



RESEARCH ARTICLE

Global development of children's palliative care: the picture in 2017 [version 1; peer review: 2 not approved]

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Abstract

Background: The growing interest in tracking the global development of palliative care provision is not matched by research on the development of palliative care services specifically for children. Yet it is estimated that worldwide, 21 million children annually could benefit from the provision of palliative care. We report on a global study of children's palliative care development and offer suggestions for further improvement in design and method.

Methods: Primary data on the level of children's palliative care development in 2017 was collected from in-country experts through a specific question in an online questionnaire that sought to measure the overall level of palliative care provision globally. Countries were assigned to one of six categories on the basis of the responses obtained. Conflicting responses from the same country were resolved with reference to a hierarchy of preferred respondents.

Results: Our data allowed the categorisation of 113 countries, accounting for 65% of the global population aged under 20. Number of countries (% of global child population) in each category were as follows: 1) no known activity, 21 (4%); 2) capacity-building, 16 (24%); 3a) isolated provision, 55 (30%); 3b) generalized provision, 5 (1%); 4a) preliminary integration into mainstream provision, 14 (8%); 4b) advanced integration, 7 (2%).

Conclusions: Children's palliative care at the highest level of provision is available in just 21 countries, accounting for fewer than 10% of the global population aged under 20. It is concentrated in high income settings, whilst the majority of the global need for such care is in low- and middle-income countries. Our study is a useful tool for global advocacy relating to children's palliative care and a stimulus for the creation of improved indicators to measure it at the country level.

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Any reports and responses or comments on the article can be found at the end of the article.

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Introduction and context

Children's palliative care – global context

The World Health Organization (WHO) has defined palliative care for children as 'the active total care of the child's body, mind and spirit, and also involves giving support to the family'¹. The WHO states that this should begin when a life limiting condition is diagnosed and should continue whether or not the child receives treatment directed at the disease. It requires health providers to evaluate and alleviate the child's physical, psychological, and social distress; and to be effective, it should be supported by a broad interdisciplinary approach that includes the family and makes use of available community resources. WHO maintains that palliative care for children can be successfully implemented even if resources are limited and can be provided in tertiary care facilities, in community health centres, as well as in children's own homes².

One-third of the global population is aged under 20 years. This is the age range to which WHO applies the idea of children's palliative care in the context of life-limiting and life-threatening conditions. Yet whilst 98% of the global need for children's palliative care occurs in low- and middle-income countries, the majority of such care is available only in high-income countries³. It is estimated that around the world, 21 million children annually could benefit from some form of palliative care⁴. The number includes more than 8 million children with complex problems that require specialised attention. Of these the most common difficulties relate to perinatal conditions, followed by congenital anomalies, Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS), and cancer⁵.

Currently we know very little about the scale of development of children's palliative care services in the global context. This stands in contrast to the growing body of information and research that is plotting patterns of growth and development around the world in palliative care for adults. We therefore focus here on this knowledge deficit relating to children's palliative care, report on a recent study that has shed some light on the issues, and reflect on the methodological and conceptual problems involved in research of this type. While the evidence we present is far from definitive, we see it as an important contribution to a crucial and emerging field of enquiry.

Mapping global palliative care development

For more than a decade, a series of studies has monitored the level of palliative care development in all the countries of the world - beginning in 2006⁶, followed up in 2011⁷ and most recently updated for 2017⁸. These studies have contributed significantly to advocacy, planning and monitoring for the improvement of palliative care worldwide. They have also sought progressively to develop more robust methods for measuring the country-level status of palliative care provision, through continuing identification and refinement of the appropriate indicators⁹. The first study allocated each country to one of four categories of development, using data synthesised from a variety of academic, professional and 'grey' literature, with expert opinion used as a substitute where necessary. The second study used a refined six category classification and was based on the identification of in-country

experts or 'champions' who were asked for their opinion on their country's level of development. The most recent iteration of the study develops the method further, again using six categories of development, but now with more detailed information gathered from a survey of national experts across 198 countries, and based on a set of 10 palliative care indicators derived from the literature.

Children's palliative care – current evidence

Despite these advances in measuring the overall level of palliative care provision globally, there remains limited evidence on the development of children's palliative care. The first two global mapping studies, for example, attempted to measure only the overall level of palliative care development in each country, with no specific focus on services for children.

Knapp *et al.*¹⁰, however, looking specifically at palliative care for children, used a systematic review of peer-reviewed and other published literature, as well as information on numbers of what the authors term 'paediatric specific organizations', to assign countries to the four categories of overall palliative care development used in the first global mapping study. This placed only 11 countries at Level 4, the highest category of palliative care development, while 19 countries were identified as being at Level 3 (isolated provision) and 36 at Level 2 (capacity building with no operational services). The majority of countries – 126 (65.6%) – were categorised as being at Level 1, indicating that there was no reported evidence of children's palliative care. Although this process used two reviewers to assign levels of provision, with further review by an expert panel, the work nonetheless shared the limitations of the 2006 global study in relying on published data (limited to English-language literature) supplemented by expert opinion, sometimes from outside the country.

Aim of this work

The aim of the work presented here was to obtain a first global overview of the national development of children's palliative care based on the knowledge of in-country experts. With this in mind, we included two specific questions in the third global mapping study that focussed, respectively, on the level of development of palliative care for children and on its implications.

The paper proceeds as follows. First, we set out the research methods and design of our most recent study, along with the protocol for assigning each country, where possible, to one of six categories of children's palliative care development. Second, we present the results of this process and compare them to the relevant countries' overall level of palliative care provision and to the results of the study of Knapp *et al.* Third, we discuss the strengths and limitations of our approach, with suggestions for future improvement.

Methods

Ethical statement

The study was approved by the University of Glasgow College of Social Sciences Research Ethics Committee. Approval was granted on 15 January 2018 (Application No: 400170065). Prior

to data collection, the purpose of the study was explained to all participants and written consent for participation in the study was obtained from each participant before access to the questionnaire was granted. Participants were informed that they had the right to withdraw from the study at any point in time, without any repercussions.

Data collection

The design and methods of the third global palliative care mapping study have been presented in detail¹¹. Data were collected via an online questionnaire completed by in-country experts actively engaged at the national level in the development, delivery and co-ordination of palliative care activity. These respondents were identified in consultation with international and regional palliative care associations. The survey was administered in 198 territories, comprising the 193 Member States of the United Nations (UN), two Observer States, along with Kosovo, Somaliland, and Taiwan, China. A total of 560 experts from 179 (90%) countries for which contacts could be found were asked to complete the questionnaire. For 19 (10%) countries we were unable to identify an expert contact.

Categorisation

While the questionnaire included multiple questions linked to a variety of indicators that enabled us to assess the overall level of national palliative care development, two questions focused specifically on the level of development of palliative care provision for children. Respondents were asked “Which of the following categories best describes palliative care activity related to children in your country?” A set of detailed category descriptors was then provided (Table 1).

A follow up question – “Please provide here any additional information on children’s palliative care services in your country you would like us to know” – allowed respondents to add more information or comments about the level of children’s palliative care.

Figure 1 explains the categorisation process. Where there was only one completed response per territory, or where there were multiple responses that were in agreement, the territory was allocated a category of children’s palliative care development on that basis. Where there were two or more responses with conflicting assessments of the most appropriate category, these

Table 1. Six levels of children’s palliative care development.

Category 1: No known palliative care activity for children	A country in this category is one where current research reveals no evidence of any palliative care activity relevant specifically to children.
Category 2: Capacity building palliative care activity for children	A country in this category shows evidence of wide-ranging initiatives designed to create the organisational, workforce, and policy capacity for the development of palliative care services for children, although no service or specific program has yet been established. There are some developmental activities including attendance at, or organisation of, key conferences, personnel undertaking external training in palliative care, lobbying of policy makers and Ministries of Health, and emerging plans for service development.
Category 3a: Isolated children’s palliative care provision	A country in this category is characterized by the development of children’s palliative care activism that is still patchy in scope and not well-supported; sources of funding that are often heavily donor-dependent; limited availability of morphine; at least a service or program can be identified by other professionals in the country as a best practice model for palliative care for children; there are a few children’s palliative care services or specific programs, but they are limited in relation to the need of the population.
Category 3b: Generalised children’s palliative care provision	A country in this category is characterized by the development of children’s palliative care activism in several locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; several hospice-palliative care services or programs for children from a range of providers; and the provision of some training and education initiatives by the hospice and palliative care organizations.
Category 4a: Children’s palliative care services at a preliminary stage of integration into mainstream health care services	A country in this category is characterized by the development of a critical mass of children’s palliative care activism in a number of locations; a variety of palliative care providers and types of services and programs; awareness of palliative care on the part of health professionals and local communities; the availability of strong pain relieving drugs other than morphine; some impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organizations; and the existence of a national palliative care association.
Category 4b: Children’s palliative care services at an advanced stage of integration into mainstream health care services	A country in this category is characterized by the development of a critical mass of children’s palliative care activism in a wide range of locations; comprehensive provision of all types of children’s palliative care by multiple service providers; broad awareness of children’s palliative care on the part of health professionals, local communities, and society in general; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of children’s palliative care on policy; the existence of children’s palliative care guidelines; the existence of recognized education centres and academic links with universities with evidence of integration of children’s palliative care into relevant curricula; and the recognition of children’s palliative care by a national association that has achieved significant impact.

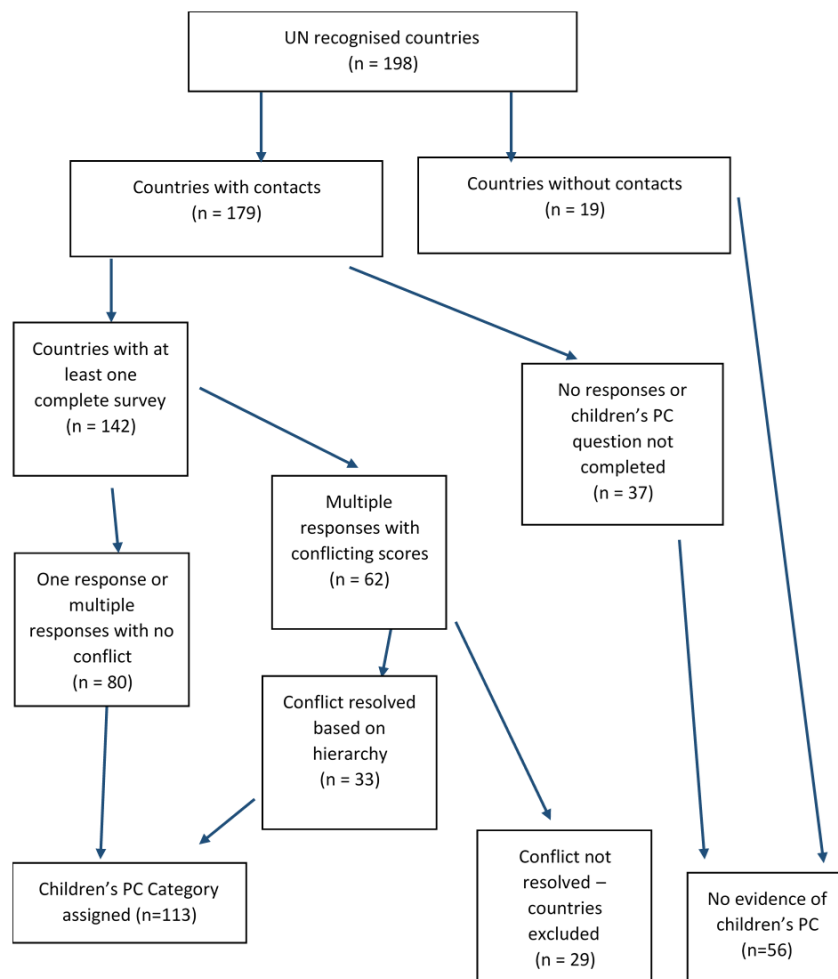


Figure 1. Categorisation process. PC, palliative care.

were resolved where possible by privileging the assessments of those survey participants closest to the top of the following hierarchy:

- I) Representatives of the national in-country hospice-palliative care association or nearest professional association (e.g. society for palliative medicine or hospice forum). The person should have an established administrative and/or leadership role in the organisation, making them a reliable source of information.
- II) Academic experts with known interests and research experience in hospice-palliative care development in-country and/or beyond, as evidenced by peer-reviewed publications. The person should have an established academic role in hospice-palliative care research or education, making them a reliable source of information.
- III) Policy specialists (in or outside government) with experience of and/or responsibility for hospice-palliative care delivery in-country. The person should have an established policy role relating to hospice-palliative care, making them a reliable source of information.

- IV) Palliative care representatives, academics or policy specialists from outside the country but with direct knowledge of its hospice-palliative care provision, making them a reliable source of information.

Where it was not possible to resolve conflicts on this basis, that is where survey participants offering differing assessments of their country's level of children's palliative care had similar roles – then the country was excluded from the analysis.

Results

The global development of children's palliative care

Using this process, an assessment of the level of children's palliative care development was reached for 113 (57%) of the 198 countries included in the study (Table 2, Figure 2). These 113 countries account for 65% of the total global population of children – defined here as being aged 0–19 in line with the WHO convention, so including infants, children and adolescents.

Only seven countries, accounting for 42M children (1.7% of the world total), were placed in Category 4b, with the most

Table 2. Countries by level of children's palliative care development.

Category	Countries (n=198) (%)	Children population (millions of children aged under 20) (% of global)	Countries
(1) No known palliative care activity for children	21 (10.6%)	92M (3.6%)	Afghanistan, Benin, Cyprus, Equatorial Guinea, Eritrea, Estonia, Grenada, Liberia, Libya, Liechtenstein, Mozambique, Oman, Palestine, Samoa, Saudi Arabia, Serbia, South Sudan, Sri Lanka, Trinidad & Tobago, Tunisia, Venezuela
(2) Capacity building palliative care activity for children	16 (8.1%)	610M (24.1%)	Cameroon, Croatia, Ethiopia, Fiji, Iceland, India, Iraq, Kyrgyzstan, Lesotho, Lithuania, Niger, Norway, Portugal, Slovenia, Tajikistan, Togo
(3a) Isolated children's palliative care provision	50 (25.3%)	763M (30.1%)	Albania, Argentina, Azerbaijan, Bangladesh, Bosnia & Herzegovina, Botswana, Brazil, Bulgaria, Cambodia, Czech Republic, Dominican Republic, Ecuador, Georgia, Ghana, Greece, Honduras, Indonesia, Iran, Jordan, Kazakhstan, Kenya, Kuwait, Lebanon, Macedonia, Madagascar, Mauritania, Moldova, Morocco, Myanmar, Nepal, Nicaragua, Nigeria, Pakistan, Panama, Paraguay, Peru, Philippines, Romania, Rwanda, Senegal, Slovakia, South Africa, South Korea, Spain, Switzerland, Thailand, Uruguay, Uzbekistan, Zambia, Zimbabwe
(3b) Generalised children's palliative care provision	5 (2.5%)	16M (0.6%)	Finland, Latvia, Mongolia, Papua New Guinea, Ukraine
(4a) Children's palliative care services at preliminary stage of integration into mainstream health care services	14 (7.1%)	190M (7.5%)	Barbados, Côte d'Ivoire, Germany, Israel, Japan, Malawi, Malta, Netherlands, New Zealand, Russia, Singapore, Sweden, Taiwan(China), USA
(4b) Children's palliative care services at advanced stage of integration into mainstream health care services	7 (3.5%)	42M (1.7%)	Australia, Belgium, Canada, Costa Rica, Ireland, Poland, United Kingdom
Conflicting data from survey returns (unresolved) (See Supplementary Table 1, <i>Extended data</i> ¹²)	29 (14.6%)	646M (25.5%)	Armenia, Austria, Belarus, Bolivia, Burundi, Chile, China, Colombia, Congo (DR), Denmark, Egypt, El Salvador, France, Guatemala, Guinea, Haiti, Hungary, Italy, Jamaica, Luxembourg, Malaysia, Mauritius, Mexico, Sierra Leone, Sudan, Swaziland, Uganda, United Arab Emirates, Vietnam
No data from survey returns	56 (28.3%)	173M (6.8%)	Algeria, Andorra, Angola, Antigua & Barbuda, Bahamas, Bahrain, Belize, Bhutan, Brunei, Burkina Faso, Cape Verde, Central African Republic, Chad, Comoros, Congo (Republic), Cuba, Djibouti, Dominica, Gabon, Gambia, Guinea-Bissau, Guyana, Kiribati, Kosovo, Laos, Maldives, Mali, Marshall Islands, Micronesia, Monaco, Montenegro, Namibia, Nauru, North Korea, Palau, Qatar, Saint Lucia, San Marino, Sao Tome e Principe, Seychelles, Solomon Islands, Somalia, Somaliland, St Kitts & Nevis, St Vincent & the Grenadines, Suriname, Syria, Tanzania, Timor L'Este, Tonga, Turkey, Turkmenistan, Tuvalu, Vanuatu, Vatican City, Yemen

Note: Population for number of people aged 19 and under (2017) by country from UN Population Database. Available at <https://population.un.org/wpp/Download/Archive/Standard/>

advanced level of integrated children's palliative care. A further 14 countries were in Category 4a (190M, 7.5%), with preliminary integration of children's palliative care into mainstream services.

Five countries were in Category 3b, indicating the presence of generalised provision of children's palliative care (16M, 0.6%), and 50 in Category 3a (763M, 30.1%) with isolated provision.

In Category 2 were 16 countries, with evidence of some capacity building activity in children's palliative care (610M, 24%).

In the lowest category (1) were 21 countries with no reported children's palliative care activity. In addition, we added to this category 28 countries for which no survey was returned, and 28 countries for which the children's palliative care question was not completed, on the basis that this suggests there is no evidence of any palliative care specifically for children in these

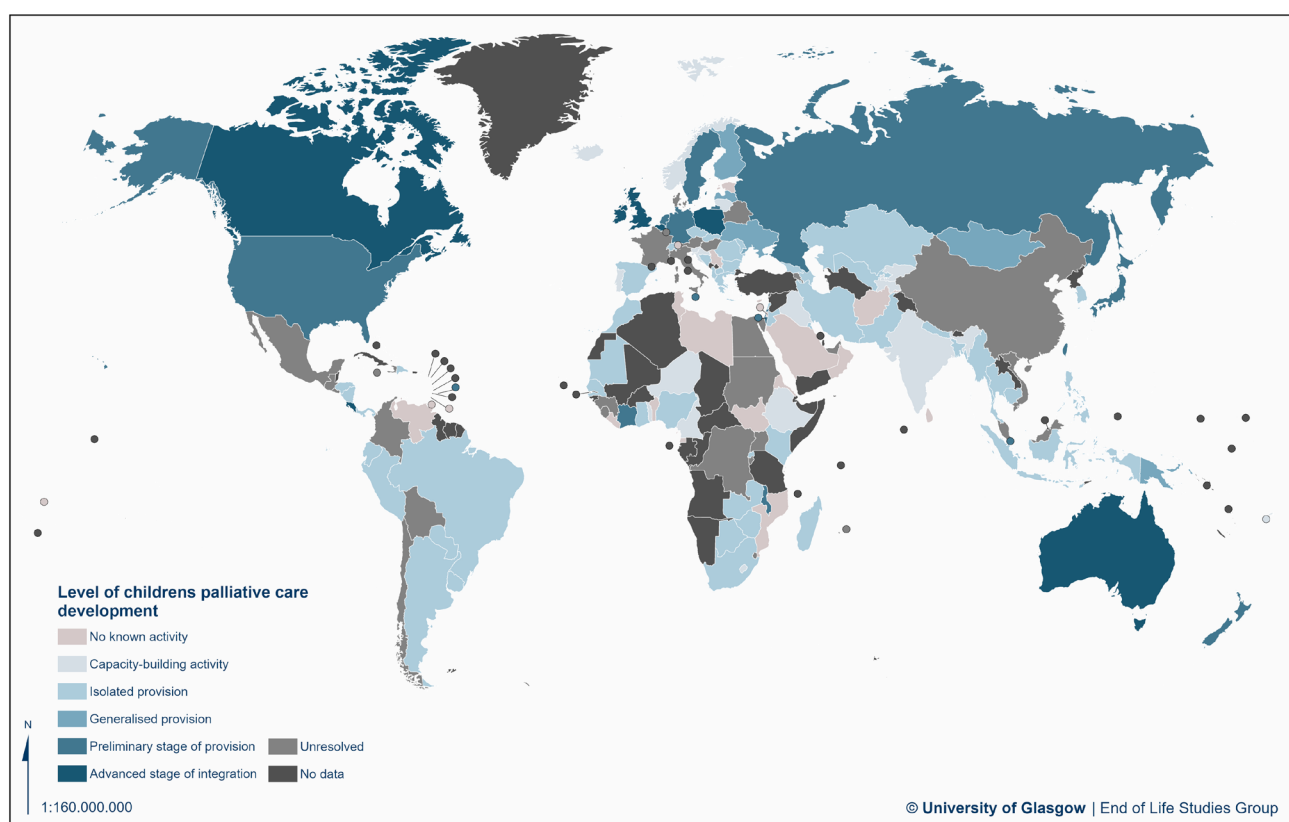


Figure 2. World map of children's palliative care development.

countries. Taken together, the countries in this expanded category 1 account for 265M children aged under 20, 11% of all the world's children.

For a further 29 countries, there were multiple responses that provided a conflicting assessment of the level of children's palliative care, and where this conflict could not be resolved with reference to the hierarchy set out above. They were therefore not assigned a category. These account for 646M children, 26% of all the world's children. In the majority of cases these had survey responses from two or three different in-country experts (in two cases there were more than three responses). In 14 of the 29 countries, assessments of the level of children's palliative care varied by one category, and in 10 cases by two categories. The remaining five countries had more significant conflicts, with respondents disagreeing by three or four categories (See Supplementary Table 1, *Extended data*¹²).

Comparison with overall palliative care level

There is a broad alignment between countries' overall categorisation of palliative care development, already reported⁷ and based on a range of indicators, and their specific categorisation for children's palliative care as presented here. Table 3 shows that all of the countries in Category 4b for children's palliative care are also in 4b overall, as are 10 of the 14 countries in Category 4a for children's palliative care. There is, however,

Table 3. Number of countries by children's palliative care and overall palliative care category.

		Children's PC Level								Total
Overall PC Level		4b	4a	3b	3a	2	1	No data	Unresolved	
	4b	7	10	1	3	4	1	0	4	30
	4a	0	3	2	10	0	0	0	6	21
	3b	0	1	1	8	1	4	3	4	22
	3a	0	0	1	28	9	10	5	12	65
	2	0	0	0	1	0	4	5	3	13
	1	0	0	0	0	2	2	43	0	47
	Total	7	14	5	50	16	21	56	29	198

PC, palliative care.

no firm relationship between the national level of overall palliative care development and that of children's services. There are a number of outliers, in particular a small number of countries in category 4b overall that are in categories 1 or 2 for the level of children's palliative care. In addition, the overwhelming majority of those countries for which there were no data on children's palliative care were placed in the

lowest category overall, indicating no known or reported palliative care activity.

Only two of the countries with responses that reported no children's palliative care activity were also placed in the lowest category for their level of overall palliative care development. On the other hand, of those countries for which no information on children's palliative care was returned, the vast majority (43/56) were in the lowest category overall.

Comparison with other country level indicators

This data can also demonstrate the relationship between the level of children's palliative care development and the United Nations Human Development Index (UNHDI), World Bank Income Level (WBIL), Universal Health Coverage Index (UHCI) and WHO region. Of the seven countries at the highest level of children's palliative care development, all are at high or very high levels of UHCI, WBIL, and in the top two quintiles of the UHCI. Four are in Europe, two in the Americas and one in the Western Pacific Region (See Supplementary Table 2, *Extended data*¹²).

Comparison over time

Since we did not collect specific information on children's palliative care in the earlier world mapping studies of palliative care development, we have no basis for comparison over time with our current findings. However, some indication is possible using the country-level classifications assigned by Knapp *et al.*, for 2011, which were based on the categories used in the first mapping study. Table 4 shows how the 113 countries for which a positive categorisation was possible on the basis of our 2017 survey, were classified (on a four-category scale) by Knapp *et al.* Most obviously, the majority of those countries in Categories 1, 2 and 3a in 2017 were placed in Category 1 by the Knapp *et al.* study. This reflects the high proportion of countries – over half – for which Knapp *et al.* found no evidence of children's palliative care provision. Given the differences in methodologies, it is not possible to say with certainty the degree to which the

results from our present study represent genuine changes in children's palliative care development over the intervening period.

Free text commentary. Respondents were given the opportunity to add more information about the development of children's palliative care in their country in an open text box. Table 5 shows some indicative quotes from respondents, arranged by their country's categorisation, that demonstrate the type of commentary provided. Respondents provided broad overviews of institutional frameworks and social contexts, further detail on the number and type of medical facilities and specialists providing palliative care for children, the geographical spread of these services, and narratives about the progress of children's palliative care development in their country.

Strengths and limitations

The research presented here is the most comprehensive attempt yet to map the country-level development of children's palliative care around the world. In basing this assessment on responses from in-country palliative care experts from 113 territories, the method moves beyond a reliance on published data and the judgement of external parties. As part of a broader study of global palliative care, this therefore represents a significant contribution to evidence and understanding about the spread of palliative care provision for children.

Nevertheless, there remain a number of limitations with this approach and these should be addressed in future research.

- Although this method – based on the assessment of 'in-country' experts with detailed knowledge of palliative care in their territory – can be considered more robust than previous approaches, categorisation on this basis is nevertheless informed to some extent by the professional judgements of survey participants. Such self-reported judgements cannot be independently verified, and some participants may have over- or under-estimated their country's levels of development. There are, for example, instances of countries at the highest level of overall palliative care development, of human development and income that have been identified as having a very low level of children's palliative care development. The deficiencies of this approach could therefore potentially be strengthened through triangulation with other sources of evidence.
- Related to this, the survey question did not define 'palliative care activity related to children in your country', meaning there was the potential for the question to be interpreted in different ways, influenced by different understandings of what constitutes palliative care and who are considered to be 'children' in different national contexts. We explore this in more detail in the section below on matters of definition.
- A significant proportion of countries included in the global mapping survey have been excluded from these results on the basis that participants provided conflicting categorisations that could not be reconciled. The exclusion of these countries limits the extent to which the results presented here can be considered a comprehensive global

Table 4. Comparison of 2017 and 2011 country categorisations of children's palliative care development.

	2011 Children's PC Level (Knapp <i>et al.</i>)						Total
		1	2	3	4	NC	
2017 Children's PC Level (Clark <i>et al.</i>)	1	17	1	1	0	2	21
	2	10	5		1	0	16
	3a	29	11	9	1	0	50
	3b	2	1	2	0	0	5
	4a	3	5	1	4	1	14
	4b	1	0	2	4	0	7
	Total	62	23	15	10	3	113

PC, palliative care; NC, no categorisation.

Table 5. Respondents' comments on children's palliative care.

Category	Comments
1	We dispense some measure of palliative care in some of our hospitals. We admit palliative care cases, manage and discharge, although there are no specialists, no morphine, no registry, no home visits etc. It is not comprehensive.
	Children can benefit from the Palliative Care Units existing in [neighbouring country]
	There are not any activities for palliative care for children in my country.
	Palliative care for children is usually provided by the programmes providing palliative care for adults. No specific paediatric palliative care programmes are currently available in the country.
	There is only one children's general hospital. This hospital provides non-specialized palliative care services to children in need e.g. HIV/AIDS and malnutrition.
2	Activities are begun by NGOs in some places. Professionals (doctors, nurses, management) in the oncological department in [capital city] Children's Hospital make efforts to establish children's palliative care. There is a symposium about children's palliative care held every year. Also, the recognition of children's palliative care by the national association has achieved a significant impact. There is also an active palliative care committee at the Ministry of Health.
	We created this year a hospital committee for children's palliative care; decrees have been signed for the national hospital and we are now working on different protocols to formalize them.
3a	There is only one children's onco-hematological hospital. This offers chemotherapy and symptom control for children in need, but there is not any palliative care or hospice for children in the country.
	There are a few complete palliative care services but they are in big cities. Palliative care for children is growing fast but in a very heterogeneous way at the national level. There are provinces/states that do not have any paediatricians trained in palliative care and other provinces who have several teams in big cities.
	There are several specialized paediatric onco-hematological hospitals that provide specialized palliative care services for children.
	There is only one NGO providing home palliative care to children and young adults as well as psychological support to parents, siblings and relatives.
	There is only one paediatric palliative care service; it is a well-established service; provides 24/7 service with inpatient and outpatient plus one home team The service is only for the patients that are seen at the centre, mostly cancer patients. Trying to help neighbouring countries by providing training to physicians and nurses.
	Progressing slowly. Health care professionals need to be sensitised and trained to refer and support children with palliative care needs. Still lagging behind adult service provision particularly in rural areas.
	The children's palliative care services are currently limited to two University Teaching Hospitals but there is a Government willingness and plan to spread the services to District Hospitals in the nearest future.
3b	Hospitalized children suffering for cancer have a palliative care support program but this is generally missing for other specialties.
	The Ministry of Social Affairs and Health recommendations for organizing palliative care includes a recommendation for building up children palliative care network and services. The official group for implementation of these recommendations and another group to revise the legislation/need for a new legislation of end-of-life and palliative care include plans for children's palliative care. University Hospitals have home care teams for children, but in general there is no official plan for children palliative care so far.
4a	There are palliative care standards at national level in children's care. Palliative care specialists are trained, before they are certified, both in children's and adult palliative care on a one year course.
	Services for children are provided by the hospital, and upon discharge, quality care is given. It should be noted that there is not a high percentage of children in need of palliative care. Should a case arise, families are very keen to give primary care with our monitoring support.
	All 6 departments of paediatric oncology in the leading university hospitals have developed an advanced service for palliative care.
	We have one children's hospice. Some children are taken care of in advanced home care teams around the country.
4b	In most cases families take the total responsibility and provide the end of life care to their dying child. Despite availability of opiates in country, there isn't proper system of prescribing and consuming opiates for reducing pain of patients. Parents get pain killers, even sometimes opiates, on an 'over the counter' basis from pharmacies to reduce pain of their loved one.
	One children's hospice that serves the country; children's palliative care team in the national children's hospital; consultant-provided service in one other large maternity hospital; care in other hospitals provided by 'champion paediatricians' (i.e. paediatricians with an interest in palliative care) with the support (either direct or indirect) from the palliative care team in the national children's hospital' children in the community cared for in every local health office area by adult community palliative care teams and local primary care and paediatric teams with support of the 10 Clinical Nurse Coordinators for Children with Life-Limiting Conditions'. Four consultants (2.2 whole time equivalents) provide children's palliative care services – two consultants are paediatricians with specialist palliative care training; two consultants are adult physicians with a special interest in children's palliative care. Children's palliative care recognised in national model of care for children.
	Seven free-standing residential hospices but many programs in all paediatric health centres

Comments have been edited for clarity and confidentiality

NGO, non-governmental organisation.

assessment of palliative care development. While there are no straightforward ways of addressing this, a number of possible approaches may be considered. At its simplest, this could take the average value of multiple categorisations. Alternatively, more detailed information could be sought about the characteristics of survey participants to allow a judgement to be made on which were best placed to assess their country's level of development, or the views of external experts could be sought to moderate the proposed categorisations.

- In some instances, it was not possible to identify palliative care experts in-country, and in others, where eligible respondents were identified, they did not complete the questionnaire or the specific question relating to children's palliative care.
- Data limitations were compounded by language constraints. Questionnaires were only available in three European languages (English, Spanish and French). This both impeded communication with reluctant respondents and might also have added to the barriers for non-English speakers willing to complete the questionnaire. Terminological issues may also have been further exacerbated by translation factors.
- The hierarchy of preferred respondents privileges the assessments of those in-country experts representing national hospice-palliative care or professional associations above, for example, those of government sources. This could be contested.

Matters of definition

Children's palliative care is a complex domain that is similar to, but also distinct from, adult palliative care. Understanding the specificities of children's palliative care, and situating it globally, requires attention to the gamut of life-threatening and life-limiting illnesses that can affect children and youth, myriad culturally diverse conceptions of childhood, and the vast range of national, ethnic, and legal contexts of care provision.

The diagnostic categories, illness trajectories and prognosis that fall under the umbrella of children's palliative care are vast, with significant variation in severity, symptoms, prognosis, and disease trajectories. Some illnesses requiring children's palliative care are 'life limiting' (i.e., those with no reasonable hope of cure and from which children will die); others are 'life threatening' (i.e., those for which curative treatment may be feasible but may fail). These conditions have been divided into the following four categories for the purposes of research and to better focus care: 1. Life-threatening conditions (e.g., infectious diseases, cancer, organ failure and transplant, long-term ventilation); 2. Conditions in which premature death is inevitable but intensive treatment can prolong life (e.g., cystic fibrosis, Duchenne muscular dystrophy); 3. Progressive conditions without curative treatment options (e.g., metabolic conditions, incurable cancer); 4. Irreversible non-progressive conditions causing severe disability (e.g., cerebral palsy, brain or spinal cord injury)¹³.

Children's palliative care therefore includes a greater diversity of illnesses and a longer duration of survival than adult palliative care¹⁴. Many of these children live with physical, neurological and cognitive impairments, therefore requiring intensive family and/or institutionalized caregiving¹⁵. Advances in rehabilitation and disability studies have shifted focus beyond functional impairments to better appreciate the interplay between a child's capacities and the accommodations available in their local environment.

Conventional biomedical 'paediatric' models parse the category of childhood into neonates, infants, children, and adolescents based upon psychological developmental models. Children's palliative care extends beyond these categories starting with the unborn child (e.g., perinatal palliative care) and into young adulthood (e.g., many children will live with life-limiting illnesses beyond 19 years old). Further, local cultural conceptions of children and youth need to be considered when developing children's palliative care services. Advances in childhood studies have challenged stage-based conceptions of child development for their simplistic depictions of children's understandings of death and dying, favouring instead conceptions of children's experiences centred on the recognition of children as active agents with morally meaningful concerns about their lives and the people around them^{16,17}.

Children's palliative care, as defined by leading authorities – e.g., the WHO¹⁸, and the UK's Together for Short Lives¹⁵ – is attentive to the family as the unit of care, offering support for the child as embedded within a family unit. This support starts with diagnosis, and proceeds throughout the illness, to end-of-life care and death, and beyond into the bereavement period. Understanding who is important to the child's life and care (e.g., extended family, parents, sibling, community), and at what age and for which kinds of treatments the child should be afforded some agency, will depend on local logics, legal systems, and cultural practices.

While conventions in the global north are to provide children's palliative care through inter-professional and interdisciplinary teams, services in rural contexts as well as in low- and middle-income countries are often without access to specialist care. Instead, care is often provided through child-focused general health professionals, with the assistance of adult-specific palliative care specialists if available¹⁹.

All of these dimensions challenge our ability to map and categorise levels of children's palliative care development at the national level and globally. Significant further work is needed to generate indicators of children's palliative care development that result in measurable outcomes but at the same time incorporate the nuanced and complex world of palliative care for children. The next step in developing a more comprehensive and robust map of global children's palliative care provision would therefore be a bespoke global survey online, adapting the approach taken in the global studies of palliative development and making use of new and more imaginative indicators, which capture the complexities of defining palliative care for children, the varied age groups

and development categories to which it applies, and the specific forms of co-production that may be involved in its design and delivery.

Conclusions

We have been able to identify a total of just 21 countries in the highest categories of development for children's palliative care (7 in 4b and 14 in 4a); these countries contain 232 million children and young people age 19 and under (9.2% of the global total).

In addition, 778 million children (30.7%) live in 55 countries with only isolated and patchy provision

Meanwhile, 610 million children (24.1%) live in 77 countries that only have capacity building activity in place.

A further 265 million children (10.4%) live in 106 countries where no known children's palliative care activity is taking place, or it has proved impossible to gather any evidence on it. An even greater number, 646 million children (25.5%), live in 29 countries where the available evidence on the level of children's palliative care development is contradictory.

Accordingly, less than 10% of those under 20 years old live in countries where palliative care for children is of the highest current standards. Almost a third of children live in countries where such care is highly limited in provision, and incommensurate with need. One quarter of all children live in countries that are only beginning to mobilise efforts for children's palliative care. The rest live in countries where it is proving difficult even to assess available levels of children's palliative care.

We have previously shown that the overall development of palliative care, despite some gains over time, is incapable of meeting existing need. For the world's children who could benefit from palliative care, the situation is even more serious and requires a global intervention of massive scale for its rectification.

Data availability

Underlying data

Enlighten: Research Data: Global development of children's palliative care: the picture in 2017: <http://dx.doi.org/10.5525/gla.researchdata.995>¹²

This project contains the following underlying data:

- SurveyResponsesQ26_995.xlsx

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](#) (CC-BY 4.0).

The authors are unable to make all data publicly available because of the terms of data sharing included in the consent process for this study. Furthermore, it is not possible to effectively de-identify all the participants and their organisations in the free-text responses to the survey. However, access will be granted on a case-by-case basis upon request to the corresponding author (david.clelland@glasgow.ac.uk). Access to the full underlying data will be granted upon request from a researcher for the purposes of further research providing the requesting researcher is in possession of a protocol that has been approved by an ethics committee and which satisfies the guarantees of anonymity originally given to the research participants.

Extended data

Enlighten: Research Data: Global development of children's palliative care: the picture in 2017: <http://dx.doi.org/10.5525/gla.researchdata.995>¹²

This project contains the following extended data:

- Supplementary Table 1: Conflicting Assessments of Children's Palliative Care Development (DOCX)
- Supplementary Table 2: Level of Children's Palliative Care Development by Country-Level Indicators (DOCX)

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](#) (CC-BY 4.0).

Disclaimer

Neither the inclusion or names of any territories for which results are presented or the boundaries and designations used on the map imply the expression of any opinion whatsoever on the part of the authors concerning the legal status of any country, territory, city or area or of its authorities or concerning the delimitation of its frontiers or boundaries.

Acknowledgements

We thank all those who took the time to complete our questionnaires, without whom there could be no study. Colleagues in regional palliative care associations around the world assisted significantly in our efforts to find key contacts in many countries. We acknowledge the contribution of our colleague who led the data collection for this study and the authorship of the previously published research protocol.

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Busisiwe Nkosi 

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The study addresses an important topic. It focuses on the state of palliative care for children at the global level. The aim of the study was to: “obtain a first global overview of the national development of children’s palliative care based on the knowledge of in-country experts”. It reports on the methodological and conceptual challenges in mapping palliative care for children.

The paper is well written, and the process of categorisation is well-explained. The study is useful in advocating for children’s palliative care, and to improve indicators to measure it at the country and international levels.

The methodological and conceptual limitations outweigh the authors’ abilities to map and categorise levels of children’s palliative care development at the national level and globally that they undermine the utility of the study results:

The study describes the limitations of self-reported data and suggests the triangulation of data sources to address this limitation. However, this could have been considered in this study given that similar work has been done previously.

On pages 8-9, the authors state: “A significant proportion of countries included in the global mapping survey have been excluded from these results on the basis that participants provided conflicting categorisations that could not be reconciled. The exclusion of these countries limits the extent to which the results presented here can be considered a comprehensive assessment of palliative care development”. The statement is self-defeating and raises questions about the study results.

The authors state that lack of definition of palliative care for children may have resulted in different interpretations, and this could have resulted in under or over-reporting, making the data unreliable.

The categorisation of children's palliative care development is useful, it also illustrates some of the limitations resulting from the reliance on the country experts sampled in the survey. For example, South Africa is categorised as 3a, yet there is an existence of a national palliative care association; and palliative care is provided by multiple providers ranging from community-based, to hospice and hospital-based services. This raises questions about categorisation of palliative care development for some of the countries.

The authors must be commended for their work in addressing this important yet complex topic. Whilst the study raises important issues on the development of palliative care for children nationally and globally, the methodological and conceptual issues undermine the results.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Research ethics, ethical and legal challenges in adolescent research; vulnerability in and through research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Author Response 22 Jun 2020

David Clelland, University of Glasgow, Dumfries, UK

We thank this reviewer for the attention given to our paper and for acknowledging the importance of our topic, the clarity of our presentation, its value in advocating for children's palliative care, and its contribution to improving the indicators by which children's palliative care can be measured.

The reviewer refers to the 'methodological and conceptual limitations of the study' and lists some examples:

1 The absence of 'triangulation' that has been used in previous work. We accept this is a reasonable point, but previous work of this type has been restricted to a much smaller number of countries than those covered here. We did not have the resource to support triangulation on this scale.

2 What the reviewer sees as a 'self defeating statement' about the problems of conflicting responses, we regard as an honest and open statement of limitation which we mitigated by not including the relevant countries in the final analysis.

The reviewer questions the grading of children's palliative care in South Africa (3a), making reference to some generic indicators that are not specific to children's palliative care. It is worth noting that our grading of adult palliative care for South Africa, published elsewhere (<https://www.jpsmjournal.com/action/showPdf?pii=S0885-3924%2819%2930664-5>) gives a grade of 4a. This is a form of 'triangulation' which may indeed demonstrate the veracity of our findings – children's palliative care in the view of in-country experts in South Africa does not reach a level of development that those same expert source provided across 10 sets of indicators when assessing adult provision.

Overall, we would suggest that this reviewer's comments and the assessment that we 'partly' addressed two of the key dimensions under review and fully addressed the three other relevant criteria, seems incommensurate with an overall judgement of 'not accepted'.

Competing Interests: No competing interests were disclosed.

Reviewer Report 10 June 2020

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This is a well-written paper on an important and understudied topic with some notable strengths

and yet significant limitations. The paper starts strong, clearly explaining the importance of pediatric palliative care and the need for global mapping. The authors appropriately cite prior studies and their limitations, and current gaps in knowledge. At the end of the introduction, they explicitly lay out the objectives of the study and the structure of the rest of the paper, which helps the reader prepare and subsequently follow the information that is to come.

Unfortunately, we have some fundamental concerns about the methodology and in turn results of the study. The authors use data from a 2017 questionnaire examining the level of national palliative care development across the globe, which included two questions specific to the development of children's palliative care. Per the paper, this online survey was completed by "in-country experts actively engaged at the national level in the development, delivery, and co-ordination of palliative care activity." Importantly, these individuals were not likely experts in pediatric palliative care. Being an expert in adult palliative care does not necessarily mean you have in-depth knowledge of palliative care services available for children. It is problematic that categorization of countries came directly from the responses of these experts. We therefore have serious concerns about the validity of the results.

Let us consider pediatric palliative care in the United States (US) as an example. As pediatric palliative care experts based in the US we wonder why it was categorized as 4a rather than 4b given the category descriptors and our knowledge of other countries categorized as such. Specifically, the US has activism for children's palliative care nationally. For example, as a result of advocacy, in 2010 with the initiation of the Affordable Care Act, policy change led to the opportunity for children to receive disease-directed therapy concurrent with hospice, a provision not available for adults^{1,2}. The American Board of Pediatrics has recognized Hospice and Palliative Medicine as a formal specialty since 2008. Interdisciplinary pediatric palliative care is now a specialty service available in a majority of freestanding children's hospitals across the US. Most health professionals, local communities, and members of our society are aware of pediatric palliative care as exemplified by media coverage of these services^{3,4}. The US has unrestricted access to strong pain-relieving drugs, including morphine. The American Academy of Pediatrics has published guidelines around children's palliative care⁵ and multiple academic centers have integrated palliative care into pediatrics residency curricula. Finally, pediatrics is a strong and integral part of the American Academy of Hospice and Palliative Medicine. Despite this level of PPC integration in the US, one of the "in-country experts" ranked the US as a 1 "No known palliative care activity for children" (Extended Data: SurveyResponsesQ26_995). We use the United States to exemplify the potential flaws of relying on adult experts to rank pediatric palliative care development across the globe. While there remains room for further pediatric palliative care integration in the US, this is also the case for the other countries categorized as 4b. And there is substantial misclassification of other countries. For example, Russia was ranked a 4a based on a single survey respondent. Our knowledge of the country is that it should be categorized as a 3a, isolated children's palliative care provision.

We do commend the authors for a paper that brings attention to the important issue of mapping children's palliative care across the globe. While we raise serious issues around the methodology and in turn the results, we appreciate the discussion around the complexity and nuances of palliative care in children and the inherent challenges around measuring it globally. As mentioned by the authors, we agree that in order to more accurately capture the current state of pediatric palliative care, there needs to be a global survey using measures and experts specific to children.

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Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

No

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Pediatric Palliative Care.

We confirm that we have read this submission and believe that we have an appropriate level of expertise to state that we do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Author Response 22 Jun 2020

David Clelland, University of Glasgow, Dumfries, UK

We thank the reviewers for their detailed response to our paper and for the 'notable strengths' in our work to which they refer. We note that they concur with our own assessment of the limitations of the study and of the need to improve on the methodology we have adopted as we make steps towards a more robust approach to research in a specialised area of palliative care where there remain many challenges.

The reviewers then raise the question of relevant expertise in the respondents to our survey, and take the view that national experts in palliative care will not necessarily have 'in-depth knowledge of palliative care services available for children'. This is an assertion by the reviewers and cannot constitute a legitimate critique of our method or of our results. We have acknowledged the distinct and perhaps contested status of children's palliative care in our discussion of definitional issues and acknowledged that a survey specifically about children's palliative care would be the desirable next step in developing an understanding of this. But it seems to us unreasonable to discard the views of palliative care experts on the grounds that they are not specialists in children's palliative care, especially when the latter may not even be present in some countries.

The reviewers also question the grading of their own country, the USA, and make reference to the underlying data as an example of the problem they perceive, specifically SurveyResponsesQ26_995. In fact, this response came from the representative of an organisation that works in one of the poorest countries in the world, but who for some reason gave the USA as the host country for the organisation – an issue we noted in some other responses, which we dealt with case by case. This particular questionnaire was therefore quickly excluded from our analysis of the USA data. Moreover, the reviewers may be reassured to know (and we regret that confidentiality principles don't allow us to give more details) that the other two responses from the USA, not only both gave the same grading (4a), but also came from impeccable organisational sources and were signed off in one case by a senior clinician of global standing in the field of palliative care.

In sum, we reiterate our thanks to the reviewers, who clearly concur with us on so many issues. We contend however that the reviewers make 'the perfect the enemy of the good'. We know, based on our experience of previous mapping studies we have conducted, that despite the limitations and our gradual efforts to overcome them, these studies have proved enormously valuable to the field. Indeed, they constituted the underlying evidence base for the World Health Assembly Resolution on palliative care, which was passed in 2014, and which of course supports the provision of palliative care across the entire life course. No other group has attempted to map the global development of children's palliative care in the manner we present in our paper. Until such an attempt is made with an improved methodology, we argue that the current work should be seen, not as definitive, but as the best evidence we currently have, and which moreover is highly likely to be of benefit to the field on which it is focussed. To take a phrase from the paediatrician Winnicott, it is 'good enough'.

Competing Interests: No competing interests were disclosed.

Comments on this article

Version 1

Reader Comment 25 Jun 2020

Joan Marston, Palliative Treatment for Children South Africa, Cape Town, South Africa

Thank you for this paper and for highlighting the need for unique research to map the development of palliative care for children; and for identifying the low level of provision worldwide that requires urgent attention.. This sort of mapping is always difficult for many of the reasons that the authors have identified when listing the limitations. From previous experience in research to identify the need for children's palliative care, the experience we had was there will always be conflicting views. While I do not agree with all the country classifications , including in South Africa and certain other countries in which I have worked quite extensively ,this research can be used to advocate for both further research and development. It s a pity that conflicting views led to the exclusion of certain countries like Belarus where palliative care for children is well-established, extensively available and of a high level. Unfortunately experience has shown that not all country leaders in palliative care have knowledge of development for children. This paper also , for me, highlights the need for those working in the field of palliative care for children to develop a stronger voice.

I look forward to the further research this paper should generate.

Competing Interests: I have no competing interests