

Original Article

Mapping Pediatric Palliative Care Development in the WHO-European Region: Children Living in Low-to-Middle-Income Countries Are Less Likely to Access It



Natalia Arias-Casais, MD, MGH, PhD, Eduardo Garralda, MA, Juan José Pons, PhD, Joan Marston, RN, Lizzie Chambers, Julia Downing, PhD, Julie Ling, PhD, John Y. Rhee, MD, Liliana de Lima, MHA, and Carlos Centeno, PhD

ATLANTES Global Observatory of Palliative Care (N.A.-C., E.G., J.J.P., J.Y.R., L.d.L., C.C.), Institute for Culture and Society, University of Navarra, Pamplona; Department of History, History of Art and Geography (J.J.P.), University of Navarra, Pamplona, Spain; Department of Neurology (J.Y.R.), Massachusetts General Hospital and Brigham and Women's Hospital, Harvard, Boston, Massachusetts; Medical School (L.d.L.) International Association for Hospice and Palliative Care, Houston, Texas, USA; Palliative Treatment for Children (PatchSA) (J.M.), Rondebosch, South Africa; European Association for Palliative Care (J.L.), Vilvoorde, Belgium; Together for Short Lives (L.C.), Bristol; and International Children's Palliative Care Network (J.D.), Bristol, United Kingdom

Abstract

Context. Approximately 170,000 children in need of palliative care die every year in Europe without access to it. This field remains an evolving specialty with unexplored development.

Objectives. To conduct the first regional assessment of pediatric palliative care (PPC) development and provision using data from the European Association for Palliative Care atlas of palliative care 2019.

Methods. Two surveys were conducted. The first one included a single question regarding PPC service provision and was addressed by European Association for Palliative Care atlas informants. The second one included 10 specific indicators derived from an open-ended interview and rating process; a specific network of informants was enabled and used as respondents. Data were analyzed and presented in the map of the figure.

Results. Data on PPC service provision were gathered from 51 of 54 (94%) European countries. Additional data were collected in 34 of 54 (62%) countries. A total of 680 PPC services were identified including 133 hospices, 385 home care services, and 162 hospital services. Nineteen countries had specific standards and norms for the provision of PPC. Twenty-two countries had a national association, and 14 countries offered education for either pediatric doctors or nurses. In seven countries, specific neonatal palliative care referral services were identified.

Conclusion. PPC provision is flourishing across the region; however, development is less accentuated in low-to-middle-income countries. Efforts need to be devoted to the conceptualization and definition of the models of care used to respond to the unmet need of PPC in Europe. The question whether specialized services are required or not should be further explored. Strategies to regulate and cover patients in need should be adapted to each national health system. *J Pain Symptom Manage* 2020;60:746–753. © 2020 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Pediatric palliative care, development, indicators

Address correspondence to: Natalia Arias-Casais, MD, MGH, PhD, ATLANTES Global Observatory of Palliative Care, Institute for Culture and Society, University of Navarra, 31080 Pamplona, Spain. E-mail: narias@unav.es

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Introduction

The world's pediatric population, defined as those younger than 20 years, accounts for 35% of the global population.¹ In 2017, a study estimated that globally as many as 21 million neonates, infants, children, and adolescents may benefit from the palliative care approach for a variety of conditions requiring it as defined by the World Health Organization (WHO).² Of this, eight million would require some degree of specialized pediatric palliative care (PPC) every year.^{2,3} According to the WHO, in children, a number of conditions commonly require palliative care; these include advanced chronic noncommunicable diseases; acute life-threatening conditions like HIV/AIDS, malignancies, and drug-resistant tuberculosis; progressive life-threatening conditions like neurodegenerative diseases; severe neurologic conditions; and severely premature neonates or those with congenital anomalies, or children dying unexpectedly;³ however children with other conditions may also require palliative care.

Defining children's palliative is a complex task. The WHO define it as ... the active total care of the child's body, mind and spirit and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at disease.⁴ More recently, Together for Short Lives elaborated this further,⁵ and The International Association for Hospice and Palliative Care developed a consensus-based definition of palliative care, which incorporates palliative care across the life span.⁶ Despite no common definition, PPC has been recognized as a fundamental component of universal coverage and the right to health and has been described as a moral imperative of health systems to tackle health-related suffering in children and adolescents.⁷

Many conditions in childhood can lead to health-related suffering that could benefit from this approach.⁸ A recent report estimated that of the 2.5 million children who die every year worldwide, 98% live in low-to-middle-income countries.⁸ Suggesting an uneven distribution of the burden of PPC, figures for Europe estimate that although much of the suffering is treatable and preventable, around 170,000 children will die every year in Europe with health-related suffering and no access to palliative care.⁹

To date, few studies have addressed PPC development at the national level. Two studies estimated the global need for PPC.^{2,4} Few studies assessed the human and financial resources required to meet the costs of providing palliative care for children. In 2011, Knapp et al.¹⁰ estimated that 65.5% of countries globally have no known PPC provision, with only 5.7% reaching mainstream providers. Other studies have

highlighted the challenges that low-to-middle-income countries face when trying to provide PPC.^{11,12}

However, there is a dearth of information about PPC development in European countries. The recently published European Association for Palliative Care (EAPC) atlas on palliative care in Europe⁹ conducted the first assessment of children's palliative care development in the region using national-level indicators. Specific indicators were implemented in the 54 WHO-European countries. Building on data gathered during the making of the atlas, this study delivers an overview on the current status of PPC service provision, the existence of standards and norms, access to education opportunities, and the activity of PPC associations.

Methods

The study received clearance from the Institutional Research Board of the University of Navarra on January 11, 2018 (IRB.2017.222). For the assessment of PPC development within the WHO-European region, two surveys were conducted, each with one ad hoc questionnaire, addressed at two groups of experts, respectively.

The first survey consisted of a single question regarding PPC service provision and was included in the general development survey of EPAC. This question was sent to the informants of the EAPC Atlas network, composed by national experts in palliative care development and board members of national associations. The second survey consisted of 10 specific indicators derived from an open-ended interview and rating process. To respond to this survey, a specific network of PPC informants was created using palliative care networks, national associations, and literature review.

Data were analyzed, sense checked, and presented in the map of the figure. The following lines explain the process followed.

Selection of Indicators

The main indicator, number and type of palliative care programs and services for children, was chosen in a Delphi consensus process with a panel of international experts in global palliative care development.^{13–15} The question was submitted to the informants of the EAPC Atlas network.

The additional nine indicators were retrieved from an open-ended interview process in which three experts in international PPC development participated (J. D., L. C., and J. M.). Selection of experts was based on the engagement in international networks of PPC and previous participation in cross-national research assessing national-level PPC development. Interviews

were recorded, transcribed, and thematically analyzed. Indicators were extracted and sent back to the experts for rating by relevance, measurability, and feasibility (scale 1–9). Ratings were used to calculate a global score that was fine tuned in a second round. Indicators scoring global score <7.5 were selected (Table 1). Selected indicators were used to build a survey addressed at a network of experts in PPC in Europe.

Building Up a PPC Network of Experts

A specific network of European experts in PPC was specifically identified for this study through informants of the EAPC Atlas; literature review, identifying papers on PPC in each European country and contacting the authors; identifying experts through the EAPC Task Force on PPC and the International Children's Palliative Care Network; and inviting PPC poster's authors from the EAPC Congress 2018 to participate. Identified experts were invited to participate via electronic mail, and the link to the survey was sent after confirmation to participate.

Data Collection and Analysis

Both surveys were sent in December 2018. Data were collected between December 2018 and March 31, 2019.

Data on service provision were categorized according to the location of the care setting as follows: home care services, hospital services, and hospices. This categorization was followed to organize the various models of care reported.

The Atlantes Research Group at the University of Navarra analyzed the collected data. Data were verified using a confirmation algorithm to triangulate information and guarantee accuracy, especially where data were related to more than one national expert. Where data inconsistencies were found, points were highlighted, and clarification sought directly with informants. Where possible, reports were confirmed with official documents, published literature, and national databases when available.

In addition, data were extracted from the free-text comments section of each question. This was analyzed using thematic analysis.

Results

A total of 92 experts in PPC development from 51 countries (94%) responded to the first survey and provided data on PPC service provision in their countries. In addition, a specific network of 98 PPC experts was enabled. About 42 of these experts (45%) completed the second survey containing the remaining nine indicators. They provided information on the existence of

Table 1
List of Indicators for the National-Level Assessment of PPC Development

Field	Indicator	Global Score
Pediatrics	Vitality of PPC associations	9.4
	Inclusion of PPC components in pediatrics curricula of specialization for doctors and nurses	9.2
	Existence of a PPC representative at the national PC association and vice versa	9.2
	Number and type of PPC services	9.1
	Availability of PPC training for neonatologists	9.1
	Existence of at least one national PPC association	9.1
	Number of specialized PPC consultants	8.8
	Existence of national standards and norms for the provision of PPC	8.7
	Existence of perinatal PC reference centers	8
	Existence of policies regulating pediatrics palliative care provision	7.7

PPC = pediatric palliative care; PC = palliative care.

specific services and the development of the discipline in 34 countries (62%). As a result, this study provides data on service provision in 51 of 54 countries of the European region and additional information on other development indicators for 34 countries.

PPC Service Provision

A total of 680 services were identified in 48 of 51 (94%) countries. Of these, 133 were as hospices, 385 as home care services, and 162 as hospital services. Most of these services (92%) are in high-income countries. Table 2 shows the number and type of PPC services in Europe.

This study reveals a wide range of models of care for children with palliative care needs. Services are provided in three types of location: hospital, home, and hospices. In some countries such as the U.K. and The Netherlands, many services are home based; in others like Lithuania, services are predominantly hospital based, whereas in Israel and Ireland, some aspects of palliative care for children are provided by adult services. Some countries reported the provision and availability of additional services, such as bereavement support, respite care, psychological support, and in some countries, such as Albania, palliative care for children was provided in orphanages.

There is increasing interest in the development of hospices specifically for children in countries, such as Lithuania, Luxembourg, Norway, and Denmark. In Italy, a new children's hospice is currently under construction.

Table 2
PPC Service Provision in Europe

Country	Income Group	Number of Services Providing PPC Identified in 2019		
		Hospices	Home Care Services	Hospital Services
Croatia	HI	NA	NA	NA
Czech Republic	HI	0	6	2
Estonia	HI	0	0	0
Hungary	HI	2	3	1
Latvia	HI	0	2	2
Lithuania	HI	0	NA	3
Montenegro	HI	NA	NA	NA
Poland	HI	8	66	0
Russia	HI	14	94	43
Slovakia	HI	0	4	2
Slovenia	HI	0	NA	10
Austria	HI	1	14	2
Belarus	HI	13	8	0
Belgium	HI	0	6	3
Cyprus	HI	0	0	0
Denmark	HI	1	5	10
Germany	HI	16	33	4
Finland	HI	0	2	0
France	HI	0	22	22
Greece	HI	0	1	0
Iceland	HI	0	0	0
Ireland	HI	1	10	4
Israel	HI	1	1	9
Italy	HI	5	7	NA
Lichtenstein	HI	0	0	0
Luxembourg	HI	0	1	1
Malta	HI	0	0	0
Monaco	HI	0	0	0
The Netherlands	HI	13	22	7
Norway	HI	0	0	0
Portugal	HI	0	5	6
Spain	HI	0	8	2
Sweden	HI	1	NA	0
Switzerland	HI	0	0	3
U.K.	HI	45	45	8
Albania	LMI	0	3	1
Armenia	LMI	0	1	NA
Azerbaijan	LMI	0	0	0
Bosnia and Herzegovina	LMI	1	NA	NA
Bulgaria	LMI	0	NA	NA
Georgia	LMI	1	4	NA
Kazakhstan	LMI	1	0	0
Kyrgyzstan	LMI	1	1	NA
Macedonia	LMI	0	0	0
Moldova	LMI	1	1	2
Romania	LMI	3	4	5
Serbia	LMI	0	0	1
Tajikistan	LMI	0	0	2
Ukraine	LMI	3	6	3
Uzbekistan	LMI	NA	NA	NA
Turkey	LMI	1	0	4

PPC = pediatric palliative care; HI = high income; NA = no data available; LMI = low-to-middle income.

Legal Frameworks to Regulate Palliative Care Provision for Children

Nineteen countries (37%) reported specific standards and norms for the provision of palliative care for children (Table 3). Most of these are in high-income countries. From the low-to-middle-income countries, only Albania, Georgia, Serbia, and Ukraine reported having specific national standards and norms for PPC.

Vitality of the Professional Activity of PPC

Twenty-one countries (42%) have specific PPC associations (Fig. 1). Seventeen (77%) are in high-income countries. Armenia, Bulgaria, Georgia, Kyrgyzstan, and Ukraine are the only low-to-middle income countries with PPC national associations. PPC specialists were identified in 20 countries (39%) (Table 3). Professional qualifications and certification processes

Table 3
Vitality of the Professional Activity of PPC

Country	Income Group	Inclusion of PPC Components in the Pediatric Specialization for Medical Doctors	Inclusion of PPC Components in the Pediatric Specialization for Nurses	Identified PPC Specialized Consultants	Existence of Specific National PPC Association	National Standards and Norms for the Provision of PPC
Croatia	HI					
Czech Republic	HI	X		X	x	
Estonia	HI					
Hungary	HI		X	X		
Latvia	HI	X	X	X	X	X
Lithuania	HI					
Montenegro	HI					
Poland	HI					
Russia	HI			X		X
Slovakia	HI			X		
Slovenia	HI					
Austria	HI	X	X		X	X
Belarus	HI	X	X	X		X
Belgium	HI			X	X	X
Cyprus	HI			X		
Denmark	HI				X	X
Germany	HI	X	X	X	X	X
Finland	HI					
France	HI			X	X	X
Greece	HI			X	X	
Iceland	HI					
Ireland	HI		X	X	X	X
Israel	HI				X	
Italy	HI	X	X	X	X	X
Lichtenstein	HI					
Luxembourg	HI					
Malta	HI					
Monaco	HI					
The Netherlands	HI		X	X	X	X
Norway	HI		X		X	X
Portugal	HI	X	X		X	
Spain	HI	X	X	X	X	X
Sweden	HI				X	
Switzerland	HI				x	
U.K.	HI	X	X	X	X	X
Albania	LMI	X	X	X		X
Armenia	LMI	X	X	X	X	
Azerbaijan	LMI					
Bosnia and Herzegovina	LMI					
Bulgaria	LMI				X	
Georgia	LMI	X	X	X	X	X
Kazakhstan	LMI					
Kyrgyzstan	LMI				X	
Macedonia	LMI					
Moldova	LMI					
Romania	LMI					
Serbia	LMI	X	X			X
Tajikistan	LMI					
Ukraine	LMI	X		X	X	X
Uzbekistan	LMI					
Turkey	LMI					

PPC = pediatric palliative care; HI = high income; LMI = low-to-middle income.

vary greatly across Europe, and generalized standards for training in PPC do not exist.

There are a limited number of opportunities for continuing education for doctors and nurses in PPC (Table 3). Fourteen countries reported having palliative care components in their pediatric medical undergraduate education and 16 in pediatrics specialization for nurses. Latvia, Austria, Belarus, Germany, Italy,

Portugal, Spain, U.K., Albania, Armenia, Georgia, and Serbia include PPC components in their specialization curricula of both nurses and doctors.

Perinatal Palliative Care

Austria, Germany, Italy, The Netherlands, Norway, Spain, and U.K. reported neonatal palliative care being available (Table 3). Eight countries reported

countries to tackle the identified needs. Data from this study also indicate that standards and norms regulating the provision of PPC are more likely to exist in high-income countries.

Models of Care for PPC Provision and the Need of Specialized Services

This study revealed a different palette of models of care covering children in the region. Those identified suggest great differences between adult and children provision and heterogeneity between countries. In contrast to adults, the models of care for PPC remain undefined and have not been conceptualized. This study addressed the categorization of children services by focusing on the setting. Such an approach is meaningful on understating the general provision across the region and its first assessment. As a matter of fact, this study revealed that countries tend to have more home care-based services and fewer hospices. Some countries reported bereavement, respite, and even orphanages as palliative care services. Further research should aim at better defining the available models of care and, if needed, enabling subcategorizations. In light that palliative care for children is a distinct speciality, with some differences regarding adult provision,⁵ it is essential that services match the specific needs of children.

As a speciality, palliative care for children has evolved from pediatrics rather than through palliative care. This supports the recommendations of the United Nation Convention on the rights of the child, which suggests that children are entitled to health care and the right to be cared for by specifically trained health workforce.²⁰ As seen in some countries, children in need are covered through pediatric provision rather than specialized services, suggesting that specialized services might not be always required as long as general pediatricians and nurses are thoroughly trained to respond to children with palliative care need. With this regard, further discussion needs to be conducted to clarify whether and when specialized services are required and to design targeted national strategies that strengthen the health care level more likely to efficiently respond to each national demand.

Education for the Future

Despite the availability of an EAPC core curriculum for PPC,²¹ there is limited provision of specific education for all health care professionals. Education is the key to improving palliative care for children and to developing services and capacities especially in countries with limited resources. This study identified and used a specific network of PPC experts across Europe. The association of health professionals within and across countries is essential for providing care to

children with palliative care needs, build and maintain the required competencies and skills,²¹ and access training and educational opportunities as seen in studied countries.

Limitations

This study provides a set of national-level indicators, which can be used for cross-national comparison. They are presented as a starting discussion point on the national-level assessment of PPC development. Further research should focus on capturing more experts' voices, the definition of the models of care, and assessment of their applicability in other regions.

The EAPC study reports on data of respondent countries that PPC may have been also available in the countries where there was no response. The identification of pediatric experts in more countries and the commitment to participate as informant of mapping studies will allow a better future assessment of its development. Yet, the process of identification of experts may have missed some people. Further efforts should focus on widening the network of informants.

As seen in countries like Norway, children's palliative care is a part of pediatric provision, which does not mean that palliative care is underdeveloped, rather integrated. This should be taken into consideration for further studies and on the definition provided regarding models of care. A consensus-based definition is required for the assessment of PPC because current differences may impact on individuals understanding of PPC.

This study is a first regional assessment on the issue, yet its scope did not consider the assessment of the quality of services identified. Future studies should consider evaluating it.

Conclusion

Regardless of income level, countries are starting to respond to the unmet need of PPC in Europe. Efforts need to be devoted to the conceptualization and definition of the models of care used to tackle the issue, especially in light of the question whether specialized services are required. Strategies to regulate and cover patients in need should be adapted to each national health system.

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Research ethics and patient consent: This research did not involve human subjects. The study was granted approval by the Institutional Review Board of the University of Navarra (latest approval: IRB.2017.222).

The authors declare no conflicts of interest.

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