

## Reported Availability and Gaps of Pediatric Palliative Care in Low- and Middle-Income Countries: A Systematic Review of Published Data

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### Abstract

**Background:** The majority of young people in need of palliative care live in low- and middle-income countries, where curative treatment is less available.

**Objective:** We systematically reviewed published data describing palliative care services available to young people with life-limiting conditions in low- and middle-income countries and assessed core elements with respect to availability, gaps, and under-reported aspects.

**Methods:** PubMed, CINAHL, EMBASE (1980–2013), and secondary bibliographies were searched for publications that included patients younger than 25 years with life-limiting conditions and described palliative care programs in low- and middle-income countries. A data extraction checklist considered 15 items across seven domains: access, education/capacity building, health system support, pain management, symptom management, end-of-life care, and bereavement. Data were aggregated by program and country.

**Results:** Of 1572 records, 238 met criteria for full-text review; 34 qualified for inclusion, representing 30 programs in 21 countries. The median checklist score was 7 (range, 1–14) of 10 reported (range, 3–14). The most pervasive gaps were in national health system support (unavailable in 7 of 17 countries with programs reporting), specialized education (unavailable in 7 of 19 countries with programs reporting), and comprehensive opioid access (unavailable in 14 of 21 countries with programs reporting). Underreported elements included specified practices for pain management and end-of-life support.

**Conclusion:** Comprehensive pediatric palliative care provision is possible even in markedly impoverished settings. Improved national health system support, specialized training and opioid access are key targets for research and advocacy. Application of a checklist methodology can promote awareness of gaps to guide program evaluation, reporting, and strengthening.

### Introduction

PALLIATIVE CARE for children and young adults, defined as the “active, total care” of a young person’s body, mind, spirit, and family, from life-limiting diagnosis until death, is an internationally recognized priority.<sup>1,2</sup> It is estimated that annually 7 million families could benefit from pediatric palliative care, but those in low- and middle-income countries seldom have such access.<sup>2,3</sup> We assess the published data on services and gaps in pediatric palliative care in low- and middle-income countries, home to nearly 90% of the world’s young people.<sup>4</sup>

Children, adolescents, and young adults in low- and middle-income countries are disproportionately impacted by life-

limiting conditions (LLC), including infectious diseases, cancer, congenital defects, and malnutrition.<sup>4–8</sup> Approximately 400,000 children are diagnosed with HIV each year; 3.4 million children are living with HIV/AIDS.<sup>5</sup> More than 90% live in low- and middle-income countries, where 75% lack access to antiretroviral therapy and have shortened life expectancies.<sup>5</sup> Approximately 160,000 children younger than 15 years in low- and middle-income countries develop cancer each year.<sup>7,8</sup> They are often diagnosed later in low- and middle-income countries, when the disease is more advanced and difficult to cure even if treatment is available. Only an estimated 20% of children in low- and middle-income countries will be cured, compared with 80% of children in high-income countries, so the need for palliative care is acute.<sup>7–11</sup> Complex conditions

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such as congenital heart defects, neural tube defects, hemoglobinopathies, constitutional chromosomal anomalies, and sequelae of prenatal infections and malnutrition in low- and middle-income countries also often lead to chronic symptoms for which palliative care is critical.<sup>12,13</sup> The first global atlas of palliative care estimates that each year, nearly 1.2 million children below age 15 are in need of palliative care at the end of life, with 98% of these children in low- and middle-income countries.<sup>14</sup> For many young people with LLC, attainment of cure or normal life expectancy is elusive. However, hope for comfort, meaning, and the highest quality of life and death possible—the goals of palliative care—is within reach. The principles of palliative care can be applied successfully and cost effectively, even in resource-limited settings.<sup>11,15–18</sup>

### What is known

In a systematic review, Knapp and colleagues<sup>19</sup> adapted a four-part system devised by the Observatory on End of Life Care<sup>20</sup> (OELC), an internationally recognized center for palliative care research, to categorize provision around the world. Two-thirds of countries reportedly offered no pediatric palliative services; 19% were classified at Level 2 (capacity building) and 10% at Level 3 (localized provision). Even countries achieving mainstream provision (Level 4), such as South Africa and many high-income countries, vary regionally in service quality and accessibility,<sup>11</sup> but detailed examinations comparing provision across settings, particularly in low- and middle-income countries, have not been published. Other researchers have mapped services using targeted surveys and described services based on responses grouped across multiple countries globally.<sup>21</sup> To complement these methods, which are vital to support advocacy efforts, analysis of published program descriptions, as recently detailed for sub-Saharan Africa,<sup>22</sup> lend a unique perspective on reporting and evidence gaps.

### What this review contributes

In this first review focusing on low- and middle-income countries globally, we evaluate the published data on pediatric palliative care services, assess the availability of core elements of pediatric palliative care reported by these publications, and examine the regional context in which these services are reported. We identify gaps in provision and reporting that will be useful for providers, researchers, and advocates for pediatric palliative care. Finally, we demonstrate the effective use of a checklist that could be adapted as a standardized programmatic or regional “scorecard” to facilitate reporting and guide program development.

### Methods

#### Search strategy

PubMed, CINAHL, and EMBASE databases were searched from January 1, 1980 through January 23, 2013, as were the authors’ personal databases and secondary bibliographies including hand searches of references from included articles. Search strategies are presented in Table 1 and Appendix A. Publications were eligible for inclusion if three criteria were met: (1) the setting was a low-, lower-middle-, or upper-middle-income country per World Bank definitions<sup>23</sup>; (2) the population served included people younger than 25 years<sup>24</sup> and diagnosed with conventionally defined LLC<sup>25</sup>; and (3) the primary objective was to describe existing palliative care program(s).

Publications describing services for adults without specification of services for young people were excluded. This was important, given that programs in low- and middle-income countries may be based on a mixed care models, in which systems for adults may accommodate a small, but variable, number of children. Case reports were excluded; there were no restrictions for study type or language. After duplicate

TABLE 1. SEARCH STRATEGY FOR PUBMED. SIMILAR STRATEGIES WERE USED FOR EACH DATABASE (SEE APPENDIX A)

1. (child OR children OR adolescent OR adolescence OR infant OR baby OR youth OR “young adult”)  
AND
2. (palliation OR palliative care[MeSH Terms] OR terminal care[MeSH Terms] OR bereavement[MeSH Terms] OR advance care planning[MeSH Terms] OR hospice care[MeSH Terms] OR hospices[MeSH Terms] OR end of life care[MeSH Terms] OR grief[MeSH Terms])  
AND
3. (developing countries[MeSH Terms] OR low income population[MeSH Terms] OR Africa or “Southeast Asia” or “South Asia” or Caribbean or “Latin America” or “South America” or “Central America” or Afghanistan or Bangladesh or Benin or “Burkina Faso” or Burundi or Cambodia or “Central African Republic” or Chad or Comoros or Congo or Eritrea or Ethiopia or Gambia or Guinea or Guinea-Bissau or Haiti or Kenya or Korea or Kyrgyzstan or Liberia or Madagascar or Malawi or Mali or Mozambique or Myanmar or Nepal or Niger or Rwanda or Sierra Leone or Somalia or Tajikistan or Tanzania or Togo or Uganda or Zimbabwe or Angola or Armenia or Belize or Bhutan or Bolivia or Cameroon or “Cape Verde” or Congo or Cote d’Ivoire or “Ivory Coast” or Djibouti or Egypt or “El Salvador” or Fiji or Georgia or Ghana or Guatemala or Guyana or Honduras or Indonesia or India or Iraq or Kiribati or Kosovo or Laos or Lesotho or “Marshall Islands” or Mauritania or Micronesia or Moldova or Mongolia or Morocco or Nicaragua or Nigeria or Pakistan or “Papua New Guinea” or Paraguay or Samoa or “Sao Tome” or Senegal or Solomon Islands or “Sri Lanka” or Sudan or Swaziland or Syria or Timor-Leste or Tonga or Turkmenistan or Tuvalu or Ukraine or Uzbekistan or Vanuatu or Vietnam or Palestine or Yemen or “West Bank” or Gaza or Zambia or Albania or Algeria or “American Samoa” or Antigua or Barbados or Argentina or Azerbaijan or Belarus or Bosnia or Botswana or Brazil or Bulgaria or Chile or China or Colombia or “Costa Rica” or Cuba or Dominica or “Dominican Republic” or Ecuador or Gabon or Grenada or Iran or Jamaica or Jordan or Kazakhstan or Latvia or Lebanon or Libya or Lithuania or Macedonia or Maldives or Mauritius or Mayotte or Mexico or Montenegro or Namibia or Palau or Panama or Peru or Romania or Russia or Serbia or Seychelles or “South Africa” or “St Kitts” or Nevis or “St Lucia” or “St Vincent” or Grenadines or Suriname or Thailand or Tunisia or Turkey or Uruguay or Venezuela)

elimination, all titles and abstracts were screened. Results are reported in accordance with the PRISMA statement.<sup>26</sup>

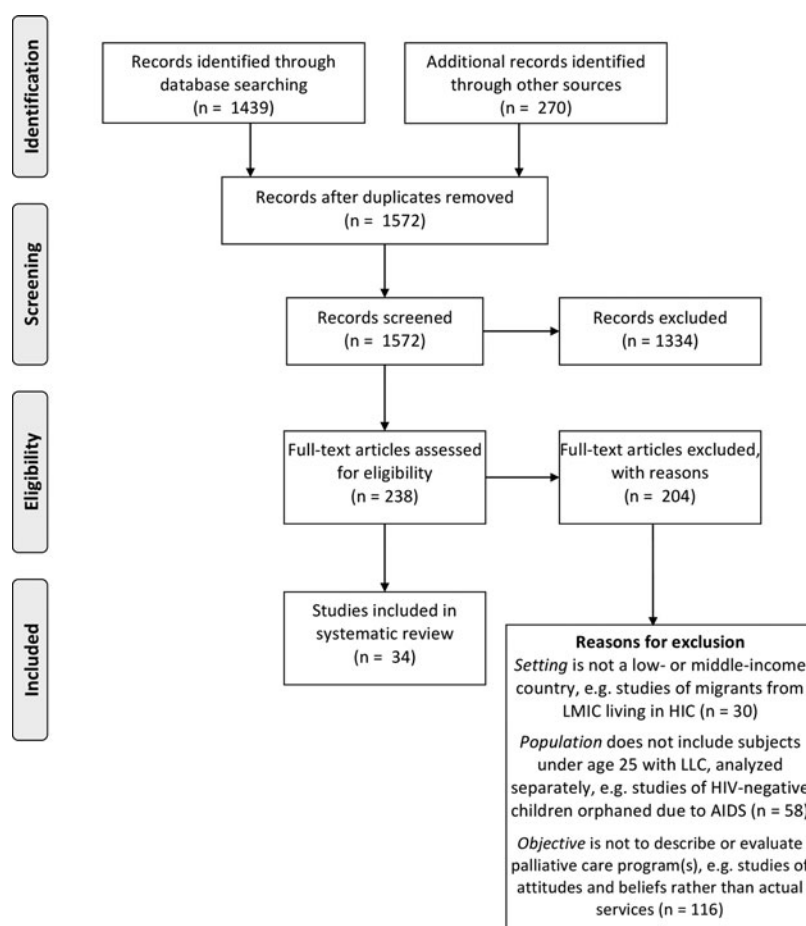
### Data extraction and analysis

Because no existing tools were suitable for our objectives, we developed a 15-item, 7-domain checklist (Appendix B) to assess provision of core elements of pediatric palliative care in published reports. The 7 domains are divided into 2 groups: delivery (access, education and capacity building; health system support) and service (pain and symptom management; end-of-life and bereavement support). A literature review of palliative care quality measures and practices in diverse settings, adapted for low- and middle-income countries and including data used by the OELC to determine provision levels, informed the checklist (Appendix C).<sup>10,11,19,20,27–33</sup> The checklist was piloted on 50 publications assessed at the full-text level, with refinement of domains and scoring; all included publications were rescored with the final checklist. Coauthors independently reviewed the checklist for face and content validity. Pertinent evaluation criteria aiming to assess study quality, risk of bias, and strength of evidence were integrated into the checklist and narrative syntheses; these included elements such as population studied, funding, and consistency of findings between multiple studies from a single program or country.<sup>34,35</sup>

Each publication was scored twice and received a total checklist score (numerator) and a total available data score (denominator). Discrepancies were resolved by discussion and consensus. The total checklist score represented the items reported to be available. The total available data score represented the number of items discussed, including items reported as unavailable, up to a maximum of 15 (6 delivery domains and 9 service domains). Publications were neither required nor expected to address all items, however, 25 publications that were insufficiently detailed to score at least 1 item as present or absent were excluded. Items not discussed were noted as absent, such that the denominator could be less than 15. Scores were compiled by country and, when possible, by program, using the highest score per item. Median scores were calculated for all countries combined, and also separately for low-income and lower-middle-income countries and upper-middle-income countries).

### Results

The search identified 1572 studies; 238 were eligible after initial screening (Fig. 1). Full text was reviewed for 236 articles (2 out-of-print articles could not be obtained) and 34 were included (Appendix D). Seventy-six studies published in 7 languages other than English were assessed at the title-abstract level and 8 studies in Spanish, Portuguese, and



**FIG. 1.** PRISMA flow chart showing study selection process.<sup>26</sup> LIC, low-income country; LMIC, lower-middle-income country; NA, not available; PPP, purchasing power parity; UMIC, upper-middle-income country; USD, U.S. dollar.

Chinese were assessed at the full-text level. All studies meeting inclusion criteria were in English. Included studies were published between 2002 and 2012, and represented services from 21 countries, 28 cities, and 30 distinct programs (Table 2).

The median number of studies per country was 2 (range, 1–5). Thirty-one publications (representing 20 of 21 countries) included national or regional level descriptions as part of their objectives, featuring a single site or region in publications from 16 of these countries, while 4 countries described multiple programs and reported service availability at a national level. Only the 3 publications from South Africa reported an exclusively local scope, with each describing services at a single site.

Patients served by the palliative care programs included those with multiple LLC (15/34; 44%), with cancer only (16/34; 47%) or with HIV only (3/34; 9%). Only 12 of 236 full-text publications reviewed reported efforts to target adolescents and young adults; none focused exclusively on this population.

### Core elements

The median total checklist score for all countries was 7 (range, 1–14) of 10 (median total available data score; range, 3–14). For upper-middle-income countries, the median score was 11 of 12 (range, 1–14/3–14); for low-income countries/lower-middle-income countries, the median score was 4.5 of 8 (range, 1–11/5–11). Table 3 lists key national health and economic indicators for each represented country.

The elements most widely reported to be available were access and non-pain symptom management. Programs in 19 countries reported items of access: 12 of 14 (86%) reporting countries had interdisciplinary teams, 17 of 19 (89%) had hospital- or hospice-based inpatient services, and 14 of 19 (79%) had some support for home-based care (such as 24-hour telephone support or nursing visits). All programs were primarily based in urban areas, although 2 countries (Costa Rica and Belarus) reported nationwide home-based services. Programs in 12 countries reported management of symptoms other than pain, with those in 11 countries reporting efforts to address both physical and psychosocial concerns. No program specified an absence of non-pain symptom management, although programs in 9 countries did not publish data regarding such a service.

The most frequently reported gaps included specialized training in palliative care, policies supporting high-quality palliative care at regional or national levels, bereavement support, and pain management (Figs. 2, 3A, and 3B). Twelve of 19 (63%) countries with programs reporting had access to specialized training; 10 of 17 (59%) described regional or national support; 10 of 15 (67%) reported bereavement services. Although almost all (20/21) reported some degree of opioid access, only 7 reported full access to essential analgesic medications.<sup>38</sup>

All countries had programs that reported items of both delivery and service. Most individual studies (94%) reported items from both. All domains were reported for a majority of publications and countries, with exceptions in end-of-life support as a domain (not specifically discussed in publications from programs in 16 [76%] countries), and standardized pain management practices as a single item (not specified in publications from 17 [81%] countries).

### Consideration of bias

Variation between publications from the same countries was common; however, most instances involved items reported in some articles and not others. In select cases, these correlated with time elapsed between publications; studies from Lebanon and Jordan (2008–2012) described the initiation of programs (in 2002 and 2003, respectively) and gradual expansion, with increasing home-based services and attempts to extend services outside capital cities (Appendix D).

Twelve studies noted external funding sources, while the remainder provided no funding information. None reported relevant conflicts of interest. Funded and unfunded studies did not appear to differ in study population or nature of reported data. Only five studies had a first author from high-income countries, and all publications from low-income countries had first and senior authors with local affiliations. As only two programs precisely defined catchment areas, and data on incidence and prevalence of LLC was inconsistently available, it was not possible to assess scores relative to total populations. The publications' descriptive nature precluded the application of conventional risk of bias and quality assessment tools.

### Discussion

In this review of pediatric palliative care in low- and middle-income countries, we identified opportunities for

TABLE 2. DISTRIBUTION OF SOURCES OF DATA BY COUNTRY, CITY, PROGRAM AND STUDY VERSUS WORLD BANK INCOME GROUP AND REGION<sup>23</sup>

	<i>Countries</i>	<i>Cities<sup>a</sup></i>	<i>Programs<sup>a</sup></i>	<i>Studies<sup>b</sup></i>
Total	21	28	30	34
Low-income	2	2	4	5
Lower-middle-income	9	12	12	17
Upper-middle-income	10	14	14	29
Sub-Saharan Africa	3	5	7	8
South Asia	1	2	2	3
Europe and Central Asia	8	9	9	12
Latin America and the Caribbean	2	2	2	3
Middle East and North Africa	7	10	10	10

<sup>a</sup>Minimums; some articles stated only that multiple cities and/or sites were involved.

<sup>b</sup>Publication totals do not equal 34 as some referenced multiple countries.



TABLE 3. NATIONAL HEALTH AND ECONOMIC STATUS INDICATORS FOR TWENTY-ONE COUNTRIES WITH PALLIATIVE CARE PROGRAMS REPRESENTED IN THE SYSTEMATIC REVIEW<sup>23,36,37</sup>

<i>Income group, 2012<sup>23</sup></i>	<i>Country</i>	<i>Total population, 2012<sup>23</sup></i>	<i>GNI in PPP terms, 2011<sup>23</sup></i>	<i>Multidimensional poverty index, 2011<sup>36</sup></i>	<i>Government health care expenditure per capita in USD, 2010<sup>23</sup></i>	<i>Opioid consumption<sup>37</sup></i>	<i>Under-5 mortality per 1000 live births, 2011<sup>23</sup></i>
LIC	Malawi	15,906,483	753	0.381	15	0.8069	83
	Uganda	36,345,860	1124	0.367	10	0.1476	90
LMIC	Pakistan	179,160,111	2550	0.264	8	0.0939	72
	Palestine	4,046,901	2656	0.005	NA	NA	22
	Moldova	3,559,541	3058	0.007	87	4.357	16
	Iraq	32,578,209	3177	0.059	162	0.1783	38
	Morocco	32,521,143	4196	0.048	58	0.7613	33
	Egypt	80,721,874	5269	0.024	43	0.8764	21
	Jordan	6,318,000	5300	0.008	253	3.9269	21
	Ukraine	45,593,300	6175	0.008	132	10.7508	10
	Albania	3,162,083	7803	0.005	94	2.7319	14
	South Africa	51,189,307	9469	0.057	286	12.4702	47
UMIC	Iran	76,424,443	10164	NA	115	101.2274	25
	Costa Rica	4,805,295	10497	NA	454	8.7354	10
	Romania	21,326,905	11046	NA	341	10.4317	13
	Bulgaria	7,304,632	11412	NA	252	55.6853	12
	Turkey	73,997,128	12246	0.028	510	12.7448	15
	Lebanon	4,424,888	13076	NA	242	4.3421	9
	Belarus	9,464,000	13439	0	249	7.3693	6
	Latvia	2,025,473	14293	0.006	439	21.5603	8
	Argentina	41,086,927	14527	0.011	405	10.0192	14

GNI, gross national income; LIC, low-income country; LMIC, lower-middle-income country; NA, not available; PPP, purchasing power parity; UMIC, upper-middle-income country; USD, US dollar.

improvement at the level of national policies to support palliative care, provider training, pain management practices, end-of-life and bereavement support, and reporting of outcomes for the core elements of comprehensive palliative care. Previous studies assessing palliative services globally that included children did not report provision of specific elements described in the published literature, or focused on broad categorization at the regional or income group level.<sup>19,21,39</sup> Many of the needs discussed here have been recognized but not previously characterized in detail nor systematically assessed across programs and regions. Two countries represented by publications in our review (Jordan and Turkey) were previously reported to have capacity-building activity only (no actual services) and two (Lebanon and Pakistan) were reported to have no activity; three of these documented availability of services at or above the median across all countries included in the review (Fig. 2).<sup>19</sup>

### Availability

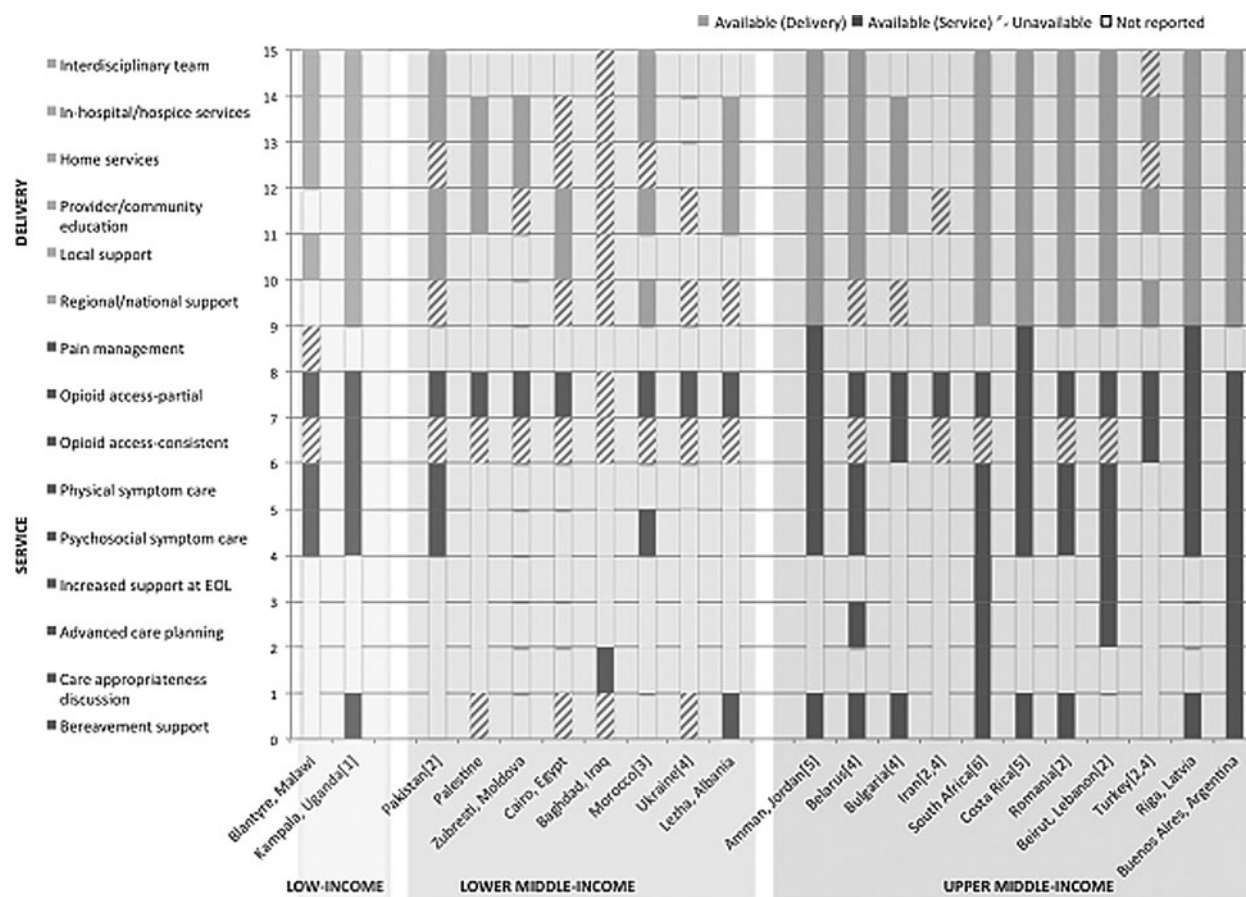
Our review highlights the reported availability of pediatric palliative care in low- and middle-income countries settings characterized by diverse socioeconomic and health indicators. Several programs described impressive provision of care despite profound challenges. This appears in part due to the impact of the AIDS epidemic, as in Africa, where some of the poorest countries in our review have developed striking programs in response to the burden wrought by HIV.<sup>40–43</sup> Several features of palliative care programs, including interdisciplinary teams, symptom management, and institutional support, may require a shift in how health care is conceived and provided. Our findings suggest that even in

resource-limited communities, which may lack advanced technology and infrastructure necessary to cure many LLC, comprehensive palliative care can be achieved even in the absence of broader systemic support.

Our review documents core elements in need of ongoing advocacy efforts at a broader policy level, with the most widely reported gaps concerning specialized provider training, national health system support, and consistent opioid access. Studies from Uganda and Malawi (Appendix D) illustrate how comprehensive provision is possible, and demonstrate how some commonly reported gaps can be addressed. Publications from Uganda described three pediatric programs in Kampala that offer hospital-, hospice-, and home-based care, as well as provider education, formal efforts to improve opioid access, and support for families' basic needs. Studies from Malawi reported services in Blantyre, where an interdisciplinary team has been providing care, including palliative chemotherapy and psychosocial/spiritual support, for over a decade. These cases demonstrate that improving palliative care provision is not contingent on macro-economic gains that may be required for other public health gains; during the past decade, Uganda and Malawi saw negligible changes in gross national income per capita, which remained at less than 1% that of leading high-income countries.<sup>23,44,45</sup>

### Underreporting

Our study highlights areas that warrant ongoing monitoring and reporting. Although we reviewed full-text publications from East Asia and the Pacific, including discussions of pain management and life-support limitation, none specifically



**FIG. 2.** Availability of core elements of pediatric palliative services, by country, in order of ascending gross national income (GNI) per capita in U.S. dollars. [1] Multiple distinct programs in the same city. [2] Previously reported to have no palliative care activity. [3] Multiple programs in different cities; data presented at a national level and not program-specific. [4] Program(s) not specified; data also presented at a national level. [5] Program based in the capital but services reported to be available throughout the entire country. [6] Multiple service sites in different cities.

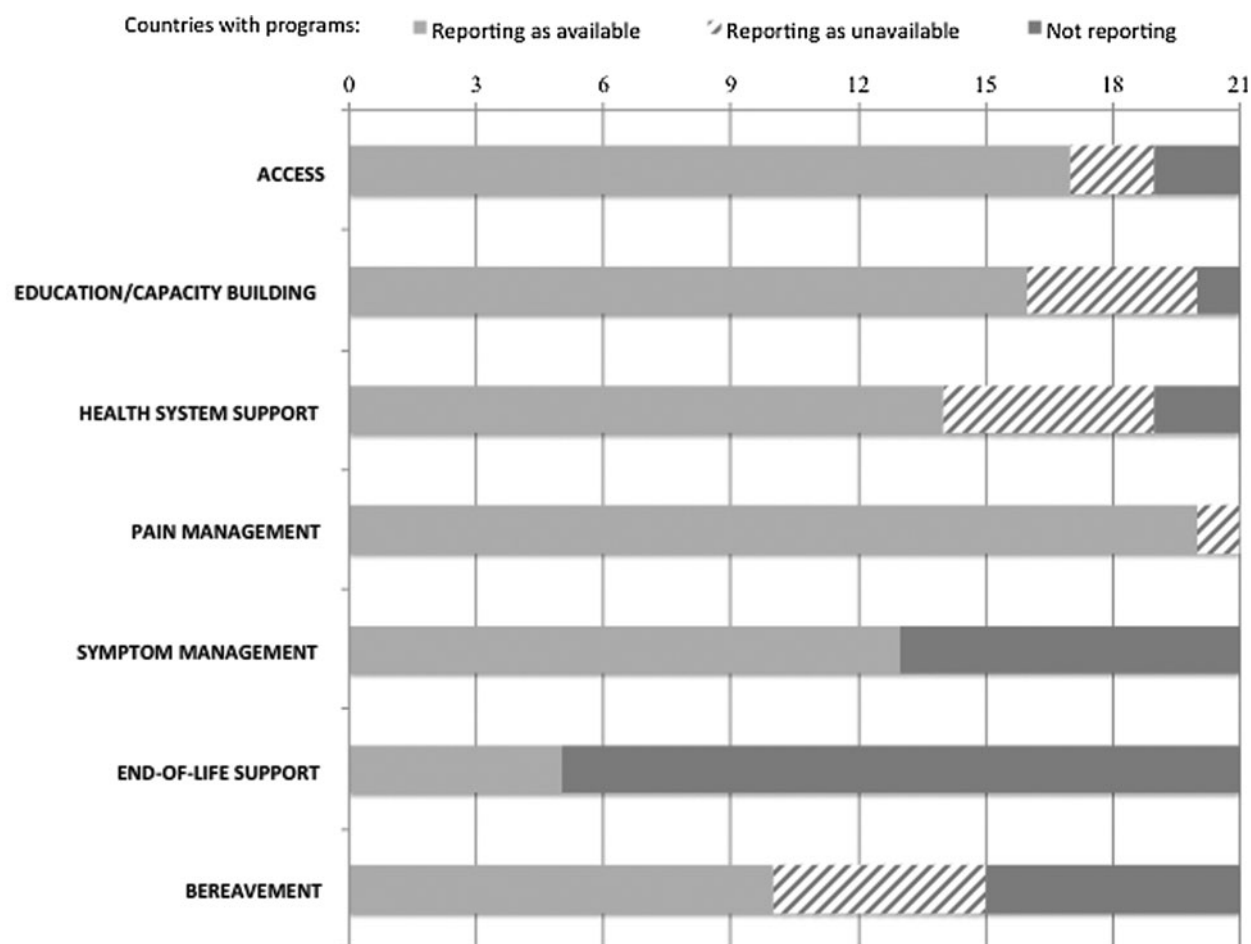
described programs providing palliative care to children or adolescents and young adults. This does not suggest that the region is without pediatric palliative care, instead, it may indicate variability in models of care delivery influencing data reporting. In many locations, pediatric palliative care is not recognized as a distinct field, although various providers may offer related services. Pediatric services may exist under the umbrella of adult care and not be specifically captured in program publications that prioritize the larger adult population. This highlights an opportunity to promote pediatric-specific reporting in these regions.

End-of-life support—the most recognized palliative care domain, which we broadly defined to include any adaptation in level of care at the end of life—was underreported. Decisions to define and limit life-sustaining measures are particularly important in settings in which resources to provide aggressive biomedical or complementary therapy are scarce. We note that some articles reviewed reported exclusively on end-of-life care outside the context of a clearly described palliative program and thus did not meet inclusion criteria. Such reporting gaps may represent opportunities for improvement as well as reflect authors' priorities and local conceptualization of palliative care; future efforts should assess how sociocultural factors impact resource allocation

and reporting. Our use of a checklist with a numerator and denominator calls attention to these gaps and could benefit programs seeking to assess their provision and reporting.

As programs tend to be concentrated in urban centers, particularly capital cities, countries with publications describing multiple programs still may not reach children in rural areas, and best practice models may not reflect care elsewhere in the region.<sup>46</sup> Legislation allowing nurses and palliative care workers to prescribe morphine can facilitate pain relief for children in remote areas, but such laws have not been widely implemented.<sup>11</sup> Even in countries with programs that provide services to a wide geographic area (i.e., Costa Rica and Belarus), service availability does not equate with care uptake by every child in need. While our assessment of health system support highlights the challenges affecting service feasibility in a given area, identifying gaps between need for services, referral, availability and uptake is an area for further investigation.

Both pain and non-pain symptom management are priorities of the World Health Organization and warrant further study<sup>1,38,47</sup> and our efforts complement population analyses of opioid access that recognize multidimensional barriers that merit attention globally.<sup>48</sup> Given how nonpharmacologic symptom management can be achieved with limited resources,



**FIG. 3A.** Reported availability of pediatric palliative care services by checklist item from 30 distinct programs in 21 low- and middle-income countries. Domains were reported as available if any checklist item was reported to be available.

we encourage consistent description of practices across low- and middle-income countries settings. Explicit reporting of funding sources for palliative services on programmatic and regional levels would help to further understand these dynamics.

### Limitations

We are aware that some countries have programs that have not been published; we recognize the difficulties of publication in the face of scarce resources, such that publications reflect in part sites above a threshold of financial and academic support. Our methods did allow a comprehensive appraisal of existing publications across low- and middle-income countries, utilizing multidisciplinary databases with international and multilingual coverage, and a standard data extraction checklist developed on sources across diverse settings. Of programs that have published their experiences, only some clearly report what services are not offered. Although consistent with the recognized publication bias toward positive findings, it limited thorough depiction of provision gaps. Finally, our study was not designed to evaluate the quality of services provided, nor was this information readily available. As with related systematic reviews, we were unable to systematically critique included publications

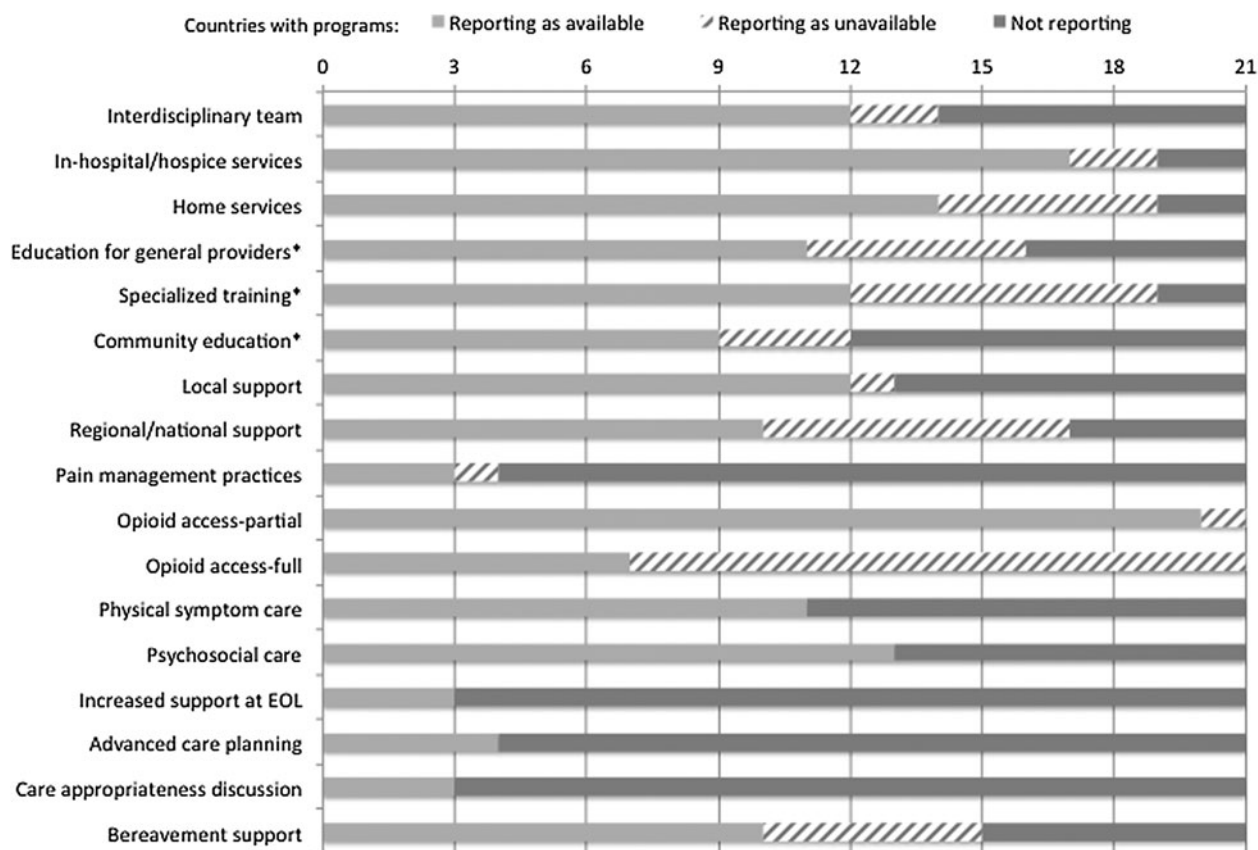
in terms of quality and bias, due to the descriptive nature of most reports.<sup>19,22</sup>

### Applicability

Awareness of gaps both in reporting and availability can strengthen advocacy for pediatric palliative care in low- and middle-income countries and promote public health strategies to reach more patients in previously underserved regions. In this review, we demonstrated the ongoing need for advocacy in pediatric palliative care policies, education, and resources, including those relevant for opioid access, and underreporting of pediatric-specific practices. A checklist-based methodology, as demonstrated, has potential applications to prospective program evaluation and self-auditing.

### Conclusions

Although provision of pediatric palliative care can be challenging in low- and middle-income countries, it is crucial precisely because resources are limited and curative therapy is less available. Comprehensive pediatric palliative care can be successfully provided in low- and middle-income countries despite unfavorable economic conditions and limited infrastructure. With recent global attention spotlighting needs



**FIG. 3B.** Reported availability of pediatric palliative care services by checklist item from 30 distinct programs in 21 low- and middle-income countries. \*The education domain was valued at 1 point if any or all 3 items were reported to be available (see Appendix B for details of scoring).

in pediatric palliative care,<sup>2,14</sup> our systematic review presents timely complementary evidence of the current status in the literature and gaps to be addressed. The development of standardized programmatic and regional scorecards incorporating qualitative and quantitative measures, similar to our checklist, could facilitate reporting and program development.

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### Author Disclosure Statement

No competing financial interests exist.

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APPENDIX A. SEARCH STRATEGIES FOR OTHER DATABASES

CINAHL

1. (MW palliation OR 'palliative care' OR 'terminal care' OR bereavement OR 'advance care planning' OR 'hospice care' OR hospices OR 'end of life care')  
AND
2. (TX child OR children OR adolescent OR adolescence OR infant OR baby OR youth OR 'young adult')  
AND
3. (TX africa OR 'southeast asia' OR 'south asia' OR caribbean OR 'latin america' OR 'south america' OR 'central america' OR afghanistan OR bangladesh OR benin OR 'burkina faso' OR burundi OR cambodia OR 'central african republic' OR chad OR comoros OR eritrea OR ethiopia OR gambia OR guinea OR 'guinea bissau' OR haiti OR kenya OR korea OR kyrgyzstan OR liberia OR madagascar OR malawi OR mali OR mozambique OR myanmar OR nepal OR niger OR rwanda OR 'sierra leone' OR somalia OR tajikistan OR tanzania OR togo OR uganda OR zimbabwe OR angola OR armenia OR belize OR bhutan OR bolivia OR cameroon OR 'cape verde' OR congo OR 'ivory coast' OR djibouti OR egypt OR 'el salvador' OR fiji OR georgia OR ghana OR guatemala OR guyana OR honduras OR indonesia OR india OR iraq OR kiribati OR kosovo OR laos OR lesotho OR 'marshall islands' OR mauritania OR micronesia OR moldova OR mongolia OR morocco OR nicaragua OR nigeria OR pakistan OR papua AND new AND guinea OR paraguay OR samoa OR 'sao tome' OR senegal OR 'solomon islands' OR sri AND lanka OR sudan OR swaziland OR syria OR 'timor leste' OR tonga OR turkmenistan OR tuvalu OR ukraine OR uzbekistan OR vanuatu OR vietnam OR palestine OR yemen OR 'west bank' OR gaza OR zambia OR albania OR algeria OR 'american samoa' OR antigua OR barbados OR argentina OR azerbaijan OR belarus OR bosnia OR botswana OR brazil OR bulgaria OR chile OR china OR colombia OR 'costa rica' OR cuba OR dominica OR 'dominican republic' OR ecuador OR gabon OR grenada OR iran OR jamaica OR jordan OR kazakhstan OR latvia OR lebanon OR libya OR lithuania OR macedonia OR maldives OR mauritius OR mayotte OR mexico OR montenegro OR namibia OR palau OR panama OR peru OR romania OR russia OR serbia OR seychelles OR south AND africa OR 'st kitts' OR nevis OR 'st lucia' OR 'st vincent' OR grenadines OR suriname OR thailand OR tunisia OR turkey OR uruguay OR venezuela)

EMBASE

1. ('palliation'/exp/mj OR 'palliative care'/exp/mj OR 'end of life care'/exp/mj OR 'terminal care'/exp/mj OR 'bereavement'/exp/mj OR 'advance care planning'/exp/mj OR 'hospice care'/exp/mj OR 'hospices'/exp/mj AND [embase]/lim)  
AND
2. ('child'/de OR 'children'/de OR 'adolescent'/de OR 'adolescence'/de OR 'infant'/de OR 'baby'/de OR 'youth'/de AND [embase]/lim)  
AND
3. (africa OR 'southeast asia' OR 'south asia' OR caribbean OR 'latin america' OR 'south america' OR 'central america' OR afghanistan OR bangladesh OR benin OR 'burkina faso' OR burundi OR cambodia OR 'central african republic' OR chad OR comoros OR eritrea OR ethiopia OR gambia OR guinea OR 'guinea bissau' OR haiti OR kenya OR korea OR kyrgyzstan OR liberia OR madagascar OR malawi OR mali OR mozambique OR myanmar OR nepal OR niger OR rwanda OR 'sierra leone' OR somalia OR tajikistan OR tanzania OR togo OR uganda OR zimbabwe OR angola OR armenia OR belize OR bhutan OR bolivia OR cameroon OR 'cape verde' OR congo OR 'ivory coast' OR djibouti OR egypt OR 'el salvador' OR fiji OR georgia OR ghana OR guatemala OR guyana OR honduras OR indonesia OR india OR iraq OR kiribati OR kosovo OR laos OR lesotho OR 'marshall islands' OR mauritania OR micronesia OR moldova OR mongolia OR morocco OR nicaragua OR nigeria OR pakistan OR papua AND new AND guinea OR paraguay OR samoa OR 'sao tome' OR senegal OR 'solomon islands' OR sri AND lanka OR sudan OR swaziland OR syria OR 'timor leste' OR tonga OR turkmenistan OR tuvalu OR ukraine OR uzbekistan OR vanuatu OR vietnam OR palestine OR yemen OR 'west bank' OR gaza OR zambia OR albania OR algeria OR 'american samoa' OR antigua OR barbados OR argentina OR azerbaijan OR belarus OR bosnia OR botswana OR brazil OR bulgaria OR chile OR china OR colombia OR 'costa rica' OR cuba OR dominica OR 'dominican republic' OR ecuador OR gabon OR grenada OR iran OR jamaica OR jordan OR kazakhstan OR latvia OR lebanon OR libya OR lithuania OR macedonia OR maldives OR mauritius OR mayotte OR mexico OR montenegro OR namibia OR palau OR panama OR peru OR romania OR russia OR serbia OR seychelles OR south AND africa OR 'st kitts' OR nevis OR 'st lucia' OR 'st vincent' OR grenadines OR suriname OR thailand OR tunisia OR turkey OR uruguay OR venezuela AND [embase]/lim)

## APPENDIX B. STANDARDIZED DATA EXTRACTION CHECKLIST

*Delivery domains (subtotal 6)***Access (subtotal 3)**

- Interdisciplinary providers (1)
- Designated in-hospital or in-hospice services (1)
- Support for home setting (e.g., home visits, phone support, supplies) (1)

**Education and capacity building (subtotal 1 for any/all of the 3 elements)**

- Continuing education for general health providers
- Specific training/certification for those seeking specialization in palliative services
- Supportive education for community members and families

**Health system support (subtotal 2)**

- Policies/Infrastructure to support high quality and ethically<sup>a</sup> sound palliative care in immediate health system (on institutional/center level) (1)
- Policies/Infrastructure to support high quality and ethically<sup>a</sup> sound palliative care in broader health system (on community/regional/national level, as reflected in government health policies or well-established, sustained nongovernmental infrastructural support, etc.) (1)

<sup>a</sup>Locally derived definition of “ethically sound” practices as primary basis (i.e., per publications/depictions from local context)

*Service domains (subtotal 9)***Pain Management (subtotal 3)**

- Standardized appropriate assessment tools or management practices available/used (1)
- Consistent opioid and adjunctive meds access (0 none, 1 partial, 2 consistent)

**General symptom management (subtotal 2)**

- Assessment and management of physical concerns other than pain (1)
- Assessment and management of psychosocial and spiritual concerns, ideally with appropriate ethical/cultural contextual considerations (1)

**End-of-life support (subtotal 3)**

- Increased palliative service support (of any form) at end of life (include decision-making support, addressing physical, psychosocial, or spiritual needs) (1)
- Advanced care planning (1)
- Consideration of care appropriateness and ethics (e.g., discussions among team and/or with family regarding options to limit care, considerations of quality of life, family’s values and beliefs, etc.) (1)

**Bereavement services (subtotal 1)**

- Any element of bereavement support for families (including anticipatory complicated grief management) and/or for providers (1)

## APPENDIX C. REFERENCES UTILIZED IN THE DEVELOPMENT AND APPLICATION OF THE DATA EXTRACTION CHECKLIST

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## APPENDIX D. PUBLICATIONS IN THE SYSTEMATIC REVIEW

<i>Sub-Saharan Africa</i>	
<b>Malawi</b>	<p>Israels T, Banda K, Molyneux EM: Paediatric oncology in the Queen Elizabeth Hospital, Blantyre. <i>Malawi Med J</i> 2008;20:115–117.</p> <p>Lavy V: Presenting symptoms and signs in children referred for palliative care in Malawi. <i>Palliat Med</i> 2007;21:333–339.</p>
<b>South Africa</b>	<p>Clifton CE: Sparrow Ministries—A South African hospice. <i>Posit Aware</i> 2003;14:26.</p> <p>Henley LD: End of life care in HIV-infected children who died in hospital. <i>Dev World Bioeth</i> 2002;2:38–54.</p> <p>Knapp C, Madden V, Marston J, et al: Innovative pediatric palliative care programs in four countries. <i>J Palliat Care</i> 2009;25:132–136.</p>
<b>Uganda</b>	<p>Amery JM, Rose CJ, Holmes J, et al: The beginnings of children's palliative care in Africa: Evaluation of a children's palliative care service in Africa. <i>J Palliat Med</i> 2009;12:1015–1021.</p> <p>De Baets AJ, Bulterys M, Abrams EJ, et al: Care and treatment of HIV-infected children in Africa: Issues and challenges at the district hospital level. <i>Pediatr Infect Dis J</i> 2007;26:163–173.</p> <p>Downing J, Birtar D, Chambers L, et al: Children's palliative care: A global concern. <i>Int J Palliat Nurs</i> 2012;18:109–114.</p>
<i>South Asia</i>	
<b>Pakistan</b>	<p>Ashraf MS: Pediatric oncology in Pakistan. <i>J Pediatr Hematol Oncol</i> 2012;34:S23–25.</p> <p>Shad A, Ashraf MS, Hafeez H: Development of palliative-care services in a developing country: Pakistan. <i>J Pediatr Hematol Oncol</i> 2011;33:S62–63.</p> <p>Silbermann M, Al-Hadad S, Ashraf S, et al: MECC Regional Initiative in Pediatric Palliative Care: Middle Eastern course on pain management. <i>J Pediatr Hematol Oncol</i> 2012;34:S1–11.</p>
<i>Europe and Central Asia</i>	
<b>Albania</b>	<p>Birtar D: National viewpoint. An update on paediatric palliative care in Romania. <i>Eur J Palliat Care</i> 2007;14:256–259.</p> <p>Dangel T: Pediatric palliative care in Europe. <i>J Pain Symptom Manage</i> 2002;24:2160–2165.</p>
<b>Belarus</b>	<p>Becker R: The legacy of Chernobyl: Palliative services making a difference in Belarus. <i>Int J Palliat Nurs</i> 2006;12:318–319.</p> <p>Costello J, Gorchakova A: Palliative care for children in the Republic of Belarus. <i>Int J Palliat Nurs</i> 2004;10:197–200.</p> <p>Dangel T: Pediatric palliative care in Europe. <i>J Pain Symptom Manage</i> 2002;24:2160–2165.</p>
<b>Bulgaria</b>	Dangel T: Pediatric palliative care in Europe. <i>J Pain Symptom Manage</i> 2002;24:2160–2165.
<b>Latvia</b>	<p>Dangel T: Pediatric palliative care in Europe. <i>J Pain Symptom Manage</i> 2002;24:2160–2165.</p> <p>Fedullo E, Jansone A, Ignatenko E: Innovative home care and hospice: Cross-partnerships in Russia and Latvia. <i>Caring</i> 2004;23:22–25.</p> <p>Hare A, Gorchakova A: The growth of palliative care for children in Latvia. <i>Eur J Palliat Care</i> 2004;11:116–118.</p>
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