



Palliative Care: From Global to Local Needs

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Abstract

Palliative care (PC) is a comprehensive approach that focuses on improving the quality of life of patients and families that face fatal diseases by optimal minimization of suffering. Seventy-eight percent of patients who benefit from palliative support live in low-and-middle-income countries, where the access to these services is limited. Six percent of the patients are below the age of 15. The aim of this study is to review briefly the history of PC and its global challenges and indicate its impact and barriers in the Dominican Republic. A literature review in PubMed and analysis of the history of impact globally of PC and a remark of Dominican Republic local program. Some of the identifiable barriers are the limited support from authorities and health systems, the discomfort of healthcare staff in providing PC, the lack of knowledge, as well as experience, and team support. Not only do low-and-middle-income countries face these challenges, but also globally there is an urgency of the integration of PC services to the different healthcare systems to improve quality of life. This was experienced in the Dominican Republic when the first PC program started in 2012. Currently, local efforts are being made to increase the impact of the program and to make it accessible to more patients and families.

Keywords

- ▶ palliative care
- ▶ global
- ▶ children

Introduction

In general, when the term “Palliative Care” is heard, the thought is usually focused on cancer patients, patients with a noncurable disease, or those on their deathbed. When this term is used for a child, the impact is more dramatic.

Globally, there is an enormous need to help, prevent, and relieve unnecessary suffering worldwide by reducing the disparity in access to pediatric palliative care (PC) and pain control. Around 78% of people in need of PC live in developing

countries. Here, continued access to essential supportive medicines for pain control is not available. PC is globally recognized as a legitimate component of healthcare. It effectively improves the quality of life (QoL) of adults and children and should be a central feature of all good clinical practices.¹

Remarkably, 6% of the requirements of PC are for children under 15 years old. This is a global concern as 27% of the world population is under the age of 15. In most parts of the world, it has been estimated that ~7 million children around

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the world will need children palliative care (CPC) each year. CPC has a poor profile and often it is inaccessible to those who need it.²⁻⁴

Discussion

Historically, when we analyze the evolution of the concept of PC, until 1980, the World Health Organization (WHO) did not officially incorporate the concept of PC as a part of the "Cancer Control" program. Fifteen years later, in 1995, the Pan American Health Organization also officially incorporated it into its assistance programs.

It is essential to observe that these approaches focused solely and exclusively on patients with malignancies. In 2002, the WHO published a proper definition of this concept: active and comprehensive care of patients whose disease does not respond to curative therapies. Without a doubt, an advancement and increase in accessibility of the approach were observed; but in reality, institutions and clinical teams still continue to limit palliative care to noncurable and terminal patients.⁵

Over time, acceptance to consider dialogue between the different stakeholders like clinical caregivers (palliativists, algologists, psychologists, nursing team members), social workers, health administrators, health authorities; interdisciplinary analysis of applicability of PC in different regional settings; and the scope of PC were expanded. Currently, the WHO understands PC as the comprehensive approach that improves the QoL of patients and families that face diseases associated with life-threatening conditions through the prevention and relief of suffering, the early identification of stressful symptoms, the impeccable evaluation as well as treatment of pain with other physical, spiritual, and psychological problems.⁶

In 2014, the first global resolution on PC was issued, urging WHO and all member states to improve access to PC as a central component of health systems emphasizing on primary health care. The WHO recommended strengthening PC programs by:

- Integration into all relevant global disease control plans and health systems.
- Develop guidelines and tools to be integrated into all disease groups and levels of care for addressing ethical issues related to comprehensive PC.
- Improving access to pain and symptom management medications.
- Promote greater access for children (in collaboration with UNICEF).
- Direct financial resources to develop programs and research on the topic, especially in countries with limited resources.

However, healthcare professionals, including pediatricians around the world, despite its importance and benefits, find several significant barriers for the early integration of PC in the disease trajectory. Healthcare providers often find it challenging to provide proper support due to barriers such as prognostic uncertainty; time constraints; discomfort of

healthcare staff in providing PC; lack of knowledge, experience, and team support.⁷⁻⁹

Palliative support begins when a life-threatening illness is reported and continues throughout the disease regardless of whether the treatment goal is curative or noncurative. It is essential for the management of chronic and severe conditions. It is imperative to emphasize that PC is no longer only advised for terminally ill patients; it can also be offered as support and as a complement to all patients with the intent of curative treatment.

Global Challenges in Numbers

It's important to highlight that most children (78%) in need of PC live in low- and middle-income countries.¹⁰ In addition, Latin America has one of the highest percentages of children in need of oncologic, pediatric, and PC.^{11,12}

Forty million people need PC yearly. Out of these, 20 million need PC at the end of their lives; 18 million die in pain due to lack of access to required pain medications; 78% of those who need it live in low- and middle-income countries; 69% of patients who need it are people over 60 years old; 6% of the requirements are for minors aged under 15 years old. Fifty-five billion people do not have adequate access to pain medication. Only in 8.5% (20 countries) PC is integrated into health systems; more than a third of the world (42%) does not have access to PC. Only in 14% countries, terminally-ill patients had their PC needs met.¹³

Local Pediatric Palliative Care Experience in Dominican Republic

There are four leading entities for which a child can and should receive pediatric palliative care: Cancer, cystic fibrosis, progressive metabolic, and neurological disorders. In January 2012, in the Dominican Republic, the first palliative program with an oncopediatric approach in the country was created in the Onco-Hematology Unit of the Dr. Robert Reid Cabral Children's Hospital, the largest tertiary childcare center in the country. So far, specialized care has been provided with exclusive attention to terminal patients, palliative interventions for clinical and psychosocio-emotional stressing situations, as well as palliative-oncological follow-ups with outpatient consults. These consults focused on topics such as refractory disease to the first- or second-line treatment, metastatic disease with added psychosocial danger factors, or recurrent disease with a nonviable curative therapeutic option, among others.^{14,15}

In the Dominican Republic, various barriers have been identified in the implementation of PC such as over demand for services, lack of health insurance coverage mainly among the most vulnerable sectors of society, even more so with catastrophic illnesses, the increase in migration over the past years, the absence of hospice care, and limited access to high-cost medications such as opioids. In educational terms, it is important to highlight the absence of formal local education

and the low interest of clinical teams in the applicability of palliative support due to taboo concepts, misinformation, and fear of the use of opioid drugs.

The Oncology Unit of the Dr. Robert Reid Cabral Children's Hospital has been characterized as offering holistic support and a palliative approach to all children diagnosed with cancer. These children benefit from comprehensive care and symptom management, which has a "zero tolerance to pain" policy through interventions guided by "WHO international therapeutic guidelines" and protocols adapted to local needs of available drugs including the rational and responsible use of opioids. This vision and project have also been started at National Cancer Institute Rosa Emilia Sánchez Pérez de Tavares since 2016.¹⁵

Conclusion

Undoubtedly, PC for children is growing around the world; all regions have been developing and advocating for CPC services, recognizing them as a fundamental human right. A lack of CPC availability for children is not acceptable.

Countries should continue learning from each other for improvement, such as the timely referral, appropriate pain management, and end-of-life interventions for a child, creating a pediatric hospice, and improving the follow-up sessions for the bereaved family. There is a need to continue to strive for access to quality PC for children worldwide as well as support and empower those working to provide quality CPC services.

Neither children nor their parents should face the disjunctive of choosing a curative or palliative perspective; they should obtain both approaches concomitantly. Ministries of health, hospitals, healthcare institutions, principally from low- and middle-income countries, should integrate PC into the regular health approach of pediatric patients in sustainable ways, by strengthening healthcare systems, providing financial protection, and contributing to universal health coverage. All these steps are necessary to ensure that all children have access to these services when they need it; through advocacy this can become real. It is time to offer children access to a better quality of life globally.

Conflict of Interest

None declared.

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