Pediatric Palliative Care in Russia: 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:

Access to Pediatric Palliative Care

41% physicians report no access to palliative care consultation in their practice

45% indicated that palliative care consultation is not available when they feel it is needed for children with cancer

32% 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

Regional range in access: 18-96%

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

Physicians in Russia 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.

Barriers to Early Palliative Care Integration

<table>
<thead>
<tr>
<th>% of physicians indicating the following barriers as important:</th>
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<tbody>
<tr>
<td>Lack of home-based services</td>
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<td>Limited Access</td>
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<tr>
<td>Limited physician knowledge</td>
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<tr>
<td>Family resistance</td>
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<tr>
<td>Physician discomfort</td>
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<td>Physician desire to maintain hope</td>
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<td>Prognosis uncertainty</td>
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<td>Time constraints</td>
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<td>89% physicians believe palliative care reduces suffering for a child with cancer.</td>
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<td>66% physicians believe palliative care should be integrated earlier in the care of children with cancer than typically occurs in their setting.</td>
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<td>79% physicians indicate that palliative care is typically integrated when no curative options are available.</td>
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Physician Confidence in Delivering Palliative Care

- 34% do not feel confident assessing and treating the physical needs of pediatric patients with serious incurable illness.
- 33% do not feel confident assessing and treating the emotional needs of pediatric patients with serious incurable illness and their families.
- 56% do not feel confident providing grief and bereavement care to the families of children who die.
- 62% feel burdened by their inability to control the suffering of children at the end-of-life.

**Physician Knowledge**

- % of correct answers by content category:
  - Timing of consultation: 65%
  - Inter-disciplinary communication: 79%
  - Misconceptions: 75%
  - Patient suffering: 87%
  - Family Communication: 45%

  - Median score for palliative care knowledge in accordance with WHO guide: 71%
  - 82% reported no previous palliative care education
  - 92% wished to have more education on how to provide palliative care to their patients.

**Strengths**

1. Strong desire among physicians (92%) for more palliative care education
2. Evidence-based clinical guidelines implemented at the national level

**Recommended Country Next Steps**

1. Increase access to pediatric palliative care consultations and other multi-disciplinary specialists in inpatient and outpatient settings
2. Introduce a section on palliative care integration into existing clinical guidelines for pediatric oncology
3. Expand educational opportunities in pediatric palliative care to increase confidence among physicians, psychologists, and nurses in pediatric oncology
4. Inclusion of diseases requiring integration of palliative care at the time of diagnosis in the Ministry of Health order for 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**


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

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