

Translating Research to Action: The Development of a Pediatric Palliative Cancer Care Advocacy Tool in Eurasia

Bella S. Ehrlich, BA¹; Taisiya Yakimkova, MD, MS¹; Tsetsegsaikhan Batmunkh, MD, MPH, PhD²; Volha Mishkova, BS³; Narine Movsisyan, MD⁴; Kirill Kirgizov, MD, PhD⁵; Marina Borisevich, MD³; Roman Kizyma, MD⁶; Dylan E. Graetz, MD, MPH¹; Michael J. McNeil, MD¹; Anna Vinitzky, MD¹; Vitaly Smelov, PhD⁷; Marilyns Corbex, PhD⁷; Catherine G. Lam, MD, MPH¹; Erica C. Kaye, MD, MPH¹; Justin N. Baker, MD¹; and Asya Agulnik, MD, MPH¹ on behalf of the ADAPT Research Group

PURPOSE The Assessing Doctors' Attitudes on Palliative Treatment study was conducted in 11 Eurasian countries to assess physician knowledge of and structural barriers to integration of palliative care into pediatric oncology. After publication, regional collaborators identified the need to disseminate country-specific study results locally and provide policy recommendations to inform stakeholders.

METHODS The Assessing Doctors' Attitudes on Palliative Treatment report was developed with Eurasian and St Jude pediatric palliative care and oncology experts to summarize study findings and deliver country-level data to local stakeholders. In parallel, an assessment was developed to explore how regional collaborators intend to use the report to improve local advocacy and dissemination of research findings. The country report and assessment were translated to English, Russian, and Mongolian.

RESULTS Country-specific two-page reports display study findings on pediatric palliative care education, access to pediatric palliative care services, and barriers to and timing of integration with cancer care, alongside clinical and policy recommendations. These reports were distributed to collaborators in 11 countries. Assessment results (N = 30) demonstrated that regional collaborators planned to distribute the report to institutional and government stakeholders, aiming to increase access to pediatric palliative care services (77%), establish a community-based palliative care network (70%), and increase opportunities for specialization (70%).

CONCLUSION We describe the development of an evidence-based advocacy tool to inform local health and education policy in Eurasia. This summary report of study findings, translated to local languages and adapted to a broader audience, is currently used to advocate for greater access and quality of palliative care for children with cancer. This work may serve as the basis for future dissemination efforts of scientific research.

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INTRODUCTION

Low- to middle-income countries (LMICs) face a disproportionate burden of childhood cancer incidence and mortality.^{1,2} To improve the quality of childhood cancer care and quality of life, pediatric palliative care services must be integrated into cancer-directed care.³⁻⁵ The WHO identifies an unfulfilled and yet growing demand for increased access to pediatric palliative care worldwide. Accordingly, there is a significant need to use research findings to inform national- and institutional-level policies and initiatives that improve capacity building, provider education, and quality of pediatric palliative care for children with cancer in these settings.

The WHO pioneered a Public Health Strategy approach to integrate palliative care knowledge and skills into a country's health care system through policies and education of policy makers and health care workers.⁶

However, evidence has shown that health policies often fail to effectively reflect research findings.⁷ This failure results in what is known as the translation gap—a gap between medical evidence and its application in clinical practice and policy making.⁸ This gap pervades in pediatric palliative care programs and their reported availability in LMICs.⁹ To date, fewer than 50% of national cancer-related health policies from LMICs recognize palliative care (and even fewer pediatric palliative care).^{10,11}

LMICs face unique barriers to knowledge translation including inadequate links with target audience institutions, limited capacity to communicate findings to a nonscientific target audience, restricted accessibility of research findings, and strained human and material resources.¹² Thus, LMICs require additional support to overcome these barriers to increase access to research and thereby improve the integration of findings into evidence-based, cost-effective policies in resource-

ASSOCIATED CONTENT

Data Supplement

Author affiliations and support information (if applicable) appear at the end of this article.

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CONTEXT

Key Objective

What are effective methods of translating palliative care research findings into advocacy work to improve childhood cancer care globally? Although studies continue to advance the field of global oncology, this work uniquely addresses the translation gap between publications and dissemination of scientific research.

Knowledge Generated

We present the creation of advocacy reports in 11 Eurasian countries on the basis of research findings of physician knowledge of and perceived barriers to palliative care integration into childhood cancer care. Assessment of key stakeholder goals in using the reports demonstrated the need to increase access to palliative care services and education and involve various institutional and government stakeholders.

Relevance

Our study increases accessibility of published pediatric palliative care research to drive advocacy for evidence-based initiatives and reforms in clinical practice, policy, and education. This work provides a relevant, culturally informed approach to integrating research in future advocacy work and fostering cross-disciplinary dialogue among researchers and stakeholders.

limited settings.^{7,12} Enhanced dissemination is essential to bridge the translation gap and drive informed policies that address existing disparities in health care delivery and clinical outcomes.^{13,14}

The Eurasia Regional Program at St Jude Children's Research Hospital, known as Eurasian Alliance of Pediatric Oncologists (EurADO), identified the need to improve palliative care as a priority to optimize the quality of patient care for children with cancer in the region.^{15,16} Therefore, the Assessing Doctors' Attitudes on Palliative Treatment (ADAPT) study was conducted in 2019 in 11 participating EurADO countries, revealing delayed integration of palliative care into pediatric oncology practice, low access to home-based and in-patient services, misalignment of physician knowledge with WHO guidance, low physician self-assessment of clinical competence, and high levels of burnout.^{17,18} Participating countries in ADAPT, representing Eastern Europe and Central Asia, although geographically and culturally distinct, share a common history and are all Russian-speaking, with the exception of Mongolia. All EurADO countries participated in the study at the time of its inception, and the study surveyed any physicians treating children with cancer within each country. After the publication of study findings, Eurasian collaborators identified the need to increase accessibility of country-level data from the ADAPT study for local dissemination in Eurasia.

Accordingly, the objective of this work was to create advocacy tools in the form of country-specific reports with the aim of increasing access to ADAPT study findings and communicating relevant information to regional collaborators. These two-page reports display study findings on pediatric palliative care education, access to pediatric palliative care services, and barriers to and timing of integration with cancer care, alongside clinical and policy recommendations. To further understand how research findings are applied to advocate for childhood cancer policy changes, our secondary goal was to explore how local

collaborators envision using reports to inform future dissemination efforts of research findings.

METHODS

ADAPT Country Report Development

The ADAPT study had 424 participants from 11 countries: Azerbaijan, Armenia, Belarus, Kazakhstan, Moldova, Mongolia, Russia, Tajikistan, Ukraine, and Uzbekistan (Fig 1).^{17,18} Country reports were designed to highlight primary findings of the ADAPT study and provide background information on the benefits of pediatric palliative care on the basis of WHO guide published in 2018.¹⁹ EurADO collaborators identified local Ministry of Health, Ministry of Education, hospital leaders, and fellow physicians as the target audience for the advocacy tool, which further informed report development. The reports were created with the following objectives: (1) summarize country-level data, (2) provide actionable recommendations on the basis of study findings, (3) make the tool easily understandable to a broad target audience, and (4) culturally relevant and applicable to the local context.

Reports were created in Microsoft PowerPoint and Excel by the St Jude collaborators and graphic designers. Reports underwent iterative rounds of review of feedback via online communication and focus groups by St Jude palliative care specialists, leading physicians in childhood cancer and palliative care in collaborating Eurasian countries, and WHO technical officers to ensure clarity and simplicity of infographics while providing sufficient details for the target audience. Unanimous feedback from Eurasian physicians and fundraising organizations requested addition of recommendations for each country identifying priorities for improvements. Physician collaborators in each country reviewed their country's ADAPT report and provided direct feedback to ensure that it aligned with current priorities and needs for palliative care delivery for children with cancer in their country.



FIG 1. Map of Eurasian countries participating in ADAPT. The map displays the 11 countries that participated in the ADAPT study conducted in 2019. Accordingly, ADAPT country-level reports were created for all participating countries. ADAPT, Assessing Doctors' Attitudes on Palliative Treatment; EurADO, Eurasian Alliance in Pediatric Oncology.

Ultimately, the ADAPT report presents findings regarding access to palliative care consultation, timing of integration in childhood cancer care, and barriers to its early integration specific to each country. Domains of findings were chosen on the basis of a combination of original results and priorities identified by regional collaborators. The report further summarizes findings of physician education, knowledge, and self-reported competence in pediatric palliative care, culminating in identified country strengths and targeted recommendations for potential areas of improvement. Physician education was evaluated by the alignment score of physician knowledge with WHO guidance on pediatric palliative care, as described in the original ADAPT study.¹⁷ Five thematic categories of physician education were identified during initial study development by the ADAPT study team: timing of palliative care consultation, interdisciplinary communication, common misconceptions, patient suffering, and family communication (Data Supplement).

Reports were created for each of the 11 participating countries in the ADAPT study in Russian and English (adding Mongolian for the Mongolia report), as well as a summary report of the Eurasia region. Russian and Mongolian reports were translated and reviewed by native speakers and study collaborators to ensure construct consistency and comprehension.

Report Dissemination and Assessment of Intended Use

Along with country reports, a survey was developed to accompany the dissemination of country-specific reports to explore how local stakeholders intend to use the ADAPT report to improve local dissemination of research findings and advocate for improvements in palliative care service

delivery for children with cancer. The survey was created by St Jude and Eurasian ADAPT study team members and reviewed by regional collaborators for content relevance and comprehension. Survey questions combining multiple-choice and open-ended response items aimed to understand what recipients hoped to achieve by sharing the ADAPT report, how the report will be used to achieve the indicated goals, and which local stakeholders were the primary audience of report dissemination (see the Data Supplement for the complete survey). Survey questions also collected demographic data such as the country, education, and years of practice of respondents. The final survey had 14 questions (nine multiple-choice and five free-text) and was translated to Russian and Mongolian by native speakers.

The survey was distributed in all three languages (English, Russian, and Mongolian) through the Qualtrics platform and sent via the EurADO listserv to all 158 members at the time. The EurADO network extends beyond pediatric hematologists/oncologists to any physicians caring for children with cancer, institutional or department directors, nurses, Ministry of Health representatives, and charity foundation representatives. Upon completion, participants automatically received the ADAPT report for their country to download in all available languages. The survey was open for two months, after which reports were made publicly available through the St Jude platform.²⁰

Survey results were summarized via descriptive statistics. Thematic content analysis was conducted on the limited qualitative free-text responses, which were incorporated with quantitative data to provide additional supporting details.²¹

The ADAPT reports and survey described in this article were conducted as part of the EurADO initiative to increase

Pediatric Palliative Care in Eurasia: ADAPT Profile

The **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 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. WHO; 2018.

Access to Pediatric Palliative Care



46% of physicians reported having **no access** to palliative care consultation in their practice

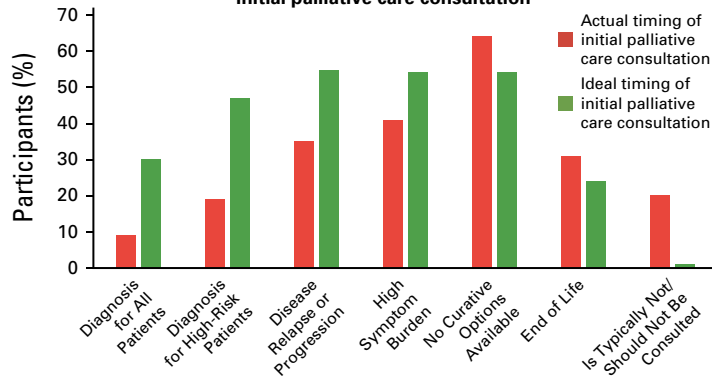


51% indicated that palliative care consultation is **not available** when they feel it is needed for children with cancer

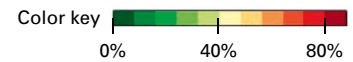
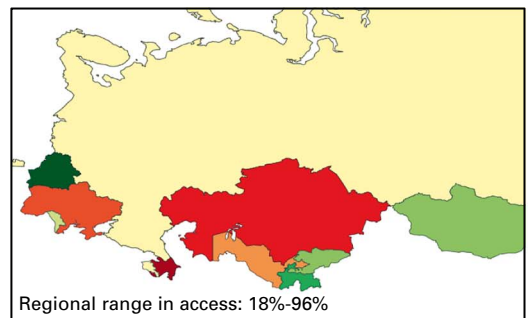


35% felt that palliative care was involved **too late** in the treatment of a child with cancer

Physician perspectives on actual vs. ideal timing of initial palliative care consultation



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



86% of physicians believe palliative care reduces suffering for a child with cancer.

67% of physicians believe palliative care should be integrated earlier in the care of children with cancer than typically occurring in their setting.

Barriers to Early Palliative Care Integration

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

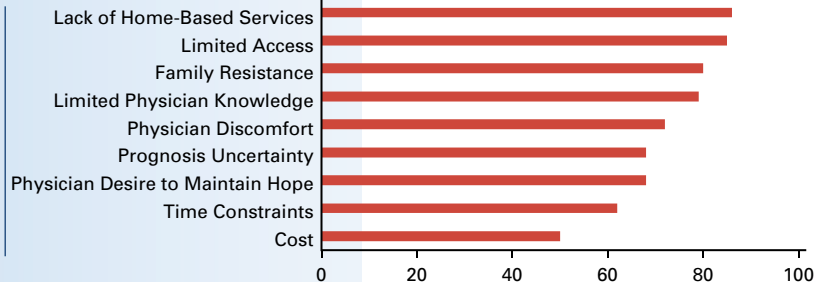


FIG 2. The Eurasia pediatric palliative care report. The figure displays a sample report generated on the basis of the collective data from all 11 participating countries in the Eurasia region. Individual country reports are publicly available through the St Jude platform.²⁰ ADAPT, Assessing Doctors' Attitudes on Palliative Treatment. (Continued on following page)

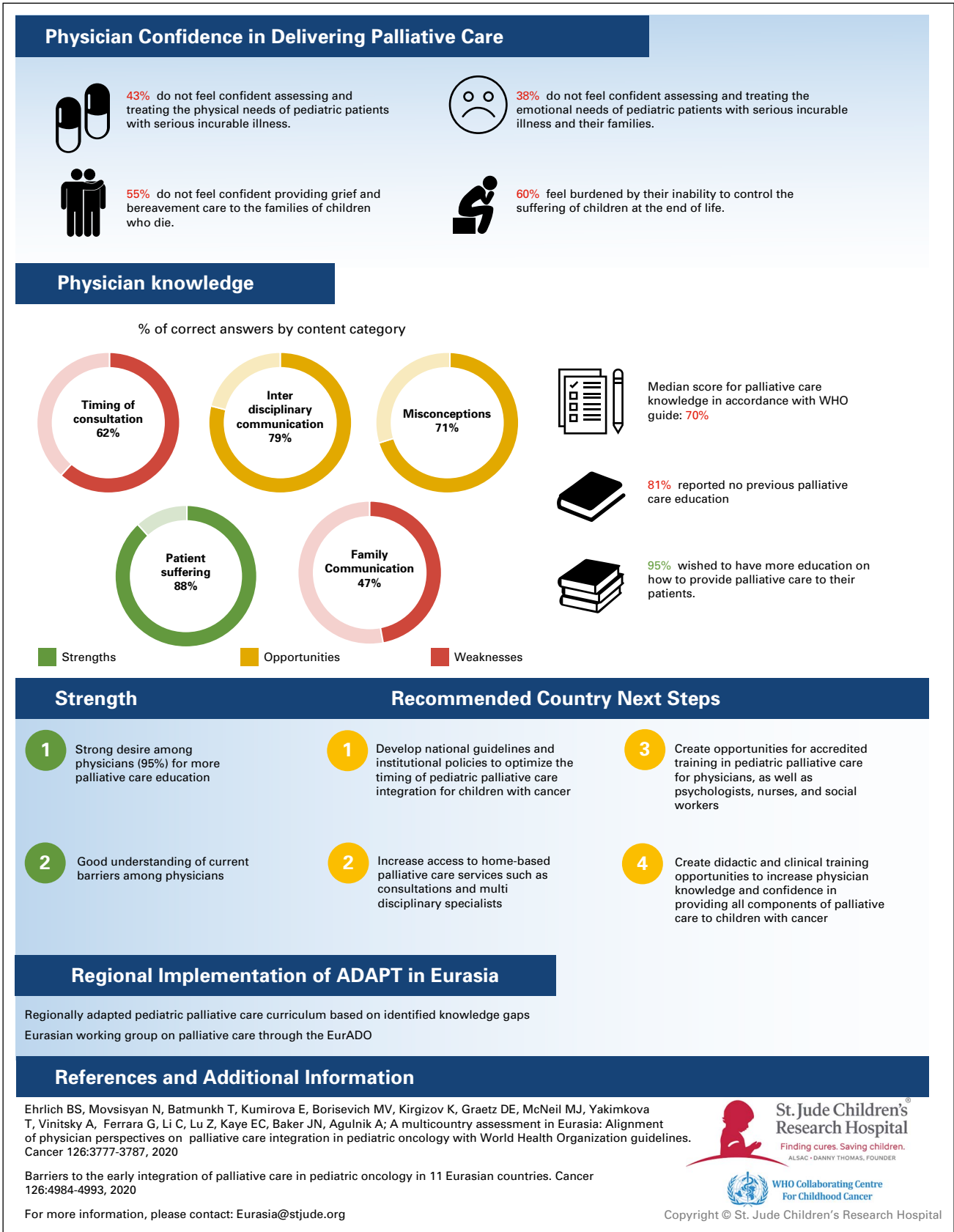


FIG 2.

TABLE 1. Demographic Information

Demographic	Overall Sample
Country, No. (%)	N = 30
Armenia	2 (7)
Azerbaijan	1 (3)
Belarus	2 (7)
Kazakhstan	3 (10)
Kyrgyzstan	1 (3)
Moldova	1 (3)
Russia	7 (23)
Tajikistan	2 (7)
Ukraine	4 (13)
Uzbekistan	6 (20)
Others (Poland and Serbia)	2 (7)
Primary medical specialty, No. (%)	n = 29
Pediatric hematology/oncology	24 (83)
All others ^a	5 (17)
Institutional role, No. (%)	N = 30
Trainee (resident and fellow)	2 (7)
Medical staff (eg, physician)	14 (47)
Unit or department director	14 (47)
Years of experience, No. (%)	N = 30
0-10	9 (30)
11+	21 (70)
Training in palliative care, No. (%)	N = 30
Yes	16 (53)
No	14 (47)

^aOther specialties include general pediatricians, pediatric anesthesia/intensive care, and pediatric radiation oncology.

advocacy and disseminate ADAPT findings. As it was not a part of any larger research study, no institutional review board approval was required. Survey participation was voluntary, and consent was implied from survey completion.

RESULTS

Report

The final ADAPT Pediatric Palliative Care Country Report summarizes country-level data on pediatric palliative care access, barriers, physician education, and perceived competence in clinical practice (see Fig 2 for the Eurasia Regional Report). In total, we created 25 reports in applicable languages (English, Russian, and Mongolian) for each of the 11 participating countries, as well as a summary report for the region.

To educate a larger audience of policy makers, hospital leaders, and Ministry of Health and Education personnel, the report contained background information from the WHO Guide for health care planners regarding palliative care integration.¹⁹ The report included information regarding the

benefit of palliative care on treatment outcomes and patient quality of life and the potential of palliative care to reduce health care costs by decreasing unnecessary resource utilization.

The end of the report outlined both strengths and recommended areas of opportunity for each country (see Fig 2 for a regional summary). Identified regional strengths included a general recognition among physicians that palliative care reduces child suffering, belief that palliative care should be integrated earlier in the care of children with cancer than what typically occurs in their setting, and a strong desire for more palliative care education. Despite variability in physician knowledge of palliative care by country, the overall Eurasian regional findings were generally representative of results from individual countries (Data Supplement). Physician self-reported confidence in caring for patients' physical and emotional symptoms and providing grief and bereavement care, significantly varied both within countries and across the region (Data Supplement).

Common identified country-specific areas of opportunity included the need to increase access to home-based palliative care services, develop national guidelines and institutional policies to optimize the timing of palliative care integration, and establish regular interdisciplinary meetings to improve collaboration with palliative care specialists early in childhood cancer treatment. Other recommendations were to increase opportunities for palliative care education, including local, accredited, and interdisciplinary training programs in pediatric palliative care, and didactic and clinical educational opportunities to increase physician confidence in provision of palliative care to children with cancer and their families.

Report Use

The ADAPT report survey received 30 responses from 12 EurADO countries, including 10 participating ADAPT countries and Poland and Serbia, which joined EurADO after the initial ADAPT study. This comprised a response rate of 19%, with a total of 158 participant members on the EurADO listserv. The majority of respondents were practicing pediatric hematology-oncology physicians (83%). Approximately half of respondents worked as medical staff physicians (47%) or unit or department directors (47%), and 53% of respondents had received previous training in palliative care (see Table 1 for complete demographic information).

Respondents indicated that they wished to receive the ADAPT report to advocate for palliative care services and education in their country (87%), distribute information among colleagues (70%), and identify deficits informing interventions (67%; Table 2). Respondents' ultimate goals for advocacy included using the report to increasing access to pediatric palliative care services (77%), establishing community-based palliative care and hospice networks (70%), and increasing opportunities for palliative care specialization (70%). Open-ended questions further described

TABLE 2. Indicated Purpose and Utilization of ADAPT Country Reports^a

Survey Items	Overall Sample (N = 30), No. (%)
Why are you interested in receiving the ADAPT Country Report?	
To advocate for palliative care services and/or education in the country	26 (87)
Distribution of information among colleagues	21 (70)
To identify deficits informing interventions	20 (67)
For personal understanding	11 (37)
What do you hope to achieve by sharing the ADAPT Country Report?	
Increase access to pediatric palliative care services for patients and/or families	23 (77)
Establish a community-based palliative care and/or hospice network	21 (70)
Establish and/or increase opportunities to specialize in pediatric palliative care	21 (70)
Educate other healthcare professionals about pediatric palliative care	18 (60)
Increase opportunities for pediatric palliative care education	15 (50)
With whom do you plan to share the ADAPT Country Report?	
Collaborating physicians	26 (87)
Nonphysician clinicians (eg, nurses and psychosocial providers)	23 (77)
Hospital leadership (eg, director)	19 (63)
Ministry of Health	12 (40)
Ministry of Education	3 (10)

Abbreviation: ADAPT, Assessing Doctors' Attitudes on Palliative Treatment.

^aAll data are based on responses to multiple-choice questions provided in the survey. Participants could select all choices that apply.

goals of creating palliative care services and infrastructure integrated into a larger health system, increased government financing, protocols for palliative care integration, and creation of national standards (Table 3).

By sharing the ADAPT country report, respondents also hoped to improve education of health care professionals (60%) and increase palliative care educational opportunities

(50%). Free-text responses described using ADAPT data and report recommendations highlighted the importance of improving palliative care education and increasing awareness of pediatric palliative care in medicine. Respondents noted the need to incorporate palliative care education into medical school curricula with the help of the local Ministry of Health, adapt pediatric palliative care material to be taught in

TABLE 3. Participant Descriptions of Goals, Hopes, and Plans for Disseminating the ADAPT Report

Thematic Categories	Participant Qualitative Descriptions
Interest and aspirations	Identify gaps and weaknesses in our work. See goals and possible paths for further development. Assessment of the situation in the region regarding the coverage of palliative care for children with cancer To improve quality of palliative care delivered to patients
Goals and intended implementation strategies	We plan to use the ADAPT findings (1) when working on the text of the National Strategy for Fighting Cancer (it has a separate section on palliative care), (2) when developing provider requirements for inpatient and home palliative care services within the framework of financial packages provided by the National Health Service of Ukraine... Development of a professional standard and approval of the physician specialty in palliative care, development of regulations to create a pediatric palliative care service, [and] development of methodological materials on pediatric palliative care in Uzbek for primary care physicians, nurses, social workers, and parents Objective: to improve the access and timeliness of palliative care for patients and their families. Plan: to disseminate the necessary information to all levels To create educational seminars for parents of sick children
Dissemination and collaboration	(1) To inform colleagues and other specialists involved in palliative work, (2) to inform leadership of the center and the Ministry of Health, and (3) create an action plan Working on ADAPT tool, we have united key stakeholders—doctors who perform palliative care, national charities, and Association of palliative care for children in Ukraine... Report will be a useful tool to show some valid data and maybe—track progress in the future.

Abbreviation: ADAPT, Assessing Doctors' Attitudes on Palliative Treatment.

local languages, create a palliative care specialty, and ultimately educate institutional leadership.

Notably, respondents indicated that although the target audience included physicians (87%), dissemination extended beyond doctors to include nonphysician clinicians such as psychosocial providers (77%) and policy makers working in hospital leadership (63%), Ministry of Health (40%), or Ministry of Education (10%).

DISCUSSION

We present the development of a tool that is adapted to the local context and languages spoken by institutional and government stakeholders in Eurasia and aimed to enhance dissemination of research findings regarding palliative care integration for children with cancer. Report recipients indicated that they plan to use the report to advocate for increased palliative care financing and access to services, guidelines, and formal education to physicians and administrators at their institution and nationally at the Ministry of Health and Ministry of Education.

More than a decade earlier, barriers and gaps in physician knowledge and institutional support were identified for palliative care in Eastern European and Central Asian countries, similar to those identified in the ADAPT studies.²² Although these findings reinforce the validity of the ADAPT study results, they also demonstrate a lack of regional progress to improve palliative care delivery, highlighting the necessity to translate research to action. Unfortunately, estimates suggest that it takes approximately 17 years to translate just 14% of research into improved patient outcomes, with most findings lost to attrition with time.^{23,24} To reduce this time lag, it is necessary that investigators have a comprehensive understanding of the consumers of information, capacity of collaborating organizations, and the larger sociopolitical context where the change is being implemented.^{25,26} The creation of ADAPT reports begins to address these challenges and yields important information on the implementation process of how to translate research findings to advocacy. This work assesses how collaborators intend to use this report to propagate change in their local settings.

An essential, yet often missing, component in the dissemination of evidence-based practices is the establishment of a close partnership between researchers and disseminators.²⁶ This close collaboration promotes the design of effective dissemination strategies that achieve the disseminator's goals and capacity.²⁶ Collaboration with local stakeholders was a core strength in the creation of ADAPT reports, which were developed in response to regional collaborators to increase outreach and improve communication with regional stakeholders. Further iterative modification to the reports with regional collaborators ensured that reports were culturally and contextually appropriate, striking a balance between clear delivery of ADAPT study results to nonscientific audiences and establishing credibility of the study findings to justify their use to inform policy. This process also led to the inclusion of concrete

institutional- and national-level policy recommendations in the report, as requested by the ADAPT regional collaborators. Moreover, ongoing support and partnership through EurADO continue to support regional initiatives aimed at improving health care services and education for children with cancer.

Our work to disseminate research findings has certain limitations. Although the relatively small response rate and number of participants in the survey of report use may limit the generalizability of findings, respondents represented a broad group of national experts and varied from clinicians to health care policy makers and representatives in fundraising organizations. Survey responses further reflected common palliative care strengths and weaknesses voiced by EurADO regional collaborators, supporting the validity of these results. Although targeted dissemination helped deliver ADAPT reports to EurADO members, we recognize that this restricted report dissemination to collaborators already within our regional network. To address this limitation, ADAPT reports are now publicly available on the St Jude platform.²⁰ In addition, we suspect that certain physicians might have participated in both the original ADAPT study and this advocacy initiative. However, although this might have indeed biased respondents to the ADAPT study findings, we believe that this would enhance and facilitate ongoing advocacy efforts as participants have a greater level of understanding of the original work. We hope that this work will promote the global dissemination of ADAPT findings. In addition, our team has recently expanded the ADAPT study to the Latin American and Asia Pacific regions, and we anticipate using this platform to facilitate future dissemination of ADAPT results.²⁷

Ultimately, understanding the target audience with decision-making capacity and stakeholder priorities for using the ADAPT report can inform the development of advocacy tools and reports to promote dissemination of future research in Eurasia. Adaptation to the language, educational background, and socioeconomic context is critical to engage vested policy makers and those with decision-making capacity in health care institutions and foster cross-disciplinary dialogue between researchers and stakeholders. Moreover, this approach to identifying local priorities and facilitating communication of scientific findings is an example of how to disseminate research in other regions. This work may also inform future interventions to improve palliative care delivery by supporting components of the implementation process, such as the action cycle in the Knowledge-to-Action framework.^{28,29} Moving forward, repeating the original ADAPT study can also track implementation outcomes and the efficacy of future pediatric palliative care interventions.

Active dissemination of local research findings to stakeholders is integral to strengthen country-level policy decisions and enhance advocacy for improvements in palliative care access, education, and timeliness of integration. This work highlights the ongoing need to increase accessibility of research to inform clinical practice and local policy aiming to improve global outcomes in pediatric oncology.

AFFILIATIONS

- ¹St Jude Children's Research Hospital, Memphis, TN
²Administrative, National Cancer Council of Mongolia, Ulaanbaatar, Mongolia
³Belarusian Research Center for Pediatric Oncology, Hematology and Immunology, Minsk, Belarus
⁴Anesthesiology and Intensive Care, Yerevan State Medical University After M. Heratsi, Yerevan, Armenia
⁵N.N. Blokhin National Medical Research Center of Oncology, Moscow, Russia
⁶Western Ukrainian Specialized Children's Medical Centre, Lviv, Ukraine
⁷World Health Organization Regional Office for Europe, Copenhagen, Denmark

CORRESPONDING AUTHOR

Asya Agulnik, MD, MPH, Mail Stop 721, 262 Danny Thomas Place, Memphis, TN 38105; e-mail: asya.agulnik@stjude.org.

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AUTHOR CONTRIBUTIONS

Conception and design: Bella S. Ehrlich, Narine Movsisyan, Kirill Kirgizov, Michael J. McNeil, Erica C. Kaye, Justin N. Baker, Asya Agulnik

Administrative support: Bella S. Ehrlich

Provision of study materials or patients: Bella S. Ehrlich, Narine Movsisyan, Asya Agulnik

Collection and assembly of data: Bella S. Ehrlich, Taisiya Yakimkova, Tsetsegsaikhan Batmunkh, Volha Mishkova, Narine Movsisyan, Roman Kizyma, Asya Agulnik

Data analysis and interpretation: Volha Mishkova, Narine Movsisyan, Marina Borisevich, Dylan E. Graetz, Anna Vinitzky, Vitaly Smelov, Marilyn Corbex, Catherine G. Lam, Erica C. Kaye, Justin N. Baker, Asya Agulnik
Manuscript writing: All authors

Final approval of manuscript: All authors

Accountable for all aspects of the work: All authors

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Anna Vinitzky

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Catherine G. Lam

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