

# Pediatric Palliative Care: Comprehensive Support for Children

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## ABSTRACT

Palliative Care (PC), is the set of actions and tools that seek relief from symptoms and suffering of patients and their families to diseases that threaten their lives. This support includes different types of resources covering the clinical, socio-economic, emotional, psychological and spiritual aspects. Due to increasing life expectancy of humans and the fact that chronic diseases account for 60% of premature death, mainly due to cardiovascular diseases, neurological and malignant tumors; has been the global need to create, implement, and enhance knowledge and PC local programs. In pediatrics, there are four main reasons why a child can and should receive pediatric palliative care (PPC): Cancer, Cystic fibrosis, Metabolic or Mitochondrial and/or Progressive Muscle Diseases and Neurological Disorders. In this article we analyze synthetically the definition, types and basic definitions on the CPP matter. Also, we share the local experience about the first pediatric palliative care program focus in oncologic patients on the Dominican Republic. To review the basics and history of palliative care. To establish the goals and definition of pediatric palliative care, symptom management, terminal illness and integral support. To describe the local pediatric palliative care in oncology unit at Dr. Robert Reid Cabral Children's Hospital in Dominican Republic as the first PPC local program in the country for children with cancer.

## PALLIATIVE CARE AND HOSPICE DEFINITION AND HISTORY

The actual definition of World Health Organization (WHO), designates the concept of Palliative Care as the integral support that seeks the quality of life of the patients and their families when they face a life-threatening disease, by combating suffering through pain relief, and offering support, psycho-social and spiritual emotional area.<sup>1</sup>

This definition has not always been the same, as has been reformulated as it evolves the world and human needs. The term palliative derives, from the word pallium

from the Latin language that means blanket or quilt, referring to the act of harboring or protect by relieving symptoms and suffering.<sup>2</sup> On the other hand, Hospice, comes from the word Hospitium, which refers to the warmth provided by the host when the guest arrives.

During the middle Ages, hospices were places of welcome for the pilgrims, who often arrive sick or dying. In 1842, again was taken the concept, where in France Mme Jeanne Garnier, created the first hospices or Calvary, later In Dublin and Ireland the Sisters of Charity gave continuity to this work, but it was not until 1967 when started the Modern Hospice Movement in London, where it was founded the St. Christopher's Hospice.<sup>3,4</sup>

In 1987, England named Palliative Medicine, defined this important area of medicine as the one focused on patients with progressive, refractory or advanced disease, with limited prognosis and the subsequently approach to quality of life.<sup>5</sup> WHO in 1980 officially promotes palliative care as part of the Cancer Control Program, in 2002 was defined as the integral care of

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patients with refractory disease, focusing on alleviate pain and symptom management.<sup>6</sup>

The actual WHO definition is that Palliative care for children is the total care support of the psychological, anatomical and spiritual sphere from the child ante his family. This total care begins when the disease is diagnosed, and continues during all the treatment regardless of whether or not a child achieve cure or regardless the child gets direct treatment to his disease.<sup>1</sup>

## GOALS OF PALLIATIVE CARE

Relieve distressing symptoms and pain;  
Affirm life and see the death as a normal process and a part of the life;  
No delay death, will not accelerate death, does not prolong life;  
Take care of the mind and body aspects of the child and the family;  
Help patients to be active as possible till the last part of their lives;  
Help the family during the child's illness and bereavement;  
Offer support for all needs, including emotional support;  
Seeks to try to offer better quality of life;

They can be offer at an early stage of the disease, along with other treatments that can cure such as chemotherapy or radiotherapy, and include the necessary measures to better understand and manage clinical complications in all human areas.<sup>1</sup>

## PALLIATIVE CARE FOR CHILDREN

It has been reported that in the United States, each year 50,000 children die and 500,000 have to face life-threatening diseases. In 2000, the American Academy of Pediatrics established that the components of palliative care can be provided from diagnosis and continue during the whole course of the disease, regardless if they finish in cure or death and that these should be available in home, hospital or school.<sup>7</sup>

It's basic, that in chronic and serious illnesses of children, health workers and family, are able to provide the interventions focus on improve the quality of life of the patients, and it is important to note that palliative care they are no longer offered only to children who will die, but can offer as support and complementary treatment to children in curative treatment. And neither the patients nor their families should choose, can take both boarding actions, concomitantly Figure 1.

In pediatrics, there are four main reasons why a child can and should receive pediatric palliative care (PPC):



**Figure 1:** Image from: [botswanaSeptember2010.blogspot.com/2014/01/what-is-palliative-care-for-children.html](http://botswanaSeptember2010.blogspot.com/2014/01/what-is-palliative-care-for-children.html)

cancer, cystic fibrosis, progressive metabolic mitochondrial and/or muscle diseases, and neurological disorders.<sup>8</sup> More precisely between the causes that can lead to a terminal illness are: congenital abnormalities, chromosomal abnormalities, injuries or neurological disorders, liver disease, immunopathies, cancer, cystic fibrosis, acquired immune deficiency syndromes, short bowel syndrome and complex chronic conditions.<sup>9</sup>

## INTEGRAL SUPPORT FOR CHILDREN, CATEGORIES

Within the comprehensive support should be offered to children who face conditions or diseases that threaten their lives, we must consider the following factors:

### SYMPTOM MANAGEMENT

The appropriate approach and anticipation of the symptoms of each patient according to their underlying disease, are essential for an integrated approach, since it will be aware of events which may occur, and how we might address them. Signs and symptoms to consider are: pain, dyspnea, anxiety, allergies or itching, nausea and vomiting, seizures, cluster oropharyngeal secretions, diarrhea, constipation. See Table 1.

### PAIN MANAGEMENT

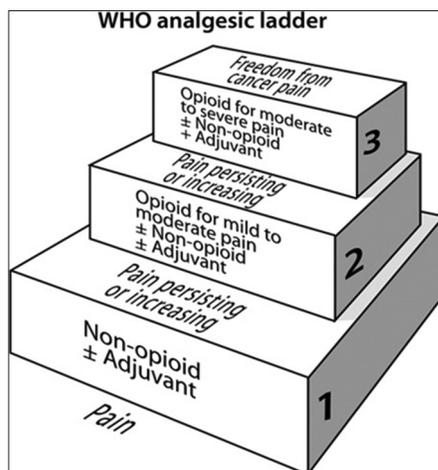
Certainly, the pain is one of the most common and prevalent symptoms in infants facing serious and threatening disease, sometimes the lack of verbal communication, and various taboos (children do not suffer pain or, if treated they will become addicted), derived from lack of proper knowledge of pain management lead to failure in their therapeutic approach.<sup>1</sup> See Figure 2.

### INTEGRAL SUPPORT

In order to provide comprehensive support, it is appropriate to offer the resources of aroma therapy, massage therapy,

**Table 1: Medication used for common symptoms and signs in PPC**

| Indication                | Proposed medication                              | Initial regimen   |
|---------------------------|--|---|
| Dyspnea                   | Morphine   | 0.3 mg/kg orally or<br>0.1 mg/kg IV each 4 hours  |
| Anxiety                   | Lorazepam<br>Haloperidol                         | 0.05 mg/kg orally each 8-12 hours<br>0.01-0.02 mg/kg orally<br>each 8-12 hours  |
| Itching or allergy        | Diphenhydramine                                  | 0.5-1.0 mg/kg VO each 6-8 hours   |
| Nausea and Vomiting       | Prochlorperazine<br>Ondansetron<br>Dexamethasone | 0.1-0.15mg/kg orally each 6-8 hours<br>0.15 mg/kg orally each 6-8 hours<br>10 mg/m <sup>2</sup> /does each 12-24 hours IV                 |
| Seizures                  | Diazepam   | 0.3-0.5 mg/kg under response  |
| Oro-pharyngeal secretions | Hyosciamine                                      | 0.0625-0.125 mg orally each 4 hours<br>in child's between 2-12 years<br>0.125-0.25 mg orally each 4 hours in<br>child more than 12 years. |
| Diarrhea                  | Loperamide                                       | 0.1-0.2 mg/kg/does orally each 8<br>hours in child's < 12 years   |
| Constipation              | Milk Magnesia                                    | 1-3 ml/kg/day orally  |

**Figure 2:** WHO pain ladder<sup>3</sup>

music therapy, psychological support, spiritual support, play therapy, socio-economic support, volunteer service and home hospice. These resources, coupled with an integral team of physicians, sub-specialists, volunteers, social workers, nurses, therapists, between others; will ensure a complete and efficient service that will aim to improve the quality of life for the patient and support system for the families.

## TERMINAL DISEASE

Terminal illness is a medical term, indicating that a disease cannot be cured, and is expected to result in death of the patient (in this case child) within a short period of time, the Manual of Ethics of the American College of Physicians states that this period by usually lasts 3-6 months.<sup>10</sup> At this stage, we can find a progressive and incurable advanced disease with no reasonable chance of response to a specific

treatment. numerous problems, or multiple and intense symptoms that cause an important emotional impact on the patient, family and care team are also observed; usually at this time, there is a life expectancy declined and needs focus on the patient.

It is essential to understand that in the terminal stage the body has a different physiological behavior characterized by:

- Decrease in food intake due to the decrease in overall metabolism and decrease normal intestinal transit. Therefore it is important not to force feed and provide the patient with food he wishes trying to include cool drinks, flavored frosty ice to refresh the throat, among others.
- Pseudo-dehydration with endogenous production of water, leading to extravasations and edema secondary, occurs decrease of fluid in the intravascular space passing it into the interstitial space, because of the decreasing of the colloid-osmotic pressure; so it is not appropriate to offer these patients intravenous hydration as far from help in their bodies will be produce more edema and extravasations, this may lead to a pleural and/or pericardial spill.<sup>11</sup>
- Dyspnea, which can be caused by different factors such as pain, agitation or pleural effusions. The use or non-use of oxygen by cannula or mask is still under discussion, it is assumed that it is not necessary to place external inputs of oxygen if there is no real hypoxemia measured by a pulse oximeter, but we must not forget that the psycho-emotional factor prevails. Therefore if the external supply of oxygen relieves symptoms of the patient, it is appropriate to offer; Moreover even if the patient evidence chest movement that could be translated into respiratory distress, if it refers to feel good, there's no need to force him to put oxygen.
- Accumulation of secretions caused by the production of endogenous water (detailed above), this may occur primarily at oropharyngeal area, producing a rattle that rather than to the patient, family members around him could become uncomfortable. The use of vacuum cleaners is not recommended as they may damage the oral mucosa of the patient, could be used the hyoscyamine, detailed in Table 1.

## INTERNATIONAL INITIATIVE ON QUICKLY EVOLUTION

Every day the PPC earning more importance and space due to the recognition of their great need and evidence reported in multiple studies where unequivocal benefits that they provide to patients and their families are reported, whether they are faced with a therapeutic approach healing or not healing, decreasing the incidence of therapeutic cruelty product only focus on the underlying diseases of patients.

|   |   |
|---|---|
| <b>Mild Pain:</b>   |   |
| •   | Paracetamol acetaminophen :15 mg/kg each 4-6 hours, orally combine with,        |
| •   | Ibuprofen : Hiosciamine 10 mg/kg each 6-8 hours orally.                         |
| •   | Also could be use ketorolac/Diclofenac/mefenamic acid base on response and case |
| <b>Moderate pain:</b>   |   |
| •   | Tramadol oral drops:  |
| ➤   | Childs :1 a 2 mg/kg does  |
| ➤   | Kids between 20-29 kg = 10-20 drops   |
| ➤   | Kids between 30 a 45 kg = 20-30 drops   |
| ➤   | Kids more than 45 kg = 30-40 drops  |
| This does could be repeated each 6 hours  |   |
| •   | Nalbuphine (Nubain):  |
| Childs between 1-14 between 0.1-0.15 mg/kg each 3-6 hours (maximum dose per day 160 mg) |   |
| •   | Ketorolac < 2 years 0.25 mg/kg each 6-8 hours                                   |
|   | >2 years 0.5 mg/kg each 6-8 hours   |
| <b>Severe Pain:</b>   |   |
| •   | Morphine  |
|   | IV 0.05-0.1 mg/kg each 2-4 hours  |
|   | Orally mg/kg each 2-4 hours   |
|   | IV Infusion mg/kg/hours   |
| Lockout interval: 5-10 minutes and rescue bolus of 0.1 mg/kg                            |   |
| Oxycodon:   |   |
|   | Orally 0.1-0.2 mg/kg each 4-6 hours   |

**Figure 3:** Adapted pain management in PPC program in DR based on local resources

The PPC have come to collect a set of strategies that reduce suffering and increase relief in all core human areas.

Actually, there are more than 8,000 palliative support services around the world that include follow-up consultation services, hospice, inpatient, volunteering, etc., It is worth noting that in September 2006 the Board of the American Academy of Medicine, gave the Palliative Medicine formal status of sub-specialty.<sup>12,13</sup> There are numerous international journals, volunteering, scientific associations and research groups focused on spread the concept and strategies based PC and PPC. Example: the

Latino American Association of Palliative Care (ALCP) and Palliative Without Borders (Paliativos Sin Fronteras), The American Academy of Hospice and Palliative Medicine (AAHPM), Education in Palliative and End of Life Course (EPEC) with the variants for Canada and Latin-American population.

### **BARRIERS AND OBSTACLES ON THE DEVELOPMENT OF PALLIATIVE CARE**

Understanding that this beautiful but difficult task requires many resources to develop, it is important to emphasize

that there are various factors that adversely impact the PC and PPC, for example:

- Lack of interest
- Absence of an interdisciplinary, available, empathetic and academically and emotionally ready to care for these patients team.
- No resources available exclusively for palliative patients and their needs.
- Poor or no access to pain medicine, mainly opiates to help to alleviate severe pain.

## PALLIATIVE CARE IN DOMINICAN REPUBLIC

In the Dominican Republic, there are no continuing or formal training in palliative care, nor is there a national program or protocol that establish the attention of care for these patients. Adults have had since 1988 the Pain Clinic Cancer Institute Dr. Heriberto Pieter, currently led by Dra. Gloria Castillo, this unit has supported occasionally pediatric patients.

In January 2012 was created the first pediatric palliative care country program, called Palliative Care & Metronomic Therapy Program in the oncology unit at Children's Hospital Dr. Robert Reid Cabral, the largest pediatric center of 3<sup>rd</sup> level in the Dominican Republic this center has now 390 beds, the program is led by Dr. Wendy Gómez García. The program has provided specialized care for 57 cases of cancer patients who for diverse reasons had need as palliative approach like refractory disease, first or 2<sup>nd</sup> line treatment in patients with metastatic disease plus psycho-social danger factors added, or recurrent/refractory disease with no curative treatment option feasible.

This program offers: exclusive follow-up appointments or in-patient attention, 24/7 emergency phone support, metronomic chemotherapy to disease control, socio-economic support from the Foundation Friends Against Childhood Cancer (Fundación Amigos Contra el Cáncer Infantil, FACCI), among others. It has created an adapted protocol for the program and a guideline to pain management, based on the reality and local resources. Figure 3.

So far, the results of this PPC project has been internationally exposed at the Conference of the American Association of Pediatric Oncology (SLAOP) in Puebla, México 2014, winning the 3<sup>rd</sup> place of free papers presented. Also has been exposed at the International Congress of Palliative Care Network 2015 obtaining a honor mention.<sup>14,15</sup> There are plans to expand this program in order to include pediatric patients of the National Cancer Institute Rosa Emilia Sanchez Perez de Tavares (INCART).

Along with the program, they were given a series of lectures and talks at national and international levels for the purpose of providing continuing medical education for general practitioners, pediatricians and hematologists-oncologists under the custom logo and so-called vision of Creating Positive Metastasis; which tries to find the goodness within the catastrophic situation of the cancer disease (resilience), and the right attitude and aptitude which the teams disseminate and share knowledge about palliative care, with the understanding that not only the bad things must be metastatic, and that we can fight them with the quickly multiplication of positive and good actions or knowledge Figure 4.

## PUNCTUAL NEEDS TO INITIATE A LOCAL PALLIATIVE PROGRAM

Recognizing the need and usefulness of the PPC.

To be open to change and incorporating the concept in our daily practice.

Preparation and continuous academic and emotional training in PPC.

Availability of resources to support drugs, drugs for pain management and comprehensive therapy.

Reduce to a minimum the suffering in our patients.

Having a National Program to endorse and issue the appropriate guidelines for intervention and implementation of PPC.

## CONCLUSION

It is important that all who work in the area of health keep in their ability to provide assistance to patients who face conditions that threaten their lives and understand the basics of palliative approach so that, they can provide better attention focused on the improvement of the quality of life and comprehensive support to adults and children. We need to create individual, collective and government awareness in each of our health centers and in each of our countries, to make the PPC a reality. Let's continue Creating Positive Metastasis.



Figure 4: Creating positive metastasis logo

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