

# CHAPTER 1

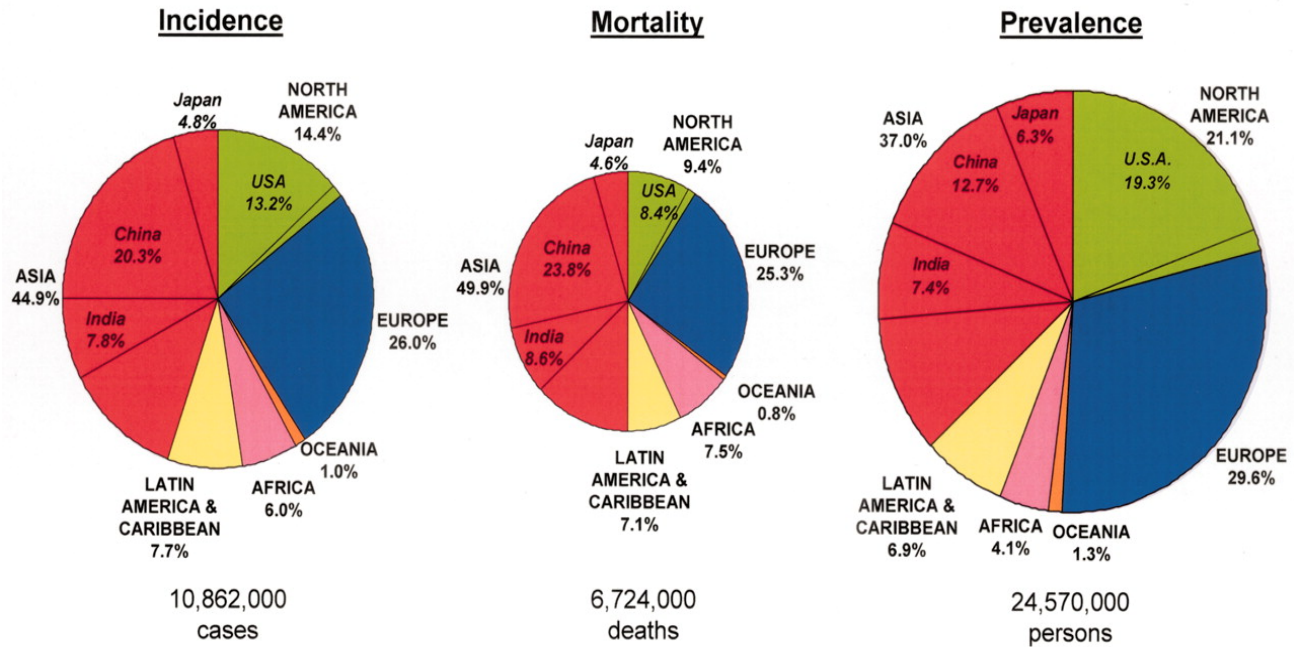
## INTRODUCTION

The prevalence of a non-communicable disease like cancer has emerged as a major public health problem, globally. Cancer or Carcinoma is defined as any malignant growth or tumor caused by abnormal and uncontrolled cell division and it may spread to different parts of the body through the lymphatic system or the blood stream. The word 'cancer' has become a metaphor for grief and pain and puts enormous strain on public health worldwide due to the huge expenditure incurred for treating the disease.

### **1.1 Global Pervasiveness of Cancer and its Impact**

During the past 30 years, the global burden of cancer has more than doubled. In 2008, it was estimated that there were over 12 million new cases diagnosed, 7 million deaths and 25 million persons alive with cancer. By 2030, it is expected that there could be 27 million incident cases, 17 million deaths annually and 75 million persons alive with cancer within five years of initial diagnosis (World Cancer Report, 2008).

Around the globe, one in eight deaths occurs due to cancer. Worldwide, cancer causes more deaths than AIDS, tuberculosis, and malaria combined. It is the second leading cause of death in economically developed countries (following cardio vascular disease) and the third leading cause of death in developing countries (following cardio vascular disease and diarrhea) (Global Cancer Facts and Figures, 2007). It is projected by WHO that new cases of cancer would dramatically increase to 20 million by 2020 with seventy percent of the cases in the developing world (ICMR, 2004). Among the developing countries, the number of new cases, mortality as well as prevalence from cancer is very high in the Asian countries (See Figure 1.1).



**Figure 1.1: Incidence, Mortality, and Prevalence of Cancer by Location**

Source: Parkin *et al.* (2005) in CA: A Cancer Journal for Clinicians

Figure 1.1 shows incidence, mortality and prevalence of cancer by continents and for several larger countries. The figure reflects that there are regional differences in the burden of cancer. These regional variations are due to the prevalence of major risk factors, availability and use of medical practices such as cancer screening, availability and quality of treatment, completeness of reporting, and age structure of the population (Global Cancer Facts and Figures, 2007).

As reported earlier, globally the occurrence of new cancer cases has ascended. The greatest impact of the rise in cancer cases falls on the ‘low- and medium-resource’<sup>1</sup>

<sup>1</sup> Low-resource countries are defined by the World Bank as having a per capita gross national income of less than \$825 in 2004 and medium-resource countries as having gross national income of \$3256-\$10,065.

countries which already have a high burden of communicable diseases. Unfortunately, their health delivery system is not upgraded to meet the rising incidence of cancer cases. A major issue for many countries, specifically the developing countries will be finding sufficient funds to treat all cancer patients effectively and provide palliative and terminal care for the large number of cancers which will be diagnosed in the coming years (World Cancer Report, 2008).

## **1.2 Global Trends in Breast and Cervix Cancer**

Worldwide, breast cancer is the most frequently diagnosed cancer among women. An estimated 1.3 million new cases of invasive breast cancer occurred among women in 2007. Breast cancer incidence rates are on the rise in Westernized countries due to changes in reproductive patterns and more recently because of increased screening. In many developing countries too, particularly Asian and African countries, the incidence rates of breast cancer are on the rise. This trend in developing countries reflects changes in reproductive patterns, nutrition, physical inactivity, and perhaps improvement in breast cancer screening programs.

Although there is increase in new cases of breast cancer in developing countries, still there is wide disparity in incidence rates of breast cancer between developed and developing countries. The female breast cancer rates for 2002 varied internationally, by more than 25-fold, ranging from 3.9 cases per 100,000 in Mozambique to 101.1 cases in the United States. This high variation in incidence cases partly reflects low screening rates and incomplete reporting in developing countries (Global Cancer Facts and Figures, 2007).

Apart from being the most frequently diagnosed cancer, breast cancer is also the leading cause of cancer death among women worldwide. An estimated figure of 465,000 breast cancer deaths in women took place in 2007. Although breast cancer incidence is on the rise worldwide, breast cancer mortality over the past 25 years has been stable or decreasing in some developed countries. Mortality rate reductions in developed countries have been attributed to early detection through mammography and to improved treatment.

Another predominant cancer is cervical cancer which is the second most commonly diagnosed cancer among women. An estimated number of 555,100 new cases occurred in the world during 2007. In comparison to breast cancer, cervical cancer is more concentrated in developing countries than developed countries as more than 80% incidence occurred in the former case. The disproportionate burden of cervical cancer in developing countries and elsewhere in medically underserved populations is mainly due to lack of screening and prevalence of unhygienic conditions.

While cervical cancer is the second most commonly diagnosed cancer, it is the third leading cause of cancer death among women worldwide. An estimated 309,800 deaths occurred in 2007. Cervical cancer kills more women in the developing world than any other cancer. More than 85% of annual cervical cancer deaths occur in developing parts of the world: 70,000 cases in Africa, 48,000 in Latin America, and 160,000 in Asia. India, the second most populous country in the world, accounts for 27% of the total cases. In many developed countries however, cervical cancer incidence and mortality rates have been declining since the 1960s primarily due to widespread screening and treatment interventions (Global Cancer Facts and Figure, 2007).

### **1.3 Cancer Care and Components of Quality Cancer Care**

Cancer care means the availability of services along the full span of care continuum which includes risk assessment, primary prevention (education and counseling for awareness), secondary prevention (screening and detection), diagnosis, treatment, recurrence-surveillance and end-of-life care. The type of care provided to individuals at different points in the history of their cancer and the transition between the different stages of the disease are collectively called the 'processes of care' (Zapka *et al.*, 2003). A complete cancer care program would mean attention to all the 'processes of care'. Risk assessment includes appraisal of the impact of exposures to harmful pollutants, lifestyle factors such as smoking and familial factors such as genetic risk and reproductive patterns. Prevention strategies are of two types i.e., primary prevention through education and counseling related to lifestyle behaviors including smoking, diet, exercise, alcohol use, etc., and secondary prevention through screening and detection. Detection involves

two distinct steps: namely, testing for cancer in asymptomatic and/or symptomatic cases, and secondly, diagnostic evaluation following an abnormal test result. After a cancer diagnosis, additional tests are done to further classify and 'stage' the disease. The staging tests provide critical information for selecting treatment options and prognostic information (e.g., likelihood of survival). The treatment of cancer often includes surgery, radiation, chemotherapy or some combination of the three. After completion of therapy, lifelong surveillance needs to take place to identify recurrence, detect new cancers and manage long-term side effects. Finally, since a large number of persons succumb to the disease, end-of-life care which includes advance care planning, palliative care and bereavement support are important components in the trajectory of cancer care.

The outcome of cancer care is positive only when attention is given to quality care. However, there is no singular definition of 'quality'. Besides, most guidelines for quality cancer care pertain to first world countries. Assessing quality in third world countries is difficult in the absence of comprehensive guidelines and recommended policies. An internet search revealed that there are some guidelines developed by WHO for developing countries which relate to only specific components of cancer care like screening and palliative care. But these guidelines are not country-specific and are not developed with an understanding of local socio-economic and political context in which cancer takes place. This makes the implementation of these guidelines unrealistic.

The most frequently cited guidelines are presented in the Institute of Medicine (IOM) USA, 1999 Report titled 'Ensuring Quality Cancer Care' (Appendix A). According to this Report, Quality Cancer Care requires that a physician is available to dedicate sufficient expertise, time and other resources to explain the diagnosis and treatment options to a patient. This may be done in a manner consistent with patient's background so that the patient may be meaningfully involved in decisions about the course of his/her therapy. It also means that the physician and staff are able to administer treatment competently, monitor and manage side-effects, explain treatment results to patients and their families and provide ancillary support to them particularly with respect to end-of-life issues.

#### **1.4 Burden of Cancer in Developing Countries**

As mentioned earlier, cancer incidence and mortality are increasing in the developing countries. The low and medium resource countries are arguably harder hit by cancer than the high-resource countries because such countries often have a high background level of communicable diseases but a limited health budget to address them (Boyle,2006). Cancer treatment facilities are not generally available, and life-extending therapies are often unavailable for economic reasons. Many middle-income countries have diagnostic and treatment structures in place but face severe economic pressures to upgrade equipments and to pay for the new drugs used to treat cancer. Most of these countries need to upgrade their technology, increase their human resources and provide them adequate training (World Cancer Report, 2008).

The data on burden of cancer are still not easily available in the developing countries. Recent increases in data availability in low-income and middle-income countries allows a better, although still imperfect picture of the cancer burden. The first big step therefore towards cancer prevention and control is to understand the magnitude and nature of the cancer burden and then move towards an understanding of avoidable causes and other priorities.

#### **1.5 Cancer Care in India**

Cancer is posing a major health problem in India with 2,400,000 prevalent cases, 800,000 new cases diagnosed per year and about 400,000 annual deaths (Ministry of Health and Family Welfare, 2008). The incidence of cancer in India in relation to total global occurrence is 7.8%, the mortality is 8.6% and the prevalence is 7.4% (See Figure1.1).

India is one of the few developing countries that has formulated a National Cancer Control Programme (NCCP) in the year 1975-76. This programme has contributed to the development of Regional Cancer Centres (RCCs), specialized Oncology wings in

medical colleges and introduction of new diagnostic and therapeutic technologies for treatment of cancer. It has also given emphasis on cancer prevention and control through the District Cancer Control Program.

The NCCP of 1975-76 was revised in 2005 to include the following schemes:

- i. Opening up of New Regional Cancer Centres (RCCs): The new RCCs are intended to provide comprehensive cancer care – treatment, prevention, early diagnosis, training, etc.
- ii. Provision of Assistance to Existing RCCs: The Government seeks to provide one-time grant of Rupees 3 crores as financial assistance to augment treatment facilities through purchase of new equipments. The RCCs would also act as nodal agencies for the District Cancer Control Program.
- iii. Development of Oncology at District Headquarter Hospital: Assistance is provided in the form of one-time grant of Rupees 3 crores for procurement of equipments. Recruitment of staff and provision of basic infrastructure are the responsibility of the State Government.
- iv. District Cancer Control Program (DCCP): The focus of DCCP is on prevention of cancer and early detection which can be achieved through increased awareness about cancer in the community and among health personnel. Provision is made for minimal treatment of common cancers and supportive care in the districts.
- v. Decentralized NGO Scheme: The scheme is meant to provide financial assistance to NGOs through the Nodal agency which may be the Regional Cancer Centre or Medical College.

However, the Ministry of Health and Family Welfare, 2008 has observed that in spite of the revised NCCP in 2005, there is still no uniform cancer management strategy for the entire country. Awareness programs are sporadic and there is no uniform standardized Information, Education and Communication (IEC) strategy for cancer prevention. There is inadequate education on risk factors, early warning signals and their management. Barring a few parts of India, cancer screening is not practiced in an organized fashion.

Diagnostic infrastructure in the country is also limited and mostly restricted to urban areas due to financial and geographic constraints and lack of manpower.

Majority of patients with cancer present themselves to a cancer treatment centre at late stages of the disease (80% are in an advanced stage of disease). To add to this sordid state, treatment facilities are mostly limited to urban areas of the country. There are no uniform protocols for cancer management. A large number of cancers diagnosed in the population are not treated. The availability and affordability of cancer treatment shows wide disparities which lead to low treatment success rates. End-of-life care is seriously limited due to absence of manpower for providing Palliative Care and unavailability of oral morphine at all treatment locations. Besides, it is observed that all elements of cancer care, from prevention to end-of- life care, are not linked and coordinated. Moreover, the funds for the cancer program are mainly from the Government, and Public-Private initiatives are few.

Taking into consideration the above lacunae, the Ministry has further revised the NCCP under the Eleventh Five Year Plan (2008-2012). The revised plan has focused primarily on early diagnosis and prevention. It has envisaged preparation of a Cancer Control Plan at different levels--National, State and District, taking into consideration the contextual factors: namely, socio-cultural and economic factors, health infrastructure, health priorities and availability of human resources. Besides, it has advocated formulation of District Cancer Societies geared for cancer control at the grassroots level. It has also increased the budgetary allocation from Rs. 266 crores in the Tenth Five Year Plan to Rs. 2,400 crores in the Eleventh Five Year Plan to meet the expenses for the above provisions.

### **1.6 Focus of the Study**

The study intends to understand the delivery of cancer care particularly access and barriers in an underserved area of India. Orissa being one of the underdeveloped states in India characterized by various constraints, namely poverty, lack of awareness, cultural inhibitions, poor medical and social care, is considered the ideal locale for understanding how local structural and social characteristics influence the spectrum of cancer care.



Acharya Harihar Regional Cancer Centre (AHRCC) is taken up as the unit of study. It is one of the RCCs and the only cancer care centre in Orissa where most of the components of cancer care continuum are available. It is also the Nodal Centre for Cancer Control Programs in the State.

The study is conducted at two levels:

- i. At the first level, the study examines the organization of cancer care at AHRCC beginning with primary and secondary prevention, diagnosis, treatment and end-of-life care. It looks into issues of service delivery and cancer-care financing by having group discussion with doctors and examination of hospital records.
- ii. At the second level, the study explores women patients' subjective experiences on cancer care using the information at the first level as backdrop.

These two levels provide a holistic understanding of cancer care integrating both the medical and social perspectives.

### **1.7 Organization of the Thesis**

The thesis has been organized into seven chapters. The next chapter deals with the objective and methodology of the study. Chapter 3 elaborates on the theoretical framework adopted for the study. Chapter 4 critically examines the literature on cancer care. The results of the study are presented in four chapters: Chapter 5 (A) deals with the organization of primary and secondary prevention of cancer by AHRCC, Chapter 5 (B) elaborates the women's experience on the later components, Chapter 6 (A) covers the service delivery at AHRCC with regard to diagnosis and treatment of cancer and Chapter 6 (B) analyses the women's experience on the above two components. Finally, Chapter 7 summarizes the findings, provides recommendations and puts forth the limitations of the study.