

# Comprehensive Cancer Care: The Need of the Hour

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## Abstract

Western world has seen a tremendous improvement in the outcome of patients with malignancies over recent years, which has not reflected in developing countries like India. There are several reasons behind this, most important being the lack of resources to cater to the varying needs of cancer patients in the country, but even in resource sufficient settings the situation is not ideal. Delayed involvement of the oncologist, poor utilisation of evidence based treatment; clinicians practising on their anecdotal experience, lack of definition of cancer treatment centres and regulatory framework, poor team work are some of the reasons behind this. Apex cancer treatment centres should dedicate their time and resources in framing policies and guidelines, research activities and decentralise the direct patient care. Integration and collaboration between cancer treatment centres in private sector will help in preventing duplication and under utilisation of resources; invest in newer modalities and will avoid unhealthy competition between these centres. There should be a cultural change in the perception of disease by patients, relatives and treating physicians. Early involvement of palliative care, especially in metastatic disease, will improve the overall outcome of the patients. There is an urgent need for implementation of clinical governance and quality regulations in all aspects of oncology care delivery.

## Background

Over the past 15-20 years, western world has seen tremendous improvement in the management of malignancies through systematic changes in basic and clinical research, supportive care, infrastructure development and staff training. Development of Imatinib has changed the outcome of chronic myeloid leukaemia dramatically, but improvement in survival of acute myeloid leukaemia is due to excellent supportive care. Multidisciplinary team and oncologist with special interests in subspecialties has taken the decision making away from individual physicians to the specialist team, which is proven to improve outcome and in certain countries it is established by law<sup>1</sup>. Evidence-based-medicine and development of national and regional guidelines has clearly aided clinicians to make treatment decisions based not just on clinical outcome, but also on the availability of resources and other local priorities<sup>2</sup>.

In a developing country like India, where the current mortality: incidence ratio for cancer is 68.6, as against 37.7 in very high human development index

countries, the spectrum of management is completely different, largely due to a lack of well developed, unified health care system catering to the needs of the entire country<sup>3</sup>. There is no minimum standard of care or benchmark for management of most diseases, let alone malignancies. The high cost of treatment in private sector, lack of resources in public sector and scarcity of screening programmes contribute to inadequate clinical care and late diagnosis with no hope of curative potential, the details of which is beyond the scope of this article<sup>4,5</sup>. But even in relatively affluent regions of India, where people have access to modern health care, there have been frequent occasions of practices not in accordance with current evidence. This could be due to the lack of common guidelines or protocols which can be followed by all, but these practices add unnecessary financial burden to the already stretched resources of the patient and family. Nevertheless, the system has its own merits with

excellent hospitals and clinicians delivering state-of-the-art service to the patients, with limited resources, both in public and private sector and hence should not be demoralised.

In the current system, where patients have the liberty to choose their own doctors, an oncologist might not get involved in the initial diagnosis and decision making process leading to fragmented management plan. The typical example is, mastectomy done by general surgeon for breast malignancy, without considering the need for neoadjuvant chemotherapy or radiotherapy.

It is surprising to notice that even experienced oncologist do lot of empirical management even when established evidence based treatment modalities are available. Sometimes chemotherapy combinations are based on the individual's anecdotal experience than established combinations and mutations specific targeted treatments are used without checking for mutation. Other major areas of concern are knee-jerk treatment of cancers where there are no clear indication to treat by any standards and few oncologists trying to treat cancers with available modality of treatment even though there is lack of evidence for the same. For example, treating early-stage lung malignancy or impending spinal cord compression due to myeloma with chemotherapy alone without considering radiotherapy or surgery even though such facilities are available in the nearby centres.

## Factors to be addressed

Indian health system is dominated by private sector and cancer treatment centres are huge revenue generators. Clinician's income is mainly decided by the number of patients he treats, encouraging clinicians to try and treat diseases which are out of their area of expertise. There is a complete

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Received: 24.02.2018; Accepted: 09.08.2018

lack of definition of cancer treatment centres and the level of care they should provide<sup>6</sup>. Similarly, there is no restriction among clinicians as to what they are expected to treat nor there is an acceptable benchmark of expertise required of them. Even in institutions where complex malignancies are managed, there is no team work, specialisation or delegation. In the public sector a doctor earns less in comparison and there are no incentives for developing the department or system, research or teaching, so clinicians end up doing unregulated private practice to top up their income. There are many instances of unethical association between doctors and other industrial allies<sup>7</sup>. Because of the vast amount of generic drugs available and increasing number of private diagnostic centres, there is a huge competition in the market. The regulatory bodies are unfortunately not able to implement the laws moderating this.

#### What could be done to change the system?

There are around 25 Regional Cancer Centres (RCC) in India, operating under the joint control and funding of central and state governments, in addition to dedicated cancer hospitals owned by state governments. These bodies are mainly acting as treatment centres and the volume of patients they handle is beyond their capacity, which limits their potential in doing research, teaching or acting as apex bodies in developing policies and guidelines. These centres should integrate with each other and with other government hospitals in delegating their clinical service effectively and dedicate their time to act as policy making bodies. In this context, the concept of National Cancer Grid of India, which started in 2012 with 14 centres and later developed to 80 centres by 2016, should be highly appreciated<sup>8,9</sup>. Unfortunately, even after 4 years of development, a single guideline has not been published online nor does it have an active website. It shows the difficulty in dedicating time for these activities beyond patient care. By decentralising the patient care using the current resources and adopting clear guidance is probably the best short term solution and in long term, formation of new centres should be considered.

For the foreseeable future, in India major public sector funding will be diverted for tackling communicable diseases and other common non-communicable diseases and cancer care will remain under private sector, which

will be keen to develop it due to its huge income generating capacity. Private hospitals with common vision, for example mission hospitals which runs on no profit no loss basis, should try to integrate and form network cancer centres sharing the treatment burden and budget. This will improve their potential to expand and acquire newer modalities of diagnosis and treatment rather than unnecessarily duplicating similar services. It is proved that, even in India, the survival of children with cancers treated in comprehensive cancer centres, approaches that in Europe or the US<sup>10</sup>. Integration will also improve their negotiating capacity with pharmaceutical and other suppliers as well as reduce unhealthy competition between hospitals and all these benefits can indirectly lead to improved patient care. If integration at financial level is not possible, hospitals with different expertise should join together for establishing multidisciplinary team or tumour board where individual cases can be discussed.

There should be a cultural change in the perception of the disease both by the clinicians and patients. Acceptance of reality is often difficult for the patients and it should be the responsibility of the clinician to communicate this to the patient and family in the best possible way taking cultural background into account rather than exploiting their reluctance to accept by giving unnecessary expensive treatment to the patient. A landmark phase III RCT showed that introduction of early palliative care to metastatic non small cell lung cancer not only improved the quality of life and mood but also improved the median survival<sup>11</sup>. Palliative care-when combined with standard oncology care or as the main focus of care-leads to better patient and caregiver outcomes. These include improvement in symptoms, QOL, and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care. Based on all these evidences, ASCO has given a position statement and guidelines on the early integration of Standard Oncology care and Palliative care for any patients with metastatic malignancy or those with high symptom burden<sup>12</sup>. Adequate communication skills training and involvement of Specialist Palliative care physicians early in the cancer diagnosis would also aid the oncologists with patient and family communication as well as to provide holistic care. Several

unnecessary interventions can be prevented by this, especially in patients with poor performance status and have survival of less than 6 months even in best centres.

There is an urgent need for implementation of various aspects of clinical governance in oncology practice. Risk management, Internal and external audits, peer review process and appraisals on the performance and practices of individual clinicians and hospitals should be done and they should be willing to change their practice based on the reports. Minimum quality maintenance should be mandatory for all hospitals, laboratories and pharmaceutical industries and should not be by choice. Professional regulatory bodies should have a strong control over clinicians and should be willing to take disciplinary action against clinicians who are violating professional conduct and having unethical relationship with industry allies.

In a country which can spend only less than 4% of its GDP for health care, with limited regulatory authorities against a strong financial drive from the corporate hospital management, pharmaceutical industry, laboratory and imaging lobbies we need to be very vigilant in optimising our resources to treat cancer patients. Policy makers should also look into these factors when implementing strategies for prevention, mortality and morbidity reduction and palliation of cancer patients in India.

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