

1. INTRODUCTION

Kerala has a long history of organised healthcare. As per documents, by the time the state was formed in 1956, the foundation for a medical care system accessible to all citizens was already laid. High level of education especially among women and greater health consciousness has played a key role in the attainment of good health standards in Kerala. The easy accessibility and coverage of medical care facilities has played a dominant role in shaping the health status of Kerala. Some of the hospitals in Kerala are more than 50 years old. Health had been a major area of spending in the budget from early years in Kerala. India's first ever Human Development Report published in 2002, placed the Southern state of Kerala on top of all the other states in India, because of easy accessibility and coverage of medical care facilities. The Ayurvedic system of treatment practised in Kerala dates back to centuries and is attracting a lot of people from India and abroad. It has become an integral part of Health tourism in this country as its philosophical base and holistic approach is unique.

In Kerala state, private healthcare sector plays a major role but they are confined to the curative area alone. They have no role in the preventive and promotional aspects of healthcare, and also in the non-profit making services like palliative care. The services in these sectors are almost exclusively delivered by public health sector institutions with the help of local self-government institutions. Social and voluntary associations play an appreciable role in this area, by assisting to the public sector institutions to make the quality of care better. 'Greying of population' i.e. increase in the number of senior citizens is a major health challenge to Kerala than any other state in India.

Providing adequate care and support to the marginalised, downtrodden, bedridden, weak and old people is considered as the responsibility of any civilised society, we are no exception. We are not behind in developing a system of our own, to cater these group of people which is now widely known as '**KERALA MODEL IN PALLIATIVE CARE**'

KERALA MODEL IN PALLIATIVE CARE

Palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients. Unlike hospice care, palliative medicine is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. Palliative medicine utilizes a multidisciplinary approach to patient care, relying on input from physicians, pharmacists, nurses, chaplains, social workers, psychologists, and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life. This multidisciplinary approach allows the palliative care team to address physical, emotional, spiritual, and social concerns that arise with advanced illness.

The state of Kerala has managed to develop an integrated health service delivery model with community participation in palliative care. The evolving palliative care system in Kerala tries to address the problems of the incurably ill, bedridden and dying patients irrespective of the diagnosis. It is also expanding to areas of community psychiatry and social rehabilitation of the chronically ill as well as the growing population of senior citizens which is a serious concern in Kerala health scenario. The primary healthcare system in Kerala plays a major role in these activities. The 'Quality of Death' study by Economist Intelligence Unit states that 'Amid the lamentably poor access to palliative care across India, the southern state of Kerala stands out as a beacon of hope.' Although India ranks at the bottom of the index in overall score, and performs badly on many indicators, Kerala, if measured on the same points, would buck the trend. With only 3% of India's population, the tiny state provides two-thirds of India's palliative care services.

The main components of Kerala's program are:

1. Community mobilization and ownership by the local community
2. Involvement of the local self-government institutions (LSGIs)
3. Incorporation of palliative care in the primary healthcare system

The major player in development of this public health model in palliative care in Kerala has been LSGIs in the state and the involvement of people from various walks of life as well as a no. of voluntary organisations interested in palliative care. This has led to the input of an array of innovative ideas in supporting the patients as well as family members in areas beyond medical care.

In addition to the medical and nursing services offered, the palliative care units in the community also offer:

1. Regular supply of food for the starving families. This usually comes as a weekly supply of rice and other items collected from individuals and shops in the neighbourhood. 'Rice for the family' has become an important component of total care for patients in the region as a good percentage of families are financially broken by the cost of prolonged treatment by the time the patient registers with the palliative care unit.
2. Support for children from families of poor patients to continue their education. The support is mainly in the form of books, uniforms and umbrellas at the time of opening of the schools. Students tend to drop out at the beginning of academic year because the parents are not able to afford the one-time expenses on books and uniforms. Intervention by the palliative care units at that point keeps them going. Also, some students are being supported for their university education.
3. Transport facilities to referral hospitals - In most situations, this is in the form of a vehicle offered free of charge for a follow-up visit/admission to the Medical College hospital or for an admission to the government institutions offering palliative medical care. The trip otherwise would have cost the family a month's income.
4. Rehabilitation - There is a regular attempt to encourage/train/support patients/family members in income-generating activities. The programs include support/training in making handicrafts, paper bags/envelopes and so on, and support in rearing chicken, keeping cattle and setting up small shops, owning a taxi autorikshaw etc. Training workshops are organized for patients and family members.
5. Financial support - Most units provide finances to very poor patients in emergency situations.
6. Community volunteers trained in psychosocial support interacting with patients and family to offer emotional support.
7. Community based programs try to link their patients with local, social or religious organisations supporting the marginalized.

8. They also link the patient with local government to identify benefits from government schemes. These include support for the destitute, electricity connection to homes of cancer patients, pension for cancer patients and so on.

RESEARCH GAP

Kerala being one of the cent percent literacy states ,the employed youth are having a tendency to migrate to abroad and to settle themselves with their own family and they are not showing much interest in looking after their parents. In this scenario the number of old age homes are increasing day by day and which is adversely affecting our culture.

Palliative care is an area of healthcare that focuses on relieving and preventing the suffering of patients. Unlike hospice care, palliative medicine is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life. Palliative medicine utilizes a multidisciplinary approach to patient care, relying on input from physicians, pharmacists, nurses, chaplains, social workers, psychologists, and other allied health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life. This multidisciplinary approach allows the palliative care team to address physical, emotional, spiritual, and social concerns that arise with advanced illness.

Medications and treatments are said to have a palliative effect if they relieve symptoms without having a curative effect on the underlying disease or cause. This can include treating nausea related to chemotherapy or something as simple as morphine to treat the pain of broken leg or ibuprofen to treat aching related to an influenza (flu) infection.

Although the concept of palliative care is not new, most physicians have traditionally concentrated on trying to cure patients. Treatments for the alleviation of symptoms were viewed as hazardous and seen as inviting addiction and other unwanted side effects.

The focus on a patient's quality of life has increased greatly during the past twenty years. A relatively recent development is the palliative-care team, a dedicated health care team that is entirely geared toward palliative treatment. We have an organised Homecare system as already mentioned. There are several more avenues we can intervene to make the medical care more

comprehensive, facilitates access to the specialist medical facilities, empower the healthcare professionals with up-to-date knowledge and other gadgets for effective management ,educate the caregivers on scientific patient care etc. This research project tries to open up a window to these strategies.

GOVERNMENT OF KERALA'S PALLIATIVE CARE POLICY

In 2008, the Government of Kerala declared a pain and palliative care policy highlighting the concept of community based care and giving guidelines for the development of services with community participation for the incurably ill and bedridden patients.

In practical terms, this policy is aimed to mobilize volunteers, providing them with training in palliative care, thus empowering them to work with the healthcare system. The policy also aimed at facilitating engagement from the LSGIs in development of home-based palliative care programs. The policy aimed to provide community-based palliative care programs with home care services available to most of the needy in the state with active participation of CBOs, NGOs and local healthcare programs, and to develop common bodies/platforms in LSGIs to coordinate the activities of these agencies.

Palliative Care Project was initiated by NRHM (Kerala) in 2008 with the aim of facilitation of development of a public health model in palliative care in Kerala in line with the Palliative Care policy of government of Kerala. The project has been trying to establish the primary, secondary and tertiary care facilities in palliative care in Kerala with community participation.

Institution-based palliative care mostly over-looks the home condition of the patient, whereas the home care programs involve not only the family members but also strata of compassionate community members. The local governments provide a common platform for their interaction and co-ordination. The central idea of this innovative healthcare model is home care units lead by trained health professionals and supported by volunteers. The efficient implementation of palliative care programs may be attributed to the flexibility of the organization setup and the ability to tailor patient-specific programs through participation of all the stakeholders. The local governments play the lead role in planning process by providing a common platform for different stakeholders. The local governments take initiative for organizing home care units, starting with the formation of a project management committee for planning and co-ordination.

We are proud in that the Kerala model offers solutions to many of the issues in palliative care in low-income and middle-income countries. In this scenario we should give more care to our patients who are in need of the same. Being a pioneer model there is a need to innovate our service delivery system continuously by adding newer modalities of care, often extending

beyond the scope of medical care. Behind the scene, there is a neglected lot, the family members and careers of these patients. We have to find ways to ease their financial, familial and social burden to a considerable extent.