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SPECIAL REPORT OPEN ACCESS

African Hospital-Based Paediatric Palliative Oncology Care Independent of Economic Indicators: An International Society of Paediatric Oncology (SIOP) Global Mapping Programme Survey

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Received: 16 September 2024 | **Revised:** 27 January 2025 | **Accepted:** 29 January 2025

Funding: This study was funded by Foundation S-Sanofi.

Keywords: Africa | childhood cancer | Global Mapping Programme | paediatric oncology | palliative care | SIOP

ABSTRACT

Background: Paediatric palliative care (PPC) is considered an essential component of the management of children and adolescents with cancer. The International Society of Paediatric Oncology Global Mapping Programme (SIOP GMP) surveyed hospital-based paediatric oncology facilities across Africa from 2018 to 2020 to document PPC and provision of PPC services. We aimed to assess possible correlations between existing PPC services across Africa with economic indicators.

Procedure: An electronic and paper survey was widely distributed to elicit the presence of components of PPC: PPC teams, bereavement counselling services, patient support groups, and spiritual and religious support. Results were correlated with the countries' Gini coefficient, World Bank income status indicators and Human Development Index.

Results: Hospital-based paediatric oncology facilities in 16/54 African countries reported having all four PPC services, while those in 12 countries reported having none of the four PPC services. No clear correlations were found between provision of such services and selected economic factors.

Conclusions: This study assesses components of PPC through four binary questions and demonstrates that hospital-based paediatric oncology facilities with limited resources caring for children and adolescents can provide PPC. Adoption of the

Abbreviations: APCA, African Palliative Care Association; GC, Gini coefficient; GMP, Global Mapping Programme; HDI, Human Development Index; HICs, high-income countries; HIV, human immunodeficiency virus; ICPCN, International Children's Palliative Care Network; LMICs, low- and middle-income countries; PC, palliative care; PPC, paediatric palliative care; SIOP, International Society of Paediatric Oncology; WBS, World Bank Status; WHO, World Health Organization.

Angidi Mauree and Khumo Myezo are the joint first authors.

World Health Organization's conceptual framework for palliative care and knowledge transfer between African facilities on the integration of PPC into paediatric oncology care, would benefit the increasing numbers of children and adolescents with cancer across the continent.

1 | Introduction

Many childhood cancers are curable, with overall cure rates reaching 90% in high-income countries (HICs) [1]. Using simulation-based analysis, the estimated 5-year overall survival among diagnosed cases in Africa range from 19% in Southern Africa to 8% in both Eastern and Western Africa [2]. Small series report higher survival rates of 57% in South Africa and of 72% in Egypt [3, 4]. Paediatric palliative care (PPC) is a vital pillar of the care of any child or adolescent with a life-threatening or life-limiting condition, such as childhood cancer [5]. PPC is still mistakenly thought by many to be introduced only at the end of life. However, PPC encompasses the holistic care of the body, mind and spirit of the child-family unit and should be initiated at the diagnosis. The World Health Organization (WHO) defines PPC as:

"the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease" [6].

PPC has been successfully implemented with limited resources in settings ranging from tertiary care services to the child or adolescent's home [5, 7, 8]. PPC becomes particularly crucial when managing children and adolescents with poor prognoses when the direction of treatment may no longer be curative.

The PPC movement began in the 1970s in Europe and the United States of America. Although more than 50% of the world's children requiring palliative care (PC) live in Africa, the implementation of PPC in Africa only started in the last 15–20 years [9]. Formal PPC is still not widely practised in low- and middle-income countries (LMICs) despite being a relatively low-cost intervention [10]. There is also emerging focus on the gaps between providing and accessing PPC [11]. PPC has been shown to improve quality of life, provide emotional support, enhance the end-of-life care experience, and offer support to children and adolescents with cancer and their families [5]. PPC has become a cornerstone in the management of distressing symptoms, which may be associated with childhood cancer and its treatment modalities [12].

Since its inception in 2005, the International Children's Palliative Care Network (ICPCN) has been informally mapping the global development of PPC. In 2019, the ICPCN identified three African countries (Malawi, South Africa and Uganda) with broad provision of PPC, training and integration into healthcare services. Another four countries had localised provision of PPC, 15 countries had capacity-building activities for PPC, with the remaining countries having no known provision of PPC [13]. The 2017 Atlas for Palliative Care in Africa indicated low availability of PPC services across the African continent. There were 57 PPC services or paediatric hospices in 16 countries; ranging between 20 in South Africa and six of the countries each having only one PPC service or hospice, and thereby highlighting the disparities in access. There were 29 countries that did not report any PPC services [14].

The provision of hospital-based PPC in paediatric oncology settings in Africa is largely undocumented. We aimed to create an updated dataset of PPC from multiple hospitals across the African continent and to analyse possible correlations between economic indicators and the provision of the four components of PPC.

2 | Methods

In November 2018, the International Society of Paediatric Oncology (SIOP) Global Mapping Programme (GMP) was launched with an online survey on the SIOP website, the Paediatric Oncology International Network for Training and Education website and various social media platforms, to collect information on global paediatric oncology services [15]. The 55-question survey included four questions on PPC: the PPC team, bereavement counselling services, patient support groups and spiritual/religious support (see Table S1). Categorical responses (Yes, No or Don't Know) were correlated with the Gini coefficient (GC), World Bank Status (WBS) indicators and Human Development Index (HDI) of each country. The survey initially concentrated on Africa as the continent with the greatest need, and data collection ended in October 2020.

The GC represents the distribution of income across a population and the extent of economic inequality. A coefficient of zero indicates a perfectly equal distribution of income or wealth within a population, and a coefficient of 100 represents a perfect inequality when one person in a population receives all the income, while other people earn nothing [16]. WBS categories include low income, lower middle income, upper middle income and high income [17]. The HDI assesses a population, and their capabilities to contribute to the development of the country [18]. HDI is a composite index based on people's health, level of education and standard of living, with categories as low (<0.550), medium (0.550–0.699), high (0.700–0.799) and very high (≥0.800) [18]. Together, these three variables (GC, WBS, HDI) provide an indication of economic status against which to compare PPC provision.

Responses to the survey were available from 48 countries, GC values were accessed from World Bank estimates for 45 countries, and the Index Mundi was consulted for the three remaining countries (Eritrea, Libya, Somalia) for which no GC values were available [16, 19]. The WBS and HDI categories of the 48 countries that participated in the survey were also identified using the World Bank Data website and Statistica website, respectively [17, 20].

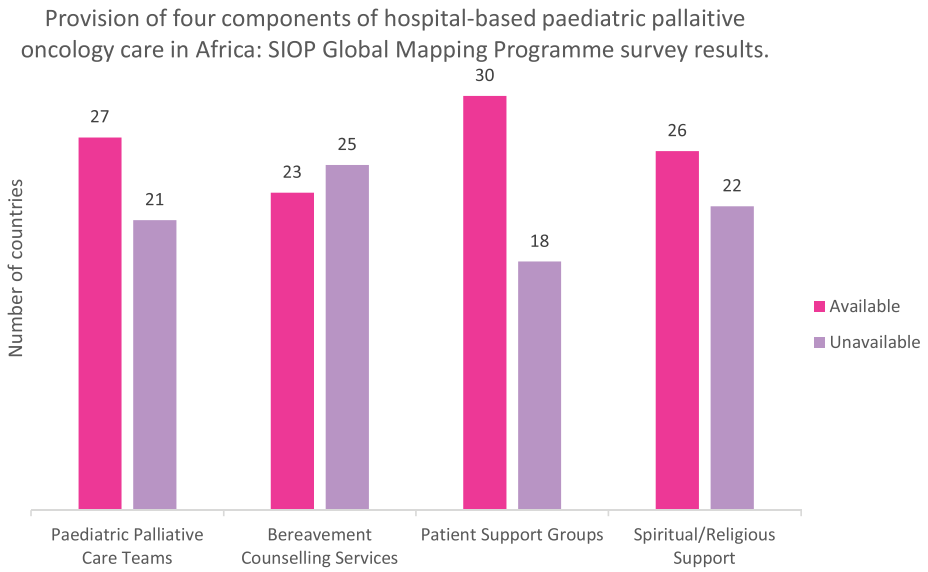


FIGURE 1 | Provision of four components of hospital-based paediatric palliative oncology care in Africa: SIOP Global Mapping Programme survey results.

Stata version 15.0 was used as software for all analyses. Correlation coefficients were presented with three decimal places. Pearson's correlation coefficient was calculated between the four binary PPC components and the four WBS income indicators as well as the GC and HDI, while Spearman's correlation was calculated between ordinal WBS and the four PPC indicators. A *p*-value of less than 0.05 was considered significant.

The SIOP Publication and Endorsement Committee approved the use of the SIOP name and logo for this study. The participants who answered the survey gave permission for their data to be aggregated and analysed for publication.

3 | Results

In total, 264 responses were received from African facilities providing paediatric oncology care. Duplicates and incomplete responses were removed, resulting in 135 (51%) individual responses that were evaluated from 48/54 African countries representing 119 hospitals. The respondents included heads of division (63), consultants (51), junior faculty (5), nurses (11) and others (volunteers, parents; 5).

At least one facility reported the presence of patient support groups (30/48, 63%); PPC teams (27/48, 56%); spiritual/religious support services (26/48, 54%); and bereavement counselling services (23/48; 48%) (see Figures 1 and 2 and Table S2). In 16 (33%) countries, all four components were reported in at least one hospital-based paediatric oncology facility, while 12 (25%) countries reported having none of the four components (see Figure 3).

Sixteen countries that reported at least one facility with all four PPC services had a mean GC of 39.7 (range: 31.5–63) [16] and a mean HDI of 0.56 (range: 0.4–0.73) [18]. Twelve countries reported having no facilities with any of the four components, and had a mean GC of 42.5 (range: 32.8–56.2) [19] and a mean HDI of 0.57 (range: 0.4–0.73) [20]. These countries included one upper middle-income country (Gabon), six lower middle-income countries (Benin, Cabo Verde, Congo, Djibouti, Eswatini and Tunisia) and five low-income countries (Central African Republic, Chad, Gambia, Liberia and Rwanda). No significant correlations were observed, and the correlation coefficients were very low in absolute value, with the highest correlation of 0.222 reported between WBS and patient support ($p = 0.129$). No clear pattern of positive or negative correlation was found across any of the four PPC components (see Table 1).

4 | Discussion

We aimed to map the provision of formal PPC in African hospitals that treat children with cancer and found that most countries provided at least one component of PPC, while 12 countries were able to provide all four surveyed components. We found no discernible correlation between the availability of PPC in hospital-based paediatric oncology facilities and various economic indicators across Africa, implying the potential for the establishment and sustainability of these services despite economic limitations.

For many African children and adolescents with cancer, cure is not possible due to advanced stage at diagnosis, poor availability of diagnostic and curative modalities, and lack of supportive care resources, particularly in conflict zones [2, 21, 22]. The high prevalence of human immunodeficiency virus (HIV) in Africa also leads to a higher number of HIV-associated malignancies than in HICs. For these reasons, the number of children and adolescents who require PPC is higher than in HICs [23]. Developing PPC is thus crucial, as the majority of adult PC services do not provide care for children and adolescents [24].

PPC services are widely reported as inexpensive to deliver and maintain; however, there are few costing models and these services are often not budgeted appropriately, particularly in

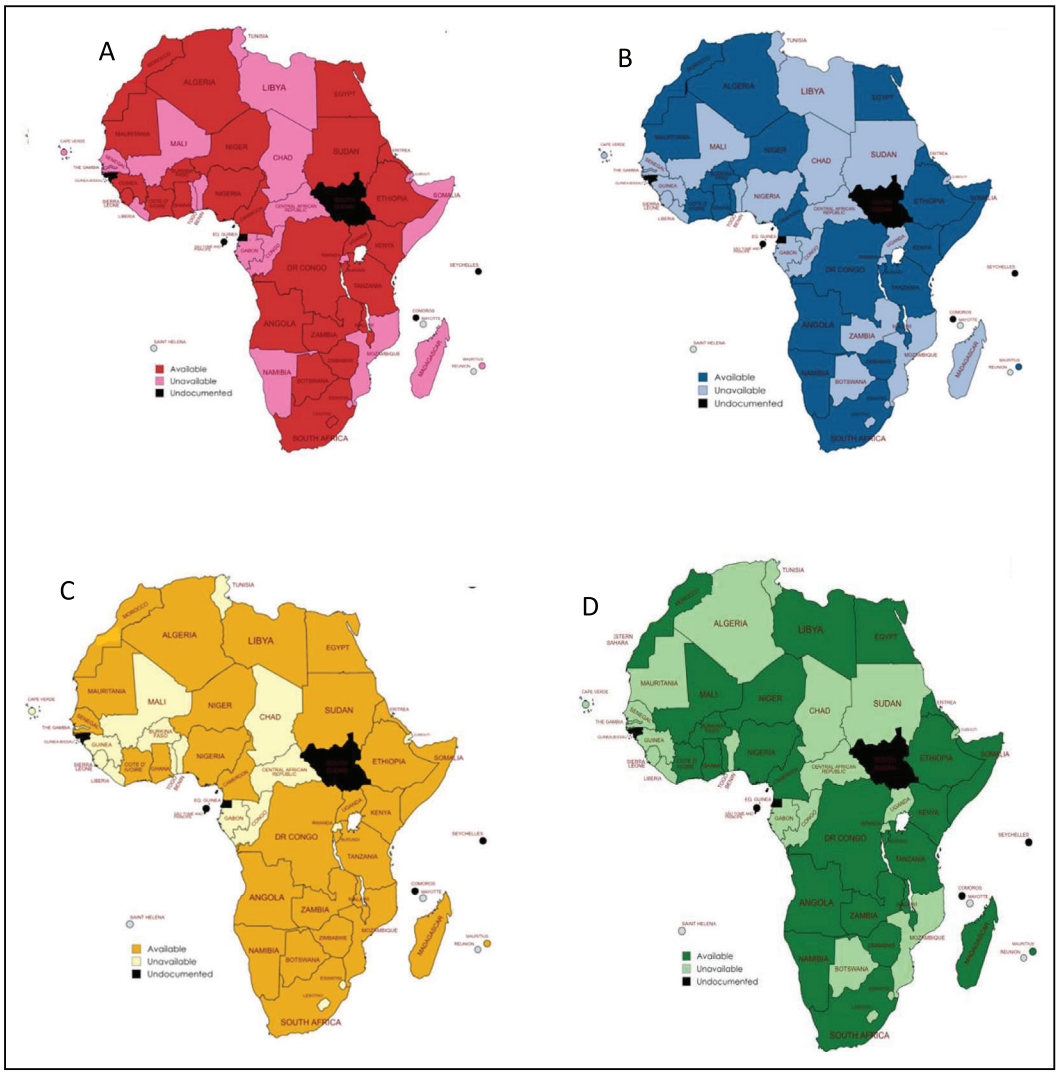


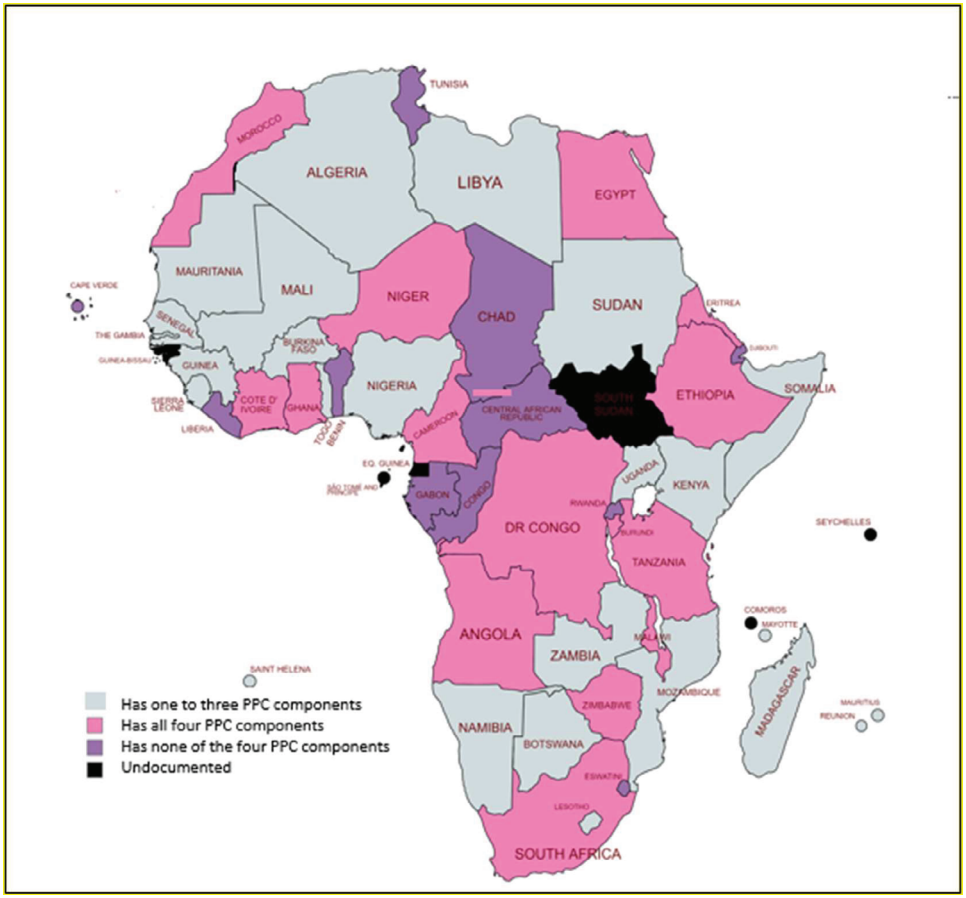
FIGURE 2 | African countries with at least one hospital-based paediatric oncology facility with each of the identified components of paediatric palliative care, that is: paediatric palliative care teams (A), bereavement counselling services (B), patient support groups (C), spiritual/religious support (D).

Africa and LMICs [10, 25–27]. The WHO suggests that PPC can be successfully implemented despite resource limitations, and this is confirmed in this study [28].

The absence of a correlation between economic indicators and service provision could potentially be attributed to the lack of HICs in the sample, which might have created a more noticeable contrast if they were included. The economies of African countries are more similar to each other compared to the significant differences between African countries and HICs. This similarity among African nations may obscure any potential variations that could link economic indicators to service provision.

4.1 | Paediatric Palliative Care Teams

Ideally, PPC should be provided by a multidisciplinary team whose members will depend on the level and type of the health services delivery site and the staff members' competence in PPC. The WHO essential package for the provision of PPC includes doctors and nurses with basic PPC training as well as social workers, psychologists, grief counsellors, community health workers and spiritual counsellors. Allied professionals such as pharmacists, dietitians and rehabilitation therapists should be included when available. It is however common for one professional to hold more than one role according to their competency levels [29]. The WHO essential package may be considered ideal, but this is very often not possible in Africa where roles are fluid and can overlap with many team members covering multiple roles in an excellent manner. The survey asked for the presence of a PPC team and of different healthcare professionals who might be offering PPC at the various facilities across Africa, namely, dietitians, physiotherapists, social workers, play therapists/child life specialists, pharmacists, psychologists. Partnerships such as those created by the African Palliative Care Association (APCA), the Groupe Franco-Africain d'Oncologie Pédiatrique and the ICPCN recommend locally relevant, sustainable programmes



Mayotte, Reunion and Saint Helena are French territories and not included.

FIGURE 3 | Countries in Africa with at least one hospital-based paediatric oncology facility reporting all four components of paediatric palliative care (PPC) and countries where there are none of the four components of PPC surveyed.

that integrate PC into established medical settings in Africa [30, 31]. PPC has been delivered effectively in many LMICs using a range of models including community- and home-based PPC, and hospital/facility-based PPC.

In this study, we found that just over half the countries surveyed reported having PPC teams. However, we did not clarify the meaning of PPC teams, and respondents may have misunderstood the survey question ('Which services do patients and their families have access to at your hospital or paediatric oncology ward?' followed by a list of services of which one item was 'palliative care team') and interpreted it as requiring a fully trained PPC specialist, which may have led to under-reporting of the presence of this service.

4.2 | Bereavement Services

Bereavement counselling is an under-recognised service, and its absence has been shown in both HICs and LMICs to impede families from actively dealing with the stress and emotional labour of grief long after death [32]. Our survey findings revealed that in 25 African countries, hospital-based paediatric oncology facilities offering paediatric oncology care lacked bereavement counselling services. This absence carries significant implications, as family members may experience complicated grief, leading to long-term mental and physical health impairments [33].

Despite the existence of WHO guidelines on the management of bereavement, barriers to implementation of these guidelines include lack of trained mental health professionals and the perception that psychological interventions developed in HICs would not be culturally acceptable unless 'alternative versions' of guidelines designed to address the local cultural landscape were developed [34, 35]. It is thus important to design bereavement services considering the local context, worldview, and diverse religious and spiritual practices in Africa, which can greatly differ even within a single country [36].

4.3 | Patient Support Groups

The most frequently reported component of PPC in this study was the availability of patient support groups, possibly because such groups are relatively inexpensive to run and no healthcare providers are required. Examples of some patient support groups for childhood cancer in Africa are CHOC Childhood Cancer Foundation in South Africa, Tesfa Addis Parents Childhood Cancer Organization in Ethiopia and l'Avenir Association in Morocco [37]. These groups are often run by non-profit organisations,

TABLE 1 | Pearson pairwise correlation coefficients of the four components of paediatric palliative care (PPC) reported as available in hospital-based paediatric palliative oncology facilities in African countries correlated with selected economic indicators.

Variables	All four paediatric palliative care components (*p*-value)	Palliative care team (*p*-value)	Bereavement counselling services (*p*-value)	Patient support groups (*p*-value)	Spiritual/ religious support (*p*-value)
Gini coefficient	0.003	−0.117	−0.020	0.201	0.123
	(0.982)	(0.442)	(0.899)	(0.185)	(0.421)
Human Development Index	−0.072	−0.100	0.138	0.209	0.013
	(0.633)	(0.508)	(0.360)	(0.164)	(0.930)
World Bank Income Status	−0.002	−0.027	0.098	0.222	0.003
	(0.991)	(0.857)	(0.509)	(0.129)	(0.982)
Low	−0.060	−0.057	−0.099	−0.209	0.029
	(0.687)	(0.700)	(0.503)	(0.154)	(0.847)
Lower middle	0.156	0.060	0.059	0.031	−0.030
	(0.289)	(0.687)	(0.690)	(0.833)	(0.840)
Upper middle	−0.096	−0.127	−0.040	0.096	0.012
	(0.514)	(0.390)	(0.788)	(0.514)	(0.938)
High income	−0.103	−0.173	0.159	0.103	0.123
	(0.485)	(0.241)	(0.282)	(0.485)	(0.404)

volunteers or caregivers who provide a wide spectrum of activities including the provision of basic necessities such as food parcels, accommodation facilities, medication and psychological support [38, 39].

4.4 | Spiritual/Religious Support

The diagnosis of a life-limiting or life-threatening illness in a child or adolescent may plunge the caregiver but also the siblings and the family at large into a spiritual crisis causing deep distress, and children and adolescents themselves may experience spiritual struggles, which may have negative consequences on healing and recovery [40]. PPC should address spiritual distress following a cancer diagnosis faced by children and adolescents, and their families. In 21 countries, a lack of spiritual/religious support services was reported in hospital-based paediatric palliative oncology facilities. Unmet spiritual needs may impede patients and caregivers from finding peace with the prognosis and possibility of death [41]. However, many children and adolescents and their families may receive such support from spiritual and religious leaders inside and outside of the hospital setting [42, 43].

4.5 | Challenges and Enablers to the Provision of PPC Services in an Oncology Setting

A major challenge in many African countries is inadequate policy-making. This often stems from unstable governments, lack of funding related to corruption, and lack of prioritisation with subsequent omission of PPC from long-term strategic healthcare plans [44–46]. However, such planning is achievable, for example, Botswana and South Africa have PC strategic policies, and Uganda is in the process of developing one [47]. Integration of PPC in healthcare curricula is yet to be achieved, although countries such as Kenya, Uganda, Botswana and South Africa have PC postgraduate training programmes [47]. The lack of medications used in PPC, such as appropriate and cost-effective analgesia, is more prevalent in Africa compared to HICs, and this is mainly due to supply issues and concerns about the misuse of drugs like opioids [45, 47, 48]. Additional obstacles to delivering effective PPC in Africa include limited accessibility to services, disparities in cultural norms and practices, and apprehension of the healthcare providers and general population towards providing PC to children and adolescents. This reluctance stems from the misconception that PPC might be equated with euthanasia, particularly in regions where it is perceived solely as end-of-life care rather than as part of a comprehensive approach to alleviate suffering across the care continuum [10, 49, 50].

The WHO conceptual model for PC includes the adaptation of four components considered to be vital to PC development: appropriate policies, education of the public and healthcare workers, access to medicines, and implementation of PC services at all levels of the healthcare system. In 2015, only 19 African countries were identified as having PC plans embedded in their national control plans, of which only seven include the paediatric population [51]. Kenya, South Africa and Uganda prioritise PC in their national cancer control plans, and their approaches include integration of PC into educational curricula and involving communities [26]. Having appropriate policies in place is essential for the development of PPC. Only by bridging the gap between policy and implementation can African countries ensure that children

with cancer receive the compassionate and comprehensive care they need.

4.6 | Limitations

This study was based on four binary questions, namely, the availability or not of a PPC team, bereavement counselling services, patient support groups and spiritual/religious support. Despite the survey evaluating the presence of different healthcare professionals at various facilities across Africa, the study did not specifically define what constituted a basic PPC team.

No responses were received from hospital-based paediatric oncology facilities in six countries despite multiple attempts to make contact. This is likely because no such facilities existed in these countries at the time of the study. Questions were phrased to elicit basic information on the four selected components of hospital-based PPC that were investigated in this study, and were not intended to assess either the quality of services or whether services existed in other departments, facilities or communities. The survey specifically looked at PPC within hospitals providing paediatric oncology services, and so the results cannot be extrapolated to the general provision of PPC within each country. In addition, it is possible that more PPC services have become available since the data were collected.

4.7 | Strengths

This study reports a dataset encompassing four components of PPC within paediatric oncology facilities in Africa. This study also used multiple validated economic indicators, demonstrating that economic factors should not be a hindrance to the provision of this essential service in specialised units treating children and adolescents with cancer.

5 | Conclusion

In the SIOP GMP survey of African paediatric oncology facilities across Africa, we found that the majority of countries provided at least one component, while 12 countries had at least one facility reporting provision of all four components of PPC. Despite this study focusing only on four binary components of PPC, it represents an up-to-date dataset of PPC provision across paediatric oncology facilities in Africa.

We furthermore found no correlation between economic indicators in the African context and the availability of hospital-based paediatric palliative oncology care in facilities responding to the survey. This observation holds significant promise, particularly due to the high number of children and adolescents with incurable cancer across Africa, underscoring the need for PPC services. It is recommended that all African countries should integrate PPC throughout their paediatric oncology services. This endeavour could be facilitated through the adoption of the WHO's conceptual framework for PC, supplemented by knowledge transfer between paediatric oncology healthcare teams in African countries on the integration of PPC, and a scale-up of training for health professionals in caring for children and adolescents with cancer through partnerships and expansion of educational programmes for current healthcare practitioners, and in particular for nurses, at a minimum who have been identified as '…at the centre of PC delivery in Africa' [45].

By adopting these measures, Africa can enhance the quality of life for children and adolescents facing cancer, whether curable or not. A concerted effort to integrate PPC services will not only alleviate suffering along the continuum of care but also contribute to a more robust and compassionate healthcare system across the continent.

Author Contributions

Angidi Mauree: contributed to and approved the final manuscript. Khumo Myezo: conceptualised and designed the study, collected and analysed data, drafted the initial manuscript and approved the final manuscript. Neil Ranasinghe: conceptualised and designed the study, revised and approved the final manuscript. Julia Challinor: conceptualised and designed the study, revised and approved the final manuscript. Rossella Bandini: designed the study, analysed data, contributed to and approved the final manuscript. Kathryn Burns: collected data, reviewed the manuscript and approved the final version. Katherine Eyal: analysed data, contributed to and approved the final manuscript. Julia Downing: contributed to and approved the final manuscript. Kathy Pritchard-Jones: contributed to and approved the final manuscript. Eric Bouffet: conceptualised and designed the study, contributed to and approved the final manuscript. Jennifer Geel: conceptualised and designed the study, collected data, contributed to and approved the final manuscript.

Acknowledgements

Thanks are due to the many volunteers who work tirelessly on this programme and the colleagues across Africa who answered the call to input and verify data.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.