
NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

Consolidated Report of Hospital Based Cancer Registries 2001-2003

An Assessment of the Burden and Care of Cancer Patients

Bangalore, India

April 2007

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Hospital Based Cancer Registries provided individual core data. Quality Control checks, tabulations and statistical analysis were done at the Coordinating Unit of NCRP, Bangalore.

The publications of NCRP are intended to contribute to the dissemination of authentic information on cancer incidence by age (Five-year age groups), sex and site (ICD-10).

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FORWARD

This three year report marks the successful completion of 21 years of systematic and organized data collection by the five Hospital Based Cancer Registries (HBCR) under the National Cancer Registry Programme (NCRP) of the Council. This consolidated report for the years 2001-2003 is the result of work carried out by the five HBCRs located at the respective institutions in different parts of the country.

The objectives of HBCRs are to assess and evaluate patient care and assist in active patient follow-up. Besides, the HBCRs provide an idea of regional patterns of cancer and contribute to the Population Based Cancer Registries (PBCR) in the geographic area. Information about types of cancers and the different treatment modalities helps in planning the facilities required in the respective hospital, thereby facilitating health services research. HBCRs provide database for developing appropriate strategies to aid in National Cancer Control Programme.

The HBCRs under the NCRP have over the years given an assessment of the magnitude and patterns of cancer in the particular region, furnished information to the PBCRs and in more recent years provided data to the project on 'Development of an Atlas of Cancer in India'. In addition, they have conducted several case control studies.

The NCRP has commenced through the HBCRs, a detailed systematic study on 'Patterns of Cancer Patient Care and Survival' in three important sites of cancer, viz., cancer cervix, cancer breast and head and neck cancers. These institutions have evolved strategies for patient follow-up. In the coming years, the results of these studies are expected to give a picture of stage and treatment based survival at a national level and more importantly in the Indian context. This would pave the way for initiating multi-centric clinical trials with the HBCR as the backbone.

It is hoped that this report will encourage other cancer centres throughout the country to establish their own HBCRs and commence patterns of care studies.

The registries and all their team members deserve special thanks for their dedicated work and providing quality data which enabled the successful completion of this report.



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12 April 2007

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National Cancer Registry Programme

In 1981 the Indian Council of Medical Research initiated the National Cancer Registry Programme (NCRP) and commenced a network of cancer registries across the country that started functioning from January 1982. Three hospital based cancer registries (HBCR) were commenced at Assam Medical College, Dibrugarh; Regional Cancer Centre, Thiruvananthapuram; and Post Graduate Institute of Medical Education and Research, Chandigarh. In order to extend the assessment of cancer patient care, HBCRs were also started in 1984 at Kidwai Memorial Institute of Oncology, Bangalore; Cancer Institute (WIA), Chennai and Tata Memorial Hospital, Mumbai.

More recently, the HBCRs have embarked on 'Patterns of Cancer Patient Care and Survival Studies' in cancer cervix, cancer breast and head and neck cancers. Several other institutions not in the NCRP network are also collaborating in this multi-centric project. A common agreed patient information form has been developed for each of the sites, incorporating details of clinical stage, different aspects of types of treatment and meticulous recording of follow-up information. A manual for completing the forms has also been developed.

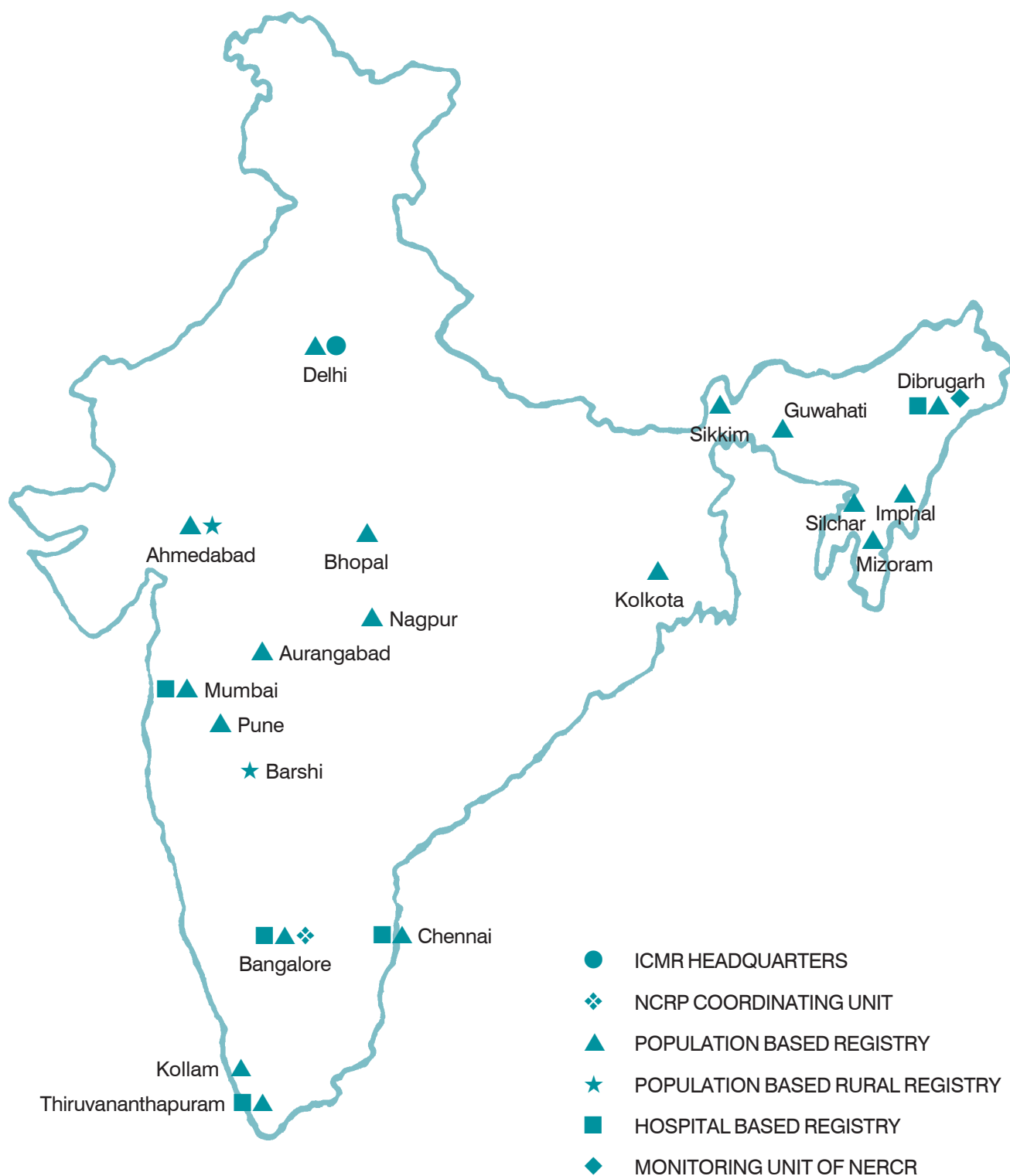
Data collection also commenced from 1 January 1982 in the population based cancer registries (PBCRs) at Bangalore, Chennai and Mumbai. From 1986 two more urban population based cancer registries were started in Delhi and Bhopal. For the first time a population based rural cancer registry was also started by the ICMR during the subsequent year (1987) in Barshi in the state of Maharashtra. PBCRs to cover the population of Ahmedabad rural district and Kolkata Municipal Corporation have started functioning from 1 January 2004 and 1 January 2005 respectively.

Under the auspices of the World Health Organization a project on "Development of an Atlas of Cancer in India" was commenced in 2001. The two-year report for 2001 and 2002 provided many interesting findings. As a fall out of this a North-Eastern Regional Cancer Registry (NERCR) has been commenced in six areas at Guwahati, Dibrugarh and Silchar in Assam, Aizawl in Mizoram, Imphal in Manipur and Gangtok in Sikkim. These registries have started collation of information on cancer cases from 1 January 2003. The first report of the six population based cancer registry of the north east region covering the two year period from 1st January 2003 to 31st December 2004 was published in September 2006. A project on developing a cancer atlas especially for the North East states (specifically to include the other four states of Arunachal Pradesh, Meghalaya, Nagaland, Tripura and other areas of Assam not included under the NERCR) has also been initiated. Role of tobacco and pesticides in the occurrence of cancer in these areas is also being investigated.

The NCRP is a long-term activity of the Indian Council of Medical Research. The programme is one of the many major activities of the Division of Non-Communicable Diseases and is coordinated from its office in Bangalore. The Programme is assisted by Steering and Monitoring Committees to help oversee and guide its functioning. A workshop followed by a review meeting is held annually. The Principal Investigators and staff of the registries present data and participate in the discussions. In recent years

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representatives of other functioning PBCRs that are not in the NCRP Network also participate. Over the years, the NCRP has laid a strong foundation to build on for cancer research. The entire activity of the NCRP and the projects under it are directed, monitored and executed (including conduct of workshops and coordination of the Annual Review Meetings and workshops) by the Coordinating Unit of the NCRP at Bangalore.

The NCRP is gradually fulfilling many of the objectives with which it was commenced. These include:

1. Generation of reliable data on the magnitude and patterns of cancer - this would be based on morbidity and mortality information in different regions of the country according to sex, age and residence of the patient, anatomical site of cancer and proportion of histological type or microscopic confirmation for each site; pattern of different types of cancer according to relative proportions or ratios in various population sub-groups such as religion, language spoken, educational status; clinical stage of disease when patients come to hospital for treatment and where possible the nature of treatment received and outcome;
2. Undertaking epidemiologic research, such as case control or cohort studies based on observations of registry data;
3. Providing data base for developing appropriate strategies to aid in National Cancer Control Programme;
4. Developing human resource in cancer registration and epidemiology.

Cancer registration in India is active. Staff of registries visit hospitals on a routine basis and scrutinise the records in various departments that include pathology, radiology, radiotherapy, in-patient wards and out-patient clinics to elicit the desired information on reported cancer cases in a "core proforma" that has been standardised for all cancer registries in India. The hospitals include the main cancer hospitals, other general hospitals in both the government and private sector. Besides, pathology laboratories that report cancer cases are also visited. Death certificates are also scrutinised from the municipal corporation units. Every attempt is made by registries to register all cancer patients in the registration area who are resident (at least one year) in the area in all hospitals and copy all death certificates in which cancer is mentioned.

Certain basic checks of data especially those related to duplicate verification and matching with mortality records are carried out by the individual registries. After this, the data is sent to the Coordinating Unit for subjecting the data to various range, consistency and unlikely combinations including a further round of possible duplicate listing. The list of cases with the items of patient information, that require verification are sent to the respective registries by the Coordinating Unit. Individual registries go through the records/reports of such cases and wherever necessary discuss with the concerned clinician or the pathologist. On receiving the clarifications the Coordinating Unit prepares the detailed tabulations by five-year age group, site and sex including rates. The individual registries use these tables to prepare the registry's annual report. The Coordinating Unit collates the data and tables to prepare the consolidated report of that year.

During the annual workshop, the various aspects of working of the registry, problematic cases, use of coding and discussion on medical terminology, statistical and epidemiologic methods are discussed. About 2-3 senior and junior staff from each registry, participate in the workshop.

Apart from the above, the Coordinating Unit undertakes and coordinates epidemiologic and other research studies including those to ensure that the quality of data is of a high standard and that coverage of cancer cases in the registry area is as complete as possible. More recently, an on-line check programme has been developed. This will enable individual registries to conduct quality checks of their data on the web-site.

Over the years, staff from registries under the NCRP, have benefited from both short and long term training fellowships in established institutions abroad. This has helped them and the registries to develop into departments of epidemiology and undertake several studies on their own and contribute to several research publications in indexed journals.

Three-Year Consolidated Report of the Hospital Based Cancer Registries: 2001-2003

An Assessment of the Burden and Care of Cancer Patients

INTRODUCTION AND SUMMARY OF REPORT

The primary purpose of hospital based cancer registries is to contribute to patient care by providing readily accessible information on the patients with cancer, the treatment received and its results. The data is also used for clinical research and for epidemiological purposes. Hospital based cancer registries are concerned with recording of information on the cancer patients seen in a particular hospital (Isabel dos Santos Silva *et al*, 1999). Within the hospital, a registry is often considered to be an integral part of the hospital's cancer programme or health care delivery system.

Objectives of Hospital Based Cancer Registries (HBCRs) (MacLennan *et al*, 1978; Young, J.L. 1991):

1. GENERAL:

- 1.1 Assess Patient Care;
- 1.2 Participate in Clinical Research to Evaluate Therapy;
- 1.3 Provide an idea of the patterns of cancer in the area;
- 1.4 Help plan hospital facilities.

2. SPECIFIC:

- 2.1 Contribute to active follow-up of the cancer patient;
- 2.2 Describe length and quality of survival in relation to anatomical site, clinical stage and aspects of types of treatment;
- 2.3 Contribute to the Population Based Cancer Registries (PBCRs) in the given area;
- 2.4 Undertake epidemiological research through short-term case control studies;
- 2.5 Show time trends in proportion of early to late stages at the time of diagnosis;
- 2.6 Help assess quality of hospital care and cancer services in covered area.

Data collection is done by the individual registries using a standardised common core proforma. The information in this form mainly consists of patient identifying information, demographic facts, details of diagnosis including method of diagnosis, the clinical stage of the disease and the broad type of treatment instituted. Attempts are made to collect particulars of follow-up as well but this has been difficult and in the absence of follow-up of the majority of cases registered by the HBCR, obtaining stage and treatment based survival has not been possible.

Registries send the data to the Coordinating Unit as soft copy in MS-Excel, ASCII or other formats. These data are then converted to a uniform format at the Coordinating Unit and quality control exercises are carried out. Once data is finalized in correspondence with the individual registries, annexure tables are generated and reports prepared.

The three year (2001-2003) report of the five HBCRs is the contribution of data from the hospitals at Tata Memorial Hospital, Mumbai; Kidwai Memorial Institute of Oncology, Bangalore; Cancer Institute-Adyar, Chennai; Regional Cancer Centre, Thiruvananthapuram and Assam Medical College, Dibrugarh. This three year report marks the successful completion of 21 years of systematic and organized data collection by these registries.

This report essentially identifies the patients who registered in these institutions and had a diagnosis of cancer. It further distinguishes those that received cancer directed treatment (CDT) or not. Those who had received prior CDT i.e., before registration at the reporting institution were considered as 'non-analytic cases'. Those who had not received prior CDT were considered as 'analytic cases'. The rationale behind such classification is simple. The main function and objective of HBCRs is to assess and evaluate patient care of that particular hospital or reporting institution. So, if a proportion of patients received some form of cancer directed treatment elsewhere, they are not expected to be reflected in the patient care of the reporting institution, even if this group had received the additional or major course of treatment at this institution. Therefore, this report deals in detail with the analysis of analytic cases.

Checks on Data

Several range, consistency and duplicate checks are carried out at the Coordinating Unit. These include all the checks based on the IARC publication (Parkin et al, 1994) on 'Comparability and Quality Control in Cancer Registration'. Some checks on certain additional items of patient information including those concerning clinical stage and treatment are also done. Detailed guidelines of each of the items in the core form and related aspects are covered in the coding manual specifically for HBCRs. Registry staff follow these guidelines while completing the core form and checks of data are entirely based on these guidelines.

The summary of checks that were carried out include:

1. **Range checks:** By this is meant that the numeric codes provided should be valid and be in conformity with the key to the codes (for example the code for sex should only be 1 or 2 and not any other number or character).
2. **Consistency checks:** By this is meant, that, while relating the codes of two variables there should be a meaningful or possible logical relationship. For example a patient with a code for prostate cancer can have a code only for male and cannot have the code for female. Similarly, the date of diagnosis should precede the date of commencement of treatment and cannot come after that.
3. **Duplicate checks** based on registration number, name, age, sex and ICD-10 are also carried out.

ICD-9 vs. ICD-10

The tabulations in this report are according to the International Classification of Disease and Related Health Problems, 10th Revision (ICD-10), whereas the previous reports were based on ICD-9. This may be kept in mind while comparing the data of individual sites with the previous reports as some minor differences could be due to this changeover.

The broad purpose of this Three Year (2001-2003) report of the HBCRs is to look into some of their functions outlined above. The HBCRs have over the years given an assessment of the magnitude and patterns of cancer in the region being catered by the centre/registry. They have also contributed to the PBCR of the area. HBCRs have also conducted several case control studies. However, in terms of assessing patient care - for various reasons, follow-up in a routine way has been difficult under Indian conditions. Therefore, the NCRP through the HBCRs has commenced a study on patterns of care and survival studies in cancer of the breast, cervix and head & neck cancers, so that focused attention could be paid to clinical aspects and management.

The report is mainly in the form of statistical tables and graphs with the corresponding text giving only the factual description. While the report has tried to analyse, compile and consolidate the data provided by the different registries in a set format, it has in no way tried to compare and therefore comment or interpret the data between or among registries. Thus, no judgement is made of the figures in the tables. This is mainly because the individual institutions where the registries are located would have, their own policies in patient care and management which is beyond the purview of this report. Individual registries, could however view their data, interpret its possible meaning and observe where, if at all modifications are required in administering patient care.

The report provides several pointers to policy makers. It gives an idea of the load of cancer patients in the main cancer hospitals of the country, the proportion and sites of cancers presenting at a late stage of the disease, the resources necessary for diagnosing and treatment according to different modalities, the proportion of patients who require palliative care, and so on. The report forms a base for both policy makers and institutions to plan for the future and would give a fair idea of the optimum number of patients a cancer centre/hospital would be able to effectively handle. The report could also form the basis of working out treatment costs and hospital stay. For the registries themselves the report should be a starting point in conducting follow-up and survival studies on at least selected sites of cancer and also initiating clinical trials.

A brief outline of the purpose and ways of interpreting each of the chapters and some areas where additional information should be gathered in order to get a more complete picture is indicated below.

Chapter 1 gives a picture of the overall magnitude of cancers diagnosed at the respective centres. This has to be further examined in the context of number of patients registered, and number who were diagnosed earlier. The chapter gives the relative frequencies of the leading sites of cancer in broad age groups.

Chapter 2 deals with different types of cancers in childhood.

Chapter 3 indicates the impact of the use of tobacco in the causation of cancer both in proportions and anatomical site of cancer. In planning tobacco control activity across the country this baseline is most important. Though, not in a defined population it gives a fair picture of the problem of cancer associated with the use of tobacco.

The basis of diagnosis in Chapter 4, is one index of the reliability of diagnosis. It indicates the proportion of methods of diagnosis used in cancer cases which are classified into microscopic, all imaging techniques, clinical and others. Microscopic diagnosis that includes histology, cytology and haematology constitutes the basis for establishing a diagnosis of cancer.

Chapter 5 gives an overview of the proportion of patients presenting in various conditions of diagnoses and treatment. It emphasises the need for distinguishing patients who have been treated elsewhere and those treated only at the reporting hospital/institution.

The proportion of patients presenting in different clinical extents of disease is shown in Chapter 6. Clinical extent of disease at presentation of cancer is directly related to the type and effectiveness of treatment. This is one of the most important baseline indicators for initiating cancer control activity in the area and the success of any education and early detection programmes in the area will be reflected in changes in proportions of stage of presentation of relevant sites of cancer.

Chapter 7 gives the details of different types of treatment at the reporting institution. This is for patients who have not received treatment earlier. The types of treatment and their proportions have been tabulated. The types of treatment and their relative proportions give an idea of the forms of treatment pursued in a given institution.

Chapters 8-14 summarize important selected sites of cancer with the comprehensive tables given in the earlier Chapters. The numbers in these tables of individual sites become more meaningful.

Chapter 15 deals with the relative proportions of histological types of cancer for certain specific sites.

Chapter 16 summarises the relative proportion of cases according to educational status, religion and language spoken.

HOSPITAL BASED CANCER REGISTRY

Tata Memorial Hospital, Mumbai

Dr. K.A. Dinshaw, Principal Investigator & Director, Tata Memorial Hospital

Dr. B. Ganesh, Co-Investigator & Head, Department of Medical Records,
Biostatistics & Epidemiology, Tata Memorial Hospital

Dr. Rajesh Dikshit, Epidemiologist, Department of Medical Records,
Biostatistics & Epidemiology, Tata Memorial Hospital

INTRODUCTION

The Tata Memorial Centre (TMC) comprises of Tata Memorial Hospital and the Advanced Centre for Treatment, Research and Education in Cancer (ACTREC) engaged in research, education and comprehensive care of cancer patients which is a grant-in-aid Institution and it is under the administrative control of The Department of Atomic Energy, Government of India. The ACTREC situated at Khargar, Navi Mumbai consists of two wings- the Cancer Research Institute (CRI) relocated from Parel and the Clinical Research Centre (CRC) which will undertake basic and clinical research using GCP guidelines. The Hospital is a comprehensive cancer centre for diagnosis, treatment, education and research institution with modern and state of art technology in all areas of cancer management. The Hospital has 564 beds, 18 operation theatres and Intensive care units. The hospital is a recognized centre for Postgraduate teaching in areas such as Surgery, Radiation Therapy, Radio-diagnosis, Pathology, Biochemistry, Radiation Physics, Cytology etc. On an average, over 1500 patients visit every day for availing various services.

Patients who seek all facilities such as diagnosis, treatment and allied facilities are registered as routine case file registrations. These patients carry unique hospital number and they are included in the cancer registry when diagnosed as cancer. Patients who require only cancer checkup are registered under care of Preventive Oncology Department and different registration numbers are allocated (PO) as long as these patients are free from cancer. For patients who require certain facilities like expert pathological opinion by submitting specimens or slides etc, or diagnostic investigations such as PET-CT, CT Scan, MRI, other rehabilitation facilities like breast prosthesis etc. are registered as Referral patients (RF) and a RF number is allocated to them. Some of the RF and PO registered patients eventually register as a regular case if they are diagnosed as cancer. The Hospital Cancer Registry includes only patients registered for comprehensive care where all necessary information like, date of diagnosis, method of diagnosis, clinical extent of disease, primary treatment and continuous follow up are available.

The Cancer Registry is using both ICD9 and ICD10 and tables are generated using both type of codes. For histological classification, the data is coded as per ICD-O III version and table on site and histology using this revised ICD-O-III codes is provided in this report. The clinical extent of disease is classified as per International staging system such as TNM for most of the cancer sites and FIGO system which is followed in TMH.

Data validation

The Cancer Registry staff scrutinizes the source document for confirmed cancer cases and collects relevant information in pre-designed proforma. The abstracted data is then recorded in the computer. The Software developed ensures entry of valid codes thus minimizing the storage space in the registry database. In addition, special software is used to validate data for range checks, cross checks, duplicate checks and blank checks as there are items which are to be entered without blanks in the data field. To ensure quality and corrections in data, a random sampling procedure was carried where a sample of 5% of case records were scrutinized and checked with the routine recording of cases.

Method of Diagnosis

About 92% of the cases were diagnosed microscopically (including cytology and bone marrow) during the years 2001-03.

Leading Sites

Leukemia remains the main leading site of cancer in males. Buccal mucosa, lung & bronchus, oesophagus continue to be among the top five leading sites among males during 2001-03. Among females, cancer of breast was the leading site followed by cervix uteri cancer.

Pediatric Cancer

During the years 2001-03, cancer in children (0-14 years) accounted for 2473 patients. Leukemia, lymphoma, bone tumors and soft tissue formed about 75 % of all pediatric cancers.

Treatment

During the years 2001-03, the number of cases treated were 7478 in 2001, 6753 in 2002 and 7275 in the year 2003. These comprise of new cases as well as cases who were treated prior to attending TMH.

Comments

The comparison of data of three years did not indicate any significant variation in the age distribution, referral pattern, histological diagnosis and clinical status for any sites. It was observed that the relative frequency of head & neck cancer was showing a decreasing trend over the years, however during 2001-03, there was hardly any change. Among females the relative frequency of female breast cancer showed an increasing trend over the years and decreasing trend among cervical cancer. Another consistent observation was the increasing load of the gall bladder cancer in the hospital over the years.

HOSPITAL BASED CANCER REGISTRY

Technical & Computer Staff

Mr. Sanjay D. Talole, M.Sc.
Mrs. T. K. Santhakumary, B.Sc.
Mrs. Snehal A. Sant, B.A.
Mrs. Sapna H. Kothare, B.A.
Mrs. Vidya R. Lanke, B.Sc.
Mrs. Elizabeth V. George, B.Sc.
Miss. Sandhya M. Bahire, B.Sc.
Miss. Amruta J. Desai, B.Sc.
Miss. Sushma Saoba, B.Sc.

HOSPITAL BASED CANCER REGISTRY

Kidwai Memorial Institute of Oncology, Bangalore

Dr. P.P.Bapsy, Director I/c & Principal Investigator

Dr. K. Ramachandra Reddy, Professor & Head,
Department of Epidemiology and Biostatistics & Co-principal Investigator

Dr. C. Ramesh, Associate Professor, Department of Epidemiology and Biostatistics

INTRODUCTION

Kidwai Memorial Institute of Oncology (KMIO) is a comprehensive and regional center for cancer research and treatment in Karnataka. The Institute has all the state of art facilities for the diagnosis and treatment of cancer and in view of this, patients from all over Karnataka as well as from the adjoining areas of neighbouring states of Andhra Pradesh, Tamil Nadu, Kerala and other regions attend this hospital. The Institute which was established in 1973 with 50 inpatient beds, a pathology laboratory and a radiology department has achieved a bed strength of 496 apart from Dharmashala, a unique project of its kind in the country built with support from the Bangalore Mahanagara Pallike and another one built with support from Infosys Foundation Trust which together provides accommodation to about 500 ambulatory patients with 500 of their attendants. These patients and attendants at the Dharmashala are provided with free food through the Perpetual Free Feeding Endowment Donation Scheme.

The Mobile Cancer Education and Detection Unit (Department of Community Oncology) organizes cancer detection clinics on Wednesdays and Saturdays at the Institute. KMIO as an apex body for the overall cancer control in the state has initiated several cancer control programmes/activities at different places. The Institute has been recognized as a National Centre of Excellence. Medical and paramedical personnel from all over the country come for training in various specialities/branches of oncology. KMIO is running super speciality courses in M.Ch. (Surgical Oncology) and DM (Medical Oncology), Post-graduate courses in MD Radiotherapy, Nuclear Medicine and Radiation Physics apart from Undergraduate courses in B.Sc. Medical Technology (Laboratory/Radiotherapy/Radio-diagnosis). These courses are affiliated to the Rajiv Gandhi University of Health Sciences.

In order to provide anti-cancer drugs at reasonably reduced prices, the Kidwai Cancer Drug Foundation Trust has been established where, the cost of anti cancer drugs are available at nearly 30% cheaper rates compared to market prices. Free drugs are provided to poor and needy patients through Karnataka Chief Minister's Relief Fund.

The KMIO is a well equipped comprehensive cancer center consisting of the departments of Surgical Oncology (General, Head & Neck, Oral, Gynaecology), Radiotherapy, Medical Oncology, Paediatrics, Radiodiagnosis, Pathology, Biochemistry, Blood Transfusion & Immuno Haematology, Microbiology, Cyto-genetics, Nuclear Medicine, Radiation Physics, Anaesthetics & Pain Relief, Epidemiology & Biostatistics, Community Oncology, Social Welfare & Public relations, Library and Information Centre, Administration and supportive care facilities for cancer patients like Physiotherapy, Ostomy clinic, occupational therapy are also available.

The Hospital Based Cancer Registry has been functioning since the inception of the Institute in 1973. However, the Registry was included in the network of NCRP in 1984. All new cases attending the Institute are interviewed during registration and required clinical data are abstracted later from the records using a standard proforma. The computerized data is checked for consistency for unlikely combinations of variables included using in-house computer programme.

Case control studies on breast, oesophagus and oral cavity has been completed and case control study on pharyngeal cancers and ovarian cancers are in progress. Reports on the activities of Hospital Registry are published regularly on an annual basis. The faculty members of the Registry are actively involved in the clinical trials/research projects being carried out by the Institute apart from teaching.

The HBCR has initiated action to conduct special studies on pattern of care and survival studies on head and neck cancers, breast and cervical cancers as proposed by the National Cancer registry Programme of the ICMR. KMIO being a referral cancer center, about 70% of the patients are referred by various medical institutions and private practitioners. The Institute has established two peripheral cancer centers at Mandya and Gulbarga with a main intention of reducing the distance of travel of cancer patients from far off places to KMIO and to provide cancer treatment facilities at the nearest places as far as possible so that it also reduces the load on KMIO. During the period 2001-2003, a total number of 42,674 new patients were registered, of which, 24,229(old + new) cases were confirmed to have cancer. About 18% of the patients registered annually are from the adjacent states. On an average, about 50 new cases are registered every day and 650 follow-up patients come for regular treatment. The Institute offers all modalities of cancer directed treatment-Surgery, RT, CT, Hormone therapy and Pain relief through a multi- disciplinary team approach.

Of the total number of confirmed cancers of 24,229 (old + new), the proportion of cancers in females were higher and accounted for 54%(13,107 cases) of the total cancers compared to 46% (11,122 cases) in males.

Staff of Registry

Mr. D.J.Jayaram	:	Sr. Investigator/Scientific Assistant
Mr. C.Shivanna	:	Asst. Social Scientist
Mr. V.Bhadraiah	:	Asst. Social Scientist
Mr. A.V.Srinivasa Gowda	:	Asst. Social Scientist
Mr. R.Lingaraju	:	Asst. Social Scientist
Mr. M.K.M.Gowda	:	Asst. Social Scientist
Mrs. B.J.Kumudhini	:	Asst. Social Scientist
Mr. M.R.Balakrishnoji Rao	:	Asst. Social Scientist (On deputation from comm. oncology)
Mr. K.Venkatesh	:	Statistical Assistant (On deputation from DCCP)
Mrs. R.Gertrude	:	Stenographer
Mr. A.Subramani	:	Coding Clerk
Mr. B.M. Gangaiah	:	Data Entry Operator
Mr. Abdul Rasool	:	Literate Attender

HOSPITAL BASED CANCER REGISTRY

Cancer Institute (WIA), Adyar, Chennai

Dr Shanta. V Chairman, Cancer Institute (W.I.A) & Principal Investigator, ICMR

Dr Swaminathan R, Senior Bio-Statistician,
Division of Epidemiology & Cancer Registry and
Co-Investigator, HCR & PBCR (ICMR)

Dr Nalini S, Tutor, Division of Epidemiology & Cancer Registry

Mrs. Rama R. Statistical Assistant, Division of Epidemiology & Cancer Registry

Cancer Institute (W.I.A) - Salient features

The Cancer Institute (W.I.A), is a non-profit charitable institution, founded in 1954 by a team of dedicated women with a social commitment under the leadership of Dr. (Mrs) Muthulakshmi Reddy, the first woman in India to graduate in medicine. Presently, it comprises four components: (i) the post graduate teaching hospital with a bed strength of 428 consisting of the departments of surgical, radiation and medical oncology, (ii) the research center including laboratories of Molecular Oncology, Microbiology, Bio-Chemistry, Bio-Physics, Immunology, Cytogenetics and Electron Microscopy (iii) the Division of Preventive Oncology comprising two components: (a) Cancer prevention and early detection - essentially educational at the public and professional levels. Over 750 VHNs and 250 rural medical practitioners have been trained. Screening activity is currently ongoing in the neighbourhood of Chennai and is also proposed to be launched at a district level (b) Division of Epidemiology and Cancer Registries: Demographic and Hospital - carrying out cancer epidemiology and registration activities and (iv) the college of oncological sciences offering super specialty degree courses in oncology. The Cancer Institute (W.I.A), Chennai, is a Regional Cancer Centre for treatment of cancer in the Ministry of Health and Family Welfare, Government of India, since 1975. It celebrated the Golden Jubilee in 2004 after 50 years of committed service in cancer care and research.

Hospital Cancer Registry (HCR)

The HCR at the institute has been functioning since 1955. It presently has 39 staff members serving in different capacities, besides a principal investigator and a co-investigator. The HCR has been responsible for descriptive statistics on the total number of patients seen, diagnosed as and/or treated for cancer annually, categorized by site, socio-demographic factors, extent of disease at presentation, providing information to PBCRs and other research activities and basic data for epidemiological studies and different types of case studies including survival analysis. In 2005, a total of 14,151 patients were registered from different parts of the country and outside: Chennai city and suburbs (26%), rest of Tamil Nadu (45%), Andhra Pradesh (22%) and others (7%); 8,950 (61%) of them were diagnosed to have cancer.

Data collection as per ICMR guidelines was started on 1st Jan 1984. New cases are registered using the hospital computer system and interviewed by social investigators for identification, demographic and epidemiological details. The remaining data as per ICMR Core proforma are abstracted from the medical records. The proformae are then scrutinized by Medical Officer/Statistician. The data are then entered into the computer. Computerized data are then checked for validity and consistency using NCRP, IARC and in-house computer programs. Quality control measures include regular exercises on coding for topography and morphology and re-abstractation of cases on a random sample.

The HCR from its inception has focused on the continued well-being and care of the patient and therefore places great emphasis on "follow-up". Follow up is an integral activity of the HCR at the Cancer Institute (WIA). A lifetime follow up of cancer cases is pursued until the death of the patient. With the follow up of cases being an arduous task in any developing environment, our HCR has evolved an efficient system of active follow up methods to augment the passive follow up. Staff is dedicated exclusively to communicate with patients and relatives through letters, telephone and e-mail for follow up. The availability of a complete follow up at five years from diagnosis, for any given site at any given time, is in the range of 70-90%. This rate is higher for specialized studies on clinical trials/protocol and survival. This has facilitated conduct of survival studies on common and selected cancers and publishing of the overall and disease free estimates as a routine in our HCR reports.

The high resolution data collection in the HCR has facilitated the conduct of many analytical epidemiological studies on cervix, female breast, stomach, oral cavity, occupational related cancers to name a few. Many inter department cooperative projects focusing on molecular and basic sciences research, are also being carried out. With the gradual increase in the level of computerization of hospital registration system, recent data on all aspects of cancer is readily available.

Hospital cancer registry publishes reports on various hospital statistics periodically. Training/ Workshops on "Cancer Registration, Epidemiology and Bio-Statistics" are organized regularly for (i) the personnel from other RCCs and institutions that are desirous of starting a registry, (ii) the students of IARC Summer Course on Cancer Epidemiology and (iii) students of medical documentation, statistics and social work from different colleges and universities. Epidemiological and survival studies on different cancers have been carried out and results have been published in international scientific journals. The registry assists in the conduct of randomized clinical trials.

HOSPITAL BASED CANCER REGISTRY

Regional Cancer Centre, Thiruvananthapuram

Dr. B. Rajan, Principal Investigator & Director

Dr. Aleyamma Mathew, Additional Professor of Statistics & Epidemiology

Regional Cancer Centre (RCC), Thiruvananthapuram, a state of the art super specialty hospital was established in 1981. This centre has all the disciplines in oncology such as radiation oncology, medical oncology, paediatric oncology, surgical oncology, community oncology, imageology, nuclear medicine, radiation physics, pain and palliative care, epidemiology, clinical and basic research all in one roof and with qualified and trained personnel. The centre caters to one third of the new cancer patient load in a year (around 10,000) in the State of Kerala. The centre records patient visit to the tune of 1.25 lakhs per annum with daily attendance numbering around 600. A multi-user computer networking is set-up for storing and retrieving of patient database. All the departments of the center are fully computerized and the entire hospital is under a local area network.

The centre is also increased in a number of basic and clinical research programmes with extramural funding. Our national and international collaborators include Indian Council of Medical Research, Dept. of Science & Technology, Govt. of India, Science, Technology and Environment of Kerala and international organizations such as World Health Organization, International Agency for Research on Cancer, National Cancer Institute, USA, Clinical Trial Unit, UK etc. The academic merit of the staff of the centre can be understood from the fact that the centre could publish more than 1350 papers in all these years of which 610 are in international peer reviewed journals.

The centre is actively involved in the implementation of the National Cancer Control Programme. This has augmented the early cancer detection facilities and the cancer awareness programme in the whole of the State of the Kerala. The peripheral activities of the centre are carried out through five of its remote units functioning at Kollam, Pathanamthitta, Ernakulam, Palakkad and Kannur. These units are connected to RCC to a Telemedicine network called "ONCONET". At present the telemedicine facilities and follow up visit are taken place through this tele link which provides a lot of help to patients and individuals by avoiding unnecessary journey to Trivandrum and the hardship associated with it. The clinical services are by a combined medical team drawn from all specialities and based on site-specific system. Treatment policy decisions are taken jointly and the best possible care is given to the patients.

The centre has also focused on human resource development. The centre conducted more than 50 national conferences and several workshops with participation by international experts. The centre has undertaken undergraduate and postgraduate training in some branches of oncology in collaboration with other acknowledged centres of academic and clinical excellence. Human resource development for all cancer control activities -medical, scientific and paramedical are undertaken by the centre.

Hospital Based Cancer Registry (HBCR)

The HBCR of the RCC started in 1982 under the network of Indian Council of Medical Research (ICMR). Initially the HBCR collected information on cancer patients attending RCC and Medical College Hospitals. All the above hospitals are located in the same campus. In 1982, around 3500 cancer patients were reported in the registry, of these 85% was from the RCC and the rest from the medical college hospitals. Over the years the HBCR patient registration has increased. In 1996 (after 15 years) the source of registration was RCC for more than 95% of the patients in the registry. Hence from 1997 onwards, the medical college hospitals were de-linked from the HBCR, and the registry is restricted to patients from RCC only. Annually more than 8500 new cancer cases are recorded now.

The registry has made significant achievements in data abstraction in the last 5 years. The data abstraction and retrieval has been made online via intranet "rccintranet.org" with easy data management. This is a paperless registry in the country. The demographic details are collected by the social investigators and entered into the computer at the time of new patient registration at RCC and transferred to the national cancer registry core-proforma of ICMR. The data transfer avoids manual documentation of the first part (demographic details) of the ICMR core proforma. The second part (diagnostic, treatment and follow-up) is entered using the above software after retrieving case-sheets from the medical records division.

Using the above in-house software, the variables in the core proforma are selected from a selection box in the hypertext mark up language (HTML) form. The selection box contains all the codes along with their descriptions for each variable. This helps to avoid mistakes beyond the range of values for each variable. The selection box corresponding to the variables topography and morphology contains the third edition of international classification of diseases for oncology (ICD-O-3) and the international classification of diseases (ICD-10).

While abstracting the HBCR proforma, diagnostic, treatment and follow-up details are also documented through the website www.onconetkerala.org. This helps clinicians and other researchers to easily obtain the necessary information. HBCR serves for evaluating the performance of hospital administration, services and medical audit. It has an important supportive role in the care of cancer patients by assisting clinicians in the follow-up of their cases and by providing statistical data on the results of therapy.

The publication of the official newsletter of the National Cancer Registry Programme of India 'CRAB' by the Hospital Cancer Registry is continued and so far 12 volumes are published.

District Cancer Control Programme, Thiruvananthapuram

The Government of India has identified RCC as the Nodal Agency for implementing DCCP in Thiruvananthapuram district. The cancer registry is involved in planning strategies, training of doctors and health workers, implementation and above all the evaluation methodologies of the programme. Appropriate cancer registration forms and habit survey forms are devised by the registry. The HBCR data will be used to evaluate the programme.

Pattern of Care and Survival Studies of Head & Neck, Breast and Cervix Cancer

HBCR is one of the collaborating centers for the ICMR initiated network of pattern of care and survival studies on cancer cervix, breast and head & neck cancers. Currently a total of 290, 140 and 225 female breast cancer, cervix cancer and head & cancer cases respectively are abstracted using the specifically designed 'Patient Information Form'.

Other staff of the registry

Ms. Padmakumari Amma G	:	Lecturer in Bio-statistics
Dr. Kalavathy M.C	:	Lecturer in Epidemiology
Ms. Anita Nayar	:	Social Investigator, Sr. Grade
Ms. Asha N.M	:	Clerk

HOSPITAL BASED CANCER REGISTRY

Assam Medical College, Dibrugarh

Dr. U.C.Sharmah, Director of Medical Education, Assam

Prof. (Dr.) D. Hazarika, Principal cum Chief Superintendent,
AMCH, Principal Investigator, HBCR

Dr. M.S. Ali, Officer in Charge & Sr. Bio-Statistician

Dr. (Ms.) R. Akhtar, Research Officer

The HBCR has been functioning at AMC, Dibrugarh since February, 1982. During the long tenure the registry has been able to generate authentic data on the burden, the common cancers, its magnitude, method of diagnosis and treatment modalities of cancer patients treated at the hospital.

The registry had successfully completed two epidemiological case-control studies during 1988-91 on cancer pharynx and cancer Oesophagus and identified a number of potential risk factors particularly associated with the practices of the indigenous populations but unfortunately remained unutilized for planning measures for control and prevention of these two predominant cancers of the region.

However, several popular articles on the pattern, causative factors of common cancers, high risk groups etc have been published both in English and vernacular languages in the regional news papers for the awareness of both the medical personnel and common populace.

The registry staff has presented several scientific papers in various national and international conferences, seminars and meetings and have also published articles in indexed journals. Moreover the staff have also participated as resourced persons in several WHO, NCRP and UGC sponsored workshops.

The registry database has been widely used for a variety of analysis resulting in several scientific publications both by the P.G students and clinicians of the institute. Moreover the registry has been extending expertise and guidance to a large number of P.G students in the matters of planning, designing and statistical analysis.

Two candidates have already obtained their Ph.D. degrees by utilizing the expertise and data of HBCR and another one is about to submit his thesis for Ph.D. under Dibrugarh University. In a big way HBCR, Dibrugarh is very much involved in human resource development in cancer epidemiology.

The base institution being only a tertiary general hospital lacks the required infrastructure of a comprehensive cancer center and because of which compared to other cancer centers, the number of cancer cases attending the institute is low. Due to the inadequate number of eligible cases in specific sites it has not been possible to undertake scientific studies on some of the important objectives of

HBCR like patient care, survival and epidemiologic studies on common cancers of the region.

However, it has been proposed to undertake from January 1, 2007, the study on pattern of care and survival of female breast, cervix and head & neck cancers at AMCH, Dibrugarh. Head and neck cancers constitute around 30% of total incident cancer cases reported for diagnosis and treatment at the hospital. Almost 100% of these cancers are diagnosed microscopically, 90% have either description of the clinical extent of disease or TNM staging and 96% of the patients receive CDT at this hospital. Around 50 new cases each of cancers of the breast and cervix reported for diagnosis and treatment yearly in the hospital and 100% of these cases are microscopically diagnosed and staged as per TNM and FIGO staging system and 95% of them receive CDT.

Moreover, the institute has received grant from the Ministry of Health, GOI under NCCP for augmenting therapeutic and diagnostic infrastructure for optimal cancer care in the hospital. Under the scheme there is a provision for opening an oncology OPD which would enable HBCR to streamline the follow-up system of cancer patients. It is expected that adequate number of incident cancer cases of breast, cervix and head and neck would be available to study the site treatment and stage specific survival pattern. Follow up strategy of the eligible patients would be evolved with the active cooperation of the clinicians and nursing staff of the respective disciplines.

Other Staff of the hospital based cancer registry, Dibrugarh:

Mrs. P. Dutta	-	Medical Record Officer
Mrs. S. Ahmed	-	Social Investigator
Mrs. S. Neog	:	Social Investigator
Sri. K. Saikia	:	Clerk (Sr. Gr)
Mrs. I. Baruah	:	Clerk (Sr.Gr)
Sri. S.R. Nath	:	Clerk
Mrs. R. Begum	:	Clerk
Mrs. J. Sonowal	:	Coding Clerk
Sri. P. Deuri	:	Typist
Sri. B. Mech	:	Helper

