

## PROBLEMS OF PAIN AND PALLIATIVE CARE PATIENTS IN KERALA

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### Abstract

#### Background

#### Aim

The main objective of the study is to analyze the problems of Pain and Palliative Care patients in Kerala.

#### Materials and Methods

The respondents of the study include Pain and Palliative care patients in the State of Kerala. The sample consisted of 871 patients comprising of 471 males and 400 females. The data collected were suitably classified and analyzed keeping in view the objectives of the study. For the purpose of analysis, statistical tools like averages, percentages, rank test and Pearson's Chi Square test were applied.

#### Results

It was found out that in Kerala palliative care services were availed by patients suffering from different type of diseases. The major physical problems faced by the patients were loss of mobility/ dependency and pain. Most of the patients followed allopathy system of medicine. Most of the patients irrespective of their age group got pain relief through pain and palliative care treatment. The major social problem faced by the patients was that they were not able to stay in their job .Huge medical expenditure was the major financial problem for the patients.

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## Conclusion

The major physical problems faced by the patients were loss of mobility/ dependency and pain. Most of the patients irrespective of their age group got pain relief through pain and palliative care treatment. The major social problem faced by the patients was that they were not able to stay in their job .Huge medical expenditure was the major financial problem for the patients.

**Key words:** osteoporosis – Arthritis, Pain and Palliative Care, Symptom Management, Curative treatment, Acquired Immunodeficiency Syndrome

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## Manuscript

### Introduction

Palliative care is interdisciplinary in its approach and encompasses the patient, the family, friends and the community in its scope. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. Palliative care becomes the focus of treatment to the patients who need support during regular medical treatment, whose condition has worsened beyond the possibility of cure, where the cure is not recommended due to other health concerns, and when the patient does not wish to pursue a cure. Through palliative care, the patient is kept pain free and the distressing symptoms are properly controlled regardless of the stage of the disease or the need for other therapies through symptom management and pain management. The individual's choices and decisions regarding care are given due importance and are analyzed and followed regularly. Palliative care will also offer help and support during the grieving process. The Marie Curie Memorial Foundation (1952)<sup>1</sup> published a survey report on end-of-life care of patients in U.K. in revealed appalling conditions of suffering and deprivation among many patients dying of cancer at home. Christ of Muller-Busch, Inge Andres and Thomas Jehser, (2003)<sup>2</sup>, in a study "Sedation in palliative care – a critical analysis of seven years experience", found out that sedation in the terminal or final phase of life played an increasing role in the management of intractable physical and psychological distress. Ethical concerns were raised by patients' requests and needs on the one hand, and the physicians' self-understanding on the other hand. Hence, ethically acceptable criteria and guidelines for the decision making were needed

with special regard to the nature of refractory and intolerable symptoms, patients' informed consent and personal needs, the goals and aims of medical sedation in end-of-life care. Sue Marsden,(2008)<sup>3</sup>,in a study ” The Place of Holistic Care in Symptom Management”, stated that symptom management needs to be viewed from the perspective of the whole person and a person's total suffering which would help to manage the dying patient holistically. Excellence in symptom management was a corner stone of palliative care.

### Significance of the Study

Palliative care patients have breakthrough pain in addition to their chronic pain. The main aim of pain and palliative care is to avoid needless suffering of the people with terminal illness and to improve the quality of life by addressing all elements of suffering. Cicely Saunders, founder of the modern hospice movement, conceptualised 'suffering' as "total pain" having four elements and identified the elements as physical, psychological, social and spiritual pain. Palliative care satisfies following needs of the patients, viz., physical, psychological, financial, social and spiritual needs. Palliative care offers best possible quality of life not only to patients but also to their families throughout the trajectory of illness care, death and bereavement. Well-rounded Palliative care programs also address mental health and spiritual needs. With rapid urbanization and change in the family structure from joint family to nuclear family, there is an urgent need for the policy makers to focus their attention on developing adequate and appropriate resources that will support families of patients with chronic illness and integrating the principle of palliative medicine into the main stream of medical education, training and practice in order to provide its benefits to all patients suffering from life-threatening illness. Pain and Palliative care is a wonderful social movement which is gaining momentum across the villages of Kerala. This movement has only limited coverage in India as well as in Kerala. In India as well as in Kerala these services are available at present only to a few needy patients (2% in India and 30% in Kerala). In order to contribute meaningfully to the enhancement of the quality of life of the patients with terminal illness, a scientific identification and investigation of the units and patients is a must. Moreover, the review of earlier literature revealed that most of the studies in palliative care have been conducted in the field of medical science. No study has so far been conducted for

analyzing the status of pain and palliative care patients. In this context, the present topic entitled “Problems of Pain and Palliative Care Patients in Kerala” assumes greater importance.

### Scope of the study

The present study has been undertaken to analyze the problems of the Pain and Palliative Care patients in Kerala. The study is confined to palliative care patients in the selected districts of State of Kerala.

### Objective of the Study

The main objective of the study is to analyze the problems of pain and palliative care patients in Kerala.

### Hypotheses of the Study

**H<sub>01</sub>** There is no association between age of the patients and the system of medicines followed by them in Kerala.

**H<sub>02</sub>** There is no association between association between age of pain and palliative care patients and their pain relief through palliative care treatment in Kerala.

### Selection of Sample

The respondents of the study include Pain and Palliative care patients in the State of Kerala. The Pain and Palliative care units and rendering Pain and Palliative care services have been selected from the data base maintained by the Institute of Palliative Medicine, Kozhikode, Kerala and Consortium of Pain and Palliative care units in Ernakulam District. The Pain and Palliative care patients have been selected from the data base maintained by the Pain and Palliative care units of the districts selected as sample for the purpose of the study.

## Selection of Pain and Palliative Patients

Pain and Palliative Patients have been selected from the records of Pain and Palliative care units functioning in the three districts earmarked for the intensive study. There were in all 8705 Pain and Palliative patients in 55 units. A sample of 10 % was selected at random from each unit functioning in the selected districts for the purpose of study. The patients include both males and females. Thus the total sample has come to 871 patients.

### Collection of Data

The data required for the study were collected from both primary and secondary sources. The primary data were collected from the respondents based on structured questionnaire. The secondary data were collected from reports, books and journals published by the Consortium of Pain and Palliative care Units in Ernakulam District. Institute of Palliative Medicine and from various web sites.

### Tools of Analysis

The data collected were suitably classified and analyzed keeping in view the objective of the study. For the purpose of analysis, statistical tools like percentages, rank test and Karl Pearson Chi Square test were used. For the rank data weighted average method was used to obtain the rank. Weighted mean is calculated and these means are ranked in order of magnitude from highest to lowest. To study the Problems of Pain and Palliative Care volunteers in Kerala the relevant questions were asked in five point scale and are scored in the order of magnitude from 5 to 1 for positive questions and 1 to 5 for negative questions. Overall score of each respondent was found out and which form the basis for comparison. To test the hypothesis that two attributes are associated or not we used the Chi-square test for independence.

### Period of the Study

The study covers a period of two years (1<sup>st</sup> May 2009 – 30<sup>th</sup> April 2011).

### Problems of Pain and Palliative Care Patients in Kerala- Analysis

The majority of the patients (59.9%) under palliative care treatment were of the age group of 50 years and above (Table 1). Most of the palliative care patients (54.1%) were males. This revealed that in Kerala, males needed more palliative care than females (Table 2). 59.5% of the patients belonged to other backward community. It was understood that in Kerala, palliative care services were availed mainly by OBC category (Table 3). 77.2% of the patients were married. In Kerala, Palliative care services were mainly provided to patients having dependents (Table 4). 27.2% of the beneficiaries of palliative care services were cancer patients, 22% were patients suffering from old age problems, 14.1% were suffering from other problems and 9.9% of them had stroke and 9.6% were patients who met with severe accidents. It was found out that in Kerala, palliative care services were availed by patients suffering from different type of diseases (Table 5). The major physical problems faced by the patients were loss of mobility/ dependency and pain which they ranked as first and second respectively (Table 6). The study revealed that 61.5% of the patients were suffering from various diseases for a period of 24 months and more and 19.9% of them were suffering for a period of 12 to 18 months (Table 7). 74.7% of the patients followed allopathy system of medicine, 8.5% followed ayurveda and only 2.5% of them followed homeopathy (Table 8). All the patients in the age group of below 20 years, 36.6% of them in the age group of 20 to 30 years, 55% of them in the age group of 30 to 40 years, 77.6% of them in the age group of 40 to 50 years, 99.2% of the patients in the age group of 50 to 60 years and 75.1% of the patients in the age group of 60 years and above followed allopathy system of medicine. 10% of the patients in the age group of 30 to 40 years, 3.9% of them in the age group of 40 to 50 years and 15.4% of the patients in the age group of 60 years and above followed ayurveda system of medicine. 14.6% of them in the age group of 20 to 30 years and 2.6% of the patients in the age group of 60 years and above followed homeopathy. The Chi-square test result showed that there was significant association between age of the patients and the system of medicines followed by them, since the calculated value of  $\chi^2$  (131.354) was greater than the tabulated value (16.81) at 1% level with 6 d.f. (Table 9). **Therefore, the null hypothesis  $H_0$  stating that there is no association between age of the patients and the system of medicines followed by them in Kerala stands rejected.**

Most of the patients irrespective of their age group got pain relief through pain and palliative care treatment. However, the Chi-square test result showed that there was significant association between age of the patients and their pain relief through treatment, since the calculated value of  $\chi^2$  (16.720) was greater than the tabulated value (13.28) at 1% level with 4 d.f. (Table 10 ). **Therefore, the null hypothesis  $H_{01}$  stating that there is no association between age of pain and palliative care patients and their pain relief through palliative care treatment in Kerala is rejected.**

41.6% of the patients had undergone palliative care treatment for a period of 6 to 12 months and 21.2 % of them were under palliative care treatment for a period of 24 months and more (Table 11).

Palliative care included different type of care. Social care was one of such cares provided to the patients to solve their social problems. The major social problem faced by the pain and palliative care patients was “Not able to stay in my job /go to school” and the second major problem faced by them was ‘Social isolation’. ‘Not able to fulfill my prior role in the family/society’ was ranked as third (Table 12). Palliative care included financial care which would help the patients to solve their various financial problems viz., poverty due to absence of income earning member, huge medical expenditure, children dropped out of school, intractable debt, family member gave up work due to illness etc. It was revealed from the study that huge medical expenditure was the major financial problem faced by the patients followed by ‘poverty due to absence of income earning member’ which was ranked as second. (Table 13).

### Conclusion

It was found out that in Kerala palliative care services were availed by patients suffering from different type of diseases. The major physical problems faced by the patients were loss of mobility/ dependency and pain. Most of the patients followed allopathy system of medicine. Most of the patients irrespective of their age group got pain relief through pain and palliative care treatment. The major social problem faced by the patients was that they were not able to stay in their job .Huge medical expenditure was the major financial problem for the patients.

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**Table 1 Age- Wise Classification of Palliative Care Patients**

Age Group	Frequency	Percentage
Below 10 years	4	.5
10-20	32	3.7
20-30	82	9.4
30-40	80	9.2
40-50	152	17.5
50-60	132	15.2
60 years and above	389	44.7
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.



**Table 2 Sex -Wise Classification of Palliative Care Patients**

Sex	Frequency	Percentage
Male	471	54.1
Female	400	45.9
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 3 Community of Palliative Care Patients**

Community	Frequency	Percentage
GEN	320	36.7
SC	20	2.3
ST	13	1.5
OBC	518	59.5
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 4 Marital Status of Palliative Care Patients**

Marital Status	Frequency	Percentage
Married	672	77.2
Unmarried	182	20.9
Divorce	5	.6
Widow/Widower	12	1.4
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 5 Type of Disease Suffered by the Palliative Care Patients**

Type of Disease	Frequency	Percentage
Cancer	237	27.2
Vertebral injury	82	9.4
Aids	16	1.8
Stroke	86	9.9
Old age problems	192	22.0
Mental problem	16	1.8
Chronic heart diseases	14	1.6
Chronic kidney problems	6	.7
Brain disease	9	1.0
Accidents	84	9.6
Acute liver problems	4	.5
Bone- joint arthritis	2	.2
Others	123	14.1
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 6 Type of Physical Problems Faced by the Patients**

Physical problem	Mean	Rank
Pain	21.4770	2
Breathlessness	20.0677	10

<b>Fatigue</b>	<b>19.6015</b>	<b>16</b>
<b>Drowsiness</b>	<b>19.64</b>	<b>15</b>
<b>Insomnia</b>	<b>20.327</b>	<b>9</b>
<b>Dehydration</b>	<b>18.54</b>	<b>20</b>
<b>Constipation</b>	<b>19.8266</b>	<b>11</b>
<b>Anorexia</b>	<b>19.2391</b>	<b>18</b>
<b>Nausea</b>	<b>18.76</b>	<b>19</b>
<b>Physical losses</b>	<b>18.0000</b>	<b>21</b>
<b>Edema</b>	<b>20.92</b>	<b>4</b>
<b>Incontinence</b>	<b>20.6620</b>	<b>6</b>
<b>Loss of Function</b>	<b>21.36</b>	<b>3</b>
<b>Vomiting</b>	<b>19.7714</b>	<b>12</b>
<b>Bed sores</b>	<b>19.65</b>	<b>14</b>
<b>Loss of Mobility/ Dependency</b>	<b>21.65</b>	<b>1</b>
<b>Fumigating wounds</b>	<b>20.54</b>	<b>8</b>
<b>Disfigurement</b>	<b>20.76</b>	<b>5</b>
<b>Difficult to Swallow</b>	<b>19.6000</b>	<b>17</b>
<b>Itching</b>	<b>19.67</b>	<b>13</b>
<b>Others</b>	<b>20.6471</b>	<b>7</b>

Source: Primary data.

**Table 7 Period of Sufferings on Account of Disease by the Patients**

Period of sufferings	Frequency	Percentage
Less than 6 months	73	8.4
6-12 months	78	9.0
12-18 months	173	19.9
18-24 months	11	1.3
24 months and more	536	61.5
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 8 System of Medicines Followed by the Patients**

Medicines	Frequency	Percentage
Allopathy	651	74.7
Ayurveda	74	8.5
Homeopathy	22	2.5
Others	124	14.3
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 9 Age of the Patients and System of Medicines Followed**

(Chi- Square Test)

Age	System of Medicines Followed					
		allopathy	ayurveda	homeopathy	others	Total
Below 10 years	Count	4	0	0	0	4
	% within Age	100%	.0%	.0%	.0%	100%
10-20	Count	32	0	0	0	32
	% within Age	100%	.0%	.0%	.0%	100%
20-30	Count	30	0	12	40	82
	% within Age	36.6%	.0%	14.6%	48.8%	100%
30-40	Count	44	8	0	28	80
	% within Age	55.0%	10.0%	.0%	35.0%	100%
40-50	Count	118	6	0	28	152
	% within Age	77.6%	3.9%	.0%	18.4%	100%
50-60	Count	131	0	0	1	132
	% within Age	99.2%	.0%	.0%	.8%	100%
60 years & Above	Count	292	60	10	27	389
	% within Age	75.1%	15.4%	2.6%	6.9%	100%
Total	Count	651	74	22	124	871
	% within Age	74.7%	8.5%	2.5%	14.2%	100%

Source: Primary data.

$\chi^2 = 131.354$  with 6 degrees of freedom. Significant at 1% level

Table 10 Age of the Patients and Pain Relief (Chi-Square Test)

Age	Pain Relief			
		Yes	No	Total
Below 10 years	Count	4	0	4
	% within Age	100%	.0%	100%
10-20	Count	32	0	32
	% within Age	100%	.0%	100%
20-30	Count	69	13	82
	% within Age	84.1%	15.9%	100%
30-40	Count	80	0	80
	% within Age	100%	.0%	100%
40-50	Count	131	21	152
	% within Age	86.2%	13.8%	100%
50-60	Count	111	21	132
	% within Age	84.1%	15.9%	100%
60 years & Above	Count	339	50	389
	% within Age	87.1%	12.9%	100%
Total	Count	766	105	871
	% within Age	87.9%	12.1%	100%

Source: Primary data.

$\chi^2 = 16.720$  with 4 degrees of freedom. Significant at 1% level

**Table 11 Length of Palliative Care Treatment of the Patients**

Period	Frequency	Percentage
Less than 6 months	170	19.5
6-12 months	362	41.6
12-18 months	118	13.5
18-24 months	36	4.1
24 months and more	185	21.2
<b>Total</b>	<b>871</b>	<b>100</b>

Source: Primary data.

**Table 12 Type of Social Problem Faced by the Patients**

Type of Social Problem	Mean	Rank
Not able to stay in my job /go to school	16.7285	1
Social isolation	15.8696	2
Not able to fulfill my prior role in the family/society	15.1274	3
Sadness	14.6924	4
Not able to be active in the society/community	13.7540	7
Depression	14.2159	6
Not able to keep up friendships	12.7176	8
Anger	12.37	12
Anticipatory bereavement	14.41	5
Lack of social safety	11.3217	13
Fear	12.71	9

No relatives available for help	12.9529	6
Neglect	12.5427	10
Change in faith/ beliefs	12.50	11

Source: Primary data.

**Table 13 Type of Financial Problems Faced by the Patients**

Type of Financial Problems	Mean	Rank
Poverty due to absence of income earning member	5.4030	2
Huge medical expenditure	5.7205	1
Children dropped out of school	4.64	4
Intractable debt	4.8484	3
Family member gave up work due to illness	4.3388	5

Source: Primary data.