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COMMUNITY-BASED PALLIATIVE CARE PARADIGM IN KERALA: REFLECTIONS AND RESPONSES ON A DESCRIPTIVE STUDY

Dr Harish Kumar Choudhary

Research Associate, Rambhau Mhalgi Prabodhini, New Delhi.

Dr Rajeev M.M.

Assistant Professor, Central University of Rajasthan, Ajmer

Abstract

Background: Community based palliative care is paramount significant nowadays. Most of the patients in need of palliative care can be looked after in the primary health care setting in the community. Care of the dying patient (Terminal Care) is an important part of palliative care however palliative care is not terminal care alone. It starts as supportive care when the diagnosis of a life-threatening illness is made, continues as terminal care if the illness progresses and provides bereavement support for the family after the death of the patient. Palliative Care is not in conflict with curative care. The principles of symptom control and psychosocial support used in palliative care are beneficial to the patient even when the disease is curable. Objectives: The main objective of the paper is to find out the effectiveness of palliative care programme in a rural setting. The objectives of the study is (1) to find out the effectiveness of home-based palliative care project conducted by PHC in Kollam district (2) to understand the impact of palliative care services rendered by PHC (3) to analyze the different types of palliative care services provided by PHC and (4) to study the level of satisfaction of patients in palliative care services. Materials and Methods:For this study, a descriptive research design was used. The researcher selected 30 samples using the purposive sampling approach. The information was gathered from care-takers at the palliative care unit of the PHC in Vallikavu, ClappanaPanchayat in the district of Kollam, Kerala. A self-created questionnaire was utilized to collect data. SPSS version 20 was used to examine the data**Results:**The study shows that most of the respondents have noncommunicable diseases and a few others are a lifestyle and geriatric health problems. The palliative care unit services are much helpful to the bedridden patients and so that this service must reach out to all the needy people. Conclusion: The study viewed at the services provided by a palliative care unit. The study emphasized the urgent need for palliative care services to meet the diverse needs of the elderly.

Keywords: Palliative care, Descriptive research design, PHC, Purposive sampling, SPSS

Introduction

Palliative care patients want to get their treatment in the familiar surroundings of their own homes. The majority of Indian healthcare is still institutional-based, despite the entry of private

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home health care services¹. Home-based palliative care services are becoming more common, with treatment brought to the patient's door. People are most at ease near the end of their life when they are surrounded by their loved ones. It is especially well adapted to Indian settings, where a family member is frequently present and eager to nurse the ailing individual. The ultimate goal of home care is to "promote, restore, and maintain a person's maximum level of comfort, function, and health, including care towards a dignified death." Home-based care models are also often person-centered and comprehensive, with the goal of taking into consideration aspects such as culture, religion, and value systems, as well as respecting people's rights to privacy and dignity, which corresponds to its mission².

Home-based specialist palliative care services are designed to suit the requirements of patients in terminal stages of cancer who are unable to leave their homes due to physical symptoms and anguish. Specialist home care services aim to enhance symptom management and quality of life, allowing patients to remain at home and avoiding needless hospitalization³. Family based specialist palliative care services are designed to suit the requirements of patients in terminal stages of cancer who are unable to leave their homes due to physical symptoms and anguish. Specialist home care services aim to enhance symptom management and quality of life, allowing patients to remain at home and avoiding needless hospitalization. Home-based palliative care from a professional increases symptom management, health-related communication, and psychological support. It aids in the better preparation of the patient and family members for death. It is offered by a professional team that comprises a doctor, nurse, social worker, volunteers, physiotherapists, and others. They pay regular visits to the patient's home and give the essential health treatment. Given the rising expense of chronic disease care, it can be difficult for families to maintain treatment in a hospital or hospice. This is especially true in situations where the people is not financially protected, such as in India. Family members are very important in home-based palliative care. They receive training from the team to master the fundamentals of palliation. Palliative care at home must be integrated into normal home health care services⁴.

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, psychosocial and spiritual⁵.Palliative care is an area of health care that focuses on relieving and preventing the suffering of patients. Unlike hospice care, palliative care is appropriate for patients in all disease stages including those undergoing treatment for curable illness and those living with the chronic disease as well as patients who are nearing the end of life. Palliative care is a multidisciplinary approach and helps to address physical, emotional, spiritual and social concerns that arise with the illness. Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from symptoms, pain, and stress of a serious illness-whatever the diagnosis. The goal is to improve the quality of life both the patients and the family. Palliative care is the active total care of patients with incurable diseases. It is patient-centered, and not disease-focused. In a rural area, most of the people have faced health

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issues and they are not aware of the serious and chronic illness and above all the rural area people are not getting the proper health care facilities. Palliative care is a prerequisite for complete medical care. It provides the best care to the patients and their families.Palliative care treats people suffering from serious and chronic illness such as cancer, cardiac disease, Alzheimer's, Parkinson's and many more. Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty in sleeping and depression.

The concept of palliative care is relatively new to India, having been introduced only in the mid1980s. Since then, hospice and palliative care services have developed through the efforts of committed individuals, including Indian health professionals as well as volunteers, in collaboration with international organizations and individuals from other countries. In 1975, the Government of India initiated a National Cancer Control Program. By 1984, this plan was modified to make pain relief one of the basic services to be delivered at the primary health care level. Unfortunately, this policy was not translated into extensive service provision. The hospice and palliative care movement in India started tentatively in the mid-1980s and has slowly increased over the last two decades. This study is an attempt by the investigators to find out the effectiveness of a home-based palliative care project in a ruralsetting.

The vast majority of India's population, however, does not have access to palliative care services such services exist in only 15 of India's 35 states and territories, according to Pallium India, one of India's leading palliative care organizations. Even in many regions where palliative care services do exist they are thinly spread, limited to a small number of medical institutions, and unavailable in communities. To date, Kerala is the only Indian state where palliative care services are available in every district. Statistics show that 80% of all palliative care services in the country are delivered in Kerala, reaching 30% of the needy patients, whereas these services reach only to 2% in India.Kerala's attempts at caring for terminally ill patients have been regarded as a model for the rest of the world. Kerala Government is the only State Government in Asia which has introduced a palliative care policy in the State for the first time. The Neighborhood Network in Palliative Care (NNPC) is a volunteer-driven movement that has gained momentum in Kerala, especially in Palakkad district, where the volunteers are the arms of the community, supporting the patient in collaboration with governmental and non-governmental agencies in Kerala. Dr. M.R. Rajagopal⁶ is the father of palliative care in India.

It is worth to realize the pain and palliative care policy of Kerala aims at collaborating the Health Department, various panchayat raj institutions and various charitable organizations which mainly focus on the people who are facing pain and palliative care. According to the 12th five-year plan Grama panchayat, municipalities and corporations must implement this mandatory project on care and palliative care. At present, there are around 100 palliative care units in Kerala. In a study done in the Malappuramdistrict of Kerala (it was found that around 40%) of those people who are dying would have benefited from applying the principles of palliative care in their management. In Kerala, with a population of 32 million and a crude death rate of 6.⁷ around 80,000 dying patients

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and their families would be benefited each year. To this if we add the number of people living for years with chronic conditions the total number will be much more.

World Health Organization observes that "The fundamental responsibility of health professionals to ease the suffering of patients cannot be fulfilled unless palliative care has priority status within public health and disease control programme; it is not an optional extra. In countries with limited resources, it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advanced disease and urgently in need of symptom control must suffer without relief"⁹.

Palliative care seeks to improve the quality of life of patients and their families facing a life-limiting illness. Unlike curative healthcare, its purpose is not to cure a patient or extend his or her life. Palliative care prevents and relieves pain and other physical, psychosocial, and spiritual problems. As a quote by Dame Cicely Saunders, the founder of the first modern hospice and a lifelong advocate for palliative care, on the wall of a palliative care unit in Hyderabad, India, proclaims: palliative care is about "adding life to the days, not days to the life." Palliative care service provides feeling at peace and having a sense of meaning in life. It is therefore vital to identify and meet the physical, psychologically, social and spiritual care needs of patients, as well as to assess and treat pain and other symptoms. Palliative care improved the quality of life of patients and their families facing a life-limiting illness. Palliative care prevents and relieves pain and other physical, psychosocial, and spiritual problems. The service also improved the quality of life of both patients and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psychosocial and spiritual support¹⁰. Death is the end-of-life (EOL) process and dying is the end process of life. It can become stressful when one comes to know that he or she is going to die due to an incurable disease. We need to understand that to heal is more important than to cure. Palliative care should focus on comprehensive pain management as well as increasing the quality of life of the patients. Palliative care can also reduce the fear of dying and prepares the family for bereavement. It is now getting attention due to the increasing number of people with terminal illness. Therefore, this review has been done to understand the spiritual, ethical, legal and cultural aspects associated with it. There are approximately 500 centers providing palliative care in India. The "Kerala Model" is very popular in the country with its own palliative policy^{11.}

Despite its limited coverage, palliative care has been present in India for about 20 years. Obstacles in the growth of palliative care in India are too many and not only include factors like population density, poverty, geographical diversity, restrictive policies regarding opioid prescription, workforce development at the base level, but also limited national palliative care policy and lack of institutional interest in palliative care. Nonetheless, we have reasons to be proud in that we have overcome several hurdles and last two decades have seen palpable changes in the mindset of health care providers and policymakers with respect to the need of palliative care in India^{12.} Another notable fact is that, 138 organizations currently providing hospice and palliative care services in 16 states or union territories. These services are usually concentrated in large cities

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and regional cancer centers, with the exception of Kerala, where services are more widespread. The below five-layer framework (Ecological Social Work Practice Framework) emphasizes the vital role of self/patient and family, other immediate caregivers such as relatives, friends, third level institutional practices, fourthly community resources and partnerships and fifthly, health care policies on treatment, rehabilitation are interrelated and each phase, each component can play a significant part in the treatment of patients in a palliative care setting.



Diagram- Partners in Care Foundation (2012) Source

Home-based palliative care services are becoming increasingly popular with care being taken to the doorstep of the patient. Ideally, this is where people are most comfortable at the end of their lives, surrounded by their loved ones. It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick person. The aim of home-based care is ultimately to "promote, restore, and maintain a person's maximum level of comfort, function, and health, including care toward a dignified death." Home-based care models are also generally person-centered and comprehensive, with the aim to take into account factors such as culture, religion, and value systems, and respect people's rights to privacy and dignity, which fits in well with its "community-driven" philosophy. It is also cost-effective as it does not entail doctors and nurses' fees and traveling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments.

The palliative care movement is one example of how health services can go well beyond the biomedical model of health and be seen as an affirmative act of living with dignity even whilst accepting that death is an inevitable part of life. Continued efforts are needed to overcome the barriers to the successful implementation of palliative care. Ways to integrate current palliative care knowledge into the care of patients include multidisciplinary educational initiatives, research

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endeavors, and clinician resources. Still, a lot needs to be done for creating awareness and training in Palliative Care¹³. A study on Impact of Alternative Models of Specialist Palliative Care says that this study set out to systematically review the research evidence about the impact of alternative models of specialist palliative care on the quality of life of patients. 86 relevant papers were identified and reviewed, including 22 descriptive and 27 comparative studies. We found a few comparative trials of reasonable quality. There was some evidence that in-patient palliative care provided better pain control than home care or conventional hospital care, but this research was dated and open to criticism. Research on palliative home care teams and coordinating nurses demonstrated limited impact on quality of life over conventional care for patients dying at home. These negative findings may be due to the limitations of the assessment tools used. Palliative care what some regard as an increasingly biological approach in palliative care by integrating the community in the design, delivery, and evaluation of services to ensure social, spiritual, and emotional needs are satisfied while still providing great symptom management¹⁴. The general objective of this paper is to find out the effectiveness of a home-based palliative care project in a ruralsetting. The Specific objectives are (a) to understand the impact of palliative care services rendered by PHC in the rural settings (b) to analyze the different types of palliative care services provided by PHC (c) and to study the level of satisfaction of patients in palliative care services.

3. The Significance of the Study

The bedridden people are not getting proper care from the family members. All are in a busy schedule and they have no time to care for their parents or for loved ones. They feel that the patients are a burden and patients themselves feel like a burden for the family member. By the palliative care unit, they are the patients in a good way and gave proper love and care. Palliative care thus becomes a help for family members and palliative care unit act as a helping hand for the patient and family members. The unit helps in cleaning the wounds and treatment for patients and they change the urinal tube of the patients. This will make the family members easy for changing the urinal tube instead of taking the patients to the hospital. The care unit will reach out to the houses of the patient frequently for giving adequate treatment and care. In this scenario, palliative care reaches out to the houses of the patients frequently for giving adequate treatment and care.

5. Materials and Methods

In order to achieve the study's goal, the researcher employed a descriptive research design. Individual responses from the Palliative care unit, Vallikavu, who have received palliative care services from the PHC unit. The study's sample size is set at 30.Purposive sampling strategies were employed by the researcher for the investigation. A semi-structured questionnaire was employed by the researcher. The instruments for the study were created depending on the demands of the study, evaluated by experts, and distributed to the sample population. The developed questionnaire was distributed to the 05 respondents, who were requested to complete it and provide feedback and recommendations. Due to the difficulties in completing the questionnaire, the researcher made

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required alterations or revisions. The data was analyzed by the researcher in accordance with the study's goals. The data was analyzed using descriptive statistics by the researcher. Data analysis was performed by entering the specifics of the data obtained and, based on that data; the researcher calculated the percentage and provided graphical representations. SPSS was used by the researcher to analyze the data. Statistical analysis was performed using statistical software such as IBM SPSS Statistics Software (version 21), Epi-info, and MedCalc. Quantitative data were presented as mean or median and also as the frequency and percentages of the total. Patients who are able to communicate and comprehend their health problems from the adult population are deemed to be inclusion criteria, whereas those who do not communicate are terminally sick and other age groups are excluded. The ethical considerations, confidentiality, the dignity and value of the individual, the importance of human connections, and informed consent was obtained during the study.

Data Analysis, Findings and Discussion

The main objective of this study is to find out the effectiveness of a home-based palliative care project in a ruralsetting. The researchers collected data from both primary and secondary sources. The collected data from the respondents were tabulated, interpreted and later analyzed. Firstly, the investigators try to analyses the socio-demographic details of the respondents followed by objective wise analysis and closed observations.

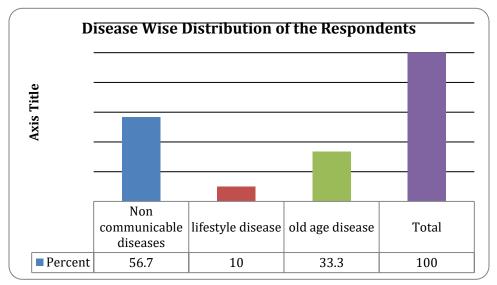
The Age of the respondents shows that 43.3% of respondents belong to the age group of 56 to 75. 50% belongs to the age group of 76 to 95 and the remaining 6.7% belongs to the age group of 96 to 106. The gender-based division, 33.3% respondents belong to a male and 66.7% respondents belong to a female. The researcher found that 76.7 percent of the respondents are OBC and 16.7 percent of respondents are General. Only 6.7 percent of the respondents are SC. This shows that most of the palliative care patients are comes under the OBC category. The study revealed that 66.7 percent of the patients are married. 30 % of the respondents are a widower and the other 3.3 percent leads a single life. The researcher found that 53.3 percent of the palliative care patients are APL category. This shows that most of the palliative care.

Category		Percentage	
Age Group	56-75	43.3%	
	76-95	75.50%	
	96-106	6.7%	
Gender	Male	33.3%	
	Female	66.7%	
Caste	OBC	76.7%	
	General	16.7%	
	SC	6.7%	
	Married	66.7%	

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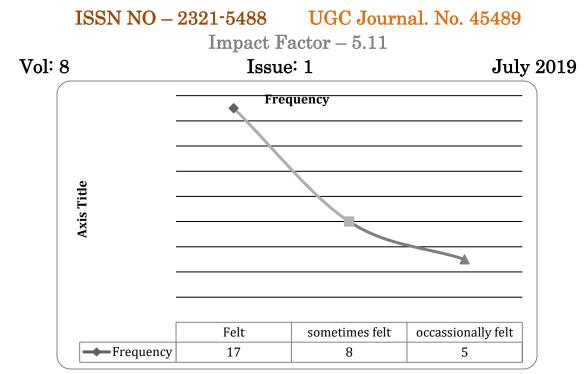
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Marital status	Widow	30 %
	Single	3.3%
Economic status	APL	53.3
	BPL	46.7

The disease wise of respondents are collected and analyzed in the table (No 1). This includes the prevalence of non-communicable diseases, lifestyle, and diseases often affected the old age people were identified and interpreted in the study as follows (Diagram No.1).



This above table (No.1) shows that 56.7% of respondents have affected by noncommunicable diseases, 10% of respondents have lifestyle diseases and remaining respondents have geriatric health difficulties. To ensure that palliative care is available and accessible to the majority of the needy, a major thrust should be on a primary health care approach. World Health Organization observes that "The fundamental responsibility of the healthprofessionals to ease the suffering of patients cannot be fulfilled unless palliative care has priority status within public health and disease control programme. In countries with limited resources, it is not logical to provide extremely expensive therapies that may benefit only a few patients, while the majority of patients presenting with advanced disease and urgently in need of symptom control must suffer without relief" (WHO, Geneva 2002). Understanding the various types of diseases will help the health care team to plan, organize and implement effective services to the needy people in the community.

Relief from Palliative Care Unit: The following diagram shows that 56.7% of respondents expressed relief from the services they received from PHC's through the palliative care centers. 26.7% respondents opined that they were got relief from the service of palliative care is sometimes only and remaining respondents opined that they occasionally got relief from the service of palliative care unit.



Palliative care among elderly people: Among the total study respondents, 50% of coming under the age group of 76 to 95 above. This is very significant information's and this clearly indicates that the majority of the service receivers are from the senior citizen's age group. This shows that the patients of palliative care are in the old age and the help is needed for these people. 43.3 percent of the respondents are in the age group of 56 to 75. Only 6.7% of the respondents came under the age group of 96 to 106. In older patients with chronic illnesses, the prevalence of symptoms is high and they are often not recognized. The frequency of symptoms in this population was illustrated by a study of community-dwelling elders age 60 or older with advanced chronic obstructive pulmonary disease (COPD), heart failure (HF), or cancer [3]. Overall, 86 percent reported at least one symptom that was rated as moderate or severe and 69 percent had at least two such symptoms. The most commonly reported symptoms included limited activity (61 percent), fatigue (47 percent), and physical discomfort (38 percent). Palliative care: Issues specific to the geriatric patient, Lynn Bunch O'Neill, MD et al (2012).

Another finding of the study is out of the total respondents, 76.7% of respondents are having the illness from 0-5 years. 20 percent of the respondents responded that they are having an illness from 6-10 years. And the rest of the respondents are having an illness from about 16-20 years. It is understood that early childhood diseases are becoming a serious concern for people receiving palliative care services in the community. Majority of the respondents, (66.7%) are known about the palliative care service through PHC. 26.7 percent of the respondents knew about the palliative care services through PAnchayat and the last 6.7 percent of respondents come to know about the service through their neighbors. The study found that 93.3% of the patients get services from other sources like private doctors near to their home and 6.7 percent of the patients said that occasionally get the services from the doctor.

The study revealed that 56.7% of the respondents are getting relief from the service of palliative care. 26.7% of the respondents said that sometimes get relief from the service of

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palliative care and 16.7% of the respondents said that occasionally get relief from the service of palliative care unit. The data shows that 33.3 percent of the respondents consider physical disability as their physical problem. 30percent of the respondents have an old age illness. 30 percent of the respondents have lifestyle diseases and the remaining 6.7 percent of the respondents have pain as their physical problem. The data revealed that 33.3 percent of the respondents get treating patient's services from palliative care nurse. 23.3 percent of the respondents get medicines services from palliative care nurse. 16.7 percent of the respondent get education services from palliative care nurse. 16.7 percent of the respondent get wound dressing services from palliative care nurse. 63.3 percent of the respondents said that cannot attend his/her job as their social problem. 30 percent of the respondents are excluded from the social problem.

From the data analysis, we can understand that 63.3 percent of the respondents decreases the intensity of the diseases after the member of the palliative care.16.7 percent of the respondents feel comfortable after the member of palliative care.10 percent of the respondents reduced the tension after the member of palliative care and remaining 10 percent of the respondents decreases the life burden after the member of palliative care. The study revealed that 46.7 percent of the respondents get medicines as physical services provided by the palliative care unit. 20 percent of the respondents get treating the patient's services from the palliative care unit. 20 percent of the respondents get BP monitoring services from the palliative care unit and the remaining 13.3 percent of the respondents get catheter change services from the palliative care unit.

In the context of mental health issues, 36.7 percent of the respondents consider insomnia as their psychological problem. 30 percent of the respondents have fear. 13.3% of respondents do not face any psychological problems. 13.3 percent of the respondents do not face any psychological problems. 10 percent of the respondents face loneliness and the remaining 10 percent of the respondents faced depression as their psychological problem. The data shows that 70 percent of the respondents are highly satisfied the palliative care and 30 percent of the respondents are satisfied with the palliative care provided by PHC. The study shows that 53.3 percent of the respondents are highly satisfied with the present palliative care treatment and 46.7 percent of the respondents are satisfied with the present palliative treatment. The data revealed that 66.7 percent of the respondents got relief from the participation of religious programme and other 33.3 percent of the respondents did not get the relief from the participation of religious programme. The data shows that 50 percent of the respondents are going to Vallikavu PHC with their urgent situation. 33.3 percent of the respondents are going to Government hospital and other 13.3 percent of the respondents are going to private hospitals. This shows that most of the palliative care patients are going to Vallikavu PHC. The study revealed that 76.3 percent of the respondents get medicines as economical services provided by the palliative care unit. 13.3 percent of the respondents get a catheter facility.6.7 percent of the respondents get chair facility and the other 3 percent of the respondents get a water bed. The study shows that 90 percent of the respondents are

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not given any suggestion.6.3 percent of the respondents expressed that the participation and service from palliative care center are satisfied and other 3 percent of the respondents said that doctor service is not satisfied. The primary palliative care services organized through local selfgovernment in collaboration with the concerned primary health centers. The major problems of all sampled Primary Health Centers were the less number of doctors, the absence of doctors from services, the lack of sanitary facilities and other infrastructure such as inpatients room, lab, bed etc.

Discussion

The current study illustrated the success of a home-based palliative care project in a rural location, and it provided a realistic image of how the palliative care unit functions efficiently in meeting patient requirements. This study highlighted the fact that a home-based form of treatment saved patients from needless hospital trips while also offering client-centered care. The immediate requirement for a multidisciplinary team composition allows for comprehensive treatment and can serve as a model for developing palliative care capability in low- and middle-income countries, according to (Sunil Rameshchandra Dhiliwal 2015). Sourav Goswami stated in 2020 that, as with any new programme, a need-based review for home-based palliative care is required.

Several research on home-based pain and palliative care services have emphasized the potential consequences of pain and palliative care services in rural settings. Palliative care practice has grown in recent years, and it has been observed that home-based Palliative care treatments enhanced patient satisfaction while decreasing expense. Outpatient or home-based Palliative care practice in the early stages of the disease was found to improve quality of life, and emergency and acute care applications were reduced as a result of training provided to patients and their families on drug use at home, crisis intervention, and patient care (Wiencek C, Coyne P etal 2014). According to Hudson PL (2010), one of the advantages of palliative care at home is that it provides psychosocial support to patients. It is understood that there a lot of focus is required to address the numerous issues of palliative care. One of the advantages of palliative treatment at home is that it provides patients and families confronting terminal illness with psychosocial support rightly mentioned by Hudson PL (2010) and the current study is enabled to look at the many issues linked to the nature of palliative care services.

Suggestions and Conclusion

The purpose of the study was to find out the effectiveness of palliative care programme in a rural setting. The objectives of the study were to find out the effectiveness of a home-based palliative care project conducted by the PHC, Secondly, the study also aimed to understand the impact of palliative care services rendered by PHC. Thirdly the study focused to analyze the different types of palliative care services provided by PHC and to study the levelof satisfaction of patients in palliative care services. A semi-structured questionnaire was used to find out the effectiveness of palliative care programmes in rural settings. The study shows that most of the

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respondents have noncommunicable diseases and a few others are a lifestyle and geriatric health problems. The palliative care unit services are much helpful to the bedridden patients and so that this service must reach out to all the needy people. The study analyzed the services of a palliative care unit. Palliative care services urgently need to be developed to meet the complex needs of older people.

It is indeed for palliative physicians to improve their familiarity with long-term care such as the administrative and clinical issues associated with older people living and dying in care homes. The capacity building exercises targeted to the various stakeholders associated with this care setting and training of health care professionals in community settings are the crucial steps to promote the palliative care services in the rural settings in Kerala. Local Self Governments should take steps to provide medicines and other accessories to poor patients with chronic diseases identified by the community-basedorganizations, with the help of the Government health care system. The private sector plays a major role in the health care scenario in Kerala. Many private hospitals in Kerala are providing palliative care to needy patients free of cost. Palliative care initiatives by private hospitals should also conform to the quality control and training criteria set by the palliative care policy. Nevertheless to say thatnowadays voluntary organizations are created an admirable platform in providing care and support services to the people those who are needed care.

"All people have a right to receive high-quality care during serious illness and to a dignified death free from overwhelming pain and in line with their spiritual and religious needs." Palliative care – the solid facts (2)

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