

# Pain and Palliative Care Services of General Hospital, Ernakulam: A Case Study based on Participatory Approach

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**Abstract:** *Palliative care giving in India, especially in the State of Kerala, is the need of with increasing life expectancy and rising number of non-communicable diseases including cancer. The Government of Kerala is the first State Government in India to adopt a pain and palliative care policy to facilitate community based home care initiatives. The pain and palliative care unit, attached to the General Hospital, Ernakulam, Kerala, India is one such initiative of the Government. The public health approach in palliative care is worth considering for research in Kerala with a growing elderly population.*

**Keywords:** General Hospital, Ernakulam, Pain and Palliative care unit, Need based home care, Palliative Care Patients

## 1. Introduction

In Kerala, the growing elderly population and an increase in non-communicable and debilitating diseases demand quality palliative care giving. Kerala, with only 2.7% of India's population (2011 Census) has more than two-thirds of the country's palliative care centres. The government of Kerala has been successful in initiating palliative care services with community participation for a large number of people. Kerala's attempts at caring for terminally ill patients have been regarded as a model for the rest of the world. The Government of Kerala's palliative care policy is in line with WHO's public health approach in palliative care. (2) The services are mainly as home care through the various government hospitals with active participation of the community and local self-government institutions. There are no studies conducted to see the working of Kerala model of palliative care offered through government hospitals. The Pain and Palliative care unit, attached to the General Hospital, Ernakulam, is an initiative of the Government. The present study aims to shed some light on the palliative service delivery of public health care system in Kerala.

## 2. Methodology

The area selected for the study was Ernakulam City, Kerala. The present study was undertaken with the main objective of studying the facilities and services provided by the pain and palliative unit of General Hospital. The palliative care unit of the hospital provides services to patients hailing from a few panchayats, municipalities and Kochi corporation areas of the district.

The information for the study was collected using interviews, participant and direct observation, and hospital records. A two-week participant observation was conducted to understand the functioning of need based home care provided by the unit. Thirty patients in need of palliative care were covered during this period. Through home visits, the investigator collected information by interviewing the palliative care team, carers and patients and by observing the

delivery of care. An interview cum observation schedule was used as the tool to gather information for the study.

## 3. Results and Discussion

The General Hospital is a 783-bed multi-specialty tertiary Government hospital situated in Ernakulam. The descriptive data collected is explained below.

### Location, Infrastructure and Staff:

The Pain and Palliative Care Unit is located in the ground floor attached to the General Hospital, easily accessible by road, and by boat services. The building has enough space, as the main activity of the centre is need based home care. The staff members consist of two medical officers, one co-ordinator, one staff nurse appointed by General Hospital, three staff nurses appointed by National Rural Health Mission (NRHM), two staff nurses appointed by hospital developmental committee, three drivers and around 50 actively working volunteers. They are leading need based home care in different panchayats, municipalities and corporation areas of Ernakulam.

### Intake of Palliative Care Patients and Financial assistance:

After registering the details of the patients with the unit, case sheets are filled in. Within 10 days of registration, the nurses, driver and volunteer conduct the first home visit to assess the condition of the patient. Based on that preliminary visit, they plan the treatment details and periodically record it on the case sheet. They further decide whether the patient needs the services of the doctor or not and also decide on the frequency of follow up. The patients are also referred by doctors, social workers etc.

The unit of palliative care is supported by the government as well as by donations received from the people. Cancer patients belonging to the lower socio economic background (up to Rs. 15000/month) are given free medicines, supported by NRHM.

The palliative care unit also generates funds through various training programmes. The NRHM provide financial support to the unit for different training programmes for government doctors and nurses. The private nurses and doctors who wish to join training programme pay a fee of Rs. 3000/- and Rs.5000/- respectively. The Kudumbasree supports the auxiliary nursing course.

**Programmes under the Palliative Care Unit:**

The palliative care unit of the General Hospital conducts the following activities. They are need based home care, training programme for doctors, nurses and volunteers engaged in palliative care, outpatient service, providing care in hospital wards (mainly cancer wards and also in the isolation ward), periodic review meetings etc.

**Need Based Home Care Services of the Pain Palliative Care Unit:**

Need based home care is the main activity of the palliative care unit. The team lead by nurses visit patient's houses and empowers the family in the care. Each team consists of a nurse, volunteer and a driver. The department of palliative care has a team of trained volunteers in and around Ernakulam who are the backbone of the activities. The volunteers of the areas where services are provided assist each home care. The frequency of visit depends upon the need of the patients. Thus the unit sees around 25 patients at their home, five days of the week. Through home care, the patients receive not only symptom control but also psychological and mental support. The volunteers or the nurses also instruct the patients and carers about the importance of complementary therapies like yoga, meditation etc. for relieving the stress, depression and anxiety. The palliative home care team also provides individualised rehabilitation strategies. They also provide bereavement care. The unit has three vehicles of their own for conducting home visits.

The quantitative assessment of home care from its inception on 2008 to 2012 are given in the Table 1

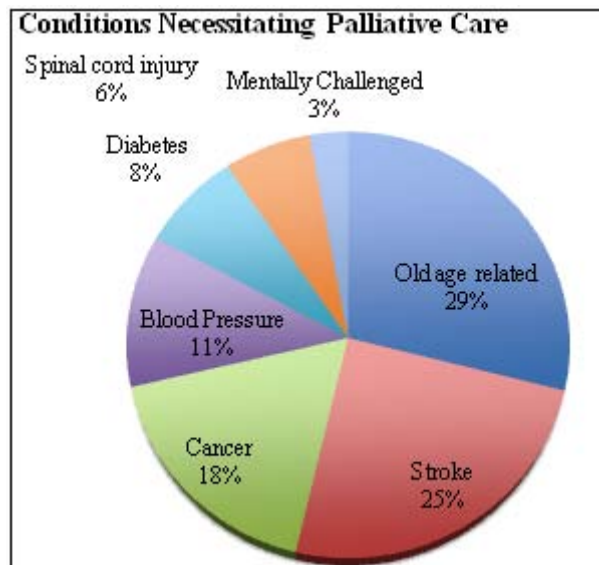
**Table 1: Quantitative Assessment of Home Care**

Year	No. of registrations	No. of home care	No. of patients in home care	No. of catheter
2008	1	3	3	2
2009	216	128	605	156
2010	444	219	1417	504
2011	697	371	2793	913
2012 till May 31	355	277	1648	441

Source: Hospital records

**Beneficiaries**

Two thousand four hundred and sixty two patients have registered in the unit for palliative care treatment since its inception, 380 patients were availing the services of home based care at the time of study in May, 2013. Many of these patients had many conditions necessitating palliative care, as illustrated in Figure 1. More than half of patients suffered from old-age-related problems and strokes.



**Figure 1: Conditions Necessitating Palliative Care (n = 380)**

Most of the patients are very poor who need support even for their daily living. The unit provides in-patient care under the oncology department. Also the unit looks after referred cases from other wards. Palliative care is also provided in the isolation ward for patients with communicable illnesses. At the time of study, in-patient care is given to 15 patients in the oncology ward of the hospital.

The information collected through home visits covering thirty patients is given under the following headings namely Age range of the patients, Gender of the patients and Duration of receiving palliative care services.

**Age range of the Palliative Care Patients**

The information on the age of patients collected as part of home care visits from thirty patients is given under Table 2.

**Table 2: Age Range of the Patients under study getting Palliative home Care Services**

Age Range (Years)	Total Number (N=30)	Percentage (%)
30-40	1	3
40-50	3	10
50-60	3	10
60-70	8	27
70-80	8	27
80-90	7	23

From the above table it is observed that over half of the people (54%) getting palliative care services were in the age group of 60-80 years.

**Gender of the Palliative Care Patients**

The gender of patients receiving palliative home care services are given under Table 3

**Table 3: Gender of the Palliative Care Patients**

Gender of the patient	Total Number (n=30)	Percentage (%)
Female	16	53
Male	14	47

From Table 3, it is clear that 53% were females and 47% were males. So there are almost an equal number of male and female patients.

Duration of receiving palliative care services: The duration of receiving palliative care by the patients is given under the Table 4

**Table 4:** Duration of Palliative Care Services availed

Duration	Total Number (n=30)	Percentage (%)
Less than 1 year	16	53
One year	6	20
Two years	5	17
More than 3 years	3	10

Table 4 shows that 67% of the patients were receiving palliative care services since less than one year, 20% of the patients were receiving palliative care services since one year. Only 7% of the patients were receiving palliative care services for two years or more.

### Impact Valuation

Impact evaluation aims to study the impact of the palliative home care services on the beneficiaries.

**Table 6:** Quantitative Assessment of Training conducted

Year	*BCCPM		**BCCPN		***BCPAN		****IAPC		
	No. of batches	No. of doctors	No. of batches	No. of nurses	No. of batches	No. of nurses	No. of batches	No. of doctors	No. of nurses
2009	1	6	2	17	2	17	2	19	22
2010	5	16	6	43	3	26	2	12	10
2011	3	25	5	33	3	25	2	20	5
2012	1	6	1	7	1	9	will start on 16/06/2012		

\* Basic Certificate Course in Palliative Medicine, \*\* in Palliative Nursing, \*\*\*in Palliative Auxiliary Nursing,\*\*\*\* Indian Association of Palliative care Certificate course in Essential in Palliative care  
 Source: Hospital Record

The quantitative assessment of outpatient service from 2010 to 2012 is given under Table 6.

**Table 7:** Quantitative Assessment of Outpatient Service

Year	No. of days	No. of patients
2010	26	337
2011	52	1231
2012 till May 31	21	651

Source: Hospital Records

**Provision of palliative care in the hospital wards:** In cancer ward, palliative care physicians and nurses" services are provided every day. References from other wards for palliative care are also seen and services are provided. The unit also provides services to patients of the isolation ward of the hospital.

**Conduct of seminars/workshops:** The department conducted a two day international workshop on "Public Health Approach in Palliative care: sharing Kerala experience", on the 12<sup>th</sup> and 13<sup>th</sup> February 2013, involving many members from different countries. Every last Tuesday of month, the palliative care unit conducts one-day workshop for doctors. Similarly every last Friday of the month the unit conducts, one-day workshop for nurses.

The degree of satisfaction experienced by the patients on the home care services of the unit are given in the Table 5

**Table 5:** Degree of Satisfaction of Palliative Care Patients with home care services

Degree of satisfaction	Total Number (N=30)	Percentage (%)
Very satisfied	22	73
Satisfied	8	27
Not Satisfied	-	-

From the table 5, it is clear that 73% of the patients are very satisfied with the palliative care services provided by the unit. And 27% responded that they are satisfied with the home care services.

### Training programme for doctors, nurses and volunteers engaged in palliative care:

The quantitative assessment of training conducted since the start of the unit is given under table 5 given below.

**Rehabilitation Services of the Unit:** The State Government organizes rehabilitation programmes for the paraplegia patients for promoting their self-employment skills. Fifteen patients form the hospital got the opportunity to learn the self-help employment skills. The palliative care unit of General Hospital under National Rural Health Mission (NRHM) organise rehabilitation camps where they learn to make products like soap powder, cleaning liquids, umbrellas etc. At the end of the camp, each participant was given raw material worth Rs.60, 000/- to begin his or her work. The paraplegic patients produce products like washing powder, umbrella, phenol, detergents etc. and the products are named „paliyam“. The paraplegic patients through an outlet situated inside in the palliative care unit sell the products. Thus the hospital serves as a marketing outlet to sell products made by the paraplegics.

The Palliative care unit of General hospital has qualified and dedicated staff and make use of the services of trained volunteers for home care. The study shows that half of palliative care patients are in the age group of 60-80 years, with more than half suffering from old age and stroke, where as a study by Santha (2011) found that 50% of the beneficiaries of palliative care services in Ernakulam district are cancer patients (1).With aging population of

Kerala increasing, the number of patients with debilitating illnesses growing steadily necessitates palliative care to be provided to increasing patients with life limiting illness. Recently Music therapy is introduced mainly for the patients of the hospital. For cancer patients in the ward, the hospital provides symptom management and also cares to the end of life of the cancer patients. Care and support are given to family members as stress among caregivers ultimately affects the quality of caregiving (4). The Impact evaluation aims to study the impact of the palliative care services on the beneficiaries. The degree of satisfaction experienced by the patients on the home care services of the unit has found that 73% of the patients are very satisfied with the home care services provided by the unit. The International workshop organised by the government, concluded with reflections on the replicability of the Kerala model by guests from outside the state and the country (3). A new project has been announced by the government of Kerala in 2014, which provides free cancer treatment for patients in the BPL group.

#### **4. Conclusion**

The palliative care unit of General hospital, Ernakulam is a good example of Kerala's successful model of community based palliative care involving volunteers from the local areas. The palliative care unit of General Hospital is doing a commendable work as the home based palliative care brings care to the door step of the patient, a place where people are most comfortable at the end of their lives. A large number of patients are found to be satisfied with the palliative home care services provided by the unit. The palliative care unit is the main centre for palliative care training in central Kerala. Emphasis needs to be directed to introducing complementary therapies to patients.

#### **5. Acknowledgements**

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