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Cancer notification in India

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Abstract

In many developed countries, notification of cancer cases is compulsory. Developing countries including India accounts for more than half of new cancer cases in the world, however notification of cancer is not yet mandatory. The primary purpose of notification is to effect prevention and control and better utilization of resources. It is also a valuable source for incidence, prevalence, mortality and morbidity of the disease. Notification of cancer will lead to improved awareness of common etiologic agents, better understanding of common preventable causes and better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs, which ultimately might improve survival. Notification of cancer can be done by the doctor or the hospital. Akin to the integrated disease surveillance project where more than 90% of the districts report weekly data through E-mail/portal, notification of cancer can be implemented if it is incorporated into the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke scheme. The need of the hour is cancer notification in India.

Key words: Cancer notification, implementation, India

Introduction

More than half of the new cancer cases in the world occur in developing countries. The rapid increase in life expectancy (largely due to a reduction in mortality from infectious disease) together with the adoption of western life-styles suggests that the burden of cancer in these countries is likely to increase in the near future.[1]

In many developed countries, cancer notification is compulsory.[2] However, in most developing countries including India, the provision of information is on a voluntary basis.[1]

The existing cancer registries in India include population based cancer registries (PBCRs) and hospital based cancer registries (HBCRs). PBCR collect and process data relating to a defined geographical area while HBCR include data available with a specific hospital.

However the available registries have many limitations. They do not include the entire country; only include data gathered from specified towns and cities. There are only 24 PBCR and 5 HBCR in India.[3,4] The survival noted from these registries has an upward bias of 3-13%, with loss of follow-up in up to 20-25% respectively.[5,6] Even within these registries there is marked variation, which can lead to miscalculation of disease characteristics, especially data from specialized and non-specialized medical institutions.[7] The need of the hour is cancer notification.

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What is Notification?

Notification is reporting by a physician or other health care provider of the occurrence of specified disease to designated health agencies. List of notifiable diseases varies from country to country and also between states, urban and rural areas. The primary purpose of notification is to achieve prevention and control of the disease. It is a valuable source for incidence, prevalence, mortality and morbidity of the disease. Notification of cancer will lead to improved awareness of common etiologic agents, better understanding of common preventable causes and better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs which ultimately might improve survival.[5]

Presently some of the communicable diseases are notifiable in India. Under the integrated disease surveillance project more than 90% of districts in India notify for some of the communicable disease.[8] These include many syndromes and diseases like dengue, Japanese encephalitis, meningococcal meningitis, diphtheria, acute flaccid paralysis in <15 years and various others diseases.[9] These diseases are made notifiable in India by bringing them under specific legal acts (e.g., Madras public health Act of 1930, Epidemic state act of 1897).[10]

Which are the Countries Where Cancer is Notifiable?

Nationwide cancer registration operates in some countries such as England and Wales, United States of America, Scotland, the Nordic countries, Canada, Australia, New Zealand, Israel, Cuba, Puerto Rico and The Gambia. The Danish Cancer Registry, founded in 1942, is the oldest functioning registry covering a national population.[11]

The large registries have very low failure in cancer notification rates. Most registries have a failure rate of <5%, thus providing valuable information.[12]

What are the Different Methods of Collection of Information in Cancer Notification?

Collection of information can be done by either active or passive reporting. Active collection involves registry personnel actually visiting the different sources and abstracting the data on special forms. This is the usual method in registries in our country.

Passive reporting involves health-care workers completing the notification forms developed and distributed by the registry, or sending copies of discharge abstracts to the registry. A mixture of both procedures, with an emphasis on the latter, is followed in most registries in developed countries.

What are the Advantages of Cancer Notification?

Prompt and appropriate reporting allows for better management of cancer through:

- Monitoring of changes in the incidence
- Identification of risk factors and causes, with better utilization of resources
- Monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs
- Monitoring of patterns of prescribing drugs
- Planning of services for better care.

The notification data can be used to compile the national cancer registry. This data from national cancer registry can further help clinicians, health planners and researchers in better management of the patients.

Who Can Notify?

Notification of cancer can be done by any of the following to the concerned authority:

a. The person/place of diagnosis which includes Primary health center, community health center (CHC), taluk hospitals, district hospitals, nursing home, polyclinics and specialty hospitals
b. The pathologists and hematologists who confirm the presence of cancer
c. The treating doctor who can be medical (physicians, pediatricians, medical oncologists), surgical (oral surgeons, gynecologists, general surgeons, head and neck surgeons, neurosurgeons and surgical oncologists) or radiation oncologists.

Who Must be Notified?

The pro-forma is filled by the health worker, doctor or the hospital in-charge after confirmation of diagnosis [Table 1].[13,14] This can then be sent either by post or online portal system to the district/state cancer registry.

What are the Already Approved Programs for Cancer Where this Can be Incorporated?

National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke (NPCDCS) was approved during the 11th 5 year plan. This program

Table 1: Proforma

Particulars of patient
Full name of patient
Name of father
Name of mother
Name (s) of son (s)
Name (s) of daughter (s)
Name of husband/wife
Permanent address
Urban (town/cities)
Road/street name
Area/locality
Town/city
Nonurban/rural areas
Name of gram panchayat/village
Name of subunit of district (taluk/tehsil/others)
Name of district
State
Pin code
Telephone number (with STD code)
Mobile number
Duration of stay
Local address
Legal identification number (ration card, BPL card, passport number)
Gender – male/female
Age (in years)
Relationship of respondent to patient
Self
Family member
Friend
Others
Hospital/clinic
Notifying health establishment
Laboratory
Private practitioner/clinic (single)
Hospital/clinic/nursing home (multi)
Centre code
Registration number
Hospital registration number
Mail ID
Hospital/clinic responsible for subsequent treatment and follow-up-same as above/others
Years of follow-up 1/2/3/4/5/6/
Date of last contact
Status of disease at last contact (dead/alive)
Date of death
Place of death
Cause of death
Diagnosis
Date of diagnosis (DD/MM/YYYY)
Primary site

Cont.....

Table 1: Proforma, Cont....

Basis of diagnosis
Death certificate only
Clinical only
Microscopic slide detected
Specific tumour markers
Type of microscopic slide
Histopathology
Cytology smear
Blood smear
Bone marrow smear
FNAC smear
Others
Pathology/slide number
Anatomical site of specimen/biopsy/smear:
Complete pathological diagnosis
Primary site of tumor topography
Morphological diagnosis
Coding according to ICD-10[13]
Primary site of tumor-topography
Primary histology-morphology
Secondary site of tumor-topography
Secondary histology-morphology
Date of report (DD/MM/YYYY)
Screen detected (yes/no)
Stage of disease-TNM staging[14]
Therapy
None
Surgical (date of therapy)
Radiotherapy (date of initiation)
Chemotherapy (date of initiation)
Biological therapy (date of initiation)
Risk factor
Tobacco consumption (Yes/No)
Type-smoked/non-smoked (current smoker/ex-smoker/never)
Pack years
Alcohol intake
Occupation
Body mass index
Infection related (HIV/HPV/HBV/EBV/others)
Co-morbidities
Family history of cancer (yes/no)
Notification details
Filled on date (DD/MM/YY)
Updated on (DD/MM/YY)

STD=Subscriber trunk dialing, BPL=Below poverty line, FNAC=Fine needle aspiration cytology, ICD-10=International classification of diseases, 10th revision, TNM=Tumor, node, metastasis, HPV=Human papilloma virus, HIV=human immunodeficiency virus, HBV=Hepatitis B virus, EBV=Epstein-Barr virus

will be implemented in 20,000 sub-centers and 700 CHCs in 100 districts across 15 states/union territories. This program aims to (a) promote healthy life-style through massive health education, (b) opportunistic screening of persons above the age of 30 years, (c) establishment of non-communicable disease clinics at CHC and district level and (d) development of trained manpower and strengthening of tertiary level health facilities. Cancer notification can be added to the NPCDCS program. Similar to the integrated disease surveillance project where more than 90% districts report data through E-mail/portal, notification of cancer can be done if incorporated into the NPCDCS scheme.[8,15]

Similar to tuberculosis notification, if cancer is declared as a notifiable disease; then cancer patients may be diagnosed and treated in precancerous and curable stages. This may help to transform the predominant palliative nature of our treatment to a curative one.

Once declared notifiable, each medical college and district hospital must create their HBCR with either the medical oncologist/surgeon/physician/radiation oncologist/pathologist/chief medical officer in charge. The person in charge must be trained in data collection and entry in a prescribed proforma. Each state must set up their state cancer registry, which receives and processes the information from the person in charge. The state cancer registry should also train heath care workers regarding the seven danger cancer signals and their appropriate management. Undergraduate and postgraduate medical students should be made aware of the notification program by incorporating this into their curriculum. Awareness among the lay public should be increased about the ill-effects of tobacco, early vaccination and screening techniques in high-risk groups through educational material in languages spread by either governmental or non-governmental (e.g., Rotary, Lion's club, etc.) organizations. Information regarding the ill-effects of smoking should be incorporated into school children's textbooks. Finally, supervision of the whole system should be handed over to an independent authority/non-governmental organization concerned with cancer care which monitors data collection, diagnostic procedures and follow-up care and awareness programs.

Possible Limitations of Notifications

The system may suffer from under-reporting.

The accuracy of diagnosis and thereby notification may depend upon the availability of facilities for histopathological diagnosis. The lack of such facilities in many parts of rural India may work against the correct reporting.

Conclusion

Notification of cancer will lead to improved awareness of common preventable causes, better utilization of health resources with better monitoring and evaluation of the effectiveness of health programs such as cancer screening and cancer treatment programs.

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