

## **Review of Community-based Health Care Movement and Palliative Care in Kerala**

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### **Abstract**

Palliative care is comparatively a new concept in Indian scenario. The changes in the family structure, nuclear family set ups, industrialization, changing epidemiology and life expectancy made the care of patients a difficult task, both in the grounds of materialistic and non-materialistic aspects. In this context a policy that make economic sustainability, participation of different forms of government and community deserves a high place. The present paper analyzes the palliative care policy of Kerala in the context of need and relevance of the population it addressed, the ongoing community palliative movement and the strategic approaches in the policy. The paper evaluates the significant contributions of the policy in relation with the decentralization of public health delivery through the active participation of the local self-governments and how it has enhanced the community based public health initiatives. Secondary data's are made use for the study.

**Keywords:** decentralization, social security, palliative care, Kerala, India

### **Introduction**

Policies and legislations are the key for initiating social security and social welfare programs; it gives a direction and systematization in application levels with special focuses. Time to time government both state and central, has taken serious concern on formulation and implementation of policies. A policy in the field of social security is aimed at the alleviation of the problems, ailments and improvement of the general concerns of the people. Public policies objective is to achieve a desired goal that is considered to be in the best interest of all the members in a society (Torjman, 2005). It initiates social welfare and promote the existing systems through advanced applications appropriate to the time. Public policies are the principal guide to state in delivering services to citizens. According to Jenkins (1978) policy is a set of interrelated decisions taken by a political actor or group of actors concerning the selection of goals and the

means of achieving them within a specified situation where these decisions should, in principle, be within the power of these actors to achieve. It is the study of 'how, why and to what effect governments pursue particular courses of action and inaction' (Heidenheimer, 1990). Here the policy makers are concerned with solving community problems and improving general wellbeing of people through decision making process at the government level and allocate resources accordingly.

In the field of health care, policy is a corner stone of practice and delivery of quality service. According to WHO (2010) "an explicit health policy can achieve several things: it defines a vision for the future; it outlines priorities and the expected roles of different groups; and it builds consensus and informs people."<sup>i</sup> Health sector is a prominent area which needs policy level intervention that can make a comprehensive change in the health care. Policy level interventions should focus on the segments that have not benefited yet to redress their existing sufferings and improve health care facilities. Policies are very crucial for a country like India, where social security measures are least developed.

There are certain typical examples of policies that are made significant change in the health sector of India both in prevention and promotion. Policy makers are given considerable importance to the health sector in all times, but some of the segment hasn't benefited from these policies. The chronically ill, bedridden patients, elderly population are the examples of such segment. Alternative approaches like palliative care have a vital role to play in this context. Palliative care is comparatively a new approach of care in Indian scenario and it's unlike in many dimensions of the western approach of end life care. "Palliative care is 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 not just a pain relieving institution which is having a wide and holistic approach in regard with patient care. The history of Palliative care movement in India goes back to the late 1990's with special concentration in the state of Kerala. Palliative care is an emerging concern of public health in Indian context. By the late of 1980's palliative care services began to exist in our country. But during the mid-90's it takes shape as an established mode of service delivery. These activities are mostly concentrated in large cities, with the exception of Kerala, where this movement has much more widespread (Abdul Azeez, 2013). Palliative care can't be consider mere as an approach of medical care its having a unique socio-economic implications in regard with Public health.

#### **Palliative Care Movement: Implications and Relevance of the Approach**

The implications and importance of Palliative care can be understood from the segments of population it addressed for, the method and approach utilized for

operating intervention. Initially Palliative care is known for the end life care and pain management and subsequently it has accepted a comprehensive approach of care in which bio-psychosocial aspects of the patients and families are addressed. Indian Association of Palliative Care (2011) defined, Palliative care as the active total care applicable from the time of diagnosis, aimed at improving the quality of life of patients and their families facing serious life-limiting illness, through the prevention and relief of suffering from pain and other physical symptoms as well as psychological, social and spiritual distress.

The definition emphasized the integrated approach of patients and family care. The palliative care delivery in the state of Kerala is well known for the unique approach of care, community participation and economic sustainability. This socio-economic implications made palliative care as unique model of intervention and attained global level attention, even by World Health Organization. A variety of models of home-based palliative care are currently being implemented in low resource countries. A popular approach in low-resource settings, where the number of people needing care is high and the number of nurses and doctors available to provide that care is low, is to provide care through community caregivers or volunteers who are supervised by a nurse trained in palliative care. The Neighborhood Network in Palliative Care in Kerala, India, and the Hospice and Palliative Care Association of South Africa, for example, have developed community-based, home-based care along these lines (WHO, 2013).

Sensitizing the issues of public health especially those addressing the disadvantaged segments of the population is need of the hour. Delivery of public health care is a complicated one in the modern scenario, even though there are various policies and programs for the same. A large portion of population is inaccessible to public health care and often marginalized from it. This happen especially those who are suffering from chronic illness, old age problems and advanced stages of life (Abdul Azeez, 2013b). The above mentioned segment constitutes a colossal section of our population and the sub divisions of this segment like poor, economically disadvantaged, rural people are most vulnerable and unable to access the appropriate health care services.

Most of the time accessibility to health care resources has hampered by the lack of resources. Economic resources, lack of appropriate information on disease, available facilities, lack of support and coping up with psychological aspects of the disease or situation is the most crucial challenge for the patient and families. A chronic illness or life threatening diseases has significant socioeconomic impact on the family. The person who is affected with such illness is no more able to support his/her family in the grounds of financial and other materialistic aspects and he/she completely become depend on the family. This dependency has serious psychosocial and economic dimension in the family in many aspects. In Indian context the burden of diseases are high while comparing to other parts of world. Around 20-30 percent of the health care resources are spends during the last years of life, this case is especially very true on the case of chronic illness like cancer/AIDS/TB and old age related problems etc.

A large number of people unable to meet their resources with themselves and become struggle to fetch such resources, this may lead to the disruption of families overall quality of life and standard of life. Families are spending large amount of financial and human resources to care the patients in the advanced stages of life threatening diseases for pain relief and care without having any hope of revert them back to life. Palliative care can significantly contribute in reducing this kind of burden of diseases and enhance the quality of life. As a low resource country like India, where around 55 percent of deaths are due to chronic illness and a large portion among that unable to access the health care resources, the interventions of palliative care interventions are relevant. The changing epidemiology, increased life expectancy and increased number of old age population again necessitate the emphasis of palliative care.

There are some characteristics that make the palliative care movement of Kerala a unique one. The initial dimension is the intervention of multidisciplinary professionals including the community volunteers. They are trained for caring the patients both in the levels of psychological and physical aspects in an empathetic manner; this helps the patients to be treated in their own homes on the advanced stages of life. This deinstitutionalization leads to psychological wellbeing and quality of life of patients and family members. Another important dimension is the economic sustainability; it enables the community palliative care's to provide free treatment and care to the needy by reaching to them with advanced mode of home care delivery. 95 percentage of palliative care's in Kerala is run by NGO's and till the recent past, they haven't got any kind of financial support from the government side. But they managed the intervention sustainably with the active participation of community; it's sustained with small contributions of community members. A large number of Palliative care units adopted social entrepreneurship also as a means of finding economic resources. Subsequently the movement has been accepted by the government as it's significantly contributes to the public health of the state, especially the health care expenditure in the advanced stages of life. These significant contributions of palliative care in the health sector necessitated the government to formulate a policy on palliative care in the year 2008.

The policy came with a great vision and mission to address the health issues that India has faces in the present and promote the community based decentralized public health initiatives in the state of Kerala. One of the innovative initiatives of the palliative care policy of Kerala is the vision on the decentralized health care with the partnership of civil society organizations. The policy has long vision on the health care issues of India. According to the projections of different studies India is going to be affected severely in regard with the effects of chronic illness like cancer and problems related old age. By 2030, the number of people aged 65 and older is projected to reach 1 billion (or one in eight of the global population), rising even more sharply (by 140%) in developing countries (National Institute on Aging & National Institutes of Health, 2007). The aging population and their care during the advanced stages of life is one of the challenge that we are about to face in severe manner. According to WHO (2008) by 2030, non-communicable conditions are projected to account for more than three-quarters of all

deaths. According to Nata Menabde (2014) every year, 10 lakh Indians are diagnosed with cancer and another six to seven lakh die of it. And it's feared that, by 2035, these numbers may almost double to 17 lakh new patients and 12 lakh deaths per year. These projections are states that cancer has devastating economic and human costs in India.

The death is followed by significant medical, psychological and financial implications for the patients and family and leads to the reduction of the quality of life and death significantly. The study on the quality of death (2010) by Economic Intelligence Unit ranked India as the 40<sup>th</sup> rank among the forty countries the study was conducted. But the reports states that, amid the lamentably poor access to palliative care across India, the southern state of Kerala stands out as a beacon of hope. While 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. These indicators of Kerala on quality of death are significantly influenced by the community based sustainable palliative care movement and show the wide range applicability of palliative cares. The empirical evidences implicated the necessity of palliative cares in the public health, as WHO (2002) states that "the fundamental responsibility of health profession to ease the suffering of patients cannot be fulfilled unless palliative care has priority status with in public health and disease control programme; it is not an optional extra. In countries with limited resources, it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advance disease and urgently in need of symptom control must suffer without relief. Kerala is advanced in this aspect and the only state in India which has a palliative care policy even though some of the developed countries are not having a palliative care policy or they are on the process of formulating it.

#### **Palliative Care Policy: Prospects and Scope**

The two decade long efforts of voluntary organization has recognized by the government in the form of formulating an innovative policy on Palliative care in the year 2008. The policy is unique in many dimensions; the most important aspect is the emphasis on the responsibility of the government on the public health system through supporting the Non-Governmental Organizations. The policy enhances the link between community based organizations and local government institutions. The other important aspect is enhancing the decentralization of social security measures by providing reasonable financial support to Local Self-Governments. Ultimately policy aims to make people to access quality home based palliative care services, which are most essential during the advanced stages of life, where the increased dependency and financial concerns are the source of psychological and social sufferings of patient and family. Policy aims to enhance the home based palliative services. The policy emphasized on the training of professionals and volunteers involved in the palliative care service delivery. The core concentration of the policy has described in the following areas of intervention.

The policy clearly states that how to develop new services, coordinate existing services, developing capacity among different stakeholders, measures for making adequate availability of drug supply and other equipment's for the patients. Policy necessitated research and budget allocation and the training of health care professionals and volunteers involved in palliative care and incorporated the prospects of different systems of medicine in palliative care service. The policy emphasize a community based approach with LSGI involvement to palliative care and considers home based care as the cornerstone of palliative care services and integrating palliative with primary healthcare.

### **Development of Services, Involvement of Different Organizations and Decentralization of Health Care**

The guiding principle of the palliative care policy is the expansion of home based palliative care services to the depth and width of population in the state. Policy emphasis the Palliative care services should be the part of general health care system, as the state accounted a large number of chronic illness like cancer are being increasingly reported and the burden of disease is also in rise. The main focus of the policy is makes efficacy of community based palliative services through the involvement of different governmental and nongovernmental organizations and institutions. In health perspective policy emphasis the participation of Primary health care centers, Taluk hospitals, District hospitals and Medical colleges. Other dimension is the participation different system of medicine in the palliative care. The policy strongly proposes to utilize the three tier system of Local Self-Institution, especially the Village level. Collaboration with nongovernmental institutions and private organizations promoted to find sustainable resources to community based activities of the palliative care. Core of the policy is the collaboration between Community Based Organizations and local self-institutions. Allocation of special fund on the five year plan also proposed to sustain the activities of palliative care. Other source of proposed funding includes Directorate of Health Service, Panchayat Raj Institutions, National Health Programmes, and Employees State Insurance Schemes. The policy is committed to develop more community based palliative care centers with home care services in the state with active participation of CBOs, LSGIs and local government and other health care institutions.

### **Training and Capacity Building**

Policy has given considerable importance to the capacity building of those aspects that will be directly influence the palliative service delivery and patient's welfare. The most important aspect is the capacity building among the professionals and volunteers, who are engaged in palliative care service delivery, including doctors, nurses, social workers, pharmacists, health inspectors, physiotherapists and volunteers. Dealing with the emotions and stress of the palliative patients' needs specific skills and training, capacity building among the professionals can brings that. Another capacity building program is proposed for the Community Based Organizations as 95 percent of the palliative care service delivery in Kerala is dealt by the CBO's. The policy emphasized for the training and facilitation to empower community to share the care and support of people

needing palliative care by organizing human and financial resources that available locally.

The policy envisaged that training on the manpower resources yields a high output as a human resources and social capital are the pillars of community based interventions. Policy emphasis to conduct sensitization programs in pain relief and palliative care for 25% of all doctors, nurses and other health / social welfare workers in the state. Training for the nurses on theoretical and practical aspects of the palliative care intervention is another proposed dimension of the policy.

### **Drug Policy and Availability**

The availability of medicines, drugs and other equipment's are essential to cope up with the advanced stages of life. Many of the families are not affordable to have such life supporting equipment's and drugs. The policy emphasized the easy availability of medicines to the needy by relaxing the policies and including those palliative medicines in the essential list of medicines. Palliative Care policy (2008), mentioned that a palliative care program cannot exist unless it is based on a rational drug policy. Persons with incurable and other chronic illnesses need medicines for a prolonged period, which they may not be able to afford financially to the family of the patients. In many areas CBOs and NGOs are now providing medicines and other equipment's, which is not enough to cover the enormous needs in the state. The policy envisaged to make provisions for the availability of essential medicines for palliative care through palliative care units / Primary Health Centers/other government hospitals. Further the policy states that policy is committed to establish a palliative care service, with availability of essential drugs including oral morphine and with at least one trained doctor and trained nurse, in all government medical college hospitals in the state and in district hospitals in districts without Medical College.

### **Effects and Impacts of the Policy: An Analysis**

Remarkable changes happened on the palliative care delivery of Kerala during the last six years after the formulation of Palliative care policy in the year 2008. Palliative care policy has made a wide impact on enhancing the community based palliative care movement in Kerala. Government has taken possible effort to address the objectives of the policy in implementation level. Realization on economic and other scenario of the going palliative care movement of Kerala, government's initial concern was to solve such issues.

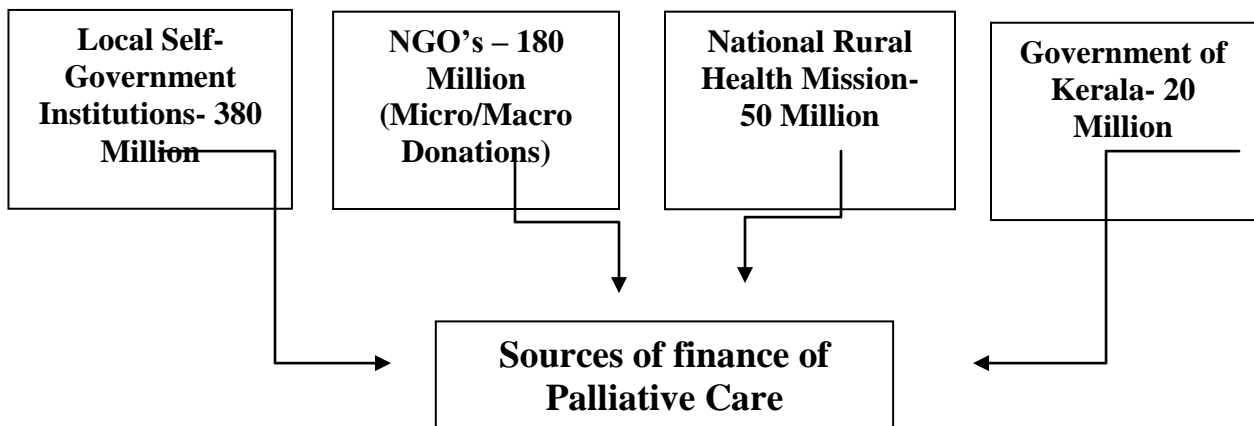
### **Expansion of Palliative Care Services**

As the vision of expansion of service delivery to the maximum population envisaged in the policy has achieved in a great extent and regional imbalances in the access of service palliative cares were solved significantly. Compared to the northern parts of Kerala, southern parts had less number and performance of palliative cares. Government has decided to start palliative cares in each *panchayats* of the state wherever palliative cares are not in existence and decided to extend support for the palliative centers that

are already working under nongovernmental organizations instead of establishing new one on such areas. Palliative cares are expanded its coverage in regard with population and areas of intervention. The traditional approaches of pain and symptoms management of palliative cares are expanded to areas including psychiatry, mental health and family welfare. As the effects of policy in the governmental level, a number of circulars are made by different government departments and agencies for making the provisions of support. Local Self-Department, health department and Kudumbasree are some of the example. Allocating fund for palliative care by Local Self-Government Institutions has been made mandatory by Government of Kerala in an official order issued in October 2012 in line with palliative care policy (E-hospice, 2013). By the end of 2013 around 1000 panchayats were started palliative care services. The coverage of palliative care has increased and automatically the need of essential drug also risen. Provisions were made to make available drugs that has widely used for the palliative care centers for pain reduces and symptom management. But its nit enough to the level and there is no remarkable changes happened in drug policy as envisaged in the palliative care policy.

### **Financial Resources**

Palliative care policy bought a large scale changes in the financing of palliative care centers. Before the implementation of the palliative care policy all the financial needs of the palliative care movement was met by the mobilization of community resources through micro/macro donations. Palliative policy expanded the collaboration and utilization of different organizations to mobilize the financial resources for the palliative care centers. Chart no 01 shows the major financial resources of the palliative care centers, it reveals that Local Self-Government Institutions are playing a vital role.



**Figure: 1**

### **Decentralization and Collaboration**

One of the innovative aspects of the palliative care policy is the decentralization of health care. As the results of the policy it became mandatory responsibility of the Local Self-government Institutions to provide palliative care services to the respective



geographical region. The involvement of LSGI's had a significant impact in relation with the maximization of the coverage of palliative services. Another important dimension needs to be discussed as the impact of the policy is the collaboration with different organizations like NRHM, Kudumbasree, Health departments and nongovernmental organizations. Government has initiated sustainable model of financial sources through social entrepreneurship also. Department of Social Welfare, Government of Kerala has initiated the production of different daily use materials in the brand name Pallium, palliative care patients and their family members are engaged in the production of this and gets benefited from this initiative.

### **Palliative Care education and Training**

Training and palliative care education was one of the important concerns of palliative care policy. Soon after the implementation of the policy government has started 16 centers across Kerala for imparting professional education and expertise in palliative care. The training offered at the Government training centers are.....

- Certificate Course in Community Nursing for 3 months.
- Basic Certificate Course in Palliative Nursing (BCCPN)
- Basic Certificate Course in Palliative Medicine (BCCPM)
- Special training program for ASHA workers in Palliative Care
- Need based training workshops are being conducted by Health department of Government of Kerala
- Training program for the volunteers.

There is a blue prints for starting a diploma or PG program for the special training and practice of palliative medicine. Different programs were organized as the part of sensitizing and disseminating the Kerala model of palliative care, Workshop on "Public Health Approach in Palliative Care- Kerala Experience" which was conducted in 2013 is an example. Community volunteers working in palliative care in Kerala organized state level meet in 2013 to assess palliative care programs and plan future strategies.

### **Discussion**

The critical analysis of the policy and its implementation status shows a number of prospects and limitations. As envisaged in the policy government has successful in strategizing and channelizing resources and other provision for the improvement of ongoing palliative care movement and initiate new centers under the local self-government institutions. But the number of palliative cares established under community based organizations and NGO's reduced significantly. Before the implementation of the palliative care policy in 2008 almost 98 percent of the palliative care movements are organized and completely funded by voluntary organizations. They used voluntarism as the main tool for initiating sustainable community based palliative care and economic resources are met through micro donations. The spirit of voluntarism and sustainability aspects cannot observe in the government owned palliative cares.

The efficacy of these palliative cares is poor while compared to the community based palliative cares. The total hours of services, number of people covered, community

participation, psychosocial interventions and holistic approaches are less in government sponsored palliative projects. There are significant structural and functional changes have happened in the delivery of palliative care services after the implementation of palliative care policy. The policy has limitations in implementation level in regard with the proposed relaxations of the drug policy. The community based palliative agencies are facing problem with the availability of the essentials drugs. Gayathri Palat and Chitra Venkateswaran (2012) observed that legal aspects related to the inclusion of oral morphine in the national and state level essential drug list and lack of enforcement of centralized opioid related regulations are affecting the service delivery of the palliative cares.

While comparing western models, community based palliative care model of Kerala and the implementation status of palliative care policy shows the absence of a trained doctor in the team of home care units. Anand (2013) in his study projects the aspirations of patients and family members for the inclusion of a medical practitioner in the palliative home care team. Further he states that there is wide lag in the training of allied staffs engaged in palliative cares. Palliative care policy had vision to set up specialized course on the medical and allied subjects still not achieved and it's the main reason that affects the availability of qualified professionals for palliative care service delivery. There are medical institutes which are providing specialized training on the palliative care for their students. Even with the limitations palliative cares in Kerala has contributing significantly to the public health of Kerala. The palliative care movement and palliative care policy is a promising milestone in the public health scenario and history of India. Many studies projects that palliative care's playing a vital role in the rise of health indicators of Kerala and subsequently it's considering as an influential factor in the so called Kerala Model of Development, in which health is an important indicator. In accordance to the Indian scenario palliative care and policy is an essential one in the national level but vibrant civil society, participation of community and voluntary sector is a mandate for the success of community based palliative. Therefore mere formulation of a policy in the national level without sensitizing the community, people and voluntary sector will be in vain.

### **Conclusion**

The palliative care policy initiated by Kerala Government is a key model for enhancing and sustains community based public health movement. The formulation of the policy is atypical example of how civil society organizations can make influence on policy formulation. Lobbying the common strategy used for influencing government is not used here, voluntary organizations showed it through the active interventions in the community and made the government to aware the needs of the palliative care for the section they are being addressed. Palliative care policy bought the collaboration of different levels of government and organizations with farsighted vision for a decentralized public health delivery. Decentralized health delivery is most essential for a country like India, which can deliver inclusive health. Community based health care movement which sensitize the community is most suitable approach for a country like

India to address the health care issues, not only for the patients who needs the care for terminal illness its having a wide applicability in other dimensions of health care too.

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