The Oncology Scenario in India: Lots of Gaps Need to be Bridged

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Abstract

As the second most populous nation and one of the fastest-growing major economies, India faces many challenges, one such burning issue is the provision of cancer care. There is a huge gap in the demand and supply of health care resources in Indian oncology scenario, mainly due to steadily aging populations and also to current trends in smoking prevalence and the growing adoption of unhealthy lifestyles. Slightly more than 1 million new cases of cancer are diagnosed every year in a population of 1.2 billion. Although incidence of cancer is low in India compared with high-income countries, mortality is high; with approximately 600,000-700,000 deaths in 2012. Many cancer cases in India are associated with tobacco use, infections, and other avoidable causes. Cancer can have profound psychological, social and economic consequences for people in India, often leading to family impoverishment and societal inequity. Currently, overall public expenditure on health care is only 1.5

Index terms— cancer, india, challenges, recommendations.

1 Introduction

opulation growth, ageing and life style changes are the largest contributors to the increasing total number of cancer cases and the shift in the burden of cancer and other chronic diseases in economically developing countries.1,2 With 1 million new cases and 683 000 deaths estimated in 2012 by GLOBOCAN, and 1.7 million new cases and 1.2 million deaths projected to occur in 2035, cancer is a major public health challenge in India.3-5 At any given point, an estimated 2.5 million people live with a previous diagnosis of cancer. Although the age-standardized rate of cancer is 92.4 per 100 000 men and 97.4 per 100 000 women, the age-adjusted incidence for all types of cancer in India in urban areas ranges from 92.1 to 126.1 per 100 000 for men and from 107.8 to 142.0 per 100 000 for women. Although overall cancer incidence is lower in India than in most high-income countries, the relative mortality rates are higher. 6-8. More than 30% of these cancers are preventable, mainly by not using tobacco, having a healthy diet, being physically active and moderating the use of alcohol.9 There is a need for commitment for tackling cancer by reducing risk factors and strengthening the existing screening and treatment facilities. Social factors, especially inequalities, are major determinants of India's cancer burden, with poorer people more likely to die from cancer before the age of 70 years than those who are more affluent. Most of the Indian population does not have access to a well organized and well regulated cancer care system. Failure to address social inequalities reduces survival and can needlessly increase the costs of cancer to individuals and Indian society as a whole.10-12 Strategies are urgently needed to formulate treatment policies that are not merely based on international guidelines from high-income countries, but are tailored to specific settings in India. Rebalancing of the distribution of power, social goods, and resources will be a crucial determinant of how India will address its cancer burden in the long term.12,13 II.

2 Dismal Public Funding

The delivery of affordable and equitable cancer care is one of India's greatest public health challenges. Public expenditure on cancer in India remains below US$10 per person (compared with more than US$100 per person in high-income countries), and overall public expenditure on health care is still only slightly above 1% of gross domestic product. Out-of-pocket payments, which account for more than three-quarters of cancer expenditures in India, are one of the greatest threats to patients and families, and a cancer diagnosis is increasingly responsible for catastrophic expenditures that negatively affect not only the patient but also the welfare and education of several generations of their family.6, 10,14 No other comparable nation spends as small a proportion of its national resources on public health care. Government of India should consider a variety of financing and delivery options to universalize health care services. The cost of universal health care delivered through a combination of public and private providers is estimated to be INR 1713 per capita per year in India. 15 Given that the poorest two-thirds of the population is in much greater need of better health-care provision than is the wealthiest third, increased public investment in health services needs to be a public policy priority for India. 12 The only way to fight this scourge under such circumstances is to have pragmatic programmes and policies based on currently available scientific information and sound public health principles.16 Some states in India have rolled out social insurance programs that provide free tertiary care to households below the poverty line, the replication of such success across the country has not been realized.10,17 III.

3 Lacunae in Cancer Registries

Cancer registration is the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms with the purpose of helping to assess and control the impact of malignancies on the community; and can be either population based (PBCR) or Hospital based cancer registry (HBCR).18 Due to lack of uniform reporting and under capture of data, the actual burden of cancer in India is much greater than reflected through the existing literature and hence can be regarded as a 'tip of iceberg' situation. The distribution of population based cancer registries is grossly uneven with certain important parts of the country being not represented at all and hence the current cancer burden is not reflected by registry data. Projection of load of cancer mortality helps in quantifying the burden of cancer and is essential for planning cancer control activities. There have not been many attempts to project the cancer mortality burden at the country level in India mainly due to lack of data on cancer mortality at the national and state level. It is recommended that all oncology centers and multispecialty hospitals maintain their hospital based cancer registries and collate the data with the state and national registries.9,19,20 Analysis of the routine data on cancers in a cancer registry remains an essential component in understanding the epidemiology of cancers in limited resources setting.21 Hospital-based registries are important tools for policy formulations and region-specific data creation. 22 IV.

4 Lack of Radiotherapy Centres

About 85% of the world's people live in developing countries including India, but these countries house only about one third of the world's radiotherapy facilities. At least 50% to 60% of cancer victims in the developing world can benefit from radiotherapy, but most developing countries do not have enough radiotherapy machines or sufficient numbers of specialized doctors and other health professionals. Establishing hospital networks and streamlining of referral services can improve cancer care in our country. 23,24 There is great diversity in the existing Radiotherapy facilities in corporate hospitals of metropolitan cities on one hand; and the government hospitals and state-funded medical colleges on the other hand. Most corporate hospitals are equipped with the state-of-art latest linear accelerators compatible with highest form of conformal radiotherapy; including intensity modulated radiotherapy, image guided radiotherapy and stereotactic body radiotherapy. Most government run tertiary-care hospitals impart radiotherapy by primitive telecobalt complexes and conventional linear accelerators. This diversity is mainly due to financial constraints, lack of enough resources, faulty planning and inadequate management.24 All efforts must be made to upgrade the infrastructure and existing facilities in state-run tertiary care hospitals. Brachytherapy can play a very important role in the definitive cure by radiation therapy in India. However, except for in a handful of centers, the majority of hospitals use it only for intracavitary treatment. The most probable reasons for the same are the lack of logistical resources in terms of trained personal and supporting staff, rather than lack of radiotherapy machines and equipment. 25 Tobacco is the single largest cause of preventable death among adults globally, as it is in India. Despite this alarming situation, there is very minimal inclusion of tobacco in formal education systems, including the medical discipline. It can be concluded that tobacco control is not receiving adequate attention in public health curricula in India. There is a need for coordinated efforts in the area of tobacco control so as to reduce morbidity and mortality from tobacco induced diseases.26 Results from recent surveys show that 274.9 million Indians (35% of the total adult population, plus 14.1% of school children aged 13-15 years) are tobacco users, mainly in the form of smokeless tobacco. Overall, tobacco-related disease is estimated to kill 2.8 million Indians annually. 6 The ban on the manufacture, sale and use of gutka and pan masala in some states of India is a big stride in prevention process of tobacco-related oral and oropharyngeal cancer.24 Public welfare organizations in India and the media have to come together to pursue the campaign against tobacco, combined with programmes of education and awareness, early detection and screening, has to be taken up. However, implementation of tobacco control directives has been hampered by

pressure from the tobacco industry, irregular taxation of tobacco products, cultural issues, and low exposure to antitobacco information without delay. Efforts should be made to increase the awareness of The Cigarettes and Other Tobacco Products Act (COTPA) focusing on younger population, less educated, and those belonging to the low SES.27

There is a need of capacity building initiatives to equip physicians with skills in tobacco cessation. 28 VI.

5 Insurance Schemes

Nearly two-thirds of Indian households seek healthcare from the private medical sector due to dismal public health scenario mainly on account of continuous neglect, worker absenteeism, long wait times, shortages of supplies, and absence of diagnostic facilities. Access to oncological care is becoming increasingly difficult for the underprivileged. Despite the emergence of a number of health insurance programmes and schemes, only 5% of households report that a household member has coverage of any kind. One admission to hospital can consume a sizeable share of a poor household's resources, commonly leading to financial crisis. Private for-profit insurers target the better-off section of the society with expensive packages but have little to offer to Indian's poor. More attention should be paid to the innovative indigenous health insurance schemes that are helping to address the weakness in health care financing and provision. Insurance is a welcome necessary step and must doubtless expand to help in facilitating equitable health care to shift to sections for which government is responsible. Indeed for those not able to access insurance it is government that will have to continue to provide the minimum services, and intervene against market failures including denial through adverse selection or moral hazard. Community based insurance, where members of a community, linked by geographical proximity or through employment-based relationships such as local trade unions, pool resources to share the financial risk of ill health, can play some role in this scenario. 24,29 VII.

6 Long Waiting Period

In India patients have to wait for a longer time before active treatment of cancer is started. This may be due to various factors like confirmation of diagnosis, arrangement of finance, seeking expert's opinion, getting date for surgery etc. If left untreated cancer continues to grow. The rate of growth can be variable but it is known to be high in many epithelial malignancies.24,30 Investigations of O' Rourke and Edwards (2000) have shown that 21 percent of potential curable lung cancer patients became incurable while waiting for treatment. 31 In this circumstances 'Telemedicine' services can be of great help. Regional Cancer Centers (RCC) must develop a web-based telemedicine system, linking various cancer centers of the state. Patients can take the help of the doctors at the local teleclinic and access specialist service at RCC for consultation and follow-up. It is much cheaper to set up telemedicine centers in smaller town than to open super specialty hospital in large cities. 24 VIII.

7 Lack of Palliative Care

At present, out of one million newly diagnosed Indian cancer patients each year, more than 50 % will die within 12 months of diagnosis and another one million cancer survivors (within 5 years of diagnosis) will show progressive disease. Out of these 1.5 million in need of palliative care (PC) less than 0.1 million patients can be covered by the existing facilities. Unfortunately, majority of patients in India present with late-stage disease and have limited access to palliative care and effective pain-relieving medications, such as morphine. It is recommended that the existing Oncology centers should include PC services with trained 'doctor nurse team'. For India, outpatient palliative care clinics will render meaningful and cost-effective practice. Thereafter, the medical institutions and NGOs can expand the service to integrate 'homecare' within a locality or region. Cancer pain relief still remains the cornerstone of optimal palliative care. Complementary and alternative medicines may play some role in selected cases in providing some help to these patients for treatment and palliation.24,32 Key barriers related to pain management include the role of nursing, opioid misperceptions, bureaucratic hurdles, sociocultural/ infrastructure challenges, limited national palliative care policy and lack of institutional interest in palliative care. Interventions should be undertaken to streamline process of morphine procurement, work within the existing sociocultural infrastructure to ensure opioids reach patients most in need, target unexpected audiences for symptom management education, and account for role expectations of health care providers.33 Systematic and continuous education for medical staff is mandatory, and a major break-through for achieving this purpose would be to increase the number of courses and faculties in palliative medicine at most universities. 34 IX.

8 Inadequate Screening and Vaccination Programmes

Widespread uptake of human papilloma virus (HPV) vaccine could reduce incidence and mortality by two-thirds in India, which bears the greatest burden of the disease with 132,000 cases and 74,000 deaths yearly. 35 Common barriers for HPV acceptability among parents include concerns about side effects, vaccine cost, and missing work to receive the vaccine. Addressing parental concerns, health worker training and polices, and efforts to minimize cost will be central to successful HPV vaccine implementation.36 Unfortunately, ill-informed anti-HPV-vaccine campaigns and media and political frenzies have substantially undermined the prospects of

introduction of HPV vaccination, which could substantially reduce morbidity, mortality, and health-care costs in the country in which a fifth of the global cases of cervical cancer occur. In view of the challenges to introduce cervical screening programmes and given the level of development of health services in several states, introduction of HPV vaccination for girls aged 9-13 years in the national immunisation programme should be a high priority, since the individuals who cannot afford vaccination need it the most. At the core of any cancer control strategy, the essential components should include costeffective interventions for the following components: tobacco control, infection control, healthy eating, a curable cancer program and palliative care. 3,24 X. Scarcity of Health Workers in India India, which has a total population of 1.25 billion, has only 1500 trained oncologists. The cancer patient-to-oncologist ratio in India is an abysmal 1600:1, compared to an estimated 100:1 in USA. It is understandable that oncologists in India have to shoulder a heavy clinical burden, leaving a little time for clinical research.37 It often leads to delay in diagnosis and instituting definitive management, thereby compromising the oncological outcome. The unequal distribution of these workers poses an even more substantial issue. Several factors explain the paucity of trained health workers in rural areas, including disinclination of physicians to work and live in low socioeconomic areas; lack of funding from the public sector to adequately staff rural facilities and provide necessary equipment; reluctance of junior medical officers to work in an isolated working environment with low salaries and inadequate supervision and training; and few private health-care institutions in rural areas where salaries are often less lucrative. Overcoming medical workforce shortages, particularly in oncology, will need efforts to reduce international emigration and strategies that can increase distribution of staff to rural areas. 6

9 XI. Sociocultural Barriers and Gender Inequality

Major sociocultural issues that affect approaches to health care in India include social taboos, castes, gender inequality, low regard for health as a priority, nihilistic approaches to cancer diagnosis, blind faith in traditional methods of healing, religious dynamics, and widespread superstitions. Although these factors are more prevalent in rural India, they also exist in urban areas. Social taboos frequently prevent individuals from seeking conventional health-care assessments, and subsequently lead to advanced stages of disease by the time a trained doctor is seen, particularly for socially stigmatized diseases such as cancer. Patients can often keep a diagnosis of cancer secret, and go to extreme lengths to conceal a cancer diagnosis from family and friends, even at the cost of compromising treatment and outcomes. Gender inequality exists in many parts of India, which results in neglect of many female health problems. Notwithstanding some changes in attitude towards the role of women in Indian society, the country remains patriarchal, with men having power and authority both in the community and in the family. Last, but not least, faith in traditional and alternative forms of medicine is widespread among the Indian public. These medicine men frequently rely on chants, rituals, worships and sacred powders to cure patients with disease. Strong faith in these healers prevents establishment of modern scientific medicine in more remote rural areas in India. 6,38 XII. Recommendations and Conclusion ? India needs to adopt immediately the concept of "nurse practitioners" who have been trained to take a call on treatment in the absence of a qualified doctor and training the rural health workers in cancer treatment so that once a patient has undergone radiotherapy and chemotherapy at a bigger centre, care in the later phase can happen at respective homes.

? New multidisciplinary oncology centers based on public-private partnership must be established in middle-tier cities, suburban and rural areas to ensure homogenous distribution of comprehensive state-of-art facilities throughout India.
? There is a need to develop cost-effective and low-maintenance indigenous Telecobalt units and Linear accelerators which can be commissioned in rural and suburban areas
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Figure 1:

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