PALLIATIVE CARE FOR PEDIATRIC PATIENTS
INTRODUCTION

• In Sub-Saharan Africa 16% of children born alive die before their 5th birthday.
• AIDS and cancer are two most commonest incurable childhood diseases in Africa, with HIV/AIDS accounting for up to 60% of child deaths, 166,000 children under 15 are diagnosed with cancer.
• Such children and their families require comprehensive, compassionate, and developmentally appropriate palliative care.
WHAT IS A CHILD?
• From the peri-natal period
• Neonates
• Infants
• School –aged children
• Adolescents
• Young adults
• Upper Age? 10/12/17/18?
WHO DEFINITION FOR P.P.C

• Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.

• It begins when the illness is diagnosed, and focuses on enhancement of quality of life for the child.

• Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it
• It can be provided in tertiary care facilities, in community health centers and even in children's own homes.
HOW DOES THIS COMPARE WITH APC?

Life is not measured by the number of breaths we take, but by the moments that take our breath away.
• Communication with children tends to be more difficult than adults.
• Children’s understanding of death and dying differs from that of adults.
• Ethical dilemmas, as children by law cannot give consent.
• Children are particularly fearful of separation from family, friends, home and school.
• Children are not small adults. They think and behave differently to the way that adults do
• Pharmacokinetics and pharmacodynamics of drugs with children differ from that of adults.
• Children have a broad range of people involved in their care, so team-working and team dynamics is very important.
• Children are developing and maturing all the time so each child will be at a different age and different stage of development.
• PPC can be more emotionally draining than adult palliative care.
GOALS OF P.P.C

1. To prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, optimizing pain and symptom management.

2. Help patients with life-threatening/life-limiting conditions and their families live as normally as possible.
GOALS OF PPC

3. Provide patients and their families with timely and accurate information.

4. Support patients and families in decision-making and goal setting.

5. Promoting hope and dignity for patients and families.
GOALS OF PPC

6. Caring for the whole family by listening, respecting their beliefs and recognizing each family and child is different.

7. Provide continuity of care – supporting families during hospitalization and coordinating discharge with Medical team, follow up with special needs clinic as appropriate.
CRITERIA FOR PALLIATIVE CARE REFERRAL

Neonatal Criteria
• Extreme prematurity
• Severe birth asphyxia
• Intra-ventricular hemorrhage
• Hydrocephalus
• Severe congenital anomalies
• etc
CRITERIA FOR PALLIATIVE CARE REFERRAL

Pediatric Criteria

• Spinal cord/Head injuries with neurological complications
• Organ failure (kidney, liver)
• Metabolic/ genetic diseases
• HIV/AIDS
• Meningitis with severe neurological sequelae
• Progressive neurodegenerative conditions, i.e. muscular dystrophy, spinal muscular atrophy,
ACT CATEGORIES FOR CONDITIONS REQUIRING PC

- The UK based ACT - Association for Children with life Threatening and life-limiting conditions - propose four different categories of children requiring palliative care.
ACT CATEGORY I

- Life threatening conditions where cure is possible but may fail. Access to palliative care is necessary when treatment fails or during an acute crisis.
- Examples: - cancer (where chemo and radiotherapy is available); Congenital/acquired heart disease; infectious diseases like MDR/XDR TB, meningitis.
ACT CATEGORY II

- Conditions requiring intensive life-long therapy aimed at maintaining the quality of life, to allow the patient to participate in normal activities.
- E.g. HIV/AIDS on HAART; Chronic renal failure on dialysis; extreme prematurity, sickle cell disease;
ACT CATEGORY III

• Progressive conditions where there is no known cure, treatment is exclusively palliative after diagnosis.

• Examples – complex inoperable cardiac disease; advanced metastatic cancer; progressive metabolic disorders; neuromuscular/neurodegenerative disorders
ACT CATEGORY IV

• Conditions that are irreversible but non-progressive and often associated with disability causing vulnerability to health.

• Examples- multiple disabilities after brain or spinal cord injury, severe Cerebral Palsy; severe perinatal asphyxia; meningoencephalocele.
EXCEPTIONS

- Children with psychiatric illnesses – this children need expert psychiatric services.
- Diabetic children – who are followed up by endocrinologists and with good blood sugar control.
• The common factor is premature death is likely or expected with many of these conditions.

• The ACT classification is useful as it helps to guide decision making: e.g. a more aggressive curative approach in ACT I compared to ACT III where the key component is palliative care.
DISEASE TRAJECTORIES

• A disease trajectory is a graphic representation of health status over time.
• They are influenced by the availability of disease modifying treatments.
• Knowledge of a disease trajectory helps with decision making and assists in determining the “end-of-life” phase.
ACT CATEGORY I

Healthy

Remission

Treatment

Diagnosis

Time

Death
ACT CATEGORY II

Healthy

Diagnosis

Time

Death
ACT CATEGOR Y IV
• It is a journey from health to ill-health for that child who is diagnosed with life-threatening or life limiting illness.

• The child and their families make multiple transitions during the course of the same illness with exacerbations and remissions along the way.

• As they enter into the terminal phase of illness, intervention priorities change, and yet another transition is made when the child dies and the family is bereaved.
• A patient can change from one class to another e.g. an ACT class I patient can go into relapse and no longer be curable and have a disease trajectory at the end similar to a patient with an ACT class III condition.

• In cerebral palsy ACT IV the demands placed on the body by growth and other changes in adolescence may lead to a decline in health and level of function with death in early adulthood ACT III
2 SPECIAL CATEGORIES..


2. Children who require supportive rather than palliative care: - HIV affected children and children whose parent(s) have died and require ongoing holistic support and future planning. (they should be referred to relevant social services once they no longer need palliative intervention.)
SUMMARY

• Pediatric palliative care and adult palliative care are to separate though similar entities.

• 4 ACTS categories of conditions that require palliative care.

• Disease trajectories are important to assist with decision making.

• Bereaved children and those who require holistic supportive care can benefit from palliative care.