Draft on Palliative Care Service Development, Education, and Research: A Concept Note on Development of Centre of Excellence.

Prof Sushma Bhatnagar, All India Institute of Medical Sciences, New Delhi

1. Introduction

In this section gaps in palliative and end of life care provision in India and concept of palliative care and its evolution in India is briefly discussed.

1.1. Gaps in Palliative and End of Life Care Provision in India

Palliative Care needs in India is estimated as 175-275 per 100,000 population. India is classified under high palliative care requirement region of the world. Around 70-140 per 100,000 people in India with cancer require palliative care and the rest needing palliative care have progressive non-malignant conditions and HIV/AIDS. More than one million new cancer cases are diagnosed each year in India and with over 80% presenting with stage III and stage IV diagnosis. Experience from the cancer centres across India confirms that two-thirds of patients with cancer are incurable at the time of presentation and are only candidates for palliative care. Besides these significant numbers of patients who receive treatment for cancer recur, and it is often not amenable to active cancer-directed treatment. About 80% of patients with advanced cancer experience moderate to severe pain due to inequitable access to essential pain relief medicines.

A study conducted at Pune showed that 83% of people in India would prefer to die at home. Palliative care at home is the most cost-effective, relevant and practical option in the Indian setting. However, due to the lack of palliative care provision, patients receive inappropriate aggressive medical interventions at the end of life, which drain the resources of patients and family. Cost of medical care and non-availability of palliative care at the end of life has forced up to 78% of patients in advanced stages of illness to leave hospital and ICUs against medical advice. Families unilaterally initiate these discharges, and these discharged patients do not receive any symptom relief or palliative care at the end of life. The current health spending in India is 1.5 % of the GDP, and there are limited allocated budgetary provisions for palliative care. 60-65% of the population in India spend out of pocket for their health-related expenses. Around 40-60 million families are becoming more poorer every year due to increasing health-related costs, and most of these costs are related to aggressive medical interventions in the last few days of life. This could be avoided if there is universal access to palliative care.

According to the 2015 Quality of Death report ranking, in India, the capacity to deliver palliative care is scored as 0.6/100, i.e., only 0.4% of the population in India have access to palliative care. Access to oral Morphine is one of the indicators of palliative care provision. In India, only 0.4% of the patient population have access to oral Morphine. In 2008, India used an amount of Morphine that was sufficient to treat pain adequately in only about 40,000 patients suffering from moderate to severe pain due to advanced cancer, which is approximately 4% of the population needing the same. Although Morphine is included in the National Essential Medicine List, its availability remains sparse. The Morphine and Morphine equivalent opioid utilisation in India at present is <1mg per capita.

India has about 100 million elderlies at present, and this is expected to increase to 324 million by 2050, constituting 20% of the total population. It is estimated that 60% of elderly patients are affected by cancer. Surveillance Epidemiology and End Results (SEER) study of the National Cancer Institute in the USA shows that cancer is 11 times more likely to develop in people over 65 years as compared to their younger counterpart. An ICMR population-based cancer registry report shows that the prevalence of cancer patients in India above the age of 60 is estimated to reach more than 1 million by 2021.

Quality end of life care is a person-centred, personalised perception of "Good Death" which encompasses all aspects of comprehensive care of an individual at his or her term of life. It involves a. Applicability to any Person, any Place and any Illness b. Relief of Physical, Psychological, Social, Spiritual and Existential symptoms c. Dying at the preferred place of choice and receiving appropriate care by a trained health care provider d. Universal access to standard palliative care at the end of life and every individual having a right to a reasonable, peaceful and dignified death.

Studies based on family/caregiver interviews of the deceased have revealed, a. Poor control of symptoms b. Incomplete health-related communication c. Lack of trained health care workforce to provide end of life care. d. Absence of holistic care e. Wishes of preferred place of death not fulfilled f. Impersonal technology-laden end of life care and g. Late palliative care referrals as significant barriers hindering quality end of life care.

Studies on hospital end of life care practices have shown that a. Continuation of disease-modifying treatments until the last weeks of life b. Inappropriate life-sustaining interventions, c. Not referring to palliative and supportive care services early and d. Lack of advanced care planning and lack of anticipatory directives for end of life as some of the critical barriers hindering quality end of life care.

1.2. Introduction to the Concept of Palliative Care

In 1974 the term Palliative Care was coined by Dr Balfour Mount a Canadian physician. It is derived from a Latin word *palliare,* which means to cloak or cover. It represents the role of palliative care is to shield and support the person and their families facing life-limiting illness and to enable them to endure their suffering. Dame Cicely Saunders is considered as the pioneer of modern palliative care and hospice movement. She was a nurse by her training who later trained to be become a doctor. She recognised that pain is not limited to a physical dimension, but also has an emotional, social and spiritual dimension. This concept is now known as total pain.

The palliative care movement started in India in late 1980s and the first hospice was set up by Lusito D'Souza in 1986. The Neighbourhood Network in Palliative Care (NNPC) a community initiated palliative care movement in 2001 was considered as one of the successful models of community palliative care delivery. It led to widespread coverage and access to palliative care in Kerala. In 2010, the Palliative Medicine was recognised as a speciality by the Medical Council of India in 2010. The first specialist palliative care training in India a three-year postgraduate program leading to MD Palliative Medicine commenced in 2012 at the Tata Memorial Centre, Mumbai and at present three centres in India offer MD Palliative Medicine training.

The new definition of palliative care according to the International Association of Hospice and Palliative Care (IAHPC), 2018 states that,

"Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers".

Four important aspects of palliative care are highlighted in this definition.

1. Palliative Care is not a passive approach towards illness. It is an active and holistic care that encompasses all domains of health care.
2. The aim of palliative care is to improve serious health related suffering in people with severe illness. Therefore, it is not restricted only to people with terminal illness or end of life care. Severe or serious illness is a condition that negatively impacts the quality of life, causes symptoms, impairs activities of daily living and carries an increased risk of mortality.
3. The primary goal of palliative care provision is improvement in health-related quality of life. The quality of life has four broad dimensions, i.e., physical health, mental health, social health and functional health. The physical dimension largely deals with disease management and symptoms. The mental dimension deals with distress, anxiety, depression and other psychological morbidity associated with illness. The social dimension deals with social support, family coping and economic impact of illness. The functional dimension deals with activities of daily living and self-care. The palliative care aims to improve all the dimensions of quality of life.
4. The patients, their families and caregivers are considered as a single unit and the care continues to the families and caregivers beyond the death of the patient.

The ten principles that govern palliative care delivery are

1. It is important to identify and assess palliative care needs early. A screening tool such as Edmonton Symptom Assessment Scale (ESAS) can identify common symptoms and its severity. Quality of life in palliative care patients can be assessed using a validated tool like EORTC-QLQ-C15-PAL. It comprehensively assesses all domains of health i.e., physical, emotional, social and spiritual.
2. Palliative care encompasses disease management, supportive care and symptom control. Often the term palliative care and end of life care is interchangeably used. Although palliative care embodies end of life care, the care is not limited to end of life. The purpose of palliative care is to help patients live as actively as possible by correcting the correctable, supportive medical management, symptom relief and improvement of quality of life. It also involves continued communication with the

family regarding diagnosis, prognosis, treatment and symptoms and involving them in discussion of goals of care and advance care planning.

3. The conventional practice is to refer to palliative care once all disease modifying treatment is complete. However, current empiric evidence supports the view of palliative care provision early in the course of illness and palliative care is relevant at all stages of the illness.
4. The traditional model of palliative care delivery was sequential model, where palliative care is provided after all curative approaches are exhausted. The current approach is an integrated model where palliative care is provided concurrently or simultaneously. It provides a unique advantage to the patient that both symptoms and disease management is happening at a single setting.
5. Palliative care provision is not limited to certain age groups, illnesses or health care setting. Although palliative care is traditionally associated with cancer, the majority palliative care needs worldwide is due to non-cancer conditions. The palliative care provision is not limited to hospital setting but also provided at home, nursing homes, hospices and respite centres.
6. Patients with chronic and life limiting illness face serious health related suffering and adverse illness experience that negatively influences the course of illness. Mitigation of serious health suffering and improvement in quality of life by palliative care provision has a positive impact on course of illness.
7. Often palliative care is misunderstood as limitation of care, early death and euthanasia. The philosophy of palliative care is life affirming. Affirming life means correcting the correctable, managing symptoms, better emotional health, social and family support and providing an opportunity to the person to live the life to the fullest. Affirming life also means avoiding harmful and futile interventions that could potentially compromise the quality of life without any clinical benefit. Palliative care does not support the view of hastening the dying process or euthanasia. Rather it supports the view of good death and good end of life care.
8. The palliative care considers patient and family as a single unit. Therefore, the care is directed towards patients and their families. The families receive communication support, counselling and are often asked to participate in the family meetings. They also receive bereavement support after patient's death.

9. Palliative care recognises cultural influences on attitudes towards disclosure of diagnosis and prognosis, beliefs about cause and meaning of illness, meaning of pain and suffering, attitudes towards death and dying, and concept of loss, grief and bereavement. These attitudes and beliefs are taken into account during communication, decision-making process, symptom management and end of life care.
10. The palliative care is provided as a multidisciplinary care where each member of the team performs their role towards whole person care. The physician addresses medical management, prescribes symptom control medications and provides supportive care. The nurse takes care of the stomas and catheters, provides mouth care, skin care and eye care and is involved in setting up the syringe drivers and non-pharmacological management of symptoms. The social worker and the psychologists are involved in counselling, psychoeducation interventions, family meeting, family support and managing finances. The volunteers play a very important role in furthering the palliative care services by their participation in advocacy, funding and direct patient related activities.

2. Centre of Excellence for Palliative Care: Clinical Services Domain

In this section, scope of palliative care in a centre of excellence pertaining to clinical services domain is discussed. The section begins with discussion of the overall scope, which is followed by a brief note on hospice-based, hospital-based and home-based palliative care. Palliative care in children and non-cancer conditions concludes this section.

2.1. Overall Scope

The overall scope of palliative care clinical services has ten sub-domains.

1. Pain and symptom management
2. Psychosocial care
3. Health-related communication
4. Eliciting Goals of Care (GOC), Shared Decision-Making and Advance Care Planning
5. Optimising Health-Resource Utilisation
6. Supportive Care
7. Discharge planning and continuity of care
8. Integration with disease-directed therapy
9. End of Life Care

10. Bereavement support

The cancer pain in a palliative care setting is recognised as a multidimensional experience with sensory, affective, cognitive, and behavioural dimensions. The patients with cancer receiving palliative care often experience moderate to severe pain. It is usually multisite, variable in intensity at each site, with a complex pain pathophysiology and presentation. It has a strong affective dimension where the sensory component of pain is associated with anxiety, depression, distress and suffering. The cognitive dimension of pain presents as unpleasant experience, negative emotions and can impact the persona of the individual experiencing the pain. Apart from pain, patients in a palliative care setting also experience other common symptoms like constipation, nausea and vomiting, breathlessness and delirium.

Studies have showed that palliative care interventions improved mood and reduced anxiety and depression. The patients experienced improvement in emotional health after 12 weeks of palliative care intervention. This effect was independent of anti-depressant usage. In these studies, improvement in depressive symptoms were attributed to regular counselling, telephonic follow up that promoted adherence to anti-depressants.

It is vital to know the preferences of patients and family caregivers about disclosure of diagnosis and prognosis. It will avoid undermining of patients and families and avoids rupture of the therapeutic alliance. In patients and their families with life-limiting conditions, health-related communication like disclosure of diagnosis and prognosis is an intricate process and not just mere handover of information. Therefore, disclosure without understanding the patient and family caregiver likings could unfavourably impact communication outcomes.

There is empiric evidence to suggest that palliative care interventions influence treatment decision making. A study in patients with non-small cell lung cancer showed that palliative care interventions positively influenced treatment decisions and these patients did not receive intravenous chemotherapy in the last few weeks before death. Palliative care interventions can facilitate advance care planning, decreased ICU admission, decreased period of ICU stay and positively influences course of illness and end of life care outcomes.

Palliative care intervention in hospitalised patients with advanced cancer decreased ICU readmission, decreased emergency room visits and lowered the health care cost. In another study, palliative care intervention reduced inpatient admission, inpatient deaths, decreased utilisation of hospital resources and promoted deaths at home. Unrealistic expectations from the patients, families or health care team can lead to unwarranted or unhelpful interventions escalating the costs and unnecessary utilisation of limited resources and health facilities. A palliative care involvement, discussing goals of care and advance care planning can facilitate optimal resource utilisation. A study showed that in patients with metastatic non-small cell lung cancer palliative care interventions led to stopping disease modifying treatments in last weeks of life, transition to hospice care, hospice utilisation and provision of good end of life care.

A study in non-small cell lung cancer showed that supportive care component of palliative care along with disease-directed treatment improved overall survival by three months. The improvement in survival was attributed to improvement in quality of life, better symptom control, knowledge of illness and understanding and positive coping behaviours. In another study in a mixed group of cancer receiving palliative care intervention a survival benefit of four months was observed. Moreover, palliative care interventions also significantly improved patient and family satisfaction of care.

In patients who are either continuing to receive disease modifying treatment or completed disease modifying treatment and having a good performance status and able to visit the outpatient department are offered ambulatory palliative care or outpatient palliative care service. Home-based palliative care is offered to patients who have poor performance status and unable to visit outpatients, or prefer to remain at home, has stable symptoms or wished to receive end of life care at home. The home-based palliative care intervention involves visit by a doctor or nurse either alone or together along with other members of the team on a need basis. At home patient receive a medical consultation, palliative nursing interventions including starting a syringe driver for patients in terminal phase of illness, counselling and support from the volunteers. The hospice care is usually offered to patients with terminal illness, short prognosis and where the goals of care is symptom control, comfort and quality of life.

Integrated Oncology and Palliative Care is a comprehensive and holistic care that provides access to competent person-centred care for patients within the environs of a tertiary oncology care centre. It is aimed at benefiting the patients, right from diagnosis of cancer through their difficult journey through the different phases of the diseases including the end-of-life phase. It helps to

1. Provide personalised, person centred holistic care to a patient with cancer when the oncologist is providing a focused diseased specific care.
2. Provide relief of pain and other physical symptoms, manage comorbid illness, concurrent illness and provide active medical care in patients receiving disease related therapy
3. Maintaining the caring environment initiated while at the hospital, continue even after discharge at home, thus paving way to continuity of care
4. Creating space for support at clinical and other dimensions, even when there is no scope for further disease modifying interventions

Palliative care at end of life should include measures to improve pain and symptom control, review and optimisation of medication charts, stopping of unnecessary medical interventions and providing psychological, spiritual and social support to patients and families.

Bereavement support should begin with identifying high-risk bereavement individuals/families much before the patient's death. Bereavement symptomatology should be identified and addressed and referral to psychologist/ psychiatrist should be initiated on a need basis.

2.2. Hospice Based Palliative Care

The principal objective of the hospice is to provide a high-quality end of life care and to ensure good death. Hospices help in facilitating

1. 'Good Death' for any person who is dying, irrespective of the diagnosis, duration of illness and place of death
2. Quality of life and quality of death
3. End of life care as a human right and every individual has a right to a good, peaceful and dignified death

The Good Death is described as

1. To know when death is coming, and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and symptom control
5. To have choice and control over where death occurs
6. To have access to information and expertise of whatever kind is necessary
7. To have access to any spiritual or emotional support required

8. To have access to hospice care in any location
9. To have control over who is present and who shares the end
10. To be able to issue advance directives, ensuring that one's wishes are respected
11. To have time to say goodbye, and control the timing
12. To be able to leave when it is time to go and not to have life prolonged pointlessly

At the end of the patient's life, hospice can facilitate

1. Relief of end-of-life symptoms such as pain, dyspnoea, delirium, respiratory secretions
2. Review of existing treatment
3. Review of current medications and stopping unnecessary medications
4. Stopping routine and unnecessary investigations that may not contribute to the process of care.
5. Continued communication throughout the care process
6. Counselling regarding optimal hydration and food intake
7. Psychosocial support to patient, family and caregivers
8. Meeting special family requests (religious/spiritual/cultural)
9. Providing after-death care
10. Providing bereavement support to the families

Hospice can provide the environment for person-centred compassionate care to the patient with a chronic life-limiting illness, especially those approaching end of their life. Hospice care team comprises of doctors, nurses, counsellors, volunteers, social workers, physiotherapist, dietician and support group teams. Multidisciplinary teams ensure the holistic care of the patient. Hospices emphasise on adequate symptom control for the patient by routine comprehensive assessment and evidence-based management. Palliative care nurses in hospices are trained to provide excellent wound management, stoma care, lymphedema care, managing infusion pumps. Counsellors ensure adequate psychological wellbeing of the patient and their family members by empathetic communication, identifying distress and ensuring spiritual wellbeing. Volunteers, social workers and support group teams engage patients and family for social welfare, identify financial needs and help in rehabilitation, including jobs for dependent family members and education of children. Hospices also provide respite to the family members, identify their burn out, empower them to take care of daily needs and provide bereavement support after the death of patients.

A significant proportion of patients declared palliative from the oncology teams have unresolved physical symptoms, early and late effects of cancer treatments, psychosocial and emotional concerns, nursing-related issues, compromised functional ability, poor quality of life and dependence. The lived experience of an illness such as cancer or an advanced, progressive disease with all the uncertainty it brings leads not only to changes to a physical body but also to many other changes in a person's life. These needs demand attention in a responsive and timely manner. In meeting the needs of the whole person, rehabilitation and supportive care must be available for all individuals living with cancer and other progressive and deteriorating conditions.

Respite and rehabilitation focus on maximising physical, psychological, social and vocational functioning. Besides, respite and rehabilitation support the individual and their families through periods of change to ensure that optimal quality of life and sense of wellbeing is achieved. The objectives of respite and rehabilitation are 1. A focus on patient-centred goals which aim to optimise independence, improving quality of life and mood, ameliorating symptoms, maximising wellbeing, and facilitating their preferred place of care, 2. A multidisciplinary approach across organisations to promote continuity of care, 3. Continual assessment of an individual's needs and strengths, 4. Planning -anticipating the needs of the individual and ability to react quickly to changing need, 5. supporting individuals and their families through periods of transitions, 6. assisting in dealing with issues such as a reduction in ability and preparing for the end of life, 7.Swift and timely access to equipment and resources and 8. Patient and caregiver education and empowering the families/caregivers to maintain continuity of care on discharge.

2.3. Hospital Based Palliative Care – Acute Palliative Care

The emerging trends in modern hospital-based palliative care are (1) acute palliative care unit (APCU) model, (2) simultaneous and shared care model and (3) integrated model. These emerging trends are reinventing and redefining the palliative medicine and aim to swing back the pendulum to normalcy such that the specialty of palliative medicine is perceived as “Treatment” rather than just “Care”.

An APCU model is different from the traditional PCU model. In the PCU model palliative interventions are provided only after acute interventions have failed and patients have been transferred to the PCU for comfort care only. In the APCU model in addition to counselling and symptom management measures, all clinically indicated interventions (e.g., hydration, opioid analgesia, anti-infective, bisphosphonates, blood products, interventional procedures, radiation therapy, oral chemotherapy, and bi-level positive airway pressure machines etc.) are provided.

Various studies demonstrate that the APCU decreased mortality, decreased ICU admission, showed better delirium control and had higher degrees of family acceptance and satisfaction. The APCU was successful at managing symptoms and facilitating the discharge of both ward inpatients and emergency department admission patients alive with symptoms better controlled back to the community. The APCU model facilitates successful development of an in-hospital mortality algorithm and would enable quality improvement efforts at the institutional level. It would also assist patients and health professionals in end-of-life decision making and apt resource allocation. Sepsis, metabolic disturbances and need for supplemental oxygen are leading causes of death in the APCU which may not be recognized and treated at all in a PCU setting.

Patients admitted to the APCU are now receiving low-intensity palliative chemotherapy and radiotherapy. Newer oral agents/targeted therapy has fewer adverse effects providing a chance for both improved length and quality of life. These patients have access to both palliative care and oncology teams; the care is simultaneous and shared which highlights the key advantage of an integrated palliative care program. Integrating palliative medicine into mainstream medical management would benefit patients, in terms of quality as well as quantity of life. Continuity of care, support, early assessment and management of symptoms and augmented physical well-being makes the therapeutic experience more acceptable to the patient and hence there are higher possibilities of completion of the disease modifying therapies. It would also determine and allow appropriate person-centred goals of care at various stages of the disease including a dignified, peaceful end of life experience.

The main purpose of the APCU is to provide sophisticated interdisciplinary transition from active care to end-of-life. For patients who are dying, the APCU enables optimal symptom control, with a focus on maximizing comfort measures for the terminally ill. For patients who are likely to go home, the APCU actively treats acute complications and symptoms related to the cancer and its treatments. For patients who are going to hospice, the APCU plays a critical role in facilitating a smooth and rapid transition, attending to patients' physical and psychosocial needs through inter-professional teamwork. Thus, the APCU facilitates complex decision-making and bridges the gap between acute care and the community.

2.4. Home-Based Palliative Care

Home-based palliative care is offered to patients who have poor performance status and unable to visit outpatients, preferred to remain at home, has stable symptoms or wished to receive end of life care at home. The home-based palliative care intervention involves visit by a doctor or nurse either alone or together along with other members of the team on a need basis. At home patient receive a medical consultation, palliative nursing interventions including starting a syringe driver for patients in terminal phase of illness, counselling and support from the volunteers. If there are poorly controlled symptoms or complications, based on patient and family preferences the patient is shifted either to a hospital or hospice.

2.5. Paediatric Palliative Care

Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

Palliative care can be introduced at any point throughout a child's life; it is completely individual. Some children may require palliative care from birth; others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments aimed to cure or significantly prolong life. In practice, palliative care should be offered from diagnosis of a life-shortening condition or from recognition that curative treatment for a life-threatening condition is not an option. However, each situation is different, and care should be tailored to the child.

2.6. Non-Cancer Palliative Care

Non-Cancer Palliative Care can be offered in various end-organ impairment conditions like chronic kidney disease, chronic heart failure, chronic obstructive airway disease, degenerative neurological conditions, HIV/AIDS etc.

Kidney supportive care is provided as an example

Patients with advanced kidney diseases have complex symptoms impairing their quality of lives. This compounded with advanced age and multiple comorbidities makes palliative care need among these patients very high. At present, integration of palliative care into CKD care is almost non-existent. Skills in kidney supportive care is essential for managing CKD patients irrespective of whether they receive renal replacement therapy. Nephrologists often find it challenging to discuss about limitation of treatment, advanced care planning. Caring for patients dying with end stage renal diseases is challenging and require expertise. Therefore, specialised renal palliative care (RPC) integrated with nephrology is essential.

Renal palliative care is integrated model of care where interdisciplinary collaboration of Palliative care and Nephrology aims to improve quality of life of patients with End stage Kidney diseases. RPC involves active holistic care of physical, psychological, social and spiritual wellbeing of patients and their families. Scope of renal palliative care involves aggressive symptom control including pain management, discussions of advanced care planning and eliciting patient preferences regarding the nature of medical care and intensive care treatment and extending the support to family and caregivers.

Patients with stage 4 or 5 Chronic Kidney Disease (CKD) whose condition progressively worsened with at least two of the indicators below:

- Difficult physical or psychological symptoms that have not responded to specific treatments.
    - Uncontrolled pain
    - Refractory nausea and Vomiting
    - Severe pruritus
    - Persistent leg Cramps
    - Anxiety or Depression
    - Persistent sleep disorder
- Repeated unplanned admissions (more than 3/year).
- Patients with poor tolerance of dialysis with change of modality.
- Patients choosing the ‘no dialysis’ option (conservative), dialysis withdrawal or not opting for dialysis if transplant has failed.
- Patient for whom the surprise question is applicable. (Would you be surprised if the patient were to die in next year, months, weeks, days?)

Any of the above is indication for referral.

The Identified patient need palliative care referral will be seen by palliative care specialist. A dedicated Kidney supportive care clinic service will be provided for referred patients. Outpatient/ Inpatient or Patients undergoing dialysis will be able to access these services.

However, those patients who need urgent care can be seen in palliative care OPD or during IP ward rounds bedside at Nephrology wards or dialysis room.

Patients referred to Kidney supportive care clinic will be assessed comprehensively for their physical symptoms, psychosocial needs, practical needs, Quality of life domains, Performance measures and nutrition. During the visits patients will also be evaluated for their understanding of disease burden, treatment outcome and patient's care preferences. Patient and family will be counselled and empowered for continuity of care at home if required.

The Renal Palliative Care Services helps the patients and families to

1. Management of complex physical symptoms including Pain management and non-pain symptoms.
2. Holistic management of psychosocial needs of patients.
3. Goals of care conversations to identify and document their decision-maker and discuss their values, goals and preferences.
4. Conservative and Supportive care for patients who opts to "Not for dialysis".
5. End of life care for patients with end stage Kidney diseases during terminal stage. Role of renal palliative care physician will be:
    a) Recognising a patient with Critical/Terminal Illness
    b) Ascertaining and endorsement of Medical Futility
    c) Ascertaining Physician Consensus on Medical Futility
    d) Communication of prognosis and limitation of treatment, Achieving consensus between health care providers and families through family meetings, Documentation of the process
    e) Eliciting preferences documentation and implementation of Limitation of Life Sustaining Treatment
    f) Providing Palliative Care at End of Life

A comprehensive centre for excellence in palliative care should have all the above-mentioned clinical domains of palliative care.

3. Centre of Excellence for Palliative Care: Education Domain

In a study conducted at AIIMS Delhi among postgraduate students, out of 186 respondents, 56% had not received any basic training in palliative care and 81% wanted palliative care education to be included in undergraduate curriculum. In a similar study conducted among paediatric postgraduates at Chennai, out of 180 postgraduates studied, 88% percent of the postgraduates had never received any training in any aspect of palliative care. In another study conducted among the medical students, only 9.2% of the students were aware about palliative care. A similar study conducted among all health care undergraduate students showed awareness of only 11%. These findings were corroborated by two studies which showed low incidence of palliative care awareness among pharmacy and nursing students. The two studies conducted at Mumbai showed poor palliative care awareness among primary health care providers and they significantly lacked skills and knowledge to provide palliative care.

Palliative care education is divided as specialist education, generalist education and palliative approach. Specialist education are longer courses, where the provider solely practices the specialty and can address complex palliative care needs of the patients. The generalist education are short courses which will enable the specialists or general practitioners to practice palliative care alongside their primary specialty or general practice. They see patients with less complex needs and act as a liaison between the specialists and other healthcare providers. The palliative approach is where all the healthcare providers dealing with chronic and life-limiting conditions should have basic palliative care skills, understand principles of palliative care and apply it in their practice.

One of the goals of centre for excellence should be to bridge the gaps in Generalist and Specialist Palliative Medicine Education in India.

4. Centre of Excellence for Palliative Care: Focus on Social Science Research Domain

A social science approach in palliative care means paying attention to the social context in which the care of the terminally ill, dying, and death itself, occurs. It is about considering the actions of those involved in palliative and end-of-life care (EOLC), including the patient, their family and healthcare staff, and the social world in which these take place. This approach can be conducted at a microlevel – for example, by looking at how individuals speak to each other or by examining the physical environment in which the care takes place – and may incorporate more macro considerations, such as how groups of clinicians interact or the financial pressures on healthcare organisations. Focusing on these factors provides vital understanding of how and why care is delivered as it is and is, therefore, implicit in much EOLC research. Palliative care, and the end of life more generally, are widely studied themes within the social sciences. Still, the knowledge produced in these studies often remains less visible by the dominant clinical disciplines (medicine and nursing) working in palliative and EOLC.

The care of dying persons has been a topic of social science exploration for decades. Most notably gaining momentum during the 1960s, 1990s and the current decade. Concepts derived from in-depth social science research are now regularly considered to be core elements to an understanding of EOLC, both within the social sciences and for those practising EOLC. Many social scientists working on EOLC research today are part of interdisciplinary teams whose research may use theories and methods commonly used in the social sciences, but the team publications do not often contain in-depth discussion of the implications of their work for sociological or anthropological theories. As such, the contribution of social sciences becomes less visible. This seems in part due to the pressures of publishing in medically oriented journals that often require shorter articles, and therefore less space for theoretical discussions.

Social scientists consider dying to be a social process. This means that we recognise that dying involves people, practices and places, and that it is not just something that happens to the body. This understanding of death is reflected in how determining the timing of death has changed over time and with advances in technology. In terms of EOLC, viewing dying as a social process also helps us appreciate who else is involved, and how their involvement is shaped by social expectations. For example, research has examined the role different professionals have when helping someone understand that they are dying, and how this is a key transition within EOLC. Furthermore, what death means is influenced by cultural norms and expectations about dying. To understand EOLC, then, also means having to unravel the cultural processes, values and meanings that are at play in death and dying. Social scientists are trained in studying and understanding these different aspects of the social process of dying and making sense of them in their cultural contexts.

Social science research seeks to understand things in their context – recognising how, where and when something occurs impacts how and why it occurs the way it does. For example, social scientists have sought to unpack current policy and practice interest in preferred place of death. Asking patients where they want to die is recommended practice in many countries, and their answers are used to influence policy and direct the care people receive. This is because preferences vary over time, depending on the patient's previous experience, who is caring for them and what support is available. Moreover, some patients may not have a preference, or place of death may not be a priority for them. Some of our own research has contributed to this debate by highlighting how problematic stating preferences and choices can be and yet how choice operates as a mechanism for service delivery. What this growing body of social science research shows us is that not only is preference of place far from universal or straight- forward, but also that we need to be critical of how such ideas shape the process of dying.

Some social scientists are particularly interested in people's stories and experiences – this can be about their care, their deaths and ultimately about their lives. There are some similarities with narrative medicine, which uses stories to promote healing. Collecting, listening to and connecting with these stories and narratives reminds us – both as researchers and as fellow human beings – that there is more to dying than a 'failing body' being treated by doctors. Instead, dying is often a very intense time of living for all involved, for a variety of reasons. Many of the popular books about EOLC feature narratives of care, and many accounts about EOLC by social scientists analytically examine people's narratives to find common patterns or to highlight particular issues.

Some social scientists take a more explicitly applied approach to their work on palliative and EOLC. 'Applied' projects seek primarily to generate knowledge that can be used to improve practice. Projects might involve co-developing tools, spaces or even models of care with patient groups, clinicians and other professionals – all the while attending to issues of representation, power dynamics and how things are made meaningful.

A centre for excellence on palliative care should focus beyond the realms of conventional scientific research and invest its time and efforts in social science research.