

Original Article

Estimating the Global Need for Palliative Care for Children: A Cross-sectional Analysis



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Abstract

Context. The need for children's palliative care (CPC) globally is unknown. To understand the scope of the need and to advocate to meet it, more accurate estimates are needed.

Objectives. The objective of this study was to create an accurate global estimate of the worldwide need for CPC based on a representative sample of countries from all regions of the world and all World Bank income groups.

Methods. This work builds on previously published methods developed by the International Children's Palliative Care Network, United Nations Children's Fund, and World Health Organization and tested in three African countries. The study used a cross-sectional design with quantitative data obtained from primary and secondary data sources. Estimation of the need used prevalence data from the Institute for Health Metrics and Evaluation, mortality data from the World Health Organization for the specific diseases known to require CPC, and Joint United Nations Programme on HIV/AIDS (UNAIDS) data on HIV prevalence. Representative data were analyzed for 23 countries representing 59.5% of the world's population.

Results. The findings show estimated need for CPC ranged from almost 120 per 10,000 children in Zimbabwe to slightly more than 20 per 10,000 in the United Kingdom. Overall, among the over 21 million with conditions that will benefit annually from a palliative care approach, more than eight million need specialized CPC worldwide.

Conclusion. The estimation of need for CPC is a critical step in meeting the needs of children with life-threatening conditions and provides a sound platform to advocate for closure of the unacceptably wide gaps in coverage. *J Pain Symptom Manage* 2017;53:171–177. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Pediatric palliative care, needs assessment, need for service, pediatrics, hospice, children

Introduction

There is growing awareness that there are major gaps in access to children's palliative care (CPC) worldwide. For this article, we use the term children to refer to neonates, infants, children, and adolescents. Adults have a greater likelihood of receiving palliative care than children.¹ Growing access to treatment services and extended periods of wellness have led to some changes in the nature of the palliative care services required.² Children are more resilient and more likely to require CPC for longer periods

than adults. Most global child health efforts are directed to reduction in mortality, and little attention has been paid to the need for CPC.

It is against this background that United Nations Children's Fund (UNICEF) and the International Children's Palliative Care Network (ICPCN), in collaboration with national palliative care associations, began a joint analysis to develop methods to assess critical needs and gaps in CPC. The initial assessment, conducted in Kenya, South Africa, and Zimbabwe, aimed to analyze existing secondary data on palliative care to estimate the palliative care need among children and explore

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key gaps in the response with service providers. A report on this research, the methods used and the results for South Africa, was published in 2014.³

There is a lack of information regarding the actual need for palliative care for children, and assessment is complex, because of uncertainty about the patient population and the nature of palliative care for children.⁴ Although there have been some studies focusing on the status of CPC in sub-Saharan Africa, the U.S.,⁵ and the U.K.,⁶ there are differences in the scope and approach to the present study. A systematic review of the provision of CPC around the world noted that more than 65% of countries have no recognized CPC service provision and concluded that service provision for CPC is not meeting the need in the majority of the world.⁷

Generally, studies estimating need for palliative care for adults and children are based on mortality statistics for chronic, incurable illnesses. Estimates focused on end-of-life care, as in the *Global Atlas of Palliative Care at the End of Life*,⁸ do not account for the children who need palliative care well before the last year of life and underestimate the need. The unmet need for palliative care for both adults and children is significant. More than 40 million patients need palliative care annually, 20 million at the end of life. Seventy-five percent of the world population live in countries that have no or very limited access to controlled substances for pain relief and almost 80% of the need for palliative care is in low- and middle-income countries.⁸

The World Health Organization (WHO) defines palliative care for children as a special, albeit closely related field to adult palliative care.⁹ In an effort to define the many diseases and conditions requiring CPC in the U.K., a directory was published in 2013 with 376 potential diagnostic labels, although the majority of deaths were from a small number.¹⁰

The objectives of this study were to:

1. Refine the methodology used in our previous study to improve the estimation process to permit an accurate global estimate
2. Estimate the worldwide need for CPC based on a representative sample of countries from all regions of the world and all World Bank income groups.

This article is organized and reported according to the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement.

Methods

Study Design

The study used a cross-sectional design with a focus on estimating the need for CPC at the national level in

a sample of countries. Country-level prevalence data were used from secondary data sources. Assessment of the need for CPC was based on estimation techniques using the prevalence and mortality of specific conditions known to require CPC according to the WHO.⁸ Prevalence was modified to eliminate sequela that would not require palliative care, as determined by a panel of CPC experts and consistent with methods agreed by UNICEF in our previous study.³ We developed the global estimate by creating a representative sampling frame of countries representing all World Bank Income Groups and WHO regions approximating the average Human Development Index (HDI).

Setting

This study was conducted from June 2014 to May 2015. The work was done by desk research by the principal investigator with regular review and discussion with the co-principal investigators and with our clinical experts in CPC.

Participants

This study used a definition of “children,” which included neonates, infants, children, and adolescents from birth through 19 years of age.

CPC in this study refers to the delivery of generalist or specialized palliative care services, which may or may not be delivered by health professionals qualified as specialists in CPC.

Variables

The development of the list of diagnostic groups that needed CPC was a logical starting point in this study. This list (Table 1) was initially determined using experts in CPC based on the ACT/Together for Short Lives four-category scheme¹¹ but was modified in discussions with WHO Department of Health Statistics and Informatics. The assumptions applied here were those agreed to for the development of the *Global Atlas*.⁸

Table 1
List of Diagnostic Conditions for Children’s Palliative Care

Diagnoses
• HIV/AIDS
• Cancer
• Cardiovascular disease
• Congenital anomalies
• Liver cirrhosis
• Endocrine, blood, and immune disorders
• Kidney disease
• Meningitis
• Protein energy malnutrition
• Neurologic disorders
• Neonatal conditions
• Drug-resistant-TB

Although the emphasis was on prevalence, for several diagnostic groups, mortality was used in place of prevalence for example meningitis, protein energy malnutrition, Drug-resistant-TB, and neurologic conditions. This was because of the fact that four of these conditions were potentially reversible, and there was also a high degree of suffering. In neurologic conditions, the data indicated that mortality was actually higher than prevalence, thus providing a more accurate statistic. Because not all those within a prevalent condition would need palliative care at a given point in time, symptom burden was used, especially pain, as an indicator for palliative care. Pain in progressive nonmalignant conditions is reported to occur at an average rate of 67%,¹² for HIV/AIDS 55%, and 80% for cancer.⁸ These rates were used as the adjustment factors for symptom burden in this study to be consistent with methods used in the *Global Atlas*. Furthermore, based on expert medical opinion, specific sequela not consistent with life-threatening or life-limiting conditions were eliminated.⁸ These adjustments are outlined subsequently.

Not all infants, children, and adolescents will need access to specialist palliative care; for many, an integrated approach by primary health providers should be adequate to meet their needs, although children with more complex symptoms need more specialized palliative care. Available data and published evidence vary with regard to the percentage of children and adults needing specialized palliative care, depending on the setting and available health care resources. In high-income countries (e.g., the U.K. or Germany), it may be lower, whereas in low- and middle-income countries it may be much higher. For this study, the estimated need for specialized services has been taken as 37.5%, which comes from recommendations from Australia where much work has been carried out on population-based palliative care needs.¹³

Data Sources/Measurement

Data sources were used to determine the need for CPC included:

1. Country-level prevalence data from the Institute for Health Metrics and Evaluation (IHME) at the University of Washington. This was the only source for prevalence data for most of the identified conditions.
2. WHO mortality data from the Global Health Estimates: Causes of Death 2000–2011.¹⁴
3. UNAIDS data on HIV prevalence in the target countries.
4. UN population data by country for ages 0–19 by year.¹⁵
5. Country population estimates for 2010 from World Bank.

All data sources used 2010 as the index year including IHME, UN population data, UNAIDS, and WHO. These were the most recently available data at the time this study was conducted.

Bias

The study relied on quantitative data from the WHO and from the IHME repository used by scientists worldwide to create global burden of disease estimates; thus, biases in the data had already been addressed to the extent that they could.

Study Size

We determined study size using the disease categories previously described.

Quantitative variables

See variables section.

Statistical Methods

This was an analysis of secondary data. Data on need for CPC were analyzed in Microsoft Excel. IHME provided excel files for all the requested conditions. Those sheets included each diagnosis for each country with sequela for each diagnosis and an age breakdown as follows: zero to six days, seven to 27 days, 28–364 days, one to four years, five to nine years, 10–14 years, and 15–19 years. Totals were generated for each condition by country and entered into the summary tables where adjustments (Table 2) were made. A stratified sample of countries was created using the following variables:

- World Bank Income Group—four groups (low, low middle, high middle, and high)
- WHO region—all six regions included
- HDI—global average.

All data were from reliable secondary sources. In creation of the sampling frame, the following statistical analyses were performed:

- We included countries that together would approximate the average HDI globally. HDI was used as one method of assuring that the population sample was consistent with the world population.
- We compared the total population percentages of World Bank income groups to achieve relative parity in our sample by group.
- We ensured that countries from all six WHO regions were included.

We intended that our sample of countries should be greater than 50% of the world's population. The prevalence data used in this study were population-level data as such we were able to look at the prevalence for whole countries for the selected diagnoses.

Table 2
Modifications and Adjustments to Data Used in PPC Conditions

Condition	Adjustments and Assumptions
All cancers	<ul style="list-style-type: none"> • All cancers included except non-melanoma skin • Symptom factor for childhood cancers is 80%¹¹
HIV/AIDS	<ul style="list-style-type: none"> • Prevalence data from IHME • All categories except HIV pre-AIDS asymptomatic • Symptom factor 60%¹¹
Progressive nonmalignant diseases	<ul style="list-style-type: none"> • Prevalence data from UNAIDS • Symptom factor for all PNMDs is 67%¹¹
Cardiovascular diseases	<ul style="list-style-type: none"> • Prevalence data from IHME • Sudden deaths removed (33%^a) before application of the 67% symptom prevalence rule. • Rheumatic heart disease <ul style="list-style-type: none"> ◦ Valvular disease due to RHD—use only 1.5% • Other cardiovascular and circulatory diseases—use only 10% • Exclude <ul style="list-style-type: none"> ◦ Acute myocarditis ◦ Atrial fibrillation and flutter ◦ Endocarditis
Cirrhosis of liver	<ul style="list-style-type: none"> • Prevalence data from IHME • Includes all causes/sequel
Congenital anomalies	<ul style="list-style-type: none"> • Prevalence data from IHME • Includes: <ul style="list-style-type: none"> ◦ Neural tube defect ◦ Congenital heart anomalies (50%^b) ◦ Heart failure due to congenital heart anomalies ◦ Chromosomal unbalanced rearrangements ◦ Other congenital anomalies • Excludes <ul style="list-style-type: none"> ◦ Cleft lip and palate ◦ Down's syndrome ◦ Turner's syndrome ◦ Klinefelter syndrome ◦ Hearing loss due to congenital anomalies
Endocrine, blood, and immune disorders	<ul style="list-style-type: none"> • Prevalence data from IHME • Excludes most anemia's except <ul style="list-style-type: none"> ◦ Sickle cell, thalassemia, Fanconi's, aplastic
Meningitis	<ul style="list-style-type: none"> • Based on WHO mortality data not prevalence
Kidney diseases	<ul style="list-style-type: none"> • Prevalence data from IHME • All causes • Chronic kidney disease unspecified— <ul style="list-style-type: none"> ◦ Anemia due to unspecified or stage III CKD—use only 10%
Protein energy malnutrition	<ul style="list-style-type: none"> • Based on WHO mortality data not prevalence
Neurologic conditions	<ul style="list-style-type: none"> • Based on WHO mortality data (higher than prevalence data) • Includes <ul style="list-style-type: none"> ◦ Alzheimer's and other dementias ◦ Parkinson's and multiple sclerosis ◦ Other neurologic conditions (Guillain-Barré Syndrome) • Excludes <ul style="list-style-type: none"> ◦ All epilepsy ◦ All migraine and headache • All other neurologic disorders
Neonatal conditions	<ul style="list-style-type: none"> • Prevalence data from IHME • Includes <ul style="list-style-type: none"> ◦ Most preterm birth complications for 0- to 9-year olds^c ◦ Impairment due to neonatal encephalopathy for 0- to 9-year olds—birth asphyxia and birth trauma (75% of these are removed due to WHO position that these can be resuscitated). • Excludes <ul style="list-style-type: none"> ◦ 25% of the 35% of pre-term babies that die on the day of birth ◦ Retinopathy of prematurity due to preterm birth complications ◦ All sepsis and other infections of new born babies • Other neonatal disorders
Tuberculosis (1.417% DR-TB)	<ul style="list-style-type: none"> • Based on WHO Stop TB mortality data, not prevalence • Only includes children with MDR or XDR-TB <ul style="list-style-type: none"> ◦ Calculation of 1.417% of mortality is based on the global proportion of TB prevalence that is drug resistant (170,000 drug resistant out of 12 million prevalence)

IHME = Institute for Health Metrics and Evaluation; PNMD = progressive non-malignant disease; RHD = rheumatic heart disease; DR-TB = drug-resistant-TB; MDR-TB = multidrug resistant tuberculosis; XDR-TB = extreme drug resistant tuberculosis.

^aThe 33% figure is used to be consistent with the Atlas of Palliative Care. Sudden death from CVD is estimated to be one third of cases based on Centers for Disease Control reports.

^bMany children with congenital heart anomalies die suddenly without symptom burden. The 50% figure is used to be consistent with assumptions used in the Atlas of Palliative Care.

^cWHO reports that for 35% of children who die, death occurs on the day of birth and do not consider most to need palliative care. We removed 25% of these cases, but 10% were retained to be consistent with the Global Atlas of Palliative Care Assumptions to account for children who we know will die shortly after birth.

Ethical Considerations

The study was reviewed by Salus IRB and determined to be exempt from review. A copy of the study protocol is housed on [Clinicaltrials.gov](#) (NCT02553148).

Results

Need for CPC

More than 18.8 million infants, children, and adolescents were identified in the prevalence and mortality data for the 23 countries included in this analysis. This is equivalent to more than 31.6 million children worldwide when adjusted for total population. After adjustment to remove unqualified sequela and to account for symptom burden, more than 21 million children annually worldwide were found to need a palliative approach. Among these 21 million, an estimate of more than 8 million would require some degree of specialized CPC (see [Table 3](#)).

Descriptive Data

The infants, children, and adolescents included in this study all had one of the 12 diagnoses identified as needing CPC and were between 0 and 19 years of age. The average HDI score for the sampled countries was 0.703 compared with the global average of 0.682. For *Outcome data*, see [Table 3](#).

Main Results

[Table 3](#) summarizes the results of the need estimation by country for both total need and specialized need for CPC. A global estimate is derived from these results that use the proportion of the world population in 2010 that needed CPC.

Discussion

Key Results

We believe these results provide a likely minimum estimate of the need for CPC globally. Additionally, they permit further differentiation concerning the need for specialized CPC. To highlight the unmet need for palliative care, it is essential to have estimates of the extent of the need and the characteristics of the population in need. This study is the first to attempt to measure the global need for CPC for a majority of the world's population.

Limitations

A number of limitations should be noted in interpreting this research. First, there was reliance on secondary data because of the paucity of in-country data, which may either overestimate or underestimate disease prevalence and mortality. Second, the use of pain as a marker for palliative care need may underestimate need as there are many other troubling symptoms affecting children with these diagnoses. Third, the estimation of specialized

Table 3
Global Estimate of the Need for PPC^a

WB Group	HDI	Country	Population	Prevalence	Total Need	Spec Need	Rate/10K 0–19
Upper middle	0.808	Argentina	40,370,000	143,905	98,395	39,194	29.1
Low middle	0.73	Armenia	2,963,000	11,329	7691	2906	33.7
High	0.933	Australia	22,300,000	47,102	31,943	12,062	21.0
Upper middle	0.744	Brazil	195,200,000	698,616	473,503	180,238	27.2
Upper middle	0.719	China	1,338,000,000	4,482,672	3,037,950	1,145,982	32.3
Low middle	0.682	Egypt	78,080,000	580,731	391,135	147,311	45.9
Low	0.435	Ethiopia	87,100,000	846,272	543,911	217,409	44.8
High	0.911	Germany	81,780,000	146,391	102,707	45,888	29.7
Low middle	0.586	India	1,224,616,000	6,308,953	4,250,559	1,632,251	34.0
Low middle	0.684	Indonesia	240,700,000	1,008,181	686,578	272,226	29.4
Upper middle	0.745	Jordan	6,046,000	33,687	22,750	8566	29.3
Low	0.535	Kenya	40,910,000	678,966	425,016	166,888	76.8
Low middle	0.628	Kyrgyzstan	5,448,000	27,967	19,955	8154	37.0
Upper middle	0.773	Malaysia	28,280,000	119,544	80,619	30,383	28.5
Low	0.414	Malawi	14,901,000	349,696	211,353	80,887	94.8
Upper middle	0.756	Mexico	117,900,000	808,413	546,643	205,980	44.0
High	0.778	Russia	142,900,000	374,470	253,632	95,618	31.6
Upper middle	0.745	Serbia	7,291,000	25,856	17,454	6578	28.8
Upper middle	0.658	South Africa	50,900,000	925,622	549,778	207,909	102.5
Low	0.607	Tajikistan	7,627,000	48,303	32,660	12,636	35.0
High	0.892	United Kingdom	63,300,000	116,876	78,796	29,637	20.1
High	0.914	United States	309,300,000	697,596	474,677	180,325	21.5
Low	0.492	Zimbabwe	13,080,000	356,465	210,849	79,465	113.3
Totals/averages	0.703		4,118,992,000	18,837,613	12,571,054	4,841,789	43.0
World average Totals	0.682		6,916,183,482	31,630,163	21,108,008	8,092,812	
% of 2010 World population			59.6%				

Spec = specialized.

^aAnyone interested in individual country level data may contact the corresponding author to request it.

need at 37.5% may not be the best estimate, especially in children, and needs further study. Fourth, the sample of countries came very close to accurately representing global population but may not be fully representational. The population of low-income countries in the sample is low. Finally, there are a number of conditions and diagnostic groups we saw as needing CPC that were excluded from the estimate because of limitations imposed by WHO in the clearance process for publication of the *Global Atlas of Palliative Care at the End of Life*. These included removal of 75% of children with neonatal encephalopathy because of birth trauma or asphyxia, all children with epilepsy, children with severe cerebral palsy, chronic lung disease, and those with severe injuries including those with severe burns and head injuries.

Interpretation

Children are different than adults, are more resilient, and tend to live with serious advanced illness longer than adults and, thus, may need palliative care for longer periods. A child may need palliative care for one day or for a decade or more, and on average, length of specialized CPC is about 40% longer than for adults (70 vs. 100 days). The rate of need was found to vary considerably from country to country and was highest in low- and middle-income countries, especially in Africa mainly because of high rates of HIV/AIDS. In general, the higher the country income and the higher its HDI, the lower the need for CPC. The one study that has shown a population rate of need for CPC found that rates for 0- to 19-year olds in the U.K.⁶ per 10,000 increased from 25 to 32 from 2000 to 2010. This study used different methods than the present study and would indicate that our results (20.1/10,000 for the U.K.) are more conservative, at least for high-income countries.

Generalizability

Given that we studied almost 60% of the world's population, we believe that the results are generalizable and the estimates fairly reflect the minimum global need for CPC. However, it will still be useful to calculate the need for every country for advocacy and planning purposes.

Conclusion

The estimation of need for CPC is a critical step in meeting the needs of children with life-threatening conditions and is necessary to begin to advocate closure of the gap in coverage and further development of capacity. Much more work is needed to better understand which children need how much CPC at which points on the continuum of care and in which parts of the health care system. Further work on estimation of the need for CPC for all countries is

essential as is assessment of the current capacity of countries to deliver CPC. These data are needed for policy makers, planners, and advocates to address this important unmet need and to inform and identify the scope of the need so that these children can receive the services they now lack.

Many barriers remain that will need to be overcome including denial of the extent of the problem and the reality that children die, resistance to provision of CPC and the essential medicines needed to relieve suffering, and lack of education of health care providers, particularly in the primary health care system, to deliver CPC. CPC now is mainly delivered parallel to the existing health care system and needs to be integrated into the existing primary and pediatric specialty services to reach so many in need. Global institutions and those concerned with the health and welfare of children need to step up and contribute to closing this unacceptable gap in meeting the need for CPC.

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