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E.mail : ijpp_iap@rediffmail.com

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SUPPORTIVE AND PALLIATIVE CARE

INTRODUCTION TO PEDIATRIC PALLIATIVE CARE

*Dighe M
**Muckaden MA
***Vora T

Abstract: *Palliative care for children is a holistic approach aimed at improving the quality of life of children and families with a life limiting illness. This article describes the important principles of palliative care practice and the range of conditions where pediatric palliative care is applicable.*

Keywords: *Palliative care, Pediatric, Dying children*

Points to Remember

- ***Palliative care is an approach that aims to relieve suffering caused by a disease process without aiming to cure the disease.***
- ***Early interaction with a palliative care team may well enhance the quality of life of patients and the families.***
- ***In palliative care a multidisciplinary approach is a must.***

* Associate Professor
Department of palliative care

** Professor and Head
Department of palliative care

*** Associate Professor
Department of Pediatric Oncology,
Tata Memorial Centre, Mumbai.

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SUPPORTIVE AND PALLIATIVE CARE

AN OVERVIEW AND RELEVANCE OF PEDIATRIC PALLIATIVE CARE IN INDIA

***Muckaden MA**

Abstract: *Pediatric palliative care is a relatively new field of speciality carved out between adult palliative care and pediatrics. It provides a holistic approach to care for children with life limiting illnesses. There are conditions defined which need such services which require team work. In India broadly these are cancer, HIV infections, thalassemia, neurological and other conditions. Palliative care aims at improving 'quality of life'. Past, present and future are depicted. Children's palliative care project for Maharashtra and it's implications are discussed.*

Keywords: *Children's palliative care, Holistic approach, Quality of life, Key role of professionals, Chronic illness.*

Points to Remember

- ***Children with life-limiting or life-threatening conditions have very specific and unique palliative care needs, often different from those of the adults.***
- ***The focus is on improving 'Quality of life' which requires introduction of palliative care early in the trajectory of illness.***
- ***Children need appropriate pain and symptom management during the course of their illness. This includes not only physical care, but psychological, social and spiritual care for the child and family.***
- ***This requires country specific education and training for all cadres of health care practitioners in paediatric palliative care***
- ***There is a need for the expansion of palliative care for children and its integration into government policies and national, regional and local health care systems.***

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* Professor & HOD,
Department of Palliative care
Tata Memorial Centre,
Mumbai.

SUPPORTIVE AND PALLIATIVE CARE

ORGANISING A PEDIATRIC PALLIATIVE CARE UNIT

*** Muckaden MA**
**** Talawadekar P**

Abstract: *The essentials of pediatric palliative care unit is the skilled and interdisciplinary attention to pain and other distressing symptoms; emotional, spiritual and practical support; assistance with complex medical decision-making; and coordination across the continuum of care settings. Though the principle of care and basic structure remains the same, organizing a pediatric palliative care in rural and urban setting differs a lot.It definitely depends on background, culture and availability of resources.*

Keywords: *Pediatric palliative care, Children, Multi disciplinary team, Place of care.*

* Professor and HOD,
Dept of Palliative Care,
Tata Memorial Hospital,
Mumbai.

** Country Co-ordinator,
Children's Palliative Care Project,
IAPC, Mumbai

Points to Remember

- ***The goal should be to assist with the care needs of children and their families to achieve the best possible quality of life in accordance with their values, preferences and beliefs.***
- ***Palliative care needs in children are varied and according to the respective diagnosis and illness trajectory different approaches and measures are indicated.***
- ***As medical and technological advances reduce childhood mortality and improve survival for children with life-limiting conditions, there is a need to integrate effective and efficient child-specific palliative care into national health and social service policy.***
- ***It is very important to integrate specialized services like palliative care into the existing health care system for maximum utilization with minimum of cost; yet providing specialty services.***
- ***It is also important to focus on the fact that the ideal place of care can change as the situation evolves. The ideal place can thus shift from home to hospital and back to home again. The decision to change the place of care should be discussed at every stage with parents, physician, nurse and if possible the child itself .***
- ***An integrated model of palliative care "in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death"has to be adopted.***

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SUPPORTIVE AND PALLIATIVE CARE

PRENATAL PERSPECTIVES IN PALLIATIVE CARE

** Dighe M*
*** Muckaden MA*
**** Deodhar J*
***** Manerkar S*
****** Tilve P*

Abstract: *Palliative care for neonates is "an entire milieu of care to prevent and relieve infant suffering and improve the conditions of the infant's living and dying." In pregnancies with a malformed fetus, the parents and the live born will benefit from early involvement of palliative care professionals. In this article we attempt to discuss the important issues related to the care of a mother carrying a malformed fetus.*

Keywords: *Prenatal conditions, Perinatal palliative care*

* Associate Professor
** Professor and Head
*** Associate Professor, Dept. of Palliative Care, Tata Memorial Centre, Mumbai.
**** Associate Professor Dept. of Pediatrics, LTMC and Hospital, Mumbai.
***** Medical Officer Dept. of Palliative Care, Tata Memorial Centre, Mumbai.

Points to Remember

- ***Breaking bad news to parents when the fetus is detected to have an anomaly needs skill and compassion.***
- ***Counseling parents in the antenatal period must take the prognosis for survival into account.***
- ***Physicians must provide adequate information and support to parents so as to help them make appropriate decisions regarding termination of pregnancy.***
- ***Parents must receive adequate information about the prognosis of the resuscitation efforts and must receive appropriate emotional support to make decisions.***
- ***All babies who need palliative care must be monitored for pain***
- ***Social workers, psychologists and volunteers who have been part of the care giving team can play an important role in caring for the bereaved family.***

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SUPPORTIVE AND PALLIATIVE CARE

COMMON PROBLEMS AND THEIR MANAGEMENT IN PEDIATRIC PALLIATIVE CARE

*Atreya S
**Tilve P
** Dhilliwal S
***Muckaden MA
****Dighe M
****Deodhar J

Abstract: *Today with growing burden of disease and children with terminal illness, there is a pressing need for pediatric palliative care. This is an approach aimed at providing holistic care to children with terminal illnesses and their family. Pediatric palliative care is unique in its approach due to dissimilarity in the presentation of symptoms between children and adults. This review article outlines various salient features of pediatric palliative care which may aid the professionals caring for children with life limiting illnesses.*

Keywords: *Pediatric palliative care, Symptoms.*

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* Post Doctoral Fellow
** Medical Officer
*** Professor and Head
**** Associate Professor
Department of Palliative Care,
Tata Memorial Centre,
Mumbai.

SUPPORTIVE AND PALLIATIVE CARE

PAIN MANAGEMENT IN PALLIATIVE CARE

***Bhatnagar S**
*** Philip FA**
***Ahmed SM**
*** Joshi S**

Abstract: *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. This article narrates an overview of paediatric pain in brief.*

Keywords: *Palliative care, Pediatric pain, Pain assessment, Children.*

* Prof and Head
** Senior Resident
Unit of Anaesthesiology,
Institute Rotary Cancer Hospital,
All India Institute of Medical Sciences, New Delhi

Points to Remember

- ***Palliative care in pediatric setting should begin right from the diagnosis of the illness and continue through the course of the disease.***
- ***Palliative care should be instituted with appropriate drugs and other supportive measures as pain may make the child noncompliant to treatment and the parents to lose their trust in the treating personnel.***
- ***Inadequate relief of pain has been found to lead onto post traumatic stress disorder, depression and stress even years after treatment.***
- ***Clinicians often have misconceptions regarding the ability of children to perceive pain and to understand the nature and extent of pain completely.***
- ***Pain is often undertreated in children due to fear of addiction to opioids and misconceptions regarding opioid usage and ignorance regarding pharmacodynamics and dosage of opioids leads to their inadequate and improper usage.***
- ***Health professionals dealing with paediatric malignancies often lack knowledge regarding simple cognitive, behavioural and supportive techniques for pain managment.***

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SUPPORTIVE AND PALLIATIVE CARE

METAPHORS AND BEYOND: A JOURNEY OF HEALING USING ART AND PLAY BASED INTERVENTIONS

*Chopra R

Abstract: *Palliative care for children goes beyond just pain control and symptom management. It is a holistic model that also caters to the psychosocial aspects of the patient, their relationships, hopes, fears and wishes. Children seldom talk about their experiences, reactions, perceptions, feelings, wishes, wants or needs like adults do. Play is considered to be the natural language of a child. The symbolic language of play often reveals the child's inner world. This understanding can help the professionals to facilitate communication between parents and the dying child and thereby promote healing during the dying process.*

Keywords: *Childhood cancer, Play/art therapy, Healing, Psychosocial*

* Counselling Psychologist and Arts based therapy practitioner
St Judes India Childcare Centre,
Mumbai.

Points to Remember

- ***Only trained professionals should initiate play and arts based therapy with children.***
- ***The act of simply having toys available for your clients or involving them in drawing does not mean that they are receiving (or that you are practicing) play therapy or art therapy.***
- ***Change does not happen overnight. The process of therapy is more important than the outcome.***
- ***There is no prescribed list of the materials/toys kept in the play therapy room. The choice of play materials has to be carefully done as some clients might be aversive to some specific items.***
- ***Even the sickest child can be helped to play.***

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SUPPORTIVE AND PALLIATIVE CARE

NUTRITION IN PALLIATIVE CARE

*** Anjali Nair**

Abstract: *Nutritional support forms one of the essential adjuncts along with other measures of palliative care. To plan for proper nutrition of patients on palliative care, we need to assess degree of nutritional deficiency, type, quality of nutrients and decide about the mode of administration. The nutritive values of food items, various routes of feeding, their indications, advantages, etc are discussed in this article.*

Keywords: *Nutrition, Palliative care, Children*

Points to Remember

- ***Dietetic management is an essential part of palliative care.***
- ***Among various routes of feeding oral route is the simplest, cheapest and most physiological one.***
- ***Factors apart from illness to be considered to influence nutrition are preference of children, parents and relatives and pleasant environment.***

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* Chief Dietician,
Tata Memorial Hospital,
Mumbai.

SUPPORTIVE AND PALLIATIVE CARE

DEVELOPMENTALLY APPROPRIATE COUNSELING NEEDS IN PEDIATRIC PALLIATIVE CARE

*Jadhav S
**Sovani A

Abstract: *Aim and objectives: This paper aims to discuss and highlight the need for developmentally and age appropriate counseling for children and adolescents. Case studies are used as a qualitative tool to understand issues that need age appropriate counseling intervention for children facing advanced life threatening illness. Key issues regarding comprehension of their condition and coping devices to handle the resultant emotions are presented. The need for age appropriate developmental counseling is highlighted. Case studies are used to illustrate the child's understanding of his/her condition and the counselor's understanding of the latter.*

Keywords: *Cancer, Palliative care, Developmentally appropriate counseling.*

Points to Remember

- ***The role of palliation needs to be explained to parents. The aim is management of symptoms and not disease cure, since the latter is no longer feasible.***
- ***The goal is of building up a relationship, rapport and trust with patient and families, leading to their empowerment and improved compliance.***
- ***Unforeseen occurrence of emergency may be there and false hope is not given.***
- ***For younger, less verbal children, therapeutic intervention in the form of play, art, craft, drawing, picutre, stories and narrations of illness trajectory can be helpful and the same can be taught to parents.***
- ***Older children may wish to be partners in disclosure and care and exert autonomy of choice of place to live.***
- ***Innate resilience of children and adolescents is apparent, often more so in India where fatalistic attitudes are often engendered by the culture and spiritual outlook. In India many children grow up and mature to shoulder familial burden of survival.***

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* Medical Social Worker,
Tata Memorial Hospital,
Mumbai.

** Associate Professor,
Department of Applied Psychology,
University of Mumbai, Mumbai.

SUPPORTIVE AND PALLIATIVE CARE

COMPLIMENTARY AND ALTERNATIVE THERAPY - YOGA IN PALLIATIVE CARE

*** Pandya SS**

Abstract: *Yoga is an ancient Indian practice of healing mind, body and soul. Today, yoga has become one of the popular areas of research and is being effectively used as a component of Alternative and Complimentary Practice of palliative care for many ailments. What is unique about the practice of yoga is that it is not confined in its application and people from all age-group can benefit from it. In the recent years, with its wide application in the field of education and health, yoga has become an integral part of learning and practice in children's lives and recent research focuses on studying beneficial effects of yoga on children.*

Keywords: *Yoga, Children, Cancer, Alternative and Complimentary Medicine, Mindfulness Meditation.*

Points to Remember

- ***Yoga, an Indian body of knowledge is widely used and practiced around the globe to achieve mind-body balance, spiritual awakening and healing.***
- ***The therapeutic powers of yoga are integrated with modern medicine today and it is suggested that it is very effective in providing comfort and in some cases cure, to the patients with various ailments and life-threatening illnesses.***
- ***Yoga is beneficial for everyone be it children, young adults or senior citizens.***
- ***Yoga is evolving as an adjunct to healing practice and there is great scope for research in this area especially to understand its effects among children and adolescents suffering from life-threatening illnesses.***
- ***There are Children Cancer Hospitals in the US who have adopted yoga practice and offer it to their pediatric patients.***
- ***"Mindfulness Meditation- a mind-body intervention" is studied and being used in pediatric clinical practice today.***

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* Pediatric Counselor,
Palliative Care Dept.,
Tata Memorial Hospital,
Mumbai.

GENERAL ARTICLES

SYNCOPE IN CHILDREN

***Chokhani Rajesh R**

Abstract: *Syncope is not uncommon in children. Since the list of causes is large, a sound clinical approach is necessary to effectively separate out syncope from its mimics, and then zero down on the probable diagnosis. While vasodepressor syncope is the commonest and benign, it is crucial to identify potentially life threatening cardiac syncope as well. This article attempts to outline a practical approach, which on one hand limits unnecessary investigations, while on the other, effectively screens for serious disorders.*

Keywords: *Syncope, Pediatric, Vasodepressor, Cardiac*

Points to Remember

- ***A detailed history and a thorough physical examination is the most important initial evaluation in children with syncope***
- ***Vasodepressor syncope is the commonest type of pediatric syncope that is diagnosed by its classical history.***
- ***Evaluation of pediatric syncope should be able to identify cardiac syncope which is potentially dangerous; an ECG, along with the history and physical examination, has a 96% sensitivity in picking up cardiac syncope.***
- ***A long list of aimless investigations may not be useful.***
- ***The mainstay of treatment of vasodepressor syncope is largely reassurance and general non pharmacologic measures; drugs are only occasionally used in cases of recurrent syncope.***

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* Consultant Pediatrician,
Mumbai.

GENERAL ARTICLES

NUTRITIONAL DEFICIENCIES IN NORMALLY GROWING CHILDREN

***Rajeshwari K**
****Dubey AP**

Abstract: *Nutritional deficiencies are common in the pediatric population specially among impoverished populations. This is more so among growing children. Overt nutritional deficiencies are well known to all; however subclinical deficiencies in normally growing children are difficult to assess and treat . This aricle focuses on the common nutritional deficiencies seen in normally growing children with special reference to Indian population.*

Keywords: *Nutritional deficiency, Normal growth, Children*

Points to remember

- ***Nutritional deficiencies are common in children.***
- ***In normally growing children it is important to diagnose various deficiencies specially when manifestations of deficiencies are not overt.***

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* Professor

* Director Professor and Head,
Department of Pediatrics,
Maulana Azad Medical College,
New Delhi.

GENERAL ARTICLES

ANTIEMETICS IN PEDIATRICS

***Jeeson C Unni**

Abstract: *A consensus on the indications for the use of antiemetics in children needs to be formulated as most drugs under this drug class have side effects and most common causes of vomiting in children do not require medication for control of emesis. This article is an attempt to resolve certain issues related to the use of antiemetics in children.*

Keywords: *Antiemetics, Cytotoxic drugs, Chemotherapy, Post operative vomiting, Acute gastroenteritis, Motion sickness, Phenothiazines, 5-HT$_3$ antagonists.*

* Editor in Chief,
IAP Drug Formulary,
Consultant Pediatrician,
Cochin.

Points to Remember

- ***Prescribe an antiemetic only when the cause of vomiting is known, as it might otherwise delay diagnosis.***
- ***In certain conditions antiemetics are unnecessary and sometimes harmful when the cause can be otherwise treated such as in diabetic ketoacidosis, or in digoxin or antiepileptic overdose.***
- ***In conditions where drug treatment is indicated for control of nausea and vomiting, drug appropriate for the etiologic needs to be chosen.***

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DERMATOLOGY

IMMUNOBULLOUS DISEASES IN CHILDREN

*Thomas J
**Kumar P

Abstract: *Auto immune blistering disorders are heterogeneous group of diseases that result from auto antibodies generated against target antigens found in the skin and mucous membranes. This process leads to a variety of disruptions in keratinocyte adhesion and cellular integrity, resulting in fluid accumulation and development of blisters. Physicians should have an appreciation and understanding of autoimmune blistering disorders in the pediatric population when formulating a differential diagnosis of a patient who presents with skin blistering. Early detection and discrimination between the varied autoimmune blistering disorders can change the course of treatment and outcome. Due to the similarity in clinical presentation among different diseases within this category, histopathologic evaluation and, especially, immunofluorescence studies are necessary to establish the definitive diagnosis.*

Keywords: *Immunobullous diseases, Children*

* Professor of Dermatology,
Sree Balaji Medical College and Hospital,
Chromepet, Chennai.

** Professor of Dermatology
Thanjavur Medical College, Thanjavur.

Points to Rembember

- ***Immunobullous disorders in children, though rare are not infrequent.***
- ***High index of suspicion will help early diagnosis and management. Steroids form the main stay in pemphigus group of diseases with or without another immune suppressant.***
- ***Pulse therapy of steroid when administered carefully gives better results with lesser side effects. Pemphigoid has a relatively better prognosis when compared to pemphigus and hence can be treated with steroid alone.***
- ***Dapsone is the drug of choice in CBDC and bullous SLE. Other drugs like IV Ig and biologic agents should be used only in selected cases where the other drugs fail.***

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CASE STUDY

LYMPHADENOPATHY - A DIAGNOSTIC CHALLENGE

***Vijayasekaran D**
****Kalpana S**
****Sarath Balaji B**

Abstract: *Chronic lymphadenopathy in children can sometimes be diagnostic dilemma. A seven year old female child presented with isolated left sided posterior cervical lymphadenopathy. Investigations for tuberculosis and lymphoma were negative. Histopathology helped to arrive at the rare diagnosis of Kikuchi -Fujimoto disease.*

Keywords: *Lymphadenopathy, Kikuchi Fujimoto disease, Children*

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* Professor of Pediatric Pulmonology

** Assiatant Professor of Pediatrics,
Department of Pulmonology,
Instutite of Child Health and Hospital for Children
Chennai

CASE STUDY

GANGLIONEUROBLASTOMA PRESENTING AS VERNER MORRISON SYNDROME

***Latha Vishwanathan**
****Anita Tarigopula**
*****Sripathi V**
******Harish S Kumar**
*******Malathi Sathiyasekaran**

Abstract: *Ganglioneuroblastoma secreting vasoactive intestinal polypeptide and manifesting as a triad of watery diarrhea, hypokalemia and achlorhydria (WDHA) or Verner Morrison syndrome (VMS) is a rare entity. We report a 4 year old boy with recurrent watery diarrhea and hypokalemia diagnosed as VIP secreting ganglioneuroblastoma with complete resolution of symptoms following surgery and on regular follow up.*

Keywords: *Ganglioneuroblastoma, VIP, Watery diarrhea, Verner Morrison syndrome.*

* Senior Consultant,
Department of Pediatrics

** DNB Resident (Pediatrics)

*** Consultant,
Department of Pediatric Surgery and Urology

**** Registrar,
Department of Radiology

***** Senior Consultant,
Department of Pediatric Gastroenterology
Apollo Children's Hospital, Chennai.

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