Vidya KR, et al., La Prensa Medica 2021, 107:4

La Prensa Medica

Research Article

A SCITECHNOL JOURNAL

An operational research on palliative care in a district of central Kerala

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Abstract

Introduction: Quality of life of patients and their families can be improved by Palliative care approach. Palliative care treatment will be given to patients who are facing 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 complications. In Kerala, a southern state of India, funding of palliative care projects by local self-government are made mandatory and thus making its implementation uniform and successful. Ernakulam is the most advanced district in the state had implemented mental health programmes also through palliative care networks. This research work is intended to study the operational aspects of palliative care services for the betterment of the programme in the district.

Objective: To study the process and outcome of palliative care programme in Ernakulam

Methodology: Design:-Operational research-descriptive ecological study.

Setting: Ernakulam District palliative care units - There are 116 Primary care units-101 in rural areas and 15 Urban areas- 12 Secondary care units in major hospitals, 14 secondary units in block hospitals and 1 tertiary care unit. Study period: - Jan 2017 – Dec 2017.

Programme process and outcome: Total of 24,287 Cases were registered and 18,304 (75.37% ; 95% CI- 74.82-75.91) attended in outpatient departments. A total of 71,178 home care services were also given. Services were provided by 162 primary nurses, 36 secondary nurses, 24 physiotherapists and 4 medical officers exclusively for the programme along with Medical officers of health institutions and 1500 trained volunteers. Long-term care is given for 10,175 patients with chronic morbidities. 6 crore Indian rupees were allocated in primary care units of rural areas through respective local self-government and INR 2,16,000 were provided by the national government. Volunteer's Training sessions lasting for 3 to 5 days, staff review meetings, basic courses of one and half months for Doctors and nurses, disease-oriented training for caregivers and Palliative Day observations were the other main process activities. Implementation of video calling facility at tertiary care Centre and mental health programs in urban areas were also initiated.

Conclusion: Satisfactory implementation of the palliative programme is made possible in the district with 32 lakhs population, through the concerted and focused efforts of all sectors of society with people's participation and making it a people owned programme. Palliative care is gaining significance due to a global increase in the prevalence of Non-Communicable Diseases (NCDs) and the consequent increase in the numbers of patients requiring long-term care for chronic conditions.

Introduction

In spite of the existence of palliative care services in more than half of the world's countries, there is a need for major expansion for its global accessibility. Palliative care has been reported to be cost-effective compared to conventional hospital-based and episodic medical care in providing symptomatic relief and improving quality of life. Palliative care is currently provided as home based care or as acute care in hospital setting or as institutional aged care settings sometimes referred to as hospice care. A systematic review by Finlay et al. demonstrated the effectiveness of palliative care, especially home based care over hospital based care with a definite advantage of multi-disciplinary team approach.

Kerala pioneered community-based palliative care through a socially innovative approach called the Neighbourhood Network in Palliative Care in an attempt to develop a free of charge, sustainable, community led, service capable of offering comprehensive long-term care and palliative care. The network aimed to empower local communities to look after their chronically ill and dying patients. Funds for running the programme were raised locally by volunteers. The programme was first piloted in 1996 in Malappuram, a northern district of Kerala, for patients with cancer which was then gradually expanded to include other conditions requiring long-term care such as cerebro-vascular accidents, dementia, paraplegia and psychiatric illness. Volunteers from the local community were trained to identify the psycho-social problems of people with chronic conditions in their area and to intervene effectively with active support from a network of trained professionals. The model was shown to be successful, and inspired the state to implement a palliative care policy to ensure universal coverage of palliative care services in all its local administrative units (~ 1000 in numbers), making it the first state in Asia to develop such a policy. The Policy considers home based care as the corner stone of palliative care services. The Neighbourhood Network in Palliative Care in Kerala as discussed above, has been described as an exemplar model of community-based palliative care for other low-resource countries world- wide. Although various provisions of Kerala model of home-based palliative care have been described, there is limited information on patient characteristics and utilization of palliative care. Earlier studies have reported that around 12–28% of patients chose to opt out of palliative care for various reasons which increases with a decrease in social support from the clinic and the number of home visits by the physician. Understanding the patient characteristics, utilization of home-based palliative care and its predictors can assist service planners in the appropriate allocation of resources and service packaging to meet the complex needs of palliative care patients.

Outcome variables and data sources

Sources of data were annual patient registers and patient case records at the Manjeri Pain and Palliative Care Clinic, Kerala. The annual registers contain the name, age and diagnosis of the patient and these have remained uniform over the last two decades. The patient case records contain baseline as well as follow-up information of the patients registered and are maintained by the caring nurses.

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