STANDARDS FOR
PEDIATRIC PALLIATIVE CARE IN INDIA

A CONSENSUS DOCUMENT

Indian Association of Palliative Care

STANDARDS FOR
PEDIATRIC PALLIATIVE CARE IN INDIA

A CONSENSUS DOCUMENT

CONCEPTUALISATION & PPC STANDARDS DEVELOPMENT TASKFORCE LEAD

DR. GAYATRI PALAT

DR. ARCHANA IYENGAR

EDITOR

NANDINI GHOSH

TABLE OF CONTENTS

FOREWORD 5

EXECUTIVE SUMMARY 12
SYMPTOM ASSESSMENT AND MANAGEMENT 12
DRUG AVAILABILITY IN PPC 12
CARE OF THE DYING CHILD 12
TRANSITION OF CARE 13
PERINATAL AND NEONATAL PALLIATIVE CARE 13
COMMUNITY BASED PPC 13
EDUCATION & TRAINING IN PPC 13
ETHICS IN PPC 14
POLICY, LAW AND GOVERNANCE IN PPC 14
PPC: RESEARCH, QUALITY IMPROVEMENT 14

PREAMBLE 15
SUFFERING IN CHILDREN LIVING WITH SERIOUS ILLNESSES 16
PPC AND ITS NEED IN INDIA 16
DEFINING INDIAN PPC STANDARDS AND THEIR SIGNIFICANCE 18
CONSENSUS DEVELOPMENT PROCESS 19

STANDARDS 21
DOMAIN1: SYMPTOM ASSESSMENT AND MANAGEMENT 21
INTRODUCTION 21
GENERAL PRINCIPLES 21
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 21
CONCLUSION 22

DOMAIN 2: DRUG AVAILABILITY IN PPC 23
INTRODUCTION 23
GENERAL PRINCIPLES 23
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 23
CONCLUSION 24

DOMAIN 3: CARE OF THE DYING IN PPC 25
INTRODUCTION 25
GENERAL PRINCIPLES 25
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 25
CONCLUSION 27

DOMAIN 4: TRANSITION OF CARE 28
INTRODUCTION 28
GENERAL PRINCIPLES 28
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 28
CARE TRANSITION TO ADULT PROGRAM 29
CONCLUSION 29

TABLE OF CONTENTS

DOMAIN 5: PERINATAL AND NEONATAL PALLIATIVE CARE 30
INTRODUCTION 30
GENERAL PRINCIPLES 30
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 30
CONCLUSION 31

DOMAIN 6: COMMUNITY BASED PPC 32
INTRODUCTION 32
GENERAL PRINCIPLES 32
CONCLUSION 32

DOMAIN 7 : EDUCATION & TRAINING IN PPC 33
INTRODUCTION 33
GENERAL PRINCIPLES 33
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 33
CONCLUSION 34

DOMAIN 8: ETHICS AND LAW IN PPC 35
INTRODUCTION 35
GENERAL PRINCIPLES 35
CONCLUSION 35

DOMAIN 9: POLICY AND GOVERNANCE IN PPC 36
INTRODUCTION 36
GENERAL PRINCIPLES 36
CONCLUSION 37

DOMAIN 10: PPC - RESEARCH AND QUALITY IMPROVEMENT 38
INTRODUCTION 38
GENERAL PRINCIPLES 37
STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS 39
CONCLUSION 39

OVERALL CONCLUSION 40

APPENDIX 1 41

WHO CONCEPTUAL FRAMEWORK 41

APPENDIX 2 42

LEVELS OF HEALTH CARE IN THE INDIAN CONTEXT 43

APPENDIX 3 44

PYRAMID OF PPC EDUCATION LEVELS 44

ACKNOWLEDGEMENTS 45

GLOSSARY 49

REFERENCES 51

FOREWORD

Dr. Geetha Joshi
President
Indian Association Of Palliative Care(IAPC)

Dr. Suresh Kumar
Director,
WHO Collaborating Center, Calicut, World Health Organization (WHO)

Dr. Julia Downing
Chief Executive
International Children's Palliative Care Network (ICPCN)

Dr. Michael McNeil
Director, Global Palliative Care Program
St Jude Children's Research Hospital

Dr. Megan Doherty,
Director Pediatric Palliative Care Program
Two Worlds Cancer Collaboration (TWCC)

Sehrish Unnisa
Sibling of child Mohammed. Abdul Qader who received Palliative Care

FOREWORD

Paediatric Palliative Care (PPC) is an essential component of comprehensive healthcare for children living with serious, life-limiting, illnesses. It addresses suffering in all its dimensions and supports children and their families from diagnosis, alongside disease-directed treatment, and across the illness trajectory.

India bears a substantial burden of childhood illness within a diverse and resource-variable healthcare landscape. In this context, the need for clear, practical, and contextually relevant standards for PPC is both urgent and critical.

The Indian Association of Palliative Care (IAPC) is pleased to present Standards for Paediatric Palliative Care in India: A Consensus Document. Developed through a robust and inclusive consensus process, this document outlines key domains and minimum expectations for quality PPC across all levels of care. The standards are aligned with international best practices while remaining adaptable to India's healthcare realities.

This consensus statement is intended to guide clinical practice, education, service development, research, and policy engagement, and to contribute India's perspective to the global advancement of PPC.

I extend my sincere appreciation to all contributors and reviewers whose commitment and collaboration have made this consensus possible. On behalf of IAPC, I commend these standards to all stakeholders dedicated to improving the care of children with serious illnesses.

Dr. Geeta Joshi
The President
Indian Association of Palliative Care (IAPC)

FOREWORD

Children with serious, life-limiting, and life-threatening illnesses represent one of the most vulnerable populations within any health system. In India, where the burden of childhood illness is substantial and health inequities are stark, the need for Paediatric Palliative Care (PPC) is both urgent and undeniable. Thousands of children and families in Low and middle-income countries live with prolonged suffering without access to timely, appropriate, and compassionate care. Addressing this suffering is not merely a clinical obligation but a moral imperative.

Over the past few decades, models of paediatric palliative care have largely evolved in high-income countries of the Global North. While these models have contributed significantly to the field, their direct translation into low- and middle-income countries (LMICs) such as India is frequently hindered by differences in disease patterns, health-system structures, resource availability, sociocultural contexts, and community realities. In such settings, reliance on High Income Country models can inadvertently widen gaps in access rather than bridge them.

What is therefore needed are approaches that are contextually grounded. This means models that are feasible, scalable, and responsive to local realities. India, like many countries in the Global South, requires PPC frameworks that recognise the central role of families, communities, primary healthcare systems, and culturally embedded care practices, while still upholding global principles of quality, dignity, and equity.

This consensus document on Standards for Paediatric Palliative Care in India represents an important step in that direction. Developed through a rigorous, inclusive, and consultative process, it reflects collective wisdom drawn from clinicians, nurses, counsellors, social workers, policy experts, families, and international collaborators, all deeply engaged with the realities of care delivery in LMIC contexts. The standards articulated here are not aspirational ideals detached from practice, but are grounded, field-tested, and informed by lived experience.

The efforts of the task force and contributors who have shaped this document deserve deep appreciation. Their work demonstrates what is possible when commitment to children's well-being is matched with contextual humility and collaborative intent.

I hope that this document will serve as both a guide and an inspiration for clinicians seeking practical direction, for institutions aiming to develop or strengthen services, and for policymakers & advocates committed to advancing paediatric palliative care across the Global South. May these standards be adapted, adopted, and built upon by those who share the vision of ensuring that no child, regardless of geography or circumstance, is left to suffer without care, comfort & compassion.

Dr. Suresh Kumar
Director,
World Health Organisation Collaborating Centre for
Building Country Capacity in Palliative Care and Long-Term Care

FOREWORD

The number of children requiring paediatric palliative care has increased substantially, with an estimated more than four million children in India, along with their families, in need of palliative care services. While significant progress has been made in the development and provision of paediatric palliative care across the country, substantial inequities in access remain, leaving many children and families unable to receive appropriate care.

These standards are central to the continued expansion of paediatric palliative care services across India. As access is scaled up, it is essential that the quality of care is maintained and strengthened. Developed by a multidisciplinary team of experts from across the country, these standards provide a framework to support capacity building and the delivery of high-quality paediatric palliative care across diverse settings.

The development process built upon existing international and national frameworks and standards, with consensus achieved on standards tailored to the Indian context. Importantly, the process incorporated input from children living with serious illness and their families, alongside healthcare professionals, palliative care organisations, administrators, policy makers, and ethical and legal advisors. Grounded in the WHO conceptual framework, the standards address key domains including transitions of care, access to essential medicines, education and training, ethics, policy, and research.

Considerable effort has been invested in the development of these standards, and ongoing evaluation of their implementation will be critical to ensure their relevance, effectiveness, and future refinement. The publication of these standards represents a significant milestone in addressing inequities in access to paediatric palliative care in India and in supporting the delivery of high-quality, equitable care for children with life-limiting and life-threatening conditions.

Prof. Julia Downing
Chief Executive
International Children's Palliative Care Network

FOREWORD

It is with great pride and a deep sense of responsibility that we present this consensus document on Quality Standards in Pediatric Palliative Care in India. This work represents the culmination of one and a half years of dedicated effort by a multidisciplinary group of professionals—pediatricians, palliative care specialists, nurses, social workers, and allied health experts—united by a shared commitment to improving the lives of children with serious illnesses and their families.

Pediatric palliative care is not merely a clinical service; it is a philosophy of care that embraces compassion, dignity, and holistic support for the child and family throughout the illness trajectory. In India, where the burden of childhood mortality and chronic complex conditions remains significant, the need for structured, evidence-based standards is urgent and undeniable. These standards aim to bridge existing gaps, promote best practices, and ensure equitable access to high-quality care across all levels of the healthcare system.

This document reflects a rigorous consensus-building process, informed by global frameworks and adapted to the unique sociocultural and healthcare realities of India. It outlines ten key domains—from symptom management and drug availability to ethics, governance, and research—providing practical guidance for implementation at primary, secondary, and tertiary levels.

We hope these standards will serve as a roadmap for policymakers, healthcare providers, educators, and community organizations, fostering collaboration and capacity-building to make pediatric palliative care an integral part of child health services nationwide. Above all, we envision a future where every child with a life-limiting or life-threatening condition receives care that is compassionate, comprehensive, and respectful of their dignity and rights.

This is an incredible undertaking that highlights the commitment of the collaborators and partners in this effort. May this effort inspire continued innovation, advocacy, and commitment to the well-being of children and their families in India and around the world.

Dr. Michael McNeil
Director, Global Palliative Care Program
St. Jude Children's Research Hospital

FOREWORD

The Sunflower Children's Network is dedicated to supporting the development of palliative care globally to ensure that holistic palliative care is available for all children with a serious illness and their families. We are honored to witness and contribute to the remarkable progress being made in India, through the establishment of the National Standards for Pediatric Palliative Care.

Children with serious illnesses and their families deserve care that is of high quality and meets their needs across locations of care; these standards reflect an important step forward in ensuring that pediatric palliative care is integrated into India's health system in a way that is practical and sustainable. They provide a roadmap for quality, equity, and accountability—ensuring that children, regardless of geography or circumstance, have access to the care they need to live well and with dignity.

We have been privileged to work alongside national and global contributors—clinicians, educators, policymakers, and families—who are deeply committed to this cause. Their leadership, insight, and vision have inspired this important work, and we are confident that these standards will strengthen care not only in India but also serve as a model for other countries working to improve serious illness care for children.

Behind these standards are the children and families, who can now feel confident in accessing palliative care services, knowing that there is a core standard for services. The success of this initiative shows what is possible when dedicated professionals unite around a shared vision of compassionate care for every child who needs it.

With deep respect and solidarity, we congratulate all those involved in the development of these standards and reaffirm our commitment to supporting their implementation.

Dr. Megan Doherty
Director Pediatric Palliative Care Program
Two Worlds Cancer Collaboration (TWCC)

FOREWORD

I am Mohammed Abdul Qader's(Ibrahim) sister, Sehrish Unnisa. My brother was diagnosed with microcephaly at 9 months. We resided abroad and received good health care for the most part.

Upon moving to India our biggest concern was healthcare for my brother and insurance to afford said healthcare both of which was very difficult to attain here.

When he first got admitted into a public tertiary hospital for children we panicked and didn't know if it was the right decision since the treatment process was vastly different here than it was abroad. However amongst our struggles we met the palliative care team(PPC physician,PPC nurse and social worker) who introduced us to the palliative care services that was hospital based home based and also about the exclusive childrens hospice and this marked the start to something we are grateful for even after the passing of my brother.

The palliative care team provided us with knowledge about treatments here and ways to handle my brother at home. They immensely helped my parents specially my mother to overcome her mental challenges as well as did regular checks on the whole family.

My brother was at peace and comfortable at home and receiving treatment at home helped him recover faster. He no longer had bruises from blood tests or oxygen masks and most of all he was with his family.

Due to the home care facility we were no longer separated into two units one at the hospital and one at home but rather spent time together and learned to take care of our little brother /son together.

From the moment we were introduced to palliative care to the moment of my brother passing away they made his life easier provided him comfort and elevated his living conditions, even after his death palliative care provided us with ways to cope, adapt and even overcome our loss.

Sehrish Unnisa

Sibling of child Mohammed. Abdul Qader who received Palliative Care

EXECUTIVE SUMMARY

Paediatric Palliative Care (PPC) is an essential component of comprehensive healthcare for Children with serious illnesses (life limiting or life threatening). Despite its significance, there are notable deficiencies in PPC services, especially in developing countries like India. This paper aims to address these deficiencies by offering a detailed exploration of key PPC domains and presenting practical recommendations to enhance the delivery of PPC services.

Ten domains of PPC identified through consensus are: Symptom assessment and management, Transition of Care, Education and training, Drug availability, Ethics, Policy, Law & Governance, Community based care, Perinatal and Neonatal care, Care of the dying and Research. Each component outlines key principles and recommendations, to assist healthcare professionals in delivering high-quality palliative care to Children with serious illnesses.

Symptom Assessment and Management

Pain assessment should be a routine part of every neonatal and Paediatric care program. Healthcare professionals should use age-appropriate and standardized tools to screen and evaluate symptoms in all seriously ill Children. Optimal symptom management and support should be provided through both non-pharmacological and pharmacological interventions. It is recommended to use a stepwise approach to analgesia based on pain severity and persistence, and to consider opioids like morphine for severe, persistent pain.

Drug Availability in PPC

Access to essential pain and palliative care, including opioids, and necessary equipment for Children with serious illnesses should be available at all healthcare levels, with proper accountability and appropriate use.

Care of the Dying Child

Holistic end-of-life care should be provided by trained professionals to terminally ill Children across all healthcare levels. Physical symptoms need to be addressed, psychosocial and spiritual support aligned with family values and culture should be offered, death with dignity must be ensured, and support during bereavement should be provided.

EXECUTIVE SUMMARY

Transition of Care

PPC can be provided in various settings, including the delivery room, postpartum ward, neonatal intensive care unit (NICU), Paediatric hospital, nursing home, hospice, or at home. Healthcare workers should collaborate to ensure a smooth and planned transition of care between these different settings and transition into an adult palliative care programme. A designated worker should oversee and coordinate the transition of care, acting as the link between the child and the various practitioners involved in their support, including the named general practitioner (GP).

Perinatal and Neonatal Palliative Care

Perinatal and neonatal palliative care offers comprehensive support to families during the antenatal and postnatal periods, focusing on providing effective care for newborns with life-limiting or life-threatening conditions. This care includes antenatal counselling, personalized birth planning, postnatal follow-up, and holistic family support services such as lactation guidance and bereavement care. Integrating these services into healthcare systems ensures compassionate, early, and comprehensive support for families and their newborns.

Community based PPC

Children with serious illnesses should have access to palliative care within their homes or as close to home as possible, supported by their community. Building the capacity of families and community health workers, training volunteers to deliver community-based PPC, and fostering the involvement of local NGOs and schools are essential steps. This approach creates a nurturing and supportive environment, enabling Children to receive care within their familiar surroundings. The community serves as a critical safety net, encompassing the child's home, siblings, family, school, and healthcare facilities.

Education & Training in PPC

PPC education should be an integral part of all Paediatric healthcare professionals' training. The education curriculum at postgraduate level should include PPC so as to have a palliative care approach in all aspects of healthcare of the child.

EXECUTIVE SUMMARY

Ethics in PPC

The unique challenges of medical ethics in PPC arise from Childen's limited decision-making capacity, vulnerability to harm, and the sensitivity of end-of-life decisions. To promote the best interests of seriously ill Children, collaborative decision-making between physicians, parents, and, when appropriate, Children is essential. These decisions should adhere to the four basic ethical principles: best interest principle, risk-benefit proportionality principle, distributive justice, and autonomy. Additionally, adherence to legal and ethical guidelines and ensuring effective communication are crucial in this process.

Policy, law and Governance in PPC

Effective governance, policies, and legal frameworks are crucial to ensuring equitable access to services, affordable medications, and high-quality, compassionate care. PPC should be integrated into national and state level plans for child health including dedicated funds for PPC . Quality indicators related to PPC should be included in the other quality indicators of child health

PPC: Research, Quality improvement

PPC must transition from being experience-driven to evidence-based to ensure high-quality, effective care for Children with serious illnesses. Current gaps in research, including cost-effectiveness, care models, and symptom management, highlight the need for active research at all healthcare levels. Prioritizing evidence-based practices, investing in training, and fostering collaboration are essential.

By incorporating these key indicators into palliative care standards, organizations can systematically evaluate the quality and impact of care delivery, identify areas for improvement, and enhance the overall effectiveness of palliative care services.

PREAMBLE

Advances in science and technology have resulted in decline in childhood mortality. However, millions of Children are still dying globally. An increasing number of Children are living with chronic complex conditions requiring specialized Paediatric care.24 There are more than 21 million Children globally , who need palliative care, including 3 million living with complex chronic conditions. 8 million Children require specialised palliative care. A study conducted in South India showed that chronic illness affects 3.49% of Children aged 0–14.[25]

In India, despite progress made in recent years, childhood mortality remains high space. India contributes to 14% of the global burden of under-5 mortality (Table 1).[26] The mortality burden is concentrated during the early-neonatal (first one week) and post-neonatal (29 days to 11 completed months) accounting for 48% and 26% respectively of total under 5 mortality.[27] The delayed identification of high-risk pregnancies contributes to an increased risk of early-neonatal mortality(at 99 per 100000 live births in 2020).

Childhood Mortality In India, Sample Registration System Indicators, Year 2025 (Deaths per 1000 live birth) -Table 1

Neonatal Mortality Rate	Infant Mortality Rate	Under 5 Mortality Rate
19	25	29

Leading causes of child mortality in India are prematurity & low birth weight (31.2%), pneumonia (17.5%), birth asphyxia & birth trauma (9.9%), other non-communicable diseases (9.6%), diarrheal diseases (5.8%), congenital anomalies (5.7%) and injuries (4.9%).[27] The leading causes of newborn deaths are prematurity & low birth weight (45.5%), birth asphyxia & birth trauma (15.1%), neonatal pneumonia (12.6%), other non-communicable diseases (8.0%), sepsis (5.2%) and congenital anomalies (4.9%).

Childhood cancer in India accounts for 0.7-4.4% of total cancer diagnoses. While in a high income country, the five-year survival rate for childhood cancer exceeds 80%, same is not true in India. Only around 4–5% of Children receive any form of cancer-directed therapy before death and the outcome of ALL (Acute Lymphoblastic Leukemia) in hospital-based studies showed overall survival between 45–81% .[30]

PREAMBLE

Suffering in Children Living with Serious Illnesses

Children living with serious illnesses or terminal conditions and their families experience a variety of physical, emotional, social and spiritual challenges. Physical challenges include high pain and symptom burden and providing end of life care. As Children with chronic complex conditions live longer, they require frequent hospitalization, increasing use of complex medical technologies and demanding therapeutic and care needs (e.g., long-term home ventilation, parenteral and enteral nutrition, and equipment to compensate for vital functions such as dialysis systems, urinary catheters and ostomies). Living with such conditions result in profound level of psychosocial distress like depression, anxiety , post-traumatic stress disorder (PTSD), behavioural issues, stigmatization, bullying, guilt, missed academic or social opportunities and limited social experiences. Children with complex conditions may need 24/7 care. Care giving presents challenges and demands, often leading to significant financial burden, time constraints, caregiver stress and burnout.

PPC and Its Need in India

Palliative care for Children is the active total care of the child's body, mind, and spirit, and also involves providing support to the family. Ideally it begins when an illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.[31]

Palliative care has been associated with improved patient outcomes, with financial risk protection for patients and their families and with reduced costs for health care systems. Improved patient outcomes include better control of pain and other symptoms, decreased spiritual distress, enhanced quality of life, improved patient and family satisfaction, and reduced number of physician office visits, emergency department visits, hospitalizations and days in the intensive care unit at the end of life. Early provision of palliative care has been associated with prolonged survival and improved adherence to curative or disease-modifying treatments.[32,33]

It is estimated that at any point of time,

4,250,559 Children & 34 per 10,000 population

need PPC in India.[34] WHO recommends a public health strategy for integrating palliative care into health care systems to reach all in need.[35]

PREAMBLE

Population that Needs PPC

Population	Examples
Children with acute life-threatening conditions from which recovery may or may not be possible	Any Critical Illness or injury, Severe Malnutrition.
Children with chronic life-threatening illness that may be cured or controlled for a long period but that may also cause death	Malignancies, Multi-Drug resistant Tuberculosis, HIV/ AIDS, Cystic fibrosis, Immotile ciliary syndrome
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal Muscular Atrophy, Duchenne's Muscular Dystrophy, Neuro Regression, Nemaline Rod Myopathy
Children with severe neurological conditions that are not progressive but may cause deterioration and death	Static Encephalopathy, Spastic Quadriplegia, Spina Bifida with complications
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, Anencephaly, Congenital diaphragmatic hernia with hypoplastic lung, Complex Congenital heart disease, Trisomy 13 or 18
Family members of fetus or child who dies unexpectedly	Fetal demise (still birth/ IUD), Hypoxic-ischaemic encephalopathy, overwhelming sepsis in previously healthy child, Trauma from motor vehicle accident, Burns

DEFINING INDIAN PPC STANDARDS AND THEIR SIGNIFICANCE

According to Article 24 of the UN Convention on the Rights of the Child, every child has the right to attain the highest possible standard of health. Global assessments of PPC development indicate that India is still in the capacity-building phase, with numerous ongoing initiatives aimed at strengthening organizational, workforce & policy frameworks.

Quality healthcare means care is effective, timely, safe, evidence based, people centred, equitable, integrated, coordinated across providers and maximise resources utilization while minimizing waste.

As India moves toward integrating PPC into mainstream healthcare, developing standards will serve as a critical framework to build capacity for delivering age-appropriate, high-quality care across various settings. These standards will provide a roadmap for:

- Ensuring seamless coordination between healthcare professionals
- Promoting best practices based on the latest research
- Supporting training initiatives for healthcare workers.
- Identifying service gaps and improve accessibility and equity
- Quality monitoring
- Healthcare policy makers for systemic improvements.

Consensus Development Process

In February 2023, an in-person meeting was organized during the Indian Association of Palliative Care (IAPC) conference in Bangalore. This was attended by PPC physicians, nurses, counsellors, social workers and NGO representatives, funders and international experts in PPC. This was followed by several virtual meetings with experts. Subsequently, a task force was formed to develop the standards.

To create a framework for PPC, key domains were identified by reviewing existing international standards from countries such as Africa, Australia, USA, UK, the EU, and adult Indian standards and based on World Health Organization (WHO) conceptual framework for palliative care development (Appendix 1).The domains to be included in the PPC framework were finalized through consensus-building discussions. Additionally, the levels of care for each domain (Appendix 2) were also defined.

DEFINING INDIAN PPC STANDARDS AND THEIR SIGNIFICANCE

Sub-task groups were then established to work on specific domains within the PPC framework. This draft was then presented to key stakeholders at different centers in the country for their input.

The stakeholders were

- Children with serious illnesses and their families
- Referring doctors like oncologists, Pediatricians, neonatologists
- Palliative care non-government organizations
- Government policy makers
- Hospital administrators
- Ethical and legal advisors

The draft of the final document was sent for both internal and external expert review by palliative care experts from India and abroad.

DEFINING INDIAN PPC STANDARDS AND THEIR SIGNIFICANCE

INITIAL PLANNING

Task force formed to understand India specific needs to create paediatric palliative care guideline for India

Based on face to face meeting at APC Conference, Bangalore followed by virtual meetings with experts

FRAMEWORK DEVELOPMENT

Domains finalized to be included in the Indian PPC framework.

Based on Review and Analysis, Examination of existing PPC standards from Australia, USA, UK, EU and Adult Indian Standards & Consensus Building

TASKFORCE ALLOCATION

Sub-Task Forces formed focused on specific PPC domains

Comprised of PPC doctors, Nurses, Social workers, Policy makers, International PPC experts

STAKEHOLDER INPUT

Child patients and families,
Referring doctors,
Specialist paediatricians

Palliative care NGOS;
Government policymakers,
Hospital administrators,
Ethical and legal advisors

REVIEWS

Internal Review

External Review

DOMAIN 1
SYMPTOM ASSESSMENT AND MANAGEMENT

Introduction

Effective symptom, psychosocial , emotional and spiritual distress assessment and management are crucial components of PPC. This standard aims to ensure comprehensive, age-appropriate, and consistent approaches to anticipating, identifying and alleviating symptoms and distress in Children with serious illnesses across all levels of healthcare in India.

General Principles

- Pain as the 5th Vital Sign: Pain should be routinely screened and documented as the 5th vital sign in all Paediatric healthcare settings.
- Anticipatory Approach and Comprehensive Assessment: Symptoms and distress in Children with serious illness should be anticipated and assessed using standardized, age-appropriate tools.
- Stepwise Pain Management: A 2-step WHO analgesic ladder approach should be practiced for managing chronic persistent pain. Each institution should follow a standardised protocol to manage procedural pain.
- Integrative Approach: Symptom management should incorporate both pharmacological and non-pharmacological interventions as per evidence- based best practices.
- Advance Care Planning (ACP): Guidelines for ACP should be established in each institution. Healthcare professionals should receive training in making ACP based on disease trajectory, child's and family's wishes, preferences and values, including place of care.

STANDARDS

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Pain should be routinely assessed and documented for all Children seeking healthcare, using age-appropriate tools.
- Healthcare professionals should be trained in non-pharmacological & basic pharmacological symptom management including use of WHO pain ladder.
- Trained health care workers should be available to take care and promote comfort of bed bound Children and support their families in the community.
- Clear pathways for referral to specialized palliative care services nearest to their homes when needed, should be available.

SECONDARY HEALTHCARE LEVEL
In addition to Primary Healthcare level recommendations

- Access to a generalist palliative care multidisciplinary team for managing complex symptoms and psychosocial , emotional and spiritual distress of the child and the family.
- Availability of opioid medications for pain management.
- Availability of dedicated Palliative Care beds for inpatient care.
- Clear policies for referral to tertiary care or primary healthcare facilities should be in place for seamless transition between home, hospice, primary, secondary, and tertiary levels.

TERTIARY HEALTHCARE LEVEL
In addition to Secondary Healthcare Level recommendations

- Availability of a specialist palliative care interdisciplinary team led by a PPC specialist to provide care to all age groups from perinatal through young adults to be ensured.
- The team should manage highly complex symptoms and psychosocial, emotional and spiritual distress of Children and their families.

CONCLUSION

Implementing the standards for symptom and distress assessment and management across all healthcare levels in India will significantly enhance the quality of life for Children with serious illnesses and overall care outcomes.

DOMAIN 2
DRUG AVAILABILITY IN PPC

Introduction

Access to essential pain and palliative care medicines, consumables and equipment is crucial for Children with serious illnesses. Health care workers should be trained in usage of opioids, procurement , stocking, prescribing, dispensing, disposal and accountability, as per the NDPS act.

General Principles

- Essential medicines, including opioids, consumables and equipment required for palliative care, should be easily available, affordable, accessible and in formulations suitable for Children, at all levels of healthcare, primary, secondary, tertiary including home care
- All formulations of opioids like morphine should be available in the palliative care center nearest to the child's home.
- Health care workers who treat Children with serious illnesses should be trained in the safe use of medications including benzodiazepines, opioids like morphine, and in recognizing their side effects, toxic effects, and proper dose titration.
- These healthcare workers should also be accountable for safe usage of opioids like procurement, stocking, prescribing, dispensing, ensuring pill count, follow-up plans for refills and proper disposal.

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Health workers should have access to essential medicines in Paediatric formulations, consumables and equipment as per the WHO palliative care essential drug lists at primary health centers and for home-based care.
- Healthcare professionals should have essential training in safe use of opioids.

STANDARDS

- Trained health care workers should be available to take care and promote comfort of bed bound Children and support their families in the community.
- Clear pathways for referral to specialized palliative care services nearest to their homes when needed, should be available.

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

- An uninterrupted supply of all formulations of morphine should be available at palliative care centers designated as 'Recognized Medical Institutions' under the NDPS Act for 'Essential Narcotic drugs.'
- A designated and trained 'Registered Medical Practitioner' and a pharmacist should be available at the palliative care center, responsible for the procurement, safe keeping, stock maintenance, dispensing, and documentation of opioid medications, in compliance with legal requirements.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

Uninterrupted supply of morphine, fentanyl and methadone in all formulations suitable for Children, should be ensured in the designated specialist PPC center

CONCLUSION

Children with serious illness should have access to essential medicines including opioids, consumables, and equipment and it should be affordable, accessible and available in formulations suitable for their needs. Due attention to safe prescription, usage, procurement, storage, dispensing and disposal of opioid medication should be followed as per the legal requirement.

DOMAIN 3
CARE OF THE DYING IN PPC

Introduction

Ensuring holistic, compassionate, and high-quality end-of-life care for terminally ill Children is a critical component of PPC. Care should focus on providing symptom relief, psychosocial and spiritual support, and maintaining dignity while avoiding unnecessary interventions that prolong death. This section outlines standards across different levels of healthcare to ensure that Children and their families receive appropriate support at the end of life.

General Principles

- Ensure a dignified and comfortable death by anticipating and managing physical symptoms.
- Provide psychosocial and spiritual support tailored to the child's and family's needs.
- Avoid futile interventions that will potentially harm the child and cause further suffering.
- Encourage memory-making and legacy activities with the child and family.
- Facilitate bereavement support for grieving families.
- Engage community support systems, including schools and faith-based organizations, to assist families.

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Ensure basic symptom management and comfort-focused care for terminally ill Children.
- Train healthcare providers and community health workers in recognizing and managing distressing symptoms at the end of life and to give emotional and spiritual support tailored to family beliefs and preferences.
- Facilitate bereavement support and counseling for families.
- Liaise with local schools and faith communities to offer extended social support.
- There should be an established referral pathways for taking care of difficult end-of-life-care situation.

STANDARDS

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

- Designated Palliative Care Facility should take the responsibility of managing difficult child's end of life care, in liaison with PPC team
- Facilitate discharge planning to home or hospice, including coordination with local healthcare teams.
- Provide families with an anticipatory medical kit to manage symptoms at home.
- Offer psychosocial support, ensuring faith-based and cultural practices are respected.
- Maintain documentation and monitor outcome measures to evaluate the quality of end-of-life care.
- Healthcare Professionals should receive support for self-care and opportunities for debriefing when dealing with difficult End of Life.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

- Establish an institutional policy for end-of-life care in both ICU and inpatient settings.
- Conduct multidisciplinary meetings including family to reach a consensus on withholding or withdrawing life-sustaining treatment, adhering to current legal frameworks.
- Ensure healthcare teams receive continuous education and training in best practices for managing complex end-of-life symptoms, and actively engage with patients' families to discuss these aspects of care.
- Provide home-based palliative care services, either directly or through partner organizations, for Children preferring home as the place of end-of-life care.
- Assign a dedicated care coordinator to oversee transitions between hospital, home, and hospice settings.
- Offer psychosocial and spiritual care in alignment with family values, including memory-making and legacy-building activities.

STANDARDS

- Provide after-hours support from the palliative care team, either directly or through referral networks.
- Implement a structured bereavement care program, including support for siblings and monitoring for complex grief, PTSD, or suicidal ideation among family members.
- Establish quality monitoring systems to evaluate end-of-life care standards and patient outcomes, and foster research and quality improvement initiatives to enhance Paediatric end-of-life care.
- Develop mentorship programs for primary and secondary-level palliative care teams supporting terminally ill Children.

CONCLUSION

By implementing these standards across all levels of healthcare, Children can experience a holistic, dignified and peaceful end of life, while their families receive essential emotional, social, and bereavement support.

DOMAIN 4
TRANSITION OF CARE

Introduction

PPC can be provided in various settings, including the delivery room, theatre, post-partum ward, neonatal intensive care unit (NICU), Paediatric hospital, nursing home, hospice, or at home. Children should have access to a continuum of palliative care services and efficient transition to adult programs when necessary.

General Principles

- Every child with serious illness should be ensured a continuum of care wherever they are and whenever they need it; in the home, community, and different hospitals they access.
- A standardized process should be in place to ensure continuity and coordination of care and services to foster efficient transitioning.
- The child and family must be actively involved in planning and implementing the transition process.

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Ensure early and appropriate referral to specialized palliative care services for Children.
- Provide training for parents and carers prior to transfer to home to equip them with necessary skills.
- Linking with locally available organizations, volunteers and resources for complex medical devices and essential medications.

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

- Facilitate smooth transitions from hospital-based PPC to community-based services and from community to hospital when needed.

STANDARDS

- Ensure comprehensive discharge plans containing relevant information and advice for the child, family, and community health professionals.
- Provide round-the-clock access to qualified PPC practitioners, including medication access and symptom control advice.
- Facilitate adequate supply of equipment, consumables, medicines and transport support before leaving the hospital.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

- Assign a member of the specialist PPC team as the care coordinator to promote seamless transition and care coordination.
- The team should manage coordination between different services and oversee the transition from Paediatric to adult services, when appropriate.
- The coordinator should be easily accessible to the family as the first point of contact for new issues.

CARE TRANSITION TO ADULT PROGRAM

Planning for transition to adult-centred healthcare—including palliative care—involves preparing, transferring, and integrating young adults into new care settings.

Recommendations

- Initiate adequate transition planning from 1-2 years prior to transfer to adult service.
- Foster partnerships between Paediatric and adult teams to effectively address all aspects of the transition.
- Standardized guidelines should be developed to ensure effective transition processes.

CONCLUSION

Children and their families experience multiple transitions alongside chronic complex medical conditions, including changes in care environments, transition into adulthood, illness-related changes, and school integration challenges. A standardized PPC transition process should be established to ensure continuity and coordination of care.

DOMAIN 5
PERINATAL AND NEONATAL PALLIATIVE CARE

Introduction

Perinatal palliative care is a specialized medical care for a fetus or newborn with a life-limiting or life-threatening condition, and their family. This includes access to antenatal counselling, individualized birth planning, and postnatal follow-up with services like, transition to neonatal palliative care, lactation and bereavement support to the mothers.

Neonatal palliative care focuses on providing comfort, dignity, and support for newborns with life-limiting conditions and their families.

General Principles

- Once a fetus is diagnosed with a life limiting/ life threatening anomaly, antenatal holistic support to the family and an individualized birth plan should be developed with the help of palliative care consultation.
- Open and honest communication and care plan among healthcare providers, families, and extended support systems is critical, aligned with family preferences, values, cultural and religious beliefs.
- There should be comprehensive training and education on perinatal and neonatal palliative care for healthcare professionals, including obstetricians and neonatologists, nurses, and social workers, to enhance their knowledge and skills in this specialized field.
- The triggers for neonatal and perinatal palliative care referral should be considered (refer appendix for the criteria for perinatal and neonatal palliative care referral)

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Staff should be trained to identify antenatal mothers with foetal anomalies and provide initial counselling and emotional support to the family and refer for specialized care.

STANDARDS

- Ensure awareness of triggers for palliative care referrals, such as antenatal/postnatal diagnoses incompatible with long-term survival or conditions causing significant morbidity or unbearable suffering.
- In the event of baby dying, bereavement support should be available to the family .
- In the event of baby surviving, follow -up support and appropriate care transition should be ensured.

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

Equip palliative care providers to manage antenatal counselling of family, developing individualized birth plan, and to provide initial symptom management/ end-of-life-care to babies born at secondary level hospital.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

- Develop and implement comprehensive training programs for obstetricians, neonatologists, nurses, and social workers in perinatal and neonatal palliative care .
- Facilitate evidence-based practices using appropriate assessment tools, medication dosing, and pain scales for neonates.
- Support legally appropriate and ethical decision-making processes while ensuring culturally and religiously sensitive care.
- Promote collaboration for research, audits, and continuous quality improvement in perinatal and neonatal palliative care.

CONCLUSION

Perinatal and neonatal palliative care should be an essential component of any obstetrics and Paediatric program. By integrating care early in the illness journey, healthcare systems can ensure that families and newborns receive compassionate, comprehensive support tailored to their needs.

DOMAIN 6
COMMUNITY BASED PPC

Introduction

Palliative care should be available for every child with serious illness either in their homes or closest to their homes in the community. The community provides the child the safety network of home, sibling, family, friends, neighbours and school.

General Principles

- Recommendation at all levels of care.

1. Every child with serious illness should have access to support from their community, whenever they need it, home, hospital or hospice.
2. Family should be adequately trained and empowered to take care of the child in their homes
3. Community health workers, such as Anganwadi and ASHA workers, should be sensitized to support Children and their families at home and serving as vital links between families and healthcare institutions.
4. Volunteers can be a key part of community-based PPC and should be sensitized and trained to provide effective care of Children with specialized needs.
5. Local NGOs, village communities, faith-based organizations, and school staff should be encouraged to actively participate in providing medical and non-medical support, as well as resources, for Children with palliative care needs and their families and siblings.

CONCLUSION

Every child with serious illness should have access to palliative care in their homes and should be supported by the community they live.

DOMAIN 7
EDUCATION & TRAINING IN PPC

Introduction

Education and training in PPC are essential for building sufficient expertise to deliver high-quality care for Children with serious illnesses.

General Principles

- All healthcare providers involved in child health like doctors, nurses, social workers, psychologists, physiotherapists, community health workers should adopt a palliative care approach when caring for Children with serious illnesses. Therefore, appropriate training in PPC must be provided to these professionals (Appendix 3).
- Paediatric specializations and related field such as Paediatric neurology, nephrology, cardiology, endocrinology, neonatology, critical care, and fetal medicine—should integrate generalist-level training in PPC.
- Subspeciality in PPC should be developed to create more number of specialists in PPC to meet the increasing needs of Children with chronic, complex conditions.
- Ongoing education and training for healthcare workers should be encouraged to build capacity and ensure the implementation of best practices in PPC.
- Awareness of PPC among healthcare professionals and public should be increased to ensure better access, acceptability, and timely referrals through training and creating IEC resources.

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Healthcare professionals treating Children with serious illnesses should be trained in a palliative care approach to manage symptoms such as pain and others, and to provide psychosocial and spiritual support to Children and their families.
- Community health workers (e.g., ANMs, ASHAs) should be trained to identify Children with palliative care needs and make appropriate referrals when necessary.
- Family should be educated and empowered to provide basic care for bed-bound and terminally ill Children at home.

STANDARDS

- Awareness should be raised among community volunteers, school teachers, caregivers, and the general public to improve access to PPC.
- Ongoing training for healthcare workers should be promoted to build capacity and ensure the adoption of best practices.

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

Paediatricians and professionals in related field such as Paediatric neurology, nephrology, cardiology, endocrinology, neonatology, critical care, and fetal medicine should receive generalist-level training in PPC.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

- Paediatricians, Paediatric nurses, psychologists, and social workers should receive specialist level training to develop dedicated PPC services.
- Palliative care modules should be created for Paediatric and palliative postgraduate students, general and specialist Paediatric and palliative care physicians, allied professionals (e.g., psychologists, social workers, physiotherapists, pharmacists), and volunteers. A sufficient pool of trainers should be built through "train-the-trainer" programs.
- Protocols and guidelines based on evidence should be established for managing Children with serious illnesses.
- Child and family- centric resources, information leaflets and videos should be developed to address various conditions, symptoms, and services in PPC. This should be disseminated through social and print media to raise community awareness.

CONCLUSION

Education and training in PPC for healthcare providers are vital for delivering high-quality care to Children with serious illnesses. A comprehensive strategy that includes customized curriculum and ongoing education ensures that healthcare providers acquire the essential skills and knowledge needed. Additionally, raising community awareness is critical for the early identification of needs and access to care.

DOMAIN 8
ETHICS AND LAW IN PPC

Introduction

Medical ethics in the context of Children is distinct and challenging due to factors such as limited decision-making capacity, reliance on caregivers for critical decisions, vulnerability to potential harm from medical treatments, and sensitive end-of-life considerations for seriously ill or frail Children.

PPC, should ensure compassionate , ethical and informed care for the best possible outcomes in the interest of Children with serious illnesses.

General Principles

- Recommendation at all levels of care.

1. Shared decision-making , based on honest and sensitive communication regarding a child's health and disease prognosis should involve physicians, parents, and the child when possible and developmentally appropriate.
2. Children's rights to autonomy, supported by their parents or guardians, must be respected by ensuring they are fully informed of available options and are empowered to engage in Goals-of-care discussions to the extent of their ability.
3. Parents or guardians must provide informed consent, while a child's assent—expressing willingness or preference—should be obtained based on their age, mental capacity, and maturity, for any therapy, procedures, care, or research participation.
4. Every child is entitled to effective medical treatment that prevents serious harm, suffering, or death.
5. It is vital to adhere to institutional, regional, state, and national regulations/ policy regarding ethical practice and law.

CONCLUSION

Medical ethics in Paediatric practice address the unique challenges and vulnerabilities of Children. It promotes their best interests through a collaborative decision-making process within the legal and ethical framework, delivering compassionate and equitable care.

DOMAIN 9
POLICY AND GOVERNANCE IN PPC

Introduction

Effective governance and policy frameworks are critical for PPC services. The World Health Organization's (WHO) public health strategy for palliative care identifies enabling policy as one of its pillars, alongside drug availability, education, research and people and community engagement. Such policies and fund allocation must be integrated into Children's national and state level health plans across all relevant health and social care programs.

General Principles

- Recommendation at all levels of care.

1. Policies for PPC should focus on equity, accountability, inclusivity, and high service standards.
2. Integrated PPC services embedded in a primary healthcare (PHC) approach are essential to achieve universal health coverage (UHC) in Paediatric health.
3. Financial resources must be allocated specifically for PPC within the National Program for Palliative Care (NPPC).
4. Ensure the availability of essential medications, consumables, equipment and resources for PPC at community levels.
5. Encourage partnerships with community-based service providers to create tailored, child-centered care plans, including preferences for place of death and bereavement support.
6. Policy should include strategies to educate and train healthcare workers to address basic and complex Paediatric palliative needs and inclusion of PPC in the curriculum of post graduate training program.
7. Legal frameworks must address advance care directives, organ and tissue donation, end-of-life decision-making, and limitations of medical treatment in PPC.

STANDARDS

8. Governance structures should monitor and evaluate PPC services through audits, feedback mechanisms, and reporting. Quality improvement efforts and strategic linkages with Paediatric health initiatives should also be prioritized.
9. Establish Paediatric-specific palliative care services as part of UHC health benefits packages and private insurance plans.
10. Facilitate access to compassionate leave, tax benefits, and homecare support for family caregivers.
11. Establish dedicated PPC directorates for strategic planning, policy oversight, and governance.
12. Include provisions for specialized care settings, such as Paediatric hospice units, and ensure constant availability of advanced medicines and technologies.
13. Facilitate research and innovation in PPC to improve clinical practices, resource management, and care outcomes.

CONCLUSION

By embedding PPC policies across all levels of healthcare, fostering governance structures, and ensuring equitable access to resources and training, healthcare systems can deliver high-quality, compassionate, and child-centred palliative care.

DOMAIN 10
PPC – RESEARCH AND QUALITY IMPROVEMENT

Introduction

Children deserve evidence-based, evaluated, and quality health care, yet much of PPC is shaped by clinical experience rather than robust evidence. Research on cost-effectiveness and effective care models remains limited, and significant gaps exist in evidence for Paediatric symptom management. Strengthening the evidence base can revolutionize clinical practices, set standards, inform funding decisions, and formulate effective training programs.

General Principles

- Evidence-based practices in PPC must integrate clinical expertise with high-quality research and child and family preferences.
- Strategic investments in researchers, training, and facilities are crucial to advancing PPC.
- PPC research should focus on Clinical and health services research, need assessments and situational analysis.
- Audits and research must incorporate diverse perspectives, including those of patients, families, professional care providers, culture and communities.
- Research and data management should adhere to national guidelines and ethical standards specific to Children as a vulnerable population.
- Minimum and aspirational quality indicators should be introduced to strengthen implementation and accountability. Examples include:
  - Routine symptom assessment documentation

  Family satisfaction and experience measures
  - Timeliness of PPC referral
  - Alignment between preferred and actual place of care/death
- These indicators should be adaptable for low-resource settings, using feasible approaches such as simplified tools, minimal datasets, and periodic audits to ensure consistent monitoring across all levels of care.

STANDARDS

STANDARDS FOR IMPLEMENTATION ACROSS HEALTHCARE LEVELS

PRIMARY HEALTHCARE LEVEL

- Service providers should contribute to research through collaboration and networking with higher-level providers and other partners, particularly in data collection and documentation

SECONDARY HEALTHCARE LEVEL

In addition to Primary Healthcare level recommendations

- Health care providers should independently or collaboratively initiate and conduct audits and research on key areas such as organizational management, holistic care provision, education, training, and information management.
- Processes must be in place to ensure that audit and research findings are effectively incorporated into service development and implementation.
- Access to resources such as peer-reviewed journals and online research platforms should be provided.
- Health care providers should be supported to publish findings and disseminate them to local, regional, and international audiences.
- Research should include patient, family, and care provider perspectives, ensuring alignment with local socioeconomic and cultural contexts.

TERTIARY HEALTHCARE LEVEL

In addition to Secondary Healthcare Level recommendations

- Dedicated infrastructure, time, and personnel should be allocated to advancing the research agenda.
- Training and mentorship programs should be made available to providers at primary and secondary levels.

CONCLUSION

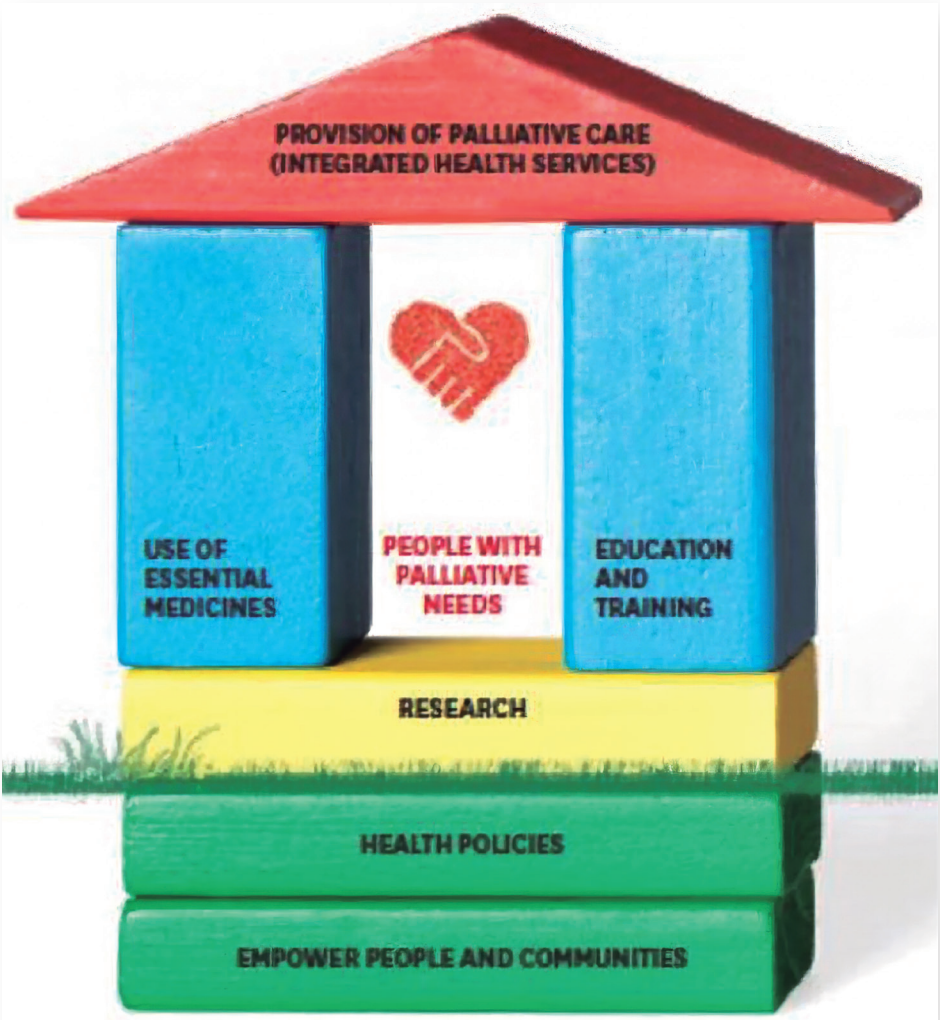
Incorporating research into PPC standards enables systematic evaluation of care quality, identification of improvement areas, and enhanced service effectiveness to foster a culture of evidence-based practice and continuous learning.

OVERALL CONCLUSION

In conclusion, this document provides a comprehensive overview of key domains in PPC, including symptom assessment and management, education and training, drug availability, governance, care of the dying, quality standards, and research. Recommendations provided in each domain set standards for achieving the highest quality care in PPC.

APPENDIX 1

WHO Conceptual Framework[39]



Reference - https://share.google/images/5bdx87e0RvYSlflVU

APPENDIX 2

Levels of Health Care in the Indian Context

These levels represent different types of care involving varying degrees of complexity[22,23]

Primary Care Level

Primary health care or essential healthcare is provided by the primary health centers and their sub-center through multipurpose health workers, ANM, ASHA, Anganwadi worker, village health guide and trained dais, home care through government, NGO and private agencies, private dispensaries.

Secondary Care Level

A more complex level of care is provided in district hospital, area hospitals and the community health center, private hospitals and clinic and government, NGO and private agencies led hospice facility which also serve as the first referral level.

Tertiary Care Level

A more specialized level of care that requires specific facilities and attention of highly specialized health workers. This care is provided by the district hospitals, medical college hospitals, specialized/ apex government and private hospitals, nursing homes and hospices. Care approach in all aspects of healthcare of the child.

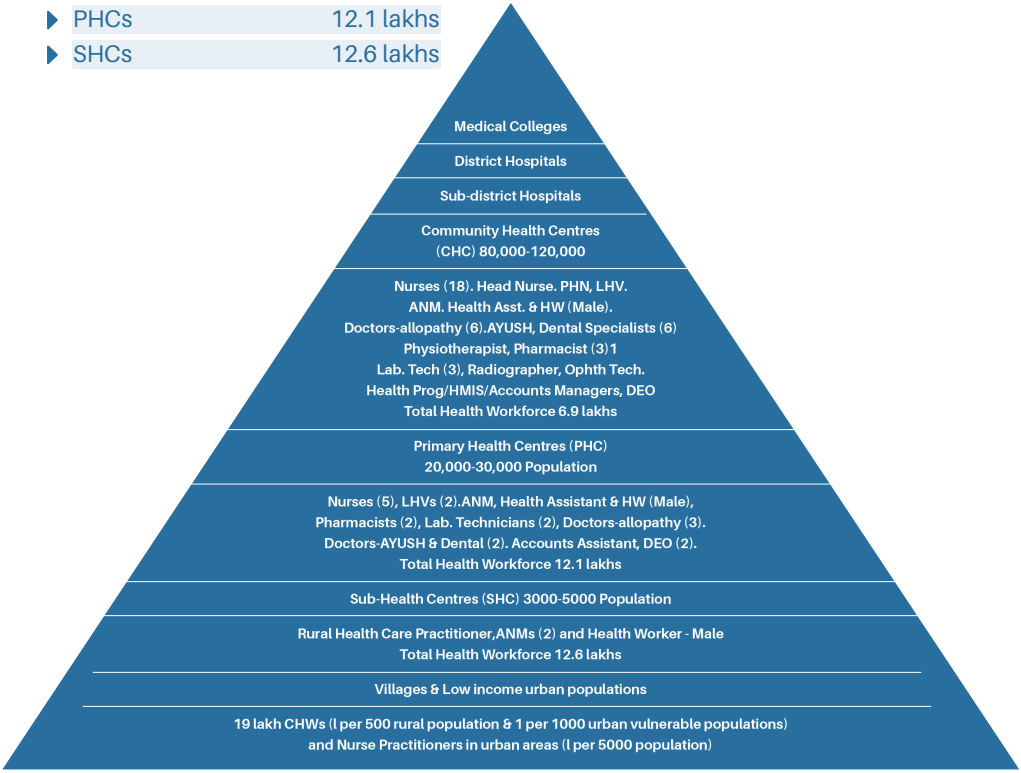
APPENDIX 2

Levels of Health Care in the Indian Context

Districts: 25 lakhs Population | Medical College Hospital : 750 beds

Medical Colleges and Sub-district Hospitals include both Government & Private Providers

Tertiary-level HRH	6.9 lakhs
Medical Colleges	4.1 lakhs
District Hospitals	2.8 lakhs
Secondary-level HRH	18.2 lakhs
Sub-district hospitals	11.3 lakhs
CHCs	6.9 lakhs
Primary-level HRH	24.7 lakhs
PHCs	12.1 lakhs
SHCs	12.6 lakhs

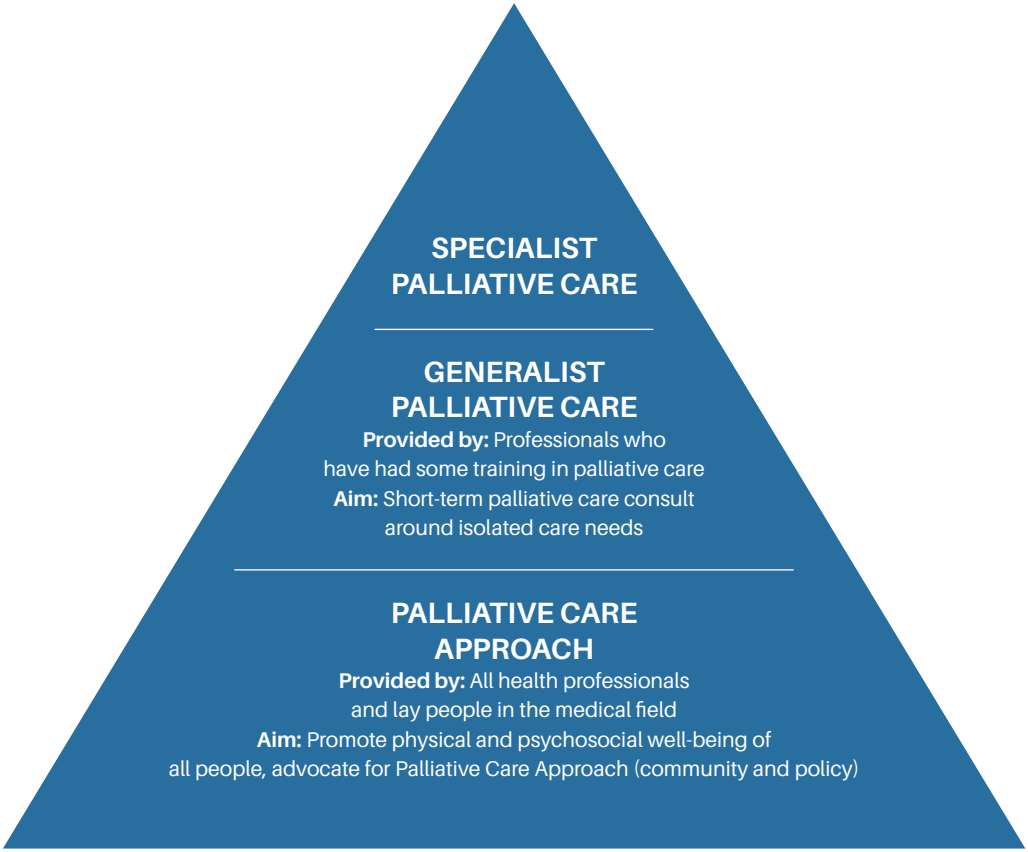


Levels of Health Care

APPENDIX 3

Pyramid of PPC Education Competency[40]

Provided by:
Inter-disciplinary, full-time team with advanced training Aim: Follow and support patients and families with complex care needs



EXPERT REVIEWERS

Dr. Lulu Mathews - Government Medical College, Kozhikode

Dr. Rachna Seth - AIMS, New Delhi

Dr. Ramandeep Singh Arora - Max Super Speciality Hospital ,New Delhi

Dr. Suresh Kumar - WHO collaborating center ,Calicut

Dr. Thota Raghu - Tata Memorial Centre, Mumbai

Prof. Julia Downing - International Children's Palliative Care Network

Dr. Megan Doherty - Sunflower Children's Network, Two Worlds Cancer Collaboration, Canada

Ms. Camara Van Breemen - Canucks place Children's Hospice, Vancouver

PPC STANDARDS DEVELOPMENT TASKFORCE COMMITTEE

Dr. Aneka Paul – Independent consultant

Dr. Archana Iyengar – MNJ Institute Of Oncology & Regional Cancer Centre, and PRPCS Hyderabad

Dr. Armida Fernandes – SNEHA,Romila Palliative Care Center, Mumbai

Dr. C Swetha – Niloufer Hospital for Women and Children

Dr. Chitra Venkateshwaran – Amrita Institute of Medical Sciences, Kochi

Dr. Dampuri Ramesh Babu-Niloufer Hospital for Women and Children, Hyderabad

Dr. Gayatri Palat - MNJ Institute Of Oncology and Regional Cancer Centre, and PRPCS Hyderabad

Sr. Hanife MacGamwell-IAPC

Dr. Ira Almedia – South Goa District Hospital, Maragao, Goa

Dr. Ishita Gandhi – CanSupport, Delhi

Dr. Jayita Deodhar – Tata Memorial Hospital, Mumbai, Homi Bhabha National Inst

Dr. Krithika S Rao – Kasturba Medical College, Manipal Academy of Higher Education, Manipal

Dr. Manjusha Nair – Regional Cancer Centre , Thiruvananthapuram

Dr. Mary Ann Muckaden-Ayuralaya Palliative Care Center, Mumbai

Dr. Mohammad Ishak Tayoob – MCGM-CTC,PHO & BMT Centre, Mumbai

Ms. Nandini Ghosh-Volunteer PRPCS, Hyderabad

Dr. P G Hariprsad – SAT Hospital , Govt Medical College, Trivandrum

Dr. Prakash Fernandes – Cipla Foundation

Dr. Sabitha Binu Ninan – The Voluntary Health Services, Chennai

Mr. Sameer Cuncolkar – Goa Medical College, Goa

Dr. Seema Mishra-AIIMS, Delhi

Dr. Shamali Poojary – Tata Memorial Hospital, Mumbai

Dr. Smriti Khanna – PD Hinduja Hospital and Medical Research Centre, Mumbai

Dr. Spandana Rayala – Sunflower Children's Network, Two World's Cancer Collaboration

Ms. Stella Matthew – Golden Butterflies Children's Palliative Care Foundation, Chennai

Dr. Veronique Dinand – B J Wadia Hospital, Mumbai

Ms. Vineela Rapelli – PRPCS, Hyderabad

PROJECT ADVISORY COMMITTEE

Dr. Alimelu - Niloufer Hospital for Women and Children, Hyderabad

Dr. Anuradha Ganigara- Indira Gandhi institute of Child Health,Bangalore

Dr. Aparna Alladi - Niloufer Hospital for Women and Children, Hyderabad

Dr. Ch Ramya - Niloufer Hospital for Women and Children, Hyderabad

Dr. D Narendra - Niloufer Hospital for Women and Children, Hyderabad

Ms. Dhvani Mehta - Vidhi Centre for Legal Policy, Mumbai

Dr. Jagdeeshwar Reddy - Pain Relief and Palliative Care Society ,Hyderabad

Dr. Kouser Sultana - Niloufer Hospital for Women and Children, Hyderabad

Dr. L.Swapna - Niloufer Hospital for Women and Children, Hyderabad

Dr. Manasi Patil - B J Wadia Hospital, Mumbai

Ms. Nadine - Canucks place and Children's Hospice,Vancouver

Dr. Nagajyothi - Niloufer Hospital for Women and Children, Hyderabad

Dr. Nirmala - Niloufer Hospital for Women and Children, Hyderabad

Dr. Philomina D'souza - Goa Medical College ,Goa

Ms. Poonam Bagai - Cankids, New Delhi

Dr. Ramesh Dampuri - Niloufer Hospital for Women and Children, Hyderabad

Dr. Raghunath Rao - MNJ Institute of Oncology and Regional Cancer centre, Hyderabad

Dr. Ravi Kumar - Niloufer Hospital for Women and Children, Hyderabad

Dr. Ravilala Vinod Kumar - Niloufer Hospital for Women and Children, Hyderabad

Dr. Sravya - Niloufer Hospital for Women and Children, Hyderabad

Dr. Srinivas Kalyani - Niloufer Hospital for Women and Children, Hyderabad

Dr. Suchitra Dontamala - Niloufer Hospital for Women and Children, Hyderabad

Dr. Suresh Kumar Yadav - Niloufer Hospital for Women and Children, Hyderabad

Dr. Sushma Malik - SNEHA, Romila Palliative Care Center, Mumbai

Dr. Tanvi Shah - Niloufer Hospital for Women and Children, Hyderabad

Dr. Uma Devi - Niloufer Hospital for Women and Children, Hyderabad

Dr. Usha Rani - Niloufer Hospital for Women and Children, Hyderabad

Dr. Vijay Kumar - Niloufer Hospital for Women and Children, Hyderabad

Dr. Vijay Laxmi - Niloufer Hospital for Women and Children, Hyderabad

Dr. Vishal Toka - Toka-MNJ institute of oncology and Regional Cancer Centre,Hyderabad

ACKNOWLEDGEMENTS

We acknowledge the significant contributions made by the following organisations:

MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad

Pain Relief and Palliative Care Society, Hyderabad

Niloufer Hospital for Women and Children, Hyderabad

Cipla Foundation, India

Indian Association of Palliative Care

Indian Childhood Cancer Initiative

St. Judes Global Children's Research Hospital ALSAC Foundation, Memphis, Tennessee

Two Worlds Cancer Collaboration, Canada

International Children's Palliative Care Network, Bristol, UK

- Motion Graphic Designer - Piyush Narayan, New Delhi
- Tech Support:
  - Abhirup Ghosh, San Francisco
  - Pain Relief and Palliative Care Society, Hyderabad

GLOSSARY

A

- Advance Care Planning (ACP) – Process of discussing and documenting care preferences.
- Analgesia – Pain relief management, including pharmacological and non-pharmacological approaches.
- ASHA (Accredited Social Health Activist) – Community health worker providing primary care support in India.

B

- Bereavement Support – Psychological and emotional support for families after a child's death.
- Breakthrough Pain – Sudden, severe pain episodes despite ongoing analgesia.

C

- Community-Based PPC – Palliative care services provided at home or within the community.
- Complex Chronic Conditions (CCC) – Long-term illnesses requiring specialized care.
- Continuum of Care – Seamless care transitions across different healthcare levels.

D

- Disease-Modifying Treatment – Interventions aimed at slowing disease progression.
- Do Not Resuscitate (DNR) – A medical directive to withhold CPR or life-saving measures.

E

- Ethical Decision-Making – Process involving physicians, families, and legal frameworks in PPC.
- End-of-Life Care – Specialized care for Children in terminal phases of illness.

H

- Hospice Care – Comfort-focused care for Children with life-limiting conditions.
- Holistic Care – Multidimensional care addressing physical, emotional, social, and spiritual needs.

L

- Life-Limiting Conditions (LLC) – Medical conditions where a cure is unlikely.
- Life-Threatening Conditions (LTC) – Illnesses where treatment may or may not be successful.

M

- Multidisciplinary Team (MDT) – Healthcare professionals providing coordinated PPC.
- Morphine – Common opioid used for Paediatric pain management.

N

- Neonatal Palliative Care – PPC provided for newborns with life-limiting conditions.
- Non-Pharmacological Pain Management – Approaches like massage, physiotherapy, and distraction therapy.

O

- Opioids – Strong pain-relief medications used in palliative care.
- Outpatient PPC Services – Palliative care provided in clinics rather than inpatient settings.

GLOSSARY

P

- Pain Ladder (WHO) – Stepwise approach to pain management.
- Perinatal Palliative Care – PPC for fetuses and newborns with life-limiting diagnoses.
- PPC: Paediatric Palliative Care
- PHC : Primary Health Center
- Psychosocial Support – Emotional and mental health care for patients and families.
- PTSD – Post-Traumatic Stress Disorder

R

- Referral Pathway – The process of directing patients to appropriate PPC services.
- Respite Care – Short-term relief care for caregivers of Children with serious illnesses.
- Right to Dignified Death – Ethical principle ensuring comfort-focused end-of-life care.

S

- Secondary and Tertiary PPC Services – Higher-level PPC care provided in hospitals.
- Serious Illness : Life limiting and life threatening
- Shared Decision-Making – Collaborative care planning involving healthcare teams and families.
- Spiritual Care – Addressing religious and existential concerns in PPC.
- Symptom Management – Strategies to control pain, breathlessness, and other distressing symptoms.

T

- Transition of Care – Movement between different care settings (home, hospital, hospice).
- Triggers for PPC Referral – Indicators for initiating palliative care.

U

- Universal Health Coverage (UHC) – Healthcare model ensuring access to essential services, including PPC.
- Uncontrolled Symptoms – Symptoms that persist despite treatment interventions.

W

- WHO - World Health Organisation

REFERENCES

1. African Palliative Care Association. (2010). APCA standards for providing quality palliative care across Africa. APCA.

2. International Standards for Paediatric Palliative Care. (2022). Journal of Pain and Symptom Management, May.

3. National Hospice and Palliative Care Organization. (2022). NHPCO standards of practice for Paediatric palliative care (2022 Edition).

4. Palliative Care Australia. (2018). National palliative care standards (5th ed.).

5. Indian Association of Palliative Care. (2014). IAPC minimum standards paper. Journal of Palliative Care.

6. African Palliative Care Association. (2011). Standards for providing quality palliative care across Africa. APCA.

7. Together for Short Lives categories + British Association for Perinatal Medicine- https://commissioning.togetherforshortlives.org.uk/about-Childrens-palliative-care/life-limiting-conditions-and-how-they-affect-Children-and-families/

8. Hanks, J., Kaasa, S., & Robbins, M. (2005). Research in palliative medicine: Getting started. In D. Doyle, J. Hanks, & N. Cherny (Eds.), Oxford textbook of palliative medicine (pp. 128-138). Oxford University Press.

9. McQuay, H. J., Moore, A., & Wiffen, P. (2005). Research in palliative medicine. In D. Doyle, J. Hanks, & N. Cherny (Eds.), Oxford textbook of palliative medicine (pp. 119-128). Oxford University Press.

10. Harding, R., & Higginson, I. J. (2007). Palliative care in Sub-Saharan Africa. In R. Harding (Ed.), Palliative care in resource-poor settings: Fallacies and misapprehensions (pp. 515–517). Journal of Pain and Symptom Management, 36(5). https://doi.org/10.1016/j.jpainsymman.2008.04.019

11. Kassa, S. (2006). A 25-year perspective on the development of palliative care research in Europe. In R. A. Powell, J. Downing, F. Mwangi-Powell, L. Radbruch, & R. Harding (Eds.), Advancing palliative care research in Sub-Saharan Africa: From Venice to Nairobi. European Journal of Palliative Care, 15(5). https://www.eapcnet.org/download/forMembersonly/pdfpapers/EJPC155Powell-Radbruch.pdf

12. Mpanga Sebuyira, L., & Moore, J. (2003). Palliative care: The 21st century challenge. Health, 2003.

13. Powell, R. A., Downing, J., Mwangi-Powell, F., Radbruch, L., & Harding, R. (2008). Advancing palliative care research in Sub-Saharan Africa: From Venice to Nairobi. European Journal of Palliative Care, 15(5). https://www.eapcnet.org/download/forMembersonly/pdfpapers/EJPC155Powell-Radbruch.pdf

14. Mpanga Sebuyira, L. (2006). Chapter 2: Overview of HIV and AIDS and palliative care. In L. Gwyther, A. Merriman, L. Mpanga Sebuyira, & H. Schietinger (Eds.), A clinical guide to supportive and palliative care for HIV and AIDS in Sub-Saharan Africa (pp. 15–30). African Palliative Care Association.

15. Adoption of a declaration to develop a global palliative care research initiative. (2006). Progress in Palliative Care, 14, 215-217.

16. Higginson, I. J., Hart, S., Koffman, J., Selman, L., & Harding, R. (2007). Needs assessments in palliative care: An appraisal of definitions and approaches used. In R. Harding (Ed.), Palliative care in resource-poor settings: Fallacies and misapprehensions (pp. 515–517). Journal of Pain and Symptom Management, 36(5). https://doi.org/10.1016/j.jpainsymman.2008.04.019

17. Downing, J., Gwyther, L., & Pawinski, R. (2006). Chapter 39: Monitoring and evaluation. In L. Gwyther, A. Merriman, L. Mpanga Sebuyira, & H. Schietinger (Eds.), A clinical guide to supportive and palliative care for HIV and AIDS in Sub-Saharan Africa (pp. 312–324). African Palliative Care Association.

18. Wool, C., & Parravicini, E. (2021). Implementation of quality indicators of perinatal/neonatal palliative care one year following formal training. Frontiers in Paediatrics, 9, 752971. https://doi.org/10.3389/fped.2021.752971

19. Akyempon, A. N., & Aladangady, N. (2021). Neonatal and perinatal palliative care pathway: A tertiary neonatal unit approach. BMJ Paediatrics Open, 5(1). https://doi.org/10.1136/bmjpo-2020-000820

20. Dombrecht, L., Chambaere, K., Beernaert, K., Roets, E., De Vilder De Keyser, M., De Smet, G., Roelens, K., & Cools, F. (2023). Components of perinatal palliative care: An integrative review. Children, 10(3), 482. https://doi.org/10.3390/Children10030482

21. African Palliative Care Association. (2011). APCA standards for providing quality palliative care across Africa. https://www.africanpalliativecare.org/images/stories/pdf/APCA_Standards.pdf

22. Chokshi, M., Patil, B., Khanna, R., Neogi, S. B., Sharma, J., Paul, V. K., & Zodpey, S. (2016). Health systems in India. Journal of Perinatology, 36(s3). https://doi.org/10.1038/jp.2016.184

REFERENCES

23. Park, K. (2015). Park's textbook of preventive and social medicine (27th ed.). M/S Banarsidas Bhanot.

24. Loura, D., Ferreira, A.M., Romeiro, J. et al. Health-illness transition processes in Children with complex chronic conditions and their parents: a scoping review. BMC Pediatr 24, 446 (2024).

25. Kapoor M, Kim R, Sahoo T, et al. Association of maternal history of neonatal death with subsequent neonatal death in India. JAMA Netw Open. 2020;3(4):e202887-e202887.

26. Levels & Trends in Child Mortality. Report 2022, Estimates developed by the United Nations Inter-Agency Group for Child Mortality Estimation. 2023. Accessed February 2025. https://childmortality.org/wp-content/uploads/2023/01/UN-IGME-Child-Mortality-Report-2022.pdf

27. Subramanian SV, Kumar A, Pullum TW, Ambade M, Rajpal S, Kim R. Early-Neonatal, Late-Neonatal, Postneonatal, and Child Mortality Rates Across India, 1993-2021. JAMA Netw Open. 2024;7(5)

28. https://nhm.gov.in/index1.php?lang=1&level=2&sublinkid=819&lid=219

29. Krishnaswamy P. In: Morbidity Study-Incidence, Prevalence, Consequences and Associates. Neelakantan S, Nair PR, Shaji H, editors. Thiruvananthapuram: Centre for Development Studies; 2004. Kerala Research Program on Local Level Development; pp. 17–59

30. Ganguly S, Kinsey S, Bakhshi S. Childhood cancer in India. Cancer Epidemiol. 2021 Apr;71(Pt B):101679.

31. https://www.who.int/europe/news-room/fact-sheets/item/palliative-care-for-Children

32. Kelley AS, Morrison RS. Palliative care for the seriously ill. N Eng J Med. 2015;373:747–55.

33. Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010;16(5):423–35.

34. Connor SR, Downing J, Marston J. Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis. J Pain Symptom Manage. 2017 Feb;53(2):171-177.

35. https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-PaediatricsWood F, Simpson S, Barnes E, Hain R. Disease trajectories and ACT/RCPCH categories in Paediatric palliative care. Palliat Med. 2010;24:796–806.

36. https://www.who.int/news-room/fact-sheets/detail/quality-health-services

37. https://www.unicef.org/child-rights-convention/convention-text

38. Clelland D, van Steijn D, Macdonald ME, Connor S, Centeno C, Clark D. Global development of Children's palliative care: An international survey of in-nation expert perceptions in 2017. Wellcome Open Res. 2020 Oct 14;5:99.

39. https://share.google/images/5bdx87e0RvYSlflVU

40. Payne S, Seymour J, Ingleton C, Palliative Care Education Task Force of the European Association for Palliative Care (EAPC). Core competencies in palliative care: an EAPC white paper on palliative care education – Part 1. European Journal of Palliative Care. 2013;20(2):86–91. Available from https://www.researchgate.net/profile/Sheila-Payne/publication/283763543_Core_competencies_in_palliative_care_An_EAPC_white_paper_on_palliative_care_education_-_Part_1/links/5649ad2708aef646e6d2a97e/Core-competencies-in-palliative-care-An-EAPC-white-paper-on-palliative-care-education-Part-1.pdf

Indian
Association of
Palliative
Care

CONTACT INFO

palliativecarepartners@gmail.com

https://palliativecarepartners.in/

Kumudini Devi Hospice, Pain Relief and Palliative Care Society,
Inside Sivananda Rehabilitation Home, Opp Pillar No. 789
Kukatpally, Hyderabad, Telangana, 500072