
COMMENTARY

Cancer Registration in Pakistan: Contemporary State of Affairs

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Abstract

An estimated 7.6 million mortalities were attributed to cancers in 2005 across the globe, and the figures keep mounting. The existing prevalence rate for all reportable cancers is at 25 million, projected to ascend to 30 million around year 2020. Some 70% of these will burden the health care services in under-resourced countries. However, reliable statistics on the incidence, prevalence, mortality and survival rates (five and ten year) are limited. A National Cancer Control Program (NCCP) in Pakistan has existed since 1994, but little is known to the public and negligible information has been made available to medical services providers. We have a poverty of local bio-medical literature related to the specialties like oncology and cancer epidemiology. Only 175 papers are indexed by Pakmedinet, seven being relevant to the cancer registration in Pakistan, an impetus for programmed documentation, and to serve as a foundation for approach to Cyber-medicine. Infrastructure and ample requisite manpower exists locally and a number of local institutions as well as outside sources are teaming up. However, there are still quite a few issues to be looked into, including the question of who will own the data arising from this pooling of assets? A community-based approach is mandatory to allay public concerns over confidentiality and possible use of the registry data. Already, there are hurdles in attaining public approval after the intentions to found a National Cancer Registry were ventilated by the Pakistan Medical Research Council.

Key Words: Cancer registration - Pakistan - public concerns

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Introduction

The cancer incidence rate has levitated from 2.9 million to 3.2 million, and an actual 10% increase over 2 years for prevalence has been projected for all cancers in the European Union, according to 2004 report by International Agency for Research on Cancer (IACR). Globally, an estimated 7.6 million mortalities were attributed to cancers in 2005, and the figures keep mounting. Existing prevalence rate (for all reportable cancers) is at 25 millions, and projected to rise to 30 millions around year 2020. 70% of these will encumber the health care in under-resourced countries. Current trends compel us to challenge this epidemic by taking preventive measures, as 40% of cancers are preventable.

A number of epidemiological studies have been conducted by cancer registry staff in Pakistan and data are available for Karachi (Bhurgri et al., 2000; 2002a), Quetta (Bhurgri et al., 2002c), Punjab (Aziz et al., 2003) Hyderabad (Bhurgri et al., 2005), and Rawalpindi (Jamal et al., 2006b). In addition, papers have appeared in the literature concerning head and neck (Bhurgri et al., 2006b), esophagus (Bhurgri et al., 2004b), oral cavity and pharynx (Bhurgri et al., 1998; 2003a; Bhurgri, 2005), gastrointestinal tumours (Mehdi, 1998), breast (Badar et al., 2005; Bhurgri et al., 2007), lung (Badar et al., 2006;

Bhurgri et al., 2006a), non-Hodgkin's lymphoma (Bhurgri et al., 2005), Hodgkin's lymphoma (Siddiqui et al., 2006), ocular malignancies (Bhurgri et al., 2003b), retinoblastomas (Bhurgri et al., 2004a), rhabdomyosarcomas (Bhurgri et al., 2004c) and childhood malignancies (Jamal et al., 2006a) in Pakistan. However, we cannot accurately estimate the percentage of deaths due to cancers at national level, despite it being the third leading non-communicable cause of mortality. Also, there are no statistics on survival rates (five and ten year), important when describing the epidemiology of any cancer. Original studies on all the likely characteristics of cancers including incidence, prevalence, morbidity and mortality, etiology, predicting trends and patterns, comparisons of therapeutic interventions with prognostic factors are based on institution- or pathology-based registry data. It will be interesting to record the percentage of the pre-malignant conditions transforming to cancers. Initial estimates give us an idea that that 3,000 new patients with tumors present to the hospitals ever year in Lahore district only.

Although large-scale pathology-based cancer data may reflect population-based cancer data (Bhurgri et al., 2002), during the past few years observers have remarked about the lack of population-based cancer data bases in Pakistan (Khan and Abdullah, 2001; Aziz, 2003; Sana et al., 2004),

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which affords familiarity with the disease burden workload and economics, and delve into the possible etiological factors. Data mining is the groundwork for predictive analyses and future trends (McNally and Eden 2004; Draper et al., 2005) This helps strengthen public health strategem to reduce the incidence, institute surveillance and screening programs for early diagnoses and make use of superior therapeutic modalities and palliation.

Maturity Factor

Although impulsive to make conclusions appreciating the maturity factor for the data, there is an ongoing premature divergence on the odds for cerebral gliomata after long-term use of mobile phones (Lakhola et al., 2007). Removal of mobile phone relay towers in densely populated urban neighborhoods, deemed as a public health hazard, was ordered by the federal government in April 2007. A study on all classes of gastric carcinomata, made use of data from the Gastric Cancer Registry of Japan from 1975 to 1989, confirming the transformation in incidence rate at the upper end of the stomach for all ages in males, recorded an upsurge for the body of the stomach in both the sexes, and verified a significant declining trend for the pylorus and antrum. The same study concluded that the incidence of tumors in cardia shows increasing trend among men and women of the elderly age but not among young ones (Liu et al., 2004). Measures to retard the mounting incidence rate follow tangible substantiation of association hepatitis B and C with hepatoma and it will take time to show an impact (Michielsen et al., 2005).

National Cancer Control Program Pakistan

National Cancer Control Program (NCCP) Pakistan has existed since 1994, but very little is known to our public and negligible information has been made available to the medical services providers. Clearly its efficacy will depend on the availability of accurate cancer statistics (Bhurgri, 2004; Nishtar et al., 2004). To-date very miniscule effort has been made at creating responsiveness to its existence, targets, functions in the long run, and its performance thus far as per WHO guidelines (World Health Organization, 2002). In developed countries, they are mandated by the authorities, well-publicized, forthcoming, communicative, and get well-deserved trust of their people (Canadian National Cancer Institute, 2006; New Zealand NCCP, National Cancer Control; Trust, 2006).

Outside Sources

Lyon-based International Association of Cancer Registries (IACR) and International Network for Cancer Treatment and Research (INCTR, 2002) in Brussels have exhibited an interest in a cancer data base for Lahore. This is in line with the Eastern Mediterranean Region's activities for population-based cancer registries in the region (Ahmad, 2003). There are annual reports on cultivating human resources and scientific sessions, and scientific items are carried out sporadically by the INCTR

Newsletter. In addition there is ongoing collaboration in research on cervical cancer with an institution in Lahore. (INCTR, 2002; INCTR, 2005). As a division of the World Health Organization, IACR was instrumental in initiating NCCP Pakistan. A PINKRIBBON promotion of complimentary alternative medicine is creating perception on all possible facets of breast cancer in which federal and provincial ministries for Women Development in Punjab and Sind are the strategic partners. This campaign envisions training health personnel for chronic ambulatory care of patients with breast cancer and is purportedly collaborating with the Health Department, Government of the Punjab for collecting data on breast cancer. (ANNIEAPPLESEEDPROJECT, 2006) Several other organizations as well as donors from abroad are keen to team up, and their funds and expertise should be appreciated by a country like ours with meager 2.0% of its GDP allocation for the health sector.

Feasibility Studies

In my writings since February 2003, I have hinted at some possible models, any one of which can be adopted to achieve this noble objective (Akhtar and Pheby, 2004). One of these models has been put under trial by a conglomeration of some oncologists and a charity-based cancer institution in this city, albeit on the non-governmental side, i.e. it has no charter, mandate or legislation. It operates entirely under the cover of the Societies Act which creates some trepidation regarding the monopoly over the data acquired mainly from the hospitals still controlled by the federal and provincial governments. They are having their fair share of problems about the level of cooperation achieved from seventeen participating hospitals (both private and public), pathology laboratories and oncology departments. For assimilating intelligence about patients with tumors at the institutional echelon and configuring a larger pool, enlisting in a proposed directory of all the institution-based tumor registries in this city should have been the next step in cancer registration practices. This has not been contemplated in this venture. Another encouraging development is the sculpting of a Medical Advisory Group in Rawalpindi, with similar goals. The Armed Forces Institute of Pathology (AFIP) is also endeavoring for the same in this district. It has already produced an original study on the incidence of gastro-intestinal malignancies, the data being derived from AFIP's histopathology reports of patients referred from all over upper Punjab and lower North Western Frontier province.

Home-grown Literature

We have a relative poverty of local bio-medical literature related to the specialties like oncology and cancer epidemiology. Only 175 papers are indexed by Pakmedinet, a smaller number being relevant to cancer registration in Pakistan, the rest covering clinical aspects. All Oncology, Radio-diagnosis, Radiation therapy, Pathology and other clinical units should be able to allow independent researchers to gain access to their records

provided confidentiality can be guaranteed. A population-based cancer registry is a vital entity for all medical or non-medical researchers. Without substantial data, to be shared by all the interested researchers, we cannot contemplate original studies and surveys and apply their results to the community for which they are intended. One big collective effort and every one will reap the rewards. Higher Education Commission is making every effort to promote original research in Pakistan, and can certainly help in profuse ways to achieve this goal. Exclusive efforts would certainly imply the elimination of the applicability.

Hospital Tumor Registries in Lahore

A tumor registry is going to be an impetus for programmed documentation, and serve as a foundation for overture to Cyber-medicine. (Eysenbach et al., 1999) Infrastructure and ample requisite manpower exists locally. The first hospital to install an automated patient database at the time of its inauguration in 1986 was Shaikh Zayed Hospital in Lahore. Shaukat Khanum Cancer Charity followed. The Institute of Nuclear Medicine and Oncology (INMOL) is noticeable as another archetype for the incorporation of informatics into our health care and is collaborating with other groups to carry out analyses in the field of cancer epidemiology (Gillani and Kamal, 2004). A trial database (REGATE), a part of a multi-national trial for studying the treatment outcomes for the gastric cancer, is on track at the Oncology Department of Mayo Hospital. Jinnah Hospital should also be cited as a cohort. By the end of March 2007, it was proclaimed by the Punjab's health department that all records in tertiary care institutions in Lahore are already being computerized on a daily basis. Most private hospitals and pathology laboratories are already automated. Now autonomous and semi-autonomous institutions are joining in.

Who Owns these Data?

Clinical data is the property of a department or a hospital, be it state-owned or in the privately-funded, but there should be no reason preventing them from reporting to a central storage facility in a format for multiple uses. Information and data are the essence of Epidemiology and Public Health Medicine, and Public Health is entirely in the province of the state. So, it is implausible for us to see a cancer data base being managed by an enterprise, outside the sphere of influence of the government, to press forward with their business agenda. Dynamic process of maintaining a medical repository cannot be a complete one without involving general practitioners and other tiers of our health care (Akhtar and Pheby 2004). This is an administrative issue and a key point when outlining the sources of data for the pilot project of Lahore Cancer Registry System. (ANNIEAPPLESEEDPROJECT, 2006) NADRA can lend a hand in anonymizing the data and following up the registered patients.

Allaying public concerns

This is most decidedly a Public Health issue and hence

a community-based approach, i.e. an open debate, is obligatory. People have every right to know. Concerns over the sensitive subject of confidentiality have to be addressed and will last if not resolved (Rind et al., 1997; Parkes, 2004; Pheby, 2004) There is angst about the giving personal information. Submission of false personal specifics to the healthcare providers and concealment of diagnoses of chronic diseases from the near ones is pervasive in our culture. A lot of cultural taboos are mixed up. Communal engagement over legislation for the security and handling of information for records-based medical research is called for in order to avoid major causes of a pile of incomplete and inaccurate data being generated. Make them comprehend the nature of the database of a longitudinal nature. Whatever the outcome of a therapeutic protocol, registering precise and undamaged information about the patient on a continuous basis is vital. As patients are taken to more than one health care facility for various reasons, a reliable mechanism has to be devised for enrolling the patients in our health care delivery system to prevent duplication.

Pooling of the Assets

Most important point is the survival of the establishment in the long run as medical registries require a long-term commitment. Policy for a National Cancer Registration System, by collecting data from Population-based Cancer Registries in selected districts all over the country and Azad Kashmir, have been detailed by Pakistan Medical Research Council (PMRC). Results will be extrapolated and applied to the whole country. It is not clear what its liaison to NCCP is.

In this paradigm, Pakistan Atomic Energy Commission (PAEC) may play a pivotal role being the sole source for nuclear isotopes used for diagnostic scans and radiation therapy by way of 13 Atomic Energy Medical Centers (AEMCs) for all the cancer care facilities across the country. There is no data but a large proportion of the stricken have to visit one of these centers and their records are maintained by the respective AEMCs. AEMCs will be up-graded to inclusive cancer hospitals like INMOL in Lahore. They can be the focal point of data capture for tumors. Basic factors like pecuniary funding by the federal government, predominant control for the data to be comparable (Pheby and Etherington, 1994), collaboration among the participating organizations, feeding the Statistics Division, legislation and monopoly over the collected data, as well as taking advantage of personnel trained for compiling cancer statistics at National Medical Oncology and Radiotherapy Institute (NORI), Islamabad with assistance received from the World Health Organization will be secured. (Government of Pakistan. Pakistan Atomic Energy Commission, 2006) Assistance from outside sources may also be devoted properly. Regular reports to IACR can ensure that we adhere to the Continental Incidence-5 (CI-5) Standards.

Observations

In a country where reportedly one out of nine post-

pubertal females is likely to endure a breast malignancy, with 40,000 fatalities annually, an effective NCCP must integrate all the possible resources for professional execution of NCCP guidelines. A National Cancer Registry now has a priority in these guidelines (Ahmad, 2003). A research base in the form a national or regional cancer registration system fed by smaller cancer intelligence units is the focal point. The need for a population-based Cancer Registry has been recognized even by National Action Plan on Chronic Diseases (NAP-NCD). Only then the target population can be made aware of the preventive measures to reduce incidence for a particular neoplasm, its screening, improved clinical and palliative care. These are the components of a comprehensive cancer care program with provincial cancer care organizations in Canada and South West Public Health Observatory (SWPHO) in the United Kingdom as good examples. Cognizance has been taken of the need for a research facility. Plans for Lahore's center of excellence in Oncology include a research center and a population-based tumor registry for Lahore district. It must not be forgotten that our Higher Education Commission is making every effort to promote original research in Pakistan. Many overseas organizations, pharmaceutical concerns and foreign missions have already expressed their interest.

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