

Pediatric Palliative Care in Uzbekistan: ADAPT Profile

The Assessing Doctors' Attitudes on Palliative Treatment (ADAPT) study was conducted in 2019, 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 424 physician responses from 11 countries. (For published references, see p.2.)



WHO Guide for Pediatric Palliative Care

Palliative care is 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

For additional information:

Integrating Palliative Care and Symptom Relief Into Paediatrics: A WHO Guide for Health Care Planners, Implementers and Managers. World Health Organization; 2018.

Access to Pediatric Palliative Care



60% physicians report **no access** to palliative care consultation in their practice

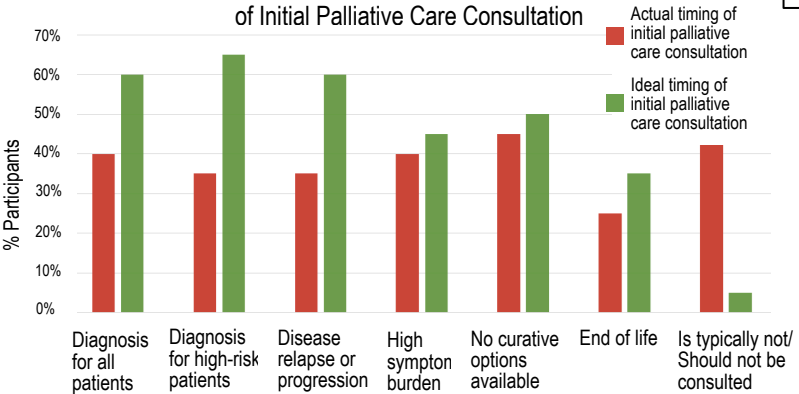


60% indicated that palliative care consultation is **not available** when they feel it is needed for children with cancer

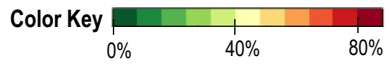
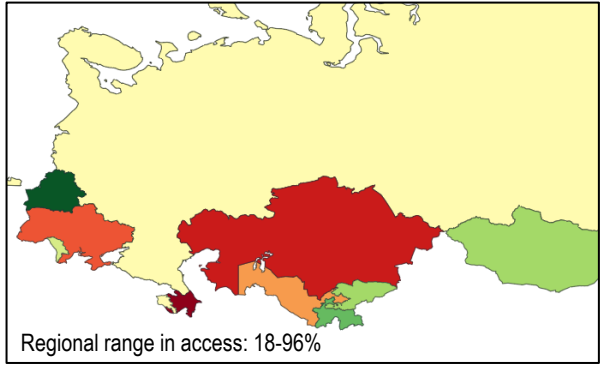


35% felt that palliative care was involved **too late** in the treatment of a child with cancer

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



Eurasia Regional Differences by Country: % physicians reporting **no access** to palliative care consultation



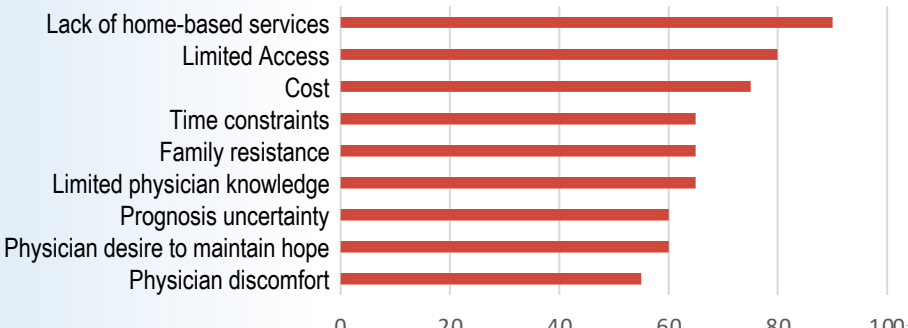
90% physicians believe palliative care reduces suffering for a child with cancer.

50% physicians believe palliative care should be integrated earlier in the care of children with cancer than typically occurs in their setting.

Barriers to Early Palliative Care Integration

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

% of physicians indicating the following barriers as important:



Physician Confidence in Delivering Palliative Care



60% do not feel confident assessing and treating the physical needs of pediatric patients with serious incurable illness.



55% do not feel confident assessing and treating the emotional needs of pediatric patients with serious incurable illness and their families.



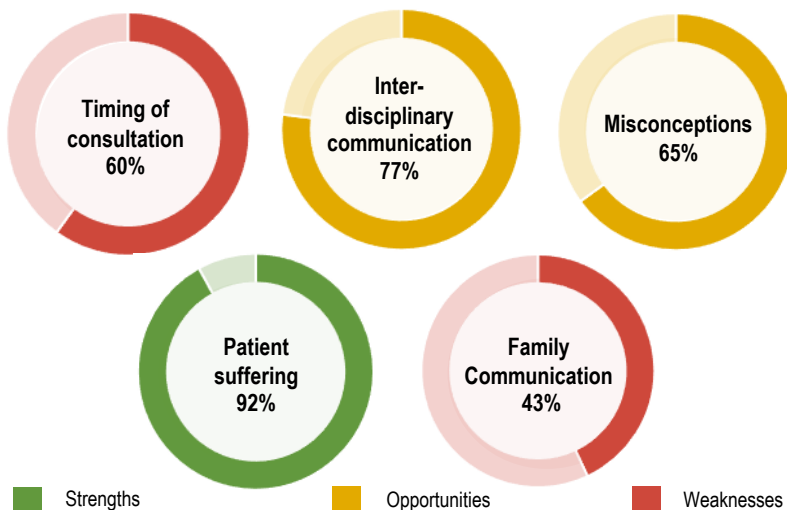
55% do not feel confident providing grief and bereavement care to the families of children who die.



55% feel burdened by their inability to control the suffering of children at the end-of-life.

Physician Knowledge

% of correct answers by content category:



Median score for palliative care knowledge in accordance with WHO guide: **68%**



100% reported no previous palliative care education



95% wished to have more education on how to provide palliative care to their patients.

Strengths

- 1 Strong desire among physicians (95%) for more palliative care education
- 2 Deep understanding of the potential of palliative care to improve quality of life for children with cancer

Recommended Country Next Steps

- 1 Expand access to pediatric palliative care consultations and other multi-disciplinary specialists in inpatient and outpatient settings
- 2 Identifying priority areas for palliative care development to ensure early integration of pediatric palliative care
- 3 Increase funding to build workforce capacity for pediatric palliative care services
- 4 Create didactic and clinical training for physicians, psychologists, nurses, and social workers, to increase confidence in providing all components of pediatric palliative care

Regional Implementation of ADAPT

- 1) Regionally adapted pediatric palliative care curriculum based on identified knowledge gaps
- 2) Working group on palliative care through the Eurasian Alliance in Pediatric Oncology (EurADO)

References and Additional Information

Ehrlich BS, Movsisyan N, Batmunkh T, Kumirova E, Borisevich MV, Kirgizov K, Graetz DE, McNeil MJ, Yakimkova T, Vinitsky A, Ferrara G, Li C, Lu Z, Kaye EC, Baker JN, Agulnik A; A multicountry assessment in Eurasia: Alignment of physician perspectives on palliative care integration in pediatric oncology with World Health Organization guidelines. Cancer 2020; 126(16): 3777-87.

Barriers to the early integration of palliative care in pediatric oncology in 11 Eurasian countries. Cancer 2020; 126(22): 4984-4993.

For more information, please contact: Eurasia@stjude.org

