







A Multicountry Assessment in Eurasia: Alignment of Physician Perspectives on Palliative Care Integration in Pediatric Oncology With World Health Organization Guidelines

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BACKGROUND: The World Health Organization (WHO) advocates for early integration of palliative care for all children with life-threatening illness. Provider awareness and misperceptions, however, can impede this imperative. In the Eurasian region, little is known about physician knowledge and perspectives on palliative care. **METHODS:** The Assessing Doctors' Attitudes on Palliative Treatment survey was developed as an evidence-based and culturally relevant assessment of physician perceptions on palliative care integration into childhood cancer care in Eurasia. Iteratively tested by American and Eurasian palliative care experts, the survey was culturally adapted, translated, and piloted in English, Russian, and Mongolian. The survey was distributed to physicians caring for children with cancer. Fifteen statements were scored in accordance with WHO guidelines to evaluate provider knowledge. The statistical analysis was complemented by a qualitative analysis of open-ended responses. **RESULTS:** This study received 424 responses from 11 countries in Eurasia. The mean alignment between provider perspectives and WHO recommendations was 70% (range, 7%-100%). Significant independent predictors of higher alignment included country, prior palliative care education, and greater experience with patient death. Respondents primarily described palliative care as end-of-life care and symptom management. Two-thirds of respondents (67%) reported not feeling confident about delivering at least 1 component of palliative care. **CONCLUSIONS:** This is the first study assessing physician perspectives and knowledge of palliative care in Eurasia and reveals wide variability in alignment with WHO guidelines and limited confidence in providing palliative care. Study findings will inform targeted educational interventions, which must be tailored to the local political, economic, and cultural context. *Cancer* 2020;0:1-11. © 2020 American Cancer Society.

KEYWORDS: Eurasia, global health, low-to-middle-income country (LMIC), pediatric oncology, pediatric palliative care, physician perspectives.

INTRODUCTION

The World Health Organization (WHO) defines palliative care as the prevention and relief of physical, developmental, psychosocial, and spiritual suffering of patients and their families facing life-threatening illness.¹ Early integration of palliative care is identified by WHO as “an ethical responsibility of health systems” in the management of children with serious illness, regardless of local resource limitations.^{1,2}

Early integration of palliative care is critical for pediatric oncology patients and has been shown to significantly improve symptom management, family communication, and quality of life for pediatric patients with cancer and caregivers while decreasing patient suffering and parental psychological distress.³⁻⁶ Furthermore, palliative care integration is associated with fewer invasive procedures, increased hospice involvement, and lower odds of dying in an intensive care unit and represents a cost-effective intervention in resource-limited settings.⁷⁻¹¹ Notably, all literature evaluating the outcomes of pediatric palliative care comes from high-income countries.

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Despite the known benefits of palliative care integration for children with cancer, palliative care services do not exist in more than 60% of countries, with decreased access in low-to-middle-income countries (LMICs).^{12,13} In resource-limited settings, decreased reporting of pain symptom control, a lack of emotional and bereavement support, and limited interdisciplinary communication hinder the quality of cancer care.^{12,14-17} The disproportionate global burden of childhood cancer in LMICs demands increased availability of high-quality, comprehensive palliative care to address patient and family suffering and needs in these settings.¹⁷

Although structural barriers, such as a lack of access to services and other financial constraints, limit utilization of palliative care services, an underlying stigma among physicians treating children with cancer further impedes the integration of palliative care into disease-directed therapy, even when resources are available.^{18,19} Studies analyzing provider perceptions of palliative care in pediatric cancer, predominantly conducted in high-income countries, find that nearly half of physicians do not initiate palliative care consultations until after the termination of disease-directed treatment or at the end of life.²⁰ Furthermore, discrepancies persist between physicians' and families' perceptions of adequate pain control in children with cancer at the end of life, affecting the quality and effectiveness of delivered care.³ To date, however, limited studies have analyzed provider perspectives on these issues in LMICs.

The Eurasian region, representing Eastern Europe and Central Asia, is a geographically and culturally distinct region with a shared history and similar medical systems. Across this region, countries experience wide variability in outcomes and age-standardized disability-adjusted life-year rates for childhood cancer.^{14,17} Facilitated by St. Jude Global and the WHO Global Initiative for Childhood Cancer,²¹ 11 initial countries formed the Eurasian Alliance of Pediatric Oncologists to improve childhood cancer care in the region. Participating countries are primarily low- and middle-income and, with the exception of Mongolia, are all Russian-speaking. To date, there has been no comprehensive evaluation of physician perspectives on palliative care in the region. The objective of this study was to assess the perspectives and knowledge of physicians caring for children with cancer on palliative care in 11 countries in Eurasia.

MATERIALS AND METHODS

Instrument Design

The Assessing Doctors' Attitudes on Palliative Treatment (ADAPT) survey was designed for physicians of all

specialties who care for pediatric oncology patients in the Eurasian region. This study population was chosen because physicians are typically those making decisions around palliative care consultation and integration in this region. Initial survey items were developed on the basis of WHO guidelines and a review of the published literature on provider perspectives on palliative care, physician responsibility, and other ethical considerations.^{1,22-25} The study received a priori approval from the Institutional Review Board.

Two panels of 5 American palliative care experts and 3 Eurasian palliative care experts serially tested survey items in English until a final consensus was achieved. Bilingual collaborators with expertise in pediatric palliative care and pediatric hematology/oncology further revised the survey for content validity and cultural relevance. The survey was pilot-tested by 12 English-speaking physicians who were representative of provider specialties in the target survey population, including pediatric oncologists/hematologists, palliative care specialists, intensivists, and surgeons. Feedback then was used to optimize item content and linguistic face validity.

Subsequently, survey questions were translated into Russian and Mongolian by bilingual native speakers. The translations underwent iterative rounds of review by regional collaborators to optimize colloquial syntax, comprehension, and construct as well as cultural and linguistic face validity. The survey was pilot-tested by 13 Russian-speaking physicians and 5 Mongolian-speaking physicians, who were representative of the diversity of specialties in the target population. Adjustments were made on the basis of feedback, and surveys were back-translated and reviewed to ensure item construct consistency.

The final survey questions included the following 5 domains: timing and role of palliative care integration, patient suffering and harm, common misperceptions, interdisciplinary communication, and family communication and perspectives (see Supporting Fig. 1 for the final survey). ADAPT relies on quantitative items and uses a Likert scale and a multiple-choice format with open-ended questions to enrich data interpretation. The survey was distributed anonymously via an electronic platform (Qualtrics²⁶) or a paper-based option in settings with limited technology access.

Target Sample and Distribution Strategy

The ADAPT survey was distributed in English, Russian, and Mongolian to physicians responsible for managing pediatric oncology patients across 11 participating countries: Armenia, Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Moldova, Mongolia, Russia, Tajikistan,

TABLE 1. Country-Specific Distribution Strategies

Country	Distribution Method	Total Distributed Surveys, No.	Total Answered Surveys, No.	Response Rate, %
Armenia	Electronic distribution via formalized contact list; paper version for those with limited technological access	27	16	59
Azerbaijan	Electronic distribution via formalized contact list	22	17	77
Belarus	Electronic distribution via formalized contact list	55	23	42
Kazakhstan	Electronic distribution via formalized contact list	71	53	75
Kyrgyzstan	Electronic distribution via formalized contact list	19	16	84
Moldova	Electronic distribution via formalized contact lists by specialty	35	21	60
Mongolia	Paper distribution in 3 main oncology centers in Ulaanbaatar	29	25	86
Russia	Electronic distribution via official listserv of National Society of Pediatric Hematologists Oncologists; partial follow-up via overlapping contact list	1275	186	15
Tajikistan	Electronic distribution via contact list by specialty, formalized by the Ministry of Health	17	16	94
Ukraine	Electronic distribution via formalized contact list in all regions and centers	140	31	22
Uzbekistan	Electronic distribution in urban hospitals via phone	40	20	50

Ukraine, and Uzbekistan. The distribution strategy was individualized to each country's respective medical structure, workforce, and specific needs in order to maximally circulate the survey to all eligible participants. Within each country, potential survey participants were identified by local study leaders with comprehensive knowledge of the relevant professional societies, medical institutions, and workforce. Study leaders were instructed to distribute the survey to physicians of all specialties who treated children with cancer in their country. Distribution strategies ranged from predetermined contact lists within hospital centers to official national pediatric oncology and hematology listservs, depending on their availability in each country (see Table 1 for details of each country's distribution strategy).

The ADAPT survey was primarily distributed electronically via the Qualtrics platform. Countries with limited technology or internet access were identified before distribution as requiring paper surveys, which were completed by respondents, delivered to a designated drop-off location, scanned by local study leaders, and manually entered into the electronic system for analysis. Both electronic and paper surveys were completed anonymously, and participation was optional at all centers. Only completed surveys were recorded by the electronic platform, and there were no missing data in either paper or electronic surveys used in the analysis. Local study leaders recorded how many providers received the survey to calculate response rates. The survey was closed after 3 months.

WHO Alignment

In accordance with WHO guidelines for pediatric palliative care, 15 statements in the survey were categorized to

be factually accurate or inaccurate (Supporting Table 1).¹ Each participant received a point for scoring correctly on a survey item if he or she indicated moderate or strong alignment with the correct response, and each participant received an overall score for percent alignment with WHO recommendations based on the number of correct responses to the 15 statements.

Statistical Analysis

Cumulative regional and country-specific demographic data were reported with descriptive statistics. The Shapiro-Wilk test tested the assumption of normality, based on which either the 2-sample *t* test or the Wilcoxon rank sum test was used to test differences among continuous variables between groups. The Pearson chi-square assessed differences among categorical variables when all cell counts were greater than 5; the Fisher exact test was used in other cases to test associations when any cell count was smaller than or equal to 5. Both univariate and multiple regression models were used to determine the predictors of WHO alignment scoring. In the multiple regression analysis, variables with $P < .2$ in the univariate analysis were included, and the stepwise variable selection was used to choose the variables with $P < .05$ on the basis of the Wald test. Russia was used as the reference group for calculating the country effect as the median scoring country and largest responder group. For secondary analyses, the 5-point Likert scale was assigned numerical values to conduct 2-sample paired *t* tests. The 5-point Likert scale was also collapsed into 3 categories (often/always, sometimes, and never/rarely) to compare the effects of demographic variables via the Fisher exact test

or the Pearson chi-square test. Two-sided significance of $P < .05$ was used for the statistical methods. All analyses were performed with SAS software (version 9.4), and the heat map was generated with R software (version 3.6.2).

Qualitative Analysis

Written survey responses to free-text questions were translated into English by bilingual native speakers. A preliminary codebook was created from a combination of inductive and deductive approaches and encompassed common themes and recurrent phrases identified in the text.²⁷ Each response served as 1 segment as a unit of analysis. Test coding on set groups of segments was conducted by 2 coders to refine codes and definitions, and the codebook was finalized through a reconciliation process to reach consensus within the analytic team. Fluent members of the analytic team were able to refer to Russian responses to provide further clarification as needed. Responses were coded by 2 coders. After double coding, a κ value of 0.90 ensured interrater reliability, and a third reviewer assisted with resolution of code disagreements. All data analysis was performed with MAXQDA software.

RESULTS

Sample Demographics

The ADAPT survey was completed by 424 physicians from 11 countries in the Eurasian region with a median country response rate of 60% (range, 15%-94%; Table 1). Most surveys were completed electronically (91%), with the remainder of participants completing paper surveys ($n = 38$ [9%]). The majority of respondents were pediatric hematologists/oncologists (67%), were female (73%), were younger than 50 years (78%), and had little experience with patient death (5 or fewer patients died under their care in the last year; 85%). A minority (19%) reported receiving some form of palliative care education or self-identified as palliative care specialists (5.2%; see Table 2 for complete demographics). Approximately half of the respondents (54%) reported access to a pediatric palliative care consultation in their practice setting. Among those who reported availability of palliative care consultation, providers typically indicated access to a physician (92%), with more limited access to interdisciplinary specialists such as psychologists (27%), social workers (16%), and nurses (13%).

Role of Palliative Care in Childhood Cancer Care

The majority of the respondents described the role of palliative care in the care of children with cancer as including

TABLE 2. Respondent Demographic Characteristics

Demographics	Overall Sample (n = 424), No. (%)
Country	
Armenia	16 (4)
Azerbaijan	17 (4)
Belarus	23 (5)
Kazakhstan	53 (13)
Kyrgyzstan	16 (4)
Moldova	21 (5)
Mongolia	25 (6)
Russia	186 (44)
Tajikistan	16 (4)
Ukraine	31 (7)
Uzbekistan	20 (5)
Age	
<35 y	152 (36)
≥35 y	272 (64)
Sex	
Female	308 (73)
Male	116 (27)
Primary medical specialty	
Adult/pediatric palliative care	22 (5)
Pediatric hematology/oncology	285 (67)
All others	117 (28)
Years of experience	
0-10 y	168 (40)
≥11 y	256 (60)
Training in palliative care	
Yes	81 (19)
No	343 (81)
Access to consultation	
Yes	230 (54)
No	194 (46)
No. of patients died in care	
0-5 patients	361 (85)
≥6 patients	63 (15)

pain and symptom management (97%) and psychological support (92%). Significantly fewer respondents, however, identified other established components of palliative care, such as help in communicating bad news to patients and families (60%), aid in communication between the patient, family, and medical teams (56%), aid in family decision making around treatment options (51%), and help in clarifying the goals of care to the patient and family (39%). Few respondents indicated that palliative care has no role in cancer care for children (3.8%; Fig. 1A).

These findings were supported by a qualitative analysis of free-response survey questions, which were answered by 89% of the respondents ($n = 379$; see Fig. 1B for the code frequency map and Supporting Table 2 for the code definitions). In response to the question “What does palliative care mean to you?”, those mentioning components of palliative care ($n = 346$) most often described palliative care as addressing patient quality of life (72%), symptom management (37%), psychological support (30%), end-of-life care (24%), and medical care (23%), whereas religious and spiritual support (8.4%) and interdisciplinary

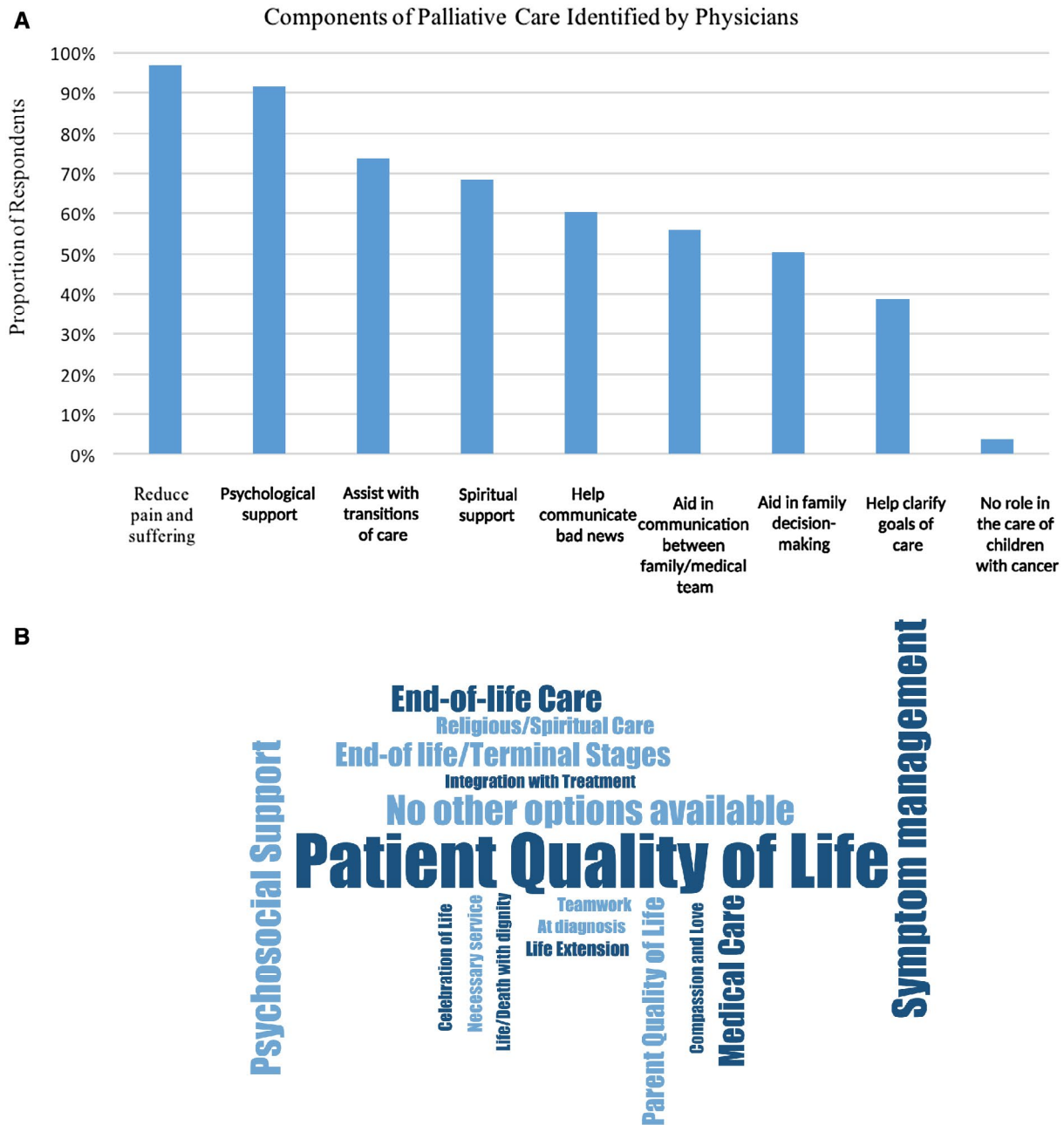


FIGURE 1. Components of palliative care: quantitative and qualitative analysis. (A) Quantitative analysis of responses to the statement “The role of palliative care in the care of children with cancer is...” (n = 424). Respondents could choose all components that they identified as appropriate. Components are listed from the most commonly indicated to the least commonly indicated by the percentage of respondents. (B) Qualitative analysis of responses to the question “What does palliative care mean to you?” (n = 379). The code map depicts the relative frequency of all codes identified in the qualitative analysis of question responses. The codebook was developed through a combination of inductive and deductive approaches (see Supporting Table 3 for code definitions and Supporting Table 4 for code frequencies).

communication (2.0%) were mentioned less frequently (Supporting Table 3). Of the respondents who described the timing of palliative care, the majority indicated that palliative care is administered when no other curative options are available (57%) and at the end of life (36%).

Many responses focused on “improving the quality of life of incurable patients” as well as mitigating patient “pain and suffering.” A minority of respondents described palliative care more positively (7.7%) as a celebration of life (“decorate last days” and “giving life”), as a form of compassion

TABLE 3. Analysis of Demographic Factors and Perspectives Significantly Affecting WHO Alignment

Demographic	Category	Mean WHO Alignment, %	<i>P</i>		Alignment Difference, %
			Univariate Model	Multivariate Model	
Age	<35 y	68	.067	Not significant	3
	≥35 y	71			
Sex	Female	71	.066	Not significant	4
	Male	67			
Primary medical specialty	Adult/pediatric palliative care specialists	81	.001	Not significant	12
	All others	69			
Years of experience	0-10	67	.034	Not significant	4
	≥11	71			
Palliative care education	Yes	75	<.001	.002	7
	No	68			
Access to consultation	Yes	71	.043	Not significant	3
	No	68			
Patients died in care in last 12 mo	0-5	69	.038	.047	5
	≥6	74			
Country	Individual countries		.002	.001	See Figure 2

Abbreviation: WHO, World Health Organization.

(“without loneliness” and “caring and loving”), or as a mechanism by which to promote life and death with dignity (“dignified passing into another world”).

Alignment With WHO Guidelines on Palliative Care Integration

Based on the 15 questions aligning with WHO guidelines on palliative care integration with pediatrics (Supporting Table 1), the overall mean WHO alignment of the respondents was 70% (range, 7%-100%). In the univariate analysis, palliative care education, country of practice, specialty (adult or pediatric palliative care versus others), more than 10 years of work experience, access to palliative care consultation, and greater experience with patient death (6 or more patients died in the last year) were significant predictors of participant alignment with WHO guidelines, with the differences between groups ranging from 3% to 12% and with medical specialty having the largest difference between groups (12%; Table 3). Mean WHO alignment significantly varied across countries and ranged from 62% to 81% (Fig. 2 and Supporting Fig. 2). Multiple regression analysis demonstrated that country, palliative care education, and having 6 or more patients die in the last year were independent predictors of WHO alignment (Table 3).

Among the questions used to measure WHO alignment, the most common regional misconceptions were as follows: 1) early consultation with palliative care causes increased parental burden and anxiety (23% disagreed), 2) it is difficult to know when a patient with cancer would most benefit from meeting the palliative care team (34% disagreed), and 3) palliative care is synonymous with end-of-life care (44% disagreed; see Table 4 for the complete ranked list).

Impact of Palliative Care Education

Prior palliative care education not only affected physician knowledge but also influenced perceptions and experiences around palliative care and the end of life (Table 5). Respondents with palliative care education were significantly less likely to believe that children receiving palliative care die earlier than those who do not (90% disagreed vs 79%; $P = .005$) and that administering opioids to patients in pain hastens death because of respiratory depression (94% disagreed vs 74%; $P < .001$).

Overall, 60% of the respondents reported that they always or often felt burdened by their inability to control the suffering of children at the end of life; feelings of burden were significantly less prevalent among those with palliative care education (52% vs 62%; $P = .021$) and

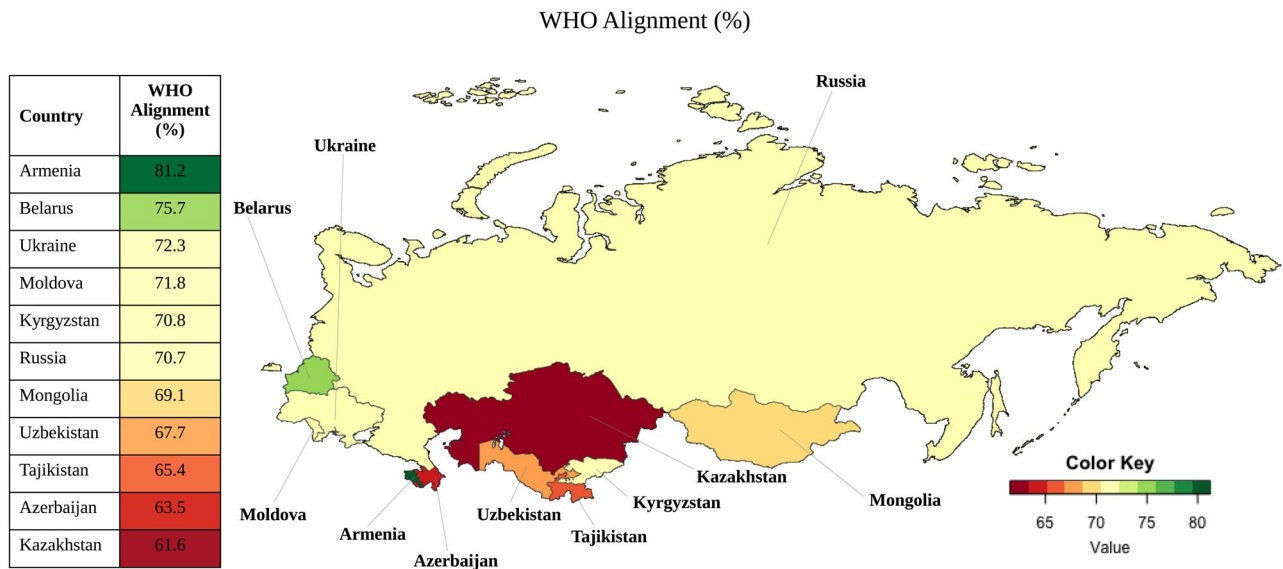


FIGURE 2. Eurasia regional country map by percent WHO alignment. Each respondent received an overall score for percent alignment with World Health Organization (WHO) recommendations based on the number of correct responses to the 15 factual statements supported by the WHO guidelines on palliative care (overall mean, 70%; $n = 424$). The mean country WHO alignment was calculated based on the performance of respondents from each country and ranged from 62% to 81%. The map displays the distribution of WHO alignment across 11 countries in the Eurasian region from highest alignment (green) to lowest alignment (red).

among palliative care specialists versus other specialties (36% vs 61%; $P = .048$).

Ultimately, the majority of the respondents (95%) reported that they would like to receive more palliative care education. Those providers desiring more education scored 19% higher in WHO alignment than those who showed less interest in learning more about palliative care (71% vs 52%; $P < .001$).

Attitudes Toward Palliative Care

Almost half of the providers (45%) indicated that quality of life is often overlooked in the face of cancer-directed treatment. The majority believed that children suffer at the end of life (87%) and that early integration of palliative care would decrease patient suffering (86%). However, 57% agreed that physicians typically continue to recommend cancer-directed treatment for children with advanced and incurable disease (Supporting Table 4).

Respondents reported generally being confident about managing the physical (57%) and emotional needs of their patients (63%), but fewer felt comfortable about addressing grief and bereavement (45%), with 67% of respondents reporting a lack of confidence in managing at least 1 of these components of palliative care. Palliative care education did not significantly influence confidence in delivering any component of

palliative care (Supporting Table 5). Respondents' assessment of their comfort was higher than their assessment of the comfort of other physicians in their setting in providing all 3 types of care addressing: physical needs ($P = .011$), emotional needs ($P < .001$), and grief/bereavement support ($P = .018$; Supporting Table 6). Further results for relevant physician perspectives are summarized in Supporting Table 4.

DISCUSSION

WHO advocates for early integration of palliative care as a standard of care for all children with life-threatening illness and specifically for children with cancer. Universal implementation is hindered by numerous factors such as provider attitudes, misconceptions, and a lack of knowledge of palliative care.¹ Understanding these perspectives is imperative for guiding educational interventions designed to align provider practice with WHO guidelines. Provider perspectives likely differ globally, and little is known on this topic in the Eurasian region. To our knowledge, this is the first study of provider perspectives on palliative care in this region.

In this large, international survey of physicians who care for children with cancer, we demonstrated suboptimal alignment (70%) with WHO guidelines on this topic, and this suggests a knowledge gap that may

TABLE 4. Misperceptions of World Health Organization Alignment Statements: Most to Least Common

Question	% Correct
Early consultation with palliative care causes increased parental burden and anxiety	23
It is difficult to know when a patient with cancer would most benefit from meeting the palliative care team	34
Palliative care is synonymous with end-of-life care	44
Palliative care for children with cancer can be delivered by health care workers of all disciplines, not only by palliative care specialists	60
Involving palliative care suggests that the oncologist has failed in the mission to cure the patient	68
Involving the palliative care team early has negative effects on the relationship between the oncologist and the patient and family	71
Palliative care can be integrated with disease-directed therapy	74
Palliative care is incompatible with curative care	76
Involvement of palliative care undermines the role of the pediatric oncologist as the physician in charge of patient care	81
Children with cancer who receive palliative care die earlier than those who do not	81
Palliative care is appropriate at any stage of treatment in a child with high-risk cancer	84
Early integration of palliative care for all children diagnosed with cancer would decrease patient suffering	86
Children with advanced and incurable cancer often suffer at the end of life	87
Early integration of pediatric palliative care with cancer care would improve interdisciplinary communication	88
Involvement of palliative care during cancer therapy gives greater attention to quality of life and symptom management (eg, pain, constipation, dyspnea, and fatigue)	89

affect the quality of care provided in this region. There are limited data on physician knowledge of palliative care in other resource-limited settings; however, these results are comparable to previous results finding that physicians had a mean score of 68%.²⁸ Respondent alignment with WHO guidance on palliative care integration varied greatly in our study both among individual participants (7%-100%) and by country (62%-81%). In a multiple regression analysis, independent predictors of higher WHO alignment included previous palliative care education, more experience with patient death, and country of practice. The effect of these factors on WHO alignment, however, was small, suggesting that additional factors likely influence perspectives.

In line with the published literature,²⁹ commonly held misperceptions centered around family communication. They included beliefs that the involvement of palliative care has a negative effect on the relationship between the oncologist and the patient and family and that early consultation burdens parents and causes increased anxiety. Importantly, recent data demonstrates that, contrary to Eurasian provider beliefs, patients and parents often

benefit and value early integration of palliative care in the context of pediatric cancer management.³⁰

Supported by quantitative and qualitative survey data, providers in the Eurasian region perceive palliative care primarily in terms of end-of-life care, pain and symptom management, quality of life, and psychological support, whereas discussion of goals of care and communication of bad news were not readily identified as pillars of palliative care. These findings reveal a narrow understanding of the role of palliative care and potentially explain the perceived conflict between palliative care and disease-directed treatment. Approximately a third of the respondents agreed that the involvement of palliative care implies failure on behalf of the oncologist, and this suggests that many physicians do not recognize alignment between the goals of cancer care and palliative care.

Knowledge of palliative care, as indicated by WHO alignment, nonetheless does not indicate proficient clinical skills or comfort in providing components of palliative care to pediatric patients. Less than half of the respondents reported that physicians limit cancer-directed therapy in the setting of advanced and incurable disease, and this signifies that clinical practice, as perceived by physicians, does not align with WHO recommendations. The majority of the respondents (67%) reported a lack of confidence in providing at least 1 of the components of palliative care to their patients; among these components, respondents were least confident in providing grief and bereavement care. This is starkly lower than previously self-reported physician competence in managing palliative care needs in high-income settings (92%).²⁹ This lack of confidence likely contributes to 60% of the respondents feeling burdened by their inability to manage the suffering of their patients at the end of life. Although those with palliative education felt less burdened, they did not report higher confidence in providing elements of palliative care, and this differs from the effects of palliative care education in other low-income settings.²⁸

This study clearly captures low exposure to formal palliative care training among physicians caring for children with cancer in Eurasia (19%), with the majority of the respondents (81%) having no prior palliative care education. This represents an urgent need to increase access to palliative care training for physicians treating children with cancer in the region. Our findings further demonstrate the widespread demand for palliative care education among these physicians, with the vast majority (95%) desiring more education. Even among those with prior palliative care education, however, the effect of this training on WHO alignment was relatively small, and it did

TABLE 5. Provider Perspectives Significantly Affected by Palliative Care Education

	Palliative Care Education (n = 81), No. (%)	No Palliative Care Education (n = 343), No. (%)	P
Involving palliative care suggests that the oncologist has failed in the mission to cure the patient:			.029 ^a
Disagree	62 (76.5)	225 (65.6)	
Neutral	1 (1.2)	29 (8.5)	
Agree	18 (22.2)	89 (25.9)	
Palliative care for children with cancer can be delivered by health care workers of all disciplines, not only by palliative care specialists:			.013 ^b
Disagree	15 (18.5)	119 (34.7)	
Neutral	6 (7.4)	29 (8.5)	
Agree	60 (74.1)	195 (56.9)	
Children with cancer who receive palliative care die earlier than those who do not:			.005 ^a
Disagree	73 (90.1)	272 (79.3)	
Neutral	1 (1.2)	41 (12.0)	
Agree	7 (8.6)	30 (8.7)	
Involving the palliative care team early has negative effects on the relationship between the oncologist and the patient and family:			.054 ^a
Disagree	66 (81.5)	233 (67.9)	
Neutral	5 (6.2)	45 (13.1)	
Agree	10 (12.3)	65 (19.0)	
Administering opioids to patients in pain hastens death because of respiratory depression:			<.001 ^a
Disagree	76 (93.8)	254 (74.1)	
Neutral	1 (1.2)	32 (9.3)	
Agree	4 (4.9)	57 (16.6)	
In my setting of practice, palliative care consultation is available when I feel it is needed for a child with cancer:			<.001 ^b
Never/rarely	13 (16.0)	126 (36.7)	
Sometimes	14 (17.3)	63 (18.4)	
Often/always	54 (66.7)	154 (44.9)	
I have felt burdened by my inability to control the suffering of children at the end of life:			.021 ^b
Never/rarely	18 (22.2)	37 (10.8)	
Sometimes	21 (25.9)	94 (27.4)	
Often/always	42 (51.9)	212 (61.8)	

^aFisher exact test.^bPearson chi-square test.

not improve comfort in providing elements of palliative care; this suggests that available palliative care education in the region may not only be limited, but also not optimally effective or aligned with international standards. These findings should inform the development of palliative care educational curricula for providers, as well as the organization of clinical residencies to build regional capacity and expertise. As demonstrated by the response variability across countries, local context significantly influences provider perspectives; thus, educational curricula must be tailored to meet the needs of local political, economic, and cultural contexts. This study expands our understanding of physicians' predominant attitudes regarding the role of palliative care in childhood cancer care in Eurasia and is a prerequisite to the creation of effective interventions aimed at improving the timeliness of palliative care integration and the quality of care provided to pediatric patients with serious illness and their families.

This study has several limitations. Differences in the size of the physician workforce and in the availability of physician listservs in each country resulted in different distribution strategies and variable response rates, with only 2 countries falling below 40%. Lower response rates in Russia and Ukraine may be attributable to the use of large listservs of all potentially eligible providers, whereas countries where the survey was directly distributed to eligible respondents had more robust rates. Listserv-based distribution was chosen in Russia and Ukraine because of a large number of centers providing pediatric cancer care and a larger pediatric hematology/oncology workforce eligible for study participation. In contrast, the remaining countries with a relatively small pediatric hematology/oncology workforce had no available listservs and relied on the country study leaders conducting hospital-based survey distribution. Although this approach may have introduced snowball sampling bias, we achieved a high

median response rate and are confident that we distributed the survey to the majority of eligible respondents by leveraging local knowledge of the provider workforce. Although respondents from Russia are overrepresented in our study sample, Russian physicians had the median WHO alignment of all countries surveyed, and this prevented the study results and conclusions from being skewed. We were also able to demonstrate country-specific differences in physician perspectives and allowed for adapted educational interventions tailored to each local context.

Although our survey resulted in a smaller sample size in certain demographic categories (eg, physicians with palliative care education) and this may have limited our statistical power, our study obtained a large number of responses achieving adequate power to detect significant differences between groups. Similarly, we were able to identify small but statistically significant differences, such as the effect of palliative care education on WHO alignment. Smaller sample sizes in some groups, however, did result in very low cell counts for some variables, and this potentially affected the validity of significant findings, particularly those with *P* values close to .05. We believe that our overall conclusions, however, many of which had much lower *P* values, are generally valid.

A minority (9%) completed the paper survey; however, all recorded responses were complete, and paper surveys were entered into the electronic system; this unified data analysis and ensured accuracy. Because this study primarily relied on electronic distribution (91% of the surveys), our survey underrepresented provider perspectives from more remote, lower resourced regional centers, where provider knowledge is likely more limited. Therefore, these findings likely skew toward more well-resourced, specialized centers in the region, with correspondingly higher levels of education and awareness of palliative care. As a result, this study presents the best case scenario with respect to physician perspectives and knowledge. Nonetheless, we believe that these findings are valid to guide targeted development of palliative care educational initiatives in Eurasia because initial interventions will be targeted to large, specialized pediatric oncology centers managing the majority of childhood cancers in each country.

Finally, our assessment clearly identified a need to increase access to palliative care services in the Eurasian region in the field of pediatric oncology. More than half of the respondents did not have access to palliative care consultation, and the majority had no access to psychologists, nurses, or social workers; this suggests that other

structural factors play a role in the delivery of pediatric palliative care in Eurasia beyond a lack of high-quality education. Although an assessment of palliative care perceptions and knowledge among pediatric oncology physicians is crucial in order to inform the development of targeted educational interventions, further analysis of regional and country-specific barriers must be conducted to better understand other challenges to high-quality palliative care integration into childhood cancer care. While this focus lies beyond the scope of the current study, we advocate for the investigation of these important questions in future work.

In conclusion, the ADAPT study is the first assessment of provider attitudes on palliative care integration into pediatric cancer care adapted to the language, political, social, and cultural context of the Eurasian region. Our study identified a number of knowledge gaps and misperceptions among physicians treating children with cancer in this region, with large variability in alignment with international standards as described by WHO. A respondent history of palliative care education affected alignment with WHO standards, perspectives, and experiences, and nearly all participants reported a desire for more education on this topic. Our results demonstrate an opportunity to improve palliative care integration into pediatric oncology care in this region through targeted, locally adapted education interventions with the ultimate goal of improving the quality of life for children with cancer.

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AUTHOR CONTRIBUTIONS

Bella S. Ehrlich: Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, software, validation, visualization, writing—original draft, writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Narine Movsisyan:** Writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Tsetsegsaikhan Batmunkh:** Writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Ella Kumirova:** Writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Marina V. Borisevich:** Writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Kirill Kirgizov:** Writing—review and editing, review and approval of the final manuscript as submitted, and accountability for all aspects of the work. **Dylan E. Graetz:** Formal analysis, software, writing—review and

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REFERENCES

- World Health Organization. Integrating Palliative Care and Symptom Relief Into Paediatrics: A WHO Guide for Health Care Planners, Implementers and Managers. World Health Organization; 2018.
- Weaver MS, Heinze KE, Kelly KP, et al. Palliative care as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015;62(suppl 5):S829-S833.
- Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol*. 2008;26:1717-1723.
- Groh G, Borasio GD, Nickolay C, Bender HU, von Lutichau I, Fuhrer M. Specialized pediatric palliative home care: a prospective evaluation. *J Palliat Med*. 2013;16:1588-1594.
- Groh G, Vyhnaek B, Feddersen B, Fuhrer M, Borasio GD. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *J Palliat Med*. 2013;16:848-856.
- Vollenbroich R, Duroux A, Grasser M, Brandstatter M, Borasio GD, Fuhrer M. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med*. 2012;15:294-300.
- Snaman JM, Kaye EC, Lu JJ, Sykes A, Baker JN. Palliative care involvement is associated with less intensive end-of-life care in adolescent and young adult oncology patients. *J Palliat Med*. 2017;20:509-516.
- Reid EA, Kovalerchik O, Jubanyik K, Brown S, Hersey D, Grant L. Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review. *BMJ Support Palliat Care*. 2019;9:120-129.
- Kaye EC, DeMarsh S, Gushue CA, et al. Predictors of location of death for children with cancer enrolled on a palliative care service. *Oncologist*. 2018;23:1525-1532.
- Levine DR, Johnson LM, Snyder A, et al. Integrating palliative care in pediatric oncology: evidence for an evolving paradigm for comprehensive cancer care. *J Natl Compr Canc Netw*. 2016;14:741-748.
- Schmidt P, Otto M, Hechler T, Metzger S, Wolfe J, Zernikow B. Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer? *J Palliat Med*. 2013;16:1034-1039.
- Delgado E, Barfield RC, Baker JN, et al. Availability of palliative care services for children with cancer in economically diverse regions of the world. *Eur J Cancer*. 2010;46:2260-2266.
- Knapp C, Woodworth L, Wright M, et al. Pediatric palliative care provision around the world: a systematic review. *Pediatr Blood Cancer*. 2011;57:361-368.
- Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Arun R. Estimating the total incidence of global childhood cancer: a simulation-based analysis. *Lancet Oncol*. 2019;20:483-493.
- Magrath I, Steliarova-Foucher E, Epelman S, et al. Paediatric cancer in low-income and middle-income countries. *Lancet Oncol*. 2013;14:e104-e116.
- Pritchard-Jones K, Kaatsch P, Steliarova-Foucher E, Stiller CA, Coebergh JW. Cancer in children and adolescents in Europe: developments over 20 years and future challenges. *Eur J Cancer*. 2006;42:2183-2190.
- Bhakta N, Force LM, Allemani C, et al. Childhood cancer burden: a review of global estimates. *Lancet Oncol*. 2019;20:e42-e53.
- Sasaki H, Bouesseau MC, Marston J, Mori R. A scoping review of palliative care for children in low- and middle-income countries. *BMC Palliat Care*. 2017;16:60.
- Lynch T, Clark D, Centeno C, et al. Barriers to the development of palliative care in the countries of Central and Eastern Europe and the Commonwealth of Independent States. *J Pain Symptom Manage*. 2009;37:305-315.
- Thompson LA, Knapp C, Madden V, Shenkman E. Pediatricians' perceptions of and preferred timing for pediatric palliative care. *Pediatrics*. 2009;123:e777-e782.
- World Health Organization. Global Initiative for Childhood Cancer. Accessed September 24, 2019. <https://www.who.int/cancer/childhood-cancer/en/>
- Pifer PM, Farrugia MK, Mattes MD. Comparative analysis of the views of oncologic subspecialists and palliative/supportive care physicians regarding advanced care planning and end-of-life care. *Am J Hosp Palliat Care*. 2018;35:1287-1291.
- Dalberg T, McNinch NL, Friebe S. Perceptions of barriers and facilitators to early integration of pediatric palliative care: a national survey of pediatric oncology providers. *Pediatr Blood Cancer*. 2018;65:e26996.
- Sanchez Varela AM, Johnson LM, Kane JR, et al. Ethical decision making about end-of-life care issues by pediatric oncologists in economically diverse settings. *J Pediatr Hematol Oncol*. 2015;37:257-263.
- Friedrichsdorf SJ, Remke S, Hauser J, et al. Development of a pediatric palliative care curriculum and dissemination model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics. *J Pain Symptom Manage*. 2019;58:707-720.e3.
- Qualtrics [computer program]. Version 2019. Provo, UT: Qualtrics; 2005.
- Elo S, Kyngas H. The qualitative content analysis process. *J Adv Nurs*. 2008;62:107-115.
- Zuniga-Villanueva G, Ramirez-GarciaLuna JL, Weingarten K. Factors associated with knowledge and comfort providing palliative care: a survey of pediatricians in Mexico. *J Palliat Care*. 2019;34:132-138.
- Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: results of the 1998 American Society of Clinical Oncology survey. *J Clin Oncol*. 2001;19:205-212.
- Levine DR, Mandrell BN, Sykes A, et al. Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology. *JAMA Oncol*. 2017;3:1214-1220.