Pediatric Palliative Care in Guatemala: ADAPT Profile

• The Assessing Doctors’ Attitudes on Palliative Treatment (ADAPT) study was conducted in 2020, in collaboration with local stakeholders.
• The study identified physician access, knowledge, and perceptions on palliative care integration for children with cancer as outlined by the World Health Organization (WHO) guide in 2018.
• The study received 874 physician responses from 17 countries (for published references, see p.2.).

PALLIATIVE CARE: defined by the WHO as the prevention and relief of patient suffering and the “ethical responsibility of health systems” that “should be integrated with and complement prevention, early diagnosis and treatment.”

Palliative care improves treatment outcomes such as:
• Improved quality of life
• Better pain control and symptom management
• Decreased hospitalizations and fewer days in the intensive care unit

Palliative care integrated into health care systems at all levels and home care reduce health care costs by:
• Decreasing unnecessary resource utilization
• Being less expensive
• Yielding better outcomes.


Access to Pediatric Palliative Care

- 25% reported no access to palliative care consultation in their practice
- 0% indicated that palliative care consultation is not available when they feel it is needed for children with cancer
- 5% felt that palliative care was involved too late in the treatment of a child with cancer
- 89% believe palliative care reduces suffering for a child with cancer
- 74% believe palliative care should be integrated earlier than typically occurs in their childhood cancer setting

Physician Perspectives on Actual vs. Ideal Timing of Initial Palliative Care Consultation

<table>
<thead>
<tr>
<th>Access to Palliative Care</th>
<th>Access to Palliative Care</th>
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<tbody>
<tr>
<td>Diagnosis for all patients</td>
<td>Diagnosis for high-risk patients</td>
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<tr>
<td>Disease relapse or progress</td>
<td>High symptom burden</td>
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<tr>
<td>No curative options available</td>
<td>End of life</td>
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<tr>
<td>Typically not / should not be consulted</td>
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% respondents indicating the following as important:
- Lack of home-based services
- Limited access
- Limited physician knowledge
- Physician discomfort
- Family resistance
- Time constraints
- Cultural differences
- Prognosis uncertainty
- Physician desire to maintain hope
- Limited access to opioids
- Cost

Physicians in Guatemala indicated that lack of home-based services, limited access, and limited physician knowledge are the most significant barriers to palliative care consultation for children with cancer.
Physician Confidence in Delivering Palliative Care

- **47%** do not feel confident assessing and treating the physical needs of pediatric patients with serious incurable illness.
- **89%** do not feel confident providing grief and bereavement care to the families of children who die.
- **68%** felt uncomfortable addressing spiritual care needs.
- **79%** do not feel confident assessing and treating the emotional needs of pediatric patients with serious incurable illness and their families.
- **26%** feel burdened by their inability to control the suffering of children at the end of life.

**Physician Knowledge**

- **79%** median score for palliative care knowledge in accordance with WHO guide.
- **30%** reported no previous palliative care education.
- **100%** wanted more education on how to provide palliative care to their patients.

### Strengths

- High levels of previous palliative care education (70%).
- Palliative care consultation is generally available when needed for children with cancer (100%).
- Strong desire among physicians for more palliative care education (100%).

### Recommended Next Steps for Guatemala

- Conduct further research to investigate the discrepancy between actual vs. ideal timing of palliative care consultation.
- Create interdisciplinary palliative care teams to meet the grief and bereavement and emotional needs of patients and families.
- Increase the development of home-based palliative care services such as consultations and multidisciplinary specialists.
- Integrate palliative care education into medical school, residency, and fellowship curricula, focusing on improving communication with patients and families in pediatric cancer care.

### Regional Implementation of ADAPT in Guatemala

- Country-adapted pediatric palliative care curriculum based on identified knowledge gap.
- Working with the Pan American Health Organization (PAHO) on their initiatives in palliative care.

### References and Additional Information