

## NEED FOR PALLIATIVE CARE

N.K.Nikhil\*

Dr.Santha S.\*\*

### Abstract

#### Background

India, with a population of over a billion people, is a country of varying social, cultural and geographic characteristics. There are real problems in meeting the health care needs of such a large population, particularly, the poor in rural areas. Palliative Care represents an important resource in the completion of good medical care which can help to take the best care of patients and their families. The availability of palliative care is very limited in much of the world.

#### Aim

The current study has been undertaken to know the need for palliative care in Kerala.

#### Materials and Methods

For the purpose of study,30 respondents were selected as samples by adopting convenience sampling method. Analysis was done via statistical software 17.0. using statistical tools ,viz. Friedman repeated measures analysis of variance on ranks and percentages.

#### Results

The study revealed that most of the patients were suffering from the problems of old age and disability and could not avail palliative care service as they were unaware of palliative care service . The major physical problem suffered by the deceased patients before one year of their

\* M.Com(IV Sem) Student

\*\* Associate Professor in Commerce

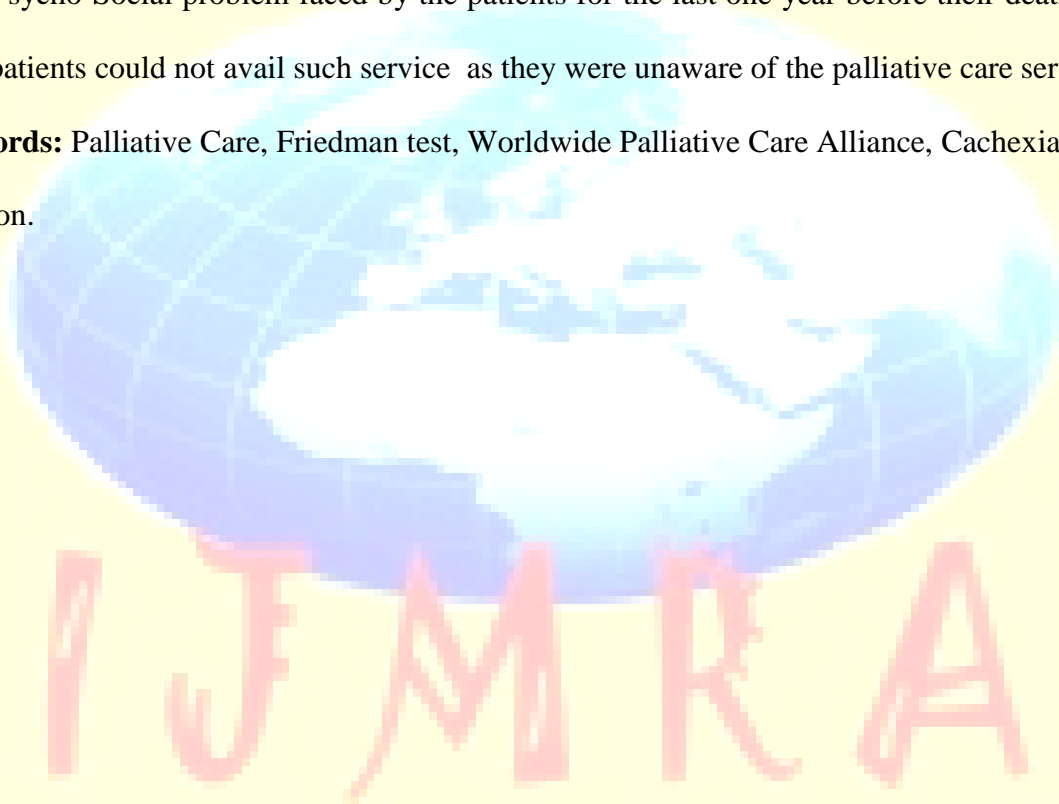
Post Graduate Department of Commerce and Research Centre, St. Peter's College, Kolenchery, Ernakulam, Dist., Kerala- 682 311,India

death was agitation and thereafter till their death was” Cachexia”. “Change in Faith and Beliefs” was the major Psycho-Social problem faced by the patients for the last one year before their death

### Conclusion

The major physical problem suffered by the deceased patients before one year of their death was agitation and thereafter till their death was” Cachexia”. “Change in Faith and Beliefs” was the major Psycho-Social problem faced by the patients for the last one year before their death. most of the patients could not avail such service as they were unaware of the palliative care service .

**Key words:** Palliative Care, Friedman test, Worldwide Palliative Care Alliance, Cachexia, Agitation.



## MANUSCRIPT

**Introduction**

In India ,though the Palliative care services began in 1993,several obstacles, viz. high density of population , poverty, geographical diversity, restrictive policies regarding opioid prescription, workforce development at base level, limited national palliative care policy and lack of institutional interest in palliative care etc. stood in the way of speedy growth of palliative care. Systematic and continuous education for medical staff is mandatory, and a major break-through for achieving this purpose would be to increase the number of courses and faculties in palliative medicine at most universities <sup>1</sup>. Palliative care provides total care to the patients with life-threatening illnesses which improve quality of life of patients and their families. The need for palliative care is projected to grow due to the aging of populations in many countries and the increasing prevalence of non-communicable diseases, such as heart disease, diabetes, dementia, and cancer<sup>2</sup>. Titty Jacob Cherian,Cherian Koshy and Rachel Cherian (2008)<sup>3</sup> “Help for the Hills-Tele-Link in Palliative Care Unique Opportunity Window in Supportive Care – A Preliminary Study”, discussed about the Tele palliative link which was established in Oct. 2007 through linking palliative care centre, Adimali and Regional Cancer Centre, Thiruvananthapuram for bridging the geographical distances in health care, improving patient care, enhancing training standardising clinical practice, stabilizing cost and uniting health care workers.

Venkateswaran, Venu, Marathakot and Kumar (2004)<sup>4</sup> stated that the aim of reaching out to large numbers led to the idea that communication skills training needs to be a non-specialist area. The resulting important innovation has been to train volunteers as trainers in communication skills.

Chaturvedi and Prabha Chandra<sup>5</sup> stated that while India has a long tradition of home-based spiritual and religious care of the dying, there has been no contemporary palliative care until relatively recently. They discussed about the existing and planned palliative care services in India and future perspectives and the opportunities for training for both professionals and lay volunteers.

Jeevy, Sebastian, Mappat, Koshy<sup>6</sup> stated in their study that the pain clinic at the Regional Cancer Centre, Trivandrum, Kerala, established with WHO subsidy in 1986, demonstrated that effective pain control could be achieved for outpatients and supported three major satellite units. Rajagopal and Suresh Kumar<sup>5</sup> stated in their study that the Calicut model became a WHO demonstration project as an example of high-quality, exible and low-cost palliative care delivery in the developing world and illustrating sound principles of co operation between government and NGOs. Franke and Chasin, (1992)<sup>7</sup> stated that the pain and symptom control clinics with satellite units seen in Kerala seemed a very appropriate model for reaching the maximum number of patients at minimum cost; however, Kerala was unusual in having the highest literacy rate and health indices in India.

### Significance of the study

India is country which is characterized by increasing number of aging population and prevalence of advanced cancer. It is estimated that one million new cases of cancer occur each year in India, with over 80% presenting at stage III and IV<sup>8</sup>. There is the immense and immediate need of palliative care in India. The study tries to draw a clear cut spread on the need of pain and palliative care for patients under acute suffering and to draw a clear foot prints of patients'

sufferings during different time frame of diseases keeping the study to the context of social, economical, and cultural frame work.

Palliative Care, a developing Specialty in India especially in Kerala need to be highlighted to the general public who are unaware of it. At the moment there are 925 Palliative Care Centres in India of which 840 are in Kerala<sup>9</sup>. The poor die in neglect because there is no one to look after them at the time of death, the middle class die in ignorance because they are unaware of it's benefits and they could pay for palliative care services if they were available but at the moment in a market health care system, there is no one selling palliative care as there is no one buying palliative care. The rich die in agony on a ventilator because there is no understanding of terminal care and prognosis and patients with very poor prognosis who are not appropriate for resuscitation end up on a ventilator with no benefit to them and considerable distress<sup>10</sup>.

### Scope of the study

The present study has been undertaken taken to analyse the need for palliative care in Kerala. The assessment has been made by considering the perception of the family members of the deceased patients (who died in 2014) .The list of deceased patients was prepared from the data base maintained by the public health dept of Chottanikkara Panchayat, Ernakulum District. in Ernakulum district. The respondents of the study include family members of the deceased patients.

### Objective of the study

The study tries to draw a framework on the need for pain and palliative care in Kerala to the context of social, physical, and Psycho-Social aspects.

### Hypotheses of the study

$H_{01}$  There is no significant difference in the nature of physical problems faced by the deceased patients for the last one year before their death.

$H_{02}$  There is no significant difference in the nature of Psycho-Social problems faced by the deceased patients for the last one year before their death.

### Selection of the sample

The analysis was made on the basis of the perceptions of the family members of the deceased patients. The list of deceased patients was prepared from the data base maintained by the public health dept of Chottanikkara Panchayat, Ernakulum District. A sample of 30 deceased Patients in Ward IX of Chottanikkara Panchayat whose death took place in 2014 was selected by adopting Convenience sampling method.

### Collection of data

The data for the study were collected from both primary and secondary sources. The primary data were collected from the family members of the deceased patients based on structured questionnaires. The secondary data were collected from reports, books and web sites.

### Tools of analysis

For the purpose of analysis, statistical tools like average, percentage and Freidman test were used. To study the need for palliative care relevant questionnaire was developed with 5 point scale. The analysis was made by using statistical techniques viz. Friedman repeated measures analysis of variance on ranks and percentages. The Friedman test is the non-parametric

alternative to the one-way ANOVA with repeated measures. It was used to compare the effect of a series of different experimental treatments on a single group. Each subject responses were ranked from smallest to largest without regard to other subjects and then rank sums for the treatments were compared.

### Period of Study

The survey was conducted during the period October 2014 to January 2015.

### Need for palliative Care -Analysis

76.7 % of patients died at the age of 60 years and above. 16.7 % died at the age of 50 to 60 years and only 6.9 % died at the age of 30 to 50 years (Table 1). Gender composition of deceased patients comprised of 53.3% males and 46.7 % females (Table 2). 70 % of the deceased patients belonged to General community and 3.3 % belonged to SC and ST community (Table 3).36.7 % of the deceased patients had five members in the family. It showed that the patients got the support of their family members at the time of death. Only 3.3 % patients had only two members in their family (Table 4). 36.7% patients had three male members in their family and 23.3 % had only one member in their family (Table 5). 36.7 % patients had two female members in their family and 13.4 % had more than 4 female members in their family (Table 6). As far the earning members in the family of the deceased patients concerned, all of them had at least one member as earning members (Table 7). 26.7% of the deceased patients were casual workers, 36.7 % of them were agriculturists and retired persons,13.3 % of them were Govt. employees and 20% of them were businessmen(Table 8).Most of the patients were suffering from the problems of old age and disability (57%) followed by cancer (20 %) (Table 9). The span of suffering for 50% of deceased patients was less than 6 months. 26.7% of them suffered for period of 6 to 12 months.



However 23% suffered for a period of more than one year (Table 10). 33.3% of the deceased patients could avail of palliative care services but 66.7 % of them did not get the service and they were not aware of the palliative care service (Table 11). 83.3 % of the deceased patients followed Allopathic medicine and 10% of them followed Ayurveda and 6% followed homeopathy (Table 12). 36.7 % of the deceased patients incurred an annual expenditure less than Rs. 1 lakh and 23.3% incurred an expenditure of Rs. 3 to 4 lakh and 6% incurred an expenditure of Rs.4 lakh and above (Table 13).63,3 % of the patients used own fund and 10 % depended on charitable institutions and borrowed fund for treatment(Table 13).

The analysis of the nature of physical problems faced by the deceased patients at different periods before their death revealed that the major physical problem faced by the deceased patients before one year of their death was agitation and the mean rank was 72.12. Thereafter, the major physical problem faced by the patients till their death was” Cachexia” with the mean rank of 72.05, 70.55, 69.98, and 65.72 for the period before 6 months, before 3 months, before 1 ½ months and last 2 weeks respectively(Table 15).

**H<sub>01</sub>** There is no significant difference in the nature of physical problems faced by the deceased patients for the last one year before their death.

One of the hypotheses of the study was that there is no significant difference in the nature of physical problems faced by the deceased patients for the last one year before their death. chi-square test results given in Table 15 revealed that there was a significant difference in the nature of physical problems faced by the deceased patients for the last one year before their death, since the p values (0.000) were less than 0.01. Therefore the **null hypothesis H<sub>01</sub> stating that there is no significant difference in the nature of physical problems faced by the deceased patients for the last one year before their death was rejected.**



“Change in Faith and Beliefs” was the major Psycho-Social problem faced by the patients for the last one year before their death and the mean rank for the periods- before 1 year, before 6 months, before 3 months, before 1 ½ months and last 2 weeks were 61.37, 63.63, 60.70, 59.12 and 58.07 respectively.

**H<sub>02</sub>** There is no significant difference in the nature of Psycho-Social problems faced by

the deceased patients for the last one year before their death.

One of the hypotheses of the study was that there is no significant difference in the nature of Psycho-Social problems faced by the deceased patients for the last one year before their death. Friedman chi-square test results given in Table 16 revealed that there is a significant difference in the nature of Psycho-Social problems faced by the deceased patients for the last one year before their death since the p values (0.000) were less than 0.01. Therefore the **null hypothesis H<sub>02</sub> stating that there is no significant difference in the nature of Psycho-Social problems faced by the deceased patients for the last one year before their death was rejected.**

### Conclusion

Most of the deceased patients did not get the service as they were not aware of the palliative care service. The major physical problem suffered by the deceased patients before one year of their death was agitation and thereafter till their death was “Cachexia”. “Change in Faith and Beliefs” was the major Psycho-Social problem faced by the patients for the last one year before their death.

### References

1. <http://ehealth.eletsonline.com/2013/10/need-to-strengthen-palliative-care-in-india/#sthash>.
2. <http://ehealth.eletsonline.com/2013/10/need-to-strengthen-palliative-care-in-india/#sthash>.
3. <http://ehealth.eletsonline.com/2013/10/need-to-strengthen-palliative-care-in-india/#sthash>.
4. Titty Jacob Cherian, Cherian Koshy and Rachel Cherian, “ Help for the Hills” -Tele-Link in Palliative Care Unique Opportunity Window in Supportve Care – A Preliminary Study”, Proceedings of XV International Conference of Indian Association of Palliative Care, Kochipallcon, India, Feb, 2008, p.212.
5. Venkateswaran C, Venu M, Marathakot G, Kumar TM. Psycho-Oncol 2004; 13:S1-S233 (S103).
6. Chaturvedi S. K. and Prabha S. Chandra, Department of Psychiatry, National Institute of Mental Health and Neurosciences, Bangalore, India, 1992 .
7. Jeevy G, Sebastian P, Mappat V, Koshy RC, unpublished study.
8. Rajagopal M.R, Suresh Kumar K, A model for delivery of palliative care in India, the Calicut Experiment., J Pall Care 1999; 15:44±9.
9. Franke R. W, Chasin B.H., Kerala State, India: radical reform as development. Int J Health Serv 1992; 22:139±56.

**Table 1 Age of Death of the Deceased Patients**

Age	Frequency	Percent
30-40	1	3.3
40-50	1	3.3
50-60	5	16.7
60 years and Above	23	76.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 2 Gender of the Deceased Patients**

Gender	Frequency	Percent
Male	16	53.3
Female	14	46.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data

**Table 3 Community of the Deceased Patients**

Community	Frequency	Percent
Gen	21	70.0
SC	1	3.3
OBC	2	6.7
Others	6	20.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data

**Table 4 No. of Members in the Family of the Deceased Patients**

No. of Members	Frequency	Percent
2	1	3.3
3	3	10.0
4	8	26.7
5	11	36.7
6	4	13.3
7	2	6.7
8	1	3.3
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 5 No. of Male Members in the Family of the Deceased Patients**

No. of Male Members	Frequency	Percent
1	7	23.3
2	9	30.0
3	11	36.7
4	3	10.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 6 No. of Female Members in the Family of the Deceased Patients**

No. of Female Members	Frequency	Percent
1	6	20.0
2	11	36.7
3	9	30.0
4	2	6.7
5	2	6.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 7 No. of Earning Members in the Family of the Deceased Patients**

No. of Earning Members	Frequency	Percent
1	14	46.7
2	13	43.3
3	3	10.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 8 Occupation of the Deceased Patients**

Occupation	Frequency	Percent
Private	1	3.3
Govt	4	13.3
Business	6	20.0
Casual worker	8	26.7
Others	11	36.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 9 Type of Disease Suffered by the Deceased Patients Causing Death**

Type of Disease	Frequency	percent
Cancer	6	20
Spinal Injuries	1	3
Problems of Old Age and Disability	17	57
Chronic Kidney Disease	2	6.6
Chronic Heart Disease	2	6.6
Chronic Liver Disease	2	6.6
<b>Total</b>	<b>30</b>	<b>100</b>

Source: primary data.

**Table 10 Span of Suffering of the Deceased Patients**

Span of Suffering	Frequency	Percent
Less than 6 Months	15	50.0
6 - 12 Months	8	26.7
12 - 18 Months	4	13.3
18 - 24 Months	3	10.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source : primary data.

**Table 11 Whether the Deceased Patient got Palliative Care**

Responses	Frequency	Percent
Yes	10	33.3
No	20	66.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 12 System of Medicine Predominantly Followed by the Deceased Patients**

System of Medicine	Frequency	Percent
Allopathy	25	83.3
Ayurveda	3	10.0
Homeopathy	2	6.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 13 Amount of Expenditure Incurred for the Treatment (Annual Average)**

Amount of Expenditure(Rs.)	Frequency	Percent
Less than 1 lakh	11	36.7
1-2 lakh	5	16.7
2-3 lakh	5	16.7
3-4 lakh	7	23.3
4 lakh and above	2	6.7
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 14 Sources of Fund for the Treatment**

Sources of Fund	Frequency	Percent
Own Fund	19	63.3
Borrowed Fund	1	3.3
Help from LSGs	1	3.3
Others	4	13.3
Own and Borrowed	2	6.7
Owned ,Borrowed & Charitable Institutions	3	10.0
<b>Total</b>	<b>30</b>	<b>100.0</b>

Source: primary data.

**Table 15 Physical Problems Suffered by the Deceased patients (Friedman Test)**

Physical problems	Before 1year	Before 6mths	Before 3mths	Before 1 ½ mths	Last 2weeks
	Mean Rank	Mean Rank	Mean Rank	Mean Rank	Mean Rank
Pain	49.98	48.28	43.36	43.07	42.07
Breathlessness	52.24	50.40	48.93	48.59	50.09
Fatigue	47.24	40.26	37.02	34.76	36.16
Drowsiness	45.79	40.93	38.50	38.50	38.50
Insomnia	53.88	46.50	44.17	44.45	42.14
Dyspnea	65.81	65.81	65.81	67.71	63.91
Dehydration	66.64	62.53	61.93	60.05	60.10
Constipation	68.17	60.97	58.48	56.17	56.10
Anorexia	62.21	60.88	56.72	51.43	53.93
Nausea	62.02	58.91	57.81	56.90	57.81



Vomiting	58.91	58.47	55.91	60.31	57.81
Disfigurements	61.02	58.09	55.29	56.03	58.07
Cachexia	70.76	<b>72.05</b>	<b>70.55</b>	<b>69.98</b>	<b>65.72</b>
Incontinence	68.21	67.19	61.38	60.41	57.86
Edema	66.40	54.41	50.95	46.88	44.00
Loss of function of limbs/Paralysis	66.74	58.17	52.47	48.98	47.84
Sleep Deprivation	59.29	44.59	36.84	31.62	34.45
Bed Sores	66.24	55.59	60.86	56.03	51.88
Loss of Mobility/ Dependency	56.76	47.55	39.50	37.22	34.17
Fungating Wounds	68.72	66.47	59.10	55.33	55.91
Agitation	<b>72.12</b>	63.36	61.81	60.83	58.48

Source: Primary data.

$X^2 = 642.094$  with 109 degrees of freedom significant at 1% level.

**Table 16 Psycho-Social problem Suffered by the Deceased patients (Friedman Test)**

	Before 1 year	Before 6 months	Before 3 months	Before 1 ½ months	Last 2 weeks
Psycho-Social problem	Mean Rank	Mean Rank	Mean Rank	Mean Rank	Mean Rank
Not Able to Stay in Job	56.48	50.12	49.82	47.80	47.67
Not Able to Fulfill Prior Role in the Family or Society	55.57	51.27	48.90	47.20	44.58
Not Able to be Active in the Society	54.45	52.33	52.97	50.48	48.45
Not Able to Keep Up Friendships	53.25	52.62	50.12	49.30	45.83
Anticipatory Bereavement	56.75	55.25	53.78	51.37	45.73
Lack of Social Safety	57.18	57.68	57.68	57.68	56.08
Fear	56.75	45.88	44.92	36.90	35.07
No Relatives Available for Help	12.75	12.75	12.75	12.75	12.75

loss of Social Roles	56.90	50.68	50.32	50.13	44.50
Social Isolation	58.10	54.40	55.00	52.80	48.15
Sadness	55.92	45.50	41.45	37.73	34.27
Depression	43.63	42.75	37.62	37.30	33.53
Anger	47.90	45.13	45.27	43.03	37.73
Neglect	57.30	59.03	58.03	52.08	52.97
Change in Faith and Beliefs	<b>61.37</b>	<b>63.63</b>	<b>60.70</b>	<b>59.12</b>	<b>58.07</b>
Financial Difficulties	55.62	47.97	48.52	45.47	44.02
Denial	56.18	47.67	43.52	39.85	31.63
Anxiety	56.83	44.37	41.78	36.88	34.83

Source: Primary data.

$\chi^2 = 761.781$  with 94 degrees of freedom significant at 1% level.

