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- (1) Sustained effort to detect cancers early.
- (2) Train health care workers on early detection.
- (3) Get equip mental support.
- (4) Develop a charitable cancer facility and thereby offer low cost treatment.

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- (1) Sustained effort to detect cancers early.
- (2) Train health care workers on early detection.
- (3) Get equipment support.
- (4) Develop a charitable cancer facility and thereby offer low cost treatment.
- (5) This experience enabled the task of cost reduction through government, non-government agencies' interface; which can perhaps be replicated in other developing countries.

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## I. INTRODUCTION

**G**lobal figures point out to a rising number of patients of cancer and India is no exception. A Planning Commission report estimates that about 2.8 million people have cancer at any point of time and half a million die of the disease each year, high death rates clearly indicating late stage diagnosis<sup>1</sup>. The number of cases is expected to go up because of an increase in life expectancy, the incidence is projected to rise five-fold by 2025 and the prevalence is likely to increase to 19% in men and 23% in women by 2020.<sup>2</sup>

According to Globocan 2012, an international cancer research project, one in five cancer insurance claims is by those between 36 and 45 years of age<sup>3</sup>. This means that the disease is set to disrupt the family's finances due to the loss of a source of income.

Disparities in income, shortage of low cost cancer facilities and late diagnosis compound this problem.

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## II. BACKGROUND

Cancer Care is not easy or cheap anywhere in the world but one of the biggest challenges for patients in India is meeting the varied costs of Cancer treatment. The main reasons for this are:

- (1) Cancers are detected late needing prolonged treatment, oftentimes multidisciplinary such as radiation or cyclical chemotherapy.
- (2) Most of the cancer treatment facilities are located in urban areas with a cultural disconnect between village folk, urban areas are well penetrated but vast rural areas remain untouched.

The present availability of teletherapy machine in India is only about 0.3 per one million population, whereas, in USA and UK, the availability is 8.2 and 3.4 per million respectively. Considering the fact that, in a developing country, the requirement of teletherapy machine is 1 machine per million population, India should have at least 1000 operating machines<sup>4</sup>, there are only about 430 teletherapy machines operating in the country<sup>5</sup> thus making affordable cancer treatment accessible to village folk which comprises of 80% of Indian population an issue. On one hand is the financial implication and on the other, the distances needed to travel for going through prolonged treatment, often necessitated by late diagnosis. Then there is the concern about the rising Cancer cases.

- (3) The number of patients is expected to go up further also because of increase in life expectancy.
- (4) The staggeringly high cost of equipment required for setting up a cancer hospital is largely due to the fact that equipments, generally imported, are costly; hospitals have to pay a fortune for imported equipment.

Aware of the fact that the facilities of treatment were rather sparse, we began our efforts by first setting up an organization fulfilling the statutory norms for establishing a Cancer center.

The focus was on India's commonest Cancer in men, a center for the head and neck Cancers, now known as the Institute of Head and Neck Oncology.

The Indore Cancer Foundation, a public charitable trust, has worked in state of Madhya Pradesh focusing on district based early cancer detection, training of health personnel, as well as development

of a charitable cancer center focusing on India's commonest cancer in men.

In Indore our legal status is of a Public Charitable Trust. Our objectives include health education, early detection and the setting up of a fully equipped Indian Institute of Head and Neck Oncology; as a flag ship project of the parent organization the Indore Cancer Foundation Charitable Trust.

### III. DISTRICT HOSPITALS; A KEY COMPONENT FOR HEALTH CARE DELIVERY

For Cancers, the health care delivery system in India follows two bifurcated pathways, commercial corporate model and the public health system. While the private, commercial hospitals run on their own steam, public hospitals have a structured system and despite monumental constraints cope not only Cancer but with multiple diseases; communicable as well as non-communicable diseases and this they accomplish with commendable tenacity.

One of the key components of the public health systems are the Primary Health Centres which are scattered far and wide, totaling 28,863 in number 6. An alarming number are in dismal conditions, severely understaffed and equipped. These are the first point of patient entry, the referral then follows a structured system to the District Hospitals, which are the real hub of activities. The last census exercise in 2011, carved out India into 64 districts 7. The health centres are within this network.

Most patients of suspected Cancer, first report to the district hospitals and then reach the nearest (7) government controlled Cancer Institutions situated mainly in the Medical Colleges. They are often referred to 'higher Centres' the regional or tertiary Cancer Centres.

Based on the generally accepted and proven perception that Cancers were detected late we focused on efforts to ensure that they are detected early, even in the rural areas. We did this by reaching out to the districts through various innovative ways.

We used the established network of government health delivery training the local doctors on early Cancer detection.

Our team of doctors examined the possibly suspect cases in these camps. It helped save patients cost. The patients did not have to travel to larger cities or towns for the first specialist's check-up, or 'queue' to see a consultant or pay for services. The push for this detection through the outreach program came from Australian High Commission, which provide a significant financial backing for it.

Reaching out to the small town folk was challenging. Many villagers had misconceptions that cancer is a death sentence. Our focus was therefore

identifying high risk groups i.e. those with suspected pre-cancerous lesions such as leucoplakia, or sub mucous fibrosis but also spreading education against the usage of tobacco. During the process of carrying out our detection camps, we honed our communication skills, and acquired a deeper insight into their psyche. Soon our credibility rose, our network grew wider and we were accepted into the grass root system.

While outreach activities gathered momentum, funds helped us to achieve multiple targets. Grants from the World Health Organisation facilitated the training of the Primary Health Workers on ways of self-examination to identify precancerous conditions. Door to door survey found prevalence of tobacco usage in 69,000 people brought to fore the use of tobacco in a high number of school children thus reinforcing the fact that tobacco outlets should be kept away from schools.

### IV. CHALLENGES WE FACED

Our aim was not just holding detection camps or targeting primary health workers, it was to empower the local doctors to detect Cancer early, most of whom were in the government health system. We reached out to them through the government controlled district administration; getting them to organise CMEs on early detection of Cancer, with a structured program that also included a component of pre and post training evaluations. Organising such programs helped us acquire first-hand knowledge of the gaps in the system in contemporary knowledge that needed to be bridged. Over the years in the Madhya Pradesh, in central India, we have undertaken more than 200 training programs in 11 districts.8 We have thereby trained doctors, nurses and paramedical staff through free CME courses. Training was provided on what would be the warning signs of Cancer and then to those who had the requisite qualification, on how to perform simple examinations like fine-needle aspiration, cytology, pap tests etc.

Credible efforts paid dividends. More work came our way. As efforts gathered momentum, we focused on palliative care training for nurses teaching them the methodology of basic and essential aspects of nursing palliative care home care of terminal cancer patients in their own environment. We honed their communication skills, a vital need when dealing with the patients' families. One of the WHO grants enabled us to train doctors in district hospitals not just in our own state but in Rajasthan and Chhattisgarh as well. The Australian agency for International Development provided a palliative care van equipped with a mini laboratory for on the spot evaluating patients suffering from terminal cancers and providing them with practical and feasible care in their own precincts.

The above programmes have gone a long way in reducing the efforts and cost liabilities of cancer patients and their families. Going to the patient has

proved to be the strategy that worked in alleviating at least some of our patients worries.

In the third decade of our work, a philanthropic organization supported us by partly funding for the development of an in-house Palliative Care Centre at the Indian Institute of Head and Neck Oncology, through running of a palliative centre in a charitable centre has challenges.

## V. SURGICAL WORK AS A COST REDUCTION APPROACH

On many occasions the cancer detection camps were converted into surgical camps. Some District Hospitals had operating facilities where surgical work for cancer was possible. Prior to these surgeries, all the pre-operative tests as per conventional checklists were followed. We began with simpler risk free minor surgeries. Surgical staff in the district hospitals, trained and adapt in operative as well as pre-operative work were identified and included. This inclusion helped in our capacity enhancement as well as increased their capacities and exposure to such surgeries, enabling them to possibilities of performing these procedures on their own in future. Our team included the surgical and its support staff. The local staffs were given special instructions on the care of the patients. Besides we ensured that our team stayed overnight in the District hospital to take care of any post-operative surgical or medical complications if any.

This strategy made sure that not only was cancer caught fairly early in many cases, but primary surgery and care was available at the nearest hospital for patients. Many of these patients would have hesitated too long before visiting a big city hospital, letting the cancer reach advanced stages, escalating remedial efforts and accompanying costs.

Here too, going to the patient has proved to be the strategy that worked.

Between 2000 and 2017 we have performed more than 3048 free cancer surgeries. We held more than 214 free Cancer Camps in Madhya Pradesh, Chhattisgarh, Maharashtra, Gujarat, Rajasthan & Uttar Pradesh, examined more than 2,50,000 people in high risk groups, organised more than 220 Cancer Awareness Programmes held more than 200 Training Programmes on early detection and palliative care for medical personnel especially for doctors, nurses and paramedical staff of the Government health delivery system, the extensive and only health services within the reach of the economically weak and distressed in the remote areas of the country.<sup>9</sup>

The various camps and training programmes are our long term strategy for reaching to these areas not only for care and treatment but also for reducing the economic burden that cancer imposes on it host with the hope that in due course the numbers of well-trained

doctors and their support staff will reach its optimum level, at least in poorer states.

In addition to the support from the state Government, Australia and W.H.O., have enabled us to reach out to all the tiers of the District Health Care system, its Doctors, the Nursing Staff and the Primary Health workers.

## VI. BEGINNING OF CHARITABLE INSTITUTE

Detecting cancers early was not enough, we needed to have a treatment facility. We decided to develop the Institute for head and neck cancer. The only teletherapy machine in our city, with an estimated population then of ten lakhs, was non-functional and the closest Radiation facility was then an overnight train journey away, at Padhar in Madhya Pradesh.

The development of any cancer Institute required several components. A plan of action, land, equipments and 'seed capital'. We had none of this to begin with.

While reaching out to people detecting cancers early as well as training in palliative care were ongoing we were committed to our core objective which was to make the cost of treating cancers affordable and the facilities accessible, Government of the Madhya Pradesh allotted ten acres of prime land on a 99 years of negligible lease rent. This was the kick start of a powerful government-support. It kick-started our Institutional process.

As though providentially, side by side we received as gift wrapped, a teletherapy unit from the Nargis Dutt Memorial Foundation, Ottawa, Canada. Armed with two key components, we began radiotherapy treatment. The gifted Cobalt unit treated patients for years, treating free patients as well as partial charity through cross subsidy. The total number of beneficiaries was 1344, our updated figures shows that till October 2017, radiotherapy was offered to 6031 patients of which 1396 were given total charity treatment by radiotherapy alone and partial charity was offered to 2050 patients.<sup>10</sup>

The teletherapy unit, received from Canada needed to be replaced. We came to know that the country's atomic energy commission had taken up the development of indigenous teletherapy unit and the indigenous machine had state-of-the-art features in safety, controls and user interface a fully closable collimator for improved radiation safety was a unique feature of the machine.

Our quest for procuring the indigenous teletherapy unit was achieved with the help of government of India.

## VII. CONCLUSION

It is possible to get support for charitable anticancer activities though sustained support is an



issue. In our thirty years of working, we succeeded in reaching out, developing a partnership with government health care systems and use their resources, reducing cost thereby.

We were supported for cancer detection, for palliative care on a project to project basis for various programmes.

The Indian Institute of Head & Neck Oncologytoday, set up in ten acres of land received at Rupees 1 lease from the State government, has nearly all the equipments received as grants in aid, a testimony to the fact that resolute action aimed at cost reduction gets supported. Credible work gets help, there are challenges though. While capital expenses are often met, operational costs need to be generated, thus making the fight against cancer and reducing its costs, relentless and needs to be addressed by policy makers in India.

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