Innovative field methods for residence confirmation and updating follow-up status of cancer cases: Experience from rural cancer registry, Punjab, India

Atul Budukh a, b, *, Prithviraj Kadam a, Divya Singh a, J.S. Thakur c

a Centre for Cancer Epidemiology, Advanced Centre for Treatment Research and Education in Cancer, Tata Memorial Centre, Navi Mumbai, Maharashtra, India
b Homi Bhabha National Institute, Training School Complex, Anushakti Nagar, Mumbai, 400094, India
c Postgraduate Institute of Medical Education and Research, Chandigarh, India

ARTICLE INFO

Keywords:
Community network
Social media
Follow-up status
Cancer registry

ABSTRACT

Background: The Sangrur population-based cancer registry, Punjab state, India experienced several challenges in confirming residence as well as updating the follow-up status of cancer cases, which is critical for accurately labelling incidence and providing cancer survival. This study presents innovative field strategies adopted by the Sangrur population-based cancer registry for residence confirmation and updating follow-up status of cancer cases.

Methods: A network was developed with the involvement of local community members to validate the address and follow-up status of cancer cases. In addition, social media was used to trace patients who were loss to follow-up.

Results: The Sangrur population-based cancer registry was unable to trace a total of 31 cancer cases. After implementing innovative field methods, 26 (83.9%) cases were successfully traced back; while 5 (16.1%) cases were untraced despite several efforts. A majority of these 31 cases were from urban areas (93.5%) compared to rural (6.5%). True Caller with the help of WhatsApp contributed significantly by tracing 9 cases (34.6%); followed by 4 cases (15.4%) traced with the help of a postman, 3 cases each (11.5%) with the electoral list and gas agency personnel, and 2 cases (7.7%) through medical shops. Also, 2 cases (7.7%) were traced with the help of treating hospital while Facebook and property tax office traced 1 case (3.8%) each.

Conclusion: By engaging with the local community, and with the use of social media, the patient’s residence and follow-up status can be updated. Due to this method, accurate labelling of the incidence can be achieved.

1. Introduction

The population-based cancer registries (PBCRs) are vital for reliable cancer data for defined populations. The quality of cancer incidence and mortality data leads to better planning and monitoring of cancer control programs as well as facilitates effective research. The PBCRs primarily capture information on patient and tumour characteristics at the time of diagnosis, as well as other information such as treatment and vital status where resources allow.1 There are challenges in recording the information in PBCRs.

As a part of acquiring the vital status of the patients, follow-up is performed by many PBCRs. The follow-up system can promote optimal patient care and provide a valuable record of patient outcomes. Furthermore, without sufficient follow-up information, the value of patient data collected have limitation. The main goals of follow-up are to ensure that medical surveillance is maintained in order to assess treatment outcomes and track patient’s health status as well as to monitor cancer care services in the population.2

Primarily, there are two types of follow-up - passive and active approaches used by the cancer registries based on the availability of resources and institutional guidelines. Passive follow-up involves linking patient records with data from routine follow-ups and combined with mortality data from the vital statistics division and/or the outpatient clinic.3 Registries implementing a passive follow-up system depend on external sources for the death notification of all registered cases. Thus no routine inquiries are generated in this method; however, the information

* Corresponding author. Centre for Cancer Epidemiology (ACTREC), Tata Memorial Centre (TMC), Homi Bhabha National Institute (HBNI), Sector 22, Utsav Chowk, GISF Road, Kharghar, Navi Mumbai, Maharashtra, 410 210, India.
E-mail addresses: atul.budukh@gmail.com, budukham@tmc.gov.in (A. Budukh).
received in this way may give rise to ad hoc inquiries, for example, when the cause of death is given as being cancer other than one for which there is in the registration.1 The active strategy involves making direct contact with the patients or their relatives via letter, phone, email, or house visits to inquire about their survival status.2 Implementation of active follow-up is however considered expensive.1 For running the rural cancer registry community involvement is necessary.2,6

Apart from the follow-up, crucial information for PBCRs is the place of permanent residence/address verification, which aids in identifying inhabitants from other areas who are residing temporarily with relatives. The non-resident cancer patients must be excluded if the patient resides outside the area covered under PBCR. Failure to record accurate residence may result in a dramatic overestimate of incidence.1 To provide an accurate incidence rate, the registry needs to ensure that the cancer case identified resides in the registry area. For rural PBCRs especially from resource-limited countries, the residential confirmation is done through routine village and household visits, interactions with village leaders, and contacting patients through phone calls.6,7 Non availability of or insufficient patient demographic information is one of the major hurdles in updating follow-up status. It has been recommended that manual review of records, telephone calls and physical tracking in the community contribute to updating follow-up status (here, follow-up status is referred to as the availability of the patient’s information on current ongoing treatment and vital status).1

To understand the burden of cancer in rural, semi-urban, and urban populations of the Punjab state and Chandigarh Union Territory (UT), the Tata Memorial Centre (TMC), Mumbai in collaboration with Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh UT as well as Ministry of Health and Family Welfare, Government of Punjab and Chandigarh UT administration has established PBCRs in Sangrur, Mansa, Sahibzada Ajit Singh Nagar (SAS Nagar) and Chandigarh covering around 0.47 million population in the year 2013.9,10 The project of population-based cancer registries is approved by PGIMER, Chandigarh UT ethics committee.

There are several challenges in confirming the residence and updating the follow-up status of cancer cases. Hurdles arise in confirming the address due to poor medical records, lack of adequate patient information in the Electronic Medical Record (EMR) department (manual medical records), and also a lack of cooperation by treating hospitals in providing complete patient data.11 Many times, the details of the address are not mentioned for some of the cases in the medical records. The registry needs to take efforts in confirming the address by house visit or contacting patients through the telephone to confirm the residence and to document the clinical records as available with the patient and update the status of the cancer patient. Furthermore, some of the other major challenges such as patients changing their residence, municipal authorities changing the ward number, the patient changing their telephone numbers or patients migrating to a neighboring area are real challenges. When municipal authorities change the ward number, it is difficult to trace the patient to the given address based on the old ward number provided in the medical record. A patient’s address is an important data variable in the cancer registry.12 If cancer cases from other areas are included in the analysis, the cancer incidence results will be misleading.

For the period 2013–2018, the Sangur registry was able to confirm the address as well as the follow-up status of 6866 cancer patients; however, the registry was unable to trace 31 cases for residence confirmation as well as to update the follow-up status. This article aims to present different field methods used to confirm the address of 31 cancer patients from the Sangur cancer registry. Sangur registry covers 69% of the rural and 31% urban population.13

2. Materials and methods

The study aims to confirm the residence and acquire the follow-up status of the untraceable cases of the Sangur cancer registry. The Sangur PBCR includes cancer registration method involving community interaction and a visit to the different hospitals and laboratories. These methods implemented are in accordance with the rural Barshi registry which relies heavily on interaction with the village community, health camps and other interventions apart from data collection from different medical institutions catering to the population.7,11 The regular method of follow-up is through hospital visits; however, in rural settings, we need support from community network.

Trained social workers of the registry regularly visit the villages as well as different hospitals, pathology laboratories, medical colleges, cancer control cells (here cancer control cell is the department of state in a public hospital that provide information on government health schemes and maintains the data of cancer patient) and the birth and death registrar office to collect cancer incidence and death cases. The registry staff interacts with the village sarpanch, Auxiliary Nurse Midwife (ANM), Accredited Social Health Activist (ASHA) workers, and primary health centre staff periodically to know the cancer cases diagnosed in the area as well as cancer deaths that have occurred in the village. With the help of community members, the registry staff interacts with the patient’s relatives and they note down the information available to the patient ensuring the confidentiality of the record being maintained. The cancer cases in urban areas were confirmed by house visits for residence confirmation. This information is further confirmed at the patient’s treating hospital. After confirming patient’s residence (resident of the registry area for at least one year) and duplicate checking by senior staff, the case is registered in the prescribed format. The data is coded as per International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) guidelines.13 The data entry is carried out in CanReg5 software.10 Regular quality control and monitoring are conducted.13,17

The follow-up of untraceable cases was obtained by using three tools; namely, community network, conventional methods, and social media applications. Using the community network (involving community helpers such as post-man, teacher, village leader, primary health centre staff, etc) as a tool to confirm the residence of the patient or his close relatives the registry staff communicated with the community leaders, postman, property registration office, cooking gas agency dealer and its staff, medical shopkeeper and staff, and election voters list.14 These community members acted as a source of residence confirmation for cases. For example, the postman is generally aware of the people in his area as he regularly distributes the post. The property registration office also has government records and it is properly maintained and it was easy to trace the address of the patient. The staff of the cooking gas agency regularly supply gas cylinders in the community so they are aware of the name and addresses of their customer. The registry staff also communicated with the medical shopkeeper. The communication was regarding the address of the patients; however, confidentiality was maintained about the disease. People extended their cooperation as the registry closely works with the district public health hospital as the office is located in the same hospital.

The other tool used to confirm residence and gain follow-up was the use of social media applications. The apps commonly used by the population were used to confirm residence and obtain follow-up. Smartphone application- True Caller where one can copy and paste contact numbers to identify the name and location of the number was used to confirm the identity and contact number of the case.19 Facebook, a widely used social media website that allows users to sign-up for free profiles, and connect with friends, work colleagues, or people they don’t know, online was used for a few cases.20 WhatsApp; a multiplatform messaging app and the most commonly used smartphone application in India that lets you make video and voice calls, send text messages, and more were also used to search for the patient’s name was used to confirm the identity of the cases.21 The True Caller app was used to confirm the address of the patient or by comparing their identity on other applications like WhatsApp and Facebook with their name as most of the people
in the community utilized these services.

In some sources of the registry, the electronic database was available online and the address was checked and confirmed. By conventional methods, follow-up was updated with additional information received from the treating hospital of the patients. The conventional method is the default method used by the registry to undertake follow-up of the patients. However, the incomplete availability of demographic information and poor maintenance of medical records called for resorting to unconventional/passive methods of follow-up i.e through community networks and the use of social media applications. None of the patient’s identity was disclosed during the process and only the staff working on the project utilized the data.

3. Results

A total of 31 cancer cases were loss to follow-up. As shown in Fig. 1, out of the total 31 cases; 29 cases (93.5%) were from urban areas while 2 cases (6.5%) were from rural areas. Of these 31 cases, 26 cases (83.9%) (10 males and 16 females) were successfully traced, while 5 cases (16.1%) were untraced despite sustained efforts. Of these 26 traced cases, 14 cases (53.8%) were traced with the help of a local community network, while 10 cases (38.5%) were traced with the help of social media. The remaining 2 cases (7.7%) were traced by using conventional methods of follow-up, that is through treating hospitals of the patients. For the total of 26 traced cases, the True Caller app contributed significantly by tracing 9 cases (34.6%); this was followed by the postman; 4 cases (15.4%), voter list; 3 cases (11.5%), gas agency; 3 cases (11.5%), medical shops; 2 cases (7.7%), and Facebook and property tax office tracing 1 case (3.8%) each. The cancer case addresses that were not confirmed (5 cases; 16.1%) were excluded from the database. These 5 untraced cases were all from the urban areas.

All the cases from the rural areas were successfully traced. This can be attributed to the limited geographic area of the village and penetration of social media usage. Village settings have small population sizes and better community networks established at the local level. In addition to this, social networking also played a key role in helping the registry staff to trace and follow-up the patients from a rural setting.

4. Discussion

Results reflect the use of both active and passive methods of follow-up to confirm residence and obtain the follow-up status of the cancer cases. A study conducted in Sub-Saharan Africa region on tracing the patients with Kaposi Sarcoma used similar methods to obtain the vital status of the patients. The study reported that of the passive method used, telephone contact contributed to trace 26% of the total cases. Study conducted by Masson et al. reflects on the use of social networking sites in social science and public health research to trace the participants. The study used Facebook to trace its participants retrospectively tracing 69.2% of the total participants. Presenting an alternative methodology to trace cancer patients of a PBCR for follow-up is considered the strength of the study. The limitation of the study can be that though these alternative methodologies might help in obtaining the follow-up status of the patients, these methods are not feasible and economical when used for a larger number of participants.

Functioning of a population-based cancer registry in low- and middle-income countries is challenging. Sustained cooperation is required from government and private hospitals and diagnostic centres to collect the cancer case data. If routine follow-up is poor, the priority is to increase the actual follow-up visits on humanitarian and scientific grounds. Improving the data by instituting rigorous active follow-up measures is required. The improvement of data by these means may indirectly improve routine follow-up activity.

Community network establishment and implementation of the above methods can be used to acquire residence confirmation and update the follow-up status of cancer patients. At the same time, registries should work on enhancing the quality of data by accurately labelling incidence cases in the registry area. Confirming the cancer cases in the registry area, and address is very essential and the registry needs to interact with the patients and their relatives and check that they stayed in this area for the last year or more than that period. A community network is essential in raising cancer awareness regarding facilities provided by TMC in Sangrur district and available health schemes for cancer care.

Population-based cancer registries should take efforts in improving the medical records of private and government hospitals and diagnostic centres in terms of completeness and accuracy of the address and telephone numbers. The field methods used by the cancer registry will be useful to other cancer registries to accurately label incidence cases and to update the follow-up status of cancer patients. This method can be used as an alternative to conventional methods of follow-up; however, it applies only to low- and middle-income countries, especially in the rural setup with a smaller population size and limited geographic spread.

The Global Initiative for Cancer Registries (GICR) promotes the development of population-based cancer registration and offers technical assistance through the Regional Hubs of the International Agency for Research on Cancer (IARC) in Africa, Asia, and Latin America, with plans for the Caribbean and Pacific Islands countries. These initiatives aim to create accurate and high-quality data on the burden of cancer. IARC regional hub Mumbai provides technical support to South-east Asia cancer registries including Nepal and Sri Lanka. These registries face similar problems with case findings and follow-up updates. According to the Nepal PBCR, inadequate medical records systems at the institutions increase the cost of registering for cancer cases and render it difficult to rely on the resident address provided by the records for this purpose. This results in increased costs/burden in terms of manpower, financial resources, and material resources since each patient/relative is required to be called to confirm residence. Similar problems are faced by the Sri Lanka cancer registry, despite timely research and program audit is feasible due to a limited geographic coverage there exists a lack of it. The majority of patients are treated and followed up in a few specialized centers. This is due to lack of adequate requisites to conduct further research. A timely audit of cancer epidemiology and treatment outcomes is essential to guide primary prevention and screening programs, allocation of resources, and revisions of guidelines. Currently, due to political unrest there exists a lot of hindrances in the functioning of the cancer registry. Furthermore, in India, there is a paucity of population-based cancer survival data mainly due to challenges in follow-up. The registries in India as well as in developing countries require different approaches to update the follow-up data as well as
confirmation of residence. Strong community interaction, as well as the use of smartphone applications, can aid in data confirmation and updates.

Social media offer both opportunities and challenges to public health professionals. Public health authorities may track information, identify possible epidemics, anticipate illness patterns, keep an eye on emergencies, and measure disease awareness and responses to official health messaging using social media data. For public health organizations, maintaining an ethical balance between disclosing public health information and safeguarding people’s privacy continues to be difficult. To due to these concerns, in our research we have used publicly available information on social media. It is reported that the use of smartphones played an important role in cancer control activities.

To update the follow-up status and residence confirmation, the study recommends an improved EMR as well as Continuing Medical Education (CME) of all the stakeholders involved in the operation of the cancer registry to understand the significance of residence confirmation and follow-up and its policy-level implications and contribution in estimating survival of the cancer cases.

Authors’ contributions
AB: Conception and design of study, Analysis and/or interpretation of data, Drafting the manuscript; PK: Acquisition of data; DS: Acquisition of data; JST: Analysis and/or interpretation of data, Revising the manuscript critically for important intellectual content.

Funding source
The Sangrur population-based cancer registry is funded by Tata Memorial Centre, Mumbai, which is a grant-in-aid institute of the Department of Atomic Energy, Government of India.

Declaration of Competing interest
The authors declare that they have no conflict of interest.

Acknowledgments
We acknowledge the support received from Dr. Rajendra Badwe (Director, Tata Memorial Centre) as well as Dr. Rajesh Dikshit (Director) and Dr. Pankaj Chiturvedi (Deputy Director) of Centre for Cancer Epidemiology, ACTREC, Tata Memorial Centre Mumbai, India. We also gratefully acknowledge the support provided by the Ministry of Health and Family Welfare, State Government of Punjab, and all the hard work done by the field staff of Sangrur cancer registry, Mr. Lakhwinder Singh, Mr. Amarjit Singh, Mr. Sandeep Singh, Mr. Charanjit Singh, and Mr. Deepak Saini.

References