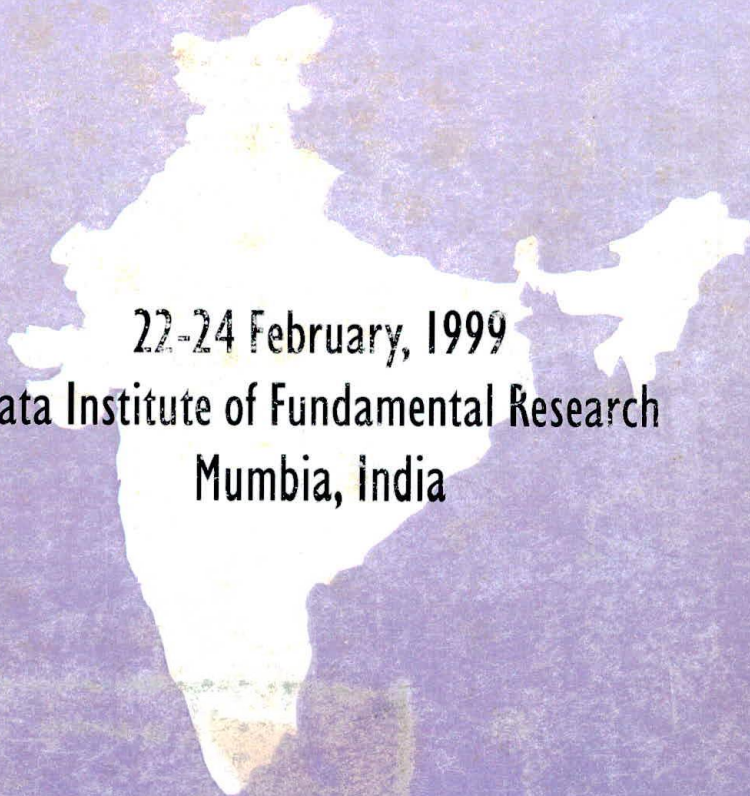


Counting the Dead in India in the 21st Century

Proceedings of the International Workshop
on Certification of Causes of Death



22-24 February, 1999
Tata Institute of Fundamental Research
Mumbai, India

Co-sponsored by the
Borhanmumbai Municipal Corporation,
World Health Organization, World Bank, and
Centers for Disease Control and Prevention

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1/21/99

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Summary

By making a few simple and practicable modifications to current practice, India can substantially improve the reliability of its birth, death, and health statistics. Reliable statistics help in monitoring the changing importance of particular diseases as causes of premature mortality and in monitoring the current and future importance of external factors such as HIV, tobacco, and alcohol as causes of death.

The International Workshop on Certification of Causes of Death, convened on February 22-24, 1999, in Mumbai, India, strongly endorsed the leadership of the Registrar General of India in upgrading India's vital statistics registration and cause-of-death systems for the next century.

The following are the key recommendations of the Workshop:

- ▶ Add brief, simple questions on the use of smoking and chewing tobacco to routinely collected death certificates.
- ▶ Strengthen the reporting and completeness of birth and death registration, especially in rural areas.
- ▶ By 2005, improve cause-of-death certification by using newer methods of collecting data and focusing on increasing the number of completed medical certifications in urban areas.
- ▶ Support further operational research and evaluation of vital registration and cause-of-death reporting systems.

Samira Asma and Prabhat Jha wrote this report, with input from Workshop participants. It reflects the views of the Workshop participants and not necessarily the sponsoring institutions.

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Introduction

Timely and accurate health data are essential to public health surveillance efforts that monitor trends in vital events, diseases, injuries, and disabilities. More timely and accurate release of vital statistics has been identified as a priority by national, state, and local health agencies; by academia; and by private organizations.

The creation of systems for collecting vital statistics in developed countries such as the United Kingdom and the United States has had an enormous effect on the organization and funding of disease control and public health programs. Reliable health data and vital statistics encourage researchers to develop appropriate interventions and discourage them from using substantial resources against insubstantial problems. Health data also help to direct research, inform public policy, and change personal behavior. They also help to inform the public about a few disturbing trends in disease, while reassuring them about other trends (the large majority of which are favorable).

The United Kingdom's nationwide death registration started in about 1837 and was functional within a few decades. India and other developing countries can benefit from such experience to implement complete systems in one to two decades. Unlike its present and past systems, India's new vital statistics registration, causes-of-death reports, and analytical epidemiology must deal with India's unique problems related to childhood and maternal mortality, communicable diseases such as tuberculosis and HIV/AIDS, and the emergence of non-communicable diseases. These new emerging diseases pose major organizational and technical challenges. It is promising to note, however, that the Registrar General of India has taken a leadership role in formulating new strategies for registering vital statistics (including causes of death) during the next century.

Objectives of the Workshop

- ▶ To discuss methods that would improve the quality and coverage of the certification of causes of death in India and to make recommendations for improvement.
- ▶ To review current analytical epidemiology on major avoidable causes of non-communicable diseases (such those related to tobacco use) and to assess its impact on public health.
- ▶ To explore feasible approaches for eliminating the magnitude of avoidable deaths due to various causes such as tobacco use.

To accomplish these objectives, the Workshop participants –

- ▶ Collaborated with the Registrar General of India and with members of academia to develop options for improving cause-of-death data and analytical epidemiology in India.
- ▶ Discussed key gaps and methodological issues in data collection.
- ▶ Critically reviewed the status of the epidemiology of tobacco use in India.

This report presents selected findings and recommendations from Workshop discussions. Appendix A is copy of the death report proposed by the Registrar General, Appendix B consists of Workshop abstracts and presentations, and Appendix C is a list of Workshop participants.

Revisions to the present death-certificate: Options for the Registrar General to consider

The Workshop participants acknowledged the strong leadership of the Registrar General in considering the suggestion of placing new, key questions on death-report forms beginning in January 2000. Listed below is the Registrar General's current proposal (see appendix A for a complete Death Report) and two suggestions (Option 1 and Option 2) proposed at the Workshop with the advantages and disadvantages of each.

Registrar General's Current Proposal

Questions 14-19 are listed from the Death Report Form (see appendix A for complete report).

14. If used to smoke regularly (enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death
15. If used to inhale snuff regularly (enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death
16. If used to chew tobacco regularly (enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death
17. If the used to chew arecanut in any form (including pan masala) enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death
18. If used to drink alcohol regularly (enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death
19. If used to take narcotic drugs regularly (enter the following information)
 - a) For how many years? i) Till death; or
 - b) Till when? ii) Till.....years before death

Advantage

- ▶ Questions are comprehensive and specific to Indian habits.

Disadvantages

- ▶ Too many of the questions could produce ambiguous responses, which would decrease completion rates.
- ▶ Term *regularly* is unclear. In the United Kingdom's International Study of Infarct Survival (ISIS) case-control study, questions about *regular* drinking created confusion, resulting in inability to analyze the answers.
- ▶ Duration of smoking is hard to measure. For example, a study by Gupta et al. in Mumbai showed that the correlation between answers given 2 years apart about *ever smoking* was 95%, but the correlation for *duration of smoking* was only 60%. Even more confusion would result when living relatives are asked about the smoking habits of a deceased person. Moreover, quitting is uncommon in India and other developing countries, so data on quitting may not be reliably obtained through questions about duration.
- ▶ Some questions are unnecessary: use of inhaled snuff is rare and so is use of arecanut without tobacco. Data from the Mumbai Cohort Study suggest only 0.5% of the population use snuff (Gupta et al. – see appendix B). In the Mumbai Cohort Study, the use of arecanut without tobacco did not indicate excess mortality (rate ratio adjusted for age was 1.01 for males).
- ▶ The question about alcohol is unclear, and responders might easily confuse 1) binge and light drinking and 2) drinking home-made liquor rather than liquor bought from a store. Moreover, the question does not capture data on deaths due to alcohol poisoning.
- ▶ The question about narcotics is general rather than specific to the various types of narcotics (e.g., bhang, hashish).
- ▶ Questions about alcohol and narcotic drugs, even when they are about the habits of dead people, could deter people from responding to any questions, given their fears of legal implications.

Option 1 of Workshop Participants

Add two simple questions to the present form for reporting the deaths of adults, and omit the proposed questions 14-19.

About 5 years* ago,	Definitely yes	Definitely no	No reliable answer available
1) Was the dead person a smoker? [†]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Was the dead person a quid chewer? [‡]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mark *No reliable answer available* if the information is not obtained from someone who lived with the dead person.

*Asking about a person's habits 5 years previous to death is intended as a way of learning about habits before they were affected by illness.
[†]*Smoker* means somebody who smoked on **most** days.
[‡]*Chewer* means somebody who chewed a quid of any type on **most** days.

Advantages

- ▶ Questions are simple, easy to complete, and well validated in studies in Mumbai, India; China; and South Africa.
- ▶ Format is consistent for all questions, with simple yes or no answers.
- ▶ Use of *No reliable answer available* column helps to ensure that comparisons are among certain categories, which helps to minimize bias in analyses of proportional mortality even if the overall number of available answers is small.
- ▶ These simple questions would probably generate powerful information and help to track the tobacco-use epidemic over time, across states, and at different ages.
- ▶ The question avoids the problem of confusing current smokers' risk for disease with past smokers' risk for disease. Data from Mumbai, India, and South Africa suggest that the former smokers' risk for lung cancer is nearly as high as that of current smokers. In India, quitting rates are low for smokers (<5%), and quitting is mainly because of disease onset. Given that the death report is unable to reliably capture long-term quitting due to insufficient knowledge and poor recall problems, it is appropriate to have only two categories: user and non-user.

- ▶ Asking about smoking that occurred 5 years previous to death (or 10 years previous) reduces or eliminates the chance that data will be skewed by changes in tobacco-use habits that arise from onset of disease (e.g., heart patient who quits life-long smoking on medical advice and then dies).

Disadvantages

- ▶ Information on the use of chewing tobacco taken from hospital records was not useful in a study in Mumbai (Gupta et al.), but questions directly to surviving relatives produced useful data in Chennai (Gajalaxmi et al. – see appendix B)).
- ▶ No question about alcohol use. This is partly because of the difficulty of doing so in a simple and reliable way, and partly because questions about alcohol can cause offence (compromising the tobacco component and leading to unreliable evidence on alcohol itself), and partly because alcohol causes fewer deaths than tobacco does.

Option 2 of Workshop Participants

Same as Option 1 (two simple questions on smoking and chewing) plus a question on alcohol use.

About 5 years* ago,	Definitely yes	Definitely no	No reliable answer available
1) Was the dead person a smoker?†	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Was the dead person a quid chewer?‡	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Did the dead person drink alcohol¶ on most days?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Mark *No reliable answer available* if the information is not obtained from someone who lived with the dead person.

*Asking about a person's habits 5 years previous to death is intended as a way of learning about habits before they were affected by illness.
†Smoker means somebody who smoked on **most** days.
‡Chewer means somebody who chewed a quid of any type on **most** days.
¶Alcohol includes both home-made and store-bought alcohol

Advantages

- ▶ Same as for Option 1.
- ▶ In addition, Option 2 captures data on alcohol use, which can be analyzed by rural versus urban residents and by age differences of deceased.
- ▶ Option 2 allows researchers to compare mortality due to tobacco use with mortality due to alcohol use.

Disadvantages

- ▶ Question on alcohol may not be able to reliably capture different patterns of drinking, and the question is not well validated by studies.
- ▶ Question on alcohol would probably miss intermittent drinking.
- ▶ Questioning people about alcohol use could decrease response rates for all questions.
- ▶ Question on alcohol can compromise the tobacco component and lead to unreliable evidence of alcohol use itself.

Issues Related to Vital Registration

In India, registering births and deaths is a major challenge. There are about 24 million births and 9 million deaths per year. Of all unrecorded births in the world, 1 in 3 occur in India. There is large variation in the extent of birth registration across states and between urban and rural areas. This situation demands that vital registration be made a priority (see Vijayanunni, – see appendix B).

Most deaths in rural areas occur in the person's home, and these are the deaths most under-reported. Overall, 7 in 10 deaths occur at home with the remainder occurring in institutions (e.g., hospitals or nursing homes). Deaths of elderly and young children are particularly prone to omission. In Tamil Nadu, for example, infant deaths are under-reported by two-thirds. With the sample registration system (SRS), overall death rates are between 50% and 100% higher than they are with the civil registration system (CRS), although the gap is narrowing in some states. In contrast, the gap between SRS and CRS rates of infant mortality is not narrowing: SRS rates are two- to three-fold higher than CRS rates.

Recently, the "capture-recapture" method was used near Calcutta to register deaths and births. After an incomplete CRS, households were canvassed for information on deaths. The capture-recapture method estimated about twice as many deaths as did either the CRS or the SRS method. (Sekar and Deming, 1993). Workshop participants did not address in detail issues related to registering maternal deaths and the deaths of children younger than 5 years old, since these issues were outside its scope of work. However, they did emphasize that these issues deserve considerable attention.

There is variation in rural-urban migration (e.g., Pondicherry has 130%) of expected deaths due to in migration. The level of registration exceeds 100% due to people from neighboring areas outside some states come to avail better medical facilities and due to de facto method of registration get registered in some states. Incentives to report deaths are poor, and the implementation of the Registrar General's guidelines varies from area to area. Timeliness of reporting and publishing the results of the reports are slow (e.g., 1994 data are presented in 1999).

A National Identification Scheme is planned, but little progress has so far been made. Evidence from the South Africa and United Kingdom methods of collecting vital statistics suggests that assignment of a unique number to each person is of great importance. Giving each person an Election Commission voter card with a unique number has been proposed in India, but the progress toward implementing the proposal is extremely slow.

Workshop Recommendations for Improving Registration of Births and Deaths

- ▶ Register all urban and rural burial and cremation grounds, and do not permit any unregistered burial or cremation ground to be used.
- ▶ Do not permit any unregistered corpse to be buried, cremated, or disposed off in any way.
- ▶ Add *Deceased's duration of stay in the city where death occurred* to the form for registering vital statistics in all municipalities. This would help to separate data on deaths of residents from data on deaths of migrants. We need this data in order to have an appropriate denominator for calculating death rates.
- ▶ Waive fee for late registration of infant deaths so as not to penalize people who are slow to report such deaths.
- ▶ Use capture-recapture methods, including better comparisons of SRS and CRS, for key areas such as infant and maternal mortality and for adult mortality and fertility.
- ▶ Review incentives, training and staffing for functionaries who register deaths, including those who coordinate records with those of other ministries (e.g., the Ministry of Health and Family Welfare).
- ▶ Encourage training for registration staff at all levels, including computer training – perhaps, at first, focusing on the staff in a few pilot states.

Issues Related to Reporting Causes of Death

The accuracy of cause-of-death data varies by cause-of-death and by location where death occurred (rural vs. urban). For example in Tamil Nadu, the percentage of medically certified deaths is about 14% of the total registered deaths and about 40% of the registered urban deaths (Ramodass. – see appendix B). Use of the International Classification of Diseases–Modification 10 (ICD-10) has been proposed but is not yet implemented in most of the country.

There is variation in the level of enforcement of burial regulations. For example, people in Calcutta can bury their dead with only a note from a doctor, but people in Chennai and Mumbai must have Form 8 (Medical Certificate of Cause of Death).

Comparisons between states presented at the Workshop showed cause-of-death data to be of variable quality. For example, the percentage of "ill-defined" death codes ranges from about 10% in Goa to 30% in Mumbai. Comparison between cause-of death reports and verbal autopsies in Chennai (Gajalaxmi et al. – see appendix B) showed that verbal autopsy reduced "ill-defined" codes from 50% to 25% of all deaths, and increased specificity of reported causes – The same verbal autopsy study shows that in comparison with the cause-of-death data gathered on deaths that occur in hospitals, sensitivity for verbal autopsy ranged from 100% for cancer deaths, 86% for respiratory deaths, and 74% for vascular deaths.

The rural cause-of-death survey has been discontinued. Instead the a new SRS is being developed to gather fertility and mortality data on the people who live in 6,000 blocks with about 1000 people in each block. As a result, about 1.1 million households will be interviewed. On average, each block will have about 10 deaths and 30 births per year.

At the Workshop, there was substantial discussion about sentinel sites. China has about 140 nationally representative disease surveillance points (DSPs). These cover a population of about 10 million people for whom almost all the deaths are medically certified and centrally collected by the Chinese Academic of Preventive Medicine. The DSPs were established in the early 1980s under a World Bank loan to China at a relatively low cost. The system has proved invaluable for generating reliable mortality statistics for China and the world.

Workshop Recommendations for Improving Cause-of-Death Reports

- ▶ Have widespread medical certification of all deaths in urban areas by 2005.
- ▶ Standardize questions on cause of death.

- ▶ Take stock of what is happening with regard to death certification in different states and municipalities, focusing on quality. Compare SRS results with CRS results.
- ▶ Expand training (including computerized ICD-10 training and use), especially in medical schools, at the Ministry of Health and Family Welfare, and at other pertinent ministries.
- ▶ Develop protocols for piloting SRS to address key risk factors in limited areas using verbal autopsy.
- ▶ Consider making cancer a reportable disease in areas with population-based cancer registries.
- ▶ Discuss methodologies for conducting analytic work. Most analytic studies will need follow-up of patients for the foreseeable future. In some areas with a high level of registration of vital statistics, studies may be able to determine total mortality through linkages with causes of deaths.

General Workshop Recommendations

Workshop participants made two key recommendations:

- ▶ During the next decade, support efforts by the Registrar General and others to strengthen registration of vital statistics, cause-of-death reporting, and analytic epidemiology in order to equip India to meet the health challenges of the 21st century.
- ▶ Support efforts by the Registrar General to add simple, brief questions on tobacco and alcohol use to death-report forms.

Workshop participants also recommended the following:

- ▶ At both the national and state level, the Ministries of Planning, Health and Family Welfare, and Biotechnology should help to finance more operational research and evaluation of vital registration and cause-of-death reporting systems. Seek support from international organizations such as the World Bank, the United Nations and its agencies such as the World Health Organization, and from the Centers for Disease Control and Prevention in the United States.
- ▶ During the next 4 to 6 months, pilot test the feasibility of suggested options for modifying cause-of-death reports. Aim to cover several hundred deaths in the pilot test.
- ▶ Form a consortium of people to work on improving the vital-statistics registration, cause-of-death reports, and non-communicable disease control and monitoring.
- ▶ Set priority areas for research. Establish and evaluate sentinel registration sites, and validate and expand verbal autopsy techniques. Further discussion about making SRS work reliably could be important, including a discussion on establishing sustainable sentinel sites.
- ▶ Meet again in October 1999 to review the status of registration of vital statistics in India, to assess progress toward goals, to conduct relevant training, and to help inform further action.

Appendix A

Death Certificate

FORM NO.2

DEATH REPORT**Legal Information***To be filled by the informant*

1. **Date of Death :** (Enter the exact day, month and year the death took place e.g. 1-1-2000)
2. **Name of the Deceased :**
(Full name as usually written)
3. **Sex of the deceased :**
(Enter "male" or "female"; do not use abbreviation)
4. **Age of the deceased :** (if the deceased was over 1 year of age, give age in completed years. If the deceased was below 1 year of age, give age in months, and if below 1 month give age in completed number of days, and if below one day, in hours)
5. **Place of death :** (Tick the appropriate entry 1, 2 or 3 below and give the name of the Hospital/ Institution or the address of the house where the death took place. If other place, give location)

1.Hospital/ Institution Name :

2.House Address :

3.Other Place

6. **Informant's name :**

Address :

(After filling all columns 1 to 19, informant will put date and signature here:)

Date : Signature or left thumb mark of the Informant

DEATH REPORT**Statistical Information***To be filled by the informant*

7. **Residence of the deceased:** (Residence of the deceased is the place where the deceased actually lived and can be different from the place where the death occurred. Only name of the Town/Village, District and State is required to be entered here and not the house address)
 - a) Town/Village:
 - b) District :
 - c) State :
8. **Religion :** (Tick the appropriate entry below)
1.Hindu 2.Muslim 3. Christian
4. **Any other religion:** (write the name of the religion)
9. **Occupation of the deceased :**
(If no occupation write 'Nil')
10. **Type of medical attention received before death:** (Tick the appropriate entry below)
 1. Institutional
 2. Medical attention other than Institution
 3. No medical attention
11. **Was the cause of death medically certified?:** (Tick the appropriate entry below)
1.Yes 2. No
12. **Cause of Death :** (For all deaths irrespective of whether medically certified or not)
13. **In case this is a female death, did the death occur while pregnant or within 6 weeks after the end of pregnancy:** (Tick the appropriate entry below)
1.Yes 2. No

To be detached and sent for statistical processing

To be filled by the informant

14. **If used to smoke regularly (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death
15. **If used to inhale snuff regularly (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death
16. **If used to chew tobacco regularly (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death
17. **If used to chew arecanut in any form (including pan'masala) (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death
18. **If used to drink alcohol regularly (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death
19. **If used to take narcotic drugs regularly (enter the following information)**
 - a) For how many years?
 - b) Till when? i) Till death; or ii) Till years before death

(Columns to be filled are over. Now put signature at left)

To be filled by the Registrar

Registration No. :
Registration Date :
Registration Unit :
Town/Village :
District :

Name and Signature of the Registrar

To be filled by the Registrar

Name
District :
Tahsil :
Town/Village :
Registration Unit :

Code No. Registration No. : Registration Date :
Date of Death : Sex: 1.Male 2.Female
Age : Years/months/days/hours
Place of Death : 1.Hospital/Institution 2.House 3: Other Place

Name and Signature of the Registrar

Appendix B

Presentations and Abstracts

RECENT DEVELOPMENTS IN THE CIVIL REGISTRATION SYSTEM IN INDIA

Dr. M. Vijayanunni
Registrar General & Consensus Commissioner, India

Civil registration was started in some areas of India in the last century. It started with the registration of deaths with a view to collecting information for control of pestilence and disease. Subsequently, registration of births was introduced. In 1886, a Central Act-the Births, Deaths and Marriage Registration Act was placed in the Statute Book. However, registration was not made compulsory but was kept voluntary. Different Acts were enforced in different parts of the country at different points of time and even in a single state there were many Acts in force in different areas. A few states had their own Acts that were adopted by a few other states. Some Municipalities had separate Acts for registration and some had enabling provisions in their Act providing for registration of births and deaths.

The enactment of the Registration of Births and Deaths Act, 1969 provided the first uniform law for the whole country which made reporting and registering of births and deaths compulsory and also replaced all the diverse laws that existed on the subject and unified the system. Foetal deaths of gestation period of less than 28 weeks of duration are not required to be registered. It provides for a statutory authority at the centre and in each state. It aims at enabling the Central Government to regulate the registration and compilation of vital statistics in the country so as to ensure uniformity and comparability, leaving enough scope to develop an efficient system of registration on the lines suited to the particular characteristics of the respective administration. The responsibility of the implementation of the Act in the states is that of the statutory authority in each state and union

the registration centres. This is true also for states that have already achieved cent percent registration viz. Kerala and Goa (last report 1994). The delay in reporting of the statistics from the local registrars, eventually delay the compilation of vital statistics and its publication at the state and national level.

The Registrar General's Office was seized of the problem and after an in-depth study of the registration and statistical functions discovered that a lot of paper work at the level of registrars is largely responsible for such malaise. Therefore, it was felt necessary to review and rationalise the actual process of registration and statistical work done by the local registrar and find ways of reducing his workload, thereby ensuring quicker transmission of data/records from the registration centres. One of the ways of reducing the workload was to keep the transcription work of the registrar at the barest minimum. Keeping this objective in view it has been now decided to replace the multi-event register by the loose-leaf single event form that is itself the legal part of the reporting form. The registrar now has to register the event in the legal part of the reporting form itself, thereby totally eliminating the need to have separate register. The reporting forms that have been modified to accommodate these new registration procedure now have two parts-legal part, that contains only those items that. required for legal purposes and statistical part, where only items that are statistical in nature are included. At the end of every month the registrar only has to detach the statistical parts of the reporting forms and despatch them for statistical tabulations. The modification of the forms gave us an opportunity to give a fresh look at the items of information currently being collected with a view to excluding items that are not necessary and include those which are important. Instructions for filling up the forms appear along with each item for easy reference and making them. user-friendly. Wherever possible, the items have been pre-coded to facilitate data entry. Different colours have been suggested for the three different forms (Reporting forms for birth, death and still birth) for easy handling

marriage, which in turn can be cross tabulated with the order of birth to get estimates of fertility levels. In itself the age at marriage data is a very useful data item.

- c) *Method of delivery* - This information is used to relate the method of delivery with certain characteristic of mother like age group, educational level, type of attention, at delivery, etc. Information from this item can be used to monitor delivery trends across the country and over the years.
- d) *Birth Weight* - This is the single most important characteristic associated with infant mortality. It is also related to the age of mother, her literary status and other factors surrounding the birth. Consequently, it is used with other information to plan for and evaluate the effectiveness of health care. This item can be easily collected from the medical institutions and through the health workers/ANMs, wherever they have been notified to collect the information on births and deaths from the informant.
- e) *Duration of pregnancy* - Duration of pregnancy when cross-tabulated by Weight and age group of mother gives a very good insight into the reproductive health status.

The items "Nationality" and Permanent Address" have been excluded from all the reporting forms.

The following items of information have been included in the new death report form (Form No.2)

- a) *Residence of the deceased* - The actual purpose it collect usual residence of the deceased. This will help in tabulating the events by place of usual residence.
- b) *Pregnancy-related death* - This item is introduced for collecting

information on female deaths that occur during pregnancy or within 6 weeks of the end of the pregnancy. It may be noted that the end of pregnancy may be due to abortion and may result in still birth or live birth. This will provide an upper limit of the maternal deaths and the corresponding rates over space and time. This item has been recommended for collection by the World Health Organisation.

- c) *Tobacco, alcohol and narcotic habits* - It has been decided to collect details of addictive habits of the persons of the deceased. The addictions included are smoking, inhaling of snuff, chewing tobacco, chewing arecanut, drinking alcohol, and taking narcotics. The duration of the habit and the time since person had given up the habit will also be collected. This information will be related to the cause of death provides a deep insight into the addiction-induced death. This information can be tabulated by age of deceased for providing useful clue to the addiction pattern prevailing in the country.

In the Still Birth Report form only those statistical part that will be used for tabulation have been retained. These are "Age of mother at time of birth", "Mother's level of education" and "Type of attention at delivery". The new item that has been included in this form is "Duration of pregnancy" as still birth, when cross-tabulated by age of mother and duration of pregnancy, provides important health information.

The proposed reduction in the workload of the Registrar and the changes recommended in the forms are likely to correct the situation to the extent that the basic returns reach the designated compilation offices in time. However, the problem would still persist if the data so received in the compilation offices were not processed in time. Therefore, we are preparing a time-bound action plan on processing of the vital statistics data to ensure that the reports are made available to the data-users in

time. Common program software to be used by all the states will be developed for use of all the states to integrate and unify the processing and tabulation of CRS based vital statistics. We expect that with the successful implementation of the new system, the civil registration system would be in a position to provide the much needed vital statistics at levels even below the state on a continues and permanent basis, at least in the states where the registration levels have reached 90%.

AGENCIES FOR REGISTRATION OF BIRTHS AND DEATHS IN STATES/UTS**CHIEF REGISTRARS**

<u>Health</u>	<u>Economics & Statistics</u>	<u>Others</u>
Andhra Pradesh, Assam, Gujarat, Haryana, Himachal Pradesh, Jammu & Kashmir, Maharashtra, Manipur, Meghalaya, Orissa, Punjab, Sikkim, Tamil Nadu, Tripura, Uttar Pradesh, West Bengal, A&N Islands Chandigarh, Lakshadweep,	Arunachal Pradesh, Bihar, Goa, Karnataka, Madhya Pradesh, Nagaland, Rajasthan, Delhi	Kerala (Panchayats), Mizoram (Chief Secretary), Dadra & Nagar Haveli (Secy.Admn.), Daman & Diu (Finance Secretary), Pondicherry (Local Admn. Deptt.),
(16 States + 3 UTs)	(8 States+1UT)	(2 States + 3 UTs)

DISTRICT REGISTRARS

<u>District Health/Medical Officer</u>	<u>District Statistical Officer</u>	<u>Deputy Commissioner Collector</u>	<u>Others</u>
Andhra Pradesh, Assam, Gujarat, Haryana, Himachal Pradesh, Jammu & Kashmir, Maharashtra, Manipur, Meghalaya, Orissa, Punjab, Sikkim, Uttar Pradesh, Andaman & Nicobar Islands, Chandigarh, Lakshadweep.	Madhya Pradesh, Nagaland, Rajasthan, Delhi.	Arunachal Pradesh, Goa, Karnataka, Mizoram, Tamil Nadu, Tripura, West Bengal, Dadra & Nagar Haveli, Daman & Diu.	Bihar, (Dy. Development Commissioner), Kerala (Distt. Panchayat), Pondicherry (Municipal Admn.)
(13 States + 3 UTs)	(3 States + 1 UT)	(7 States + 2 UTs)	(2 State + 1 UT)

RURAL REGISTRARS

Panchayat Secretary

Andhra Pradesh, Bihar, Goa, Gujarat, Himachal Pradesh, Kerala, Maharashtra, Manipur (Sub-Registrars), Rajasthan, Tripura (non - TTAADC areas), Uttar Pradesh, West Bengal (Sub-Registrars) Daman & Diu, Delhi, Pondicherry.

Police Officer

Haryana, Jammu & Kashmir, Madhya Pradesh, Punjab, Chandigarh.

Village/Revenue Official

Karnataka, Tamil Nadu, Dadra & Nagar Haveli.

Block Development Officer

Manipur (Non-hilly areas).

Tehsildar Sub-Divisional Officer/Extra Asstt. Commissioner

Arunachal Pradesh (Extra Assistant Commissioner /Circle Officer), Tripura (Tehsildar in TTAADC areas).

Primary Health Centre Incharge/Health Inspector/ Block Sanitary Inspector

Assam, Manipur (in hilly areas), Meghalaya, Orissa, Sikkim, West Bengal, A&N Islands, Lakshadweep.

Teacher of Govt. School

Arunachal Pradesh (Sub-registrars), Mizoram, Nagaland, Rajasthan (Sub-registrar in Some areas)

URBAN REGISTRARS

In urban areas registration is done by the Municipal authorities.

ANNEX 2

Progress of Registration of Births and Deaths - India, States and Union Territories
Level of Registration and Receipt of Returns for the years 1992, 1993 and 1994

India/ State/ Union territory	Level of Registration ¹						Percentage of Returns Received		
	Birth			Death					
	1992	1993	1994	1992	1993	1994	1992	1993	1994
1	2	3	4	5	6	7	8	9	10
India	50.8	51.4	51.6	44.1	46.0	46.3	80.0	83.6	79.7
States									
Andhra Pradesh	33.1	35.0	33.2	30.0	34.4	29.9	36.8	41.6	39.8
Arunachal Pradesh	77.3	66.3	67.1	15.2	15.5	19.5	100.0	100.0	100.0
Assam	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.
Bihar	21.2	21.6	17.4	29.6	29.8	24.1	98.8	96.8	78.6
Goa	119.9*	121.5*	117.4*	102.7*	110.0*	112.3*	100.0	100.0	100.0
Gujarat	92.7	92.1	95.9	64.8	62.4	70.5	94.1	96.5	91.2
Haryana	63.8	61.4	68.5	67.6	64.7	75.5	100.0	95.9	99.6
Himachal Pradesh	52.8	51.5	58.4	37.4	38.0	42.9	71.0	73.0	75.7
Jammu & Kashmir ²	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	100.0	100.0	100.0
Karnataka	68.8	72.4	75.6	55.3	66.5	75.5	N.A.	84.2	85.3
Kerala	99.2	100.7*	99.2	89.9	87.9	89.3	100.0	100.0	100.0
Madhya Pradesh	49.9	51.0	49.7	48.1	52.6	53.2	99.9	99.6	99.6
Maharashtra	77.6	77.2	76.2	68.9	71.7	69.4	91.6	95.5	91.2
Manipur	18.1	18.8	13.7	15.1	16.5	27.1	46.7	57.8	55.0
Meghalaya	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.
Mizoram ³	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	81.5	88.1	81.5
Nagaland	87.9	88.3	94.6	60.2	49.9	52.1	82.8	82.3	73.1
Orissa	70.1	67.1	N.A.	54.7	58.4	N.A.	100.0	100.0	N.A.
Punjab	86.9	89.0	89.6	77.7	82.8	81.3	100.0	100.0	100.0
Rajasthan	20.5	22.0	21.8	24.7	26.7	29.6	66.4	70.5	73.2
Sikkim	22.9	23.6	22.3	7.9	9.0	9.2	100.0	100.0	100.0
Tamil Nadu	88.6	88.9	91.4	76.6	80.8	82.0	92.7	92.7	93.9
Tripura	68.3	74.6	103.3*	37.2	41.8	44.1	100.0	100.0	100.0
Uttar Pradesh	32.6	35.1	37.0	25.9	25.9	28.3	81.9	86.6	80.6
West Bengal	47.0	44.7	53.4	24.7	23.2	24.9	76.5	70.3	78.2
Union Territories									
Andaman & Nicobar Islands	N.A.	120.0*	118.7*	N.A.	78.5	71.4	N.A.	100.0	100.0
Chandigarh	163.3*	147.9*	128.2*	259.5*	277.1*	220.6*	100.0	100.0	100.0
Dadra & Nagar Haveli	80.6	78.6	79.2	52.7	61.4	57.6	100.0	100.0	100.0
Daman & Diu	135.1*	N.A.	N.A.	67.4	N.A.	N.A.	N.A.	N.A.	N.A.
Delhi	115.9*	111.8*	110.1*	113.6*	109.6*	116.5*	100.0	100.0	100.0
Lakshadweep	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.
Pondicherry	216.4*	205.7*	200.6*	150.6*	146.8*	131.3*	100.0	100.0	100.0

Notes :

- The level of registration is the percentage of registered events to the SRS estimated events.
- S.R.S. data for Jammu & Kashmir are not available.
- S.R.S. was implemented in Mizoram only from 1996 onwards and hence level of registration could not be worked out.

* The level of registration exceeds 100 percent in these States/UTs because the people from the neighbouring areas outside these States/UTs come here to avail of better medical facilities and due to the de facto method of registration all such events get registered in these States/UTs.

N.A. Not available since reports are yet to be received from these States/UTs.

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MORTALITY DATABASE IN CHENNAI

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Introduction

The population of Chennai is 4.2 million as on 1st July 1997 with a male-female ratio of 1:0.93. It has 33 registered burial grounds. The health authority requires a death certificate at the time of disposal of the body. A copy of the death certificate is sent to the Vital Statistics Division (VSD) in Chennai for deaths that occur at the hospital. A medical certificate is obtained from the private medical practitioner for deaths that occur at home. If medical certificate is not available, then symptoms, complaints, duration of illness etc are collected from the relatives at the burial ground. Based on this, the probable cause of death is determined by the Medical officer in the VSD. Autopsy of the dead body is not routine. Deaths due to unnatural, accidental, or violent causes are usually subjected to postmortem examination.

Accurate information on cause of death could help health authorities to prioritize problems and interventions. Despite inaccuracies death certificates remain as an important source of mortality data. Our earlier study has shown that the sensitivity of death certificates to detect cancer deaths is 57% (Gajalakshmi et al., 1998). So in order to compute cause specific mortality for the residents of Chennai we need a tool other than the death certificate. Verbal autopsy (VA) has been used extensively to assess cause of death among children and adult females. VA is an attractive alternative tool to assess the cause of death in countries where a large proportion of people die at home with out medical care at the time of terminal event and the registration of death is almost complete. In Chennai the death registration is almost complete and about 70% of deaths occur at home. Hence we undertook a pilot study on VA among

randomly chosen male deaths that occurred in Chennai during 1995-97 to assess whether it can be used as an indirect method to compute cause specific mortality in a developing environment like India.

Methods

The Population-based Cancer Registry at the Cancer Institute (WIA) commenced data collection in Jan. 1982 from the VSD. The procedure followed to collect the morbidity data is described in detail elsewhere (Shanta et al., 1994). The data required for the registry are not computerized by the VSD but maintained in the registers by trained staff. The Registry staff abstract data from death registers in the VSD to a standardized format which includes the following: deceased's age, gender, marital status, occupation, place of death, permanent address, date and cause of death (immediate/ underlying/ contributory), and informant's name. These were computerized in the registry and linked with the incident cancer cases registered since 1982 through linkage programs using computer. From 1982 to 1991, mortality data only on cancer deaths were collected from the VSD. Since 1992, data on all deaths irrespective of stated cause of death on the death certificate have been collected from the VSD.

The Division of Epidemiology and Cancer Registry at the Cancer Institute (WIA) has given special training to male university graduates to interview the spouse and/or close relative of the deceased to collect data on symptoms, signs and circumstances leading to death when they visited the family of the deceased person. The field visit report was entered in the blank page. The questionnaire has filter questions only for heart attack and respiratory diseases. To avoid distress over the terminal event the field visit was carried out 6 months after death. We assume even the longer recall period will not affect reporting the circumstances that lead to the terminal event.

cancer, 7-8% due to respiratory diseases including pulmonary tuberculosis, 29-34% due to vascular disease, 40-44% due to ill-defined causes and for about 4-9% of deaths, the cause of death was not available in the VSD.

The pilot study on VA was carried out with 2500 randomly chosen deaths that occurred in Chennai during 1995-97. About 311 houses could not be traced due to the following reasons: shifted the house after death, house demolished or inadequate address to locate the house. About 71% of deaths in the random sample occurred at home (Table 6). Table 7 shows that more deaths were seen over 55 years of age and most of the responders were in the age group of 35-64. About 27% of the deceased and 37% of responders were illiterates (Table 8). Table 9 compares the cause of death stated on the death certificate with the cause of death derived from VA. As a result of verbal autopsy the deaths due to ill-defined causes were decreased from 41% to 25% and the percentage of deaths due to cancer, respiratory diseases and vascular disease were increased compared to the data from the VSD. The cause of death was derived based on verbal autopsy report for deaths which were grouped under 'unknown cause' at the time of death registration, at the VSD.

The diagnosis derived from verbal autopsy was compared with hospital diagnosis of cause of death stated on the death certificate (Table 10). The sensitivity of verbal autopsy to detect cancer deaths is 100% , vascular deaths 73.6% and respiratory deaths 86%. In Table 11 the cause of death stated on the death certificate of deaths that occurred at home was compared with verbal autopsy report. The sensitivity of death certificate issued for deaths that occurred at home to detect cancer deaths is 66.3% , vascular deaths 53.4% and deaths due to respiratory diseases 38.6%.

Discussion

Accuracy of cause of death stated on the death certificate is essential to compute cause specific mortality, estimate survival rates and for health care planning. The death registration in Chennai is almost complete and certification of deaths, which occur at home, is of poor quality. The 'mortality to incidence ratio' or 'death in period' which is one of the indices of quality of registry data was 22% when the Registry collected data on only cancer deaths from the VSD. This is because of the low (57%) sensitivity of death certificate for cancer as underlying cause of death $[(1955/3420) * 100]$, i.e. 43% of cancer patients die due to causes other than cancer. Thus collecting data only on cancer deaths will result in registering only 57% of total deaths of cancer patients available in the VSD, and 43% of deaths due to non-cancer causes will not be registered. In India 65% to 70% of cases are seen in late stage of the disease at the time of initial diagnosis. So majority of cancer patients might have died due to cancer even though a non-cancer cause of death was mentioned on the death certificate. Hence Registry started collecting data on all deaths since 1992; this procedure has improved the mortality registration in the population-based cancer registry in Chennai.

We need an alternative method to collect data on the cause of death to minimize the misclassification of cause of death stated on the death certificate. The VA appeared to be an alternative method, which is widely used to collect data on cause specific mortality. The pilot study on verbal autopsy carried out in Chennai among randomly chosen male deaths that occurred during 1995-97 showed the possibility of ascertaining the leading causes of death, reducing the misclassification of cause of death on the death certificate and deriving cause of death when it is not available in the VSD focusing on the importance of collecting complete address with pincode would help in tracing the houses for field visit and improve quality of death data being collected from the VSD. They also should be given orientation courses on abstraction of cause of death from death certificate. Organizing

Table 1: Mortality data in Chennai PBCR: 1982-95

Years	Mortality			Morbidity	M:I ratio
	VSD (no)	Active F-up (no)	Total deaths (no)	Incident cases (no)	%
1982-84(3yrs)	1601	373	1974	7418	26.6
1985-91(7yrs)	3893	6116	10009	21555	46.4
1992-93(2yrs)	3420	548	3968	6642	59.7
1994-95(2yrs)	3335	424	3759	6887	54.6

Table 2: Extent of disease at the initial diagnosis-PBCR: 1992 & 1993

Extent of disease	No	%
Localised	237	3.7
Regional extension	4147	65.3
Advanced/metastas.	1020	16.1
Lymph & Leukae	470	7.4
Unknown	476	7.5
Total	6350	100.0

DCO excluded (n = 292)

Table 3: Extent of disease at diagnosis and cause of death by place of death from VSD
Data - PBCR : 1992 & 93

Extent of disease	Place of death					
	Govt hospital		Private Hospital		Home	
	Ca	Non-ca	Ca	Non-ca	Ca	Non-ca
Localised	10	12	11	15	53	100
Regional extension	138	76	148	85	577	801
Advanced/metastas.	128	9	147	20	146	141
Lymph & Leukaem	56	5	57	5	61	45
Unknown	20	13	37	18	74	120
Total						
No.	352/467	115/467	400/543	143/543	911/2118	1207/2118
%	75.4	24.6	73.7	26.3	43.0	57.0

DCO excluded (n = 292)

Table 6: Place of death of the deceased in Pilot Study
On verbal autopsy

Place of death	No	%
Hospital	631	28.8
Home	1558	71.2
Total	2189	

Table 7: Age group-wise distribution of the deceased and responders in Pilot Study
on verbal autopsy

Age group	Deceased		Responders	
	No	%	No	%
<25	-	-	38	1.7
25-34	100	4.6	220	10.1
35-44	176	8.0	429	19.6
45-54	334	15.3	552	25.2
55-64	456	20.8	511	23.3
65-74	512	23.4	337	15.4
75+	611	27.9	102	4.7
Total	2189	100.0	2189	100.0

Table 8: Educational level of the deceased and responders in Pilot Study on verbal
autopsy

Educational level	Deceased		Responders	
	No	%	No	No (%)
Illiterate	584	26.7	817	37.3
<6 yrs	321	14.7	380	17.4
6-8 yrs	429	19.6	454	20.7
9-12 yrs	566	25.9	408	18.6
>12 yrs	289	13.2	130	5.9
Total	2189	100.0	2189	100.0

Table 9: Causes of death based on the data from the vital statistics division (VSD) and verbal autopsy

Causes of Death among males	Based on Death Certificate from VSD		Based on Field visit report	
	No	%	No	%
Cancer	118	5.4	165	7.5
Respiratory diseases including PT	155	7.1	304	13.9
Vascular disease	653	29.8	760	34.7
Infection except Tuberculosis	26	1.2	56	2.6
Illdefined causes	896	40.9	549	25.1
Other medical illness	193	8.8	300	13.7
Unknown	148	6.8	-	-
External causes	-	-	55	2.5
Total	2189		2189	

Table 10: Causes of death of those who died at the hospital were compared with Verbal autopsy

Causes	Hospital deaths from VSD				
	Cancer	Vascular	Respiratory	Other causes	Total
Cancer	51	5	1	7	64
Vascular	-	170	1	100	271
Respiratory	-	17	50	22	89
Other causes	-	39	6	162	207
Total	51	231	58	291	631

Verbal autopsy compared against hospital deaths:

Sensitivity of verbal autopsy to detect cancer deaths is 100% $[(51/51)*100]$; vascular deaths 73.6% $[(170/231)*100]$; respiratory deaths 86% $[(50/58)*100]$.

Table 11: Causes of death of those died at home compared with verbal autopsy

VSD	Verbal Autopsy				
VSD	Cancer	Vascular	Respiratory	Other causes	Total
Cancer	67	-	-	-	67
Vascular	13	261	45	103	422
Respiratory	1	4	83	9	97
Other causes	20	224	87	641	972
Total	101	489	215	753	1558

Home deaths compared against verbal autopsy:

Sensitivity to detect cancer deaths is 66.3% $[(67/101)*100]$, vascular deaths 53.4% $[(261/489)*100]$ and respiratory deaths 38.6% $[(83/215)*100]$.

DEATH REGISTRATION IN RURAL TAMIL NADU

R. Ramodass

Tamil Nadu

Introduction

The registration of vital events keeps a continuous check on demographic changes. Once the registration of births and deaths is complete and accurate, it can serve as the back bone for the Health Information System.

Tamil Nadu has a long tradition of registration of births and deaths. Prior to the introduction of "**Registration of Births and Deaths Act 1969**" (Central act 18 of 1969) by the Government of India, registration of births and deaths in Tamil Nadu was carried out under the provisions of Madras Panchayat Act XI of 1899 in the Rural areas, the Madras Districts Municipalities act 1920 in the Municipalities and select Town Panchayats and the Madras city Municipal act 1919 in Madras Corporation. Even though these acts provided the procedures for registration of births and deaths, they were not covering the entire state and not uniform.

The Registration of births and deaths was made compulsory at the place of occurrence with the introduction and implementation of "**Tamil Nadu Births and Deaths Registration Rules 1977**". with effect from 15th March 1977 in accordance with the provisions in section 30 of the RBD act 1969.

Registration Hierarchy

The Registration hierarchy in Tamil Nadu is as follows:

Director of Public Health and Preventive Medicine	Chief Registrar
Joint Director (State Bureau of Health Intelligence)	Deputy Chief Registrar
District Revenue Officer/Additional Collector	District Registrar
Deputy Director of Health Services	Additional District Registrar
Village Administrative Officer	Registrar of Births and Deaths in the Village Panchayat
Executive Officers/Sanitary Inspectors of the Town Panchayat	Registrar of Births and Deaths in the Town Panchayat
Sanitary Inspector of the Ward	Registrar of Births and Deaths in the Municipalities/Corporations

The powers or legal actions against the defaulters are vested with the Additional District Registrars in the Non Municipal Areas and Municipal Health Officers/Commissioners in the Municipal Areas.

A time limit of 14 days for births and still births and 7 days for deaths is provided in the rules for registration of births and deaths. The rules also provide for late registration of births and deaths beyond the time limit specified above with late fee and other administrative procedures.

There are more than 13,000 registration units in Tamil Nadu as detailed below:

Village Panchayats	12,456
Town Panchayats	643
Municipalities	104
Corporations	6
Cantonments	2
Total	13,202

The birth and death returns from the village panchayats are sent to the Deputy Director of Health Services concerned through the Tahsildars and in the case of town panchayats the returns are sent direct to the Deputy Director of Health Services concerned for compilation. The returns from the Municipalities/Corporations/Cantonments are sent directly in the consolidated form to the Director of Public Health and Preventive Medicine.

Efficiency of the Registration System

The efficiency of the registration system in the State is monitored through indicators like registration efficiency and reporting efficiency. The reporting efficiency under the Civil Registration System (CRS) has improved from a level of about 80% to above 90% over the last 10 years. The registration efficiency of births has increased from a level of about 70% to 90% over the last 10 years. The registration efficiency of deaths has increased from a level of about 60% to 75% over the same period.

Status of Death Registration

The responsibility to report the death for registration is fixed on:

1. The eldest male member of the household or the nearest adult relative of the deceased in the case of domiciliary deaths.
2. The medical officer incharge of the institution in the case of institutional deaths.
3. The person incharge of the vehicle in case of deaths occurring in moving vehicles.
4. The person incharge of lodging houses/choultries in the case of deaths occurring in lodging houses and choultries.

5. Police officials in case of death occurring in the platforms or due to road accidents. In the case of deaths involving inquest the responsibility is fixed on the enquiring officer.

About 3.6 lakhs of deaths get registered every year in the State as against an expected 4.8 lakhs of deaths. Of these 3.6 lakhs of deaths, about two thirds get registered in the rural areas and about one third get registered in the urban areas. About 19% of deaths are institutional deaths in the State as a whole. The percentage of institutional deaths in the urban areas is about 46% and only 5% in the rural areas. The percentage of medically certified deaths is about 14% of the total registered deaths and about 40% of the registered urban deaths. The medical certification of cause of deaths is obtained in form 8 for institutional events and in form 8A for non-institutional deaths. But the certification in the prescribed forms is missing in quite a few cases, for which action is being taken to rectify the deficiency.

In corporations and municipal areas, cause of death is insisted upon at the time of registration of deaths. In Chennai Corporation, doctor's certificate on cause of death is insisted upon even at the time of disposal of the dead body. In the rural areas this is not insisted upon due to lack of facilities.

Impediments in Death Registration

The following are the obstacles in ensuring 100% death registration and in improving upon the cause of death statistics.

1. Infant deaths especially those happening within the first seven days of life seldom get reported and registered, Infant deaths from around 12% of total deaths as per the recent survey conducted in the state while only 4% of infant deaths get registered under civil registration. The omissions in registration of infant deaths is probably due to some infant deaths getting misclassified as still births, and also due to the prevalence

of female infanticide in some pockets and the consequent fear of legal action.

2. The deaths of persons getting discharged against medical advice do not get registered especially when the body is taken away to native villages far away from the urban institutions.

3. Deaths involving police inquests are registered belatedly or registered without correct cause of death particulars for want of post-mortem reports or inquest reports.

4. There are no registered burial/burning grounds in the rural areas and also in most of the municipal towns, due to which systematic notification of all deaths cannot be ensured.

5. Section 10 (3) of the RBD act provides for the issue of a certificate regarding the cause of death from the medical practitioner who attended during the last illness of the deceased. The proof of attendance lies with the medical officer and hence enforcement of this portion of the act is rendered difficult. Most of the poor people are made to obtain a certificate at a cost.

6. About 40% of the deaths occur to old age people and it is possible that such cases are not attended to by any medical practitioner and hence getting cause of death certificate is a problem in such cases. If cause of deaths certificates are insisted for such cases they may turn out to be a routine certificate with respiratory arrest as cause of death.

Measures Taken To Improve Death Registration

Tamil Nadu Govt. have introduced social security measures such as the following:

1. Grant of financial assistance from the Chief Ministers Relief Fund to

the family of the persons died in natural calamity, fall from trees and snake bites.

2. Grant of financial assistance for the funeral rites of scheduled caste/tribes.

Both of the above two measures help in improving death registration, as the cash is disbursed on the production of death certificate.

Suggestions For Improvement of Death Registration

1. All burial/burning grounds must be registered and no corpse should be allowed to be disposed of in unregistered burial/burning grounds or river sides.
2. The local bodies may arrange to open a death registration counter at the major institutions to enable on the spot registration and issue of extracts.
3. Late fee should be waived I the case of infant deaths reported or detected after the time limit, by suitable amendments to RBD Act.
4. For deaths occurring in moving vehicles the place of registration may be changed as "permanent place of residence of the deceased' instead of the "place of first halt".
5. To improve the cause of death statistics and medical certification of cause of deaths all the doctors both in government and private sector must be given a sensitization on the needs to certify the cause of deaths in the ICD format. Trainers training should be arranged at the National/Regional levels.

Rural Survey of Cause of Death Scheme in Tamil Nadu

In the rural areas of Tamil Nadu, 95% are domiciliary deaths and it is here that the relevant statistics on cause of death is missing.

In order to have some reliable data on cause of deaths the scheme of "survey of cause of death" was implemented in 150 Health Sub Centers of Tamil Nadu covering a population of 7.3 lakhs for a period of 3 years from 1996 to 1998. In the earlier years, lesser number of units were covered under the banner of "Model Registration Scheme".

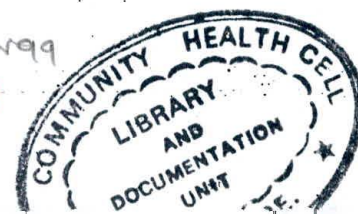
In these 150 Health Sub Centers, the Female Health Worker at the health Sub Center level acts as the field agent who is responsible to record births and deaths that occur to the usual resident population. The probable cause of death is arrived at through an after death enquiry of the facts and circumstances of deaths as recalled from the memory of the household. The medical officer of the Primary Health Care Center test checks the cause of deaths. Have yearly surveys are conducted once in six months by the Health Inspector of the Health Sub Centers during January and July every year and all the births and deaths that take place in the area to the usual resident population are netted. Now the Rural Survey Cause of Death scheme stands withdrawn by GOI with effect from 1-1-99. Since it will take a long time before civil registration system attains the desired level of efficiency, the scheme of survey of cause of death needs to be continued. The statistics on cause of deaths is also useful for planning purposes especially those related to Infant Deaths and Maternal Deaths. If this scheme is continued with an increase in the sample size it will definitely yield cause of death statistics at state level and at district level also. It is suggested that 40 Health Sub Centers per district covering 2 lakhs population can be taken up.

Cause of Deaths as per Civil Registration System - 1996
Tamil Nadu

S.No	CAUSE OF DEATH	%
01	CHOLERA	0.02
02	LEPROSY	0.04
03	WHOOPING COUGH	0.02
04	POLIOMYELITIS	0.02
05	MALARIA	0.00
06	TYPHOID & PARA - TYPHOID	0.16
07	OTHER FEVERS	8.94
08	DIARRHOEA-DYSENTERY - A.G.E	1.15
09	ANAEMIA	0.91
10	TUBERCULOSIS	3.96
11	BRONCHITIS & ASTHMA	5.26
12	JAUNDICE	1.27
13	CANCER	2.51
14	HEART ATTACK	22.28
15	DIABETES	1.57
16	PARALYSIS (CEREBRO - VASCULAR)	3.37
17	TETANUS	0.23
18	DIPHTHERIA	0.003
19	SUICIDE	1.19
20	INFLUENZA	0.002
21	FOOD POISONING	0.024
22	CHRONIC LIVER DISEASE	0.34
23	ULCER OF STOMACH	1.67
24	RABIES	0.04
25	BITES OR STINGS OF ANIMALS, INSECTS ETC	0.33
26	SYPHILIS & OTHER GENITO-URINARY DISEASES	0.34
27	MATERNAL DEATHS - OTHERS	0.20
28	MATERNAL DEATHS - ABORTIONS	0.03
29	PREMATURITY, BIRTH INJURY	2.84
30	MENINGITIS	0.13
31	SENILITY	18.69
32	MEASLES	0.03
33	BURNS - ACCIDENTS	1.09
34	APPENDICITIS	0.03
35	FALLS , DROWNING	0.14
36	ACCIDENTAL POISONING (EXCEPT FOOD POISON)	0.05
37	TRAFFIC ACCIDENTS (ALL TYPE OF TRANSPORT)	1.13
38	OTHER ACCIDENTS	0.32
39	PNEUMONIA	0.31
40	HOMICIDE	0.11
41	ALL OTHER CAUSES	19.25

SURVEY OF CAUSE OF DEATH (RURAL)

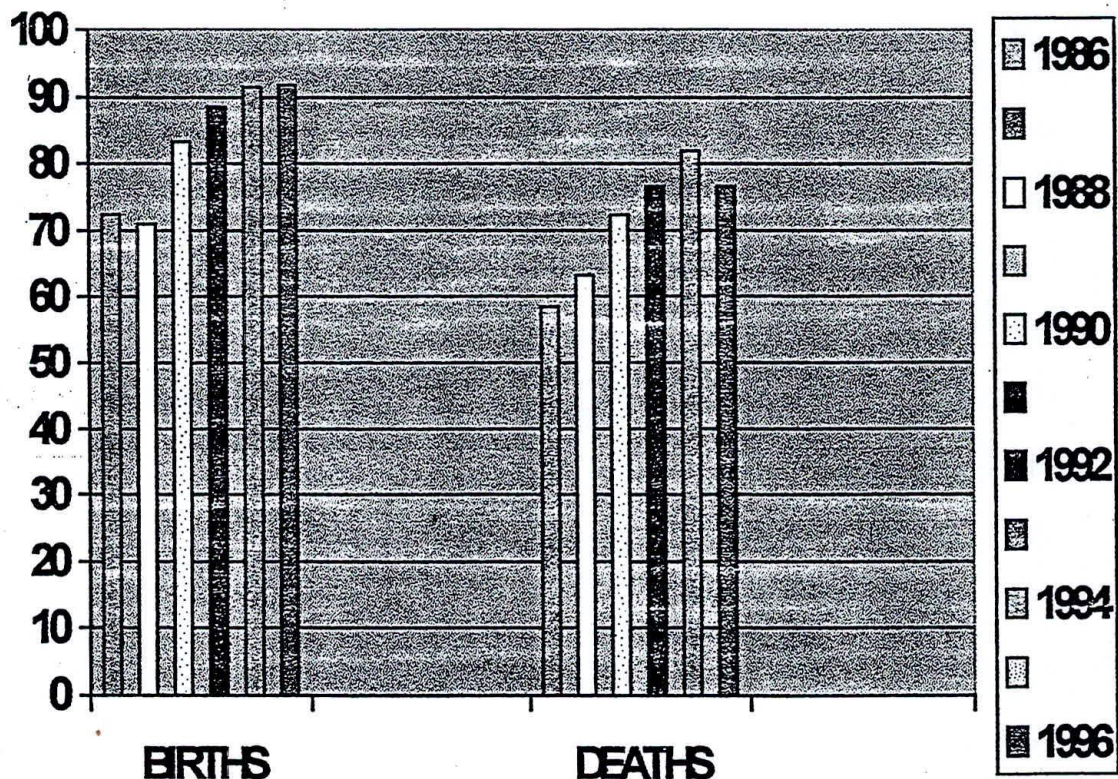
S.No	Major Cause Groups	1997	
		No.of Deaths	%
1.	Accidents and Injuries	801	13.96
2.	Child Births and Pregnancy	28	0.49
3.	Fevers	100	1.74
4.	Digestive Disorders	310	5.40
5.	Disorders of Respiratory System	636	11.08
6.	Disorders of Central Nervous System	467	8.15
7.	Disorders of Circulatory System	1220	21.26
8.	Other Clear Symptoms	780	13.59
9.	Causes Peculiar to Infancy	594	10.35
10.	Senility	802	13.98
	Total	5738	100.00



Chapter wise Percentage of Deaths As per ICD

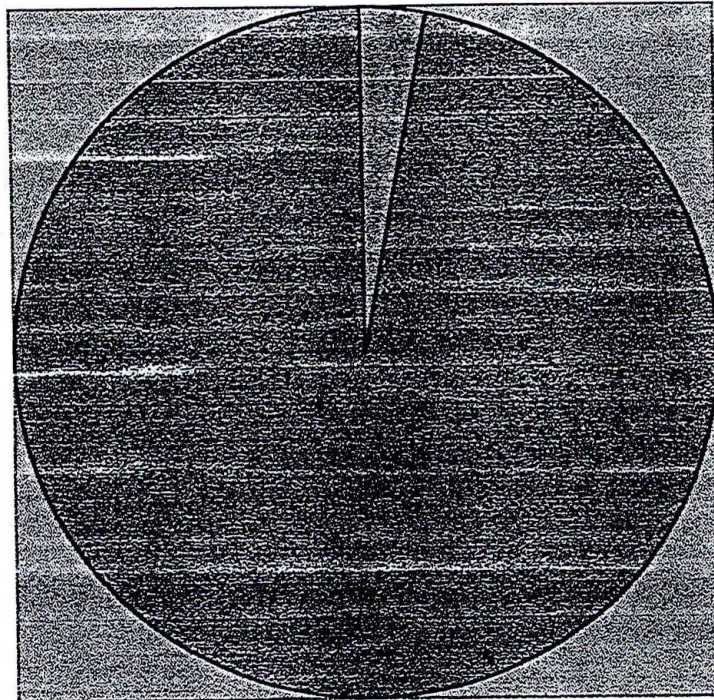
S.No	Cause of Deaths	%
1.	Infectious and Parasitic Diseases	10.2
2.	Neoplasm	2.7
3.	Nutritional and Metabolic Diseases and Immunity Disorders	3.2
4.	Diseases of Blood and Blood Forming Organs	1.3
5.	Mental Disorders	0.5
6.	Disease of Nervous System and Sense Organs	2.8
7.	Disease of Circulatory System	24.1
8.	Disease of Respiratory System	3.3
9.	Disease of Digestive System	3.4
10.	Disease of Genito Urinary System	2.3
11.	Complication of Pregnancy, Child Birth and the Puerperium	1.1
12.	Disease of Skin and Subcutaneous Tissue	0.2
13.	Disease of Musculoskeletal System and Connective Tissue	0.1
14.	Congenital Anomalies	0.8
15.	Certain condition Originating in the Perinatal Period	13.4
16.	Symptoms Signs and Ill defined Conditions	11.7
17.	Injury and Poisoning	18.9
	Total	100.0

BAR CHART SHOWING THE REGISTRATION EFFICIENCY OF BIRTHS AND DEATHS IN TAMILNADU



**CHART SHOWING PERCENTAGE OF
INSTITUTIONAL DEATHS AND DOMICILLARY DEATHS
IN RURAL AREAS**

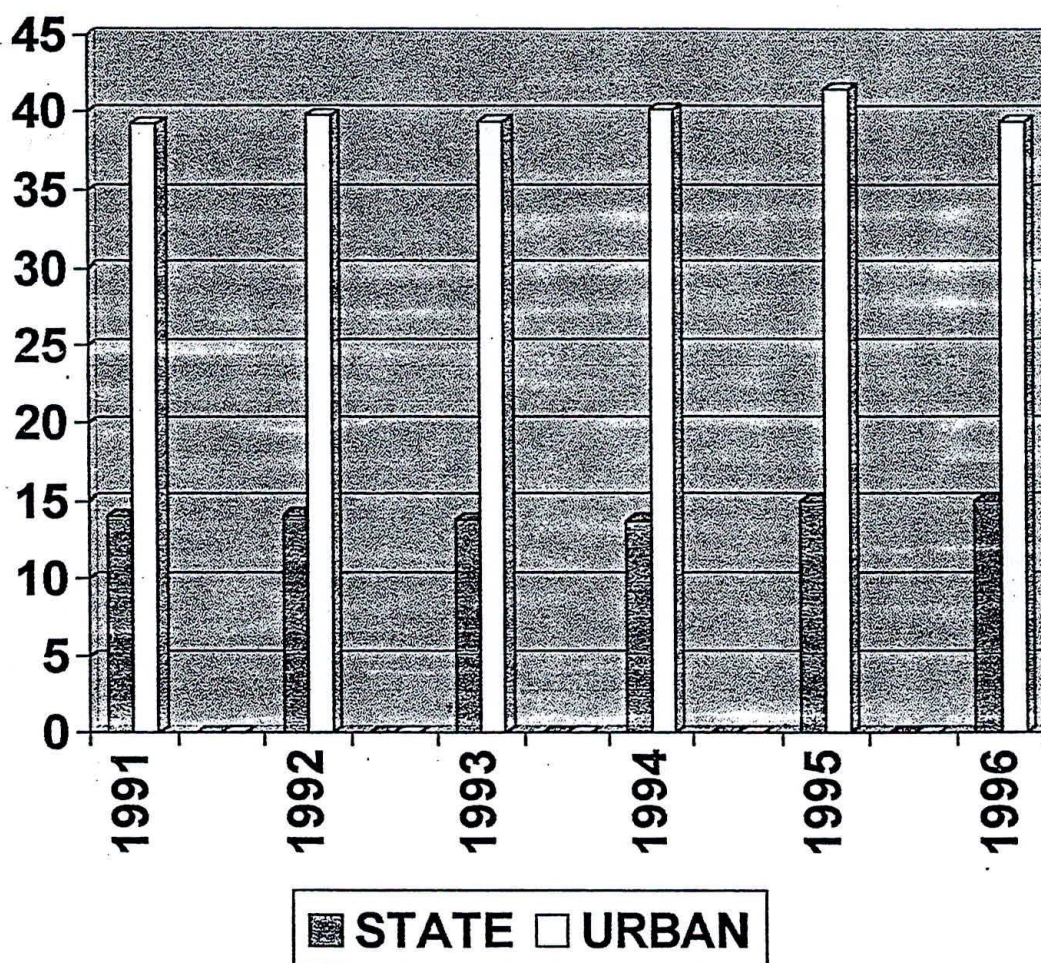
3.1



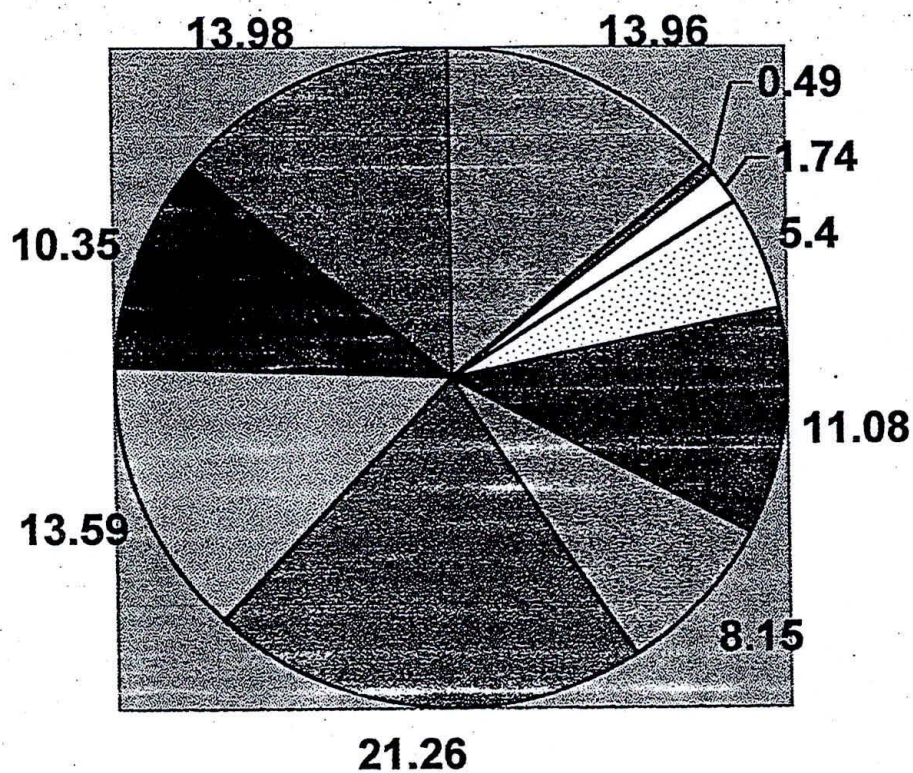
96.9

INS DOM

PERCENTAGE OF MEDICALLY CERTIFIED DEATHS IN TAMILNADU



TAMIL NADU - 1997 (SCD(R))



Accident	Pregnancy compli
Fever	Digest Disorders
Cough	Disorder of CNS
Disorder of CS	Other clear symptoms
Peculiar to infancy	Senility

**CANCER AS A NOTIFIABLE DISEASE - IMPROVEMENTS IN
SYSTEM OF REGISTRATION AND CERTIFICATION OF DEATH**

**Nandakumar
Bangalore**

Cancer As A Notifiable Disease

Improvements in System of registration and Certification of Death

What is Notification?

Compulsory for a diagnosing or treating physician/laboratory/medical institution or any other allied departments to report to a specified authority about a particular disease soon after its confirmed diagnosis

Need for such a rule in India?

- Quality of Average Medical Record
- Numerous and varied sources of cancer registration
- High proportion of cases from private sources
- Inadequacies in system of registration of death
- Incomplete certification of cause of death

Broad Aim/Purpose

- Enhance Cooperation to registry of all medical and allied personnel
- Contribute to Active Registration
- Wherever feasible initiate Passive Registration
- Improve system of registration and certification of causes of death

Specific Areas where such a rule will help

- Minimize cases where Residential Status is unknown
- Minimize cases where Duration of Stay is unknown
- Increase accuracy of identifying and eliminating duplicates
- Improve mortality data

Legal Basis of Cancer Registration

- Voluntary
- Compulsory - Notifiable
 - Legislation
 - Administrative Order

Latter is more common.

Could also depend on source of notification.

Reporting of Cancer is Compulsory

● Africa	0 %
● Central and South America	55.6%
● North America	82.6%
● Asia	38.1%
● Europe	47.2%
● Oceania	100%

Types of Confidential Information

- Core Information - Diagnosis of Cancer
- Epidemiologic Data - Personal: Sexual/Drinking
- Details of Treatment - Treating physician's name
- Information on Follow-up - House visits for survival information:

When Patient is alive:

Knowledge of cancer

Knowledge of treating physician

Medical Records

- Treated as Legal Documents and therefore are Confidential Documents
- No written code or legislation or Government Regulation to treat as Confidential
- Only Court of Law has the right to Requisition
- Information on Diagnosis and Treatment also furnished to Insurance Companies

Medial Law and Ethics in India

H.S. Mehta & V.J. Taroporvala

- CONSENT - Defined as:

Voluntary Agreement

Compliance

Permission

- May be Express or Implied

Express may be Verbal or Written

- Therefore in a Cancer Registry -

Answering or Completing Question

Indicate Implied Consent

Patient/Relative

- **Need and Importance of Information**
- **Reassured about holding information on Identity and Disease as Strictly Confidential**
- **Information used for Scientific purpose only**

Right to refuse Information

- Has the Individual (Patient or Treating Clinician) Really the Right to Refuse

Hospital/Medical Institution

- **Has the Right to utilize Data of Patients Without Identifying the Individuals(s)**

Follow-up in Mumbai Cohort Study - Preliminary Results

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The major objective of the Mumbai Cohort Study (MCS) is the estimation of tobacco attributable mortality in India. A cohort of about 160,000 individuals, recruited during 1991-97, is being followed up through house-to-house visits. Until Jan. 1999, some 52568 individuals age 35 years and over were followed up. Among them 0.1% were unidentified, 14.1% had migrated and 8.4% were reported dead. A total of 293,368 person years were observed, giving crude annual mortality rate (per 1000) among men as 20.1, among women. Among women who had reported using smokeless tobacco, the age adjusted relative risk (AARR) was 1.35 and among men smokeless tobacco users, it was 1.22. Among men smokers the age adjusted relative risk was 1.73 and although the number of women smokers was very small, the AARR among them was 1.28. These results are similar to those reported in earlier cohort studies from rural areas. The relative risks were high for bidi compared to cigarette smoking. A dose response relationship was also apparent.

Tobacco Attributable Mortality in South Africa

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³National Center for Occupational Health, Department of Health

⁴National Council Against Smoking ⁵Statistics SA ⁶WHO, Geneva

⁷Epidemiological Studies Unit, University of Oxford, UK

In order to estimate tobacco attributed mortality in South Africa, the Minister of Health was approached in 1995 and approved the addition of two questions on the death registration form:

- *Was the deceased a smoker five years ago?*
- *Was the informant/next to kin a smoker five years ago?*

A smoker was defined as someone who smoked on most days. These two questions allow for the construction of a case control study and follow up study of the next of kin.

National and provincial facilitation/implementation teams comprising key role players were formed in all 9 provinces and the new death

registration forms were introduced in July 1998. An instruction manual for filling in the new death registration forms also now available for the first time.

'Statistics South Africa' is responsible for coding of the death registration details and the production of mortality reports. However, there is a 2-3 year backlog, so all of the 200-odd regional Home Affairs offices around the country were asked to send copies of the first 200 death forms (about 40,000 deaths) from 1 October - 1 December 1998, i.e., 2 months after implementation for fast track coding and evaluation of the new forms. These forms have now been gathered and are about to be processed.

Depending upon the level of completeness of the information on tobacco an initial case control analysis will be carried out to measure tobacco attributable mortality for selected causes of death.

Tobacco Prevalence and Death Registration System in Bhopal

Rajesh Dixit

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The knowledge of tobacco usage as well as mortality data is particularly important in Bhopal population as this population underwent exposure to methyl isocyanate due to chemical accident in 1984 and hence is different from other parts of the world.

Tobacco survey was conducted in Bhopal population to estimate the prevalence of various kinds of tobacco use. The area wise voter list were obtained, and by random sampling, individuals were selected for interview using random numbers. Interview were conducted by the cancer registry staff on pre coded performa by house to house visit. Total number of 2560 males and 2576 females of the ages 18 years and above were interviewed. 46.6% of male and 43.1% of females were found to be users of tobacco, while 12.1% had habit of both smoking and as chewing. Among females only 0.16% were smokers while 42.5% were tobacco chewers. Only 0.47% of females had double habit of smoking and chewing. Among smokers bidi smoking were more common.

The mortality statistics has not been used so far in Bhopal to observe the tobacco related deaths. Total number of 5213 deaths were recorded in Bhopal urban area during 1997, however, the death registration system in Bhopal is poor. The details of methodology of death registration system, its problem and scope for improvement will be discussed. The possibility of using existing death registration system to carry out epidemiological studies will also be presented.

Death Registration and Cause Specific Mortality in a Semi-urban Adult Population in South Kerala

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¹Regional Cancer Center, Trivandrum, India ²International Agency for Research on Cancer, Lyon, France

³Medical College, Trivandrum, India

We aim to specify cause-specific mortality in a cohort of 114 601 subjects (48 809 males and 65 792 females) aged 35 years or more, recruited for a population-based oral cancer screening intervention trial in the northern suburban area of Trivandrum City, Kerala, India. This cohort, which consists of residence of 13 panchayaths (a local administrative structure) in Kazhakuttam and Chirayinkil development blocks, has been recruited over a period of three years during 1996-1998. Half of the males are tobacco recruited over a period of three years during 1996-1998. Half of the males are tobacco smokers, while less than 1% of females smoke. Tobacco chewing is practiced in the form of betel quid by a fourth of subjects; a fourth of males report alcohol drinking habit.

Deaths occurring in the target population are registered in the concerned panchayats registration office, if it occurred in home or in a hospital

within the geographical limits of the panchayaths. Usually a relative of the deceased notifies death to this office. On the other hand, if a resident of the panchayats expires in a hospital in Trivandrum City or other nearby towns, such as deaths are notified to the concerned urban death register. Physicians certify mostly hospital deaths. The urban death registers receive a copy of the hospital death certificates.

Though the death register ultimately registers most deaths, the cause specific mortality data are either not available or unreliable or non-specific. Some of the commonly stated 'cause of death' is 'cardio-respiratory arrest' or 'old age'.

For research purposes, we have established an active method to collect information on antecedent medical history from hospitals/households. A health worker visits death registers on a regular schedule and relevant details are abstracted. These are traced back to hospitals/households and relevant records are reviewed and information is abstracted. A panel of physicians review all the information thus collected to assign a cause of death *aposteriori*.

We present preliminary findings based on 1652 deaths occurring in 1996 in subjects ages 35 years (942 males and 706 females) and above. The cause of death was either not available or non-specific for 71.3% of the cases. A panel of physicians reviewed the actively collected information

and assigned the cause of death *aposteriori*. This exercise reduced the proportion of deaths with no-specified causes to 6.3%, coronary heart disease 922.1%), cancer (15.4%), obstructive pulmonary disease (14.6%), cerebrovascular disease (13.7%), and diabetes mellitus (6.8%) were the broad categories of cause of death assigned by the physicians after review.

Improvement in the completion and quality of death registration in India would require sincere inputs in legislation, physician education, public awareness and further investments in death registry organization and training of staff in coding and analysis.

Cancer Mortality in Greater Bombay

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Mumbai, India

Mortality statistics have an impressive history as a useful tool for undertaking epidemiological studies of cancer. The mortality analysis of various occupational groups has provided the evidence, which led to the discovery of several chemical carcinogens. Examination of time trends of the death rates, has in turn lead to the development of new etiologic hypotheses. Furthermore, international comparison of mortality data has been productive in outlining new directions for undertaking epidemiological field studies.

The significant role played by mortality data in epidemiologic studies, in the past, was largely due to the unavailability of morbidity data, which is considered more valuable for undertaking epidemiologic investigations. Gradually, the role of mortality studies has diminished with the establishment of population based cancer registries in various countries throughout the world and the availability of adequate morbidity data. The value of mortality data has also decreased with the increasing use of epidemiological field studies undertaken to test specific etiologic hypotheses, developed as a result of analysis of mortality statistics.

At our registry, mortality data has been obtained from the death records maintained by the vital statistical division of the Bombay Municipal Corporation. Copies are made by us of all death certificates which mention the word 'cancer' or 'tumor' as being the cause of death.

During the year 1995, a total of 5422 cancer deaths were recorded by the Bombay Municipal Corporation. Out of these, 860 were known non-residents of greater Bombay. 4112 were residents for over one year and the remaining 450 did have adequate addresses in Bombay at the time of death but their duration of stay in the city was not mentioned on the death certificate. The percentage of total resident cancer deaths to the total new cancer registration, was 51.7% during 1995.

The age-adjusted death rates for 1995 at all sites were found to be 67.8 for males and 63.8 for females per 100,000 population. Deaths from cancers of the lung, top the list in males, followed by deaths from cancers involving oesophagus, larynx, and stomach. Cancers of the female genital organs predominate in this sex, the breast being the leading site followed by the cervix and oesophagus. The age-specific rates were found to follow the general pattern of increase with age. An increase for the first time, was seen to occur in the fourth decade, in both sexes. The age-specific rates for females were found to be generally lower than males, except in the age-group 20 to 59. This can be explained by the high mortality rate of female genital cancers that occurs in the reproductive age groups.

Problems in Mumbai Feasibility Study

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Mumabai, India

Tobacco has been identified as one of the most important modifiable risk factor in leading causes of death. The mortality effects of tobacco is very well documented in developed countries. Even though there is enough evidence to demonstrate the higher overall mortality due to tobacco in India, there remains considerable uncertainty about total number of deaths tobacco will eventually cause. To monitor the growth of the epidemic of tobacco deaths in India, a series of long term epidemiological studies with large population base is required.

WHO recommended that tobacco status on death registrations, along with cause of death reporting, provide an inexpensive and long-term method to monitor the tobacco epidemic. Such simple methodology requires validation in India. A study to evaluate the validity and practicability of questions on smoking and chewing tobacco on death certificate in Mumbai, was planned at TIFR. The study group encountered many problems due to lack of cooperation from the professionals, bureaucratic hurdles, and indifferent attitude due to lack of awareness of concerned medical and non-medical hospital staff.

A Feasibility Study in Mumbai - Recording Tobacco Use on Death Certificates

H.C. Mehta, P.C. Gupta

Tata institute of Fundamental Research, Mumbai, India

It has been suggested that recording of tobacco use status prior to death on death certificate will provide a reasonably robust and cost-effective method for monitoring the tobacco epidemic. A feasibility study was initiated in Mumbai to investigate such an approach. In the first phase, the feasibility study was limited to hospitals where a large proportion of deaths (about 70%) occur. It was reported that cultural practices do not favor interviewing relatives after death of patient and the common practice is to fill out details in the death certificate from existing medical records. This study therefore investigated feasibility of abstracting information about tobacco use from existing medical records of patients who died in three large government hospitals in South Mumbai. An investigator sat in the medical record room with a small laptop computer and looked at the death certificates starting from most recent ones. For individuals over 35 years, information on age, gender, occupation and causes of death were abstracted. Corresponding case paper was identified and scanned carefully to abstract the tobacco use status and if available details of tobacco use for estimating reliability of the information. The cause of death was coded as per the ICD10.

Among total of 1658 death records abstracted from three different hospitals, 25.9% had some information on tobacco use, 1.3% did not mention any tobacco information at all and 72.8% were mentioned as no tobacco users. Major causes of death were circulatory system disease (29.3%), respiratory diseases (18.6%), tuberculosis (18.2%), digestive system disease (8.8%) and neoplasm (5.4%). Classifying tuberculosis, respiratory and neoplasm by tobacco use and comparing them with rest of the causes combined, the odds ratio was 1.97. The majority of tobacco habit recorded was smoking habit (20.5%). Since the prevalence of smokeless tobacco use is much in the population it appears that smokeless tobacco use is not adequately recorded in medical case paper.

**The Death Registration System in Calcutta - A review of Death Cases
with reference to Calcutta PBCR- 1997**

Urmi Sen, O.P. Ghosh, S.S. Mondal

Chittaranjan National Cancer Institute, Calcutta, India

The divisional offices of the Vital Statistics department of Calcutta Municipal Corporation are the major source of mortality for PBCR-Calcutta. All information is available in the death registers maintained for the different crematoriums and burial grounds at these units of Calcutta Corporation. However, mortality data from some of the suburban areas of Calcutta covered by the registry area was not available due to lack of proper documentation. Analysis has been made on the basis of the available data.

The total number of cases registered for the year 1997 with PBCR-Calcutta was 4081. This being the first year of operation the possibility of some under registration of cancer cases should be taken into account. The total number of cancer deaths as per the registry record was 448.

The total number of Death Certification Notification Cases (DCN) for 1997 obtained from the VSD units was 2121. Out of these only 277 deaths cases could be matched with the existing registry data. Attempts have been made to trace the remaining 1844 unmatched DCN cases by

pre-paid postal inquiries. The response rate observed is poor. An analysis of the postal replies obtained so far has been given. An overall analysis of total death cases due to cancer has been made. Attempt has also been made to analyze the confirmed death cases of 1997 with the existing registry records for some major cancer sites in both males and females.

Death Registration in a Rural Area in India - An Evaluation

B.M. Nene

Tate Memorial Center Rural Cancer Project

Barshi, Maharashtra, India

Panchayat office in each village maintains the death records. The information is registered with the Block development Officer at tehsil Head quarters and then sent onwards to the Joint Director of Health Services of the region. New Government Resolution was passed in June 1997. However, its implementation is poor. The drawbacks of the present system are highlighted and some suggestions are made, which if implemented will improve the death registration system.

Appendix C

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