Pediatric Palliative Care in Paraguay: 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

- 37% reported no access to palliative care consultation in their practice.
- 77% indicated that palliative care consultation is not available when they feel it is needed for children with cancer.
- 58% felt that palliative care was involved too late in the treatment of a child with cancer.
- 96% believe palliative care reduces suffering for a child with cancer.
- 81% 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

- % respondents indicating the following as important:
  - Lack of home-based services
  - Limited physician knowledge
  - Physician discomfort
  - Limited access
  - Family resistance
  - Physician desire to maintain hope
  - Prognosis uncertainty
  - Cultural differences
  - Time constraints
  - Cost
  - Limited access to opioids

Physicians in Paraguay indicated that lack of home-based services, limited physician knowledge, physician discomfort, and limited access are the most significant barriers to palliative care consultation for children with cancer.

For more information, please contact GlobalPalliative@stjude.org
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Physician Confidence in Delivering Palliative Care

- 72% do not feel confident assessing and treating the physical needs of pediatric patients with serious incurable illness
- 78% do not feel confident providing grief and bereavement care to the families of children who die
- 77% felt uncomfortable addressing spiritual care needs
- 78% do not feel confident assessing and treating the emotional needs of pediatric patients with serious incurable illness and their families
- 40% feel burdened by their inability to control the suffering of children at the end of life

Physician Knowledge

- Mean % of correct answers by content category:
  - Timing of consultation: 73%
  - Inter-disciplinary communication: 95%
  - Misconceptions: 82%
  - Patient suffering: 92%
  - Family communication: 71%

- Median score for palliative care knowledge in accordance with WHO guide: 82%
- Reported no previous palliative care education: 69%
- Wanted more education on how to provide palliative care to their patients: 96%

Strengths

- General alignment to WHO guidance (82%)
- Good understanding of the potential of palliative care to reduce suffering for children with cancer (96%)
- Strong desire among physicians for more palliative care education (96%)

Recommended Next Steps for Paraguay

- Build the capacity of the palliative care workforce by addressing staffing and funding shortages to ensure the availability of palliative care consultation when needed
- Create interdisciplinary palliative care teams to meet the complex needs of patients and families
- Conduct further research to investigate the discrepancy between actual vs. ideal timing of palliative care consultation
- 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 Paraguay

- 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

