*Review Article*

# Pediatric Palliative Care in Sub-Saharan Africa: A Systematic Review of the Evidence for Care Models, Interventions, and Outcomes

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## Abstract

**Context.** The progressive disease burden among children in sub-Saharan Africa means the provision of palliative care is essential and should be provided alongside treatment where it is available.

**Objectives.** To systematically review the evidence for pediatric palliative care models, interventions, and outcomes to appraise the state of the science and inform best practice.

**Methods.** A systematic review search strategy was implemented in eight electronic databases, the search results reported using a PRISMA statement, and findings tabulated.

**Results.** In terms of evidence of palliative care provision and outcomes, only five articles were identified. These represent a small range of acute, community, and hospice care and offer some limited guidance on the development and delivery of services.

**Conclusion.** Pediatric palliative care is a pressing clinical and public health challenge in sub-Saharan Africa. Explicit evidence-based models of service development, patient assessment, and evidence for control of prevalent problems (physical, psychological, social, spiritual, and developmental) are urgently needed. Greater research activity is urgently required to ensure an evidence-based response to the enormous need for pediatric palliative care in sub-Saharan Africa. J Pain Symptom Manage 2014;47:642–651. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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**Key Words**
*Pediatric, palliative, Africa, HIV, cancer*

## Introduction

The Joint United Nations Programme on HIV/AIDS estimates that there are 1.8 million 0 to14-year-old sub-Saharan Africans with HIV infection and 15 million HIV-related orphans.[1] More than 90% of the world's pediatric HIV cases are estimated to live in sub-Saharan Africa, a region that comprises less than 10% of the world's population.[2] Without access to life-saving drugs (e.g., antiretroviral therapy and cotrimoxazole prophylaxis), about one-third of HIV-infected infants die by age one year, and 50% by age two years.[3,4] Evidence is emerging of antiretroviral treatment (ART) resistance and failure.[5] Infection of the child's parents is associated with reduced parenting, poor economic status, and stigma. These issues present additional growth and development challenges to the infected child.

Although the lack of developed African cancer registries hampers the collection of surveillance data,[6] available Tanzanian data revealed that 11.5% of recorded malignant tumors were in children aged 0–14 years.[7] In Malawi, 7.2% of all incident cancers are among children[8] under 15 years. A significant rise in HIV-related pediatric malignancies has been identified, most commonly lymphoma (36.9%) and Kaposi's sarcoma (12.7%).[9,10] Burkitt's lymphoma is the most prevalent pediatric cancer in Africa, and although usually treatable, end-of-life care is often needed because of late presentation and unaffordable curative options.[11] A review of childhood cancer treatment in developing countries predicted that Western cure rates will not be replicable because of lack of resources and local treatment protocols, late presentation, and poor compliance.[12] The provision of palliative care is an essential and feasible component of a proposed strategy to improve pediatric cancer care in Africa.[13]

The World Health Organization's (WHO) definition of palliative care for children and their families (Table 1) is notable in its focus on active and community-based care and developmental/psychological aspects.[14] Although WHO states palliative care to be an essential component of HIV care,[15] supported by a systematic review demonstrating improved outcomes,[16] the evidence has been largely generated among adult populations living in high-income countries. The lack of strategies for pediatric pain management is an obstacle to the receipt of appropriate palliative care.[17]

A previous review appraising the status of palliative care within sub-Saharan Africa identified a wealth of experience yet a dearth of evidence,[18] and a further pediatric-specific appraisal was recommended. This study aimed to systematically identify and appraise the evidence for pediatric palliative care models, interventions, and outcomes in sub-Saharan Africa to identify best practice and effective models of care.

## Methods

In this review, we operationalized a working definition of pediatric as 0–17 years inclusive. A palliative care service is understood to be in line with the WHO definition and provide care to children with non-curable life-limiting disease, holistic supportive care with pain and symptom assessment and response, and terminal care where needed.

### *Search Strategy*

The systematic review methods replicated the original adult review.[18] Electronic databases were searched and reference lists subsequently hand searched, using the search strategy described in Fig. 1. The search was conducted in July 2011 and updated in June 2012.

### *Inclusion/Exclusion Criteria*

The retrieval of articles was restricted to those reporting human child subjects within sub-Saharan Africa in the English language. Case studies and reviews were excluded. Peer-reviewed publications retained in the final review and analysis were one of the following: pediatric-only palliative care services, palliative

*Table 1*
**WHO Definition of Pediatric Palliative Care**

"Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is 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.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes."

WHO = World Health Organization.
Source: http://www.who.int/cancer/palliative/definition/en/.

care services that serve children and adults, and pediatric services that provide palliative care. Articles reporting data on any one or more of the design, delivery, organization, content, or outcomes of pediatric palliative care in sub-Saharan Africa were included.

### *Data Extraction and Analysis*

Data were entered into common tables. This enabled models, the types of data reported, and study designs to be presented and potentially compared and make recommendations for greater consistency in future data collection. The searches were undertaken by author R. A. and the results reviewed with R. H. before being sent to the full expert panel (all authors) for interpretation. The common data extraction headings were country, aims, methods, sample description, service description, findings, lessons, and comments. We were unable to apply study quality criteria or undertake a meta-analysis because of the quantity and type of evidence retrieved.

## Results

The PRISMA flow chart is reported in Fig. 2. A total of five articles that met the search strategy inclusion criteria were retrieved and analyzed.

*Databases*:
PREMED & MEDLINE 1966-present
CINAHL 1982-present
AMED 1985-present
CancerLit 1975-present
PsychInfo 1974-present
Embase 1980-present
Sciences Citation Index (SSI) 1981-present
Social Sciences Citation Index (SSCI) 1981-present

*Search terms:*
The union of the following keywords:

i) (hospice, terminal, terminal care, terminally ill, palliat*, hospice*, dying, end of life, advanced disease, life-limiting, life- threatening, death, bereavement, pain) intersected with the union of the following keywords

ii) (Sub-Sahara, Africa, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Democratic Republic of Congo, Djibouti, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, Guinea Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Rwanda, Sao Tome, Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Uganda, Western Sahara, Zambia, Zimbabwe) intersected with the union of the following keywords:

iii) (minors, paediatric, pediatric, infant, child*, paed*, ped*, youth, adolescent, baby, newborn, neonates, teen*)

Fig. 1. Search strategy.

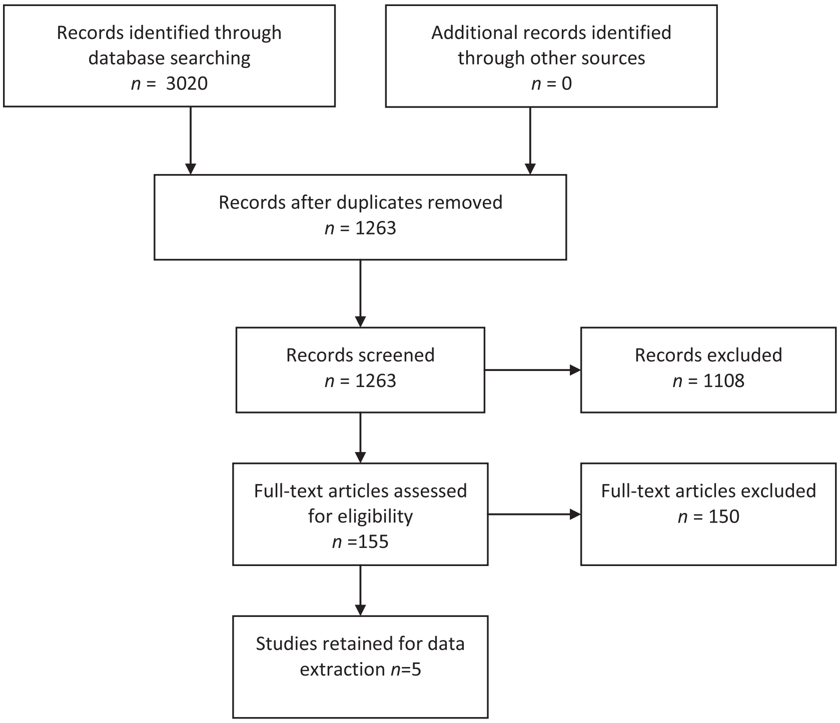

Fig. 2. PRISMA flow chart.

### *Models of Care, Activity, and Outcomes*

The identified articles are reported in Table 2. In light of the epidemiological data on the burden of progressive pediatric disease in sub-Saharan Africa, few models of palliative care intervention have been described. Of the five articles identified in the peer-reviewed literature, four reported services with evaluation data and the fifth reported only service description. The articles report on two countries recognized as leading in palliative care provision—South Africa (one service being reported in two articles) and Uganda. Of the five articles, one reported quantitative outcomes[19] and the others reported evaluation of activity and process[20–22] and a description of the service aims and services offered.[23]

The only published article to report on sustainability was the descriptive international comparative article,[23] which noted that a relationship with the government health departments provided much needed sustainability for pediatric palliative care.

## Discussion

It is important to note first that, in light of the enormous epidemiological need for pediatric palliative care in sub-Saharan Africa, and innovative practice, very little evidence for models, interventions, or outcomes exists. The few reported evaluations are useful, as both operational and process evaluations are essential alongside outcome evaluation.[20–22] The models described acute, hospice, and network care models, demonstrating the feasibility of children's palliative care being delivered at the point of need. Only two studies were found that reported studies of specifically pediatric palliative care services. The study by Amery et al. is important as it is the first to examine the impact of a children's palliative care service. It identified important benefits including increased referrals and proportion of service users that are children, improved drug interventions, and compliance. The valuable description of the service development offers potential replication, and the next step should be to implement methods and tools to begin to measure outcomes at the patient level.

Several of the models present examples of delivery that offer potential sustainability through integration. The hospital care study[21] is important because, with the large numbers

*Table 2*

**Studies Reporting Models, Interventions, or Outcomes**

| Author, Year, Country, Reference | Intervention | Evaluation Aim, Methods, Sample | Findings | Conclusions |
|---|---|---|---|---|
| Harding et al., 2009, South Africa[19] | Specialist children's hospice providing inpatient care, home care, and day care. The hospice piloted ART initiation for children referred with advanced disease and/or poor prognosis. | • To evaluate outcomes of children with advanced HIV disease initiated on ART under multiprofessional specialist pediatric hospice care<br>• Retrospective cohort file review with six-month follow-up<br>• 37 children, mean age 5.5 years | 31/37 children survived at six months.<br>From baseline mean body weight 13.3 kg, average of 3.2 kg increase ($P < 0.001$). Mean CD4 counts more than doubled ($P < 0.001$), with a mean increase of 467 cells per $mm^3$ blood.<br>Mean CD4 percentages increased from 13.6% to 19.4% ($P < 0.001$).<br>Viral load decreased significantly from a median 271,000 copies per $mm^3$ blood to a median of 25 (imputed value for undetectable viral load) ($P < 0.001$).<br>Twenty-three children had an undetectable viral load. | Hospice palliative care can successfully improve outcomes for children who may be expected to benefit least from ART. |
| Henley, 2002, South Africa[20] | Secondary and tertiary teaching children's hospital | • To evaluate terminal care among hospitalized children who died of HIV/AIDS<br>• Retrospective chart review<br>• 165 inpatient deaths, mean age 10 months (median four months) | 84% had DNR orders, written simultaneously in medical AND nursing notes 41% of the time.<br>44% had comfort care plans.<br>Pain and distress in final 48 hours recorded for 55%.<br>Half of those with pain/distress received analgesia. | Assistance is needed to transition care management to palliative care and ensure comfort care plans are made and implemented. |
| Uys, 2003, South Africa[21] | Model of HIV home-based care linking hospitals, clinics, and home-based care | • To explore the realization of counseling, palliative care, and terminal care in seven settings<br>• Descriptive study including infected adults and children, their caretakers, health care workers, and community members using semi-structured interviews, observation, taping of onsite meetings, and questionnaires. | Staff identified training needs in counseling skills when working with children.<br>No other data differentiated between adults/children. | Counseling training needed for staff working with children plus need for additional palliative care-trained staff across settings. |

| | | | | |
|---|---|---|---|---|
| Amery et al., 2009, Uganda[22] | Focused children's service and training program within existing hospice. Nurse-led with medical backup, across acute, home, and outpatient settings. | • To evaluate a new pediatric palliative care service<br>• Mixed methods: retrospective chart and activity review ($n = 362$) with pre-service historical controls ($n = 243$). Qualitative interviews with 11 children, 12 informal caregivers, and 10 professional staff. | Quantitative data:<br>Increases in: referrals 129%; proportion of children on program 49%; morphine prescriptions 175%; chemotherapy prescriptions 118%; chemo compliance 282%; cost of $100 per child.<br>Qualitative data:<br>Most valued service strengths were free drugs, food, play, learning, and staff attitude. | Affordable, nurse-led, volunteer-supported children's palliative care services are both achievable and effective in sub-Saharan Africa. Palliative care units should provide a specialized service focused on children. |
| Knapp et al., 2009, South Africa[23] | St. Nicholas Children's Hospice, offering inpatient beds, home-based care, family bereavement care, day care, respite, counseling, orphan care, child/grandmother-headed household support, coordinated care with hospital services | Descriptive only: services/components offered. | — | — |

ART = antiretroviral treatment; DNR = do not resuscitate.

of children with advanced illness, hospitals are likely to be feasible (and sustainable) places that experience high numbers of children presenting with palliative care needs and where they may be appropriately managed. This study by Uys[21] offers a model of integration that may enhance sustainability thorough effective referral networks, achieving a model of care aimed at delivering palliative care across diverse health care settings and at the geographical point of need. This model of flexibility and responsiveness is also likely to be successful in terms of coverage. In terms of offering a new and evolved role that may further integrate and sustain hospice and palliative care, the study by Harding et al.[19] offers an effective route of ART delivery via hospice. Much more evaluative data are needed on the supporting role of palliative care in ART provision and outcomes, and such rigorous data may yet prove to be a route to successful integrated and sustained palliative care (and improved outcomes) for persons with HIV. A clinical trial is currently underway to test the effectiveness of palliative care for adults on ART in Africa.[24]

A much larger scientific body of evidence from process, outcome, and health economic evaluations is urgently required. The need for well-designed and validated tools to measure children's outcomes is underlined by the statement that assessment is the most important aspect of delivering children's palliative care in Africa.[25] The measurement of pain and symptoms must be conducted using methods recognizing that children's experiences and expressions of pain and symptoms will be mediated by age, experience, family, and culture.[26] Skills to communicate with children were the greatest need identified in a study among palliative care health professionals in Uganda.[27] The lack of evidence identified by this review is the result, in part, of the fact that assessment of symptoms and suffering in children is challenging, and few reliable, valid, and developmentally appropriate methods are available.[28] The first African pediatric version of the APCA African Palliative Outcome Scale[29] is in final stages of validation.[30] As often found in articles reporting the models of complex interventions, there is a lack of detail in the aims, components, and protocols of the reported models of care, which reduce opportunities for replication.[31]

Further qualitative research also is needed to better understand the cultural context of death and dying for children and their families in African countries. The meaning attached to a dying child may carry implications for health practice; for example, in Ghana, a child's death is seen as the result of the child's own "evil" actions, and a home death is seen as a good death.[32] Cultural rules and expectations on the breaking of bad news in terms of a child's poor prognosis have informed recommendations for working with Ethiopian patients.[33] Medical care of life-threatening illness also may need to be negotiated through the family's cultural beliefs; for example, cerebral malaria may be interpreted in some Tanzanian communities as being caused by a "spirit bird."[34] Appropriate family-based care is also important. In Ghana, for example, for an adult to die well they must know that their child's education has been provided for.[32] In Mozambique, terminally ill mothers assumed that their extended family would take care of their child following their death, although none had formulated a plan for this to happen.[35] In infected households, children carry the burden of caring for their dying parents and have been identified as a group with the most pressing needs.[36] Where orphan care services exist, they have been found to focus on physical rather than psychosocial needs.[37] There is large and robust body evidence generated in a number of countries that demonstrates the high psychological burden and morbidity associated with bereavement and orphanhood among children in Africa.[38–40] Palliative care services are well placed to provide emotional support pre- and post-death of the child's significant adult.

We found little data on acute care settings' provision of palliative care. In contrast, there is a large body of evidence demonstrating end-of-life care needs: in Niger, 138 of 461 children aged two years and under admitted to a national hospital died over a period of two months (47% dying within the first 24 hours of hospitalization);[41] in Mali, 345 of 1644 children died during their admission, and 40% of these died within 24 hours;[42] in Guinea Bissau, 24% of all child deaths occurred in hospital.[43] A description of experiences on a pediatric unit in a Ugandan hospital underlined the lack of priority attached to, and availability of, adequate pain control.[44] Therefore, good pediatric palliative care is demonstrably essential in acute inpatient settings, although many of these children will die from acute problems such as pneumonia, measles, and malaria (but may still benefit from pain control and their parents from support in bereavement). It also is recognized that pain management models for children in Africa are needed among medical staff.[45] Even if the necessary drugs and training are made available for pain relief (such as opioids), clinicians report refusal among colleagues to prescribe opioids for children.[46]

There are several limitations to our study. It is important to clarify that lack of evidence does not equate to lack of innovative effective practice in clinical care—simply that there is a paucity of reported evidence to support and develop what is currently being achieved. We searched in the English language only and are aware that a body of grey literature may be available.

We make a number of recommendations. First, in the absence of service descriptions and evaluative evidence, we urgently call for services and interventions to be developed within an evaluative framework, to ensure that feasible, acceptable, accessible, and effective pediatric palliative care services are provided. For existing centers of excellence, evaluation efforts are required so that reliable and robust evidence can inform policy through replication of effective components and models. With respect to HIV epidemiology, and the increasing cancer burden, palliative care should expand and integrate within the acute sector to ensure quality coverage for all those children who may benefit from palliative care at an appropriate point in their disease trajectory. Hospice services require evaluation of advanced care and the initiation of ART. A number of pediatric clinical guides for sub-Saharan Africa have been developed, offering feasible approaches that are appropriate to local need.[25,26,47–50] We also urge international collaboration in light of recent evidence that, in the global community of pediatric palliative care services, African providers have the greatest numbers of patients and fewest resources and also have greater confidence in the management of HIV and spiritual problems.[8]

Development of children's palliative care through research activity is essential.[51] Although we have identified a lack of an evidence base, we also recognize the specific methodological challenges of conducting palliative care research in sub-Saharan Africa[52] and the further challenges of pediatric palliative care research.[53] Children and their families in Africa facing progressive incurable and life-limiting disease should have the same right to evidence-based and effective care increasingly achieved for adults. To date, the science has not progressed for children as it has for adult palliative care in sub-Saharan Africa. The conduct of ethical, robust, and rigorous research among children must address problems that are specific to the population. Although some issues are common,[19] there are questions to address in identifying the needs of children across settings, diagnoses, and age groups, in collecting data and designing appropriate measures, and in configuring and evaluating pediatric interventions and services.

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The authors have no conflicts of interest to declare.

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