

Developing a Dynamic Conceptual Model of a Home-Based Palliative Care Plan Using the Comprehensive Primary Health Care (PHC) Approach

Mousami Kirtania¹, Ajitha Katta^{2*}

^{1,2}School of Medical Sciences, University of Hyderabad, Hyderabad, India

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ABSTRACT

Background: Palliative Care (PC) was a core component of Primary Health Care services during the World Health Assembly Resolution, 2014. The study aims to develop a Comprehensive Palliative Care Model (CPCM) for patients with life-threatening conditions compliant with the local context and unmet needs.

Materials and Methods: A mixed-methods approach will be adopted for the three-phased study in two districts of Telangana. Phase I, a literature review, will be performed to explore globally available PC models, followed by an on-ground observational study. Phase II will address the gaps in existing models while identifying the unmet needs of the patients and caregivers. The outcome of the above phases will help develop a CPCM in Phase III. The developed model will be validated using the Delphi technique.

Results: The expected outcomes of the study are a) Phase-I: Details of the PC models available globally and locally, b) Phase-II: Availability of essential resources in the Health and Wellness Centers (HWCs), Knowledge and Attitude of the PC team, Barriers to provide PC, Unmet needs, and c) Phase-III: CPCM model

Conclusion: The study attempts to provide a holistic PC model, considering the health system, patients, and caregivers and offering policy suggestions to the state.

Keywords: Comprehensive care, Home-based care, India, Model, Palliative care, Primary Health Care Approach

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***Correspondence:** Dr. Ajitha Katta (Email: ajithakatta.publichealth@gmail.com)

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INTRODUCTION

According to WHO, Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness.¹ Palliative Care was born in India in the year 1986 as the Shanti Avedna Sadan in Mumbai, a hospice. The care strives to prevent and relieve suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual.² Palliative care is provided by a team of trained and specialized doctors, nurses, and other required specialists as per the needs of the patient. Palliative care can be given at any age and any stage of the severe illness, along with curative treatment.³ Palliative care treats the symptoms and stress of serious illnesses such as Cancers, Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), kidney disease, and many more. The symptoms treated include pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, lack of sleep, and anxiety. As the world is dealing with the non-communicable diseases transition, the need for palliative care has risen though only a few have access to the care. Globally, only 14% of the population has access to palliative care as reported by WHO. Whereas the care is limited to only 1% when it comes to India.⁴

Providing effective Palliative Care at different levels needs the knowledge of the various models in operation. Models of palliative service delivery include inpatient palliative care units and hospices, outpatient services, consulting teams at hospitals, homes, and community levels, and integrated care involving different levels of care.⁵ The common principle of all the models follows a holistic approach towards physical, social, emotional, and spiritual well-being, considering the patient and the caregiver as a unit of care.⁶ We need to understand that Palliative care is based on the patient's needs and not on the patient's prognosis.⁷ Acute care and long-term hospital stays may not be the choice of the dying patient at the end of life. Home-based palliative care is for patients who choose to hold on to their loved ones and have a peaceful death at home. Patients choosing to stay in home-care setting are found to incur less cost and more satisfaction at the end of life.⁸ While most of the patients prefer home-based services, the outcome is not achieved in many of the cases.⁹ The inconsistency between the patient's choice and the care delivery represents a service gap that needs to be fulfilled by the palliative care teams.

Palliative Care is an interdisciplinary approach that focuses on improving the quality of life for terminally ill patients. Research has shown that the integrated approach involving the community has lowered acute care service use alongside high patient satisfaction.¹⁰ The community-based approach to delivering home care has meant to improve patient outcomes while reducing the cost of care. Home-based care can

be proven effective in terms of providing potent psychosocial care by the carers which is not possible in long-term hospital stays.¹¹ Also, the communication gap with healthcare professionals due to lack of training can be filled as one-on-one attention is provided in home settings.

A pre-requisite for community-based home care is sufficient training of grassroots workers which is equally necessary like the other professionals as they perform a critical role in the program. Though they are provided a few days of training, it is not sufficient as they are still confused with the topic.¹² Due to several misunderstandings, palliative care could not take its initiative at the homes.¹³ Therefore, a palliative care model will be developed to address these gaps.

The study protocol aims to develop a new Comprehensive Care Model for patients with a life-threatening condition and in need of Palliative Care. The objectives of the study are to review and explore all the palliative care models available globally; to visit all the palliative care centers (government and non-government) in both the districts; to assess the essential resources available in the HWCs, to conduct a knowledge, attitude, and barriers survey with the health-care professionals; to administer the POS (Palliative Care Outcome Scale) to the patients receiving palliative care along with identifying their challenges to receive the care; and to validate the developed model using Delphi technique.

METHODOLOGY

To achieve the objectives, the study is divided into three phases, each addressing a specific research question and objective (Figure 1).

Study design and setting: A mixed-method study design will be used for data collection. Two districts are selected purposively, namely Hyderabad and Rangareddy. The surveys and interviews will take place at the palliative care centers, 2 non-profit, and 4 state service palliative care centers.

The study will pursue the following three phases;

PHASE I

An observational study with a mixed-methods design will be adopted. The following activities will be executed in phase I of the study;

Literature Review: A review of the literature will be done to understand the palliative care models existing globally as well as in the country. This process will help in creating a base of the model accompanied by knowledge enhancement. For the process, electronic databases such as PubMed, Scopus, and Web of Science will be used for a thorough review process. The search will try to focus more on the models based on the Indian context to recognize the common components of the models.

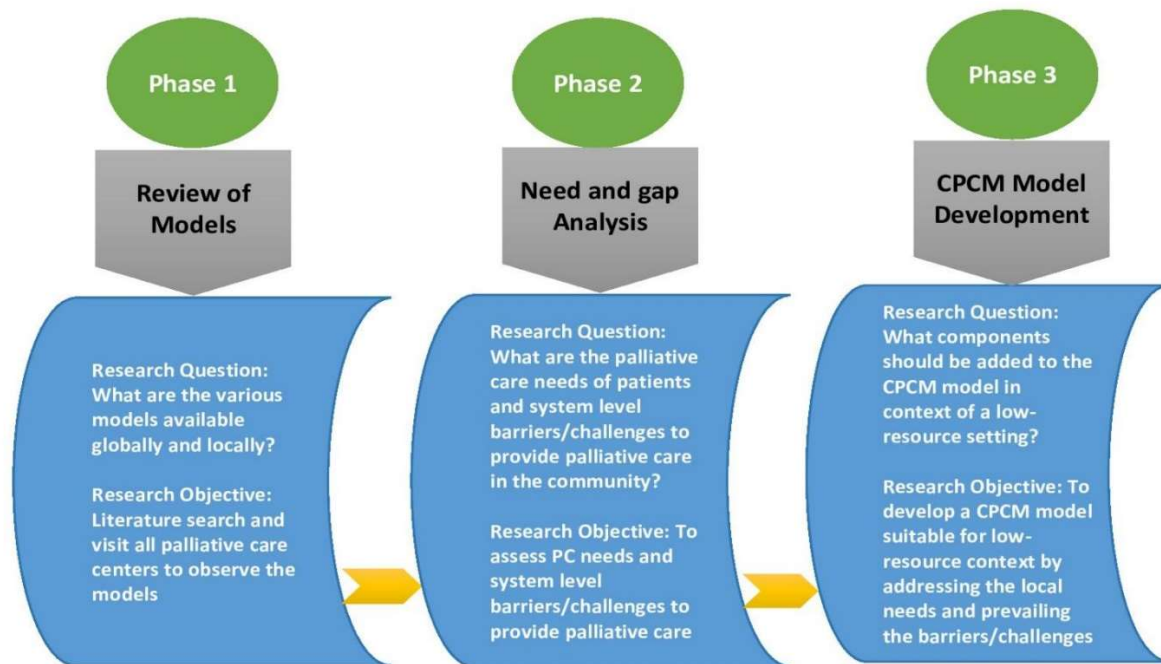


Figure 1: Phases of the Study

The review process will be continued throughout the research to remain updated and identify inconsistencies.

Observational Study: To understand the models in Telangana, all the palliative care centers including the tertiary hospitals, hospices, and NGOs will be visited in the two districts, Hyderabad and Rangareddy. A cross-sectional observational study will be performed by attending the OPDs, in-patient wards, and home-care vans depending upon the services provided by various centers. The home-care vans will be accompanied as per the distribution in different blocks of the community. The different models will be observed and noted for future reference.

PHASE II

The cross-sectional mixed methods study deals with the needs and gap analysis related to palliative care at the level of the healthcare sector and patients/caregivers. The second phase will proceed in the following manner;

Assessment of Resources in Health and Wellness Centers: Palliative Care provided within the primary healthcare package through the Health and Wellness Centers (HWCs) has gained more strength.¹⁴ The addition of palliative care as a part of comprehensive primary care represents the inclusion of a new sub-population-group into the activities of HWCs.¹⁵ To effectively provide palliative care services at the sub-centers turned HWCs, it is necessary that all the basic facilities be present at the centers. To assess the availability of the resources, a checklist referred by National Health Mission will be used.¹⁶ The checklist will be analyzed based on the dichotomous scoring, i.e., Yes and No responses. The facility/resources present will be marked Yes and vice versa. The mean

score will be calculated and compared for both the districts.

List of Essential Supplies: A list of essential supplies including medicines, equipment, and amenities will be prepared following the checklist analysis. The process will follow the NHM operational guidelines and the WHO essential drugs list required for the Sub-centers and Primary Health Centers.¹⁷ The prepared list will help in making an operational budget plan for the centers.

Investigation of Persisting Barriers to Provide Palliative Care: An online survey will be followed by telephonic interviews to identify the major barriers and challenges faced by the healthcare workers providing palliative care services. The barriers and challenges will be considered while developing the model and also during the policy recommendations.

Knowledge and Attitude Assessment of Palliative Care Providers: Palliative Care is a multi-disciplinary approach consisting of domains like physical, psycho-social, and spiritual involving the patient and their families. Therefore, this study will assess the basic knowledge as well as the attitude of the health care providers towards palliative care. The convenient sampling will include the healthcare workers who are engaged in providing palliative care for 6 months or more.

The Palliative Care Knowledge Questionnaire - Basic (PCKQ-B) and Palliative Care Attitude and Knowledge (PCKAK) Questionnaire will be adopted and modified according to the Indian context.^{18,19} The validation process will include pre-testing and pilot testing of the questionnaire before administering it to the actual sample size. The pre-testing phase will deal with the face and content validity and the

pilot testing will consider the reliability of the questionnaire.

Needs Analysis of Patients Receiving Palliative Care: The needs of the patients diagnosed with chronic illness will be assessed through the Palliative Care Outcome Scale - version 2 (POSv2).²⁰ The scale will be translated into the local languages Telugu and Hindi and administered to the patients and the primary carers as their proxy. The translation process will include forward and backward translation of the scale for both the local languages. The final version of the scale will be administered to the representative sample of the respondents for pilot testing. The content and construct validity will be measured along with internal consistency of the scale using Cronbach's alpha. Post-validation, the translated scale will be delivered to the main sample of the study.

The individual and overall profile scores will be calculated to interpret the outcomes. However, if the patients or their caregivers are uncomfortable or do not give consent to take the survey, the study will be terminated immediately. Open-ended in-depth qualitative interviews will be organized with the same patients to understand their perspectives toward the palliative care service they are currently receiving.

PHASE III

The CPCM model will be developed based on the results obtained from the phase-I and phase-II study, expert opinions, and the WHO public health model for palliative care.

Model development: A tentative model will be developed including all the essential elements of Home-based palliative care in compliance with WHO guidelines directing to the local context.^{21,22} Appropriate training modules and strategies will be suggested according to the Knowledge, Attitude, and Barrier's survey with the palliative care team in the phase I. The PC needs and challenges to access the care in phase II will form the base of the model which could be addressed in the future implementation programs.

A referral pathway will be suggested by liaising with the community and the key stakeholders such as the village head, community health workers mainly the Accredited Social Health Activists (ASHAs), Auxilliary Nurse Midwives (ANMs), and the self-help groups. The pathway will start right from the Health and Wellness Centers to the Palliative care centers, Hospices, and NGOs. The pathway will try to fill the gap in the existing model by extending the referral from the community to the centers following a bottom-up approach.

Model Validation: The model will be validated using the Delphi technique.²³ The technique will follow 2-3 rounds of validation process based on the feedback received. The process will begin with open-ended

questions followed by a quantitative analysis of the responses and opinions gathered. The stakeholders involved in Phase II will also be included. Once there are no more novel opinions, the rounds will be terminated and the model will be considered constructive.

Ethical Considerations: The study protocol was approved by the Institutional Ethics Committee, University of Hyderabad. Permission for the study has been granted at the respective district levels. The protocol will follow the IEC regulations. The reports will be submitted to the stakeholders to remain updated.

Confidentiality will be maintained by replacing the participant names with unique codes, age grouping, files containing electronic data will be password-protected and encrypted, and data will be stored till the end of the study. Individual consent will be taken by the principal investigator before beginning the survey and they will be explained about the format of questions that can be asked to them. If they give consent, only then the survey will be done.

Data Analysis

Quantitative data: A cross-sectional descriptive observational study will be executed among the Palliative Care team (Physicians, Nurses, Allied Health Professionals). A Basic knowledge and Attitude Questionnaire will be developed and validated considering the local context. Post-validation, the questionnaire will be tested for reliability through a pilot study. The data will be analyzed by using the SPSS statistical software. The knowledge of palliative care and attitudes towards care for the dying will be the primary outcome variable whereas age, gender, educational qualifications, years of professional experience, experience in palliative care, and training in palliative care will be taken as independent variables. Univariate descriptive analysis will be performed using frequency distribution for categorical variables and measures of central tendency (mean, median) and dispersion (standard deviation) for the numerical variables.

Bivariate descriptive analysis will be done to relate the results of the knowledge and attitude scale with each other and with the independent variables. Independent samples Student's t-test and Mann-Whitney U test will be used for categorical, normally distributed continuous, and non-normally distributed continuous variables, respectively. Similarly, Spearman's correlation coefficient will be used for analysing the relationship between the numerical variables. A P-value <0.05 will be considered statistically significant. To estimate the level of knowledge in palliative care and attitude toward care for the dying, a linear regression model will be used.

Qualitative data: The interviews will be conducted by the principal investigator and a moderator for the focus group discussions. The interviews will take place in a quiet and comfortable place according to

the participants. English, Hindi, and Telugu languages will be used during the interviews based on the participant's preferences. The interviews will be tape-recorded accompanied by field notes to corroborate the findings. Interviews in Hindi and Telugu will be translated into English and back-translated to ensure appropriateness. The verbatim will be transcribed to text and analyzed in the Atlas.ti software by using the thematic approach.²⁴

Expected outcomes of the study

The expected outcomes of the study according to the phases are expressed in the table below (Table 1).

Table 1: Expected Outcomes of the Protocol

Phases	Expected Outcomes
Review of Models	<ul style="list-style-type: none"> The existing models and referral pathways in the Hyderabad and Rangareddy districts in Telangana will be unfolded which will further help in identifying the gaps and formulating a model for the state.
Needs and gap analysis	<ul style="list-style-type: none"> Needs analysis of the patients will allow to add the necessary components in the model improving their access to palliative care and quality of life. Knowledge and Attitude assessment of the palliative care providers will help in suggesting palliative care training modules, courses and programs.
CPCM* model development	<ul style="list-style-type: none"> The validated model will provide an outlook of essential components and integral referral pathways for effective home-based palliative care for the state.

*CPCM - Comprehensive Palliative Care Model

DISCUSSION

For a home-based palliative care program to expand it has to be cost-effective while delivering high-quality care to the beneficiaries.²⁵ This can be achieved by the integration of Palliative Care into Primary Health Care which has been a focus of action by the Indian healthcare system. One of the initiatives by the Government of India is to transform the Sub-centers and the Primary Health Centers into 1,50,000 Health and Wellness Centers (HWCs) to provide comprehensive care, wherein palliative care is also a component under the primary care provision.²⁶ Home-based palliative care service is a way to increase access to the remote population as a part of the primary healthcare system.²⁷

Home-based palliative care programs (like CPCM) need to have a basic evaluation of the needs of the beneficiaries, and the health system in terms of logistics (Phase I and II). Post-resource-based evaluation, the competent authorities need to be involved to analyze the program (model) to re-frame and verify it (Phase III).²⁸

In India and many other low-middle-income countries, there is a lack of resources in terms of manpower, infrastructure, essential drugs, and other ser-

vices due to low funding opportunities.²⁹ Palliative care is funded from the NHM flexi pool rather than having separate funding for its program. The PHCs are mostly run by Medical Officers supported by community health workers like ASHAs, ANMs, and Mid-Level Health Providers (MLHPs). Community-based home care is lagging in the country because of limited reimbursement schemes for the grassroots workers and the operational complexities of delivering care through a wide-network referral system.¹²

Home-based Palliative Care is provided in a scattered way in India because there is not enough knowledge about the care among the beneficiaries as well as the healthcare workers.³⁰ The latter factor is majorly responsible for not initiating home palliative care services among community by the primary care workers. Though some of the staff are trained in palliative care, very few are confident regarding the concept and terms. A knowledge-based survey of health professionals is effective in deciding the mode and duration of the training facilitation programs.³¹

Defining the patient population and assessing their needs helps in exploring the gaps in the existing care to enhance the quality of care (Phase II).³² For instance, only 5.8% of the palliative care centers are providing uninterrupted access to oral morphine.³³ The resources and the facilities can be managed according to the needs of the patient alienating towards a potent policy response. Several approaches have been used for assessing needs such as the comparative, corporate, and epidemiological approaches. Needs assessment is also defined as a process of developing and implementing services planned from the results obtained.³⁴

Lack of knowledge, cultural hesitancy, insufficient training, funding, and community awareness are the major barriers reported to the provision of palliative care which need to be addressed (Phase III - components to be added for the model) to ensure a sustainable palliative care model.³⁵ Poverty, geographical constraints, social stigma, and lack of trust in the palliative care team also add up as barriers from the patient's perspective which requires acquaintance (Phase - II Qualitative Interviews with patients).³⁶

STRENGTHS

The current literature has assessed the knowledge and Attitude of either the Physicians or the Nurses rather than the whole team. To the best of our understanding and knowledge, this will be the first study to assess the palliative care knowledge and attitude of the complete team by developing a questionnaire suitable for all of the members of the team. Also, the comprehensive palliative care model (CPCM) will be the first and foremost available for the state concerned. The collaborative model development process by including the governmental and non-governmental organizations will manifest the panoramic view of the system. On the other hand, in-

volving primary health care in the system will assist in reaching the outreach population.

LIMITATIONS

It would be challenging to apply the wider definition of palliative care, especially in a resource-limited setting. As only two districts are chosen for the study, the sample size may not be higher leading to lower chances of generalization. The smaller sample size could be a limitation of the study as there are limited staff available concerning palliative care.

CONCLUSION

The Comprehensive Palliative Care Model (CPCM) will be developed, validated, and disclosed to the healthcare system and the government to act accordingly to implement the model coherent with the resource setting. The model could potentially suggest new guidelines or policies directing funding, morphine regulation, and capacity building for the state.

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