

Assessment of Status of Patients Receiving Palliative Home Care in A Rural Area in Kerala

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I. Introduction

Palliative care is defined 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 Palliative care is best administered by an interdisciplinary, multidimensional team comprising of doctors, nurses, counselors social workers and volunteers

Palliative care in India

It is estimated that in India the total number who need palliative care is likely to be 6 million people a year. ⁽¹⁾There is therefore a crucial need for a system of care at home that can best be built by a community based palliative care movement. Home based palliative care services are becoming increasingly popular with care being taken to the doorstep of the patient.

Palliative care in Kerala

Kerala has shown enormous progress in the field of palliative care(PC). ⁽³⁾ Most of the palliative care services are through the Neighbourhood Network of palliative care (NNPC). ⁽⁴⁾ Kerala is the only state in India where palliative care services are available in all the districts . Kerala's attempts for caring for the terminally ill has been a model for the world. The community palliative care projects of Northern Kerala and the NNPC -Neighbourhood Network in Palliative Care exemplify a solution to a worldwide problem how to achieve meaningful coverage and care for the terminally ill. They demonstrate the way to palliative care for all In India currently there are approximately 908 palliative care centres. More than 841 of these centres are in Kerala.

The NNPC - Neighbourhood network in palliative care is a volunteer driven organization.. Here the volunteers are the arms of the community . The patient and the family get regular support from the community around them. The NNPC- neighborhood network in palliative care caught the attention of the world in palliative care provision. ⁽⁴⁾ The volunteers in collaboration with governmental and non governmental agencies care for the terminally ill.

II. Materials and methods

The study was conducted by the seventh semester M.B.B.S. students during their community Medicine posting in September 2015 The study was conducted at Makkam grama panchayath. Makkam is a small village in Kunnamangalam taluk of Kozhikode district The population of Makkam is 30338 Men -15132 Females - 15206 Density -970/sq km Female : male ratio 1005 Totalliteracy rate- 91.7% Female literacy – 87.8% Male literacy rate - 95.6

Grace pain and palliative care clinic -Makkam

This clinic provides home based palliative care services , since 2006 in the panchayaths of Makkam, chathamangalam, and karassey. This centre provides home care to almost 200 patients at a time in these three panchayaths. The aim of home based care is ultimately to promote , restore and maintain a person's maximum level of comfort and function. This clinic has the services of a doctor, nurses and volunteers trained in palliative care . They provide home care on all 6 days a week. About 80% of palliative home care is provided by community based organizations or NGOs ⁽⁵⁾ in Kerala.

Study tools

A retrospective study was conducted by collecting information from baseline data at entry point, prospective case records, and nurse's diary notes of all patients of Mukkam panchayath enrolled in the year 2014 and received home based palliative care services.

The collected variables include demographic, medical, physical, psychological and social aspects of patients which indicate quality of life and the needs of patient's family, services provided by the team and its outcome.

Statistical analysis

Data was analysed using Microsoft Excel for Windows XP and analysed using SPSS 16.0

III. Results

During the year 2014, 31 patients were enrolled from Mukkam panchayath Age (table 1) ranged from 40 to 100 years with mean age of 67 years and SD 14.9 Sex - out of 31 patients 16 were females and 15 males Sex ratio -48:52 (1080 for 1000 males) Family - out of 31 cases studied 28(90%) are living in a joint family and the rest 3 {10%} live in a nuclear family Status - of the 31 patients 21(67.7%) are below poverty line and the rest 10(32%) are above poverty line Diagnosis- table 2 - out of the 31 cases studied most cases had geriatric related disease (42%) 40% suffer from degenerative disorders -coronary artery disease. MI, hemiplegia 6.6% have neoplasms - carcinoma breast and renal carcinoma Hypertension - out of the 31 cases studied 13 (41.9%) have hypertension and the rest have normal blood pressure Associated illness - out of the 31 cases 19 (61.2%) have lifestyle diseases as diabetes mellitus, hypertension and IHD 10 (32.2%) have respiratory disorders along with lifestyle diseases 2(6.6%) suffer from other associated illnesses. Complaints table 3 - out of the 31 patients pain was a complaint of all the patients. 32% had GIT CNS and respiratory symptoms in addition to pain. 10% have GIT and renal symptoms along with pain Current Medications - table four Chemotherapy - of the 31 patients 2 had received chemotherapy.

IV. Discussion

The goal of palliative care is to improve the quality of life of both patients and families, by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psychosocial and spiritual support. It is best administered by an interdisciplinary multidimensional team comprising of doctors, nurses, counselors and social workers. Kerala is the only state where palliative care services are available in all districts Kerala Model of palliative care is an example for the world The Neighbourhood Network of Palliative care programme is a volunteer driven programme that is well established in Kerala. There are 840 palliative care centres in Kerala. This study was conducted in September 2015 by the seventh semester students of 2012 batch during their community medicine posting. The patients enrolled during the year 2014 were studied. Details of the patients were collected from records at the Grace palliative care centre Mukkom. A similar study was conducted by Dr. Jayakrishnan and Jeeja (7) of the Calicut Medical college. Their study was conducted at Mavoor grama panchayath of Kozhikode district. Details of patients enrolled in the year 2010 and 2011 were collected and analysed. A comparison of the study conducted at Mavoor grama panchayath and Mukkom grama panchayath is given.

AGE In this study 65% of persons were in the age group of >60 years. In the study by Jayakrishnan and Jeeja 72% patients were in the age group > 60 years Enrollment -In this study 31 patients were enrolled during the year 2014. Mukkam panchayath has a population of 30,338. In that population at least one person requires palliative home care every year. In the study conducted by Dr Jayakrishnan in Mavoor panchayath which has a population of 30,961, on an average 51 patients were enrolled every year. At least 1.6 patients require palliative home care every year. According to the Kerala state policy for palliative care(5) there are at least 100 patients requiring palliative home care in a panchayath at a point of time. Sex ratio - In Mavoor the sex ratio was 40:60. In Mukkam the sex ratio was 48:52

Status - In Mavoor 46% were in the BPL category. In Mukkam 68% were in the BPL category. Symptoms - Pain - In this study all the patients complained of pain. In the study by Santha (8) it is stated that pain was a major physical symptom in all the patients. In the study by Jayakrishnan only 27% complained of pain.

Oedema - In this study 26% had oedema and in the Mavoor study 10.6% had oedema.

Weakness - In the study of patients of Mavoor panchayath 31.7% had weakness and in Mukkam panchayath study 42% had weakness

Urinary incontinence - In this study 26% had urinary incontinence. Pg9/15 In the Mavoor study 25% had urinary incontinence. Activity of Daily living - ADL- In this study 2 (6.4%) were bed ridden. In the study at Mavoor 25% were bedridden. In this study there was only one patient with pressure ulcer(3.2%). In the Mavoor

study 18% patients had pressure ulcers. **Diagnosis - Malignancy** - In the study at Mavoor panchayath 15.3% had malignancy and in the study at Mukkam panchayath 6.6% had malignancy

Degenerative diseases - In the study at Mavoor 36% had degenerative diseases and in Mukkam 38.7% had degenerative diseases.

Traumatic - In the study at Mavoor 8.7% had traumatic causes and in the study at Mukkam 6.4% had traumatic causes. **Associated illnesses** - In the Mavoor study 5.8% had diabetes and in the study at Mukkam 25.8% had diabetes.

Treatment - In the study at Mavoor 77% had received medical treatment .In the study at Mukkam 97% of patients had received medical treatment.

Catherisation - In the study at Mavoor 22% were catherised and in Mukkam 6.6% were catheterised. .

Medications - table four - all patients received some medicines . In a study by Unni and Eddasseri (9)90% of patients had received medicines.

V. conclusion

The service could address most of the medical, psychosocial and supportive needs of the patients and reduce their pain and symptoms. Kerala has shown enormous progress in the field of palliative care. Most of it is due to the

NNPC- Neighbourhood Network in palliative care. In this programme volunteers from the local community are trained to identify problems of the chronically ill in their area, and to intervene effectively , with active support from a network of trained professionals. It exemplifies a solution to a worldwide problem-how to achieve meaningful coverage and care for the terminally ill.

Conflict of interest - there is no conflict of interest in this study Ethical issues- this article has not been published earlier. There are no issues involved with patients Consent was obtained from the Grace pain and palliative care centre Mukkam

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Annexure

Table-1 - age in years

Age in years	number	percentage
Between 40 &50	4	12.9%
between 50& 60	7	22.5%
between 60& 70	8	25.8%
between 70& 80	4	12.9%
between 80& 90	6	19.3%
between 90& 100	2	6.4%

Table 2 - Diagnosis

Diagnosis	number	percentage
inflammatory diseases	2	6.4%
Degenerative	12	38.7%
Neoplasms	2	6.4%
Traumatic/musculoskeletal	2	6.4%
Diabetic	8	25.8%
Others	5	16.1%

Table 3- complaints

Complaints	Number	percentage
Pain	8	25.8%
Pain+GIT+RS+other symptoms	5	16.1%
Pain+renal+other symptoms	2	6.4%
Pain+CNS+renal+other symptoms	3	9.6%
Pain+GIT+CNS+resp symptoms	10	32.2%
Pain+GIT+renal+others	3	9.6%

Table 4 -Current Medications

Medications	number	percentage
CVS+oral hypoglycemic drugs	5	16.1%
Analgesics+HTN/cvs+antacids	12	38.7%
RS+oral hypoglycemic+analgesics	3	9.6%
Antimicrobials+analegics	5	16.1%
CNS+HTN/ CVS+antimicrobials	1	3.2%
Analgesics+CNS+GITdrugs	1	3.2%
Anticancer drugs	2	6.4%
Catheterisation	2	6.4%