site	Female	
	Barshi	Mumbai		Barshi	Mumbai
Hypopharynx	5.2	6.3	Cervix	29.3	17.2
Oesophagus	4.2	8.5	Breast	8.8	28.6
Penis	3.0	1.3	Oesophagus	2.6	6.7
All sites	46.2	115.4	All sites	57.7	119.1

TABLE III. Stage distribution of cervical cancer during 1990–2006

Stage	Period				
	1990–94	1995–99	2000–01	2002–03	2004–06
\leq IIa	46	40	21	32	53
IIb	50	43	14	8	16
>IIb	131	107	40	27	54
Unknown	53	59	25	11	20
Total	280	249	100	78	143
Early \leq IIa (%)*	20.3	21.1	28.0	47.8	43.1

*excluding unknown cases

TABLE IV. Average stage-specific crude incidence rate of cervical cancer during 1990–2006

Stage	Period (crude incidence rate/100 000 women)				
	1990–94	1995–99	2000–01	2002–03	2004–06
\leq IIa	4.2	3.5	4.4	6.6	7.1
IIb+	16.5	13.1	11.4	7.2	9.3
Unknown	4.8	5.2	5.3	2.3	2.7
Total	25.5	21.8	21.1	16.1	19.1

TABLE V. Observed survival (%) of cervical cancer cases in three time periods

Period	n	1-year	3-year	5-year
1988–1989	83	54.6	27.5	26.2
1990–2001	629	68.2	38.0	30.6
2002–2006	221	71.0	41.2	32.5

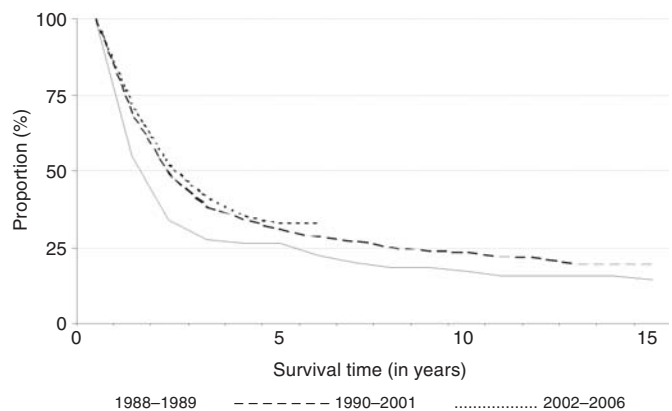


FIG 1. Observed survival of patients with cancer of the cervix diagnosed during 1988–2006 at the rural cancer registry

females is lower in rural Ahmedabad compared with that in urban Ahmedabad (43.1 v. 89.7 per 100 000) and is similar to what was observed in Barshi whereas in Ambillikai there does not seem to be much of a rural–urban difference (122.3 v. 119.7 per 100 000). On the basis of the limited data available for rural areas, it cannot be concluded that the relatively low incidence of cancer (at all sites) observed in the Barshi registry is true for other rural areas in Maharashtra or indeed for all rural areas in the country as a whole.

The impact of the registry activity leading to the improved stage at diagnosis and improved 5-year survival of cervical cancers, 3 years after the inception of the registry have already been reported.^{17,18} We have shown that the positive results have been sustained over the years and the registry has an important role in control of cervical cancer.

The community rapport created by the registry and NDMCH and the human resources and infrastructure developed have attracted international attention and large-scale funding of studies on prevention of cervical cancer, which is still the predominant cancer among women in the area. Even as one of the programmes achieved its specified objectives,^{19,20} it has helped greatly in cervical cancer control by detecting and treating several pre-cancers besides frank cancers. The extent of the contribution to cancer care can be appreciated when we realize that in this one programme, 397 cervical cancer cases in 131 746 women in the age group 30–59 were detected and treated for free during the period 2000–03 in 4 subdistricts adjacent to the registry. A cohort study to evaluate the risk factors in relation to cancer in this area has also been undertaken by the Tata Memorial Centre, Mumbai.

Furthermore, the success of the registry has encouraged us to expand the scope of the registry in 2008 to a neighbouring district, Beed with a population of 2.5 million, by spreading cancer awareness and holding cancer detection clinics in the area with local support. Preliminary analysis shows that the activities have motivated a larger number of patients to seek medical attention which we expect, in turn, will lead to early detection of cervical cancer as has been the case of the Barshi registry and contribute to cervical cancer control.

For the success of a rural cancer registry, a rural cancer hospital providing cancer-related services in the rural settings is essential. Apart from the difficulties of getting trained personnel to run the hospital, it takes a long time for the hospital to grow in stature and attract patients. The NDMCH was started with much technological help from the Tata Memorial Hospital Mumbai, the premier cancer institute in India. In 1982, the annual outpatient attendance was around 600 and increased to 1500 in 5 years. With the establishment of the registry, the attendance at the NDMCH doubled itself in the first year to 3000 and continued to grow. The methodology adopted by the Barshi registry of creating cancer awareness and motivation to get medical attention ensures the viability of the hospital due to a regular flow of patients. Thus, a rural cancer hospital and a rural cancer registry are of mutual benefit to each other and together provide the necessary setting for cancer prevention/control programmes in the vast rural areas in India. It might be mentioned here that WHO in their World Cancer Report considered both NDMCH and Barshi Rural Cancer Registry as model cancer initiatives for developing countries with limited resources.²¹

ACKNOWLEDGEMENTS

We thank National Cancer Registry Programme (NCRP), Indian Council of Medical Research, New Delhi, and the Tata Memorial Centre, Mumbai for their continuing financial assistance to the registry. We gratefully acknowledge the valuable support given by Nargis Dutt Memorial Cancer Hospital and the Ashwini Rural Cancer Research and Relief Society, all village leaders, health workers and residents of villages, pathologists and laboratories which serve the registry population. We also gratefully acknowledge the diligent work of the registry staff, Gaikawad N. P., Pise D. R., Dudhankar T. S., Honmane B. D., Padwal N. D., and Mathapati S. R. and the support given by Mr M. K. Chauhan, Chief Coordinator, Projects.

REFERENCES

- Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG. *Cancer registration, principles and methods*. Lyon:International Agency for Research on Cancer; 1991. IARC Scientific publications no. 95.
- International statistical classification of diseases and related health problems. Tenth revision. Vol. 1*. Geneva:WHO; 1992.
- Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin DM, *et al*. *International classification of diseases for oncology*. 3rd ed. Geneva:WHO; 2000.
- Curado MP, Edwards B, Shin HR, Storm H, Ferlay J, Heanue M, *et al*. *Cancer incidence in five continents. Vol. IX*. Lyon:International Agency for Research on Cancer; 2007. IARC Scientific publications no. 160.
- Consolidated Report of the Population Based Cancer Registries 1990–1996. Bangalore:National Cancer Registry Programme Coordinating Unit, Indian Council of Medical Research; 2001.
- Cutler SJ, Ederer F. Maximum utilization of the life table method in analyzing survival. *J Chronic Dis* 1958;**8**:699–712.
- Jayant K, Rao RS, Nene BM, Dale PS. Cancer awareness in the rural population covered by the registry. In: *A report of Rural Cancer Registry Barshi, Paranda and Bhum Maharashtra, India for 1988–1992*. Barshi:Rural Cancer Registry; 1994:63–9.
- Jayant K, Rao RS, Nene BM, Dale PS. *A report of rural cancer registry Barshi, Paranda and Bhum Maharashtra, India for 1988–1992*. Barshi:Rural Cancer Registry; 1994.
- Thorat RV, Panse NS, Budukh AM, Dinshaw KA, Nene BM, Jayant K. Prevalence of tobacco use and tobacco-dependent cancers in males in the rural cancer registry population at Barshi, India. *Asian Pacific J Cancer Prev* 2009;**10**:1167–70.
- Murthy NS, Juneja A, Sehgal A, Prabhakar AK, Luthra UK. Cancer projection by the turn of century—Indian scene. *Indian J Cancer* 1990;**27**:74–82.
- Yeole BB. *Cancer in India in the year 2001. An epidemiological study. Vol. 552*. Tampere:University of Tampere; 1997.
- Rajkumar R, Sankaranarayanan R, Esmi A, Jayaraman R, Cherian J, Parkin DM. Leads to cancer control based on cancer patterns in a rural population in South India. *Cancer Causes Control* 2000;**11**:433–9.
- Swaminathan R, Selvakumaran R, Esmi PO, Sampath P, Ferlay J, Jissa V, *et al*. Cancer pattern and survival in a rural district in South India. *Cancer Epidemiol* 2009;**33**:325–31.
- Gangadharan P, Jayalekshmi P, Mani KS, Jayadevan S. *Natural background radiation cancer registry, Karunagappally, Kerala, India. Technical report 2 (1990–1994)*. Trivandrum, India:Regional Cancer Centre; 1997.
- Two-year report of the population based cancer registries 2004–2005. Bangalore:National Cancer Registry Programme Coordinating Unit, Indian Council of Medical Research; 2008.
- Population based cancer registry Ahmedabad urban agglomeration area and Hospital based cancer registry, Annual Report 1996*. Ahmedabad:The Gujarat Cancer and Research Institute; 2000.
- Jayant K, Rao RS, Nene BM, Dale PS. Improved stage at diagnosis of cervical cancer with increased cancer awareness in a rural Indian population. *Int J Cancer* 1995;**63**:161–3.
- Jayant K, Nene BM, Dinshaw KA, Budukh AM, Dale PS. Survival from cervical cancer in Barshi registry, rural India. In: Sankaranarayanan R, Black RJ, Parkin DM (eds). *Cancer survival in developing countries*. Lyon:International Agency for Research on Cancer; 1998:69–77.
- Sankaranarayanan R, Nene BM, Shastri SS, Jayant K, Muwonge R, Budukh AM, *et al*. HPV screening for cervical cancer in rural India. *N Engl J Med* 2009;**360**:1385–94.
- Nene BM, Hiremath PS, Kane S, Fayette JM, Shastri SS, Sankaranarayanan R. Effectiveness, safety, and acceptability of cryotherapy by midwives for cervical intra-epithelial neoplasia in Maharashtra, India. *Int J Gynaecol Obstet* 2008;**103**:232–6.
- Stewart BW, Kleihues P. Cancer control in developing countries. In: *World Cancer Report*. Lyon:International Agency for Research on Cancer; 2003:312–19.