

CHARACTERISTICS OF PAIN AND PALLIATIVE CARE IN KERALA

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Abstract

Background

Aim

The main objective of the study is to study the characteristics of Pain and Palliative Care 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

Prescribing medicines was the major physical care provided by the doctors both to male and female patients. The major physical care provided by the nurses to male patients included 'attending to the bed sore' and 'changing clothes'. 'Giving medicines' was the major physical care provided by the nurses to female patients. The major physical care provided by the volunteers to male patients included 'bathing' and 'Changing clothes'. For female patients, the

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major physical care given by the volunteers was 'giving medicines'. Most of the male and female patients opined that they did not require any service other than those provided by the units and said that palliative care service was absolutely essential for the society.

Key words: Kruskal –Wallis Test, Pain and Palliative Care, Chi square test , Palliative medicine, Psychological boost.

Manuscript

Introduction

Palliative care is offered through a formal palliative care program or through a variety of other avenues. Palliative care can be provided in the person's own home, from a community-based palliative care service or a community nurse, at a specialist in-patient hospice unit, or at some other health facility, depending on where the patient is living, and where they choose to die. Palliative care is also available in many residential aged care facilities. Regional consultancy services provide advice and assistance to the patient and his/her family through a range of palliative care specialists. Specialized palliative care programs and specialized care giving are needed for diseases like cancer , AIDS , organic changes in the brain lead to coma or dementia. Palliative care services can support a patient through a local General Practitioner or specialist physician. Palliative medicine offers a model of care that is based on control of the disease and its symptom (psycho-social and spiritual support symptoms) are systematically evaluated and addressed by simple interventions where possible. Palliative care services are committed to caring for everyone regardless of their race, culture, background, and religion or belief system. Billings and Block, (1997)¹, in their study "Palliative care in undergraduate medical education, Status report and future directions", the study concluded that the increasing attention to palliative

care education had created major opportunities for improving education about care at the end of life. It is recommended that educational programs should be rigorously evaluated to identify best educational practices.

Heller, Wegleitner, (2006)², in their study stated that the main elements of palliative care were not simply seen as an end in itself, but also impact upon the quality of the process. Collective thought, learning, and cognitive production processes function as the premise for organizational and regional development.

Willke , Helmut (1989)³,in their study stated that organizations are, by nature, highly complex and restricted social structures that follow an inner logic. All efforts for change must therefore be introduced gradually to the regionally specific environments and to the inner workings of such organizations.

Significance of the Study

In most countries, hospice and palliative care is provided by a net work of agencies consisting of doctors, registered nurses, nursing assistants, social workers, psychologists, physiotherapists, dieticians and allied health personnel, volunteers, and most important, the family to cover all aspects of care. Teamwork becomes crucial for providing total care to the patients. The different skills and support are united when the team members work together. Each member is important in his or her own way, and good communication between team members is crucial. The palliative care team provides: expert treatment of pain and other symptoms ,close, clear communication ,help navigating the healthcare system ,guidance with difficult and complex treatment choices ,detailed practical information and assistance and emotional and spiritual support for the patient and his/her family^{2,3}. The main goal of Palliative care is enhancing

quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs and culture(s). 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 features of patients on pain and palliative care services. In this context, the present topic entitled “Characteristics of Pain and Palliative care in Kerala” assumes greater importance.

Scope of the study

The present study has been undertaken to analyze the characteristics of pain and palliative care service 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 analyse the characteristics of pain and palliative care service provided to patients in Kerala

Hypotheses of the Study

H₀₁ There is no association between gender of the patients and the type of care received.

H₀₂ There is no association between gender of the patients and the type of home care received.

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

For the purpose of analysis, statistical tools like percentages, rank test, Karl Pearson Chi Square test and Kruskal –Wallis 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 type of care provided 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. Kruskal –Wallis Test is a **non-parametric** method for testing whether samples originate from the same distribution. It is used for comparing more than two samples that are independent, or not related.

Period of the Study

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

Characteristics of Pain and Palliative Care in Kerala-Analysis

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychological and spiritual”(Cecilia Sepúlveda2002). Palliative care may be provided at any time during a person’s illness along with curative therapies meant to prolong life, even from the time of diagnosis.

In this chapter an analysis of the characteristics of pain and palliative care in Kerala has been made.

The study found that 61.1% of male patients and 72.8% of female patients received home based care and 28.5% of male patients and 12.5 % of female patients received institution based care. However, 10.4% of male patients and 14.8% of female patients received both home based and institution based care (Table 1).Chi square test result (Table 1) revealed that there was a significant association between gender of the patients and the type of care received, since the calculated value of χ^2 (33.726) was greater than tabulated value(9.21) at 1% level with 2 d.f.

Therefore, the null hypothesis H_{01} stating that there is no association between gender of the Pain and Palliative care patients and the type of care received is rejected. Home based care could be either hospital pain clinic or community based care. Following table threw light on the type of care received by the patients. 34.8% of male patients and 23.8%of female patients received community based care and 65.2% of male patients and 76.3 %of female patients received hospital pain clinic care(Table 2). Chi square test result ((Table 2) revealed that there was a significant association between gender of the patients and the type of home care received, since the calculated value of χ^2 (12.685) is greater than tabulated value(6.63) at 1% level with 1

d.f. Therefore, the null hypothesis H_0 stating that there is no association between gender of the Pain and Palliative care patients and the type of home care received is rejected.

Doctors provided different type of physical care to the patients viz. prescribing medicines, exercises and aids, touch & closeness discussion between me and family members etc. Prescribing medicines was the major physical care provided by the doctors both to male and female patients. The second physical care provided to male patients was exercises and aids where as it was 'touch and closeness' to female patients (Table 3).Kruskal –Wallis Test (Table 4) revealed that there was a significant association between gender of the patients and the physical care viz., exercises and aids provided by doctors, since p value was less than .01.However, there was no significant association between gender and physical care provided by doctors viz., touch and closeness, medicines, and discussion between me and family, since p value is greater than .01. Different type of physical cares viz., attending to the bed sore, changing clothes, giving medicines, dressing the wounds, changing the “condom catheter”, training the family members in simple nursing tasks etc. were provided by the nurse. The major physical care provided by the nurses to male patients included 'attending to the bed sore' and 'changing clothes'. 'Giving medicines' was the major physical care provided by the nurses to female patients. The second physical care provided to male patients was 'giving medicines' where as it was 'Changing the “condom catheter ‘of female patients(Table 5).Kruskal –Wallis Test (Table 6) revealed that there was a significant association between gender of the patients and the type of physical care provided by nurses viz., attending to the bed sore and training the family members in simple nursing tasks by nurses, since p values were less than .01.However, there was no significant association between gender and physical care provided by nurses viz., changing clothes, condom catheter, giving medicines and dressing the wounds, since p values were greater than

.01. Volunteers, in most cases, rendered the same type of physical care which was usually provided by the nurses viz., bathing, attending to the bed sore, changing clothes, giving medicines, dressing the wounds, changing the “condom catheter”, training the family members in simple nursing tasks etc. It was understood that the major physical care provided by the volunteers to male patients included ‘bathing’ and ‘Changing clothes’. The second physical care provided to them was ‘giving medicines’. For female patients, the major physical care given by the volunteers was ‘giving medicines’. Second, they attended to the bed sores of female patients (Table 7). Kruskal –Wallis Test (Table 8) revealed that there was a significant association between gender of the patients and the physical care viz., attending to the bed sore and dressing the wounds, since p values were less than .01. However, there was no significant association between gender and the type of physical care provided by volunteers viz., bathing, changing clothes, condom catheter and training the family members in simple nursing tasks by nurses, giving medicines and, since p values were greater than .01. The major psychological care provided by the volunteers (Table 9) to both male and female patients was ‘chatting with the patients’. Sharing of problems with patients and the family counselling’ was the second psychological care provided to male patients. For female patients, volunteers listened to the sorrows and fears of the patients.

The Kruskal –Wallis Test (Table 10) revealed that there was a significant association between gender of the patients and the type of psychological care provided by volunteers viz., chatting with the patients, listening the sorrows and fears of patients and sharing of problems with patients and the family counseling, since p values were less than .01. However, there was no significant association between age and psychological care provided by volunteers viz., listening to the concerns of the family members, since p value was greater than .01. The major financial

care provided by the volunteers (Table 11) to both male and female patients was 'Supply medicines at free of cost'. 'Supply rice and provisions for the family' was the second financial care provided to both. The major spiritual care provided by the volunteers (Table 12) to both male and female patients was 'Love and affection'. 'Psychological boost' was the second spiritual care provided to both. The Kruskal –Wallis Test (Table 13) revealed that there was a significant association between gender of the patients and the spiritual care provided by volunteers viz., psychological boost and helped to establish /re-establish a sense of meaning , since p values were less than .01. However, there was no significant association between gender and spiritual care provided by volunteers viz., encourage to reminisce with family and friends , prepare advance directives, love and affection assisting with life closure and fulfilling the wishes , since p values were greater than .01. An enquiry was made among the patients to know whether the patients required any services other than those provided by the units. 90.9% of male patients and 87.5% of female patients opined that they did not require any service other than those provided by the units. But 9.1 % of male patients and 12.5% of female patients opined that they required services other than those provided by the units (Table 14). Chi-square test result (Table 14) revealed that there was no significant association between the age of the patients and their need for other services not provided by the units, since the calculated value of χ^2 (22.290) was greater than the tabulated value (13.28) at 1% level with 4 d.f. 85.6% of male and 84% female patients opined that palliative care service was absolutely essential for the society, whereas, 14.4% of male and 16% female patients opined that these services were essential to the society (Table 15). Chi-square result (Table 15) revealed that there was no significant difference in the opinion about the need for palliative care in the society among male and female patients,

since the calculated value of χ^2 (0.411) was less than the tabulated value (6.63) at 1% level with 1 d.f.

Conclusion

Prescribing medicines was the major physical care provided by the doctors both to male and female patients. The second physical care provided to male patients was exercises and aids where as it was 'touch and closeness' to female patients. The major physical care provided by the nurses to male patients included 'attending to the bed sore' and 'changing clothes'. 'Giving medicines' was the major physical care provided by the nurses to female patients. The major physical care provided by the volunteers to male patients included 'bathing' and 'Changing clothes'. For female patients, the major physical care given by the volunteers was 'giving medicines'. The major psychological care provided by them to both male and female patients was 'chatting with the patients'. Sharing of problems with patients and the family counselling' was the second psychological care provided to male patients. For female patients, volunteers listened to the sorrows and fears of the patients. The major financial care provided by them to both male and female patients was 'Supply medicines at free of cost'. 'Supply rice and provisions for the family' was the second financial care provided to both. The major spiritual care provided by them to both male and female patients was 'Love and affection'. 'Psychological boost' was the second spiritual care provided to both. Most of the male and female patients opined that they did not require any service other than those provided by the units and said that palliative care service was absolutely essential for the society.

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Table 1 Gender of the Patients and the Type of Care Received (Chi-Square Test)

Gender	Type of Care Received				
		Home based care	Institution based care	Both	Total
Male	Count	288	134	49	471
	% within gender	61.1%	28.5%	10.4%	100%
Female	Count	291	50	59	400
	% within gender	72.8%	12.5%	14.8%	100%
Total	Count	579	184	108	871
	% within gender	66.5%	21.1%	12.4%	100%

Source: Primary data.

$\chi^2 = 33.726$ with 2 degrees of freedom. Significant at 1% level

Table 2 Gender of the Patients and the Type of Home Based Care Received

Gender	Type of Home care based received			
		Community based care	hospital pain clinic care	Total
Male	Count	164	307	471
	% within gender	34.8%	65.2%	100%
Female	Count	95	305	400
	% within gender	23.8%	76.3%	100%
Total	Count	259	612	871
	% within gender	29.7%	70.3%	100%

Source: Primary data.

$\chi^2 = 12.685$ with 1 degree of freedom. Significant at 1% level

Table 3 Gender of the Patients and the Type of Physical Care Provided by the Doctors

Type of Physical Care	Male		Female	
	Mean	Rank	Mean	Rank
Medicines	5	1	4.976945	1
Exercises and aids	4.040134	2	3.814655	3
Touch & closeness	3.704878	3	3.829365	2
Discussion between me and family members	3.12	4	2.821429	4

Source: Primary data.

Table 4 Gender of the Patients and the Type of Physical Care Provided by the Doctors (Kruskal –Wallis Test)

Type of Physical Care	Chi-Square	df	Asymp. Sig.
Medicines	4.168	1	.041
Exercises and aids	13.441	1	.000**
Touch & closeness	4.920	1	.027
Discussion between me and family members	1.708	1	.191

Source: Primary data.

** Significant at 1% level

Table 5 Sex of the Patients and the type of Physical Care provided by the Nurses

Type of Physical Care	Male		Female	
	Mean	Rank	Mean	Rank
Attending to the bed sore	8	1	7.277778	3
Changing clothes	8	1		
Giving medicines	7.682609	2	7.721763	1
Dressing the wounds	6.425287	4	6.460674	5
Changing the “condom catheter”	7.358333	3	7.504132	2
Training the family members in simple nursing tasks	6.353982	5	6.482353	4

Source: Primary data

Table 6 Gender of the Patients and the type of Physical Care provided
by the Nurses (Kruskal –Wallis Test)

Type of Physical Care	Chi-Square	df	Asymp. Sig.
Attending to the bed sore	36.320	1	.000**
Changing clothes	2.565	1	.109
Giving medicines	1.061	1	.303
Dressing the wounds	4.328	1	.037
Changing the “condom catheter”	1.733	1	.188
Training the family members in simple nursing tasks	36.320	1	.000**

Source: Primary data.

** Significant at 1% level

Table 7 Gender of the Patients and the Type of Physical Care Provided by the Volunteers

Type of Physical Care Provided by the Volunteers	Male		Female	
	Mean	Rank	Mean	Rank
Bathing	8	1		
Attending to the bed sore	7.181818	4	7.230769	2
Changing clothes	8	1		
Giving medicines	7.95082	2	7.816619	1
Dressing the wounds	6.375	6	6.628571	5
Changing the “condom catheter”	7.394737	3	7.2	3
Training the family members in simple nursing tasks	6.625	5	7.144231	4

Source: Primary data.

Table 8 Gender of the Patients and the Type of Physical Care Provided by the Volunteers

(Kruskal –Wallis Test)

Type of Physical Care Provided by the Volunteers	Chi-Square	df	Asymp. Sig.
Bathing	3.706	1	.054
Attending to the bed sore	21.335	1	.000**
Changing clothes	1.328	1	.249
Giving medicines	1.484	1	.223
Dressing the wounds	8.642	1	.003**
Changing the “condom catheter”	3.324	1	.068
Training the family members in simple nursing tasks	3.706	1	.054

Source: Primary data. ** Significant at 1% level

Table 9 Gender of the Patients and the Type of Psychological Care Provided by the Volunteers

Type of Psychological Care Provided by the Volunteers	Male		Female	
	Mean	Rank	Mean	Rank
Chatting with the patients	4.287582	1	4.619718	1
Listening the sorrows and fears of patients	3.133117	4	3.891566	2
Listening to the concerns of the family members	3.70317	3	3.546429	3
Sharing of problems with patients and the family counselling	3.765957	2	3.347328	4

Source: Primary data.

Table 10 Gender of the Patients and the Type of Psychological Care Provided by the Volunteers
(Kruskal –Wallis Test)

Type of Psychological Care Provided by the Volunteers	Chi-Square	df	Asymp. Sig.
Chatting with the patients	26.579	1	.000
Listening the sorrows and fears of patients	61.343	1	.000
Listening to the concerns of the family members	3.635	1	.057*
Sharing of problems with patients and the family counselling	19.526	1	.000

Source: Primary data.

*Not Significant at 1% level

Table 11 Gender and the Type of Financial Care Provided by the Volunteers

Type of Financial Care	Male		Female	
	Mean	Rank	Mean	Rank
Supply medicines at free of cost	5.0000	1	4.92000	1
Supply rice and provisions for the family	4.027397	2	4.3875	2
Provide wheel chairs / water beds, commodes etc	3.685714	3	4.09375	3
Books, clothes and school fees for the kids	3.20000	4		

Source: Primary data.

Table 12 Gender and the Type of Spiritual Care Provided by the Volunteers

Type of Spiritual Care	Male		Female	
	Mean	Rank	Mean	Rank
Psychological boost	9.290816	2	9.4	2
Helped to establish /re-establish a sense of meaning	7.926316	6	8.255102	4
Encourage to reminisce with family & friends	6	7	6.32	6
Prepare advance directives	8.42735	3	8.564356	3
Assisting with life closure	8.078431	4	7.921348	5
Love & affection	9.521212	1	9.418301	1
Fulfilling the wishes	8	5	8	5

Source: Primary data.

Table 13 Gender and the Type of Spiritual Care Provided by the Volunteers (Kruskal – Wallis Test)

Type of Spiritual Care	Chi-Square	df	Asymp. Sig.
Psychological boost	7.992	1	.005**
Helped to establish /re-establish a sense of meaning	9.774	1	.002**
Encourage to reminisce with family & friends	.892	1	.345
Prepare advance directives	.955	1	.328
Assisting with life closure	1.385	1	.239
Love & affection	6.106	1	.013
Fulfilling the wishes	.000	1	1.000

Source: Primary data. ** Significant at 1% level

Table 14 Gender of the Patients and Their Need for Other Services not Provided by the Unit (Chi-Square Test)

Gender	Need for other services not provided by the Unit			
	Count	Yes	No	Total
Male	% within gender	43	428	471
	Count	9.1%	90.9%	100%
Female	% within gender	50	350	400
	Count	12.5%	87.5%	100%
Total	% within gender	93	778	871
	Count	10.7%	89.3%	100%

Source: Primary data.

$\chi^2 = 2.576$ with 1 degrees of freedom. Not significant at 1% level

Table 15 Gender of the Patients and their Opinion about the Need for Pain and Palliative Care Services in the Society (Chi-Square Test)

Gender	Need for Pain and Palliative Care Services in the Society			
		Absolutely Essential	Essential	Total
Male	Count	403	68	471
	% within gender	85.6%	14.4%	100%
Female	Count	336	64	400
	% within gender	84.0%	16.0%	100%
Total	Count	739	132	871
	% within gender	84.8%	15.2%	100%

Source: Primary data.

$\chi^2 = 0.411$ with 1 degrees of freedom. Not significant at 1% level

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