

COMMENTARY

Population-Based Cancer Registration in Indonesia

Mugi Wahidin¹, Rini Noviani¹, Sofia Hermawan², Vita Andriani², Ardi Ardian³, Hernani Djarir⁴

Abstract

Cancer is a major public health problem in Indonesia, becoming the 7th largest cause of death based on a national survey in 2007, accounting for 5.7 of all mortality. A cancer registry was started in 1970, but it was partial and was stopped mainly because no government body was responsible. Realizing the above situation, the Indonesian government established the Sub Directorate of Cancer Control within the Ministry of Health, with responsibility for developing a national cancer control program, including a cancer registry. A sustainable cancer registry was then started in 2007 within Jakarta Province, first hospital-based but then expanded to be population-based. Steps of cancer registration in Jakarta are data collection, data verification, data validation, data management and analysis, and data publication. Data collection is conducted by health facilities (hospitals, laboratories, primary health centers) at the district/municipal level, with reports to the provincial level. Data are collected passively by holding meetings every three months in the district/municipality. Verification of data is the responsibility of the medical doctor or pathologist in each data source. Data validation is conducted by a team in the cancer registry, consisting of district/municipal/province health officers, pathologists, and registrars. Data management and analyses are conducted by a cancer registry team at the provincial level, assisted by the national team. We use software named Indonesian Cancer Registry System (SRIKANDI) which is adopted from CanReg4 IARC. Data from the population-based cancer registry in Jakarta Province showed the leading cancers among females in 2005-2007 to be breast cancer, cervical cancer, ovarian cancer, colorectal cancer and among males are bronchus and lung cancer, colorectal cancer, liver cancer, pharyngeal cancer, and prostate cancer. The leading childhood cancers are leukaemia and retinoblastoma.

Keywords: Cancer registration - population-based - Jakarta, Indonesia

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Introduction

One main public health problem in Indonesia is cancer. Based on Basic Health Research 2007, cancer is the 7th cause of death among all causes of deaths (5,7%). National prevalence of cancer is 4.3 per 1000 population.

The above data is baseline data of cancer burden in Indonesian population. But, the data is not represent valid information in such population, because it is survey based. Valid cancer data will be resulted from cancer registry that avoid data duplication.

Cancer registry is ongoing and systematic data collection of cancer on occurrence, characteristic, and outcome, and data processing, storage, and data analyze to produce information on cancer. Information resulted from cancer registry will be source of policy development, planning, and evaluation of cancer control program. There are several cancer registry types based on data collection method, such as hospital-based cancer registry and population-based cancer registry.

Hospital-based cancer registry is a registry which is

conducted for cancer diagnosed by all parts of hospital. This registry is aimed to help hospital management to make good plan, organize resources and optimize cancer treatment in hospital. Population-based cancer registry is registry which is conducted based on cancer data in a certain population from all health facilities diagnosing and treating cancer, such as hospital, laboratory, health center, and clinic. This registry is aimed to get cancer burden in a certain population, both morbidity (prevalence, incidence) and mortality, that will be sources of planning and evaluation of cancer control program.

Attempts to develop cancer registry in Indonesia was started in Semarang, Central Java in 1970. Then, many cancer registries, such as hospital based, pathological-based, and population based were developed till 2004. Unfortunately, these attempts are stopped because of some reasons, such as lack of human resources and no national body/unit which is responsible to develop policy and implementation of cancer registry.

Then, since establishment of Sub Directorate of Cancer Control within Directorate of Noncommunicable Disease

¹Sub Directorate of Cancer Control, ²Sub Directorate of Specialistic Medical Services, Ministry of Health, ³Jakarta Province Health Office, ⁴WHO Representative to Indonesia, Jakarta, Indonesia *For correspondence: wahids_wgn@yahoo.co.id

Control, Ministry of Health in 2006, sustainable cancer registry was restarted again. Population based cancer registry was started in 2007 with modeling in Jakarta Province. The registry was started by hospital based, then expanded to be population-based. This model is developed by sub directorate of cancer control in collaboration with many parties such as directorate of referral medical services, Dharmas National Cancer Hospital, Provincial Health Office of Jakarta. This model becomes reference on developing cancer registry in other areas in Indonesia.

Procedures

Steps of development of cancer registry in Jakarta province are advocacy and socialization to related stakeholders, establishment of cancer registry team in national, provincial, and municipal level (5 municipalities, Central Jakarta, East Jakarta, West Jakarta, North Jakarta, South Jakarta), development of forms (abstract) and software, trainings, implementation, monitoring, and evaluation.

Technical steps of cancer registry in Jakarta province are data collection, data verification, data processing, analyze, and publication. Data collection is done in each health facility by trained registrars. Sources of data are 79 hospitals, 44 sub district primary health centers that cover 301 village health centers, 2 clinics, and 90 pathology laboratories. Data is collected using abstract forms that is inputted to software named SRIKANDI (Indonesian Cancer Registry System). Raw data from each facility is reported to Municipal Cancer Registry Team, then reported to Provincial Cancer Registry Team. Data collection is done passively by holding meeting every 3 months.

Data verification is conducted to ensure that data inputted are cancer cases, not other cases. This activity is done in each data sources (health facility) by verifier, pathologist or trained medical doctor. Data validation is done in municipal, provincial, and national level by cancer registry team in each level. This steps is conducted to clean data and avoid duplication. Besides data validation, cancer registry team in each level process re-verification.

Data processing/managing and analysing are conducted in municipal, provincial and national level. Provincial Cancer Registry Team assists these activities in municipal level, and National Team assists provincial team. Because of limitation of SRIKANDI software that only process data input, data processing and analyse is conducted using Microsoft Excel or SPSS. Information resulted from data analyse are incidence (cumulative incidence) and prevalence. Then, final information from is published through releasing documents/report book, seminars, and papers and electronic medias.

SRIKANDI software is adopted from CanReg 4 software, a software developed by International Agency for Research on Cancer (IARC). The software consists of 3 main parts, social information of patients, tumor information, and follow-up. The software is Microsoft Access based, and works independently. Total variable in the software are 32 for hospital and 18 for other facilities (primary health center, clinic, laboratory).

Findings

Data resulted from Jakarta Cancer registry shows that top 10 leading cancers among female 2005-2007 are breast cancer (incidence 18.6 per 100,000), cervical cancer (9.25 per 100,000), ovarium cancer (4.27 per 100,000), colorectal cancer (3.15 per 100,000), and bronchus and lung cancer (2.40 per 100,000), thyroid cancer (2.21 per 100,000), corpus utery cancer (1.76 per 100,000), pharyngeal cancer (1.72 per 100,000), leukaemia (1.61 per 100,000), and liver cancer (1.41 per 100,000).

The top 10 leading cancers among male are bronchus and lung cancer (incidence 5.81 per 100,000), colorectal cancer (4.13 per 100,000), liver cancer (4.01 per 100,000), pharyngeal cancer (3.65 per 100,000), and prostate cancer (2.82 per 100,000).

These results were submitted to Cancer in 5 Continents Volume X of International Agency for Research on Cancer (IARC) in 2011.

Conclusions and Recommendations

In conclusion, the leading cancers in Jakarta province are breast cancer and cervical cancer (among females), bronchus & lung cancer and colorectal cancer (among males), as well as leukemia and retinoblastoma in childhood. Modeling of population based cancer registry in Jakarta province has been successfully established, but needs improvement. Mechanism of cancer registry has been approved by related stakeholders and has been implemented well so we are ready to expand cancer registration to other areas of Indonesia.

Recommendations include: cancer registry in Jakarta province need to be strengthened continuously through collaboration of all related stakeholders; strengthening team of cancer registry in each level, municipality, provincial and national; improve SRIKANDI software (online, analyze process) to be implemented national wide; based on result of cancer registry, introduce adequate interventions for cancer control especially for the leading cancers; expand cancer registry to other areas in Indonesia based on lesson learned of modeling of cancer registry in Jakarta province.

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