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Palliative Care Movement in Kerala: A Historic Overview

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Abstract

From ancient period itself, Kerala holds a rich heritage of a plethora of curing practices. Several systems of treatments have emerged and flourished here to offer cure and relief to patients. Kerala, the birthplace of ayurveda, still attracts patients from all over the world. In addition to it, several ethnic medical systems also have rooted in Kerala. Generally these systems offer vital thrust on curing diseases with immediate and minimal effect. The aspect of relief for those beyond cure has yet to be acquired enough attention in these systems. Moreover the emotional dimensions of miseries of those on the verge of death have not attained sufficient momentum. The system of palliative care is a novel attempt towards this limited thrust area. Malabar region in Kerala has become a forerunner in it by showing way for the entire Kerala. Now the concept is slowly gaining momentum all over the state even seeking the attention of organised government mechanism. Hence it would be worthy to trace the history and functioning of palliative care movement and the present paper tries to evaluate the nature of evolution and role of palliative movement in the medical system of Kerala.

Keywords: Palliative care, grey population

Introduction

Kerala, the southern state of India, has always projected as a model by the social scientists mainly because of its achievements in education and health. The significant progress in these key sectors along with the enhanced social security measures has realised development in Kerala, even in the absence of growth in productive sectors. Even now, Kerala has marked significant progress through the commendable achievements of these service sectors. Hence it is important to enhance the quality of the services delivered by these prime domains.

A health system mainly performs three key roles to the people. Firstly it tries to ensure a robust practice capable of preventing diseases and maintain a healthy lifestyle. Secondly the system should adopt suitable measures to reverse and cure the diseases with immediate and minimal effect. Finally the system is responsible for extending relief measures for those

patients who are beyond the level of cure but demand long term care and attention. The former two aspects of prevention and cure have received sufficient attention in the general health system and policies. But the third aspect was almost eclipsed in the shadow of these tall pillars till recently and this segment is mainly dealt with the palliative care movement.

A health system will cater to the needs of people if and only if it is capable of satisfying these three basic dimensions of health care. Similar to the literacy programme in education sector, health sector also affords another vibrant programme termed 'palliative care movement'. According to the Government of India, out of the 922 palliative centres in India, more than 850 centres are located in Kerala (Ministry of Health & Family Welfare, GoI, 2012). Even though in India 59 lakh people are in need of palliative care, only 2% are receiving palliative support (IPM, 2013). Several socio economic factors specific to Kerala also contribute to the development of palliative care system in Kerala. These features are contextual to the state and significant in the socio economic domain of the state.

1. High Life Expectancy

Kerala tops the country in terms of life expectancy of people. The average life expectancy is 72 years for female and 68 years for male. The overall life expectancy is 74.1 years in contradiction with the national average of 65 years (Economic Review, 2018). It is comparable to the advanced countries in the world. According to a population projection by State Planning Board, the growth of old population will grow at a rate of 7.5% during 2011-21 and the number of old people will increase from 3.62 million in 2001 to 8.93 million in 2051. This will record a hike of 166 percent. Moreover by 2061, the relative share of elderly would be 40 percent of the total population of Kerala (State Planning Board, 2009). With increase in longevity, the old age population is high in Kerala. The improved health networks and better medical care facilities function as contributory factors towards this tremendous growth. Hence the health issues specific to old people emerge as a burning issue to be dealt with utmost care.

2. Prevalence of Grey Population

Grey population means old people. Due to the surge in the population of elderly in total population, Kerala population is termed as grey population. People above 60 constitute 13% of the state population in comparison with 8.2% of national figure (Census, 2011) and due to his uniqueness some observers have termed Kerala as '*old's own country*'. The increased life

expectancy coupled with prevalence and awareness of better health facilities and existence of social security measures in Kerala; naturally increase the rate of grey population. The '*aged dependency ratio*' (the number of persons above 60 years of age per 100 persons in the working age group of 15-59 years) is expected to increase from 17 to 76 during the span of 2001-2061(Centre for Development Studies, 2012). The old aged demands constant medical care because with increase in age, chances of curing the illness completely come down. Here rather than recovery and curing, a holistic supportive mechanism is required.

3. Lifestyle diseases and chronic disability

Even though Kerala has witnessed significant improvement in health sector comparable to advanced nations, fresh challenges are posing serious threats to the health sector. The outbreak of new diseases and mushrooming of lifestyle diseases together constitute chronic disability. According to the Human Development Report published by the Government of Kerala in 2005, the prevalence of disabilities in Kerala is lower than all India level but the state ranks second highest in terms of prevalence of chronic conditions. The Disability Census 2014-2015 reveals that 9.87 lakh households in Kerala have disabled people and this constitutes 11.01% of the total households. In all these instances constant palliative support is essential.

4. High Morbidity Rate

One of the highlighting features of Kerala population is low mortality rate coupled with high morbidity rate. Morbidity refers to the ill feelings associated with physical and mental condition. It is an indication of ill-health of a person. Increased prevalence of lifestyle diseases along with cancer and other chronic situations put the morbidity status of Kerala at a gloomy level. The morbidity prevalence rate in state is estimated as 181 out of every thousand people in comparison with national average of 103(Gangadharan, 2016). It increases the average years of morbidity and the condition become worse with progress of ageing.

5. Nuclear Family System

Besides the above health challenges, the transition in the family system also pose serious challenges in healthcare of people. With the transition into nuclear family system, the number of people in the families has drastically reduced. It seriously affects the quality of care to be extended to the patients. When someone in the family turns to be chronically disabled, it

raises serious problems in providing continuous and regular care. This necessitates external institutional support and increases the potential of home care facilities.

Palliative Care System

In the advanced countries, palliative care system is an integral component of the total health care. It aids a patient's right to live with dignity and die in peace. The World Health Organization in 2002 defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2002). Palliative care is aimed at improving quality of life, by employing what is called "active total care", treating pain and other symptoms, at the same time offering social, emotional and spiritual support (Palliative Care policy, Government of Kerala, 2002).

The basic aims of the palliative care system are the following

- ❖ Offers relief from pain through constant care and support
- ❖ Enhance the quality of life by making them as lively as possible and extend emotional as well as psychological support
- ❖ Relieve the patients from the fear on death and enable to admit dying as a normal phenomenon
- ❖ Extend support to the family to cope with the situation

Palliative care: Indian Experience

The initial policy attempt to palliative care was undertaken in India by the Central government through the framing of a National Cancer Care Policy in 1975. Later in 1984 it was modified as a pain relief policy by incorporating the local public health centres. But the unfortunate thing is that it did not materialise into a workable model except the policy initiative. But after this, from mid 1980s onwards medical professionals from cancer care domain recognised the need for practical measures to alleviate the severe pain associated with the cancer treatment. In connection with this some units were initiated in the cancer care centres located in Ahmedabad, Bangalore, New Delhi, Mumbai, Thiruvananthapuram, and Varanasi (Shanmughasundaram et al, 2006; Khosla, 2012). The Indian Association of Palliative Care came into existence from Gujarat in 1985.

Paradigm shifts of Palliative Care Movement in Kerala

Following the initiatives from western and central India, Kerala started its first palliative unit in 1993 at Kozhikode Medical College in connection with the Institute of Palliative Medicine. It marked the launching of the hitherto unheard palliative movement in Kerala. As a result, the supportive system of medical care was also integrated with the traditional curing systems of health care. This can be considered as a paradigm shift in the health care model of the state. Later by 1999, four NGOs-Malappuram Initiative in Palliative care, Pain and palliative Care Society(Kozhikode), Alpha Palliative Care Clinic(Thrissur) and Justice Sivaraman Foundation- together constituted a community initiative named '*Neighbourhood Support in Palliative Care*' with the active involvement of volunteers. It paved way for community level initiatives in palliative movement. This move served as a positive pressure group to initiate official level activities in a tremendous way towards this segment. This is the pioneering paradigm shift in the palliative care movement of Kerala.

Adding momentum to these community initiatives, Government of Kerala framed an official policy - *Pain and Palliative Care Policy* - in 2008. Through this government declared palliative care as an integral component of primary health care and promoted community based home care under the initiative of local self governments. The National Rural Health Mission (NRHM) was also integrated into this project and Kerala is the only state with an NRHM project in palliative care. The 'Arogya Keralam' project is an outcome of this commendable move. This government initiative in collaboration with local self governments really enhanced the coverage of this network. Starting from 400 panchayaths in 2008, now it spreads in the local bodies and extends the service in collaboration with primary health centres, student volunteers, local field staff etc. This extended official intervention marks the second phase of paradigm shift.

Streams of Palliative Care

Palliative care initiatives in Kerala can broadly be categorised into five sections. The first segment functions under the monitoring of government agencies as well as local self government institutions, and this official initiative makes use of ASHA (Accredited Social Health Activist) workers. National Rural Health Mission (NRHM) serves as the co-ordinator for this. Another major stream is run by registered charitable trusts, and this is the forerunner in the state with grass-root level initiatives in North Malabar regions through 'neighbourhood network groups'. These community based organisations (CBOs) are purely volunteer driven.

In recent times, political and religious organisations also play a dominant role in this initiative. The third category is in association with hospitals and under the supervision of health care professionals. The chronic and incurable patients are provided with separate facilities and adequate emotional as well as mental support is offered to them. The service of counsellors and psychologists are also provided to equip them to face the inevitable. Institute of Palliative Medicine located in Kozhikode is the beginner in this stream. Specialised home care initiative for supporting the bedridden patients is the fourth segment of the palliative initiative. Here besides a staff nurse, volunteers and field staff will also be included. Student volunteers also extend their service to this team. The fifth section is the patient- outpatient (IP-OP) care by utilising the existing facilities in hospitals. Health professionals having expertise in palliative care extend their services by offering specialised Ops and domestic care to the needy chronic patients.

IPM: The Real Champion of Palliative Care Initiative in Kerala

The Institute of Palliative Medicine located in Kozhikode is still the dominant player in palliative initiative of Kerala comprising inpatient care, outpatient care and home care services. It runs a 30 bedded inpatient clinic for the most severe patients. Along with this an Outpatient clinic also functions with a weekly enrolment of more than 250 patients. Utilising the service of student and medical volunteers and in collaboration with the Palliative Care India Society, it also undertakes a home care unit by offering palliative assistance at the doorstep for the enrolled patients in a round the clock (24x7) basis.

Besides the medical attention, it also offers rehabilitative measures to patients and supportive measures to family. The programme titled 'footprints' is a novel attempt to provide vocational training to the chronically disabled patients with the financial assistance of Ratan Tata Trust. The raw materials are provided through this initiative and the marketing is also done through the volunteers.

Through the activities of Palliative Care Patient Benefit Trust, it also offers educational aid to the students from disabled family. Travel allowance for the patients for availing outpatient service is also facilitated through this initiative. Through forming a broad network with educational institutions, it provides food kits to families of disabled either on a monthly or weekly basis. This initiative titled food for survival is a form of extension activity.

Besides serving as the technical advisor for Central and state Governments, IPM also serves as the collaborator of WHO in spreading this service across the world. Institute of Palliative Medicine in Kozhikode and Regional Cancer Centre in Thiruvananthapuram is conducting training programme for professionals. These unique training programmes offered for the medical professionals and student volunteers besides its initiative to tie in hand with international governments and medical institutions are aimed at equipping professionals with compassion and emotional quotient.

Innovative Practices and Offshoots of Kerala Model of Palliative Care

The most highlighting features of the palliative care movement in Kerala is its grass root level coverage with a well connected network of local self governments, students and community initiatives and political parties. More than 80% of the palliative units in Kerala are run by non-governmental organisations. The extension of this network to educational institutions through innovative attempts like Our Responsibility to Children (ORC) and Students in Palliative Care (SIPC), this movement ensures a quality base and continuation for the programme. Another commendable feature is that this movement has succeeded in making it a socially responsible move to a significant extent. The incorporation of various cross sections of the society transfers it into a really democratic system. The movement has really succeeded in transforming the movement from a pure medical model to a socially responsible participatory system with the active involvement of democratic institutions and different cross sections of the society. The involvement of political as well as religious organisations has helped in widening the outreach and coverage of this novel model.

Conclusion

Palliative care is a vital domain which still needs to be encompassed into the health care system. It serves as a bridge between chronic morbidity and decent demise. Beyond the dimensions of cure and recovery, it concentrates on the emotional relaxation of the patients. The experience and lessons from this Kerala model should be publicised and promoted all over India considering the vast gap between need and achievement level. This paper can be concluded by quoting the opinion of Richard Smith, Editor, *British Medical Journal* “The Kerala model does provide a feasible way of achieving the vision of palliative care covering all patients, all diseases, all nations, all settings, and all dimensions. It’s hard to see how it will be achieved in another way”(Smith, 2011).

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