

TRAINING MANUAL ON PAEDIATRIC PALLIATIVE CARE



Children's Palliative Care Project
Indian Association of Palliative Care

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PAEDIATRIC
PALLIATIVE CARE**

*"Dedicated to children and their families who bravely
face the reality and challenges of life limiting
conditions, and to people who come together to spread
awareness about Paediatric Palliative Care."*

Foreword

When babies, children and young people face life-limiting and life-threatening illness the particular vulnerabilities linked to their age and development are increased. They need all the protection, care and support that every child should enjoy, and more than that, they have the right to receive good palliative care provided by compassionate, informed and skilled professionals and volunteers; care that recognizes the special needs of children and their families, and care that is holistic, of the body, mind and spirit.

Palliative care for children begins in the peri-natal period, affirms that each child and family is unique, and that while facing serious illness, children remain children, who still need to play, to grow and to develop, and enjoy quality of life, as far as possible.

This Handbook is an important unique and tool to further the development of palliative care for children in India, and to help relieve the suffering of this special and often neglected group of children. The various chapters reflect the multi-disciplinary nature of palliative care; concern and compassion for these children is reflected throughout the pages.

I congratulate all involved in the production of this excellent Handbook and encourage professionals and volunteers caring for children with life-limiting conditions, to learn from and use this in their practice. My hope is that many will be encouraged to study further in this field, and become advocates for these children who are often too young, too disabled and too ill to speak for themselves. We are all responsible for ensuring that palliative care for children becomes essential care for children. They deserve nothing less.

-Joan Marston

Chief Executive: International Children's Palliative Care Network

Acknowledgement

Through the course of working with the Children's Palliative Care (CPC) Project, since its inception we came across a number of experiences of children and families and also the expertise of Professionals working in the area of Paediatric Palliative Care.

It was a felt need to design and compile a Handbook on Paediatric Palliative Care as there was not much training material on Paediatric Palliative Care for Health Care Professionals in Indian Context. This handbook would comprise of a wide range of topics with a multidisciplinary dimension with the necessary knowledge, attitude and skill required in Paediatric Palliative Care as well as to sensitize Health Professionals in the field.

On behalf of the Children's Palliative Care Project of Indian Association of Palliative Care (IAPC), I wish to express my sincere gratitude to all the authors who have contributed their expertise to this endeavour.

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Chapter 1

Introduction to Children's Palliative Care - Gaps in India

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Every child is special, every child is unique... however what each and every child needs is the same....a warm hug , a comforting smile, a love filled heart and a guiding hand to go on...

Palliative Care for children with life limiting conditions aims at taking total care of the child including body, mind and spirit. It is a holistic, professional and active approach to caring that includes but is not restricted to pain and symptom management. It also involves providing support to the family. The care 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 can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in child's home. It extends throughout the continuum of the care.

Childhood is considered to begin from the perinatal and neonatal period until 18 years of age. There are numerous conditions which affect children and their families like:

- Congenital disorders
- Metabolic disorders
- HIV infection in children
- Thalassaemia and other haematological disorders
- Organ failure
- Cancer

These conditions prevent children from enjoying the possible quality of life that would normally be enjoyed by children. The conditions

bring with them pain, discomfort, medications, investigations, hospitalization, and emotional, psychological and social challenges. The families of these children also face immense emotional, psychological and social challenges as they cope with taking care of the sick child and coming to terms with their own feelings like sadness, helplessness and anxiety.

The Need for Children's Palliative Care Services:

There are no accurate figures on the number of children worldwide in need of palliative care services but is estimated to be between 7 - 20 million.

Quantification of the need is complicated by factors such as uncertainty of population numbers and the unpredictability of disease trajectories. Baum et al estimates that for every 50,000 children 50 will have a life-limiting/life-shortening illness (10 : 10 000) half of which will require Palliative Care at any one time. Worldwide there are not enough children's palliative care services to meet the need.

In a systematic review to map Children's Palliative Care services worldwide carried out by Knapp, et al found that there are 78 countries where there is no known children's palliative care activity, 41 countries where there is evidence of capacity building in children's palliative care, 80 countries with localised provision of services and 35 where the services are approaching integration with mainstream service providers. India has localised provisions of Palliative care.⁽¹⁾

In India around 220,000 children are suffering with HIV. Children (<15 years) account for 3.5% of all infections. Around 25000 HIV infections occur in children annually.

1.6 to 4.8% of all cancer in India is seen in children below 15 years of age and the overall incidence of 38 to 124 per million children per year.⁽²⁾

More than 12,000 Thalassemia children are born in India every year. Around 50 to 60 thousand children are suffering with Thalassemia⁽³⁾. The exact number of other life limiting conditions is unknown. It is estimated, however, that at present less than 1% of them have any access to Palliative Care⁽⁴⁾.

Goals of Children's Palliative Care

- To prevent and relieve suffering
- Relief of physical symptoms
- Psychological support to the child and his family
- Addressing other needs like education, recreation, nutrition
- Home care-Empowering the family to care for the child at home
- To improve quality of life of children with serious and complex medical conditions

Palliative Care ensures child's comfort throughout the course of the illness. The guiding ethical principle of palliative care includes autonomy, beneficence, non-maleficence, and justice. Thus, the family and child are full partners with the health care team in management decisions. Its benefits are not just reserved for end-of-life care.

In the case of HIV, it starts from the time an HIV-1 infected woman becomes pregnant, and then through the course of disease and eventual death of her child. A child with life-limiting illnesses should receive palliative care and hospice services that give them the best quality of life and ease the burden of dying.

Gaps in India:

In India, currently the provision of Paediatric Palliative Care is totally insufficient. Though there is an enormous need of specialised Pediatric Palliative Care Centres, the existing number is disproportionate to the need. A systematic and comprehensive approach is needed at all levels: From policymakers to Health Care workers.

The Constitution of India has special provisions for children guaranteed through Fundamental Rights and Directive Principles (e.g. Article 15(3), Article 21(A), Article 23, Article 24, Article 39(e & f), Article 45 and Article 51A). As per all these provisions rights of a child are to be protected. A child with life limiting condition has a right to live and die with a dignity. There is a poor integration of palliative care into health services. National cancer and AIDS control programs do not contain meaningful palliative care components, with

the result that palliative care has second-tier status and does not receive adequate public funding⁽⁵⁾.

Palliative Care, especially Children's Palliative Care should be a top priority in the list of Governmental Departments such as Health and Child Welfare. Since Health is a state subject, each State has to adopt a 'Palliative Care Policy' to ensure that every child suffering with a life limiting condition gets access to Palliative Care and holistic support. In India, only Kerala has adopted a state policy for Palliative Care. Palliative Care centres should be developed at urban and rural hospitals throughout the state. Strict rules regarding Opioids are many a time a hindrance in providing pain relief. Access to pain relieving drugs like Morphine is necessary.

Health Care Professionals are still not aware of the basic concept of the Palliative Care. They still perceive it as an 'End of Life Care'. Many still relate it only to Cancer. Conditions such as HIV, Thalassaemia and Cerebral Palsy need lifelong interventions to improve the quality of life of the children. The medical practitioners have myths about Opioids.

Obstacles to effective Palliative Care for children start with the very basic need to assure pain control, and include difficult ethical issues of limits to treatment and the determination of the child's best interests. In areas such as the pharmaco-dynamics of opiates, where good data already exist, it remains unacceptable to have children suffer because of misperceptions and incorrect assumptions about appropriate drug use⁽⁶⁾.

Palliative Care has to be included in the curriculum of Medicine, Nursing and Social Work at the undergraduate and post graduate levels. A multidisciplinary and holistic approach of the Palliative Care has to be inculcated by every medical practitioner. Though consultation with a specialised palliative care service is required for some difficult problems, the focus of care can be based primarily where the child and family are cared for. By linking the primary care team with the palliative care program early in the disease course, resources can be combined to provide the best available support to the child and the caregivers.

How can we do this?

1. Integrating palliative care in to existing health care services and make it part of the services offered to children suffering from

chronic and incurable illnesses.

2. Identify and engage key stakeholders and policy makers who can affect improving access to Palliative Care for children.
3. Improve the access to opioids at all centres where care is delivered to children.
4. Empower children and their families to access palliative care.
5. Sensitize all medical professionals about the need and the scope of paediatric palliative including emphasis on need for offering palliative care "when illness is diagnosed", and not only as "end of life care."
6. Impart communication skills to all Health Care workers
7. Integrate Palliative care into medical curricula to train all doctors who may care for children with life limiting or life threatened conditions,
8. Train other professionals like nurses, social workers, Occupational therapists .
9. Build capacity of and work closely with community based organizations, volunteer groups and grass-root workers who are involved with the delivery of the non-medical aspects of palliative care.

India's international human rights obligations include ensuring that reasonable steps are taken to facilitate the development and integration of palliative care into existing health services. The denial of access to pain relief can result in a violation of the right to health, as well as of the strict prohibitions against torture and cruel, inhuman or degrading treatment (5).

Children's Palliative Care Project in India:

The Children's' Palliative Care (CPC) Project was initiated in Maharashtra, India in October 2010 by Indian Association of Palliative Care (IAPC). The aim is to bridge the gaps and advocate the need of Children's Palliative Care by developing a sustainable model for response to the suffering and needs of children with life limiting conditions such as HIV/ AIDS, Cancer, Thalassaemia, Neurological disorders etc. by improving their quality of life. The project is funded by the Department for International Development (DFID), UK. Tata

Memorial Hospital, Mumbai is supporting the project with its mentorship. International Children's Palliative Care Network (ICPCN) and Help the Hospices (HtH) are the partners of the project.

The project has set up two sites in Maharashtra and the third site would be shortly be decided. The model centre at Jawhar Rural Cottage Hospital is a Community Based Model Approach. This is in collaboration with the National Rural Health Mission (N.R.H.M) whereas the urban Paediatric HIV Centre in association with Lokmanya Tilak Municipal General Hospital (L.T.M.G.H), Sion Mumbai which is the Paediatric Centre of Excellence (PCoE) for Paediatric HIV provides psychosocial support to children and families. The commitment of Policymakers and other Stakeholders is envisaged to ensure the sustainability of the Children's Palliative Care.

The sensitisation of Health Care Workers through the project has changed their knowledge, attitude and practices. The need and importance of adoption of Palliative Care Policy for State is explained to the Policy Makers and the Secretaries of Health and Medical Education. The efforts are in progress to ammend the NDPS Act to ensure easy access to pain relieving medicines. It has been emphasised that public health programs should include Children's Palliative Care. Inclusion of Palliative Care in the medical and nursing undergraduate and post graduate curriculum has also been proposed. Educating the health care professionals from two sites (Rural-Jawhar& Urban-Sion) in Maharashtra State has changed their perception and this has been helpful in improving the quality of life of Children with life limiting conditions and their caregivers. The initial disease centric approach is changed to patient centric holistic approach.

References:

1. Paediatric Palliative Care Provision Around the World: A Systematic Review & Mapping, Caprice Knapp, Lindsey Woodworth, BS, Rev. Michael Wright, Dr Julia Downing
2. Arora RS, Eden T, Kapoor G. Epidemiology of childhood cancer in India. Indian J Cancer 2009;46:264-73
3. <http://www.medindia.net/news/Children-With-Thalassemia-at-Risk-for-HIV-79142>
4. Rajagopal MR, Joranson DE. India: Opioid availability - an update. J Pain Symptom Manage 2007; 33(5); 615-622.
5. Human Rights Watch report :India: Provide Access to Pain Treatment- 28TH OCT, 2009
6. Liben S.J Palliat Care. 1996 Autumn; 12(3):24-8. Pediatric palliative medicine: obstacles to overcome. Source McGill University, Montreal, Quebec, Canada.

Chapter 2

Palliative Care in Children

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Introduction:

Paediatric Palliative Care is a developing area in India. This emerging subspecialty focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. Palliative care for children is complex and lays stress on patients comfort. Many doctors caring for children at the end of life are uncomfortable or untrained in managing symptoms in children.

Our goal is to help and empower physicians recognize and treat the symptoms optimally. It is rather apt that Palliative Care should not be considered as a part of charitable treatment rather viewed as a part of a larger picture of dignity of life which is a right of everyone. Presently Palliative Care is somewhat structured towards management of adult patients with terminal malignancies.

The guidelines that are appropriate for adults are often inappropriate for children. The horizons of Palliative Care need to extend beyond oncology conditions and should be given to any individual with life limiting illness. More progress in the field is desirable as the subject becomes more formalized and research networks are established. The need for more widespread dissemination of Palliative Care knowledge to general practitioners, nurses, and allied health professionals is being recognized. The involvement of parents as care givers and decision-makers further increases the complexity of care. The subject is getting more formalized and research networks are being established.

A Palliative Care approach encourages a focus on comfort and symptom management, and prompts more open communication about end-of-life issues. Home care givers and healthcare providers require education to ensure a palliative approach that meets the physical, psychological, spiritual and social challenges facing patients and their families, and enhances dignity and quality of life. Some of the most troublesome symptoms as patients approach the end of life

are seizures, agitation, and spasticity.

Palliative Care approach facilitates identification of the wishes of patients and their families about care throughout a period of declining health and especially during end-of-life care. The aim is to improve the quality of life of individuals affected with life-threatening illness and of their families, by preventing and relieving suffering through early identification, assessment and treatment of pain and other problems - physical, psychosocial, psychological and spiritual.

To achieve this goal, the individuals working in this field need to:

- Clearly define the population served
- Understand the needs of children with life-threatening conditions and their families
- Develop an approach that will be appropriate across different communities
- Provide care that responds adequately to suffering
- Advance strategies that support caregivers and health-care providers
- Initiate the change by cultivating educational programs
- Respite programs need to be developed and widely available to provide intensive symptom management so that we can to some extent protect the wellbeing of children living with life threatening and terminal conditions.

In general the pace of development of Palliative Care in India has been rather slow; the national coverage is grossly inadequate. There is a genuine need to develop sustainable and affordable Palliative Care programs.

The package of services helps the patient and the family in alleviating pain to the patient, providing confidence in facing the difficult period, continuing treatment, increasing survival rate, reducing drops outs where prolonged treatment is necessary. Palliative Care can be part of the treatment repertoire of any health worker, supported by intermittent consultation or referral to specialist Palliative Care services (e.g. for management of neuropathic pain).

Apart from malignancies, HIV infection, end stage major organ disease, Palliative Care forms an essential component of care in the

following neurological conditions:

1. Congenital myopathies, Muscular dystrophy like Duchennes and Beckers Muscular Dystrophy
2. Spinomuscular atrophy
3. Neurological sequelae of Birth Asphyxia
4. Cerebral Palsy
5. Brain Damage resulting from Status Epilepticus, Head injury, Encephalitis, hypoxic events
6. Neurometabolic conditions and Neurodegenerative disorders , Niemann Pick disease, Gauchers disease, Metachromatic leucodystrophy etc
7. Autism, Fragile X syndrome, Mental Retardation
8. Chromosomal defects, Downs syndrome, Multiple congenital anomalies.

Medical Problems that need to be addressed:

1. **Nutrition:** Adequate nutrition to be provided, diet balanced in calories, fats, carbohydrates, proteins and micronutrients [need supplements]. Patient may need assistance for feeding, nasogastric feeds or feeding gastrostomy. The feeds may be mashed foods or blended foods. Change of the NG tube on a regular basis is required.
2. **Fluids and Electrolytes:** Maintaining electrolytes and preventing dehydration during acute infections and febrile illnesses. Children may need replacement with oral rehydration fluids or IV fluids.
3. **Preventing Aspirations:** Provide NG tube feeds to children who do not have coordinated swallowing or have palatopharyngeal incompetence. Medications for gastroesophageal reflux may be given where indicated.
4. **Infections:** Patients with neuromuscular and debilitating conditions are prone for pneumonias, urinary tract infections and skin infections.
5. **Bed sores:** Need for regular dressing, debridement, skin grafting in severe cases. Water bed and air cushions must be given to

prevent bed sores.

6. **Incontinence:** Catheterisation (prolonged or intermittent), change of catheters, provision of appropriate diapers is necessary
7. **Constipation:** Dietary modification with high amount of fiber, medications like Duphalac, Lactulose, Cremaffin may be prescribed.
8. **Fractures:** Avoid vigorous physiotherapy in patients with severe demineralization. Patient should be nursed in a bed with railings. Provide adequate calcium and vitamin D supplements to prevent calcium deficiency.
9. **Mental changes:** Assessment by a psychiatrist in those who have depression, aggression, mood changes, self-injurious behavior.
10. **Control of Seizures:** Appropriate dosages of anticonvulsants medications, the dosages may be adjusted and monitoring with drug levels where indicated, the long acting preparations could be used.
11. **Contractures and Muscle Spasms:** Use drugs like baclofen, muscle relaxants, splints Occupational and physiotherapy.
12. **Exposure Keratitis:** Artificial tears and eye drops to be used to prevent exposure keratitis, antibiotic eye drops if required.
13. **Menstrual Problems:** Girls may have anemia due to excess menstrual bleeding and need a lot of care and attention during menses.
14. **Palliative Interventions:** These are essentially non-curative interventions, which aim to control symptoms and improve quality of life. These interventions include palliative radiotherapy, surgical procedures and anaesthetic for pain relief, and may be used at any time during an illness.

1. Address issues in Pediatric Palliative care:

- i] Who needs palliative care,
All children with a prolonged terminal illness.
- ii] Who provides palliative care?
Nurses, trained staff, family physicians, pediatricians
- iii] In what setting is palliative care delivered?
Hospice, nursing homes, hospitals, at home?

- iv] What is the aim of palliative care?
 - v] What are the components of palliative care?
 - vi] When is palliative care offered?
2. At diagnosis of a life-threatening or terminal condition, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome.
 3. Changes in the regulation and reimbursement of palliative care and hospice services are necessary to improve access for children and families in need of these services. Modifications in current regulations should include
 - a) broader eligibility criteria concerning the length of expected survival
 - b) allowance of concurrent life-prolonging and palliative care
 - c) provision of respite care and other therapies beyond those allowed by a narrow definition of "medically indicated." Adequate reimbursement should be available.
 4. All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children. Residency, fellowship training, and continuing education programs should include topics such as palliative medicine, communication skills, grief and loss, managing prognostic uncertainty, and decisions to forgo life-sustaining medical treatment, spiritual dimensions of life and illness, and alternative medicine. Pediatric postgraduate and other certifying examinations should include questions on palliative care.
 5. An increase in support for research into effective pediatric palliative care package, regulation and reimbursement, pain and symptom management, and grief and bereavement counseling is necessary. The pharmaceutical industry must provide labeling information about symptom-relieving medications in the pediatric population and provide suitable formulations for use by children.
 6. The practice of physician-assisted suicide or euthanasia for children should not be supported.

The initiative of palliative care as is gaining importance and development of a structured package of care is on the horizons. Training of care givers is also being planned. A formal training module on palliative care in children would evolve.

References:

1. Affirmation of value standards of practice for Pediatric Palliative Care and Hospice.
www.pediatrics.org/cgi/doi/10.1542/peds.2010-1309
2. American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care. 1999 - 2000.
3. A palliative care approach to end stage neurodegenerative conditions. J A Low, W S Pang, D KY Chan, R Chye, *Ann Acad Med Singapore* 32: 778-784, 2003.
4. Pediatric Palliative Care Challenges and Emerging Ideas. Stephen Liben, Prof Danai Papadatou, Joanne Wolfe, *Lancet* Vol 371[9615] 852 -864, 2008.
5. Pediatric Palliative Care. B P Himelstein, J M Hilden, A M Boldt, D W Eissmann, *NEJM* 350: 1752 -1762, 2004.
6. Management of common neurologic symptoms in pediatric palliative care, seizures, agitation, spasticity. Wusthoff CJ, ShellhaasRA, Licht DJ, *Ped Clinics of N America* 54:5, 709 -783,2007

Chapter 3

Education: A Key Ingredient for Delivery of Comprehensive Pediatric Palliative Care Services

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If there is no struggle, there is not progress. Those who profess to favor freedom, and yet deprecate agitation, are men who want crops without plowing up the ground. They want rain without thunder and lightning. They want the ocean without the awful roar of its many waters. This struggle may be a moral one; or it may be a physical one; or it may be both moral and physical; but it must be a struggle. Power concedes nothing without a demand (Wallack, Dorfman, Jernigan & Themba, 1993, p. 39)

Introduction:

There has been significant progress in both the art and science of Pediatric Palliative care (PPC) over the last 15 years. Nevertheless, the current reality is that today over seven million children globally remain in need of PPC services: an unacceptable situation and one that is indirect violation of the United Nations Convention on the Rights of the Child (1990).

So, the question that demands an answer is how and why does this existing state of affairs continue to exist? There is of course no simple response, with a number of factors identified as impeding PPC. These include; palliative care delivery limits, cost-benefit issues, and a lack of education.

Today the delivery of health care services within this globalized environment has become increasingly complex and political. There are now regular news reports of national health agendas coming under attack by a public who demand more comprehensive and expanded health care services. While concurrently, governments are scrambling to cut budgets forcing health departments to do more with less. Against this backdrop of re-entrenchment in health care

budgets, the delivery of Pediatric Palliative Care programs must be re-thought and new novel approaches considered.

Education remains is a key ingredient for expanding PPC programs. Changing and/or enhancing existing education programs are sometimes likened to making a 'cognitive lane change'. Making this change remains difficult from within the social context where currently, through mass media. Society is bombarded with multiple messages such as, "cancer can be beaten" and there is an implicit assumption that one should fight until the bitter end.

Moreover, where Palliative Care is often viewed as tantamount to giving up and the patient is imminently close to death. These messages influence health care professionals, who work in environments where death has become sanitized and viewed as a medical failure.

The relevance of education can never be understated but we must also be realistic and recognize that education alone will not be the panacea or a comparatively unproblematic solution for health care problems. For example, if group x were educated about y then problem z would be solved or eliminated. Oh, if solutions were only that simple, then transmission of HIV Aids would cease, as would other problems such as smoking, unwanted pregnancies, fetal alcohol syndrome etc.

However, health care issues as we know them to be are far more complex and solutions must reflect this reality. Nevertheless, education targeting the right populations and utilizing the suitable approaches is a necessary step for realizing the dream and vision of ensuring every child globally will have access to comprehensive PPC services.

To ensure success, education in PPC must target several different and often distinct groups. The fact that they are different requires educational approaches that are appropriate for not only each group, but also allowing for differences that exist within each of these groups.

1. Fellow health care professionals
2. Policy makers
3. Elected government officials
4. Public
5. Health care worker

This may seem to be a formidable challenge but there are global success stories documented, where in some cases a single committed individual has championed this cause (Pfund & Fowler-Kerry 2010; Knapp, Madden, & Fowler-Kerry 2011).

Prior to adapting a particular educational program/curriculum there needs to be awareness, that each program has evolved from a cultural or religious conviction about the world. Therefore, all educational curriculum and teaching materials must be culturally relevant and contextualized to fit your unique environment. In this quest, remember that knowledge does not flow always from west to east, north to south rather it is from collective shared experiences that we build, expand and translate PPC knowledge utilized in educational curriculums (Knapp, Madden & Fowler-Kerry 2011).

Despite differences that exist globally, there is a common vision providing the conceptual framework for educational programing.

This vision advocates that children everywhere don't have to suffer physical, emotional and spiritual pain resulting from a life-limiting or life-threatening diagnosis; where families do not have to endure economic hardships when they care for their child, and death and dying will no longer be viewed as medical failures, but as a natural process.

A vision has as its genesis the WHO definition of Palliative Care (WHO, 1998), where the concept of care, places the needs of the child at the forefront, followed by the needs of the family and/or significant others. The goal of Palliative Care is to add life to the child's years, not simply years to the child's life.

Care is directed at controlling unpleasant symptoms (pain, dyspnea, etc.), while addressing the psychological, social, or spiritual issues of the children and their families. Additionally, palliative treatments also ensure that families receive adequate bereavement support following their child's death. To meet these needs, an efficacious and comprehensive care must be provided by a multi-disciplinary group of physicians, nurses and other personnel, such as social workers, chaplains, and bereavement counselors, while addressing the psychological, social, or spiritual issues of the children and their families (World Health Organization, 1998).

In addition, PPC while including both the family and community is provided in a range of settings from hospital, to clinic, to home and can be implemented even if resources are limited.

Where to Start:

From a scan of the internet, resources there are a significant number of courses and curriculums available. Some are free of charge others are for purchase and still others are affiliated with educational institutions where completion will result in a certificate or educational credit. Important to note, most programs target either medical doctors or nurses; unfortunately, leaving out other health care professionals, who are also necessary for the multidisciplinary approach to PPC.

With increasing demands for PPC care services stretching the capacity of persons, currently working in the field there is an urgent need to provide educational programs to mobilize more trained health care professionals and health workers. To meet these challenges PPC educational programs must focus on core competencies based on transnational, multiprofessional needs of individuals and populations.

Thus, the purpose of this chapter is not to suggest that you should design a new PPC program nor recommend an existing curriculum, but rather the goal is to provide and highlight key components to consider and adapt to your distinctive environment.

A good starting point is to consider this definition of health education that offers a useful framework from which to consider the key elements of a PPC program. While not stated per say, research utilizing this framework establishes that learners gain knowledge and understanding of the theoretical knowledge, develop skills, and acquire attitudes, values and beliefs common in their disciplinary practice through an effective educational program (Krathwohl, Bloom Maisa 1964).

Health Education any intentional activity that is designed to achieve health or illness related learning, i.e. some relatively permanent change in an individual's capability or disposition. Effective health education may, thus produce changes in knowledge and understanding or ways of thinking; it may influence or clarify values; it may bring about some shift in belief or attitude; it may facilitate the acquisition of skills; it may even affect changes in behavior (Tones and Tilford's 2001:301).

Key Components:

Cognitive Knowledge, Affective and Psychomotor Skills:

All curricula/educational programs in Pediatric Palliative Care should include cognitive, affective and psychomotor skills content to prepare new practitioners for practice (Ferguson, Fowler-Kerry & Hain, 2006). This content should be stated in terms of expected outcomes from a planned learning experience. In addition, these objectives form not only the basis for selection of appropriate learning experiences but also for evaluation of outcomes.

Cognitive knowledge is available in textbooks, journal articles and on web-based sites, and easily taught through conventional formats such as lectures or readings. Facts provide learners with the information on which to base their clinical practice. There is significant content for pediatric palliative care included in most medical and nursing curricula. Therefore, educational programs can build from this base and as some would suggest 'fill in the blanks'.

Cognitive knowledge in the areas of symptom management are the most frequently presented aspects of palliative care (Fowler-Kerry, 2007) and is considered essential content in the preparation of health care professionals. Symptoms that need to be addressed include pain, anxiety, seizures, bowel and bladder problems, and nutrition and fluid management. Extensive research in the area of pain control and other symptom management provides the basis for evidence-based practice. Although this content can be readily addressed in lectures and presentations, health care professionals must have values and beliefs that support the use of this knowledge.

Unfortunately, there remains a significant gap between what is known about pediatric pain management and what is practiced. This gap can no longer be tolerated; no child should be suffering in pain.

New guidelines for the management of pain are soon to be released by the World Health Organization (WHO) providing a valuable outline for those working in the area of PPC.

Bloom's taxonomy of objectives in the cognitive domain (Bloom, 1956) reflects a belief that knowledge is structured in a hierarchy. Thus, students learning will progress through predictable stages, from knowledge of facts and comprehension of information to the application of that knowledge in a particular situation. With well-designed learning experiences and sufficient experiential learning, students will develop cognitive skills reflecting a higher level of thought about a topic such as Paediatric Palliative Care, including

the evaluation of approaches based on particular standards of practice.

Harrow (1972) identified the normal progression that learners experience while developing their psychomotor skills a progression that is generally not affected by the particular practice setting. One of the most important considerations with psychomotor skill development is the incorporation of family values and practices in the performance of the skill. This issue often relates to family control over the provision of care, and one that is particularly challenged when multiple caregivers are involved.

Good communication among caregivers and a commitment to quality of care that reflects family preferences are the most important considerations. New practitioners in paediatric palliative care need good role modeling to demonstrate how families are involved in care to the extent that they wish.

New learners in the area of PPC often need assistance to create an effective partnership in the provision of care. This is particularly important where family members are often the primary caregivers especially in the home and expect to be part of the team providing care in hospital or hospice. Rather than a focus on how to learn psychomotor skills for palliative care, new learners need to learn how to modify psychomotor skills to better meet the needs of the patient, combined with the values and commitment to do so.

Values and Beliefs:

Teaching values, beliefs and attitudes in the affective domain is challenging and sometimes not without controversy. Teaching in this domain is time consuming requiring strategies such as seminars, group discussions and case studies. These approaches are necessary however for learners to examine and explore their values, beliefs and emotional responses to presented patient situations. However, research has confirmed that the time invested, provides learners with the necessary opportunity to move through the stages of receiving information, challenging and reconciling their own value systems to reach a professional commitment, to provide safe and compassionate PPC.

For new learners, Pediatric Palliative Care, the values of patient/family autonomy, quality of life, and compassionate care may be in

continuing conflict with values more attuned to curative functions. Thus, learners will attain a level of organization when they accept the values of palliation and create for themselves a meaningful relationship between curative and Palliative Care.

The highest level of the affective domain relates to the characterization, wherein the individual practitioner's behavior remains consistently commitment to palliation in care. Faculty members who teach Palliative Care or practitioners who advocate for palliation in all relevant aspects of patient care are assumed to have attained this level.

The affective aspect of programming often falls into the informal component of curricula, as educators experience difficulties enunciating expected outcomes and determining appropriate ways of teaching and evaluating values, attitudes, and beliefs. A classic example is the focus on compassionate care in palliative care. Although this term is frequently used in referring to Palliative Care, educators have difficulty teaching 'genuine caring', and even more difficulty evaluating the level of acceptable 'caring' or 'compassionate caring'. Unfortunately, educators can more easily identify the absence of the expected attitudes or values.

Choosing learning experiences to assist learners gain the desired values and beliefs requires patience and a willingness to explore ones thoughts about the proposed values. Today's learners rarely accept or incorporate new values into their existing belief systems without thorough personal reflection and examination.

Teaching in the affective domain is time consuming, utilizing teaching strategies such as seminars, group discussion, and case studies that focus on exploration of values and beliefs, emotional responses to patient situations, and clarification of values evident in effective and compassionate patient care. Ethical issues frequently arise for learners, as they are socialized into the values of the discipline while simultaneously confronting their own personal attitudes about Palliative Care.

Attitudes about death and dying especially when the patient is a child are complex in nature, based on cultural, societal, philosophical, legal, spiritual, and religious belief systems. These attitudes and beliefs develop over a person's lifetime, affecting the meaning that these individuals ascribe to the process of dying, and their role in

caring a child with palliative care needs and their families.

Anxiety around the concept of death is common, assisting new learners to explore and clarify their own attitudes and beliefs about palliative care may be the single most important aspect determining their commitment to palliation in their later practices (Ferguson, Fowler-Kerry & Hain, 2006).

Providing learning opportunities that allow for the exploration of one's current beliefs and the implications of incorporating new beliefs and values is critical to preparing new practitioners to be successful in PPC experiences with patients and their families.

While some programs do acknowledge this need, the most frequently used teaching strategy to address Palliative Care issues is the traditional lecture method, which is probably the least effective way of addressing values clarification (Ferguson, Fowler-Hain, 2006).

Strategies that are more effective for helping learners acquire values of paediatric palliative care include case studies, group discussions, simulations, role-playing, role modeling, questioning, and reflective techniques such as writing and journaling.

The intent of these strategies is to assist learners to explore values, interests, attitudes, and beliefs that are foundational to affective behaviors. In terms of Pediatric Palliative Care, these strategies help learners gain positive attitudes, and to learn values that support the incorporation of compassionate holistic care and symptom management in pediatric palliative care.

Ethics:

Ethical issues arise constantly in Pediatric Palliative Care as health care professionals attempt to address matters that patients encounter, while balancing the needs of family caregivers especially in home settings. In addition, the needs of health care professionals add another layer of complexity to issues of ethics in paediatric palliative care.

Health care providers are guided by ethical principles such as beneficence, autonomy, non-malevolence, and fidelity; however, these ethical principles are frequently challenged by patient and family situations. New practitioners in PPC need opportunities to work through these dilemmas, often through discussion with other health care providers, patients, their families, and educators. Although

answers to these dilemmas reside in the patient situation, individuals can effectively analyze their own actions and feelings, often in discussion with others who are experiencing similar situations.

Communication Skills:

Most health care professionals report communication difficulties in pediatric palliative care in terms of honesty with patients and their family. Some of the challenges with communication are broad and include negotiation skills, relationship building, and breaking bad news.

Communication skills remain a very important element of Palliative Care, and are constructed from previous acquisition of this skill from earlier educational programs. Nonetheless, communication issues that ought be addressed in preparation for Paediatric Palliative Care experiences include; breaking bad news, discussion of limits of care or treatment, resolving conflicts among family members, interactions with parents at the child's death, allowing time for questions, exploring options for end-of-life care, pronouncing the death of a child and managing the death certificate, dealing with avoidance of patient and family, and exploring patients' cultural practices, and dealing with parents of different ethnic and cultural backgrounds (Devita, 2002).

Role-playing provides learners with 'safe' learning opportunities to practice specific skills and to critique their own performances and those of peers without repercussions for patient care. DeVita (2003) identified several scenarios that provided learners with opportunities to develop their skills; establishing rapport and wording requests for organ donation, conducting family meetings, and attending to patient emotions. Regardless of the learning opportunities in the classroom, new learners will still find the actual patient situation challenging and unpredictable and whenever possible there needs to be opportunities to debrief and discuss those situations that are anxiety provoking or that seemingly fail to meet patient expectations for empathetic and caring interactions.

To become more socially and ethically responsible as health care professionals, there are numerous other ethical dilemmas challenging practitioners in this specialty every day. For example with increased global migration, cultural and religious differences are becoming more commonplace in the clinical setting. How can educators teach

learners to deal with the plethora of possibilities that emerge from this issue? No easy answer, but educators need to allow learners time thru discussion to re-examine the ethical principles representing their discipline all the while focusing on the definition of Palliative Care and the principle that children with palliative care needs, "live, until they die, at their own maximum potential, performing to the limits of their physical activity and mental capacity with control and independence whenever possible" (ACT, 1994).

Summary:

Pediatric Palliative Care and its principles of holistic patient care and teamwork provide a model for all other areas of clinical practice. For Paediatric Palliative Care programs, the intent of programming is the development of competencies and essential qualities that can be addressed thru basic education, continuing education, or orientation programs (Ferguson, Fowler-Kerry & Hain, 2006).

Once learners have acquired the necessary knowledge and competencies related to PPC, the most effective way to solidify learning is in direct interaction with patients and families, under the supervisor of an expert practitioner in the field. This level of engagement with the child and family requires prolonged interactions over time, but allows new practitioners to acquire experience while observing the practice of experienced practitioners and discussing aspects of care with them.

Preceptored or mentored learning situations are an effective strategy in assisting new learners to understand the complexities of decision-making in Pediatric Palliative Care situations. Working with expert practitioners in the area, new learners sees the expert's depth of knowledge in practice, recognize the multiple sources of patient data that experts respond to, and gain an appreciation of how to work more effectively with children and their families. Expert practitioners can impart knowledge to explain their decision-making as new learners cannot see the salient patient and family cues that experts take into account in their care.

Typically, expert practitioners interact with children and their families in an engaged and committed manner, and have come to acquire knowledge of usual patient responses to illness, stages in progression of illness, and patient and family issues in palliation, this knowledge is gained through extensive experience, and can be modeled in

practice and conveyed through stories and narratives of care about previous patients.

While this learning is time consuming, it remains and an important approach to provide newpractioners with opportunities to practice their new knowledge, skills and judgments about PPC, but it affords a safe learning environment prior to new health care practitioners engaging in practice and, in some cases alone.

The decision to select and adapt an educational program in pediatric palliative care is not without its challenges. There exists no one ideal curriculum nor is there one ideal educational approach. Nevertheless, passion and commitment to improve the quality of life for these special children their families is what keeps us all to push forward, learning from failures and successes.

With increasing demands for paediatric palliative care services globally, there is a corresponding need to education more health care professionals. With rapid growth in technology and telecommunications, clinicians and educators can acquire and disseminate expertise globally while also providing new practioners with some supports in the practice setting. Through organizations such as the International Children's Paediatric Palliative Care Network (ICPCN) (www.icpcn.org.uk), there are numerous colleagues willing to assist you. While distance separates each of us from one another, we're connected through technology and a shared commitment to improve the lives of children and their families.

References:

1. Association for Children with Life-threatening or Terminal Conditions and Their Families (1994). Institute of Child Health, Royal Hospital for Sick Children, Bristol, England.
2. Bloom BS, Englehart MD, Furst EJ, Hill WH, Krathwohl DR (1956). Taxonomy of educational objectives: handbook I, cognitive domain. New York: David McKay.
3. DeVita M, Robert A, & Barnard D. Teaching palliative care to critical care medicine trainees. 2003; 4: 1257-1262
4. Ferguson, L.M., Fowler-Kerry, S., & Hain, R. (2006). Education and training. In A. Goldman, R. Hain, & S. Liben (Eds), Oxford textbook of palliative care for children (pp. 594-6124). Oxford, UK: Oxford University Press

5. Fowler-Kerry, S., & Pfund, R. (Eds.). (2010). *Perspectives on palliative care for children and young people: A global discourse*. Oxford, UK: Radcliffe Publishers.
6. Fowler-Kerry, S. (2007). Need for pediatric palliative care framework. *The International Journal of Interdisciplinary Social Sciences*, 1(5), 145-150.
7. Harrow, AJ. *A Taxonomy in the psychomotor domain* (1972). New York: David McKay.
8. Knapp, C., Madden, V. & Fowler-Kerry, S. (Eds.). (2011). *Pediatric Palliative Care: Global Perspectives*. Netherlands, Wiley-Springer Publishers.
9. Krathwohl DR, Bloom BS, Maisa BB. *Taxonomy of educational objectives: handbook II, affective domain*. New York: David McKay, 1964.
10. Tones, K. & Tilford, S. (2001). *Health education: Effectiveness, efficiency and equity*. London: Chapman Hall.
11. United Nations. *The convention on the rights of the child*. New York: Resolution A/Res/54/263; 1990.
12. Wallack, L., Dorfman, L., Jernigan, D., & Themba, M. (1993). *Media advocacy and social marketing approaches*. In Atkin, C., & Wallack, L. (Eds.). *Mass communication and public health: Complexities and conflicts*. London: Sage.
13. World Health Organization. (1998). *Cancer pain relief and palliative care in children*. Geneva: Author

Chapter 4

Pediatric Palliative Care in Oncology

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Introduction:

Cancer is curable at diagnosis in 70-90% of children; the tumours being more sensitive to anti-cancer therapy than in adults. This is truer for haemato-lymphoid malignancies than solid tumours. The therapy is prolonged, often away from the child's home and causes tremendous financial and psychological burden. All this is acceptable, as long as the aim is cure.

This holds true even for children presenting with relatively advanced disease; the chance for cure being grasped by both Oncologists and parents.

In India, most cancer centres would also provide financial assistance for this treatment. However, for some of these children; disease would progress or relapse in spite of adequate therapy and the burden of disease in physical, psychological, social and spiritual realm is tremendous and there is an obligation on the part of professionals to address these needs.

Incidence of Cancer in children:

The most common cancers are leukemias 30%, brain tumours 20%, lymphomas 10% and other solid tumours form the rest. Fig 1 shows some data from the US. In India, in the absence of population based cancer registries; there are no accurate figures.

At the Tata Memorial Centre, the incidences of cancers presenting every year along with the referrals to Palliative Care are also shown in Fig. 1.

Disease Trajectory and Palliative Care: As mentioned above, in some children disease would relapse in spite of adequate therapy. An encompassing care needed for both the child and family is provided by Children's Palliative Care teams.

Definition by WHO:

Paediatric Palliative Care as '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 illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes. It's role for children with cancer is the same as with any other illness and is discussed elsewhere.

In Western literature, the incidence of children needing Palliative care in Canada was 14.7 /10,000 children between 1984 and 1994. In Australia the crude average incidence is 13.8/10,000 under the age of 15. There are no accurate estimates for developing countries which include India; though it is estimated to be lower as children die more from acute infections and severe malnutrition.

However, taking into consideration the population, there are large number of families needing the care scattered over the whole country; with the majority rural based.

The disease trajectory of cancer at relapse is depicted in fig 2; the time frames being largely predictable, depending on the type of cancer and time to relapse. This new trajectory gradually introduces the Palliative care team into the care pathway; providing supportive or holistic care along with palliative anti-cancer treatment. This shared care allows child and family become familiar with the Palliative care team. As the disease progresses, the involvement of the latter team in the care increases; the reverse being true of the Oncologist.

At the Tata Memorial Centre, the Palliative care team is part of every decision regarding therapy by attendance at every Joint Clinic where treatment options are discussed between the different specialists.

Introduction of the team by the Oncologist helps the family come to terms with the situation. As the toxicities of the therapy increase and benefits are less, the family support continues, enabling a smooth transition into stopping all therapy and continuing only with Palliative Care.

Common Symptoms and their Management:

Occurrence of symptoms is depicted in Table 1. Pain is the most common symptom and managed with drugs from the WHO ladder as discussed elsewhere, along with management of other symptoms. Emphasis is on oral medication, though many of the children have a Hickman catheter or Peripherally Inserted Central line (PICC).

Since parents have been trained to manage these even at home; where deemed necessary; they are encouraged to retain the line i.e. Morphine for terminal breathlessness.

In cancer, the role of Palliative radiotherapy or chemotherapy is very vital for symptom control as outlined below.

Use of anti-cancer therapies for improving Quality of Life:

Cancer in children is more responsive to active therapy than in adults. The judicious use of palliative chemotherapy, radiation and even surgery can relieve distressing symptoms by optimum tumour shrinkage.

1. *Chemotherapy:*

Regimes depend on the tumour pathology. Oral chemotherapy is preferred so that children can take treatment at home. 2-3 courses should be taken to assess optimum benefit with minimum toxicity. Treatment should be stopped at tumour progression or when the toxicities outweigh benefits. A commonly used regime, otherwise defined as 'metronomic therapy' is outlined in Table 2.

2. *Radiation:*

Similarly, radiation is used to cause tumour shrinkage. A high-dose, short fractionation is used. Cobalt machines are preferred as long term toxicities are irrelevant and the facility may be available closer to the child's home. Some commonly used regimes are elaborated in Table 3.

3. *Surgery:*

Amputation of a useless limb, colostomies and urinary diversion are some surgical techniques useful in Palliation. The surgery must be discussed with child and family to explain benefits vs. toxicity and informed consent taken. Amputations of limbs and

removal of eyes are seen by Indian families as against the normal course of life. In palliation, there is even more resistance. Counselling can help them weigh the medical benefits of the procedure.

Psychological Care for the Child and Family:

These are similar to those experienced by any family with a life limiting conditions are support is discussed elsewhere. The major differences are:

1. The spectre of death is ever present due to possibilities of severe infections, as a response to palliative therapy. The delicate balance between benefit and toxicity must always be foremost to decide continuation. Families need time to adjust to every phase.
2. The disease trajectory is more predictable and this may help both palliative care teams and families adjust better than with non-cancer diseases.

Place of Care:

Even while Palliative therapy is continuing, the discussion with the family is necessary to ensure the best possible Quality of life for the child. In India, most of the families have been staying close to the cancer centre since diagnosis; disrupting family, especially for the siblings who are left at home in the care of grandparents, Uncles or even neighbours. It is an uphill task to help parents understand the importance of keeping the family together; they feel safe with the familiar surroundings; returning 'home', often in the village would be traumatic for them; there is an absence of trained Paediatricians. When they decide to return, care is enhanced with the presence of help lines which keep communication channels open between local physician, parent and Palliative Care specialist; calls are made weekly. Since they are assured that they can return at any time if there is need; this gives them the confidence to return home for some periods of time. Often, the circle of care is developed at home and they may never return. Home care is provided when available; hospice care is seldom. The concept of hospice is alien and the very small number of children who would be referred in a specific location has made it an unviable option. The role of local paediatricians is crucial in maintaining the circle of care.

End of Life Care in Cancer:

The same reasoning is followed for the terminal phase. Many families still return to the hospital as they do not have the confidence for a death at home. They are cared for in the ward by the team of Oncologists, nurses and Palliative Care team. Adequate discussions between Oncologists, Palliative care team and family should preclude any communications barriers. The role of advance directives is very relevant here. Hospice deaths are rare. Parents need to care for the rest of the family and getting admitted in a distant hospice would make that family's life too difficult.

Bereavement Support:

As with all families, the death of a child is very difficult. In cancer, this may be more so, as sudden deaths are much more common. An engagement of the Palliative Care team early in the disease trajectory is helpful, as the teams dealing with active treatment, may not have the necessary training to deal with the sudden death. With siblings also, the chance to say goodbye may not happen; especially if the death is sudden.

The parents and siblings need extensive bereavement support which may last for months. Abnormal grieving patterns must be carefully watched for. Here, the role of support groups are very important, to help newer bereaved families cope, along with the professional help.

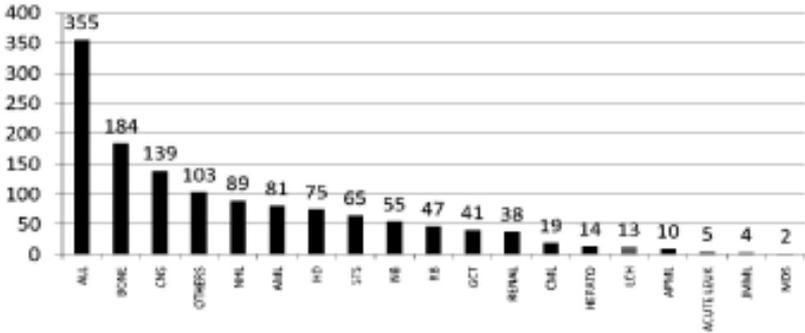
Table 1: Incidence of Childhood Cancers in US

Cancer	Incidence (%)
Leukemia	30.2
Central nervous system tumor	21.7
Lymphoma	10.9
Neuroblastoma	8.2
Soft tissue sarcoma	7.0
Renal tumor	6.3
Bone tumor	4.7
Others	11.0

Adapted with permission from Linet MS, Ries LA, Smith MA, Tarone RE, Devesa SS. Cancer surveillance series: recent trends in childhood cancer incidence and mortality in the United States. J Natl Cancer Inst 1999;91:1051-8.

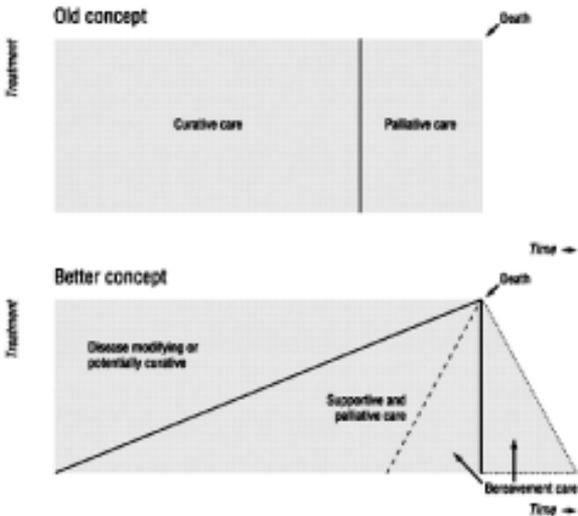
CHILDREN DIAGNOSED WITH CANCER AT TATA MEMORIAL CENTRE 2010

Fig. 1 :
DIAGNOSIS WISE DISTRIBUTION
(N=1339)
 0-15 AGE GROUP



NOTE: OUT OF 1540 PATIENTS 1339 HAVE DEFINITE DIAGNOSIS AND HAVE BEEN INCLUDED. REMAINING 304 PATIENTS WITH NO MALIGNANCY & UNINVESTIGATED CASES HAVE BEEN EXCLUDED.

Fig. 2 : Trajectory of Illness in Cancer



Model for palliative care. (Reproduced from Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *Br Med J* 2005;330:1007-1011, with permission from BMJ Publishing Group Ltd.)

Table: 1
Signs and Symptoms of Childhood Cancers and
Conditions That Can Mimic These Cancers

Sign or Symptom	Type of Cancer	Common conditions in the differential diagnosis
Fever	Leukemia, lymphoma	Infection
Vomiting	Abdominal mass, brain tumor	Infection, gastroesophageal reflux
Constipation	Abdominal mass	Poor diet
Cough	Mediastinal mass	Upper respiratory infection, reactive airway disease, pneumonia
Bone or muscle pain neuroblastoma	Leukemia, bone tumor,	Musculoskeletal injury, viral infection
Headache	Brain tumor	Tension headache, migraine, infection
Lymphadenopathy (> 2 cm)	Leukemia, lymphoma, metastatic disease	Lymphadenitis, systemic infection, collagen vascular disease
Hematuria	Wilms' tumor	Urinary tract infection, glomerulonephritis
Voiding difficulty	Rhabdomyosarcoma	Congenital urinary tract abnormalities

Adapted from 'Recognition Of Common Childhood Malignancies' Guy Young, M.D., Jeffrey A. Toretsky, M.D., Andrew B. Campbell, M.D., And Allen E. Eskenazi, M.D., University Of Maryland School Of Medicine, Baltimore, Maryland Am Fam Physician. 2000 Apr 1;61(7):2144-2154

Table: 2

Common Oral Chemotherapy Schedule for Palliation

Week	1	2	3	4	5	6	7	8	9	10	11
Days	1-7	8-14	15-21	22-28	29-35	36-42	43-49	50-56	57-63	64-70	71-77
Celecoxib 200mg/m2/d	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Etoposide 50mg/m2/d	✓	✓	✓	×	×	×	×	×	×	×	×
Temozolamide 60mg/m2/d	×	×	×	×	×	✓	✓	✓	✓	✓	✓
Isotretinoin 100mg/m2/d	✓	✓	×	×	✓	✓	×	×	✓	✓	×

Table: 3

Some Radiation Schedules

1. Very quick Palliation - 20 Gy/5Fr/5 days
2. Quick palliation - Optimum tumour shrinkage
30 Gy/10Fr/10 days
3. Radical dose for palliation- seldom practised

In the presence of metastasis where cure is not an option but local control is desirable and reactions need to be kept to a minimum -

40-60 Gy/ using 180 cGy/ Fr using sophisticated machines.

These regimes should be utilised weighing benefit vs toxicity very carefully for every individual case.

References:

1. WHO definition of Pediatric Palliative Care
2. Linet MS, Ries LA, Smith MA, Tarone RE, Devesa SS. Cancer surveillance series: recent trends in childhood cancer incidence and mortality in the United States. J Natl Cancer Inst 1999;91:1051-8.
3. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. Br Med J 2005;330:1007-1011, with permission from BMJ Publishing Group Ltd.

Chapter 5

Paediatric Cancer Pain

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In 2000 Joanne Wolfe and her team at Boston Children's published data suggesting that over 75% of children with cancer suffered from pain in their last month of life.

Studies from Australia, Europe, Canada and Japan have reported similar high rates of suffering from pain in children dying from cancer.

This guideline is about how to assess and manage cancer pain in children.

It has been prepared by Adrian Dabscheck, Palliative Care Practitioner in Melbourne Australia with the kind assistance of the Oncology Pharmacy Staff at the Royal Children's Hospital Melbourne and was inspired by "Palliative Medicine Guidelines for HMOs. Peter MacCallum Cancer Centre."

Types of Pain:

Pain is subjective but can be described and categorized. For clinical utility we discuss pain as either nociceptive or neuropathic. This is important in cancer pain as it allows an understanding of the pathogenesis of the pain and hence enables us to use the most appropriate treatment.

1. *Nociceptive Pain:*

- This is pain due to stimulation of nociceptors.
- Nociceptors are receptors in the free terminals of specific nerve fibres, in various tissues and organs that are stimulated by a pathological process.
- Nociceptive pain is further categorized into somatic and visceral pain.

Each of these sub-categories has different symptom characteristics.

- Somatic pain is intermittent to constant, sharp, knife-like, localised.

- Visceral pain is constant/intermittent, crampy/squeezing, poorly localised and referred.
- Bone pain may be a constant dull ache, localised and have neuropathic features

The extent of damage and/or the degree of stimulation does not necessarily predict an individual's clinical response. There may be a large variation in pain perception. Not all patients with extensive cancer suffer severe pain.

2. *Neuropathic Pain:*

- Can be caused by cancer-induced damage to the sensory nerves through infiltration or compression.
- May also be caused by interventions such as chemotherapy and surgery.

The Characteristics of Neuropathic Pain:

- Paroxysmal, shooting, stabbing, burning, intermittent, spasmodic, tingling, electric-shock, pins and needles.
- The time-course and severity of neuropathic pain may appear unrelated to the extent of tissue or nerve damage.
- Symptoms may be spontaneous, unrelated or disproportionate to the stimulus.

Associated symptoms and signs in the skin:

- Allodynia: pain caused by a stimulus on the skin that does not usually cause pain (e.g. wind, cold, clothes, movement). Allodynia is pathognomonic of neuropathic pain.
- Dysaesthesias, numbness, paraesthesia, hyperalgesia
- Autonomic instability with vascular and temperature changes.

Neuropathic pain may be difficult to diagnose, especially if its distinguishing features are not elicited, which is so often the case in children. Nerve injury confers relative resistance to opioids and therefore treatment is complex. It is critical therefore to spend time assessing the child's pain, actively looking for signs of a neuropathic component. Although neuropathic pain is generally less responsive to opioids, higher opioid doses may be effective, especially in combination with specific anti-neuropathic analgesic agents (e.g. antidepressants, anti-epileptics, membrane stabilisers) and/or invasive

anaesthetic procedures. Combinations of medications from different pharmacological groups are often synergistic, not just additive.

THE PATHOGENESIS OF CANCER PAIN:

Identification of the causal mechanism of pain will guide both investigation and management.

Cancer pain is:

- A complex syndrome where inflammatory, neuropathic and ischaemic mechanisms are involved, often at more than one site.
- Inflammatory changes caused by direct tissue damage resulting from tumour growth.
- Inflammatory changes caused by the release of pain mediators by the cancer cells themselves.
- A neuropathic component caused by cancer-induced damage to the sensory nerves such as infiltration or compression.
- A neuropathic component which may also be caused by interventions such as chemotherapy and surgery.

Because cancer pain is often a mixed-pain syndrome (i.e. neuropathic-nociceptive), the use of opioids and adjuvant analgesics in combination is often justified.

Cancer-Induced Bone Pain:

Recent evidence suggests that cancer-induced bone pain has a large neuropathic component:

- The periosteum is densely innervated by both sensory and sympathetic fibres.
- Bone marrow and mineralized bone also have significant sensory and sympathetic innervation.
- Sensory fibres in all 3 compartments may play a role in generation and maintenance of cancer-induced bone pain.

For this reason, neuropathic agents such as gabapentin are now being used, usually in conjunction with opioids, for cancer-induced bone pain with good anecdotal success. Radiotherapy may also be appropriate.

ASSESSMENT OF CANCER PAIN IN CHILDREN:

This can be extremely difficult, especially in young children or those with disabilities. Under-recognition of pain is a major problem in paediatric cancer pain management. Children with chronic pain may be particularly easy to miss as the signs can be subtle; clinginess, reluctance to move, poor sleep, loss of appetite. The use of pain rating scales as a routine is to be encouraged.

Below are some examples of commonly used scales. (See also attachments)

1. *Visual Analogue Scale:*

These are recommended for children 8 and over.

They are easy to administer, low cost and correlate with parent and health team ratings.

2. *The WONG BAKER FACES Scale:*

This scale is well liked by children and frequently used. It has the advantage of not needing to understand abstract numerical values or words and correlates with other self - report scales.

For children who are unable to communicate:

The FLACC scale and the Non Communicating Children's Pain Check List are useful.

Measurement of pain intensity is just one component of assessment. It is also important to determine the following:

- Location (there may be more than one site. As well as pointing to the body part that is affected, children may be able to draw their pain on a picture of a person or can indicate on a doll or teddy where their pain is)
- Radiation
- Quality with particular attention to signs of neuropathic pain
- Exacerbating and relieving factors
- Trust is a critical element of pain assessment. Children may under-report pain if they think that admission, painful injections or unpleasant tasting medication will be the consequence of reporting pain.

CANCER PAIN MANAGEMENT:

Three main approaches are used.

- Modification of the source of pain. The use of chemotherapy and radiotherapy can be very successful in modifying the disease process and hence the source of pain.
- Alteration of the central perception and modulation of pain through the use of pharmacotherapy as well as non-pharmacological means such as distraction, play therapy, music therapy and hypnotherapy.
- Blocking the transmission of pain by using procedural interventions (e.g. nerve blocks).

This focus of this document is on the use of opioids and other medications.

As a general rule:

- Nociceptive pain responds to opioids.
- Neuropathic pain tends to be less responsive to opioids.
- Combinations of opioids and adjuvant agents are synergistic.

General Principles:

- Be proactive: it is better to address pain early than to play 'catch-up' later on Address all factors that are contributing to pain (e.g. anxiety) by using a multi-modal approach
- Use the least invasive route of medication administration
- There is almost never a need for intramuscular injections
- Try and minimise the number of doses of medication required each day (e.g. for stable pain, consider using a slow-release opioid)
- Plan ahead for exacerbations and crises and ensure the family has the necessary medications and instructions available
- Review regularly

Routes of Administration:

1. Oral
2. Parenteral
3. Transdermal

1. *Oral*

The oral route of administration remains the preferred route. Unlike adults, many children with cancer tolerate nasogastric tubes for prolonged periods and most oral medications can be given by the nasogastric or occasionally, the nasojejunal route.

2. *Parenteral:*

There are two ways opioids can be given parenterally; intravenously (IV) and subcutaneously (SC).

In the hospital setting, and where children have existing IV access, the intravenous route may be appropriate. At The Royal Children's Hospital in Melbourne, the Pain Team uses the intravenous route of delivery of drugs. This can be given as a constant background infusion or as patient-controlled analgesia (PCA).

Opioids and many other medications can also be given via the SC route and this can be more readily supported in a community setting. A continuous subcutaneous infusion (CSCI) is given with medications pumped into the subcutaneous tissues via a SC device such as a Saf-T-Intima. This device is inserted after application of topical analgesic cream (e.g. Emlar, Angel) and may stay in situ for as long as 1 week without replacement. The site should be changed if it is inflamed. A separate site is usually needed for breakthrough doses of medication (See below). This method of administration is supported by all community based palliative care services in the State of Victoria, thus removing a potential barrier to discharge.

However in India where Syringe drivers may not be available in most centres, families may be taught to give intermittent Subcutaneous injections. An in-dwelling Scalp vein is inserted into the subcutaneous tissue at any of these sites- the infraclavicular fossae, the back, thigh or the anterior abdominal wall. Once inserted, the scalp vein may be kept in situ for upto a week.

3. *Transdermal*

Fentanyl is the most commonly used opioid by this route. It is administered by way of a patch.

Which Opioid should you use?

1. *Codeine:*

A weak opioid. Analgesic effect due to metabolism to morphine.
Limited role in paediatric palliative care

Advantages:

- Readily available

Disadvantages:

- At least 10% of patients will not be able to metabolise it (i.e. it will be ineffective)
- Ceiling effect (i.e. there is a dose beyond which further increases will not produce increased analgesia)
- It is very constipating

2. *Tramadol:*

- Weak mu opioid receptor agonist.
- Also affects serotonin/noradrenalin transporters.
- Depends on Cytochrome CYP2D6, the activity of which differs with various populations hence benefits may vary.
- Lowers seizure threshold.
- Limited role in paediatric palliative care.

3. *Morphine:*

- Opioid of first choice for moderate to severe cancer pain.
- Metabolised in the liver by conjugation with glucuronic acid to M6G and M3G.
- M6G binds to opioid receptors, M3G does not.
- Animal studies suggest M6G contributes to analgesic effect of morphine, data not clear in humans.
- Animal studies suggest M3G is probably an antagonist of morphine and its metabolite M6G
- Animal studies also suggest M3G probably responsible for the neurotoxic side effects of morphine, such as myoclonus.
- No evidence from human studies of M3G antagonism to morphine or M6G.

Advantages:

- Low cost
- Considerable experience with its use in paediatrics and palliative care
- Due to ease of use, predictability, price, multiple preparations and many years of accumulated knowledge relating to its specific use, MORPHINE remains the drug of first choice for the control of cancer pain

Commencing Oral Morphine

- Exclude neonates from this discussion
- Formulations of rapid-release morphine available

Morphine mixture

Morphine tablets

Starting dose, for the opioid naïve patient:

- 6/12-12/12 100microgram/kg 4hrly.
- 1-12 years 200 microgram/kg 4hrly.
- 12-18yrs 5-10mg 4hrly depending on size and severity of pain.
- If these doses are ineffective, adjust the next dose up by 25%-50%.

"Rescue" or "Breakthrough" Dose (BTD)

- These terms presume mainly adequately controlled background pain. They are given for a transient exacerbation or recurrence of pain. They are prescribed on a p.r.n. (as needed) basis. Three or more BT doses in any 24 hr period implies unstable pain (exclude predictable incident pain related to movement).
- The break through dose (BTD) should be roughly 1/6-1/10 of the total 24hr dose of morphine.
- When commencing morphine in an opioid-naïve patient, the BTD will be equivalent to the 4hrly dose.
- If, after 24 hours, the patient's pain is well-controlled, total up the amount of morphine used over that previous 24 hours

(regular doses + breakthrough doses) and convert to a long acting preparation (see below).

Converting to long-acting Morphine

Formulations available

- Tablets (cannot be crushed)

Converting

Total up the amount of morphine used over the previous 24 hours (regular doses + breakthrough doses) and divide this by two to give the 12 hrly. dose.

Titration Morphine to effect

- Accept 2-3 BTD in any 24 hour period as reasonable pain control.
- Incident pain associated with movement should probably not count as a BTD.
- If more than 3 BTD required, titrate up by adding the total BTD to the 24hr background dose.
- Remember to titrate up the BTD so that it is 1/6-1/10 of the total 24 hour dose.
- Show flexibility

Morphine prescribing, an example

Morphine prescribing, an example

- 25kg child
- Metastatic disease, complaining of pain
- Able to tolerate oral medications
- Dose of rapid-release oral morphine 200microgram/kg 4hrly
- $25\text{kg} \times 0.2 = 5\text{mg}$ 4hrly,
- 5mg BTD.

Side Effects:

- Constipation is almost inevitable: "The hand that writes the opioid script must also write up the aperient".
- Sedation: parents should be warned that the child may be sleepy initially but that this will settle after 2-3 days

- Nausea is rarely a problem in children. It may become a problem with teenagers.
- Metoclopramide is probably more effective than ondansetron.
- Pruritus
- Urinary retention
- Dysphoria, hallucinations: uncommon
- Respiratory depression is very rare when opioids are titrated appropriately

Alternative routes of delivery:

- Morphine infusion-intravenous
- Favoured route for a child with a central line who is unable to tolerate oral medications
- Reduces mobility: child attached to an IV pole.
- Usually supervised by the Pain Team at Royal Children's Hospital.
- Starting dose is 10-20mcg/kg/hr or one third of the total 24 hour oral morphine dose
- BTD is hrly dose (i.e. 1/24 or 4%)
- Morphine infusion- subcutaneous
- The only parenteral route that is supported in the community.
- Run through a subcutaneous device such as a Saf -t -Intima.
- Infusion pumped in over 24hrs at a continuous rate by a Graseby or equivalent battery-powered pump.
- Infusion rate should not exceed 1 ml per hour.
- Break though dose volume should not exceed 1 ml.
- Starting dose 10microgram/kg/hr for all ages or one third of the total 24hour oral morphine dose.
- The greater a child/teenager/young person weighs the easier it is to narcotise them if you follow the microgram/kg/hr dosing regime blindly.
- The BTD is 1/6-1/10 of the 24 hour background dose. This can be given up to hourly as needed.

- If the pain is unstable, the child requires frequent review with up-titration as needed.
- Aim to control pain within 24 hours of presentation
- Work closely with Pharmacy and check doses with pharmacists where possible.

Using other medications in a subcutaneous infusion

- Midazolam, ketamine, metoclopramide and levomepromazine can be added to the syringe pump.
- Cyclizine should be administered via a separate site.
- Some medications cannot be given subcutaneously (e.g. prochlorperazine, chlorpromazine, diazepam)
- Further information and compatibility charts are available-see palliativedrugs.com

Dose Titration:

- Upward dose titration is to be expected and is most commonly the result of:
 - Disease progression
 - Effects of treatment- chemotherapy or radiotherapy (dose may need to be titrated down)
 - Tolerance: this is the reduction in response to the same dose of an opioid after repeated exposure (i.e. increasingly high doses must be administered to obtain the effects observed with the original dose)

Clinically it is difficult to separate a change in pain stimulus (disease progression) from, tolerance. Less commonly, increasing doses of opioid may be needed because of

- Psychological factors-anxiety/depression
- Opioid-induced hyperalgesia
- Opioid addiction is almost never seen in the setting of cancer pain.

Cross Tolerance and Opioid Rotation:

- Cross tolerance refers to the fact that tolerance to the effects of one opioid confers partial tolerance to another opioid.

- Is the basis for the use of opioid switching or opioid rotation in pain management?
- As tolerance or dose-limiting adverse effects develop, incomplete cross tolerance allows us to achieve improved analgesia and/or fewer side effects using a lower dose of another opioid.
- Alternative opioids include oxycodone and fentanyl. Fentanyl may be less constipating but an opioid-naïve child should not be started on a fentanyl patch.

General Principles of Opioid Rotation:

- Equi-analgesic tables provide a guide only (see below).
- The key to success is continuous patient assessment.
- Ensure availability of an adequate BTD of the new opioid.
- Because of incomplete cross tolerance, reduce the calculated dose by between 30%-50%.
- During transition, both opioids are present in the plasma, so there is a need to be aware of the pharmacodynamics of the old and the new drug (e.g. give last dose of long-acting morphine at the time of application of the fentanyl patch, assuming 12hr excretion of morphine and 12 hr build of plasma levels of fentanyl from patch)

Some examples of opioid rotation:

- Morphine to oxycodone
- Child on total oral morphine dose of 30mg/day develops urine retention
- Oxycodone is a widely used alternative to morphine but is currently unavailable in India.
- Morphine 30mg is equianalgesic to Oxycodone 20mg.
- Hence equianalgesic dose of oxycodone is 20mg oral.
- Rule. When rotating, reduce the dose of the new opioid by between 30%-50%, depending on the clinical situation
- So oxycodone 20mg becomes 10mg (50% reduction)
- Ensure adequate breakthrough dose, say 1.5mg
- Reassess early and often to ensure adequate analgesia

Morphine to Fentanyl

- Child with stable pain on 30mg oral morphine per day
- Conversion ratio
- Fentanyl 12microgram/hr patch roughly equal to 30mg oral morphine per day.

Opioid Dose Conversion Ratios

Morphine oral (30mg):	Morphine sub cut (10mg)	3:1
Morphine oral (30mg):	Oxycodone oral (20mg)	3:2
Morphine oral (40mg):	Hydromorphone oral (10mg)	4:1
Morphine sub cut (10 mg)	Hydromorphone sub cut (10 mg)	5:1
Hydromorphone oral (40mg):	Hydromorphone sub cut (10mg)	4:1
Oxycodone oral (20mg):	Oxycodone sub cut (10mg)	2:1
Morphine oral (10mg):	Codeine oral (80mg)	1:8
Morphine s/c (100mg/24hours)	Fentanyl patch (100mcg/24hrs)	See Below
Morphine oral (300mg/24hours)	Fentanyl patch (100mcg/24hrs)	

"Rule of thumb = Three to One"

Morphine Oral (300mg/24 hours) to Fentanyl patch (100mcg/hr):
i.e. Divide 24 hour po morphine dose (mg) by 3 to get Fentanyl patch (mcg/hr)

To avoid the risk of overdose when rotating opioids, reduce the dose of the new opioid by 30 - 50% from the dose calculated on the above conversion table. No need to reduce when changing route of delivery of the same opioid. Always check with the Oncology Pharmacist if unsure of conversion.

Cancer Pain Management - Top Five

1. Laxatives accompany opioids (unless a specific contraindication is identified).
2. Aim to use the same opioid for breakthrough doses and background analgesia (with the exception of fentanyl)

- Breakthrough doses equate to 1/10-1/6 of the background oral or subcutaneous opioid dose (not intravenous) and are charted hourly PRN.
- Opioid titration for new onset or escalating pain is best managed by REGULAR SHORT ACTING OPIOIDS rather than slow release formulations.
- OPIOID doses are specific (i.e. NO DOSE RANGES). If the dose is insufficient it requires medical review and charting of a new dose of breakthrough and/or background analgesia.

ASK, ASSESS, DOCUMENT, ACT

DRUGS USED CANCER PAIN MANAGEMENT

1.1 Properties and Dosages Available for Common Opioids in Australia

Opioid	Active Metabolite	Dose adjust renal impaired	Formulation / Dose	Duration of action (hrs)	General Comments
Buprenorphine	No	No	Transdermal Patch 5mg (5mcg/hr), 10mg (10mcg/hr), 20mg (20mcg/hr)	7 days	No Current role established in Paediatric Palliative Care.
Codeine	Yes Norcodeine (10-20% and morphine (5-15%))	Yes	Linctus 5mg/1ml Tablet 30mg tablet DOSE: 0.5-1mg/kg/dose 4-6hourly (Max of 240mg/day)	3 to 4	Usually in combination with paracetamol The ability to metabolise codeine varies considerably between individuals resulting in decrease of therapeutic actions or increase in side effects Acts as a pro-drug of morphine Codeine has a minimal direct analgesic action Rarely has a role in Paediatric Palliative Care
Fentanyl	No	No	Lozenges 6 strengths: 200, 400, 600, 800, 1200, 1,600mcg DOSE: For Break-through Pain(BTP) Patients >10kg: 15 - 20 micrograms/dose (Max=400 micrograms/dose) If more than 4 BTP doses/24hours increase background pain relief	Patch: 72hrs Loz: 1-2hrs IV: 30-60mins IM: 1-2hrs	NOT FOR USE IN OPIOID NAÏVE PATIENTS Consultation with Palliative Care Team is suggested before commencing treatment with patches or use of BTP doses Patches for use in when pain control stabilized Not recommended in opioid-naïve patients due to high AEs

Opioid	Active Metabolite	Dose adjust renal impaired	Formulation / Dose	Duration of action (hrs)	General Comments
			Injection (SC/IV) Dose dependant on previous opioid requirements Transdermal patch (Durogesic) 2.1mg (12mcg/hr), 4.2mg (25mcg/hr), 8.4mg (50mcg/hr), 12.6mg (75mcg/hr), 16.8mg (100mcg/hr) Dose dependant on previous opioid requirements Do not cut in half		Drug of choice in renal failure and causes less constipation Lipophilic forms subcutaneous reservoir; therefore more rapid uptake in cachectic patients. Also in pyrexia patients. May not stick if patient very sweaty. If analgesia does not last 3 days, increase dose. In 10%, patients, q2day admin is needed.
Hydromorphone	Minimal except in patients with renal impairment Main metabolite is the analgesically inactive hydromorphone-3-glucuronide (>90%), dihydromorphone (<1%) and dihydroisomorphine (1%)	Yes	Oral liquid 1mg/ml Tablet - Immediate Release 2mg, 4mg, 8mg Tablet - Modified Release 4mg, 8mg, 16mg, 32mg & 64mg Injection 2mg/ml, 10mg/ml, 50mg/5ml, 500mg/50ml DOSES: Young Children: Oral: 0.03 - 0.08mg/kg/dose every 3-4 hours as needed (Max dose=5mg/dose) IV: 0.015mg/kg/dose every 3-6 hours as needed Older Children: Oral: Opioid Naïve: 1-2mg dose 3-4 hourly Usual: 2 - 4mg/dose 3-4hourly Maximum dose = 8 mg/dose IV, IM, SC: Opioid Naïve: 0.2-0.6mg/dose 2-3 hourly	4 - 5 hours	10mg of Morphine IM = 1.5 mg of Hydromorphone IM Oral bioavailability is 50-60% Good alternative if high dose in small volumes required for SC administration Oral doses should be given with milk/food to minimise GI upset Fewer neuropsychiatric side effects DUC Approval required MODIFIED release tablets (Jurnista™) is NOT for initial treatment - patients should be started on immediate release preparations first.
Metadone	No	Note that duration of effect increases with chronic dosing due to accumulation in tissue	Oral liquid 5mg/ml Tablet 10mg Injection 10mg/ml DOSES: IV: 0.1mg/kg/dose every 4 hours for 2-3 doses then increase interval to 6-12 hourly as tolerated (max 10mg/dose) Oral/IM/SC: 0.1mg/kg/dose every 4 hours for 2-3 doses then increase interval to 6-12 hourly as tolerated OR	4-5 hours initially, then with chronic dosing up to > than 24 hrs orally IM: 3-5 hours	Recommend use limited to palliative care team Initial frequency of dosing may range from 4-12 hours, once doses accumulate with repeated doses If used as first line, many more side effects

1.2 Non-steroidal Anti-inflammatories

NSAIDS are never used in the setting of ALL/AML or with any chemotherapy which may insult the bone marrow

However, they can be very useful in patients with solid tumours but should only be used after consulting with the treating team.

Non-Steroidal Anti-inflammatories	
Mechanism	<ul style="list-style-type: none"> • Peripheral and central acting • Inhibits cyclo-oxygenase (COX) and reduces prostaglandins • Non-selective COX-1/ COX-2 inhibitors: diclofenac, ibuprofen, naproxen, ketorolac • COX-2 selective: celecoxib, parecoxib (both contain sulphur) • Analgesic and anti-inflammatory
Indication	<ul style="list-style-type: none"> • Mild to moderate pain. • Especially bone pain, inflammation, paraneoplastic fevers and sweats. • CAUTION: Causes platelet dysfunction as a result of acetylation of platelet COX-1. Aspirin causes an irreversible effect, whilst Ibuprofen, Naproxen, Ketorolac cause a reversible effect. Diclofenac does not effect platelet function at normal doses
Formulation/ Dosing:	<p><i>Ibuprofen (Brufen)</i> Oral: (tablets/ suspension): 5 - 10mg/kg/dose, 6 - 8-hourly Cap dose at adult max 200-400mg 4-6 hourly</p>
Non-selective COX-1/ COX-2	<p>Diclofenac Oral: (tablets) 0.3-1mg/kg/dose, 8 - 12-hourly (max 50mg/day) Topical gel</p> <ul style="list-style-type: none"> • Naproxen (Naprosyn) <p>Oral: (slow release tablets/ suspension): 5 - 7.5mg/kg/dose, 12-hourly (max 1250mg/day)</p> <ul style="list-style-type: none"> • Ketorolac - PARENTRAL USE ONLY (IV or SC)

	<p>For short term use only due to risks - Ketorolac is an irritant: risks include gastrointestinal haemorrhage and renal impairment.</p> <p>Can be very useful in the treatment of pain due to solid tumours, should be used in consultation with the Palliative Care Team</p> <p>Dose: 0.2mg/kg/dose (max 10mg/dose) , 6-8 hourly</p> <p>CSCI: patients Children >12yrs & <50kg : 60mg/24hours</p>
Adverse Events	<ul style="list-style-type: none"> • GIT: nausea, diarrhoea, constipation, ulceration • Cardiovascular: hypertension, fluid retention • CNS: headache, confusion • Haematological: anaemia, platelet dysfunction, BM depression • Hepatic: hepatotoxicity, should be avoided in severe hepatic impairment • Renal: impaired renal blood flow, glomerulopathy, ARF • Respiratory: asthma
General Comments	<ul style="list-style-type: none"> • Different therapeutic and adverse events in individual patients • Recommend adding gastro duodenal protection - either H2-antagonist e.g. Ranitidine IV:1mg/kg/dose 6-8 hourly Oral:2-4mg/kg/dose 8 - 12hourly or proton pump inhibitor e.g. Omeprazole <10kg 0.7mg - 3mg/kg d max. 20mg daily, 10-20kg 10mg d, max. 20mg daily, >20kg 20mg daily, can be increased to 40mg daily if severe - Pantoprazole is the IV formulation, Dose:1 mg/kg/dose 12-24 hourly max: 40mg daily) • COX-2 agents selectively reduce GI toxicity but other SEs are similar, issues have been raised re: cardiovascular safety and thus should be used 2nd line

2. Non-opioid analgesia

2.1 Paracetamol

Paracetamol	
Mechanism of Action	<ul style="list-style-type: none"> Centrally acting. Inhibits prostaglandin synthetase in hypothalamus, prostaglandin synthesis in spine and inducible nitric oxide in macrophages. Analgesic and anti-pyretic.
Indication	<ul style="list-style-type: none"> First line: mild to moderate pain.\ Especially soft tissue or musculoskeletal. Combination with opioids, paracetamol is synergistic in reducing opioid doses and minimising side effects.
Formulation/ Dosing	<p>Oral</p> <ul style="list-style-type: none"> Tablets, capsules, chewable, soluble, suspension 15mg/kg/dose, 4 - 6-hourly (max 60mg/kg/day) Cap dose at adult maximum of 4g/day <p>Parenteral</p> <ul style="list-style-type: none"> 15mg/kg/dose, 4 - 6-hourly (max 60mg/kg/day) Cap dose at adult maximum of 4g/day Short term use only, when oral administration is not feasible Infusion to be run >15 mins, undiluted
Time to Effect	<p>Oral: 30 mins</p> <p>Parenteral: 5 - 10 mins</p>
Adverse Events	<ul style="list-style-type: none"> Generally well tolerated Increased INR if on warfarin Toxicity increased: fasting (decreased hepatic glutathione), other enzyme inducing drugs e.g. anticonvulsants, rifampicin and cachexia

	<ul style="list-style-type: none"> • Can be used with liver metastases (reduce dose) <p>Overdose:</p> <ul style="list-style-type: none"> • Doses > 125mg/kg - 500mg/kg (smallest fatal dose 18g) • Severe hepatotoxicity, hypoglycaemia, acute renal tubular necrosis • Measure serum paracetamol levels 4/24 post-dose • Treat with acetylcysteine
General Comments	<ul style="list-style-type: none"> • Do not write on the drug chart 'panadol or panadeine or panadeine forte, prn'. • Be decisive - one or the other. Doing this makes it difficult to review the patient's actual analgesia requirements in retrospect.

2.2 Medications Used for Neuropathic Pain

Medication	Dose/Form	Comments
First Line		
Gabapentin	<p>FORM:</p> <p>Capsules: 100mg, 300mg, 400mg</p> <p>Tablets: 600mg, 800mg</p> <p>Increasing dose regimen:</p> <p>2-10mg/kg/dose</p> <p>Day 1: nocte</p> <p>Day 2: bd</p> <p>Day 3: tds</p> <p>Titrate to response</p> <p>Usual dose range is 8-35mg/kg/day in divided doses.</p>	<ul style="list-style-type: none"> • Doses of up to 60mg/kg/day may be required • Maximum adult dose is 3600mg/day • Not PBS-listed for neuropathic pain • Requires slow withdrawal • Side effects: sedation, dizziness, peripheral oedema • Precaution: renal impairment - reduce dose frequency • Adequate trial: 2-4 weeks • When titrating to response, increase night time dose first • If part capsules are required or the patient is unable to swallow, the powders can be diluted up in fruit juice

<p>Pregabalin</p>	<p>FORM: Capsules: 25mg, 75mg, 150mg, 300mg Start at 75mg d Titrated up by 75mg daily until 150-300mg/ day in divided doses Maximum dose: 300mg/d</p>	<ul style="list-style-type: none"> • Trial when gabapentin not tolerated or ineffective • Precaution: renal impairment - refer to product information for dose reduction with respect to creatinine clearance • PBS-Authority listed for neuropathic pain refractory to other treatments • Requires slow withdrawal • Dose increases should occur every 3-7 days • Treatment over 12 weeks should be assessed for risk/benefit
<p>Amitriptyline</p>	<p>FORM: Tablets: 10mg, 25mg, 50mg 0.1-2 mg/kg/day given as a single dose at night time MAXIMUM doses - unless consultation with Palliative Care 2 - 12 year olds: 25 mg nocte 12 - 18 year olds: 75mg nocte</p>	<ul style="list-style-type: none"> • More evidence for efficacy however often use after a trial of gabapentin because of side effects, poor tolerance and multiple drug interactions • May see improvement in 48-72 hours • Titrate up gradually, over 2-3 weeks • Use minimum effective dose, but adequate trial is at least 2 weeks at maximal tolerated dose • Side effects include sedation, postural hypotension, dry mouth, also cognitive decline, ataxia. Side effects reduced at low dose • Precaution: cardiac disease, decreases seizure threshold • Increase risk of suicide ideation in patients with depressive disorders

Ketamine (NMDA antagonist)

Ketamine	
Mechanism of Action	<ul style="list-style-type: none"> • Dissociative anaesthetic • Provides analgesia a subcutaneous-anaesthetic doses (<1mg/kg/hour) • Blocks transmission of glutamate at the NMDA receptors • Use requires specialist opinion where parenteral use is not appropriate
Indication	<ul style="list-style-type: none"> • "Wind-up" pain • Secondary hyperalgesia of burns • Neuropathic pain • Adjuvant to opioids • Incident pain • Ischaemic pain • Inflammatory pain • Mucositis of radiotherapy and chemotherapy
Contraindication	<ul style="list-style-type: none"> • Raised intracranial pressure (brain metastases) • Psychosis (including delirium) • Uncontrolled hypertension
Formulation/ Dosing	<ul style="list-style-type: none"> • Subcutaneous infusion 0.05 - 1.5mg/kg/hr (higher doses may be required depending on patient response) Maximum dose - 500mg/24hours • Oral - consult Palliative Care Team and Pharmacy 0.1 - 0.3mg/kg/dose
Adverse Events	<ul style="list-style-type: none"> • Delirium, vivid dreams, sensory distortions • Depersonalisation, derealisation • Acute severe memory disruption • Nausea and vomiting • Tachycardia, hypertension, and raised intracranial pressure

General Comments	<ul style="list-style-type: none">• When given orally, ketamine is metabolised to norketamine - norketamine is equipotent to ketamine as an analgesic• Long term use induces hepatic enzymes and enhanced ketamine metabolism• Very bitter taste when given orally• Narrow therapeutic window• Benzodiazepines, alpha-agonists and neuroleptics are used to treat the psychotomimetic side-effects• Ketamine is an irritant when given IV - dilute to largest volume possible• USE WITH GUIDANCE FROM PALLIATIVE CARE TEAM
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Attachments:

This diagram illustrates that pain and physical symptoms are but one aspect of suffering.



Pyramid with Ribbons

In Paediatric Palliative Care we tend to follow the Pyramid with Ribbons rather than the WHO ladder

Pyramid with Ribbons

- Better format to follow than the WHO steps as it acknowledges the complexity and multidisciplinary approach to paediatric cancer pain management.

Pyramid with Ribbons

Consultants' estimates of prevalence of use of progressively more invasive therapies

- Nerve blocks, palliative surgery, and ablative surgery, 1-5%
- Epidural and intrathecal analgesics, 2-5%
- ▒ Intravenous and subcutaneous drugs, 5-30%
- Oral, transdermal, and rectal drugs, 75-85%

US Dept Health
AHCP - 1994

- ◆ Pyramid – hierarchy of least (Base) to most invasive (apex)
- ◆ Ribbon – therapies may benefit patient at any level
- ▶ analgesics are the cornerstones
- ▶ MDT approach needed to optimize pain relief

Wong - Baker FACES Pain Rating Scale

Wong-Baker FACES Pain Rating Scale® Instructions for Usage

Explain to the person that each face is for a person who has no pain (hurt) or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little more. Face 6 hurts even more. Face 8 hurts a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

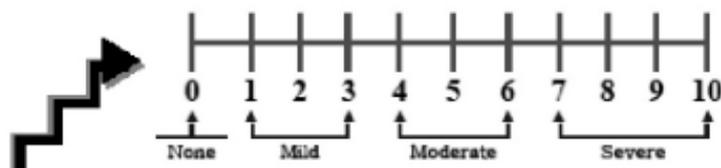
Ask the person to choose the face that best describes how much pain he has.



NATIONAL INSTITUTES OF HEALTH
WARREN GRANT MAGNUSON CLINICAL CENTER

PAIN INTENSITY INSTRUMENTS
JULY 2003

0 – 10 Numeric Rating Scale (page 1 of 1)



Indications: Adults and children (> 9 years old) in all patient care settings who are able to use numbers to rate the intensity of their pain.

Instructions:

1. The patient is asked any one of the following questions:
 - What number would you give your pain right now?
 - What number on a 0 to 10 scale would you give your pain when it is the worst that it gets and when it is the best that it gets?
 - At what number is the pain at an acceptable level for you?
2. When the explanation suggested in #1 above is not sufficient for the patient, it is sometimes helpful to further explain or conceptualize the Numeric Rating Scale in the following manner:
 - 0 = No Pain
 - 1-3 = Mild Pain (nagging, annoying, interfering little with ADLs)
 - 4-6 = Moderate Pain (interferes significantly with ADLs)
 - 7-10 = Severe Pain (disabling; unable to perform ADLs)
3. The interdisciplinary team in collaboration with the patient/family (if appropriate), can determine appropriate interventions in response to Numeric Pain Ratings.

Reference

McCaffery, M., & Beebe, A. (1993). Pain: Clinical Manual for Nursing Practice. Baltimore: V.V. Mosby Company.

Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME: _____ UNIT/FILE #: _____ DATE: _____ (dd/mm/yy)
 OBSERVER: _____ START TIME: _____ AM/PM STOP TIME: _____ AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

I. Vocal

1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Crying (moderately loud).....	0	1	2	3	NA
3. Screaming/yelling (very loud).....	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....	0	1	2	3	NA

II. Social

5. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
6. Less interaction with others, withdrawn.....	0	1	2	3	NA
7. Seeking comfort or physical closeness.....	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify.....	0	1	2	3	NA

III. Facial

9. A furrowed brow.....	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning.....	0	1	2	3	NA
11. Turning down of mouth, not smiling.....	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering.....	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out.....	0	1	2	3	NA

IV. Activity

14. Not moving, less active, quiet.....	0	1	2	3	NA
15. Jumping around, agitated, fidgety.....	0	1	2	3	NA

V. Body and Limbs

16. Floppy.....	0	1	2	3	NA
17. Stiff, spastic, tense, rigid.....	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts.....	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts.....	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch.....	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.).....	0	1	2	3	NA

VI. Physiological

22. Shivering.....	0	1	2	3	NA
23. Change in color, paler.....	0	1	2	3	NA
24. Sweating, perspiring.....	0	1	2	3	NA
25. Tears.....	0	1	2	3	NA
26. Sharp intake of breath, gasping.....	0	1	2	3	NA
27. Breath holding.....	0	1	2	3	NA

VII. Eating/Sleeping

28. Eating less, not interested in food.....	0	1	2	3	NA
29. Increase in sleep.....	0	1	2	3	NA
30. Decrease in sleep.....	0	1	2	3	NA

SCORE SUMMARY:

Category:	I	II	III	IV	V	VI	VII	TOTAL
Score:								

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USING THE NCCPC-R:

The NCCPC-R was designed to be used for children, aged 3 to 18 years, who are unable to speak because of cognitive (mental/intellectual) impairments or disabilities. It can be used whether or not a child has physical impairments or disabilities. Descriptions of the types of children used to validate the NCCPC-R can be found in: Breau, L.M., McGrath, P.J., Camfield, C.S. & Finley, G.A. (2002). Psychometric Properties of the Non-communicating Children's Pain Checklist-Revised. *Pain*, 99, 349-357. The NCCPC-R was designed to be used without training by parents and caregivers (carers). It can also be used by other adults who are not familiar with a specific child (do not know them well).

The NCCPC-R may be freely copied for clinical use or use in research funded by not-for-profit agencies. For-profit agencies should contact Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

The NCCPC-R was intended for use for short or long-term pain in the child's home or in a long-term residential setting. If suspected pain after surgery or pain due to procedures conducted in hospital are the reason for measuring pain, the Non-communicating Children's Pain Checklist - Postoperative Version should be used. It can be obtained by contacting Lynn Breau. Information regarding the NCCPC-PV can be found in: Breau, L.M., Finley, G.A., McGrath, P.J. & Camfield, C.S. (2002). Validation of the Non-Communicating Children's Pain Checklist - Postoperative Version. *Anesthesiology*, 96 (3), 528-535.

ADMINISTRATION:

To complete the NCCPC-R, base your observations on the child's behavior over the past two hours. It is not necessary to watch the child continuously for this period. However, it is recommended that the observer be in the child's presence for the majority of this time (e.g.; be in the same room with the child).

Although shorter observation periods may be used, the cut-off scores described below may not apply.

Eating/Sleeping Subscale: Items on the Eating/Sleeping subscale may not occur during the two-hour observation. In this case, the rating

should be based on the child's behavior over the day of the observation.

All other subscales: At the end of the observation time, indicate how frequently (how often) each item was seen or heard. This should not be based on the child's typical behavior or in relation to what he or she usually does.

A guide for deciding the frequency of items is below:

0 = Not present at all during the observation period. (Note if the item is not present because the child is not capable of performing that act, it should be scored as "NA").

1 = Seen or heard rarely (hardly at all), but is present.

2 = Seen or heard a number of times, but not continuous (not all the time).

3 = Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the child for a few moments during the observation time.

NA = Not applicable. This child is not capable of performing this action.

SCORING:

1. Add up the scores for each subscale and enter below that subscale number in the Score Summary at the bottom of the sheet. Items marked "NA" are scored as "0" (zero).
2. Add up all subscale scores for Total Score.
3. Check whether the child's score is greater than the cut-off score.

CUT-OFF SCORE:

Based on the scores of 71 children aged 3 to 18 (Breau, McGrath, Camfield & Finley, 2002), a Total Score of 7 or more indicates a child has pain. This was accurate in the study group 84% of the time. A Total Score of 6 or less indicates a child does not have pain. This was correct in the study group 77% of the time.

USE OF CUT-OFF SCORES:

As with all observational pain tools, caution should be taken in using cut-off scores because they may not be 100% accurate. They should

not be used as the only basis for deciding whether a child should be treated for pain. In some cases children may have lower scores when pain is present. For more detailed instructions for use of the NCCPC-R in such situations, please refer to the full manual, available from Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

References:

1. Cancer Pain From Molecules to Suffering, IASP 2010 Pain 2010 Updated Review IASP
2. Dr Ross Drake, Pall Care Physician NZ, personal communication Opioids in Cancer Pain 2nd Edition Oxford 2010
3. University of Manitoba lecture series-palliative-info.com Cancer Pain. IASP 2010
4. Symptom Management in Advanced Cancer. Palliativedrugs.com
5. Therapeutic Guidelines Analgesic 2007 version 5
6. MC Sabino, DR Clohisy. Mechanisms and management of bone cancer pain. Chapter 26 in "Bone Cancer". Academic 2010
7. L Colvin, M Fallon. Challenges in cancer pain management-bone pain. European Journal of Cancer 44 (2008) 1083-1090
8. P Mantyh. Mechanisms of Malignant Bone Pain. Chapter in Cancer Pain. IASP Press 2010
9. MC Sabino, P Mantyh. Clinically related behaviour models: bone cancer pain. Drug Discovery Today: Disease Models (2004) Vol 1 No. 2 127-133.
10. Palliative Medicine Guidelines For HMOs. Peter MacCallum Cancer Centre 4th Edition 2009.

Chapter 6

Management of Gastrointestinal Symptoms

Dr Ross Drake

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Introduction:

Gastrointestinal (GI) symptoms are relatively common [1-6] in children and adolescents requiring palliative care and, in many, are likely to have been present prior to the child being considered palliative either because of the primary disease and/or treatment effects. This section will focus on the commonest GI symptoms of nausea and vomiting, constipation, diarrhoea and anorexia-cachexia syndrome.

The impact these symptoms have on normal bodily functions can be very disturbing for families. The inability to nourish and feed may symbolize failure of the parenting role, while loss of bowel control could be viewed by some children/young people as a final embarrassment. The escalation or return of symptoms like anorexia, disturbed bowel function, nausea and vomiting may result in significant distress for the family as it signals deterioration in the condition or be viewed as the child entering of the final stages of the illness.

The evaluation of any GI symptom requires a thorough and careful history followed by a focused clinical examination. An interdisciplinary approach to care is then usually necessary to effectively manage children and their families with life limiting conditions. A completely mechanistic or biological approach can allow for control of bothersome symptoms and, in so doing, open the door to allow wider emotional, psychosocial and spiritual issues to be addressed. Not addressing these ultimately means lost opportunities and inferior care.

Psychological approaches can be seen as an extension of the exploration of emotional and spiritual issues and can be used to help the child relax, feel calmer, and have a greater sense of control with

younger children being helped to engage in these by a parent. In general, such a line of enquiry [7] should comprise:

- Assessing the symptoms impact on the child and their family
- Exploring the emotional components and the meaning of the symptom on their child
- Assessing the quality of life of the child and their family
- Encouraging child and family interaction to reduce psychological distress
- Supporting the family to distinguish between things they can and can not control such as normal disease progression versus helping their child find comfort

1. *Nausea & Vomiting:*

Nausea and vomiting should be considered as separate symptoms and have been reported to occur in 40 to 63% of children requiring palliative care. They are one of the most common GI symptoms with nausea often under-estimated as a symptom both in terms of frequency and distress caused, while vomiting is more easily contained.

Vomiting is regulated by two distinct brain centres, the vomiting centre and the chemoreceptor trigger zone (CTZ). Both are located in the medulla oblongata with the CTZ lying outside the blood-brain barrier in the area postrema, at the bottom of the 4th ventricle, while the vomiting centre is located inside the blood-brain barrier.

The majority of receptors in the vomiting centre and CTZ are excitatory meaning they provoke the symptom with stimulation. An exception to this is the morphine opioid receptor (MOR) which responds to opioids in these brain centres in a dose-dependent manner. At standard doses opioids can cause nausea and/or vomiting by stimulating dopamine receptors but at high doses opioids can be inhibitory or anti-emetic [8,9].

Evaluation and Assessment:

There may be several concurrent causes in the pathogenesis of nausea and/or vomiting but, usually, one major factor presides. Identification of this main reason will most likely lead to a more accurate prescription with improved efficacy.

The following factors should be considered:

1. *Gastrointestinal problems*

- A. Pharyngeal irritation
 - Local infection i.e. candida, herpes
 - Difficulty expectorating sputum
- B. Oesophageal dysfunction
 - Neuromuscular inco-ordination
 - Intrinsic/extrinsic compression
 - Oesophagitis
 - Gastro-oesophageal reflux
- C. Gastric compression/outlet obstruction (squashed stomach syndrome)\
- D. Gastric stasis
- E. Tense ascites
- F. Intestinal obstruction
- G. Constipation

2. *Metabolic*

- Hypercalcaemia
- Uremia

3. *Pain*

4. *Medication*

- GI irritation - NSAIDs, iron supplements, antibiotics
- Gastric stasis (see constipation)
- Chemoreceptor trigger zone stimulation - opioids, antibiotics, cytotoxics
- 5HT₃-receptor stimulation - cytotoxics, selective serotonin reuptake inhibitors

5. *Toxic*

- Radiotherapy
- Chemotherapy
- Infection
- Carcinomatosis

6. *Other Tumours*

- ENT
- Vestibular apparatus
- Auditory nerve
- Cerebral including metastases
- Raised intracranial pressure
- Direct pressure on CTZ or vomiting centre

7. *Psychogenic Factors*

- Anticipatory vomiting
- Anxiety
- Fear

Management:

Drugs are not the only consideration in managing either symptom as the introduction of simple strategies can be very helpful such as changing the dietary habit from large feeds to several small feeds each day, the introduction of pleasant aromas for the child and the avoidance of stimuli recognized as triggers of nausea and/or vomiting.

Randomised controlled trials in children with nausea and vomiting are, largely, isolated to management of cancer and postoperative nausea and vomiting. These results may not be directly applicable to children with non-malignant conditions but a rationale approach is to take the best available evidence and experience to inform the targeted use a single anti-emetic as the first step. If this is not successful then another agent can be introduced with this agent targeting a different receptor action profile than the first medication.

Anti-emetics can be classified by their main receptor action and include:

- 5-HT₃ Receptor Antagonists - ondansetron, granisetron
- Dopamine Receptor Antagonists - metoclopramide, haloperidol
- Anticholinergic Histamine and Acetylcholine Muscarinic Receptor Antagonists - hyoscine, cyclizine, prochlorperazine
- Neurokinin 1 Receptor Antagonists - aprepitant
- Cannabinoids - nabilone, dronabinol

- Corticosteroids - prednisone, dexamethasone

2. *Constipation:*

Constipation is common with 27 to 59% of children at the end-of-life troubled by this symptom. As a topic it is, arguably, the cause of more discussion than any other GI symptom as constipation is a frequently dealt with problem in the paediatric population outside of palliative care. Yet, constipation in the palliative care can have a significant impact on the child and their family and be difficult to manage.

Evaluation and Assessment:

Of any symptom, constipation needs to be enquired about as changes in bowel habit may not be volunteered. This lack of information sharing is quite apparent in the adolescent age group as it may be the cause of embarrassment or activate unpleasant memories of past management including rectal examinations, suppositories and enemas. Heraldng symptoms for constipation include abdominal pain, bloating, flatulence, nausea and vomiting. Likewise, soiling and the passing of sloppy foul smelling faeces may point to constipation with overflow incontinence rather than diarrhoea.

Ideally, examination would involve a rectal examination to evaluate the presence and consistency of stool in the rectum and is strongly indicated when the warning signs of neurologic compromise from, amongst other things, spinal cord compression are present. However, the emotional impact this procedure may have on the child and their family must first be carefully considered and, if required, full explanation provided prior to being done. At the simplest level it may help shed light on easily treatable conditions such as anal fissures or haemorrhoids. There are, also, a number of situations where a rectal examination is not advisable such as when the child is neutropaenic or thrombocytopaenic.

If there is a lack of certainty around the diagnosis then an abdominal radiograph or an ultrasound may be helpful.

The following underlying causes for constipation should be borne in mind:

- Anorexia
- Weakness and decreased abdominal muscle tone

- Inconvenient toilet access
- Poor posture
- Medications - opioids, tricyclic antidepressants, phenothiazines, diuretics, antihistamines/anticholinergics, iron supplements
- Metabolic - hypothyroidism, hypokalaemia, hypercalcaemia
- Mechanical - bowel obstruction
- Psychological factors - depression

Management:

Avoiding constipation is the first step in management with helpful measures including:

- Maintaining a regular bowel routine
- Encouraging increased activity - can help activate peristalsis
- Increased fluid intake
- Increased dietary fibre
- Abdominal massage (clockwise)

There are a variety of laxatives with their mode of action through either being a:

- Stool softener
- osmotic agent - lactulose, sorbitol, polyethylene glycol
- surfactant agent - docusate
- Stimulant agent - sennosides, bisacodyl
- Prokinetic agent - metoclopramide, low-dose erythromycin

They can be administered orally, by suppository or enema.

Pharmacological management should start with the regular use of a stool softener with a stimulant added if this does not prove useful. However, if constipation is distressing and associated with hard stool in the rectum then a rectal suppository or an enema may be required at the start of treatment. Lactulose is often preferred by paediatricians but, anecdotally, for children with life-limiting conditions it often does not provide any benefit. This is particularly the case for children with opioid-induced constipation.

Manual evacuation should be reserved for intractable constipation that has failed less interventional approaches and be conducted with adequate analgesia and sedation or under general anaesthetic depending on the child's age and wishes.

Adults with opioid-induced constipation have been shown to benefit from the specific administration of an opioid-antagonist such as naloxone or methylnaltrexone. Unfortunately, no studies have been published in children.

3. *Diarrhoea:*

A significant number of children (21-40%) experience diarrhoea during their end-of-life period. This may have been a long standing issue related to the condition or be of acute onset, which invites a careful evaluation as common causes may be at play.

Evaluation and Assessment:

The causes of diarrhoea are numerous but chronic diarrhoea due to conditions causing intestinal, liver or pancreatic dysfunction are likely to already have been diagnosed and under treatment. This leaves the assessment of diarrhoea of acute onset. If this occurs in a child with pre-existing diarrhoea then an exacerbation of the known cause is the most likely cause but if it occurs in a child who did not previously have this symptom then common, treatable causes (see below) should be the first consideration [10]:

- Overflow incontinence secondary to constipation
- Feed intolerance
- Irritable bowel syndrome
- Infective agents - particularly immunocompromised children
- Medication related - laxative overuse, antibiotics, chemotherapy
- Treatment related - radiation or chemotherapy induced GI damage
- Anxiety

Management:

All types of diarrhoea should be initially managed by standard measures such as encouraging oral rehydration with a suitable fluid (particularly when associated with dehydration), attention to perianal

skin hygiene and application of a barrier cream and the use of appropriate incontinence aids.

If a specific cause is identified then management will be directed toward this such as an increase in pancreatic replacement therapy for a child with cystic fibrosis or a decrease in enteral intake or change in the formula for a child who has developed feed intolerance.

Evidence for the use of anti-diarrhoeal medications in children with life-limiting conditions is minimal. If required the standard agents available are:

- Loperamide - potent MOR agonist
- Bismuth subsalicylate - ? mechanism of action
- Colestyramine - bile acid sequestrant
- Octreotide - somatostatin analogue

4. *Anorexia and Cachexia:*

At its simplest, anorexia is a loss of appetite, while cachexia is "a complex metabolic syndrome associated with underlying illness and characterized by loss of muscle with or without loss of fat mass" [11]. The symptoms appear to be highly prevalent in children with life-limiting conditions of both malignant [3,6,12] and non malignant origin [3]. However, this did not seem to result in a high level of suffering but neither was it successfully treated [3,6].

These symptoms tend to be acknowledged together as the anorexia-cachexia syndrome, an advanced protein calorie malnutrition that inevitably leads to death [13]. This condition is characterized by anorexia, tissue wasting, weakness, poor physical function and involuntary weight loss, the latter of which may manifest in children as growth failure. It can have a major emotional impact on the family as the sight of their child losing weight may intensify feelings of impotence and 'failure' and challenge powerful and innate beliefs such as the necessity to feed in the face of reduced intake and raise concerns that their child is receiving inadequate care.

Evaluation and Assessment:

This syndrome has no specific diagnostic criteria but knowledge of the disease process, clinical history and focused physical examination makes for an uncomplicated clinical diagnosis. The use of measures

such as body weight, skin fold thickness and body composition are, often, not required. However, body weight can be useful when loss is too rapid and along with assessment of hydration can indicate changes in fluid balance which may reasonably require correction. Laboratory tests evaluating nutritional depletion are of limited value and can not be recommended as routine.

The presence of anorexia-cachexia syndrome in the palliative setting would suggest an unavoidable deterioration to death. However, the presence of anorexia and/or cachexia can represent correctable causes such as:

- nausea and vomiting
- pain
- dehydration
- adverse effects of medication
- mouth problems - oral thrush, xerostomia
- gastrointestinal dysfunction - dysphagia, gastro-oesophageal reflux, constipation, intestinal obstruction
- infection - local and systemic
- psychological factors - anxiety, fear, depression

Management:

Informing and educating the child and their family about this condition is extremely important and the positive effect this can have should not be underestimated. It can allow for exploration of commonly held beliefs that, if left unaddressed, may be destructive to the therapeutic relationship and, by addressing, lead to strategies being developed in advance that may help empower the child and family and, potentially, improve appetite and food intake.

Such strategies include:

- Offering the child favourite foods and nutritional supplements
- Eliminating dietary restrictions
- Reducing portion sizes and increasing the number of meals
- Making food look more enticing
- Avoiding disliked food smells

The use of hypercaloric feeding does not significantly improve survival [14].

Pharmacological management is adjunctive to the above. Medications are not overly successful in alleviating either anorexia or cachexia and a large number exist providing further evidence for lack of efficacy. In children there is limited support for two agents Megestrol acetate [15-19] and Cyproheptadine hydrochloride [19].

References:

1. Wolfe J, Hammel JF, Edwards KE, Duncan J, Comeau M, Breyer J, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol* 2008;26(10):1717-23.
2. Friedrichsdorf SJ, Brun S, Zernikow B, Dangel T. Palliative Care in Poland - The Warsaw Hospice for Children. *Europ J Pall Care* 2006;13(1):35-8.
3. Drake R, Frost J, Collins JJ. The symptoms of dying children. *J Pain Symptom Manage* 2003;26(1):594-603.
4. Hongo T, Watanabe C, Okada S, Inoue N, Yajima S, Fujii Y, et al. Analysis of the circumstances at the end of life in children with cancer: symptoms, suffering and acceptance. *Pediatr Int* 2003;45(1):60-4.
5. Goldman A. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342(26):1998; author reply -9.
6. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000;342(5):326-33
7. Mason P. Anorexia-cachexia - the condition and its causes. *Hospital Pharmacist* 2007;14:249-53.
8. Twycross R, Back I. Nausea and vomiting in advanced cancer. *Europ J Pall Care* 1998;5(2):39-44.
9. Santucci G, Mack JW. Common gastrointestinal symptoms in pediatric palliative care: nausea, vomiting, constipation, anorexia, cachexia. *Pediatr Clin North Am* 2007;54(5):673-89.
10. Beckwith C. Diarrhea in Palliative Care Patients. In: Lipmann A, Jackson II K, Tylor L, editors. Evidence based symptom control in palliative care. New York: Pharmaceutical Products Press; 2000 p. 91-108.
11. Evans WJ, Morley JE, Argilés J et al. Cachexia: A new definition. *Clin Nutr* 2008;27(6):793-99.

12. Goldman A, Hewitt M, Collins GS, et al. Symptoms in children/young people with progressive malignant disease: United Kingdom Children's Cancer Study Group/Paediatric Oncology Nurses Forum survey. *Pediatrics* 2006;117:e1179-e1186.
13. Inui A. Cancer anorexia-cachexia syndrome: Current issues in research and management. *CA: Cancer J Clin* 2002;52(2):72-91.
14. Kotler DP. Cachexia. *Ann Intern Med* 2000;133:622-34.
15. Azcona C, Castro L, Crespo E, Jiménez M, Sierrasesúmaga L. Megestrol acetate therapy for anorexia and weight loss in children with malignant solid tumours. *Alimentary Pharmacol Therapeutics* 2003;10(4):577-86.
16. Orme LM, Bond JD, Humphrey MS et al. Megestrol acetate in pediatric oncology patients may lead to severe, symptomatic adrenal suppression. *Cancer* 2003;98(2):397-405.
17. Marchand V, Baker SS, Stark TJ, baker RD. Randomized, double-blind, placebo-controlled pilot trial of megestrol acetate in malnourished children with cystic fibrosis. *J Pediatr Gastroenterol Nutr* 2000;31(3):264-69.
18. Eubanks V, Koppersmith N, Wooldridge N et al. Effects of megestrol acetate on weight gain, body composition, and pulmonary function in patients with cystic fibrosis. *J Pediatr* 2002;140(4):439-44.
19. Couluris M, Mayer JL, Freyer DR et al. The effect of cyproheptadine hydrochloride (periactin) and megestrol acetate (megace) on weight in children with cancer/treatment-related cachexia. *J Pediatr Hematol Oncol* 2008;30(11):791-7.

Chapter 7

Management of Nausea and Vomiting

Dr. Balaji

Consultant Oncology Comprehensive Cancer Care

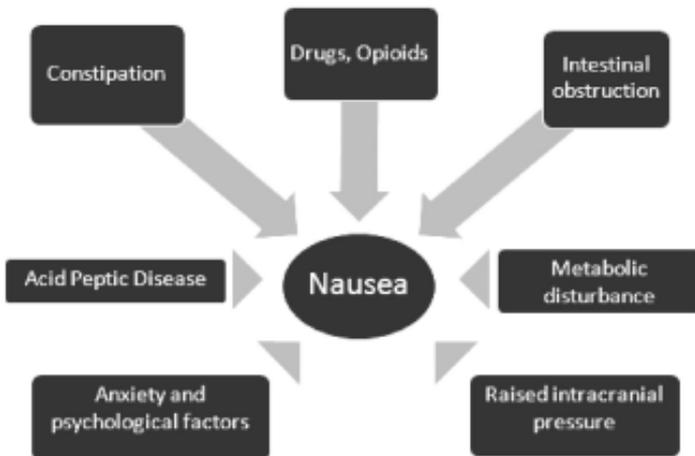
Introduction:

Chronic nausea is a common distressing symptom of with a frequency of 30-90% in the advanced cancer patient population. It occurs in almost 100% of the patients in the terminal phase of life. Chronic nausea is defined as nausea persistent for more than 4 weeks. However, in the palliative care population nausea persisting for more than a week can be considered chronic nausea. If not treated properly, nausea can make kids irritable and adversely affect their quality of life.

Etiology:

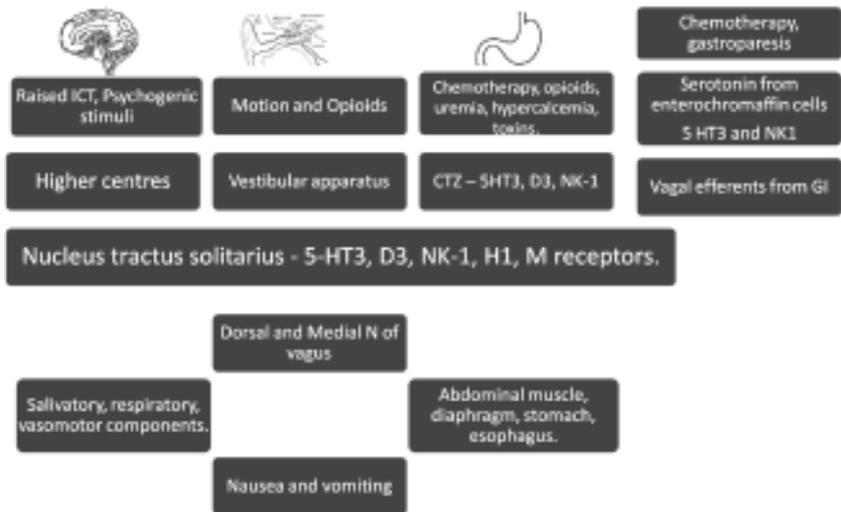
As in adults, nausea in children with cancer occurs due to interplay of many factors. Gastroparesis is a major factor causing nausea in the advanced cancer population without mechanical gastric outlet obstruction. Gastroparesis is characterised by delayed gastric emptying, early satiety, bloating, nausea, anorexia and occasionally vomiting.

Figure 1: Multifactorial Causes of Chronic Nausea.



Pathophysiology:

The vomiting centre is located in the medulla oblongata. It receives afferent signals from the GIT, pharynx, thorax and the serosa through the vagus, glossopharyngeal and splanchnic nerves and descending impulses from the cerebral cortex, thalamus, vestibular system and higher brain stem structures. The vomiting centre is under the direct influence of the chemoreceptor trigger zone (CTZ) near the area postrema in the floor of the fourth ventricle. The CTZ is deficient in blood brain barrier and is directly influenced by chemical mediators of nausea and vomiting in the blood like opioids and its metabolites. The CTZ is usually inhibited by the vomiting inhibitory centre. Nausea and vomiting is mediated through various chemo and mechano-receptors located centrally and peripherally. Modulation of these chemical mediators and their receptors forms a major part of the treatment of nausea and vomiting.



The salivatory and other autonomic responses associated with vomiting seem to be due to the proximity of the vomiting centre to the dorsam and medial vagal nuclei.

Assessment:

Like for all symptoms, nausea and vomiting have to be assessed carefully.

- A. Rate the severity on a numerical rating scale 0-10.
- B. Assess the frequency, onset and duration of nausea.
- C. Assess associated emesis, pattern of vomiting, content, volume of vomitus.
- D. Assess palliative and provocative factors.
 - Review patient history regarding site of tumour involvement, previous therapies including chemotherapy, radiation, current medication and constipation to determine possible causes of nausea.
 - Examine to rule out bowel obstruction, CNS involvement, autonomic failure, other mechanisms and patient hydration.
 - Perform relevant investigations - Liver function tests, Renal function tests, electrolytes, serum calcium and any other parameters that may be relevant.

Management:

The management of chronic nausea is different from chemotherapy induced nausea. A mechanism based approach to management is preferred over an empiric treatment.

General Measures

Patients with nausea may not tolerate odour which might not be as offensive to the health care worker or the patient care giver. It is advisable to avoid perfumes, incense sticks, room fresheners and the odour of food being cooked.

Small, frequent, cold feeds are better tolerated than the three square, hot meals. Naturally appetising food ingredients like mint leaves are sometimes helpful.

Natural lighting and ventilation whenever possible may be helpful.

Treatment of underlying cause:

- Constipation - improve bowel regimen, laxatives or enema as appropriate.
- Opioid - opioid rotation - try Fentanyl patch.
- Electrolyte imbalance, hydration need to be corrected appropriately.

- Antacids, proton pump inhibitors as appropriate for gastritis.
- Hydration, bisphosphonates for hypercalcemia.
- Antibiotics for infection.
- Radiation and corticosteroids for raised intracranial pressure.

For mechanical bowel obstruction with copious vomiting, consider venting gastrostomy or decompression through naso-gastric tube as appropriate.

- Malignant intestinal obstruction - manage accordingly.

Counselling, explanation, diversion and anxiolytics for patients with heightened anxiety or other psychogenic causes.

Pharmacological Treatment:

Management is aimed at moderating the mediators of nausea and vomiting - dopamine, serotonin, histamine and cholinergic pathways.

Dexamethasone is used for chronic nausea with good patient reported relief, even though there is no evidence for the claim. It is advisable to reduce steroids to the minimal effective dose as early as possible.

Metoclopramide has both peripheral and central actions on D2 receptors and at high doses ~ 120 mg/day it has anti 5 HT3 actions too. Metoclopramide is the drug of choice for Gastroparesis and opioid induced nausea. It is cheap and is the most common and widely used anti-emetic in the palliative care population.

If opioid induced nausea does not respond to metoclopramide, the more centrally acting haloperidol is more likely to help. Haloperidol is also the anti-emetic of choice for chemical/toxin induced nausea as in metabolic disturbances.

Haloperidol and metoclopramide may cause extrapyramidal side effects necessitating a change in anti-emetics.

Table 1:

Drug	Receptor(s)	Indication	Dose	Adverse effects
Metoclopramide	D2	Opioid induced, gastroparesis	10 mg q 4 hours po, sc, iv	Extrapyramidal effects
Prochlorperazine	D2	Opioid induced	10 mg q 6h po, iv	Sedation, hypertention
Cyclizine	H1	Vestibular cause, Intestinal Obstruction	25-50 mg q 8h po, sc, pr	Sedation
Promethazine	H1	Vestibular, motion sickness, obstruction	12.5 mg q 4h po, pr, iv	Sedation
Haloperidol	D2	Opioid, chemical, metabolic	1-2 mg bd po, iv, sc	Rare extrapyramidal effects
Ondansetron	5 HT3	Chemotherapy	4-8 mg q 8 h po, iv	Headache, constipation
Diphenhydramine	H1, Ach	Intestinal Obstruction, Vestibular	25 mg q 6 h po, iv, sc	Sedation, dry mouth, blurred vision
Hyoscine	Ach	Intestinal Obstruction, colic, secretions	0.2-0.4 mg q 4h sl, sc, td	Dry mouth, blurred vision, urine retention, agitation.

Summary:

- Chronic nausea is a common distressing symptom in the Palliative Care population.
- Underlying factors - physical, psychological, social and spiritual- have to be identified and corrected.
- Always rule out constipation.
- Anticipatory prescriptions and round the clock medications are helpful.
- It is good to avoid sedating medication as patients with chronic nausea will need medications for a long time.
- Metoclopramide is the most widely used drug. Haloperidol is very useful too.
- Dexamethasone should be tapered down to the minimum effective dose in case it has to be used as an adjuvant.
- 5 HT3 antagonists are not very useful in chronic nausea of palliative care patients.

References:

1. Pereira J, Bruera E, Chronic nausea. In: Bruera E, Higginson I (eds). *Cachexia - anorexia in Cancer Patients*, 2:23 - 37. New York: Oxford University Press, 1996.
2. Lichter I. Nausea and vomiting in patients with cancer. In Cherny N, Foley K (eds). *Hematology/Oncology Clinics in North America: Pain and Palliative Care*, vol 10, no 1, pp 207 - 220. Philadelphia: W.B. Saunders, 1996.
3. Mannix K. Palliation of nausea and vomiting. In Doyle D, Hanks GWC, MacDonald N (eds). *Oxford Textbook of Palliative Medicine*, edn 2, pp 489-499. New York: Oxford University Press, 1998.
4. Dalal S, Del Fabbro E, Bruera E, Symptom Control in Palliative Care - Part I: Oncology as a paradigm example. *Journal of Palliative Medicine*. 9(2): 391-408. 2006.

Chapter 8

Palliative Care for babies who are "not going to get better"

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Modern Neonatal Care has helped to save the lives of thousands of babies worldwide. However more infants still die in the neonatal period (birth to 27 days of life) than those in any other time in childhood. (1) Despite this, the provision of Palliative Care to the neonates who are "not going to get better" is very limited.

What is Neonatal Palliative Care?

The principles of Neonatal palliative care are similar to those of Pediatric Palliative Care in general.

Catlin and Carter (2) provide a conceptual definition of Neonatal Palliative Care as follows-

- It is "an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant's living and dying."
- It is a team-based approach also aimed at relieving the psychosocial, emotional, and spiritual suffering of the family.
- In cases where the delivery of an extremely premature or malformed baby is anticipated, the palliative care approach may well be applied prior to the birth.
- Along with the primary team of obstetricians and neonatologists, the palliative care team can assist the parents or family in making decisions about care (e.g. resuscitation) for the newborn, place of care and provide psychological support.
- Post-delivery, the palliative care team can provide comfort care to the baby, after death care and bereavement support to the family.

When should Neonatal or Perinatal Palliative Care be introduced?

Palliative Care for the baby and the family should ideally be offered from the time that it becomes evident that the baby has a condition-

congenital or otherwise, that may result in death in the perinatal period.

1. Preterm Deliveries: In cases of expected *preterm births*, the important issues to be considered are- the prognosis for survival, long term outcomes, burdens of intensive care versus benefits, effective and empathic communication with the family and decision making about the intent of care of the newborn after birth.

A prospective study from Houston, Texas showed that out of 4192 study infants (94%) for whom outcomes were determined at 18 to 22 months, 49% died, 61% died or had profound impairment, and 73% died or had impairment. In multivariable analyses of infants who received intensive care, exposure to antenatal corticosteroids, female sex, singleton birth, and higher birth weight (per each 100-g increment) were each associated with reductions in the risk of death and neurodevelopmental impairment. (3) Despite this, decisions about provision of resuscitation and intensive care are controversial (3) and the practices are variable across various centres. (3)

The American Academy of Pediatrics (AAP) also provides guidelines for withholding and discontinuing resuscitation, while acknowledging that the approach must be individualized taking into consideration the parents' wishes and assessment of morbidity and mortality risks. (See fig. 1)

Fig. 1- AAP Guidelines for withholding or discontinuing Neonatal resuscitation

Condition	Outcome	Resuscitation indicated
Extreme prematurity (<23 weeks or birth weight <400 gm), anencephaly, major chromosomal anomalies e.g. trisomy 13	Early death almost certain or rare survivors with unacceptable morbidity	Not indicated
gestational age ≥25 weeks and those with most congenital malformations	High rate of survival and acceptable morbidity	Indicated
uncertain prognosis in which survival is borderline	the morbidity rate is relatively high, and the anticipated burden to the child is high	parental desires concerning initiation of resuscitation should be supported

The above are general guidelines and decisions must be made in an individualized manner taking into account accuracy of the dates, growth retardation and accuracy of ultrasound estimates of fetal weight, while making decisions about resuscitation. (4)

2. *Congenital Anomalies:*

In 1999, congenital anomalies were responsible for approximately 12% of all childhood deaths in the USA (5). Nearly 6% of babies born with a congenital anomaly die in the first week of life. The shortest median survival time for those who died was in cases with urogenital tract and kidney anomalies, musculoskeletal and connective tissue anomalies and respiratory system anomalies. (5)

Palliative care can be offered in cases where congenital anomalies have been diagnosed antenatally. The Palliative Care team must be involved in care giving along with the Obstetric and the Neonatal team. The Palliative Care team can provide emotional support the family, assist in counseling and complex care issues and provide comfort care to the baby.

Counseling parents in the antenatal period must take the prognosis for survival into account. In situations where it is difficult to ascertain the survival outcome, it is advisable to acknowledge the uncertainty while remaining focused on the quality of the baby's life.

Medical termination of the pregnancy may be offered to couples where appropriate. In cases where medical termination of pregnancy is not possible or when the parents refuse, palliative care is an effective alternative. In a study from the US where a perinatal hospice was available, it was found that the structured program providing ongoing, comprehensive, multidisciplinary, supportive perinatal care offered a tangible and safe alternative to early elective pregnancy termination for patients carrying a fetus with a lethal congenital condition. (6)

Palliative Care Delivery:

1. *The Team:*

Palliative care is best delivered by a multi-disciplinary team. The team comprises physicians, nurses, psychologists, social workers, volunteers and spiritual counselors. The entire team works seamlessly with the aims of relieving the baby's physical suffering, providing

psychological support to the family and assisting with practical issues related to caring for the baby.

Home care ideally must be offered when families choose to take the baby home. Plans must be made beforehand for any foreseeable emergencies that may arise and the family must have access to a local general practitioner, hospital or a hospice if it is available.

2. *Place of Care:*

Babies who are moribund or are born with severe congenital anomalies are often admitted to the Neonatal Intensive Care units (NICUs). However the NICU is often "hi tech" alien environment for the parents, where they may have limited access to the baby.

In cases where palliative care is the option, it may be preferable to move the baby to a ward where the family members can spend precious time with the newborn.

With appropriate preparation and support, many families would prefer to care for the baby at home. The palliative care team can help the families to achieve the preferred place of care. A plan of anticipated actions in the case of an emergency, transfer to another care facility like a hospital or hospice and support for caring for the baby at home are important issues that will ensure optimal care for the baby and the family.

3. *Comfort care for the baby:*

Babies with life limiting conditions may have problems related to feeding, sleeping and pain. Simple comfort measures, such as positioning the baby with suitable boundaries, gentle rocking and swaddling, can be very effective in relieving discomfort.

The following principles for the management of dying infants are adapted from the Basic symptom control in paediatric palliative care-The Rainbows Children's Hospice guidelines. (7)

Feeding- The aim of feeding the baby is to reduce distress from hunger and to ensure some hydration. Oral feeding must be encouraged as far as possible.

4. *Pain:*

All babies who need palliative care must be monitored continually for pain. However there are no "gold standards" currently for the

assessment of prolonged pain in the neonate.(8) This is because- these methods were developed from studies of neonates who underwent an acute painful procedure (8) and behavioral and physiologic responses (seen as a result of pain) require the subjective evaluation of a clinical observer.(9) The mismatch between measured parameters for acute versus prolonged pain may be explained by the fact that- because of their limited energy reserves, preterm infants cannot maintain the psychophysiological activation if the pain becomes persistent. (10)

Some signs that indicate pain are- Persistent crying, Furrowing or bulging of the brow, Furrowing of the nasolabial folds and tight squeezing of the eyes. Babies in pain also respond poorly to handling.

Management of Pain:

In the setting of Perinatal Palliative care, painful procedures like heel punctures and blood draws must be kept to a minimum.

The recommended drugs for the management of pain are paracetamol or ibuprofen for mild pain and morphine for more severe pain. Drugs can be given orally or rectally.

Morphine- For acute pain, morphine can be given intravenously - at starting doses of 10-20 micrograms/kg/hour and is then titrated to response. Orally morphine must be given as a liquid formulation with appropriate dose for breakthrough pain. The starting dose is double the IV dose.

5. *Other Common Symptoms:*

For babies who are dying other common symptoms are seizures, gastro-esophageal reflux, excessive secretions and irritability. These symptoms must be managed as for any other neonate. Sedatives may be required to help a baby to sleep; chloral hydrate orally or rectally is the preferred drug.

6. *Emotional support for parents and family:*

Parents of babies who need palliative care need emotional support from the care giving team. At the same time they also need to fulfill the role of being parents of the baby and having some control over the situation.

According to Leon (11), bereaved parents never forget the understanding, respect, and genuine warmth they received from

caregivers, which can become as lasting and important as any other memories of their lost pregnancy or their baby's brief life. (11)

The steps that care givers must follow while caring for a baby in Palliative Care are (12)

- Providing information and offering choices about treatments, place of care
- Discussing both sides of all options e.g. a complex surgical intervention
- Giving families time to make difficult decisions or to be with their baby before or after death
- Creating a space for privacy and intimacy, beyond just pulling a curtain or putting up a screen
- Being sensitive to room location or activities going on near baby's bedside
- Being present when needed and also being absent when needed
- Striving for seamless continuity between areas of care/ changes of shift of caregivers
- Calling the baby by name, humanizing, not objectifying the baby
- Using gentle touch and tone of voice
- Offering to contact supports they desire (chaplain, clergy, social worker, friend)

Thus Palliative care teams can make a difference to the care received by families of neonates who are not getting better.

The mother of a newly born baby in palliative care needs post-partum care while the physiologic changes that she has undergone over the period of the pregnancy are a constant reminder of the actual or the impending loss of the baby. The mother should receive treatment for any physical pain or discomfort, lactation suppression if required in addition to receiving psychological support.

7. *Spiritual Care:*

While the death of a child can precipitate intense spiritual distress among parents, (13, 14) spirituality actually helps parents to cope with their loss. Robinson et. al. (15) report that parents of children who had died in the Intensive Care setting reported that their spiritual beliefs helped them in making end of life decisions, making meaning

of the loss and sustaining them emotionally. Therefore it is recommended that clinicians and nurses must assess the broad spiritual concerns of the family and refer families to skilled spiritual advisors if necessary.

In India, access to formal spiritual care is often unavailable with families seeking spiritual support from their own spiritual gurus, religion and symbolic religious practices. Professionals caring for families of dying neonates must be willing to elicit spiritual concerns and offer empathetic support to parents and other family members. In the absence of designated spiritual support staff, families may be encouraged to access any other informal spiritual support that may be available to them.

8. *Bereavement Care:*

Bereavement care is care that is offered to the parents, siblings and extended family after the death of the baby. Perinatal mortality can have a major emotional impact on members of the affected family, particularly the mother, with significant repercussions on the health and well-being of the family. (16) However bereaved families benefit from help from professionals including those who have been involved in the care for their newborn.

The aims of providing bereavement care are- to help the family to mourn the loss, mitigating feelings of guilt, helping the family to remember the baby, identifying abnormal grief and offering appropriate support. A designated member of the palliative care team such as a social worker or a nurse should take charge of the bereavement care. Talking to the family on the telephone or a home visit should be carried out wherever possible after taking the family's permission. The emotional needs of siblings, extended family members such as grandparents must be addressed. Referral for a genetic consultation may be necessary in those cases where the death of the baby resulted from genetic abnormalities.

The duration of bereavement support may vary from one family to another and families must ideally be supported as long as they need it.

The Need for Perinatal Palliative Care in India:

Advances in Neonatology have significantly reduced deaths in this age group. However the Neonatal mortality rate of India reported in 2009 is 34 per 1000 live births as per the UNICEF, much higher than

in the developed world.(17) The principal causes of neonatal mortality in India are sepsis, perinatal asphyxia, and prematurity.(18,19)

While it is hoped that level III NICUs will help in improving the survival of very sick newborns, death in the NICU is an inevitable reality. For babies who are not going to "get better," the health care team still has a duty to alleviate the physical suffering of the baby and to support the family through this time of psychological and existential suffering. (20)

Future Directions:

Palliative care is an integral part of the care of neonates who are not going to get better and of fetuses with potentially fatal conditions, and their families. Educating clinicians and any other significant professional care givers in basic palliative care principles and practice is crucial towards improving the care of babies who are dying. This can be achieved through curricular changes and advocacy with professional bodies and policy makers.

References:

1. Moro T, Kavanaugh K, Okuno-Jones S, Vankleef JA. Neonatal end-of-life care: a review of the research literature. *J Perinat Neonatal Nurs.* 2006;20(3):262-73.
2. Catlin A, Carter B. State of the Art. Creation of a Neonatal End-of-Life Palliative Care Protocol. *Journal of Perinatology* 2002; 22:184 - 195.
3. Tyson J, Parikh N, Langer J, Green C, Higgins R for the National Institute of Child Health and Human Development Neonatal Research Network. Intensive Care for Extreme Prematurity -Moving Beyond Gestational Age. 2008. *N Engl J Med* 358; 16: 1672-81.
4. Kattwinkel J, Perlman J, Aziz K, Fairchild K, Gallagher M, Hazinski M. et. al. [Internet] Neonatal Resuscitation: 2010 American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care. [cited 2012 Mar 17] Available from: <http://pediatrics.aappublications.org/content/126/5/e1400.full>
5. Field MJ, Behrman RE, eds., for the Institute of Medicine Committee on Palliative and End-of-Life Care for Children and Their Families. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington, DC: National Academies Press; 2003.

6. Calhoun BC, Napolitano P, Terry M. et. al. Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med.* 2003; 48(5):343-8.
7. Jassal S.[Internet] Basic symptom control in paediatric palliative care. The rainbows children's hospice guidelines-7th edition: 2008. [cited 2012 Apr 10] [http://cnpcc.ca/documents/2008 Rainbow Hospice Symptom Control Manual.pdf](http://cnpcc.ca/documents/2008%20Rainbow%20Hospice%20Symptom%20Control%20Manual.pdf)
8. Anand KJS. Pain Assessment in Preterm Neonates. *Pediatrics.* 2007; 119:605-607.
9. Craig KD, Lilley CM, Gilbert CA. Social barriers to optimal pain management in infants and children. *Clin J Pain.* 1996; 12: 232-242.
10. Anand KJS. Long-term effects of pain in neonates and infants. In: Jensen TS, Turner JA, Wiesenfeld-Hallin Z, eds. *Proceedings of the 8th World Congress on Pain.* Seattle, WA: IASP Press; 1997: 881-892.
11. Leon IG. Perinatal loss: A critique of current hospital practices. *Clin Pediatric* 1992; 31: 366-74.
12. Stokowski LA. [Internet] Palliative care and neonatal loss. Medscape education <http://www.medscape.org/viewarticle/494959>
13. Wheeler I. Parental bereavement: the crisis of meaning. *Death Stud.* 2001;25:51-66.
14. Himelstein BP, Hilden JM, Boldt AM, Weissman D. Pediatric palliative care. *N Engl J Med.* 2004;350:1752-1762.
15. Robinson MR, Thiel MM, Backus MM, Meyer EC. Matters of Spirituality at the End of Life in the Pediatric Intensive Care Unit. *Pediatrics* 2006;118:e719- e729.
16. Gausia K, Moran AC, Ali M, Ryder D, Fisher C, Koblinsky M. Psychological and social consequences among mothers suffering from perinatal loss: perspective from a low income country. *BMC Public Health.* 2011; 11: 451.
17. UNICEF Statistics. [Internet] [Cited on 2012 Apr 25]. Available from: http://www.unicef.org/infobycountry/india_statistics.html .
18. Faculty Investigators of the National Neonatal Perinatal Database: Neonatal Morbidity and Mortality: Report of National Neonatal Perinatal Data Base. 2000.
19. Baqui AH, Darmstadt GL, Williams EK, Kumar V, Kiran TU, Panwar D, et al. Rates, timing and causes of neonatal deaths in rural India: Implications for neonatal health programmes. *Bull World Health Organ*. 2006;84:706-13.
20. Dighe M, Muckaden MA, Manerkar S, and Duraisamy B. Is there a Role of Palliative Care in the Neonatal Intensive Care Unit in India? *Indian J Palliative Care.* 2011; 17(2): 104-107.

Chapter 9

Palliative Care and Pediatric HIV

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Introduction

By the end of 2008, an estimated 33.4 million people worldwide were living with human immunodeficiency virus (HIV) infection, of which 2.1 million were children.¹ Based on National AIDS Control Organisation (NACO) statistics 2008, India has an estimated 23.9 lakh people infected with HIV, of which, 3.5 percent are children.² Children and adolescents are an ever-growing part of the human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) pandemic. HIV takes an enormous physical and psychological toll in infected children as well as their families who care for them. Over the past decade, advances as well as availability of antiretroviral therapy nationwide through government programmes have considerably improved the outcome for HIV-infected children. Most children with HIV can now live longer benefiting from the treatment that, while not curative, can delay the onset of AIDS for an indefinite period of time. Thus, HIV infection has transformed from a rapidly fatal illness to a manageable, chronic illness.

We also need to understand that children have different metabolism and manifestations of HIV disease as compared to adults. Most often a child with HIV infection is usually not the only family member with the disease. The parents and siblings are also infected and frequently, parents with AIDS do not survive to care for their HIV-infected child. At the same time, the high prevalence of pain and symptoms of the disease, associated co-morbidities, psychological distress, discrimination, and toxicity of antiretroviral therapy

highlights the need to address quality of life in the management of Pediatric HIV. Hence, integration of palliative care into the existing routine HIV care services becomes necessary to improve quality of life, promote better health outcomes, increase compliance, reduce stigma and provide cost-effective services to HIV-infected children and their families.³ This chapter will discuss how children infected/affected by various aspects of HIV/ AIDS can benefit from palliative care.

Need and Importance of Palliative Care in Pediatric HIV

In the past two decades, with the increasing burden of HIV and other chronic diseases, there has been a revolution in the scope and availability of palliative care services. Although palliative care is an essential form of care, it is frequently unavailable to those who need it. Every year, millions endure pain and psychosocial suffering and several more struggle to care for sick loved ones or grieve their loss. The availability of pediatric palliative care programs is even more limited than for adults. This could be due to lack of national policies and guidance, barriers to accessing essential palliative care medicines such as oral morphine, and limited availability of pre- and in-service training in palliative care. The quality of life of HIV-infected children can be enhanced through palliative care, which provides relief from all forms of suffering, including side effects, opportunistic infections, and emotional and spiritual stress. Providing comprehensive palliative care for a child must also include care for the mother or primary caretaker as well as for other members of the family, as the child is dependent on the support of the family for survival. The needs of the HIV-infected children and their families will vary over time, but access to palliative care services enables both the patient and the family to better anticipate and address these needs.

Types of Palliative care interventions in Pediatric HIV

Palliative care for children begins when an infant is exposed to HIV (in utero, in labor, and/or through breastfeeding). It continues through diagnosis, care, and treatment, and extends to end-of-life care. Palliative care services should address the physical, emotional, social, and spiritual needs of the HIV-infected children and their families. The care and support must be in line with the developmental stage of children which determines their ability to understand and

cope with the illness. Palliative care services in HIV-infected children can be provided under the following four categories:⁴

1. *Clinical care*

HIV-infected children may experience a wide range of symptoms, involving virtually every major organ system. Clinical care provided to HIV infected children varies based on the presence or absence of clinical symptoms:

- a) **Asymptomatic patients:** The interventions include: routine clinical monitoring and assessment, determining the optimal time to initiate ART, prevention of opportunistic infections, nutritional assessment, and the assessment and management of HIV-related psychosocial problems.
- b) **Symptomatic patients:** In addition to above, clinical care in symptomatic children should also include: treatment of symptomatic illness; pain control (with opioids and non-opioids), basic nursing care, preparation and support prior to and throughout ART, and nutrition rehabilitation and supplementation for clinically malnourished infected children.
- c) **End-of-Life and bereavement care:** Bereavement care is required as the patient and family passes through the various stages of disease progression. It includes intensive management of symptoms and pain [using non-opioids and/or opioids as per the World Health Organization (WHO) analgesic ladder].⁵ Bereavement support should be individualised and culturally sensitive. Giving parents information about HIV helps them to understand and face the reality of their child's situation. Appropriate succession planning and referrals for orphans and vulnerable children should also be considered as and when required.

2) *Psychological care:*

Parents of HIV-infected children often feel guilty as the child is infected through them, leading to psychological distress. In such situations it is vital to provide them counselling and support. This includes: enhanced family support and inclusion into People living with HIV (PLHA) support groups, disclosure of HIV status, bereavement care, development and implementation of culture and age-specific initiatives for psychological care, and treatment of HIV-

related psychiatric illnesses such as depression and related anxieties. It has been found that openness with children relieves their fears, as they often make irrational links between their actions and illness. Answering their questions, giving age-appropriate information, and offering help in a nonjudgmental manner will allow them to ask questions and express feelings that they may find difficult to verbalize. For children of all ages, nonverbal means of expressing feelings through play or the creation of art can be very helpful.

3) *Spiritual care*

Spiritual beliefs provide individuals with a sense of meaning and importance in their lives. Life-limiting illness often brings up painful questions associated with facing death, losing faith, or reconnecting with one's belief and/or support system. When children and their families face an illness that cannot be cured, they search for answers to difficult questions, such as, "Why me?" "Where is God?" and "What happens when I die?" It is important to talk about spiritual issues with everyone affected by HIV, including young children. As children may not always speak about things the way adults do, one may miss the chance to discuss spiritual concerns with them.

4) *Social care*

Many HIV-infected children and their families struggle with inadequate financial resources, especially when the breadwinner has been ill for some time and then dies. They may be left without enough food to eat, face stigma, discrimination and isolation. The objective of palliative care is to assist families in preparing future plans for survival needs and in preparing wills and other legal arrangements, appointing a guardian for children, and determining end-of-life care arrangements. It is also important for palliative care programs to establish linkages with other social service providers who will assist in securing government grants and generating sources of income. Also efforts to increase community awareness about HIV infection should be done to reduce the associated stigma and discrimination. Schools are an important institution in most communities and can play a vital role in supporting palliative care interventions. School and friends are an important social support system for children. Teachers and students in school should be taught how to support children whose parents are ill, and/or children who are HIV-infected.

Who can provide palliative care?

Several categories of health care providers are necessary for an effective palliative care program.⁶ Each has a unique role and training needs.

a) Medical Providers

The role of medical providers (physicians, clinical officers, and cadres of nurses) includes assessment, prevention, diagnosis, treatment, and management of pain and suffering experienced by HIV-infected children and their families. Medical providers should be trained in the use of standard protocols for assessing pain, symptoms, and opportunistic infections. They must be able either to diagnose and treat the patient, or to refer the individual for appropriate care. Access to continued training for all medical providers is essential.

b) Traditional Healers

Traditional healers play an important role in delivering health care to many HIV-infected children and their families. They are often the link between the community and the health care system. When appropriate, they should be included in the palliative care team. It is important to recognize the cultural, psychological, and spiritual role of the traditional healer when patients and their families are searching for meaning in illness and death. To support the participation of traditional healers in the palliative care team, training should be made available to them.

c) Community Health Workers

The training of community health care workers such as volunteers, medical assistants, and counsellors can improve the delivery of palliative care in the community setting. They can provide basic nursing care, support for treatment adherence and HIV prevention and referrals. They can also help in pain and symptom assessment and management, psychosocial and nutrition counselling, and determination of need for, and provision of, social support.

d) People Living with HIV/AIDS

The success of palliative care programs depend on the involvement and leadership of people living with HIV/AIDS (PLWHA). Parents of HIV-infected children as well as peer groups can counsel and educate HIV-infected children and their families, particularly in

regards to their experience, treatment literacy, symptom and pain management.

Role of Interdisciplinary Teams

Given the many ways in which HIV disease affects individuals, communities, and families, it is important to establish interdisciplinary teams for an effective palliative care. This collaboration allows for a more integrated and holistic approach to complex and interrelated problems and needs of children infected or affected by HIV/ AIDS. These teams should consist of professional health care workers such as palliative care nurses, community volunteers, clergy or religious leaders, family members, mental health counsellors, traditional healers when appropriate, and other health care and support service providers and community workers.

Delivery sites for Palliative Care

Palliative care services should be available to HIV-infected children at all levels of the healthcare system. This includes tertiary, secondary, primary, and community levels of care. Palliative care will be more effective when it is provided in combination with existing HIV services. This integration will help in assessing and treating pain and other symptoms, and psychosocial problems as part of routine HIV care. Palliative care interventions are not specific to any one setting or location. These can be delivered as home-based, community-based, facility-based or hospice care.⁶

Care of orphans and vulnerable children

Children living with and affected by HIV infection, like all children, require special attention because of needs unique to their physical and emotional development. They require a safe and nurturing environment for their well-being and survival. They require assistance when they are living with an ill family member or when they have recently lost a loved one, or when they have been orphaned. Palliative care services through linkages with other programs and services in the locality can help orphans and vulnerable children enroll and stay in school, provide legal support, assist with providing alternative care if needed, offer child protection and abuse aftercare. They can also play an important role by helping parents plan for the future of their children and prepare succession plans. When plans have not been made for the care of orphaned children, they may suffer

serious consequences such as inadequate food, shelter, and education, with accompanying emotional and social distress.

Role of Palliative Care in HIV Prevention

Palliative care programs also have a role in preventing transmission of HIV infection in affected families. Strong relationships between caregivers (family members and/or health workers), people living with HIV, and their families are an important opportunity for sharing prevention messages and providing counselling. Family caregivers should be offered guidance on how to reduce the risk of infection in the home (universal precautions). For people living with HIV and their spouses or partners (regardless of their HIV status), education on reducing the risk of infection or re-infection should be offered, as well as information on the reduction of mother-to-child transmission through PMTCT programs and family planning. Prevention programs targeted specifically to their age group, if available, should be encouraged.

Gaps in the area of practice

Though palliative care has been a part of medical care for several decades, it has not been integrated into routine standard care in most health settings. It needs to be available to all children with chronic and life limiting illnesses not only at tertiary level, but also at primary and secondary level. Presently, it is not included in the undergraduate or postgraduate curricula in most universities in our country and therefore is not a part of training. Achieving this is extremely crucial for long term sustenance of the palliative care programs in the future.

Policy development

As far as Pediatric HIV is concerned, NACO (National AID Control Organization) already has incorporated palliative care for children with HIV infection into the national guidelines. This has been disseminated to all the paediatricians in the country. However, implementation of the same needs to be emphasized through CMEs, workshops and seminars. Also, this needs to percolate to the primary health care through formal trainings. As an organization that has achieved significant positive impact on the HIV epidemic in the country, NACO definitely would show the way to integrate palliative care in care, support and treatment protocols for children with HIV infection.

References

1. UNAIDS AIDS epidemic update.
http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf] 2009. Last accessed on the 14/07/2012.
2. NACO Annual Report 2011.indb - National AIDS Control Organisation. <http://www.nacoonline.org/upload/REPORTS/NACO%20Annual%20Report%202010-11.pdf>. Last accessed on the 14/07/2012.
3. Harding R, Karus D, Easterbrook P, Raveis VH, Higginson IJ, Marconi K. Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence. *Sex Transm Infect* 2005;81:5-14.
4. HIV/AIDS Palliative care guidance. U.S. Department of State. Available from: <http://www.state.gov/documents/organization/64416.pdf>. Last accessed on the 14/07/2012.
5. World Health Organisations pain ladder. <http://www.who.int/cancer/palliative/painladder/en/>. Last accessed on the 14/07/2012.
6. Green K, Horne C. Principles of adult and pediatric palliative care. <http://ftguonline.org/ftgu-232/index.php/ftgu/article/view/2040/4076>. Last accessed on the 14/07/2012.

Chapter 10

Nursing Issues in Pediatric Palliative Care

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Pediatric Palliative Care may be needed for a wide range of diseases. Which differ from adult disease and many of which are rare and familial. Palliative Care may be needed from infancy and for many years for some children, also the transition between aggressive treatments to cure or prolong good quality life and palliative care

Aspects of Care in Children & Care at Home:

An intrinsic aspect of childhood is children's continuing physical, emotional, and cognitive development. This influences all aspects of their care.

Most children with life limiting disease are cared at home parents must be included in the care team-provided with information, able to negotiate treatment plans, taught appropriate skills, and assured that advice and support is accessible 24 hours a day

Common Nursing Issues:

1. Bleeding:

Bleeding can be a major problem in number of malignancies. The sight of blood is very distressing to patient, parent and care giver. If bleeding is likely, or if it has already started, gentle warning of the possibility that it could happen, or get worse, may help to reduce the distress and shock the parent's experience.

- Bleeding gums can be helped with tranexamic acid mouthwashes or absorbable haemostatic agents.
- For small bleeds can often be dealt with by using oral tranexamic acid or topical Adrenaline 1: 1000 on a gauze and applied directly on the wound
- To minimize the shock of seeing their child's blood, the use of dark colors towel may be tried

- Liver dysfunction with coagulation abnormalities can be helped with vitamin K both orally or by injection

2. *Bladder Care:*

A number of children with neurodegenerative disorders may have problems with emptying their bladder

- In children gentle bladder massage, warm baths or application of hot water bag or catheterization can easily alleviate the obstruction
- The loss of bladder function in a child or a incontinent can often be a source of great distress to parents, or child may feel indignity or another 'loss
- The use of pads or use of disposable pants is useful.
- Catheterization of children is similar to adults use smaller no like below 10.

3. *Mouth Care:*

This is an overlooked aspect of palliative care but correct management can easily enhance the quality of life for dying children

- As in all cases take a good history and look inside the mouth

Causes:

Oral candidacies ,poor oral hygiene, dry mouth due to Mouth breathing, on humidified oxygen ,drugs i.e. morphine, hyoscine or amitriptyline, radiotherapy, Mouth ulcer Bleeding gums hematological cancers, liver disease clotting disorders

- Oral hygiene can be maintained by careful and gentle cleaning of teeth and gums.
- Gauze soaked in mouthwash can be applied to the gums and teeth to keep the mouth moist and Vaseline or cream applied to the lips to prevent dryness and cracking.

This attention to mouth care will go a long way to maintaining hygiene, preventing some of the complication and aiding the child's comfort

- Oral thrush can be cleared using various anti-fungal agents. Nystain drops are helpful, fluconazole once in a day oral anti- candidal agent is more effective

- K.Y. JELLY is very effective for dry mouths and is well tolerated.
- Bleeding gums can be helped with tranexamic acid mouthwashes, bleeding from blood malignancies may require platelet transfusion even palliative setting

4. *Seizures:*

The child who has seizures falls into two categories:

1. The child with a neurodegenerative disorder who has had multiple seizures and is on a multitude of anti-epileptic. The parents' are normally relaxed and knowledgeable about the seizures and who to manage it
2. The second case is linked to malignant and here seizures are a new and frightening complication of illness for parents
 - A calm and gentle warning to the parents of what can happen
 - A positive explanation of what can be done to reduce the child's distress may help to reduce the parent's shock.

Causes:

Look for reversible causes of increase seizures e.g. infection, biochemical imbalance, hypoglycaemia, raised intra cranial pressure and inappropriate epilepsy management.

- The first line of treatment for persistent seizures is diazepam

5. *Skin:*

Management of skin problem is often challenging children's are often wasted and immobile because the metabolism of the body enters a catabolic phase during sever illness the skin becomes very vulnerable to breakdown and subsequent poor healing

- Good nursing care is required to predict where potential problems may occur.
- Special mattress, aids and appliances can be organized.
- Turning of the child needs to be frequent and regular.
- Teach the parents how to move the child
- If pressure sore occurs, protect the skin with dry dressing, once it breaks down then Duo-Derm can be used, care must

be taken when removing these dressings so as not further damage the skin.

- Infected skin ulceration will require skin crème, sofratull dressing
- Oral antibiotics may be necessary if cellulites or discharging pus is present.
- Fungating tumors when infected can very smelly
- Metronidazole orally or topically is very effective .honey and sugar can be used topically to reduce the smell of ulcers and they are also bacteriostatic.

Chapter 11

Nutrition in Paediatric Palliative Care

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Introduction:

There is growing empirical evidence that the health care system is failing children and families, when they are confronted by a life-threatening illness. But an interdisciplinary team that provides sensitive and skilled care to meet the physical, psychosocial and spiritual needs of both the patient and the family delivers it. The largest team could involve several physician and nurses, therapist, psychologist, social worker, dietician and several volunteers.

Too many children undergo painful procedures and suffer from the symptoms of advancing disease without adequate relief, despite the fact that modern medicine has the means to relieve their pain and improve most symptoms. Families of gravely ill children can feel abandoned and overwhelmed, often suffering emotional and sometimes financial consequences for years to come.

Maintenance and correction of nutrition is a major problem in terminally ill patients particularly when they are suffering from advanced malignant disease. Food is not only important for nourishment, but also as a source of pleasure and comfort. Parents and care givers of children who are unwell are often worried about making sure their child's nutritional needs are met.

Food is important for improving quality of life, relieving symptoms and to provide pleasure and comfort. Hence the need for improved multinational intake is necessary for mental and physical health; proper dietary guidance is an integral part of a patients care.

Thus to help with proper nutrition for palliative patient one needs to pay attention to

- Confirm and assess the degree of nutritional deficiency.
- Decide on the type and quality of nutrients.

- Decide and arrange the route and method of administration.
- Assess effects and side effects for further continuation.
- Consider social and psychological aspects of the patients and relatives.

1. *Minimizing Weight Loss:*

- Loss of appetite resulting in weight loss is common in palliative care. It is very difficult for family and caregivers to watch their child lose weight. There are many reasons for weight loss including nausea and vomiting, anxiety and decreased food intake. However, the disease process itself plays the biggest role.
- It is important to understand that your child's reluctance to eat is not a reflection of the foods you are offering. Never blame the child for their reluctance to eat but instead try to focus on making eating an enjoyable experience.
- Let your child eat the foods that they feel like. It is better to eat and enjoy rather than struggle to maintain a balanced diet. Create a positive eating environment - share meals and eat together. If your child is not well enough to eat at the table, consider sharing meals in a room where your child can lay down.
- Try not to comment if food goes uneaten.
- Try to obtain past favourite foods.
- Small frequent meals may be easier to eat. Offer food every couple of hours if your child has no appetite. Small meals are less overwhelming.
- Ignore set meal times - encourage your child to eat when they feel hungry.
- Food preferences will change often - offer a variety of foods.
- Soft foods that are easy to chew and swallow may be easier to eat.
- Chewing on gum, sucking on icy chips, sugar free lollies or ice blocks may help to stimulate saliva flow if your child experiences a dry mouth.

2. *Fortifying Foods:*

Your child may find it difficult to eat large volumes of food. Eating small amounts of energy dense foods may help your child maintain their weight. The following ideas help to increase the energy content of foods your child enjoys. It is important not to force a food if your child does not like it.

- Creamy milk drinks are easy to consume. Try adding ice cream, frozen yoghurt, milk powder (1 tablespoon / glass) or cream to fortify.
- Fruits can be blended with milk and ice cream to make smoothies.
- Add butter and ghee/oil to plain cooked vegetables. Salts and sauces (small sachets) can be used to improve flavour.
- Add fresh cream to soups and scrambled eggs.

Nutritional supplements can be a useful source of energy and nutrients.

Eg:- Pediasure can be found in the chemist. Obtaining supplements with a prescription can help reduce the cost. Altering the serving temperature may help. Some children like these drinks served very cold, others prefer room temperature. Supplements can be added to smoothies and milkshakes (on advice by a dietitian).

3. *Nasogastric Feeds (Tube Feeding)*

There may come a time when your child is not able to eat or drink enough. Another way to provide food and fluid is via a nasogastric tube. The tube is inserted via the nose, passes down the back of the throat and into the stomach. Special formulas are given through the tube to provide nutrition. The formula is delivered by a portable pump. Tube feeding may help your child feel more comfortable, and increase their energy and strength to play or join in family activities. It may relieve the pressure of trying to get your child to eat and drink. This may help improve their quality of life. Medications can also be given via the tube.

Some families decide that tube feeding is not the right option for them. Sometimes feeds may worsen symptoms such as nausea or stomach pain, but this can be managed in most cases. You may feel that tube feeding will impact on your child's

quality of life. The decision to start tube feeding will be different for each child and family.

A special tube called a gastrostomy can be placed into a child's stomach if they require tube feeding for a long period of time. If tube feeding starts, the dietitian can help plan a feeding regime that suits the child's needs and requirements.

4. *Nausea and/ or Vomiting:*

- Nausea, with or without vomiting, is common during palliative care. The cause can be hard to identify. It may be related to your child's medications, anxiety or progression of the disease. Always notify your health care team as they will be able to decide on the most appropriate treatment.
- Small frequent meals are usually better tolerated.
- Smells of cooking foods can make nausea worse. Try to keep your child away from the kitchen, serve foods cold or cook in the microwave to reduce smells.
- Try dry salty foods such as vegetables on toast, crackers, plain boiled vegetables (salt can be added to taste) and plain potato chips.
- Fluid intake is important; try water, flat lemonade, lime juice, ginger beer, ice blocks or sports drinks.
- Fresh air can help; try a gentle walk or push in the pram outside or open the windows and doors in the house.

5. *Constipation:*

There are many reasons why your child may become constipated. Pain control medications are a common cause. Reduced food and fluid intake and decreased activity can also contribute. While diet alone may not be sufficient to treat constipation, there are some strategies you can try:

- Offer plenty of fluids.
- Offer small frequent meals during the day.
- Try to include some high fibre foods. Add fruits to smoothies or serve with desserts (e.g. banana and custard, strawberries and cream).
- Try soft mashed vegetables, or vegetables grated in cooked food preparations.

- Baked beans are high in fibre and easy to consume.
- Legumes and lentils can be added to casseroles and meat dishes.

Alternative Diets:

There are an overwhelming number of diets on the market, some that make extraordinary claims. Unfortunately there is no diet that has been proven to cure cancer. Many of the supplements and diets available on the market are very expensive.

You may wish to try alternative diets or supplements with your child. Some supplements can provide important nutrients and energy. Unfortunately most alternative diets are very restrictive and hard to stick to, can taste unpleasant and may have uncomfortable side effects. Sticking to a restrictive diet may be stressful for both you and your child.

Easy meal and snack ideas!

- Yoghurts
- Ice creams
- Chocolate dairy desserts
- Milk shakes (add ice-cream or cream, topping, Milo, Nesquick)
- Blended fruit smoothies with frozen yoghurt (add banana, mango, berries)
- Creamy custards
- Two minute noodles
- Cheese sticks or cubes
- Toast or crackers
- Hot potato chips
- Dal khichdi
- Stuffed parathas
- French fries
- Cheese on toast
- Peanut butter
- Spring Rolls
- Small snack packs of children's biscuits

- Pikelets / pancakes with butter / jam / cream / ice-cream
- Sprouted chaat /bhel
- Potato Salad
- Chips
- Buttered popcorn
- Crackers and cheese
- Creamed rice
- Home-made mini pizzas
- Scrambled eggs (add cream, bacon, cheese)

Nutritional needs of the Caregiver:

Caring for a child who is unwell is both physically and emotionally demanding. Your own nutritional needs are also important. To ensure you are well nourished it is important that you eat healthy meals as much as possible. During particularly stressful times, eat the foods you enjoy most and do not worry if your diet is unbalanced for a day or two.

Meal preparation can be time consuming. Where possible cook in bulk and freeze meal sized portions for later. Friends and family will often ask what they can do to help. You could suggest they bring prepared meals for the freezer, fruit platters, ready to eat snacks or even a take away meal for you to share.

References:

1. Palliative Care Queensland (2008). About Nutrition in Palliative Care. Retrieved December 17, 2009 from: <http://www.pallcarevic.asn.au>
2. <http://medilectures.blogspot.com/search/label/Nutrition>
3. Solomon MZ, Dokken DL, Fleischman AR, Heller K, Levetown M, Rushton CH, Sellers DE, Truog RD. for IPPC, 2002.
4. Wolfe J, Grier H, Klar N, Levin S, Ellenbogen J, Salem-Schatz S, Emanuel E, Weeks J. Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine*, 2000;342(5)
5. Galloway KS, Yaster M. Pain and symptom control in terminally ill children. *Pediatric Clinics of North America*, 2000;47(3):711-746.

Chapter 12

Communication in Pediatric Palliative Care

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Introduction:

When a child is diagnosed with cancer, the entire family goes through severe stress. Advanced stage of cancer of the child is stressful for parents as the hope of cure is limited. Parents feel helpless and try to face the event by adopting varied coping strategies.

The Palliative Care Unit attempts to understand the parental needs and offer care not only to the ill child but also to care givers in totality.

"Many families are affected emotionally, financially and physically by the burden of caring for children with life threatening or chronic conditions requiring complex care at home" (Monterosso, 2007). To support the ill child and his/her family in holistic manner, individualised care is provided by Paediatric Palliative Care.

The definition of palliative care is "an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the patients and support for family and includes the management of distressing symptoms, provision of respite and care through death and bereavement" (Lenton et al, 2006).

In this service provision system, communication plays a major role. The trained counsellors of the Unit use the communication effectively to understand concern, worries and needs of the child and family.

Definition:

Communication is defined by Oxford dictionaries (2011) as the imparting or exchanging of information by speaking, writing, or using some other medium. Communication is very important in our life because humans as social beings.

All our socialization depends on communication so it has to be effective. It is used as a tool for exchanging information, sentiments, social norms and so on.

Forms of Communication:

Communication may be verbal or non-verbal.

1. Verbal Communication:

It involves the use of language. The words used might be written or oral. It is the most common form of communication. This might be direct (face to face) or indirect. The exchange of information, thoughts or feelings is quick in this type of communication and the feedback is also received immediately. In this type of communication, conscious use of spoken language is important.

The selection of words is significant as it reflects the age, education, developmental level, culture. The simple, brief, clear, well timed, relevant sentence formation is effective as the decoding by receives becomes easy. Minimal usage of medical jargons is essential while imparting the information to a lay person.

Paralanguage: This term refers to the vocal qualities of oral communication. The 'way' message is given and 'how' effectively information is communicated depend on the following things. The rate of speaking (slow or fast) , pitch, loudness of voice, use of pauses, emphasis, voice clarity are few of the factors which are considered as important factors while communication orally.

2. Non-Verbal Communication:

This is the way of communication in which the usage of words/ language is nil. This is sort of silent language. This includes physical aspects such as facial expressions, eye contact, gesture, posture and so on. The gestures like eye contact denote the honest conversation. It is of course influenced by cultural norms. Usage of right gestures such as nodding the head, leaning the body, can be used effectively as it shows the willingness of listener.

This type of communication can be used more effectively while counseling the ill children and their family. It is seen that sometimes it is hard to find words to empathize with them. In such situation, just patting on the back or gently touching the client help a lot to counselor. Usage of pause can be used

effectively. The silence can be proved as important tool of communication if used appropriately. The pause or silence in counseling session helps client to think, understand and respond.

While communicating with children, usage of non-verbal communication is more appropriate as the children have limited vocabulary.

Communication in Paediatric Palliative Care:

The palliative counsellor is an integral part multidisciplinary Team of the Unit. The role of palliative counsellors is not restricted only for the ill people but also to provide support to their care givers. While describing communication as a vital component of palliative care Seth (2011), mentions the importance of effective communication skill of medical practitioner helps to allay the fear of parents related to the unknown and provided empowering information. The task and responsibility of the counsellor is to help the patients to cope effectively with the life threatening situation. It is essential to make the patient and care givers aware of the prognosis of the disease. Awareness of the fact though bitter, helps them to cope with the eventuality. It is seen that fear related to uncertainty is reduced when the factual information is revealed to them. They get enough time to accept the poor prognosis.

The counsellor working with Palliative Care Unit has to deal with the issues of death and dying. Death is inevitable and it is still a taboo subject. Topic of death and dying is avoided by ill as well as healthy individuals. When the patients are nearing death it becomes extremely important to deal effectively with physical, spiritual, social, psychological and emotional aspects of the child and other family members at this stage.

Involvement of ill child:

"What do child understand?", or *"why to disclose the bitter truth to the child?"* and so on are few of the opinions of the care givers of the ill children. Most of the time, adults feel inappropriate to involve the child while discussing the advanced stage of disease. As the intension of family members is to guard the child from the bad news they prefer to hide the facts from them. But literature and experience of the author has found that the children understand and have inbuilt capacity to sense the bad news. The parental expressions, deteriorating physical

condition and unsaid word by family members are used as cues by children. They show curiosity to understand the disease related facts. So it is essential to impart the true information to the ill children (with consent of care givers) in empathetic and sensitive manner.

Components of Palliative Counselling:

The essential component of the Unit is to break the bad news. The health professional is expected to break the bad news in sensitive and empathetic manner. When the patients are referred to the Unit, they approach the Unit with ray of hope of cure and expect the Unit to provide curative treatment. The role of counsellor begins before the medical health care givers. To assess the patients' awareness and understanding related to disease is the first responsibility of counsellor. To understand these sensitive issues of individuals, communication plays a vital role in the entire process.

Assessment areas in Paediatric Palliative Counselling:

As the Units aims to provide care in totality, it is essential to assess the needs of the patients. Along with the physical discomfort, the patients undergo the emotional, psychological, spiritual and social pain. It is essential to assess the needs properly and understand the priority of needs for the patient and care givers as based on this need assessment by the counsellor, the Unit plans the appropriate intervention to help the patient in totality.

- **Emotional discomfort of the patient:**

The counselor attempts to assess emotional and psychological pain component of patient. The anticipated symptoms, uncertainty of future and fear associated with thought of permanent separation from the dear once are few of the important areas which a counselors need to assess.

- **Spiritual discomfort:**

The disease such as cancer is connected with punishment by God for the sins of this life or last life. 'why me', 'what I have done wrong?' are the questions which bother the patients.

- **Social discomfort:**

The social stigma attached to the disease such as cancer force the patients to hide the disease from community, neighbors or

other family members. 'now my friends do not play with me.', or ' my HIV status might influence my relationship with my peers' are the thought which they possess. To deal with this situation, they prefer to isolate themselves from others which results in stress.

Communication skills required by the palliative counsellor:

An empathetic approach is essential along with the effective communication skills to understand the patient. Palliative counsellor has to be patient listener and sensitive towards patients' pain. Proper use of body language, facial expressions, tone, and pitch of the voice and selection of proper words by the counsellor prove helpful in the Unit to understand the patient completely. Usage of small and simple sentences, avoiding medical jargons, providing information in parts help patients to understand the information. The skill of counsellor to read between the lines, making appropriate use of pause and silence is useful.

Language:

It is easy for a person to express himself or herself in her/his mother tongue. They feel comfortable communicating in the mother tongue when professionals make extra efforts to speak in the language of the patient and care givers to create better trust and build rapport.

Techniques used in Paediatric Palliative Care Unit by the Counsellor:

To motivate the patient to ventilate his/her feelings, thought and concerns is the main job of the counsellor. This is done by providing a conducive atmosphere to patients. When it is observed that the patient is not able to communicate, then he/she is helped by providing paper and pencil. When the patients write their concerns they feel less burdened. When the child is in terminal phase of disease, then the apt use of colours, pencils, various types of toys and other forms of art therapy such as storytelling, sentence completion task are used in the Unit as per the need.

Play:

This can be used effectively to initiate the conversation. Without instructing and insisting on the rules of the games, if the free hand is given to the children they involve themselves well and this gives opportunity to form a rapport.

Observation:

Observing the body language of the child, a trained professional can understand the pattern of inter personal relationship within their family. The way child enters the room, if eye contacts are well maintained, if fidgeting is frequent are few of the cues which prove helpful to understand the current emotional and mental status of the child.

Listening:

This is a wonderful technique which helps to strengthen the bond of trust with the child. Assurance of patient listening encourages the child to open up. Catharses of feelings help them to feel unburdened.

It is essential to understand that it might be difficult for a child to express the self in words but several options of ventilation is necessary to offer to them. After receiving the oral consent from their care givers, the first towards breaking bad news is to assess the willingness of the child to listen to the news.

The amount of involvement in the disease related discussion from the beginning determines the understanding level of the child. The age, exposure and understanding of disease decide the content of communication. "Seriously ill and dying children are much more aware of their illness and prognosis than it is comfortable to acknowledge. They are known to harbor anxiety about their situation and are helped by the provision of age-appropriate information. Equipped with the knowledge, the caregiver can certainly be more attentive to the child's verbal and non-verbal communication and seek, where possible, to lessens the child's anxiety" (Stevens, 2005). To provide enough time to think over the newly gained knowledge is a key of effective communication. To pass the messages hurriedly might affect the mental health of the child.

To summarize, it can be said that, every child shown willingness to be involved in the communication. The information should be provided without using medical terminology and preferably in the mother tongue of the child. Non-threatening atmosphere, assurance of privacy and confidentiality help them to open up. When they speak it is essential to acknowledge the emotional stress of the child. Being a non-judgmental person wins the half battle. Willingness to share and patient listener create a strong bond of trust. Communication is vital key aspect of effective patient care.

References:

1. Lenton , S., Goldman, A., Eaton, N., and Southall, D. (2006). 'Foundation of Care-Development and Epidemiology', In A. Goldman., R. Hain., and S. Liben, (Eds), *Oxford Text Book of Palliative Care for Children*,(1st ed.,pp.3-13), Oxford: Oxford University Press.
2. Monterosso, L., Kristjanson, L., Aoun, S., and Phillips, M. (2007). 'Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service', *Palliative Medicine*, 21, 689-696. <http://pmj.sagepub.com/content/21/8/689>.
3. Seth, T. (2010). 'Communication to pediatric cancer patients and their families: A cultural perspective', *Indian Journal of Palliative Care*, 16(1), 26-29.
4. Steven, M. (2005). 'Psychological Adaptation of dying child' In D. Doyle, G.Hanks, N. Cherny, K. Calman. (Eds) *Oxford Medicine for Palliative Medicine*, (3rd ed. pp.798- 805), NewYork: Oxford University Press.

Chapter 13

Play Therapy

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"You can discover more about a person in an hour of play than in a year of conversation." -Plato

Origin & Definition:

Play Therapy finds its roots in a plethora of disciplines like Sociology, Anthropology, Social Work, Education, Psychiatry and Psychology. Today there are various models of Play Therapy such as Cognitive Behavioural Play Therapy, Gestalt Play Therapy, Child-Centred Play Therapy, Therapeutic Play, and Filial Play Therapy which are practised widely in a variety of settings and with a variety of clients.

Psychodynamic Play Therapy finds its origin in Sigmund Freud's Psychoanalysis. His work with and thinking about his adult patients aroused new insights into the emotional development and experiences of children, specifically the profound relationship of children's psyches, bodies and sexuality (1905). Although he clinically focused on adult patients, his informal analyses about the development of children set the stage for the logical next step of treating children.

Hermine von Hug-Hellmuth, a school teacher in Vienna, however, became the first to formally treat children with talk and play. Later, the therapists and theorists like Anna Freud, Margaret Lowenfeld and Melanie Klein worked to develop ideas to gain insight into child's inner emotional world through Play and use play as a means for understanding and healing children's distress.

Because play therapy takes a developmental perspective it is especially important for the practitioners to be familiar with theoretical frameworks based on research in both typical and atypical child development.

Play Therapy, as the name suggests uses play as a therapeutic intervention to help children as well as older clients to gauge insights into their inner selves, and articulate their abstract thoughts and feelings which may seem a difficult task otherwise.

The Association for Play Therapy thus defines Play Therapy as the "Systematic use of a theoretical model to establish an interpersonal process wherein trained play therapists use the therapeutic powers of play to help clients prevent or resolve psychosocial difficulties and achieve optimal growth and development." The definition of Play Therapy emphasizes on the role of the therapist for its successful culmination.

In this chapter, we shall focus on using Play as an intervention for healing emotional and psychological distress of paediatric cancer patients who are under palliative care.

Application of Play Therapy:

At the heart of Play Therapy is a troubled child who is allowed freedom to explore his/her ideas and feelings about self and others through play.

Bruno Bettelheim, a child psychologist has rightly stated that "Play permits the child to resolve in symbolic form unsolved problems of the past and to cope directly or symbolically with present concerns. It is also his most significant tool for preparing himself for the future and its tasks."

Play becomes a child's vocabulary to articulate his/her feelings and thoughts. Through play, children; who developmentally lack cognitive ability to meaningfully communicate their thoughts, feelings and experiences through abstract means of language; test out various situations and behaviours in the presence of a supportive therapist in a safe environment.

Concrete objects and toys, and play-based experiences offer age-appropriate and safe means for children to express themselves. Unconditional positive regard and acceptance from the therapist encourage children to try out different roles, deal with conflicting emotions and thoughts, and motivate them to explore and understand their inner world. Children are able to reveal their fears and hopes to the trusting adult, the therapist. Play experience also brings psychological healing to the children.

Although everyone benefits from Play Therapy, it is especially appropriate for children between 3 and 12 years of age (Carmichael, 2006; Gil, 1991; Landreth; 2002; Schaefer, 1993).

Play Therapy techniques and recreational processes have been applied to teenage as well as adult clients within the realm of mental health.

In recent years, play therapy interventions have also been applied to infants and toddlers. Play Therapy is suggested to be specifically more effective with children who cannot or do not want to talk about their problems and concerns.

Play Therapy is a developmentally sensitive intervention and therefore, the therapist needs to take into account chronological age of the client as well as the functioning age of the client in the course of the therapy.

Play Therapy is extensively used with children with a wide range of mental health problems, diagnoses and other difficulties. It is most effective for problems like:

- Anxiety
- Depression
- Hostility
- Aggression & Anger
- Post-Traumatic Stress Disorder (PTSD)
- Managing Emotions
- Behavioural Problems
- Social Adjustment Problems
- Mental Disorders
- Learning Disabilities
- Psychosomatic Symptoms

Play can be used both as a corrective measure as well as a preventive intervention. Play provides children an opportunity to develop understanding of the world matching their cognitive level.

Children learn to build trust in relationships through their interactions with the therapist and this indeed boosts their self-esteem, self-efficacy, confidence, feeling of control and decision-making ability. Increasing literature on Child Therapy emphasizes on the use of Play as an effective means to treat social and emotional difficulties (Bratton, Ray, Rhine & Jones, 2005; Josefi & Ryan, 2004).

Application in a Hospital Setting:

Research suggests that hospitalization creates intense negative emotions for children. Even routine medical check-up and visit to doctors can be stressful and anxiety causing for children.

Children under medical care may find the medical check-up routines, immunization processes, treatment regimes, separation from the parents for surgical/medical procedures, undressing/showing their wounds to unfamiliar doctors and nurses very unpleasant and embarrassing. It creates intense anxiety and helplessness among them. It may also lead them to think negatively about the whole situation and may generate guilt feelings within them about the occurrence of sickness and they may even look at the injections and other painful medical procedures as a punishment for their past mistakes.

In a hospital setting, Play Therapy is usually used as a technique to facilitate paediatric patients to open up and express their fears and anxieties related to illness and hospitalization which they are otherwise afraid to pronounce. From their expression of inner feelings and thoughts, the therapist gains insights into the child's psyche and further uses interventions to help the child cope with his/her negative feelings and unpleasant experiences.

Play encourages creative expression, it helps develop a sense of control, and helps cultivate problem-solving skills, and undergo catharsis and progress towards positive change. Studies have noted that use of therapeutic play could make a difference as to whether hospitalization was a positive or negative experience for the child.

Children when diagnosed with life-threatening illness like cancer undergo trauma of diagnosis, witness crisis at home front due to the illness and often feel alone, and experience despair in the battle against the disease. Hospitalization, difficult treatment regimes, frequent follow-up visits to hospital, physical and emotional pain, dependency, loss of strength, change in daily routine, missing of school and play cause paediatric patients immense distress and suffering.

In addition, often these children do not understand the gravity of the disease and when terminal, are mostly unaware of their palliative status. Due to this ambiguity, often these children create painful ideas in their mind about themselves and the disease and fall prey to

anxiety, stress, guilt, helplessness, hostility, depression and other severe psychological problems.

Webb (1991) noted differences in practise of Play Therapy in the hospital setting such that in the hospital setting, the play is more informal in nature, there is flexibility, no time boundaries, and interruptions like treatment, medication are allowed. Webb suggested that hospitalized children have heightened need to communicate through means of play. Sense of control acquired through play is of immense importance to a hospitalized child who is bound to feel helpless, anxious and depressed in a hospital environment.

There are Child Life Programs especially designed and developed for helping these hospitalized children cope with the anxieties and unpleasant experiences of hospitalization. This approach uses play with intent to minimise anxiety and promote growth of these children. Helping the child to achieve feelings of control, safety and well-being in a hospital environment, which is threatening and distressing for the child; is a biggest challenge for a child life specialist.

Techniques of Play Therapy

There is a wide range of Play Therapy techniques used differently with different age-groups. There are different techniques to address different problems. Choice of Play technique requires discretion of the therapist for the therapy to be effective. Play Therapy can be non-directive, i.e. the child decides what to do during the session within the set boundaries, or it can be directive where the therapist guides the child or it can be a mixture of both. Usually, in paediatric palliative care setting we use non-directive strategy or the mixture of directive and non-directive strategies to help patients.

Colours, clay, sand, shapes, miniature animals, dolls, doll houses, puppets, plastic media, symbols, stories, creative art & writing, are all used as play materialism Therapy.

Out of all of the above, Puppets are extensively used in Play Therapy. Puppets are crucial in Play because children frequently project their thoughts and feelings on to the puppets and this projection helps them create safe distance necessary in expressing their deepest thoughts. Puppets also serve as a medium for a therapist to reflect understanding, and provide corrective emotional experiences in the context of child's play. Often puppets are used as symbolic client to

overcome resistance of involuntary child clients. Puppets increase child's comfort level, remove focus from self & provide safe emotional distance.

Environment for Play Therapy is very important. It should be non-threatening, comfortable, and should allow enough space for the child to explore and experiment within its boundaries. Conducive environment encourage children to come out of their shell and express themselves freely.

In therapy, the therapist has to refer to the child, ask questions and interpretations for accurately understanding what the child is putting across through his/her work. It is therapist's duty to bring forth and make the child realize the discrepancies and conflicting emotions that become evident in the child's play and verbal and non-verbal expression.

E.g., the child may say she loves her mother but in the play suggests hatred towards the mother figure. The therapist may bring out this discrepancy gently, without threatening the child, which leads the child to further suggest that she loves her mother but hates her and gets scared of her when she reprimands her when she makes fuss about taking food and medication.

In Play Therapy, every act of the child, all the objects, symbols, colours used carry significance and must not be ignored or overlooked by the therapist. The therapist is a crucial part of the Play Therapy and is required to be skilled, trained and experienced to make Play Therapy a successful intervention.

An experience at Paediatric Palliative Care, Tata Memorial Hospital

With anxious, apprehensive steps a number of children walk into the paediatric palliative care OPD at the Tata Memorial Hospital on Tuesday and Thursday afternoons with their parents and caregivers. The age group of these paediatric patients varies from 6 months to 20 years. These children are referred to the palliative care clinic either because they are terminal or the parents of these children are required to receive pre-treatment counselling due to the demanding nature of the treatment and its future implications. Some children are also referred to the palliative care clinic for symptom relief.

With the age-group vary the concerns of the sick children. Also

different cultural and socio-economic backgrounds and varied lifestyles affect their perception of the situation and the sickness. These children's concerns are many and are often only addressed at the palliative care clinic at a juncture where there are a lot of uncertainties surrounding the cure of the disease.

Most of these children suffer from guilt feelings and express being burden to their families. They feel responsible for financial crisis at home-front occurring due to expensive nature of the treatment. Especially adolescent patients express feelings of worthlessness as they are unable to fulfil their education, establish career and support their parents financially due to the disease.

Children express treatment related anxiety, apprehension about the disease progression and the future, pain and other symptoms and symptom control in general. Children do have concerns related to attending school, engaging in play with their peers if they have developed any deformity or disability due to the disease or curative treatment procedures. Often children express occurrence of sickness to be a punishment for their past mistakes or suggest some kind of cause-effect relation for having developed the disease. They develop understanding about the disease on their own and this understanding is often based on their past experiences, beliefs and family and culture.

E.g. a 12 year old patient suffering from OGS suggested that he developed this disease because few years back, when he was about 6 yrs. old, he had gone cycling in spite his mother's refusal and had met with an accident. He must have developed a crack or something in his limb which went undetected then but now has developed into cancer. He said he was guilty and said it would have been better if he would have never gone cycling in the first place. If he would have then avoided cycling, today he would not be seeing such a day in his life.

Another patient of OGS, 14 yrs. old suggested that he has developed the disease may be because he may have done something wrong sure in the past, because he doesn't remember any wrong doing in this life at least (he doesn't smoke, eat tobacco or lie at home while he knows many of his friends who do so in the native place).

About usual counselling sessions, when a child comes in for counselling, the child is greeted and welcomed by the counsellor. The child is made to feel comfortable and after a brief introduction,

the counsellor builds rapport with the child by asking him/her about family, hometown, hobbies, activities, likes and dislikes. Then the counsellor asks the child if he/she would like to engage in any activity like drawing or painting, sing or play musical instrument or would like to read stories. The child is also shown some fascinating books with pictures and animated stories. Browsing through the books, most children often share about their schooling, what they have learned in school, what are their favourite subjects and who all are their best friends. Most young children then engage in colouring and painting activities.

The counsellor, during this hour gently brings up the topic of illness. From this junction, each child's response to the discussion, the amount of sharing and disclosure as well as the reaction all differ.

Illustration of a Play Session

Name : SB (identity concealed)

Age : 7

Gender : Girl

Diagnosis : Neuroblastoma

SB, a playful, pretty looking little girl from Bengal entered the counsellor's room in the Palliative Care Unit with a broad smile on her face. She had a sweet Bengali accent to her Hindi speech which had caught everyone's attention when she spoke. Chirpy little SB, familiar with the hospital surroundings due to long-term treatment visits; made herself comfortable in the presence of a counsellor, was fascinated by the attention and the opportunity to have some fun time in the hospital and was all up for playing. She was informed by the counsellor that there is a didi in this clinic who would play with her and talk to her while they wait for their turn in the OPD. After brief introduction and sharing of likes and dislikes, hobbies, SB suggested that she would like to draw and so was provided with the materials.

- With a pencil in her hand and eyes on the blank sheet her mind got engrossed in sketching a huge Banyan tree. She took care of minute details when drawing. She drew the tree trunk, the branches, and the roots of the trees buried deep under the ground. She also drew the underground water.
- She then described this tree as a "good tree" and so was blessed.

Then she drew a beautiful butterfly that was again described to be "good". Then she drew another butterfly which she named "devil butterfly" and this devil butterfly disturbs the good butterfly and the good tree because they are good. She sketched mountains and the Sun and the Moon and referred them as "God".

- From her vivid imaginations and description, the counsellor got the following insights:
- The child had strong and conflicting ideas and beliefs about the good and the evil, the Gods and the Demons. She believed that good people are troubled by the bad people but still one must be good because then only will God protect one from evil and after suffering one who is good will win against the evil.
- SB feels that she is suffering from brain tumour because of some devil. Devil is disturbing her life and as she is a good girl she is troubled. But because she is a good girl, one day God will favour her and cure her. She behaves like a good girl and believes that this is why she doesn't have to take injections or undergo painful treatment like many others. She believes that if she behaves badly, she will be punished by God.
- She feels that those who are older should behave nicely and young ones have all the freedom to behave badly if they want. Here the child had conflicts with younger sibling but because she is older she is taught and expected by her parents to forgive the younger one and not fight with her. She had repressed anger against the sibling.
- When speaking about likes and dislikes she mentioned she likes to eat fish but she feels bad that a fish is killed. So she would never kill a "good" fish and eat but kill all the "bad fishes" and eat them rather. Such strong were her notions about good and bad.
- Then counsellor played a game called "3 Wishes" with SB. SB was asked to imagine: One morning as you wake up from the bed, you see a fairy... a fairy which is beautiful, wearing a long white gown which has diamonds and beads studded on it. She is wearing a silver crown and has a silver wand in her hand. She smiles at you and walks up to your bed. She comes to you

and gently places her hand on your head and says, "SB, I like you very much and I am very happy so I am going to grant you 3 wishes. Tell me SB, what are your 3 most desired wishes."

- To this, SB replied, "Umm, my 1st wish is that my parents should never fight. I don't like when they fight and my head aches when they fight. 2nd wish is that my sister should become a good girl and we should never fight. I don't like when we fight. And my 3rd wish is that I become alright and fine again (my disease gets cured)."
- The play and talk gave insights into the thinking patterns of the child, what disturbs her, and what she desires most.
- During the conversation, the child expressed having inhibitions about sharing anything with her parents. She suggested that she felt less understood and expressed anxiety about their fighting and quarrelling to the counsellor. She expressed anxiety that her family will break down if her parents quarrel and she would become lonely. She confided into counsellor only after taking a promise from the counsellor that she would not tell anything she shares with her to her parents. SB suggested that she didn't have any friends as she doesn't go to school like her younger sister. She feels lonely and this also creates anger and jealousy in her mind against her younger sister. She had anger towards the servant who teased her and a neighbour who threatened her often when she took his mobile phone to play games. She felt alienated as the neighbour allowed other children in the house to play with the mobile but not her.
- SB was suffering from loneliness and alienation which led to over identification with the animated characters in the TV programs, magical thinking and imaginations.
- SB revealed her dreams which revolved around family, spending time with family, holidaying in scenic places and also her nightmares which revolved around seeing some demons, some dark, huge and scary figure through the sessions. It was observed that SB was influenced and fascinated by Nature and believed in magic and superpowers.
- Play with SB was insightful and it provided her space and safe environment to express her deep-rooted beliefs and ideas, her

fears and anxieties, her desires and hopes. It was visible that more than the symptoms of the disease, the ideas about the cause of the disease, reasons she is suffering, pressure of being good and other such thoughts are troubling her immensely.

Demonstration Exercise:

Play activity should help children boost their imagination and express their ideas effectively. It should allow them understanding of their own emotions and feelings. One such technique that helps discuss affective states experienced through life in a non-threatening way is 'Colour Your Life' technique. It is appropriate for children between six and twelve years of age. This technique when used in a group can prove to be more effective.

A. *Colour Your Life:*

1. Pair different Colours with Feelings
2. Red:_____, Blue:_____, Green:_____, Black:_____, White:_____, Grey:_____, Orange:_____, Purple:_____, Brown:_____, Yellow:_____
3. Describe feelings in as concrete terms as possible
4. Take a blank sheet and fill it with the colours to show the feelings you have had throughout life
5. Use your creativity- the shapes, designs of your choice
6. Discussion: Various life events, assorted quantity of various colours

Shortcomings:

Play Therapy, though widely used does not have well documented empirical research data to support its effectiveness. It is extensive and time consuming process and results are not reflected immediately. Also, it requires the therapist to be thoroughly trained and skilled to use techniques and accurately interpret child's work to bring about a positive change in the child's life through therapy.

To conclude, Play Therapy has a wide scope of application and practise in modern world. Today, it is used by many other professionals from different fields interacting with children including nurses, social workers, speech therapists, occupational therapists, teachers and hospital play specialists besides play therapists. The

therapeutic powers of play benefit a wide range of paediatric population today as its practise is not restricted and bound by any one field or few authorized practitioners.

References:

1. A Total Approach: Play Therapy retrieved from <http://www.atotalapproach.com/docs/play-therapy.pdf>
2. Judy, R. W., (1995). Play therapy with hospitalized children, *International Journal of Play Therapy*, 4 (1), 51-59. Retrieved from <http://kythe.org/site/wp-content/themes/kythe/resources/play-therapy-with-hospitalized-children.pdf>
3. Rye, N., (2012). Child-centred play therapy. In: JH Stone, M Blouin, editors. *International Encyclopaedia of Rehabilitation*. Retrieved from <http://cirrie.buffalo.edu/encyclopedia/en/article/275/>
4. Tara, M.H., Heidi, G.K., Charles, E. S., (2002). Fifteen Effective Play Therapy Techniques, *Professional Psychology: Research and Practice*, 33 (6), 515-522. DOI: 10.1037//0735-7028.33.6.515

Chapter 14

Spirituality in Pediatric Palliative care An Indian Perspective

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Introduction:

"SPIRITUALITY IS A DOMAIN OF AWARENESS" Dr. DEEPAK CHOPRA, well known author.

The word "Spirituality" comes from the Latin root "Spiritus", which means "breath"- breath of Life. Broadly it can mean faith, hope, healing, inner peace, a quest into the meaning and purpose of life and a search for the perfect "way of Life". It also helps one to communicate with others without barriers - an open hearted conversation.

In the Indian context spirituality and religion are so closely associated that the words are often used interchangeably. Religion, rites and rituals play a prominent role in the lives of most Indians and many do not seek answers or solutions to their problems beyond their implicit faith that God will do what He thinks is best. Most situations, particularly difficult ones, that a person finds himself in are attributed to God's will.

Need and importance of Spirituality in Pediatric Palliative Care:

In India, where religion and spirituality are so closely linked, the latter can provide a foundation for hope in life. Impending death can certainly pose a threat to this faith; however with guidance this hope can be moulded to bring some meaning to the dying process. Terminally ill patients always ponder about their life's pattern and the direction it is moving in. Forgiveness and a search for peaceful transition are sought after and we caregivers have to guide them through this process. It may form the basis for their belief in afterlife.

Faced with a cancer diagnosis, pediatric patients are usually disturbed

at the changes this means to their education and social life. They fear that their dreams of a perfect planned future may not be fulfilled due to the prognosis of their disease. Their "safe, bright world has collapsed".

In Pediatric Palliative Care spirituality can play a key role in acceptance of the situation by the child and his family and can help them to come to terms with the poor prognosis. At the outset however it is important that spirituality is understood by the reader, irrespective of his religious leanings.

Even before the reader tries to determine the spiritual leanings of a child, the reader has to first introspect and try to find out what spirituality and religion mean to him/her and whether he can clearly distinguish them in his mind and his way of life. Only then will he be able to discuss this with a child

Our conversations with them have to be gentle and articulate, as they like to hang on to words and take cues from us about their disease.

A person's spiritual growth is essentially a measure of his response and modification in behaviour and attitude to situations, objects and persons around him which may cause him either pleasure or pain.

Broadly speaking a person's spiritual journey begins with a quest for answers to questions such as:

- "Why me? Or "why have I been singled out for this disease?"
- "Is this what I get for praying the whole day?"
- "I have been a good human being.... Now, why do I have to go?"
- "What have I done to deserve this?"
- "What is the purpose of life in general and mine in particular?"
- "What happens when life ends?"

Children suffering from life threatening diseases too are likely to introspect in these lines and may have other issues that are pertinent to their age, such as:

- "My life has been cut short, I had big plans for the future ... what do I do next?"
- "Who will look after my parents?"

- "What will they do after all the expenses they have incurred?"
- "Why no Cure, when this is such a big hospital?"

Perhaps the answers that emerge reflect the patients' maturity, exposure to death or life threatening situations around them in the past and their family circumstances.

With older children we can discuss FAITH and its importance in their lives before and after the disease.

- Has it altered their perception of LIFE?
- Who do they share their emotions with?

Now that their parents are looking after them, do they feel bad that roles are reversed? In the Indian context, children are expected to look after their elders.

- Are they angry with GOD?
- Are these huge expenses incurred by their parents causing an emotional disturbance in them?
- In view of the above, do they feel their siblings are neglected?

It is important to understand that not everything can be explained. There may not necessarily be answers to the questions put to and by the child; but that is not really the purpose of the exercise. You may not know the answers but you can help the child express the questions. It is sufficient if one can pave the way for the child to reflect on these issues and to come to terms with his/her situation.

Gaps in the area of practice:

1. Time:

In our hospital most of our patients are from other cities, towns or villages. The immediate reaction on being told that no more active treatment is feasible is to want to go back to their native place as soon as possible. They want to go back to the safe environs of their home, where they are not disturbed with "bad news". They need to embrace the warmth and love of folks waiting for them. There is always some "elder" person awaiting them with better and hopeful news that "We will do something", even if it is some magical cure. Often we see our patients only

for one visit, which is not enough to cover all psychosocial issues including spirituality.

2. *Physical Distress:*

Often the patient is suffering a lot physically and it is not an appropriate time to bring up a topic such as spirituality which needs in-depth discussion or at least introspection.

3. *Privacy:*

More often than not, we are restricted from discussing any matters with the patients by the parents or caregiver accompanying them. Parents / caregivers fear that we will discourage their patients and hence the patients will lose whatever hope they have.

Discussion:

In India people attribute most things that happen to them to their 'karma'. This simply means the result of one's past action. Since Hindus believe in rebirth, patients and their families often attribute their present situation to their actions in some past life. Parents often voice their thoughts that they have to see their child suffer or bear his loss because of something bad they may have done in the past. (No one ever implies that the child could have done something wrong and hence is suffering, parents always consider this misfortune to be a result of their own karma)

There is also a tendency to be passively fatalistic; believing whatever has happened is in their 'naseeb' or 'kismet'. The belief is that what they are going through is preordained and they will have to go through to it no matter what. This is a form of acceptance but usually with a depressed frame of mind, not acceptance which is proactive and can lead making the most of whatever life there is left.

When we seek to question them on spirituality, we should cautiously clarify our reason for doing so. We have to explain that it has nothing to do with the disease, but would help us to find out their needs and to try and help them achieve their goals.

Young children raised to be "God fearing" may think of their illness as something resulting from their having angered God. They were 'bad' hence God is angry with them and so they are suffering. Older children, particularly adolescents may be angry with God for having

brought them to this situation. Some may even say they have lost faith in His existence.

It is helpful to discuss issues with them by giving examples or telling little stories. Uncertainties in life can be brought into the discussion in this manner. Gentle probing can reveal what it is that they fear most and also what upsets them the most about their present condition. Adolescents invariably are upset about the effect their illness and prognosis has on their parents.

Many regard what they have been through as a great learning experience. Many youngsters who have been under treatment in hospitals away from home seem to distance themselves from their former colleagues and friends. They have learnt to live in the present and seem to regard their current circumstances as being more relevant. It is almost as if the entire journey of illness and treatment has been such a process of growth that they may find themselves at a different level from their old friends. This is a reflection of their spiritual growth in trying circumstances

Summary:

Spirituality holds different meanings for different people, but, for most of them it will be a source of finding out the meaning of life, comfort, peace, and most of all hope for a peaceful transition. It is also a great coping mechanism. It is important to understand that not everything can be explained and there may not necessarily be answers to the questions put to and by the child.

Parents of children under palliative care usually find acceptance of the situation extremely difficult. It is important to allow them to vent their feelings. Their emotions may range from disbelief, despair and anger to a complete breakdown. The palliative care team can initially only be there while the parents struggle with acceptance, hoping to win their confidence. At this stage it is best to arrange for the young patient to be in another room preferably involved with some kind of activity, such as drawing, so that he may not be distressed by the parents' reactions. The activity should be supervised by a child psychologist so that the child can gradually be guided to express his thoughts, hopes and fears, through the activity.

Pitfalls/ Lacunae:

In India the family plays a very crucial role in the life of a patient and very often:

1. The family learns about the diagnosis/prognosis before the patient does.
2. Decisions regarding treatment options are often taken by family elders often without consulting the patient.
3. Families tend to be over protective of the patient and often prefer to withhold the truth regarding his condition from him.

All of the above is seen more often in the case of pediatric patients. Indians generally are very protective of their children and parents play an important role in most of the major decisions taken in life by their children, regardless of age.

Naturally this is magnified in the case of children who are ill and even more so if they are in a palliative stage. This attitude can often be a barrier in trying to discover the spiritual leanings of a child. The reader may not be successful in his attempts to get the child to share his feelings; he may face resistance from the family when he expresses a desire to talk to the child alone.

Therefore it is very important that the reader be clear what he wishes the child to introspect about. With patience and gentleness and appropriate self-revelation it may be possible to win the child's trust. He may then be able to get the child to think about issues which may be deep seated. In time perhaps the child may vocalize and deal with them. Care has to be taken that one's personal religious or spiritual beliefs do not colour one's discussion or attitude towards the patient.

Questions:

1. What is your personal understanding of spirituality?
2. How do you think you will respond when a teenager asks you "Why me?"
3. How would you try and determine the pediatric patients' outlook towards life?
4. Is it always necessary to talk about poor prognosis and invade their hopeful life? Or, should we allow them to believe in their ideologies of "KARMA" "FATE" etc.?

"You cannot travel the path until you have become the path."

- Gautam Buddha

Chapter 15

Management at End of Life

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Introduction:

One of the major concerns that doctors and nurses who look after children profess to having, is that of managing children during the final stages of their lives. This is not surprising when one considers some of the fundamental problems of dealing with end of life; from being able to predict the time of death, to how the death will occur when dealing with children whose diagnoses are uncertain.

In addition this subject also brings about the concept of a good or bad death, as well as issues around where a child wishes to die, and communication issues with the family. The key point on this subject is that one does not require a specialist Pediatric Palliative Care consultant and team to look after all children who are dying.

In the majority of cases, good compassionate care from a primary health care team or local paediatric team can be just as effective. The secret lies in using basic common sense medical practice, with sound holistic care and sensitive communication skills.

Many doctors and nurses who work in Pediatric Palliative care will talk about the good or bad death. For doctors, "A good death" may mean a child who has had optimal symptom control and a painless death. To the nursing team this may mean a child who has received good holistic care with adequate time to look after the child and family, and supportive medical backup. To a child and family, all of these things are equally important, but in addition they also need to feel in control, without fear, and with a sense of ease of access to medical and nursing support.

Although the ideology of helping a child achieve a good death is sound in practice, this is sometimes not achieved. There are many reasons cited for this including finance, resources and access to technology. However it has been shown by units all over the world in both the West and Third World countries, that these problems can

often be overcome by simple solutions. In parts of Africa, healthcare assistants are taught by experienced palliative care doctors to look after children within distant rural communities. In parts of Eastern Europe excellent community services are delivered on shoestring budgets. In places such as India, the challenges will stem from the diversity of environments, from the technology rich major cities to the socially deprived rural areas.

Discussion:

Prognosis:

Probably the most common question asked by parents of doctors is; how long does my child have left to live? This is actually one of the most difficult questions in children's palliative care to answer and stems from some fundamental differences between children and adults. An adult approaching death may be suffering from a number of possible medical conditions which over time doctors have grown to understand and can predict in terms of course. This allows the doctor to estimate fairly accurate timeframes particularly towards the end of life, for an adult dying from either cancer or noncancerous conditions. Children however are much more difficult to predict. Firstly, the child with cancer can often do very well with current aggressive chemotherapy and adjunct treatments. Conditions that were previously thought of as terminal can sometimes revert into long-term remission.

Unfortunately if other factors such as infection intervene, the child may well suddenly succumb. In other circumstances a child with cancer may go through various levels of chemotherapy treatment before the paediatric oncologist finally accepts that the child has entered the terminal phase. Sadly this can lead to the Pediatric Palliative Care team having only a few days to develop a relationship with the family and child, before the child subsequently dies.

In noncancerous conditions there is often a deterioration curve for the child which involves slow progressive deterioration with increasingly frequent episodes of dipping, associated with other intercurrent illnesses such as infection. During these episodes, a child may succumb to their illness, whilst others may subsequently pick up. This is often associated with the fact that unlike adults, children's organs may be damaged by certain types of illness, but their other

organs tend to be very healthy and resilient. The difficulty for parents when their child goes through this type of disease process is that they often have to be warned that they may lose the child during the specific episode, only to then find the child improving and going home. This puts a major emotional strain on the family and parents as they have to relive the process of watching the child potentially dying over and over again.

So when presented with parents requesting a timeframe for the child's death how should one proceed? It is important to let the parents know that you are uncertain. Parents do not perceive this as a negative, but more as an honest approach. We would recommend that the parents take each day as it comes, and try and tackle the issues within the day, with the knowledge that you as their doctor will regularly communicate with them as to the progress of their child's condition.

Indicators of poor prognosis and deterioration include [1]

- Deteriorating vital signs
- Loss of interest in surroundings
- Decreased interactions with others
- Loss of appetite
- Decreased urine and stool output
- Increased periods of sleep and/or withdrawal
- Worsening laboratory tests (if being monitored)

The final mode of death to consider is that of sudden unexpected death. In many neurodegenerative and genetic disorders, situations arise where a child, although relatively well, may suddenly deteriorate and die within a matter of a few hours or days. This is often linked to the development of resistant infections. It is important in these situations to be clear with the parents that this type of event does happen, and is not linked with anything that they or any other health care professional may or may not have done. These types of deaths tend to be particularly distressing for the family as they often have not had time to prepare emotionally for the loss of the child, and this is often linked to recriminations and regret.

Management:

When first presented with a child who is entering the final stages of their life, it is useful to consider various issues of symptom management, communication and planning.

ACT is a UK charity which has produced a very helpful prompt list [2] for healthcare professionals to use. The following discussion uses the ACT prompt list as its basis.

The child's needs should be assessed and a plan of care should be discussed and developed with the child and their family or carers.

When first presented with a child who has end of life needs, it is important that as the healthcare professional that you do not panic. The parents will have sufficient anxiety in their minds without the healthcare professional adding to their concerns. A clear, calm approach will help to settle both the child and the parents and help establish the initial rapport that is required for good communication. In paediatric palliative care, assessment cannot be done in 5 to 10 minutes. It is important to set aside sufficient time to do a detailed and thorough assessment of the child, allowing for discussion with the child, parents and surrounding support system. Within the UK a system of Palliative Care called the Gold Standards Framework [3] recommends a management plan called 'PEPSI COLA'. This is both simple to use and covers all the main subject matters.

- Physical issues
- Emotional issues
- Personal issues
- Social issues
- Information

Information: does everybody know what they need to know?

Control: place of death, dignity, autonomy.

Out of hours/Emergency.

Late: what is the end of life management plan? Has non-palliative treatment been stopped?

Afterwards: Bereavement support for the family.

It is very important at this stage to involve any other healthcare professionals within the assessment and discussion process. This allows parents to know that there is a multidisciplinary team approach to their child's care. The family can then ask questions of the healthcare team even when the doctor is not present, which can be answered with a unified approach if there is a clear understanding of the plan.

1. *Communication and information should be provided for the child, siblings and parents appropriate to age and understanding.*

One of the key differences between adult and Pediatric Palliative Care is the need to understand the importance of age and development of the child when trying to communicate with them. This is further complicated by the effect on cognition from many neurodegenerative conditions, disease progression and drugs. It is therefore beholden to the doctor to take all of these factors into account as they endeavour to communicate with a particular child.

Parents' understanding of medical conditions will be influenced by many factors, including their education, language difficulties, religious and social beliefs. There is little point in giving any written plan to a parent who is unable to read. It's far better to consider who may be able to read the plan to the parents to allow them to fully understand and follow the management plan.

2. *The religious and spiritual needs of the child, family and carers should be considered.*

Religious beliefs are very important in almost all cultures. The issues around dying and subsequent death vary between all the different religions. Each faith has only slightly different ways of dealing with things, but if these differences are not upheld then this can cause offence. Any healthcare professional dealing with end of life issues in children should make themselves fully aware of the appropriate religious and spiritual needs of the child and family. It is important to remember that within any one religion there may be a diversity of views and opinions regarding appropriate protocol. It is also unwise to assume that a family from a particular religious group would wish to follow the beliefs of that faith. The health care professional should make every effort to discuss with the family what the individual belief systems are.

3. *The child's, family's and carers' understanding of the child's condition should be considered.*

It is very important that when the doctor first does his/her assessment of the child, that they endeavour to find out just

how informed the family and carers are of the child's condition. Sadly there are many situations where the child is sent for end of life care to a specialist team, only for the team to discover that the parents have not been informed of why they were sent across, the seriousness of the child's medical condition, or the fact that the child is expected to die. In these situations it is important to show care and compassion towards the family, as you explain the fundamental issues around the child's medical condition.

Some cultures feel that entering the end of life phase may be a case of giving up on the child, and their beliefs are such that they are obliged to continue to preserve life at all costs. In these situations it is very important to communicate effectively with the parents to help them to understand that this is not giving up, but a continuation of the medical care for the child.

In other situations difficulties may arise from denial by the family and carers of the severity of the child's condition. There may be seeking behaviour where parents will try alternative practitioners and therapies. It is important to allow them to do this, whilst still maintaining a presence to support the family should these fail.

4. *The child's and families wishes and views should be incorporated into the end of life care plan.*

When one considers the issues around the causes of a bad death, a common theme is that the families feel that their wishes were not considered by the healthcare team. It is critical that the family's wishes and views are not only listened too, but form a critical pillar within the end of life care plan. This enablement of the family gives them a sense of ownership of the care plan and a feeling of control in a situation which they otherwise have very little ability to affect.

5. *Ensure that the family has all the relevant and up to date emergency contact details of staff and agencies that they may need to contact.*

The ability to provide 24hour emergency backup for the family is an issue which affects units throughout the world. In many cases there are significant logistical issues, such as the distance

between the child and health care teams. There are also issues of access to local expertise and fear amongst other healthcare professionals to become involved. In the majority of cases, a child with an end of life problem can be managed by local healthcare professionals with basic access to, and telephone support from a specialist team.

The key to this is around good care planning, with effective planning around the worst case scenarios and the appropriate actions that should be taken. Palliative care cannot be conducted on a 9 to 5 weekday basis, and the end of life plan must incorporate information about how the parents can obtain support out of hours.

6. *The child's current medication should be re-assessed. If appropriate consider discontinuing any non-essential medication.*

Over a period of time, a child can develop a long list of medications that various specialists have instigated. This polypharmacy, although appropriate through the child's medical journey, may no longer be appropriate towards the end of life. It is helpful at this stage to go through all the drugs to see which may be stopped or reduced. There are situations where parents may have strong feelings towards the continuation of certain types of drugs, even when they would no longer be considered beneficial, and in these situations the priority is to maintain one's relationship with the parents and just continue with the said medication.

7. *It is important to anticipate and prescribe for a range of possible symptoms.*

This will be discussed in further detail towards the end of this chapter.

8. *Consider, discuss and decide whether to discontinue inappropriate interventions such as blood tests, intravenous fluids and routine observations of vital signs.*

As a child enters their end of life stage, one needs to assess what tests and interventions are actually of any benefit to the management of the child. Most children require very little in the way of interventions, and often these can be disruptive or

cause discomfort to a child within the final days of their lives. As the doctor it is important to consider what difference any interventions that you request will actually make to your care of the child. It is often better to use your eyes to observe deterioration in a child, rather than to do repeated blood tests. A natural part of the dying process is the need for less and less food and fluids, and use of intravenous fluids may just prolong the agony of dying rather than provide any increase in quality of life.

Most routine observations of vital signs are of little or no benefit, although it can be very difficult sometimes to get parents to move away from using technology that they have used to monitor their child, such as oxygen saturation monitors. It is always best in these situations to present your case but to avoid conflict and allow the parents to continue using these technologies if they feel it gives them a sense of control.

9. *Ensure the family and carers are given appropriate written information to back up your discussions and plans.*

After the initial assessment, it is important to develop a plan of action and to write this plan down rather than keeping it in one's head. There is a difference between medical notes and a care plan in terms of the language and jargon used. It is important that the information in the care plan is written in such a form that doctors, health care professionals and family can all read and understand. This may require a healthcare professional to read and interpret the plan for an illiterate family or for the plan to be translated into their preferred language.

10. *The primary care team, specialist community services, hospitals specialist, ambulance services and out of hours services should be made aware of the child's condition and that they are now at the end of life phase.*

It is critical that good communication should operate throughout all levels of the healthcare service. This will allow everyone to follow the care plan through correctly. This should also prevent situations where a child is rushed into hospital inappropriately as part of an ambulance protocol, to be managed within the hospital aggressively but again inappropriately.

11. *The family should be given the opportunity to discuss their plans for death care.*

The family should have information about who to call when a child dies, what should be done immediately and what can wait. They should also be able to discuss their wishes regarding what happens after the death and subsequent funeral arrangements.

12. *Help the family to think about support systems after their child's death and who they might like to support them.*

The emotional trauma felt by a family after the death of child cannot be underestimated. It is important to consider the support systems that may be required by the family after the loss of a child. These support systems do not necessarily have to be related to the health care profession. Family, friends and religious support can all be very effective. Although counselling can be of great benefit to certain individuals, it does not automatically follow that all parents require counselling after the death of their child. In fact many would choose to use the local support systems in preference.

Symptom Management at End of Life:

Symptom management in Pediatric Palliative Care is extensively covered throughout this book within its individual chapters. In this section we will consider the specific symptoms that may occur towards the end of the life. Details of the drug usage and dosages can be found in individual chapters. The chapter on emergencies in paediatric palliative care covers many of these issues in detail.

As a child approaches end of life, there will be considerable anxiety amongst family and healthcare professionals to ensure that all symptoms are adequately controlled. Preplanning of what type of symptoms may occur and the management of these individually is essential. An emergency box of drugs can also be helpful if financially feasible.

1. *Pain:*

It is not unusual to see an increase in pain towards the end of the child's life although it should be recognised that some children actually will die without experiencing any significant degree of pain. The key to managing pain in these situations is

to have pre-planned management, with access to fast acting opioids. Most children can be managed with the use of morphine elixir, used every four hours and increased in increments of 30 to 50% as required. Detailed use of morphine is outlined in the chapter on pain. Be cautious when using slow release preparations as any change in dosages can take a long time to become effective. When a child is unable to swallow and there is no access via a nasogastric tube or gastrostomy, then morphine can be used either buccally or rectally. If facilities allow, then the use of syringe drivers can be most effective. They facilitate the provision of fast effective control of pain and other symptoms, avoiding the peak and trough effect of oral opioids. Where breakthrough pain occurs, then a dose of 1/10 to 1/6 of the 24 hour morphine dose can be given as required. There is no maximum dose of morphine. The dosages if increased correctly will neither cause nor postpone death.

2. *Death Rattle:*

The death rattle is often seen in the terminal phase. This can sound very distressing to the family and it is important that they are pre-warned regarding this. The rattle is caused by noisy secretions when the child is no longer able to cough up or swallow secretions within the large airways. As this tends to occur when the child has dropped their level of consciousness, it is not a direct cause of distress to the child.

Management should consist of the following:

- Positioning of the child's head to allow secretions to drain
- If linked with dyspnoea then treat with opioids and/or benzodiazepines
- Use hyoscine either subcutaneously or in the form of a patch
- Gentle suction only

3. *Seizures:*

The management of epileptic seizures is covered in a previous chapter. However in the acute situation a seizure can be controlled with either buccal midazolam or rectal diazepam. Occasionally rectal paraldehyde can be helpful. In situations where seizures are recurring and a syringe driver is available

then a subcutaneous infusion of either midazolam or phenobarbitone can be used.

4. *Dyspnoea:*

The first priority when presented with a child with dyspnoea is to rule out any treatable causes such as heart failure or asthma. When the dyspnoea is purely due to the terminal condition, then a low dose of opioids or benzodiazepines can be helpful.

5. *Fluids:*

The ethical issues' concerning withholding fluids is covered in the chapter on ethics. In general terms giving fluids via intravenous lines is normally inappropriate towards the end of life. There is a general multi-organ failure and shut down of the body, and as such the fluid requirements of a child are considerably diminished. Running the child slightly dry can also help reduce respiratory secretions. There is a natural shutdown by the body of renal function, and so urine output falls naturally. Thirst is rarely an issue towards the end of life, however it is important to continue to give the child small volumes of water even if this is just wetting the mouth or lips. Parents find this action comforting and reassuring.

Summary:

The actions that one takes as a healthcare professional when managing a child who is approaching the end of their life can have a profound effect on whether a child has a good or bad death. This will subsequently either help the parents cope with the loss of a child, or cause them great distress. The key to successful management rests with professional assessment, planning, communication and access to adequate resources. It is important that all the appropriate members of the team develop their knowledge and expertise within the subject, whether this involves symptom management, nursing care or understanding the religious and spiritual needs of the family. The death of a child is not the end of the journey for the parents or family and it can take many years for the parents to come to terms with the loss of a child, even if they ever truly do so.

References:

1. mery, J., *Children's Palliative Care in Africa*, ed. J. Amery. 2009: Oxford University Press.
2. ACT. Prompts for care in the last hours and days of a child's or young person's life. (cited; Available from: www.act.org.uk.)
3. GSF. HOLISTIC PATIENT ASSESSMENT - PEPSI COLA AIDE MEMOIRE. [cited; Available from: www.goldstandardsframework.nhs.uk.

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Conclusion

CPC is a child friendly approach enhancing holistic care for child and family while protecting their basic rights for alleviation of needless suffering and empowerment of their families thus improving Quality of life for children and caregivers.



CPC aims to create a Child Friendly environment where children are not threatened with the illness; especially where poverty, illiteracy, ignorance, superstitious beliefs, gender differences and social stigmatization is prevalent in society.

- *Advocacy for CPC by adoption of Paediatric Palliative Care Policy by the Govt. Involvement of National & International Organizations & Health Ministry*
- *To impart training and awareness to Doctors, Nurses, Social Workers, Health Care Professionals, Volunteers and NGO's in Knowledge, attitude and skill base to deliver supportive care to children*
- *Availability to pain relieving medication especially Morphine*
- *To empower children and families for improving QOL*

Children need to have Holistic development. Protection of the rights of the child is a must.

Right to Survival - Fundamental Right to Life
Right to Free and Healthy Development - Holistic Development
Right to Protection - Freedom from Exploitation
Right to Participation - Voice of the Child

ACT - Together for Short Lives (WHO, ICPCN) & CPC, India

Category 1	Category 2	Category 3	Category 4
Life - threatening Conditions Curative treatment may be feasible but can fail E.g. Cancer, irreversible organ failures of heart, liver, kidney	Premature death inevitable long periods of intensive treatment E.g. Cystic Fibrosis, Duchenne Muscular Dystrophy	Progressive conditions without curative treatment, where treatment is purely palliative E.g. Metabolic and Storage Diseases, like mucopolysaccharidosis	Irreversible but non-progressive disorders which increase risk of illness and premature death E.g. Cerebral Palsy, Multiple disabilities spine or brain injury
Focus on Holistic Care	Issues faced By both Child and Caregivers	Intervention	
Physical Symptoms	<ul style="list-style-type: none"> • Pain • Nausea • Poor appetite • Fatigue, tiredness • Burnout 	<ul style="list-style-type: none"> • Pain & Symptom Management • Medication & Referrals • Dietary and Nutritional Planning • Rehabilitation Services • Liaisoning with L.G.P • Home Care/ Respite / Hospice Care 	
Psychological & Spiritual Concerns	<ul style="list-style-type: none"> • Fear of pain and suffering • Anxiety & Grief • Depression • Spiritual Issues • Bereavement 	<ul style="list-style-type: none"> • Counseling - Individual, Family & Siblings • Alternative Therapies - Play, Music, Art • Addressing spiritual concerns • Support Groups • Rehabilitation • Bereavement support 	
Social Issues	<ul style="list-style-type: none"> • Stigma • Socialization • Change in family dynamics • Financial burden on the family 	<ul style="list-style-type: none"> • Creating a child friendly atmosphere at home, school, peers, community and Hospitals • Educating Caregivers • Sensitization & raising community awareness • Linking to Govt. schemes for subsidized aids - wheelchairs 	
Advocacy & Legal Measures	<ul style="list-style-type: none"> • Lack of Govt. support • No trained Health Care Professionals • Lack of legal aid 	<ul style="list-style-type: none"> • Child Rights & Child Protection • Education of Health Care Professionals - Doctors, Nurses, Social Workers • Networking with NGO's • Volunteer/ Lawyer Networks • Inclusion in Govt. Policies - Qualitative & Quantitative Health Services • Strengthening Govt. and Community participation • Focus Group Discussions FGD's addressing needs 	

"Voice of the Child"

CPC is a Child Friendly approach enhancing Holistic Care for "Child" and Family while Protecting their Basic Rights for alleviation of needless suffering and Empowerment of their families

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