CANCER CONTROL IN KERALA, INDIA

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Abstract

Cancer control programmes have been adopted by many countries. However inadequate assessment of needs and resources, insufficient political will, lack of proper planning, execution and evaluation are the major factors that makes the programme inefficient. Participation from the various sections of society & groups has not been optimal. The experience & achievements in this regard in Kerala are described. This State in India has a high literacy rate and health conscious population. A 10 year plan of action was formulated for the initiation of the program. The Governmental support and involvement for the control program is highlighted. The modus operandi for early detection, public education and professional reorientation are described. District Cancer Control Programme, School Children's involvement, District Cancer Control Society and the role of Regional Cancer Centre are highlighted. Anti tobacco education in schools, propagation of self examination methods, extension of cancer detection and treatment facilities are the major activities undertaken in Kerala. For meeting the economic needs while a patient is diagnosed as having cancer, a cancer insurance scheme launched is described. The lessons learnt while implementing the program are described.

Introduction

It need not be stressed that cancer control unlike other disease control programmes is highly complicated and that a certain uncertainty looms large in all cancer control activities unlike in other disease control programmes because of the simple fact that individually each cancer is different from one another in its aetiology, clinical progression, early detection and control strategy and ultimate outcome. It is apparent that we are dealing here with a spectrum of diseases and not just one disease. In other disease control programmes, the main activity is single mode one and is limited to administration of a drug, a vaccine, or a surgical procedure, or control of some environmental factor. In the case of cancer control a multiplicity of approaches has to be

resorted to as demanded by the nature of the disease about which the public and profession are mostly unaware of especially the logistics. Hence for cancer control proper public and professional education is mandatory. Most cancer control procedures are high technology procedures for which the means and experience are not available in developing countries. It should be remembered that only a limited success has so far been achieved and that too in a few developed countries with intense effort and large financial investment in the control of a few forms of cancers. If such methodologies are imposed on the less developed countries with huge populations they are bound to fail because of inadequate resources, technical support as well as the inability of the public and profession to co-operate with the same simply because of their ignorance and so success in all mammographic and pap smear screening in developed countries cannot be transferred to the developing countries easily. Mammography requires not only money but also high level technical expertise. Similarly pap smear screening mandates high technical expertise and organised health care delivery system.

The prime objectives of a cancer control programme are reduction in cancer mortality, and cancer associated morbidity. Reduction of incidence is thus an essential pre-requisite for cancer control. The WHO in its documents on Managerial Guidelines of National Cancer Control Programme (NCCP) has identified and classified the cancers which are preventable, easily detectable, effectively treatable and those which can only be palliatively treated. This provides the corner stone for formulation of NCCP in different countries depending on their cancer load and cancer pattern1.

Inspite of all these, except in a few Developed countries of Western World, Cancer Control limits itself as a vigorously talked about health programme. In some countries the programme has received a lackadaisical approach, especially in the developing world and these have demonstrated that only through co-operation of several health agencies a sustainable cancer control programme can be implemented and made productive.

The priorities of Government health policy continues to focus on eradication of communicable and parasitic diseases, population control, etc. This is the situation even in Kerala which has recorded a negative

growth rate of population. There are no agencies or programmes planned or executed on a community level for cancer control. The human resources needed like maintaining cytology screening services, etc. are not at all taken into consideration. No coordinating or committed agency now function in the Governmental health sector for cancer control. Cancer mortality ranks 4th or 5th in most of the developing countries. Even when a legislation for curtailing tobacco habit usage is brought forward, political issues like employment, tax, etc. take precedence over health issues. Here the political will is lacking and administrative skills are not applied.

The Government of India, in its National Cancer Control plan, set up Regional Cancer Centres for cancer control in the region. Apart from delivery of State-of-the-art therapy, these centres were also envisaged to undertake cancer control activities in the communitycancer registration, cancer research, rehabilitation, palliative care and cancer pain relief. These centres were not planned to be just another therapy outfit. However, majority of RCC's in the country have been vigorously equipping themselves with advanced therapeutic technology. In most of the centres, year after year almost 80% of cancer cases which presented for treatment were with more than localised disease. Due to this, the therapeutic advantages anticipated have not materialised and thus cancer control programme continues to be limited to treatment of advanced cancers. The work culture in these centres continuous to be of the traditional outfits of curative medicine and neither a reduction in mortality or in morbidity from cancer has resulted.

Majority of professional medical societies and associations are yet to put their imprint in anticancer activities and this widely disseminated organisation can actively involve in cancer control activities through its many branches and members spread all over the country but very few attempts are seen in this regard.

The general practitioner and family physician can be a very useful source for health education on cancer. Primarily such personnel are busy with the ailment presented by the patient and hardly any health education is imparted. Secondly the ethos seems to be dependent on ethnocentrism.

Apart from these, the basic attitude of the population has always been for sickness management rather than health maintenance. Regular or periodical Health check-up is rarely practised. If only the cancers warning signals are properly looked for and self awareness increased regarding the danger signals, the population will benefit by public education. There should be consistent and continuous propagation on cancer's warning signals and self examination techniques.

The NCCP of India was formulated in 1984, focusing (i) primary prevention of tobacco related cancers as 50% of all cancer in India was due to tobacco use (ii) early detection of cancers of accessible sites as the 3 major forms of cancer were accessible (iii) augmentation of treatment facilities and (iv) establishment of equitable pain control and palliative care network throughout the country as more than 80% of cancer patients reported for treatment in very late stages. Kerala was the first state in the Indian union to formulate a cancer control programme as early as in 1988 (called 10 year action plan). The State programme was prepared with the same goals and with advice from WHO. The programme consisted essentially of creation of awareness on risk factors & early warning signals, thus empowering the population to seek good life styles and health related examinations supported by medical procedures to detect and diagnose the disease in early stages and undergo treatment in institutions re-oriented for this purpose. This programme on evaluation has been found to achieve:- Reduction in tobacco consumption, down staging of advanced tumours, augmentation of comprehensive therapy programmes, net working of palliative care centres.

Kerala is the south western state of India with a population of 31 million spread over 38,863 kms2. Over 75% of the population (23 million) live in rural areas. However, most of the rural areas in Kerala have modern facilities like electricity, water supply, transport and communication facilities like telephone, e-mail, fax and access to cable television channels etc. Due to effective control of communicable and parasitic diseases as well as because of healthy habits, long life expectancy, high literacy rate and affluence there is a fast shift from infectious to chronic and metabolic disorders. There is a well-knit health service provided by the government and the private sector. Such socio-demographic changes has resulted in achieving vital

indices in Kerala far advanced from other parts of the country. Of late, decentralization of administration has taken place and as a result 'Health' has become a subject under the control of the local bodies (Grama Panchayaths). This has empowered the public especially women to care for and maintain their health. Even panchayaths have envisaged cancer control activities as part of their Peoples Plan Programmes. These were profitably utilized for a vigorous implementation of cancer control in the State of Kerala. But there are conflicting claims for the above achievements. The social scientists believe that the achievements in cancer control are mostly due to the societial improvements which have taken place in Kerala during the last 20 years whereas the medical community and the health service system emphasize that the major changes have been brought about by the implementation of a cancer control plan. What ever be the forces which made this transition possible, the changes have been a healthy one and to a great extent can be credited to the motivated institutions and non-governmental organizations at least to begin with.

The cancer control programme in Kerala was launched after a full understanding of the epidemiology, risk factors, the resources and the needs of the programme available from hospital cancer registry started in 1982 as a major source material for planning the programme. This is assisted by the Population Based Registries also. A suitable methodology was also adopted. The Regional Cancer Centre spearheaded the programme in the State.

Using the registry data it was possible to identify cancers and their risk factors. The seven leading cancer types in rural Kerala are shown in table II.

Table II Seven leading cancer types and their Age Adjusted Incidence Rates.

Karunagappally: Rural Cancer Registry (1993-97)²

Site (AAR) - Males Lung (19.4) Oesophagus (6.3) Other Mouth (5.1) Stomach (5.1) Tongue (4.5) Lymphoma, HD (4.4) Liver (3.9)

Site (AAR) - Females Cervix (15.0) Breast (14.9) Thyroid Gland (5.0) Ovary (3.0) Lung (2.9) Other Mouth (2.6)

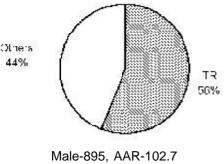
Breast

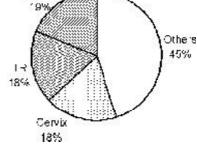
Oesophagus (2.6)

It can be seen from the above table that in Kerala like other developing countries has preventable and curable cancers more than in developed countries.

In figure 1, the proportion of cancers among males and females 'Amenable' for control are shown.

Fig.1 Cancers amenable for control-Karunagappally, 1993-'97





Female-742, AAR-75.5

Among males, almost 50% of cancers were tobacco related and among females, 18% was tobacco related - 19% was breast cancer and 18% was cervix cancer. These cancers were identified as 'Amenable for control'.

The following summarises the activities undertaken for cancer control in Kerala.

Tobacco habit prevention:

Tobacco control was the most important requirement for primary prevention activities. 33.53% of men above age of 14, use tobacco for chewing or smoking. 10% of women chew tobacco and only less than 1% of women smoke. The smoking rate among children <15yrs is very low (<0.5%). The tobacco control programmes in Kerala, thus were mainly targeted towards teenagers and women to prevent them from taking up tobacco habits and to help all habituees to quit smoking.

Two State wide programmes were targeted towards teenagers through schools. A programme carried out in 1993-'94 'One lakh Tobacco Free Homes' in which 1.26,000 families were declared as tobacco free. During last 2 years a similar programme was

implemented in over 6000 schools. These two programmes received international acclaim and helped Kerala to win the 'World No Tobacco' award of WHO in Bangkok.

Village level volunteers propagated the anti tobacco messages throughout the villages. 130,000 volunteers were trained to render support to the campaign and bring in credibility. The electronic and print media were also profusely used for propagation of Anti tobacco messages. Training & CMEs were conducted for 5000 Doctors, 120 Dentists, 4900 nurses, 4200 PHNs, 200 Health Inspectors, doctors of other systems of medicine and Anganwadi workers who work mainly in rural areas. Books, pamphlets, posters, stickers etc. were developed for health education. The World No Tobacco Day' was observed every year since 1996 with participation of NGO's in different parts of the State and along with workshops on anti tobacco themes for a week in different parts of the State as part of the advocacy campaign.

There is no legislation to control tobacco consumption in Kerala so far. But several executive orders are there banning smoking in educational institutions, government offices, public transport and other public places. In July 1999, the High Court of Kerala made a landmark judgement banning smoking in public places and authorizing the police to take action against those who violated the rule. The police were to report the details of action taken once in three months to the honourable High Court. Keeping a Cigarette lighting equipment in a tobacco retail shop is also banned by a court order. Though there was an initial 40% drop in sale of cigarettes, due to tardy implementation of the restrictions, this advantage is being rapidly lost.

The reduction in Oral cancer, the absence of any alarming increase in lung cancer during the last 20 years ever since cancer registration has been started, indicate that tobacco control in Kerala is effective. It has been noticed that there is one percent reduction in tobacco consumption yearly in the Trivandrum Oral Cancer Screening (TOCS) project area though this is only a small sample.

Primary Prevention of dietary and other life style cancers:

Regular programmes on the importance of healthy diet is done in all awareness talks and propagated through Non Governmental Organisation (NGO) groups, Residents Associations, etc.

Early Detection Programme:

The community oncology division of the Regional Cancer Centre has been actively involved in early cancer detection programmes throughout the State. The early detection programmes were undertaken in a campaign mode as fancy, hightech expensive methods were beyond our reach. Hence education followed by screening was the emphasis. Awareness cum screening camps are being organised periodically with the support of Governmental and Voluntary organisations. Public education is the ardently pursued activity. methods were emphasised, particularly of oral cavity along with need for quitting tobacco. Methods of Breast self examination is taught and physician Breast examination is propagated. Rehabilitation methods available are also stressed in these sessions. It is our experience that many listeners of the awareness talk seek our help to organise and conduct screening camps. We have also observed that a cancer screening camp is most productive only if conducted within 2 weeks after an awareness programme.

12600 Village level cancer control programme volunteers were trained to create awareness on cancer, early signs, in advocating and motivating people to undergo diagnostic screening tests, therapy and to extend financial support. This activity covered 85 villages in the State. The village level volunteers are usually trained in a one day programme and supplied with material to be distributed among the public for a period of 3 weeks. Members among the public who suspect any cancer or pre-cancerous condition are motivated to undergo physical examination by a medical team in a camp organised by them.

In a nut shell, the philosophy behind early detection is empowerment of the high risk population through awareness and making use of available facility of a physician verification of the symptoms if any. The role of NGOs in this endeavour is equally important as the Governmental work force alone cannot activate the population in such a massive way. To test simple methods like self examination in oral and breast cancer, two studies have been conducted by the RCC. These have proved their feasibility but major strides are yet to take place.

Early Cancer Detection Centres (ECDC):

Achievements of Kerala programmes can be greatly attributed to the facilities organised for early detection. The early cancer detection centres are the focal points for co-ordination and verification of early detection of cancer programmes in the State. Early cancer detection centres were originally government initiated programmes. These are now run by the RCC (2) and NGOs (5) with technical support of RCC. They depend mainly on clinical examination, cytology and histopathology. They provide an easily accessible diagnostic facility for people in a District and also function as co-ordinating agency for cancer related activities such as prevention, palliative care and follow up care. Cases referred from these centres are relatively earlier in the stage of presentation than those referred from hospitals to RCC. Both the ECDCs run by RCC are located far away from the District hospitals. This helped to motivate symptomless people to attend for a checkup. Hospitals are still recognised as places for sickness management. But ECDCs are to screen normal people. The Early Cancer Detection Centre at Erankulam has since in its inception in 1984 has screened more than 80,000 people. Further expansion of such centres is hampered by absence of cytotechnologists to man the laboratories.

District Cancer Control Programme (DCCP):

The DCCPs were conceived by the Government of India as demonstration modules for universalising cancer control. However, this win win programme was neglected by Governmental agencies and NGOs alike as the philosophy & modus operandi were not neither well propagated nor understood. The district cancer control programme in the rest of the country could not be managed successfully as either the districts are too large, the human resource development programme required for early detection programme was not in place and the administrators were not aware of the logistics of cancer detection programmes. This programme has been highly successful in the sole district in Kerala because of the availability of a diagnostic centre in the District (ECDC), which also functioned as the dedicated coordinating centre for executing the planned activities. The laboratory facilities and a staff support have helped to run the programme and establish it as an ongoing activity. In this programme teams of medical

personnel go to the periphery and systematically comb an area for early cancer. They also detect and discuss habits and other diseases. In the screening camps the attendees mostly have been women as such screening camps are held on working days. The screening camps are held in the Primary Health Centres of the Governmental Health Services. Doctors who attend the camps are trained in the Regional Cancer Centre in Early Cancer Detection methodologies and early cancer management. Some of the doctors have shown reluctance to leave their place of work to attend such screening clinics. Anticipating such reluctance, to avoid any break downs, the entire scheme was executed with the Governmental District Medical Chief as the programme officer. Hence for grass root level work the multi purpose health workers were deployed. We could thus establish a sustainable and feasible modus operandi for cancer control in the District of Eranakulam, which could be a model for other Districts.

District level Cancer Control Societies:

The programmes referred so far were stand alone programmes. They were not or only partially integrated with the Directorate of Health Services and hence did not have the universal support from the health care delivery system. To overcome the disadvantages, the district level cancer control societies were formed by the government which were totally integrated with the Directorate of Health Services.

The Kerala Government earmarked 25% of the money collected through Small Scale Savings for cancer control activities in the financial year 1995-96. This money was utilized to improve the facilities in existing Government and private cancer centres and to start District Level Societies for Cancer Control. Now the State Health Department has mandated the District level Cancer Control Societies as cancer control agencies of the district.

Cancer Registration:

It need not be emphasised that in any cancer control programme cancer registration assumes a significant function. The Regional Cancer Centre started a hospital based cancer registry in 1982 and currently over 9000 cancer cases are being registered annually by this registry(3). Apart from this, two population based cancer registries were also started one in 1990 and the other in 1994. The first population cancer registry of Kerala functions in Karunagappally since

1990, 100 Kms away from Trivandrum. This is a rural area and is devoid of any dedicated cancer treatment facility. The population based registry of Trivandrum started in 1994 covers 500,000 population in Urban Trivandrum and 500,000 residents in Rural Trivandrum which lives adjoining to the urban area(4). These registries are managed by the Regional Cancer Centre and provides the necessary information to programme strategies for cancer control in Kerala.

Human Resource Development for cancer control activities:

The RCC has conducted a number of programmes to support the cancer control activities in the State. These include training Cytotechnologists, Cytotechnicians, Radiotherapy technicians, Tumour Registrar Training, Reorientation Training for Radiotherapists, Paediatric Oncology programmes, Oncology nursing and Palliative care programmes. Even personnel from other states have taken advantage of these training programmes. It may also be mentioned that some of these programmes were conducted with WHO and International support.

Cervical precancers are detected through Colposcopy and Papsmear and when indicated are treated with Cryo-therapy a loop electro surgical excision procedure LEEP. With the support of the IARC and BillGate's foundation the Regional Cancer Centre will soon set up an International School of Colposcopy for training of Gynaecologists, Nurses and health workers in Colposcopy. Low cost Cervical Cancer detection methodologies as alternatives to pap smear screening and the treatment of precancers of cervix are tested.

The Regional Cancer Centre has been conducting programmes to train cancer registry personnel since 1984. This programme, the only one of its kind in the country envisages uniformity of cancer registration procedures, so that comparability of information is ensured. This activity has an important function while evaluating cancer control programmes.

Cancer diagnosis and treatment:

Emphasis was given to improve therapy hand in hand with early cancer detection. General development of diagnostic technology in the State is our committed objective. A new brachytherapy equipment has been fabricated in RCC as a cheaper alternative for treating

cancers of the uterine cervix. During the last 10 years the therapy programmes have become comprehensive Unfortunately the distinction between palliative and radical therapies on universally accepted guidelines are being forgotten and are being replaced with drug oriented modalities which are beyond the means of the common man.

Advances in diagnostic technology:

Tumour pathology facilities are available in RCC and in all the 6 Medical Colleges of the state. There are a number of private laboratories offering pathological diagnosis of cancer. X-ray, ultrasound and endoscopic facilities are available in RCC and all other Medical Colleges as well as in major private hospitals. Mammography facility is available in RCC and in about 5 private centres. Gamma camera and other radioactive isotope uptake facilities are available in RCC and a few private centres. More than 20 MRI and 100 CT facilities exists in the State. Radioimmuno assays and study of tumour markers are carried out in RCC as well as in two or three major private labs. A wide range of Endoscopic techniques are available in the RCC as also PDT for selected tumours. These have considerably enhanced the chances of accurate diagnosis and treatment of cancer.

Pain relief and Palliative Care:

RCC started the pain control and palliative care division as early as in 1986. It was the first institution in India to manufacture and supply morphine liquid (1988). Morphine tablets were made available from 1991 and the local manufacture of morphine tablets were also started.

Six doctors and two nurses were sent abroad for training in palliative care and cancer pain relief methodologies. One National workshop and two international workshops and several regional/state workshops were held to train doctors, nurses and pharmacists to organize pain clinics. Now there are 2 nodal centres in the state for pain control and palliative care, one in RCC and the other in Medical College, Calicut. More than 30 peripheral centres are networked under the guidance of these main centres. A unit to make home visits of terminally ill patients and to train the relatives of terminal cancer patients in principles of cancer pain control have started functioning

in RCC since this year and had been in existence in Calicut since 1990. A State level programme to network all palliative care centres and to make available pain relief (morphine) nearer to the homes of patients is being implemented now. The present level of morphine consumption of 10 kg is expected to go to 25 kg annually.

In the accompanying map of Kerala the available cancer related facilities and control programmes are shown.

Cancer Insurance Programmes:

RCC has a unique cancer insurance programme called 'Cancer Care for Life' initiated from 1986. Any person paying once in a life time amount of Rs.500 is entitled to free cancer investigation and treatment in RCC 2 years after enrolment. So far, over 3 lakh persons have taken up this policy and more than 1500 patients have benefited from this scheme.

Some of the General Insurance companies in India have mediclaim policies which will give fixed amount for the treatment of cancer or any other illness, during a specified time. Such policies are to be renewed every year.

The Employees State Insurance Scheme is a major programme by which the work force in industrial establishments get medical coverage and reimbursement of expenditure. Government servants, employees of autonomous bodies and public sector undertakings are eligible for most of the expenditures incurred in connection with treatment of cancer.

The 10 year action plan focusing on antitobacco programme for children and women, early detection of oral, cervical and breast cancer, establishment of diagnostic facilities at district level, expansion of therapeutic and palliative care in a low resource setting, adapted fully to the attitudes and desires of the local people and maintaining them, implemented with the determination and political will can be a model for other developing societies with such high levels of literacy and certain affluence.

Lessons Learnt from Organising the NCCP in Kerala.

- A committed group is essential for technical guidance, execution, co-ordination and responsible for evaluation and mid course correction if required, such as the RCC and their peripheral outfits.
- 2. Grass root level workers such as volunteers are essential in large numbers to motivate people for habit curtailment, attend for screening and prompt treatment as in a campaign.
- Updating of medical personal on an ongoing basis is necessary.
 Ultimate objective 'Every Physician office a cancer control clinic'.
 (advise for habit cessation, propagate screening and cancer related check-up and palliative care).
- 4. The chosen technology should be easily available which ensures that coverage of such technology is wide acceptability and applicability universal.
- 5. Public education to be vigorously and continuously pursued especially in younger population.
- 6. Programme running should not be hampered by non availability of staff supplies or funds.
- 7. Programme evaluation done periodically is essential.
- As in most of the developing countries, the medical services are carried out through Governmental organisations, Cancer control also should be implemented through essential health services by a committed executive body.
- The Non-Governmental agencies can effectively participate in the programme for cancer control.
- 10. Cancer screening and detection programmes address normal people. Traditionally the hospitals are recognised as sickness management centres and hence the antipathy for a normal person who is urged to attend a hospital for cancer detection should be recognised. As for as feasible the detection centres should function separate from the main treatment facilities.
- 11. School going children and women should receive special focus to propagate the programme.

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