Editorial

A primary care–based patient centric palliative care model

Abstract

The World Health Organization defined 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 patient centric primary care model (PCCM) promises to provide a solution to control these health-care challenges. The model is largely based on the chronic care model (CCM) and the model developed by the Organized Medicine Academic Guild (OMAG) for delivering health care in India.

Keywords: Palliative care, patient centric, primary care

Background

Societies worldwide are excessively being challenged by the ongoing growth in health-care expenditures from the changing patterns in the demand for management of chronic life-threatening health conditions. It is being observed that long-term care (LTC) for such health conditions is growing rapidly and is expected to double within the coming decades.[1,2] The management and care of patients with such conditions is not only physically demanding but also monetarily exhausting. Added to this is the fact that contemporary health-care systems face difficulties in solving these challenges, as they have originally been designed to solve single, acute, and mainly short-term diseases. The fragmented speciality driven and existing in silos health-care system has not been of help as ongoing specialization and technological improvements have led to fragmentation of care delivery thereby rendering management and care of chronic life-threatening health conditions beyond reach of common man. In addition, structural and financial barriers have further increased the segmentation of organizations that provide primary and secondary care health care and associated social care.[1,3] Importantly, this fragmentation of care negatively affects the provision of integrated LTC and support for the chronically ill life-threatening health conditions and for people with complex care needs. Despite the wide array of health services they use, these patients do not always receive appropriate and coherent care. Over last decades or so efforts have been made to deliver palliative care using home-based or community-based approaches. However, the experiences are few and limited to certain geographies only. Unless the delivery of palliative care is ingrained in the health-care system of this country, the benefits of such efforts will not be realized.

Challenges

The World Health Organization defined 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."[4] Given the way, palliative care is defined *per se*, it is imperative that it is best administered by an interdisciplinary, multidimensional team, comprising doctors, nurses, counselors, social workers, and volunteers. Given the way our health-care resources are stretched, it appears difficult for present day health-care system to deliver an interdisciplinary, multidimensional team-based care. No doubt, less than 1% of India's 1.2 billion population has access to palliative care.[5]

Current trends in health care at one hand decrease the access to palliative care for patients with life-threatening health conditions having and undermining the basic philosophy of palliative care on the other hand. Added to it is the limited availability of palliative care services in a predominantly disease-oriented patient care. The key aspects of palliative care are clearly absent in current health-care systems. The idea of communication about patient goals and preferences for care is missing. The most important communication for a patient with serious and life-threatening disease is communication focusing on patient's preference regarding pain, symptom control, avoidance of prolongation of the dying process, a sense of control, concern for family burden, and an opportunity to strengthen relationships with loved ones. The current health-care system is inadequate to deliver on this.

At present, an additional challenge to implementation of palliative care is the limited evidence to guide better decisions regarding symptom management, different health-care models, decision-making approaches about treatment options, and communication on sensitive topics such as death, and support for family caregivers.[6] Probably, the most important of them

all is the absence of a model scalable, sustainable, universally acceptable and ingrained in the health-care system of the country. An Adhoc program run in a project mode is going to do no good to delivering palliative care and prevent making it accessible to large populations.

The patient centric primary care model (PCCM) promises to provide a solution to control these health-care challenges. The model is largely based on the chronic care model (CCM) and the model developed by the Organized Medicine Academic Guild (OMAG) for delivering health care in India.[7,8] PCCM will use following elements:

Principle

PCCM envisages assisting in changing from a disease-focused approach to a patient-centered philosophy, where the needs of the patient and the patient/family goals are essential to planning care. Even though it is know that the patient-centered approach broadens the focus of care, it increases the cost and makes operations difficult as it requires coordination across specialties and disciplines. Putting primary care physicians at the center of PCCM intends to meet these challenges rendering it more lucrative to operate.

As per the design of the model, the primary site for the designed intervention is optimized around the Community Health Centers and the Primary Health Centers. The idea is to explore the processes of the suggested intervention through primary care. Through use of specialists trained in family medicine and primary care the facilitating factors and barriers will be identified along with the application of corrective measures. As a generic makeup the designed intervention will be delivered using participatory approach to:

a. provide preventive and therapeutic services for life-threatening illness principally through a community-based approach extending into a primary health-care center patient centric primary care model centered on primary care/family physician.
b. provide palliative care using a continuum of care approach centered around primary care/family physician under the patient centric primary care model at secondary and tertiary care health facilities, and
c. create an enabling sociocultural environment for healthy social and treatment-seeking behavior.

Design

As shown in Figure 1 and Table 1, all chronically ill patients with or without serious health conditions will be stratified into three strata. The process of stratification will be home-based carried in a community-based approach by a primary care team (PCT) trained in screening patients as per complexity of care needs. Again as a generic rule the strata will take into account

1) The complexity of care needs
2) The level of frailty
3) The availability of care giver and
4) The accessibility to health-care delivery.

Based on these four criteria a score ascribes the patients to three broad strata:

(A) Patients without complex care needs also referred to as healthy profile. This strata is further divided in two: Healthy profile A (with a caregiver or easy access to health-care delivery) and B (without a caregiver or difficult access to health-care delivery).

B) Patients at risk of complex care needs.

(C) Patients with complex care needs.

Strategy

The patient centric primary care model for palliative care intends to integrate the primary care model essentially driven by primary care physicians/family physician with a highly compartmentalized palliative care model into a person centered health-care model using the skills of primary care physicians in its effective delivery through a continuity of care. The referral and back referrals will stay as the key in ensuring this continuity.[8]

The weaving of this model around the primary care physician on one hand ensures that community-level services delivery is not at high risk of fragmentation and inefficiency and on other ensures availability of specialist and multidisciplinary care closer to the community.

The idea is to ensure an unrestricted access to high–quality palliative care (QPC) and also to ensure that through a patient centered model, a specialist trained in primary care will deliver,

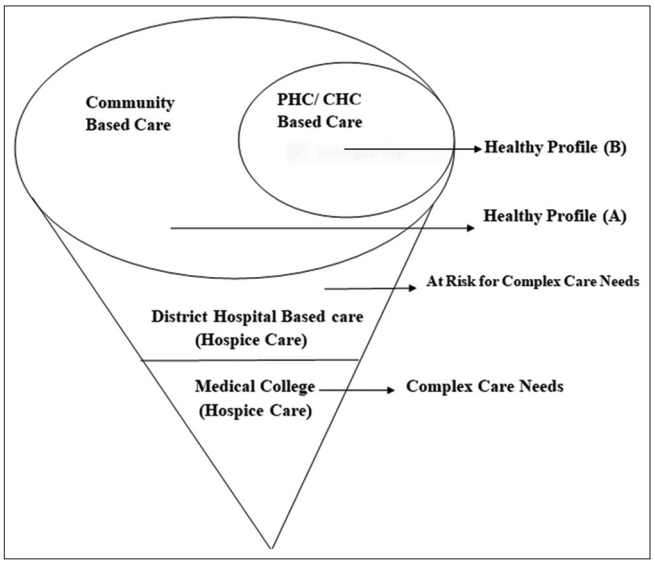

Figure 1: Diagrammatic representation of palliative care delivery

Table 1: The Palliative Care matrix, a management model for service delivery

	Healthy profile (A and B)	At risk profile	Complex care needs profile
Stratum	A	B	C
Level of care and support	Low-intensity	High-intensity	High-intensity
Care and support coordination	Primary care team (PCT)	PCT and clinical experts	PCT and clinical experts
Type of care	Preventive, promotive, curative	specialist	Multidisciplinary
Patient-service giver interaction	On patients' initiative or initiated by PCT	Structured: ±1/month	Structured: ±2/month
Duration of individual care and support	Not applicable	Extendable	Extendable
Approach	Community based through PCT with community participation (B) Facility based through PCT (B)	Hospital based individual (PCT and clinician)	Hospital based individual (Palliative care team and clinician)
Focus	Community-based management	Risk reduction and palliation	Palliation

or assist delivery of QPC in centers delivering specialist and multidisciplinary health care.

The PCT lead by the primary care physician, as part of community-based approach will aim at ensuring that individuals in *Healthy profile* strata remain healthy. The team will further help these individuals enhance their self-management capabilities. PCT members will organize events to introduce individuals in these strata to local health care and welfare organizations and facilities. Individuals will be informed about contacting the PCT in case of significant changes in physical or mental health or in living situations. When a higher level of care and support is needed, the PCT will be consulted and the individuals will be transferred to another profile.

Individuals in the other two profiles, i.e. the *at-risk profile* and *complex care needs* profiles will be visited regularly by PCT with efforts to obtain a sustainable "community-based" palliative service for the individual and a capability of offering comprehensive LTC and QPC at secondary and tertiary health care facility to those in need. This extension of services approach through a primary care physician from community to specialty and back will ensure community ownership and provide alternative to the currently fragmented palliative care approaches. The primary care physician will lead the individuals to receive personalized care at secondary and tertiary health-care facility for a specified period of time and ensure delivery of the same palliative care through community-based approach later. This is to provide cost-effective community-based home care for patients with end stage clinical condition. The PCT team will offer case management to the *at-risk profile* with help of the clinical staff at the District level hospital. The care and support plan will be evaluated regularly and updated and adapted when necessary. Once every 4 weeks the PCT will discuss the progress in reaching the care and support plan's goals and the effectiveness of the interventions.

Summary

Home-based palliative care services are becoming increasingly popular. However, the services are mostly run in a project mode, NGO driven, or temporary. The approaches have fragmented and limited to a few success stories. This despite the fact that people tend to be most comfortable at home during the end stages of their lives, surrounded by their loved ones. Instead, a sustainable, scalable and universally applicable model will ensure delivery of QPC on a long-term basis. The aim of the patient centric model is to "promote, restore, and maintain a person's maximum level of comfort, function, and health and delay events compromising on these through a community based approach delivered by a primary care physician."

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

Sunil Kumar Raina[1], Raman Kumar[2], Rajiv Kumar Gupta[3]

[1]Department of Community Medicine, Dr. RP Govt. Medical College, Tanda, Himachal Pradesh, [2]President, Academy of Family Physicians of India, New Delhi, [3]Department of Community Medicine, Government Medical College, Jammu, Jammu and Kashmir, India

Address for correspondence: Dr. Sunil Kumar Raina, Department of Community Medicine, Dr. RP Govt. Medical College, Tanda, Himachal Pradesh, India.
E-mail: ojasrainasunil@yahoo.co.in

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Access this article online

Quick Response Code:

Website: www.jfmpc.com

DOI: 10.4103/jfmpc.jfmpc_391_19

How to cite this article: Raina SK, Kumar R, Gupta RK. A primary care–based patient centric palliative care model. J Family Med Prim Care 2019;8:1519-22.