REGISTRY PROCEDURE AND STATISTICAL METHODS

p. 2-ดำ

CHAPTER

I

REGISTRY PROCEDURE AND STATISTICAL METHODS

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Cancer registration in Thailand was established in 1963 as a hospital-based cancer registry by Prof. Okas Blangura head of the Department of Surgery, Chiang Mai University. The first relative frequency study of cancer in Chiang Mai was reported in the year 1971 (Menakanit *et al.*,1971). In 1971, the National Cancer Institute (National Cancer Institute 1973) collected information on cancer patients treated in 53 hospitals throughout the country (7 in Bangkok and 46 provincial hospitals). Data collection was passive and relied upon notification from hospitals. Though the collaboration has increased lately, this system was still unsatisfactory, because almost all community hospitals were not included in the registry. Incidence rates are, therefore, under estimated.

The first population-based cancer registry started in 1986 in Chiang Mai, followed by Khon Kaen in 1988, Songkhla and Bangkok in 1990 and Lampang in 1993. In the year 1993, with the cooperation of the registries of Chiang Mai, Khon Kaen and Songkhla, the National Cancer Institute, and the International Agency for Research on Cancer (IARC), the first volume of Cancer in Thailand (Vatanasapt *et al.*, 1993) was published. Published in 1999, the second volume of Cancer in Thailand included the data from five registries of Bangkok, Chiang Mai, Khon Kaen, Songkhla and the recently established one of Lampang (Deerasamee *et al.*, 1999).

SOURCES OF DATA

BANGKOK CANCER REGISTRY

Data of cancer patients is collected passively from 5 university hospitals, in both active and passive manner from 32 government hospitals, 82 private hospitals, 3 laboratories and death certificates. All certificates of death are reviewed and matched with the incident case records in the registry. Those without traces of other information are registered as death certificate only cases (DCO).

The minimum information for each cancer patient consists of : registry number, name, residential address, date of birth, age, sex, date of diagnosis, date of last contact (alive or death), site of cancer, cancer histology, method of diagnosis, extension of cancer, and number of primary tumors. In each hospital, cases are ascertained from medical records, both in and out-patient departments, pathology records (including cytology, hematology, and autopsy reports), imaging reports, and from hospital tumor registry, if available. Data notification forms are checked for duplication and keyed into the database, using the CanReg program for data entry and analysis.

CHIANG MAI CANCER REGISTRY

The cancer registry of Chiang Mai University was established in 1963 as a hospital-based cancer registry. The first statistical report was published in 1978. The population-base cancer registry was started in 1986 (Martin *et al.*, 1989) as a research project to study the incidence and mortality of cancer in Chiang Mai in the period 1983-1987. This project was a collaboration with and received financial support from China Medical Board and Faculty of Medicine, Chiang Mai University. The result was

published in Cancer Incidence in Five Continents, Volume VI (Parkin *et al.*, 1992). The incidence data of Chiang Mai Cancer Registry during the period 1988-1992 was published in Cancer Incidence in Five Continents, Volume VII (Parkin *et al.*, 1997), and the incidence data in the period 1993-1997 was published in Cancer in Five Continents, Volume VIII (Parkin *et al.*, 2002).

Chiang Mai Cancer Registry is operated by the Cancer Unit, Faculty of Medicine, Chiang Mai University and Cancer Committee. Four registered nurses and three practical nurses form the registration team of the unit. Method of data collection and verification the validity of the collected information are supervised by members of the Cancer Committee.

Data on patients diagnosed with cancer are collected actively from every hospitals in Chiang Mai province, composed of one university hospital (Maharaj Nakorn Chiang Mai Hospital), 8 government hospitals, 1 municipal hospital, 14 private hospitals, and 21 community hospitals, with the total number of 6 846 beds. The data are also collected from medical clinics and pathological clinics and also from death certificates from Department of Local Administration, Ministry of Interior. Sources in hospitals include the medical record sections, pathological laboratory records, section of hematology, radiation oncology, outpatients departments and hospital tumor registrations. All patient identifications are compared and matched to exclude multiple registration.

LAMPANG CANCER REGISTRY

A hospital-based cancer registry was established in Lampang provincial hospital in 1989 (Pongnikorn *et al.*, 1990). The first report of population-based cancer registration in Lampang from 1988 to 1992 was published in 1993 by retrospective finding of cancer cases in the province (Srivatanakul *et al.*, 1994) and the results in the period 1992 to 1994 was reported in Cancer in Thailand 1999 (Martin in Deerasamee *et al.*, 1999). The statistical report in the period 1993-1997 was published in 2002 (Pongnikorn *et al.*, 2002) and also in the Cancer Incidence in Five Continents Vol. VIII (Parkin *et al.*, 2002).

Lampang Regional Cancer Center was established in 1994 for cancer prevention and control, cancer research, as well as continuing education of health professionals particularly family physicians and general nurses. Therefore, the population-based cancer registration in the province has been set up at Lampang Regional Cancer Center.

All data on cancer patients are collected by passive methods. Sources of data include the provincial hospital, the Lampang Cancer Center, 1 military hospital, 2 private hospitals, 13 community hospitals, 1 laboratory in Chiang Mai, Cancer Registration Unit of Maharaj Nakorn Chiang Mai hospital, National Cancer Institute in Bangkok and death certificates from the Provincial Chief Medical Officer's Office of Lampang. All data are checked for duplication and keyed into CanReg programme.

KHON KAEN CANCER REGISTRY

Khon Kaen Cancer Registry was established in 1984 at the Faculty of Medicine, Srinagarind hospital, Khon Kaen University as a hospital-based cancer registry started in January 1988. The first published report was in 1989 (Vatanasapt *et al.*, 1989).

The data on cancer patient is collected by both active and passive methods from 1 university hospital (Srinagarind hospital), 1 Regional hospital (Khon Kaen Central hospital), 1 military hospital (Sripatcharin), 8 private and 19 community hospitals, 2 health promotion centers (region 4 and 6), the Provincial Chief Medical Officer's Office and Civil Registration Section of all districts.

The data of those who are registered as Khon Kaen residents are extracted from hospital-based cancer registry of Srinagkarind hospital. The medical charts of patients diagnosed as cancer are reviewed and registered from other hospital medical records by Khon Kaen Cancer Unit staff. Death certificates are collected from the Provincial Chief Medical Officer's Office and Civil Registration Section of all districts. All data are verified, checked for duplication, coded, and entered into the CanReg programme.

SONGKHLA CANCER REGISTRY

The Cancer Registry of Songkhla was set up in the Faculty of Medicine, Prince of Songkla University in 1990. The first statistical report of the registry appeared in 1991. Sources of data are from the Songklanagarind hospital, Hat Yai hospital (both of which have hospital cancer registries), Songkhla hospital, all community hospitals, one dental hospital and private hospitals. New cancer cases

are collected from the out-patient departments and wards, radiotherapy unit, cytology and surgical pathology records in Songklanagarind, Songkhla and Hat Yai hospitals and cancer clinics. Death certificates are collected from the Department of Local Administration, Ministry of Interior. The data are abstracted onto the registry forms, checked for duplication, verified, coded, and keyed into CanReg programme.

REGISTRY METHODS

The methods specific to each registry are described in the corresponding paragraph above. Briefly, data on cancer cases are collected from hospitals, laboratories and death certificates. The data collected for each cancer patient consists of registry number, name, residential address, date of birth, age, sex, date of diagnosis, method of diagnosis, site of cancer, extension of cancer, histology, date of last contact and status of cancer patient (alive or death). The methods of collection differ between registries, depending on the presence of hospital registries (which can supply information to the population-based cancer registry), and the use of registry staff for active case finding.

Copies of death certificates are collected from the Chief Medical Officer's Offices. All certificates of death are reviewed and matched with the incident case records of the registries. The cases for which no matching records are found are traced back to the data sources together relevant data. Cases which cannot be trace are registered as a death certificate only (DCO).

The primary site and histology are coded according to ICD-O, 2nd edition (Percy *et al.*, 1990). Second and subsequent primary cancers are also registered. A new registration number is given for each new primary cancer as indicated by the 3-digit code, (or cancers with different histology at the same site), as specified in the ICD-O manual.

Cases of carcinoma in situ are registered but not included in the calculation of incidence rates. Those that become invasive are re-registered as invasive carcinomas, with the behavior code changed to "3" (malignant). The most valid basis of diagnosis is recorded for all registered cases.

FOLLOW UP

Follow-up of registered patients were performed in all registries. It was done by both active and passive methods. Registered cases are first matched with death certificates, for the remaining cases thought to be alive, follow-up information was obtained by repeated scrutiny of hospital case records, postal inquiries and, if this measures failed to established a patient's vital status, by home visits. For more than 50% of cancer cases, information on vital status was obtained by reply paid postal inquiries. The result of follow-up was very important for calculation of survival rate and to evaluate outcome of cancer care and cancer control program.

STATISTICAL METHODS

Population denominators

The population denominators

used for the calculation of rates were estimated from 1990 and 2000 censuses published by the National Statistical Office (National Statistical Office, 1994; National Statistical Office, in press) which provide annual estimate by age group and sex for each province in Thailand. Inter census estimates of the population in 1996 and 1999 by age group and sex were calculated with the assumption of an exponential change of the population between the two censuses.

The annual populations at risk are calculated for the two periods (1995-1997 and 1998-2000) in each registry area. They are shown in the section of each particular registry.

The population of Thailand and of the four regions in 1996 were estimated based on the two censuses with the procedure described above.

National estimate

The data from the two Northern cancer registries of Chiang Mai and Lampang were first pooled by adding together the cases and the person-years at risk from the two registries. Then the age (five-year age groups) and sex specific rates for Chiang Mai plus Lampang (North), Khon Kaen (Northeast), Bangkok (Central), and Songkhla (South) were applied to the populations of the representative regions in 1996.

The sum of these provided the estimated total by sex, site and age group for the country as a whole and the corresponding incidence rates were calculated using the 1996 population of Thailand.

Childhood cancer

The result for cancer in Childhood are presented according to the diagnostic groups defined in "In-

ternational Classification of Childhood cancer 1996" (Kramarova *et al.*,1996). Because of the relatively small number of cases from each registry, their results have been pooled to produce a national estimate. This was done by simply adding together the cases from the different registries in age groups 0, 1-4, 5-9 and 10-14 as well as person-years at risk and calculating a "pooled" combined incidence rate. Results are expressed as a number of cases, relative frequency of different cancer types, age-specific incidence rates, the crude incidence rate and age-standardized and cumulative incidence in the 0-14 year age range as annual rate per million.

Crude Incidence Rate (CR)

Crude incidence rate is the number of new cancer cases observed during a defined period of population divided by the population at risk in the same period. It is expressed per 100 000 of population.

Age-Specific Incidence Rate

Age-specific incidence rate is the incidence rate in a specific age group. So age-specific rates are calculated by dividing the number of cancer cases in each five years age and sex structure of population in that age group and multiplied by 100 000. The rates are expressed per 100 000 of population.

$$AR = N_i/P_i \times 100\ 000$$

N_i = Number of new cancer occurring in the i th age group

P_i = Population of the i th age group

Age-Standardized Incidence Rate (ASR)

The age-standardized incidence rate is a summary measure of a rate that a population will have if it has a standard age structure. It is calculated first by estimating the age-specific incidence rates and then applying these rates to the standard population. The world standard population is used in this book. It is also expressed per 100 000 population. Standardization is necessary when comparing several populations that differ with respect to age because age has powerful influence on the risk of cancer.

Quality control was carried out though the following indices:

1. Percentage of Histologically Verified Cases (%HV) : The percentage of cases diagnosed was based on histology examination of tissue from primary site or from metastatic site, bone marrow, cytology and peripheral blood for leukaemia.

2. Percentage of Death Certificate Only Cases (%DCO): The percentage of cases where diagnosis was based on information obtained from a death certificate.