

Social Interventions in Palliative Care in Kerala: A Study on Community Owned Home-Based Palliative Care Unit

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Abstract:

Background: The state of Kerala, India adopted a community based social network model for the provision of palliative care and as such many community owned Palliative Care Units are providing home based palliative care services in the state. Whether these units are functioning with a view to materialise the long-term objective of serving the neediest patients with quality care is a matter of enquiry. Hence, a micro level study, analysing the structure and organisation of palliative care units under social network model and the level of quality of palliative care services provided by such units becomes productive.

Materials and Methods: A representative Community Owned Palliative Care Unit, K.K.C Memorial Pain and Palliative Care Unit is selected for in-depth case study. Fifty patients and their care givers were randomly selected from those registered currently in the selected unit, and interview schedule was administered to them during August, 2020. Socio economic status and disease particulars of the patients are examined and quality of palliative care is analysed using the quality care questionnaire –palliative care (QCQ-PC).

Results: Sample unit serves the neediest patients and quality of care is satisfactory. The palliative care team has brought about improvement in the overall quality of life of the patients suffering from the life limiting diseases, via preventing and relieving the distress by unimpeachable evaluation and managing the complaints related to the various physical, spiritual and psycho-social domain. The selected unit stands out as a model of community-based approach to palliative care and home-based medical care and has been widely appreciated and represents a viable model for providing palliative care

Key Word: Palliative Care, Community Based Social Intervention.

Date of Submission: 01-08-2021

Date of Acceptance: 15-08-2021

I. INTRODUCTION

Increased prevalence of chronic diseases is a major public health issue all over the world (Webster, R., Lacey, J., & Quine, S., 2007). With demographic, epidemiological, nutritional and life style changes worldwide, the number of people suffering from chronic diseases is increasing at a faster rate. Debilitating conditions, such as cardiovascular disease, obstructive pulmonary disease, diabetes, cancer, chronic kidney disease intersecting with physical or mental impairment, economic hardship, and social isolation demands social interventions from multiple stakeholders. Community based palliative care services assume importance against these social circumstances. Palliative care services encompass provision of symptom management and pain relief for chronic and life-limiting illnesses, taking into account the distinct needs and capacities related to the patient and often require collaboration between multi-professional health workers across different settings in the form of social support interventions. Effective palliative care for persons involves both patient and family needs and integrates physical, psychosocial, legal, and spiritual support.

The state of Kerala, India is projected as a beacon of hope with respect to social innovations in health care delivery (Nair, 2016). With only 3 per cent of India's population, the state accounts for two thirds of India's palliative care services and adopts community-based social intervention strategy towards palliative care (Kumar, 2007). Neighborhood Network in Palliative Care (NNPC) which was established in the state in 2001 is a community-led initiative to provide home-based palliative care (Jayalekshmi, R.&, Suhita,C.C., 2017). The major features of the model developed in Kerala include community-based outpatient clinics, supportive home care services, participation of trained volunteers from the community, empowerment of family to care for the patients, social rehabilitation services, free of cost services, use of locally available resources, training activities for health professionals and funding through community participation (Raj, 2016).

Considering the structure, organization and implementation of NNPC, the social support intervention in palliative care is widely discussed and the intervention is claimed to be a 'model for resource – poor settings'

(Bollini, Venkateswaram & Sureshkumar, 2004) at the international level. Many social interventions focusing on palliative care services emerged and sustained over the last decade, and it is important to understand the iterative process of intervention development, feasibility testing, effectiveness evaluation to get valuable insights into the problems and prospects in experimenting such palliative care models. Alongside, these social networks, with its multi component programs seems to have an added advantage of widening social capital which helps in implementation of other intervention strategies, especially in times of public health emergencies. The diverse social support interventions ranging from peer/family support interventions to support group interventions has been cited as a solution to the complex problems arising in the social system, especially with relation to health and health care.

Against this background it is essential to understand the structure and process of social interventions in the form of social networking that provide home based palliative care services at the local level, and the way in which sensitivity has been brought into health care system by the coordinated efforts of different stakeholders. The proposed study envisages to analyse social network interventions in the palliative care services and its impact on the life of patients in the form of increased quality of life. The project specifically looks into the structures, functions and relevance of social intervention in the form of community owned home-based palliative care services in Kerala context and the impact it left over on the well-being of palliative care patients and their families, by looking into attributes of home-based care model, effectiveness of case management and quality of life, by undertaking an elaborate case study of a particular Palliative Unit.

II. OBJECTIVES

1. To explore the structures, functions, joint responsibilities of relevant stakeholders in pain and palliative care unit under the social network model.
2. To analyze the effectiveness of selected palliative care model in addressing the health related, economic, and social issues of bedridden and incurably ill patients by assessing the quality of palliative care and the impact on patient's quality of life.

III. METHODOLOGY

Hybrid methodology culminating both qualitative and quantitative methods is essential since the study is conducted among patients suffering from both physical health issues and psychological distress. The study makes use of secondary data sources including official websites, Government reports, research papers, books, annual reports etc. In order to understand the social network model in palliative care, K.K.C Memorial Palliative Care Unit, Kayamkulam, Kerala is selected for case study and fifty patients are surveyed. Along with this, major stakeholders including health care professionals, local self-government officials, social activists and staffs were interviewed. Socio economic status of the patients and disease details are examined. Quality Care – Palliative Care (QC-PC) patient reported assessment of quality of palliative care, Quality of Life – Questionnaire (Yun et al., 2018) are used to examine the effectiveness of social intervention through palliative care.

IV. STRUCTURE, FUNCTIONS AND RESPONSIBILITY OF K.K.C. MEMORIAL PAIN AND PALLIATIVE CARE UNIT

K.K.C. Pain and Palliative care society was registered during 2016 and provides home based palliative care services to 2360 patients in Kayamkulam region of Kerala state, spread across the 14 zones in which 110 wards are included. Beneficiaries include patients from all age group who are suffering from chronic illness/genetic problems and aged persons who are in need of palliative care. The patients include those who hail from very poor backdrop who are not able to afford medical care, and those who are financially well off but are abandoned and needs psycho-social support. Conception, origin and development of the society were need based and was the result of people's initiative under leaders who are visionaries and the unit has become a mass network.

The stated objectives of the unit include 1.To provide holistic care to patients in need of palliative care who comes under the Kayamkulam legislative assembly area, 2.To ensure home based palliative care services scientifically to patients who are suffering medical complications including cancer, stroke, neurological problems, mental health problems, diabetics and other ailments relating to old age, 3.To provide special care to patients who are affected with chronic illnesses and need care for the entire life time, as medical care is ineffective and is referred for palliative/ pain management, 3.To cater to the patient centric needs, which are diverse, complex and continuous in nature, 4.To avail support from, government, non-governmental, cooperative institutions and other palliative care units to accomplish the needs of patients and their family, 5.To fight against social evils including alcoholism, drug use by conducting awareness camps and train the youth to act as volunteers, 6.To conduct blood donation camps and awareness class about the need for blood donation so as to cater to the needs of beneficiaries, 7.To train youngsters to act as palliative care volunteers and 8. To

establish lab facilities and food kit distribution as extension activities in future so that the quality of life of patients and their families can be enhanced.

Structure:

The palliative care unit is organized in a way that the decision-making process is democratic and opinion of every member is respected and accepted. The palliative care unit is governed by a 23-member governing body at the regional level in which experts in the palliative field are also included. The area is divided into 14 zones and each zone has an advisory panel which guides the working committee in planning and implementation of palliative care services. There are ward committees in the 110 selected wards for identification of patients and to maintain regular contact with the patients. These ward committees are also supported by advisory panel at the ward level. In addition, around 400 trained volunteers support the palliative care team in making the services effective and empathetic.

Resource Mobilization:

The Palliative society mobilises funds mainly through membership fees. There are mainly seven type of memberships: namely primary membership (Rs.1000), Mercy Membership (Rs.2000), Silver membership (Rs.5000), Golden membership (Rs.5000), Diamond membership (Rs.25000), Platinum membership (Rs.50000) and Smart membership (above 1 lakh). Each member has to pay at least Rs.100 towards palliative services from their income every month, which can be contributed either through the online bank transaction or through contribution to charity box. In order to ensure transparency in financial dealings audited report verified by chartered accountant is submitted in the general body meeting conducted every year and all transactions are done through the bank account of the palliative society. Collecting donations through charity boxes is another important initiative, and boxes are placed in 16 places. During 2019, around Rs.70,000 was collected from 250 charity boxes. On special occasions individuals choose to donate money towards palliative care and with the money, medicines, assistive devices are donated to patients or special programs are conducted.

Services provided:

House Visits by Medical Team: A team of palliative nurses and volunteers visits around 2360 patients in the area and provides nursing care. During the first visit the health survey form is filled and patient is registered to the palliative care unit. Details of treatment and medication, family particulars and insurance details are collected by the team and a need assessment is done. Basic nursing services such as catheterization, wound management, routine checkup etc. are also done. Along with this, the care givers are given advice on how to manage patients and maintain the basic metabolism intact by controlling blood sugar level and blood pressure control. Advice is given about keeping patient in hygienic conditions and following up with the medical treatment. The team has essential medicines and equipment and owns three ambulances. Doctors accompany the team in case the patients need special care and gives advice to the nursing team.

Free medicines, assistive devices and medical camp: Medical camps are conducted by the palliative care team under the initiative of physicians. Many organizations sponsor medicines that is given free of cost to needy patients. During the covid pandemic, the palliative care society made special efforts to distribute essential medicines to the families, as due to lockdown it was difficult to get medicines. Palliative care patients are in grave need of assistive devices, and the palliative team with the support of other agencies provides assistive devices including wheel chair, walkers etc. to the patients.

V. SOCIO-ECONOMIC DETAILS AND DISEASE CHARACTERISTICS OF PALLIATIVE PATIENTS

Primary data is collected from fifty palliative patients selected randomly from among the patients given palliative care by the Palliative Unit. Data is elicited from both patients and their care givers with the help of interview schedule.

The socio economic and demographic details of the patients is provided in the table no 1. Age wise classification of the patients show that 24 per cent of them are in the young age (below 60) and 76 per cent are above sixty. The number of people aged less than sixty in the total sample gives the picture that these people have become bedridden not because of old age, but because of other diseases or accidents. Also, the younger aged normally face severe psychological and physical stress on account of their inability to carry on their daily activities and because of the dependence that they have on their family members. Gender wise classification reveals that male female distribution in the sample is thirty two-sixty eight per cent. Of the total sample, 44 per cent are married, 8 per cent never married, 40 per cent widowed and 8 per cent divorced/separated. The patients that were covered by the research team belonged to lower socio-economic status as evidenced by their educational and occupation details. Very few of the samples had an educational level above secondary level.

Table no 1: Socio Economic Status of sample respondents

	Number	Percent		Number	Percent
Age			Education		
Below 50	4	8	Illiterate	2	4
50-60	8	16	Below secondary	20	40
Above 60	38	76	Secondary	12	24
	50	100	Higher secondary	10	20
Gender			Graduation and above	6	12
Male	16	32	Total	50	100
Female	34	68	Earlier occupation		
Total	50	100	Government	6	12
Religion			Private/Own business	8	16
Hindu	44	88	Casual labour	2	4
Muslim	6	12	Others	6	12
Total	50	100	Unemployed	28	56
Marital status			Total	50	100
Married	22	44	Economic status		
Never married	4	8	Above Poverty Line	30	60
Widowed	20	40	Below Poverty Line	20	40
Divorced/separated	4	8	Total	50	100
Total	50	100			
	N	Minimum	Maximum	Mean	Std. Deviation
Current monthly family income	50	1200	45000	18956	12272.74
Prior monthly family income	50	8000	50000	26720	12317.06
Prior monthly income of patient	32	0	30000	12250	10529.32

Source: Primary data

Majority had secondary or below secondary as their educational qualification, and five of the patients had higher secondary as their education. Occupational status prior to the illness and associated health problems shows that 18 per cent were casual labourers and had other related jobs, 16 per cent were having private/small business and 12 per cent had government job. Above 55 per cent were unemployed, majority belonging to the female group. Socio-economic status of the sample is also evidenced by the fact that 40 per cent belong to Below Poverty Line category and 60 per cent belong to Above Poverty Line category. A comparison of the current and prior monthly family income of the patient is also worked out. It is found from the data that there has been a reduction in average family income of the patients from Rs. 26,720 to 18,956 recording a decline of forty-one per cent. Sixteen of the sample had some sort of employment prior to their disease and on an average a palliative patient earned an average income of Rs.12,250.

Table no 2: Assets, Occupation, Income, Land holdings and Liabilities

	Number	Percent		Number	Percent
Current Monthly Family income source			Assets		
Government .Pensions	18	36	Land	48	96
Maintenance by children	4	8	Gold	18	36
Private	14	28	Deposits	16	32
Other occupations	26	52	Buildings	46	92
N	50	100	Cash holding	18	36
Prior occupation			N	50	100
Unemployed	28	56	Land Holdings		
NRI	2	4	Up to 5 cents	6	13
Govt Retired	10	20	5-10 cents	10	21
Casual labourers	4	8	10- 15 cents	12	25
Others	6	12	Above 15 cents	20	42
	50	100		48	100
	N	Minimum	Maximum	Mean	Std. Deviation

Average land holdings	48	4	50	25.1667	16.63
Liabilities					
Bank	26	50000	1500000	280769.2	3913
Relatives	12	20000	100000	46666.67	29439.2
Money lenders	20	20000	100000	58000	25733.68
Total	32	50000	1500000	281875	361058.1

Source: Primary data

Table no 2 shows the asset, liabilities and income details of the families. For 36 per cent, government pensions form the major source of income for sustenance, for eight per cent children provide the income for sustenance and for 52 per cent, small business, casual labour, and other petty jobs are the main source of income. The liability details of the family show that the average liability of the household is Rs.2,81,875. Thirteen have bank loan as their source of liability, six have borrowed from relatives and ten have borrowed from money lenders at a high rate of interest. The land holdings of the patients shows that around 33 per cent have below ten cents of land and 25 per cent have between 10 to 15 cents. These are indicative of the fact that the livelihood diversification possibility of the patients has been very less, which has adversely affected their standard of living.

Disease Particulars of the Palliative Patients

Disease particulars of the patients including health condition, name of disease, year of diagnosis and immediate symptom of the disease is shown in Table no 3. Ninety-two per cent reported chronic disease and only eight per cent required palliative care because of ageing. The disease pattern of the patients shows that 20 are cancer patients, 48 per cent met with accidents and other incidences, 16 per cent became bed ridden because of stroke, eight per cent had physical disability because of ageing, and one person reported heart disease. Sixteen per cent are bed ridden for the last ten years and 36 per cent are bed ridden for last eight years. This implies the length of the care that has to be provided to the patients. The immediate symptom of the disease was physical for 88 per cent of the patients, while 12 per cent had both physical and mental symptoms.

Table no 3: Disease details of patients

Health conditions	Number	Percent	Year of diagnosis		
			Number	Percent	
Chronic	30	60	Prior 2012	8	16
Ageing	20	40	2013- 2015	18	36
Total	50	100	2016-2018	18	36
Disease Type	Number	Percent	2019-2020	6	12
Cancer	10	20	Total	50	100
Kidney disease	2	4	Immediate symptom of disease		
Stroke	8	16	Physical	44	88
Physical disability	4	8	Mental	0	0
Heart disease	2	4	Both	6	12
Others	24	48	Total	50	100

Source: Primary data

Most of the patients had a major health shock which needed immediate medical intervention and later they had to be given palliative care. Forty-four per cent of the sample had surgery, twenty per cent had radiation, sixteen per cent were given Intensive Care Unit treatment and twelve per cent were given physiotherapy treatment. The source of treatment has been private hospital for majority, only with the exception of radiation facilities. Sixty per cent of the samples were admitted in private hospitals while forty per cent were admitted in government hospitals. The average treatment expense for the patients had been Rs. 1,29,091 for surgery, Rs. 1,01,600 for radiation, Rs.1,20,000 for Intensive Care Unit, Rs. 48,000 for physiotherapy and Rs.90,040 for hospital charges.

VI. FACILITIES PROVIDED BY K.K.C. PALLIATIVE UNIT

Primary data analysis shows that 48 per cent of the patients have started palliative care during 2016 to 2018 and the remaining 52 per cent prior to it. Doctors, Nurses, Volunteers and other team members including Accredited Social Health Activists (ASHA) are expected to visit these patients for care giving. Data shows that nurse and ASHA workers visit the palliative patients once in every month, whereas volunteers visit these patients often biweekly. Doctors visit them as on request and 100 per cent reported that they are visited by doctors once in every half year. On discussion with the palliative patients and the medical team, it is understood

that in addition to the routine monthly visit, the nurse visits the patients on call in times of emergencies like catheter change.

The main physical services provided by the Unit include both medical and non-medical services. The components of the medical services include provision of medicines, pain relief tab, routine check-up, injections, cleaning bed sore, care giver services, cleaning material provision, assistive devise support and provision of permanent assistive devices, whereas non-medical services include provision of finance, by stander facility and provision of life support. The KKC has taken care to provide the needed medical and non-medical services to the patients. Cent per cent needed medicines, 64 per cent pain relief tablet, 32 per cent routine check-up, 76 per cent injections, 12 per cent bed sore and wound cleaning, 12 per cent care giving services etc. Majority of those who needed these medical services were provided the necessary provisions.

Table no 4: Physical services available through KKC

Sl.no	Services Aailed	Need		Provision		Satisfaction			
		Yes	%	Yes	%	Medium	High	Very high	Total
1	Medical Services								
a	Medicines	50	100	50	100	4	80	16	50
b	Pain Relief tab	32	64	26	52	0	69.2	30.8	26
c	Routine check-up	16	32	12	24	0	16.7	83.3	12
d	Injections	38	76	38	76	0	5.3	94.7	38
e	Bed sore, wound cleaning& stitching	6	12	6	12	0	33.3	66.7	6
f	Care giver services	6	12	4	8	0	50	50	4
g	Cleaning material provision	8	16	4	8	0	50	50	4
i	Permeant Assistive devices	8	16	0	0	0	0	0	0
2	Non-Medical Services								
a	Food Kit	10	20	6	12	0	0	100	6
b	Financial Help	22	44	0	0	100	0	0	10
c	By stander facility	14	28	0	0	100	0	0	10
d	Daily life skill support	4	8	2	4	0	0	100	2
d	Others	4	8	0	0	0	0	0	0

Source: Primary data

Regarding non-medical services, the K.K.C. unit provides financial help to all those who needed it (44 per cent). Those who needed food kits were provided with it (20 per cent). Same is the case with provision of bystander facility. The satisfaction rated by majority regarding the provision of services is generally high, with difference seen in the rating with reference to financial help and provision of bystander facility.

Sufficiency of services given by the KKC

Table no 5 shows the sufficiency of services received by the patients from the K.K.C. unit. The particular problems identified are daily life skills, personal transportation, physical problems, problems related to autonomy, social issues, psychological, spiritual, financial problems and lack of information. The details regarding whether there exists a problem, whether the service provided to address the problem is sufficient etc. is given in Table no 5. Sixteen per cent had problems in daily life, 16 per cent had problems in personal transport and 40 per cent, 36 per cent, 32 percent, 48 per cent, 16 per cent, had physical problems including pain, fatigue, sleeplessness, breath problems and skin infections respectively. In many cases the palliative care team provided the services always. With regard to autonomy, social activities, psychological, spiritual and financial issues also majority had problems and many were provided with necessary services. A few reported issues like unable to find anyone to talk, problems with close relatives, not wanting to be a burden to others etc. In majority of the cases, the palliative team was able to provide solutions to the patients reporting such social issues. The financial problems faced by the patients were severe because majority had additional expenses due to disease and loss of income. Psychological issues including depression, fear, anxiety etc. were faced by around thirty to fifty per cent of the patients and they were given solace and consolation by the palliative team. The palliative patients were satisfied by the sufficiency of the services provided by the palliative team.

Table no 5: Distribution of sufficiency of services

		Is there a problem		Service Provided by Palliative care				No	%
		Yes	%	Alwa ys	%	Sometime s	%		
I	Daily life skills	8	16	0	0	6	75	2	25
II	Personal Transport	8	16	2	25	6	75	0	0

III	Physical Symptoms								
a)	Pain	20	40	8	40	6	60	0	0
b)	Fatigue	18	36	2	11.1	10	55.6	6	33.3
c)	Sleeplessness	16	32	4	25	6	37.5	6	37.5
d)	Breath problems	24	48	4	16.7	8	33.3	12	50
e)	Skin infections	8	16	2	25	4	50	2	25
IV	Autonomy								
a)	Difficulty to continue daily activities	30	60	6	20	20	66.7	4	13.3
b)	Difficulty to give tasks out of hand	22	44	4	18.2	16	72.7	2	9.1
c)	Feeling dependent	24	48	14	58.3	4	16.7	6	25
d)	Experiencing	10	20	8	80	2	20	0	0
V	Social issues								
a)	Problems in relation with close relatives	4	8	4	100	0	0	0	0
b)	Don't find anyone to talk	12	24	4	33.3	6	50	2	16.7
c)	Difficulty in sharing disease details to relatives	4	8	0	0	2	50	2	50
d)	Doesn't share pain because doesn't want to be a burden to others	16	32	10	62.5	4	25	2	12.5
VI	Psychological								
a)	Depression	16	32	14	87.5	0	0	2	12.5
b)	Fear	26	52	20	76.9	4	15.4	2	7.7
c)	Difficulty to show emotions	12	24	4	33.3	8	66.7	0	0
d)	Difficulty to cop up with unpredictable nature of future life	26	52	24	92.3	2	7.7	0	0
VII	Spiritual Issues								
a)	Unable to engage life usefully	38	76	20	52.6	14	36.8	4	10.5
b)	Difficulty to be avail for others	20	40	10	50	4	20	6	30
VIII	Financial Problems								
a)	Additional expense due to disease	26	52	6	23.1	20	76.9	0	0
b)	Loss of income due to disease	24	48	4	16.7	20	83.3	0	0
IX	Lack of information	4	8	2	50	0	0	2	50

Source: Primary data

VII. ASSESSING THE QUALITY OF PALLIATIVE CARE PROVIDED BY KKC PALLIATIVE UNIT

The quality of palliative care provided by KKC palliative unit is measured using several tools, the important ones being

1. Quality care-palliative care patient reported assessment of quality of palliative care
2. Quality of Life of the patients

1. *Quality care – palliative care (QC-PC) patient reported assessment of quality of palliative care*

a. *Communication with palliative care team*

Patient reported assessment of quality of palliative care is done under four domains – a) communication with palliative care team b) value of life and goals of care c) support and counselling for needs of holistic care and d) accessibility and sustainability of care. Communication with palliative care team involves facets such as satisfaction with the careful manners, way of communication, receipt of adequate care etc. along with support, clarity in conversation etc. Data collected from the patients show that majority are always satisfied with the different facets of quality of communication with the palliative team. Only with reference to the understanding of the accurate description of the care plan some have reported that they never or rarely understand the plan. Around 56 per cent of the patients reported that they are sometimes satisfied with the manner of the staff, quality of explanation of medical staff, support of the staff on care plan etc. Majority (more than 76 per cent) are always satisfied with the quality of communication with the palliative team.

The patients were asked to rate the facets on a five-point scale with one indicating the least satisfaction and five indicating the highest level of satisfaction. **Table no 6** shows that the mean satisfaction index is above four in all categories of facets indicating satisfaction in communication with the palliative team.

Table no 6: Rating on communication with palliative team

	N	Minimum	Maximum	Mean	Std. D
I am satisfied with the careful manner of medical staff	50	2	5	4.32	0.69
I am satisfied with the way of communication of medical staff	50	4	5	4.76	0.43
I was able to receive adequate care from medical staff	50	2	5	4.32	0.85
I have heard and understood an accurate description of the progress of my disease	50	4	5	4.52	0.5
The medical staff explained terms that I was curious about	50	4	5	4.56	0.5
I was able to receive the healthcare service I demanded	50	2	5	4.4	0.7
The medical staff support my decision on care plan	50	4	5	4.48	0.5
I have heard and understood an accurate description of my care plan	50	4	5	4.48	0.5
I was able to have a conversation with medical staff in a relaxed atmosphere	50	2	5	4.44	0.71
The medical staff paid attention to various symptoms I felt and adjusted them well	50	2	5	4.48	0.71
Overall rating on communication with palliative team	50	3.4	5	4.476	0.5

Source: Primary data

b. Value of life and goals of care

The patient reported assessment of quality of palliative care is also understood by the second domain termed as value of life and goals of care which include nineteen facets like ability to discourse with medical staff about the value of life, ability to recall what is important to achieve the values and goals of life while discoursing with the medical staff, ability to express the family and self-expectations from care, ability to modify plans when the demand for treatment changed, receipt of education that is helpful to care etc.

Table no 7 shows that the with regard to contributing to value of life and goals of care, the palliative team was mostly successful. Above eighty per cent of the patients reported that they always received such care as indicated by the data. Hence the average score of individual facets in quality of care in terms of value of life and goals of care is higher than four and the overall score is 4.39.

Table no 7: Rating on value of life and goals of care

Rating on value of life and goals of care	N	Minimum	Maximum	Mean	Std. Deviation
I was able to discourse with medical staff about the value of my life	50	4	5	4.52	0.5099
I was able to recall what is important to achieve the values and goals of my life while discoursing with medical staff	50	4	5	4.48	0.5099
I was able to express what my family and I expected from care	50	2	5	4.28	0.73711
My care plans included the things I was able to try myself	50	2	5	4.28	0.67823
I was able to receive adequate help from medical staff, while I was having difficulties in setting up specific goals related to care	50	1	5	4.2	0.86603
My family and I received an education that is helpful to care	50	4	5	4.48	0.5099
The medical staff suggested an adequate care plan in consideration of values of my life	50	2	5	4.32	0.69041
I was able to modify my plan when my demand for treatment changed	50	2	5	4.28	0.67823
The medical staff managed intermediate checkups to verify whether I could execute my goals	50	2	5	4.48	0.71414
Overall rating on value of life	50	3.56	5	4.39	0.50445

Source: Primary data

c. Support and Counselling for needs of holistic care

Provision of support and counselling for needs of holistic care is yet another way by which the self-reported quality of patient care is assessed. It includes seven facets like receiving telephone counselling, support to solve spiritual concerns, help to overcome social crisis, smooth communication, less delay in outpatient care and telephone counselling etc. and receipt of psychological support from medical staff. **Table no 8** shows that except few of them majority reported that they always receive support and counselling services for needs of holistic care. Hence the index value of quality of self-reported assessment of palliative care is also very high, with the overall index very close to 4.5.

Table no 8: Rating on support and counselling

Rating on support and counselling	N	Minimum	Maximum	Mean	Std. Deviation
I was able to receive outpatient care and telephone counseling with plenty of time	50	4	5	4.2	0.40825
The medical staff provide support to me and my family to solve spiritual concerns	50	4	5	4.28	0.45826
The medical staff provided support to me and my family to overcome social crisis	50	4	5	4.36	0.4899
The medical staff knew what I wanted	50	4	5	4.32	0.4761
The medical staff communicated smoothly with me and my family	50	4	5	4.72	0.45826
Outpatient care and telephone counseling were done at the appointed time without delay	50	3	5	4.16	0.47258
My family and I received psychological support from medical staff	50	4	5	4.76	0.43589
Overall rating on support and counseling	50	3.86	5	4.401	0.35661

Source: Primary data

d. Accessibility and sustainability of care

Under the domain of accessibility and sustainability of care, six facets are included, like provision of expert care, provision of immediate medical care in a state of crisis, reflection by family regarding the health plan, understanding of the goals of care etc. With regard to the first facet, thirty-six per cent opine that the services provided for care are given by experts in the field. Similarly, only thirty-two per cent are having positive opinion regarding the provision of services at the location of need by the patients. In other facets, the patients are mostly satisfied with the accessibility and sustainability of care. The same result is indicated by the index reporting accessibility and sustainability of care, the average for the domain being 4.4.

Table no 9: Rating on Accessibility and sustainability of care

Rating on Accessibility and sustainability of care	N	Minimum	Maximum	Mean	Std. Deviation
Services needed for my care are provided by experts in their respective field	50	4	5	4.28	0.45826
I was able to get care services at the locations I wanted	50	4	5	4.36	0.4899
Medical care is immediately provided in a state of crisis	50	4	5	4.32	0.4761
The medical staff periodically confirmed my goals and plans toward care	50	4	5	4.72	0.45826
The decision on a healthcare plan was reflected by my family and my opinion.	50	3	5	4.16	0.47258
I understand the goal of care	50	4	5	4.76	0.43589
Overall rating on accessibility and sustainability of care	50	3.83	5	4.4328	0.36065

Source: Primary data

e. Overall Quality of Palliative Care as reported by the Patients

Overall quality of palliative care is obtained by averaging the indices of the four domains, communication with palliative care team, value of life and goals of care, support and counselling for needs of holistic care and accessibility and sustainability of care. The overall quality of care index is very high (4.42) as reported by the patients.

Table no 10: Overall Quality of care

Overall Quality of care	N	Minimum	Maximum	Mean	Std. Dev
Communication with palliative care team	50	3.4	5	4.476	0.50931
Value of life and goals of care	50	3.56	5	4.3692	0.50445
Support and counseling for needs of holistic care	50	3.86	5	4.4012	0.35661
Accessibility and sustainability of care	50	3.83	5	4.4328	0.36065
Overall quality of care	50	3.69	5	4.42	0.39089

Source: Primary data

2. Assessment of quality of life

Seven facets are considered for assessment of quality of life of the palliative care patients, the facets being activity, self-care, health status, choice of treatment, support, communication and psychological effect. Within the activity domain, many are not working, some deal with household works, many keep enjoying life pleasures and also retain their hobbies.

Table no 11: Assessment on quality of life

I	Activity	No	Sometimes	Yes	IV	Choice of treatment	No	Sometimes	Yes
	I keep working	N 24	6	20		I would like to choose the therapeutic schema	N 48	0	2
		% 48	12	40			% 96	0	4
	I am dealing with house chores	N 10	2	38		I am capable to choose the therapeutic schema	N 50	0	0
		% 20	4	76			% 100	0	0
	I keep enjoying life pleasures	N 10	10	30	V	Support			
		% 20	20	60		Support of relatives or friends	N 10	12	28
	I retain my hobbies	N 12	8	30			% 20	24	56
		% 24	16	60		Support of health care team	N 10	12	28
II	Self Care						% 20	24	56
	Capable of driving	N 46	0	4		Support of palliative team	N 0	4	46
		% 92	0	8			% 0	8	92
	Self sufficient	N 16	4	30	VI	Communication			
		% 32	8	60		My social relationships	N 0	6	44
III	Health status						% 0	12	88
	I feel pain	N 16	0	34		My economic profession prob	N 2	4	44
		% 32	0	68			% 4	8	88
	I feel nausea and/or vomit	N 2	2	46		My family problems	N 2	6	42
		% 4	4	92			% 4	12	84
	I feel lack of appetite	N 6	18	26	VII	Psychological affect			
		% 12	36	52		I feel calm	N 4	10	36
	I feel weak and/or tired	N 22	16	12			% 8	20	72
		% 44	32	24		I feel optimistic	N 0	14	36
	I have dyspnoea	N 12	22	16			% 0	28	72
		% 24	44	32		I feel blue	N 30	14	6
	I have diarrhea or constipation	N 0	4	46			% 60	28	12
		% 0	8	92					
	I have sleep disturbances	N 4	38	8					
		% 8	76	16					

Source: Primary data

Regarding self-care only two are capable of driving. Feeling of pain, tiredness, lack of appetite, sleep disturbance etc. is reported by many, but for some this has been solved by the palliative team. Regarding support, all opine that they receive the support of health care team and palliative care team. They also communicate their economic/financial problems and family problems with the palliative team. Majority of them feel calm, optimistic, and in control of the situation after the visit of the palliative team. All these are indications of the fact that the quality of life of the palliative patients has improved tremendously after registering with the palliative unit of the K.K.C.

VIII. DISCUSSION

K.K.C Memorial Pain and Palliative care unit exhibits the features of a palliative care model that is suitable for resource poor settings; the core element that makes the endeavour successful are the following:

Identification and allocation of community resources: The most important feature of the Palliative care unit is that it is owned and operated by the community. The team succeeded in identifying human capital from the community itself and each member is allotted with responsibilities that suit them. Each and every member associated with the palliative care are given responsibility, such as raising funds, coordinating meeting, identifying patients, making follow ups and so on. Instead of employing a full-time doctor, the unit make use of doctors available in the locality whenever needed and this becomes possible because of the coordination skill of

conveners at the grassroots- the social capital created. The nurse is from the locality itself and she knows each and every patient and their background, and is ready to serve the patients at any time. There is not a single funder for the projects, but every one contributes to it. And this was specifically evident during the Covid time, when people joined hand to deliver food and medicines to patients on time. The shop owners, drivers, medical shops and the political representatives played their role in doing their little part and made the initiative a success.

Knowledge creation and dissemination: Other than the medical care received by the patients, the knowledge imparted to the patients is also important. Particularly, when it comes to patients suffering from diabetics or blood pressure, other than medicines, what is important is the knowledge of balanced diet and life style. The Palliative team maintains a close contact with every one and so that the essential information is shared. On a wider scale, the close contact in the community, helps the members in the unit to identify the new patients and provide care. The visit by palliative care team in itself create an awareness among the bystanders and family, that the patients have certain rights and that should be respected. Also, as the team consist of members from the locality, families become more cautious to take care of patients.

Psycho-social support: One important problem that the patients in need of palliative care and their bystanders face is the loneliness and feeling of desperateness, partly due to the chronicity of illness and partly because of social stigma attached. The Palliative team makes efforts to provide psycho social support to patients. Visiting the patients and enquiring about their wellbeing itself makes a sense of happiness in the patients and their family. And they feel a sense of ownness towards the team members and opens up their problems.

Empowerment of community: Other than patients and their families, the activities of the unit create a team that is empowered. The training programs and weekly meetings as a part of the palliative care develops the skill of agency among patients, especially among women and a sense of responsibility is imparted to citizens. It enables the team members to demand for basic health rights and intervene in social issues and helps in nurturing decision-making skill.

IX. CONCLUSION

To summaries, K.K.C. Memorial Pain and Palliative Unit goes along with the WHO definition of palliative care 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.” The goal of Palliative Care unit 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 psycho-social and spiritual support. This is why it is best administered by an interdisciplinary, multi-dimensional team, comprising doctors, nurses, counsellors, social workers, and volunteers. The Palliative Care team has brought about improvement in the overall quality of life of the patients and their caregivers suffering from the life limiting diseases, via preventing and relieving the distress by, unimpeachable evaluation and managing the complaints related to the various physical, spiritual and psycho-social domain. KKC Memorial Pain and Palliative Unit stands out as a model of community-based approach to palliative care and home-based medical care and has been widely appreciated and represents a viable model for providing palliative care. As Richard Smith, Editor, British Medical Journal (June 2011), puts it: “The Kerala model does provide a feasible way of achieving the vision of palliative care covering all patients, all diseases, all nations, all settings, and all dimensions. It’s hard to see how it will be achieved in another way”. K.K.C Pain and Palliative Unit substantiates and exemplifies the argument of Richard Smith.

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