



**THE STATUS OF PAEDIATRIC PALLIATIVE CARE  
IN SUB-SAHARAN AFRICA - AN APPRAISAL**  
DR RICHARD HARDING, PROFESSOR LORRAINE SHERR,  
DR RENE ALBERTYN, JULY 2010

**KING'S**  
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## AUTHORS

Dr Richard Harding, King's College London  
Professor Lorraine Sherr, University College London  
Dr Rene Albertyn, Red Cross War Memorial Children's Hospital, Cape Town



## PROJECT ADVISORY GROUP

Dr Julia Downing  
Eunice Garanganga  
Dr Liz Gwyther  
Professor Irene J Higginson  
Joan Marston  
Dr Michelle Meiring  
Dr Jennifer Ssengooba

The Diana, Princess of Wales Memorial Fund  
The County Hall, Westminster Bridge Road  
London SE1 7PB, UK  
Tel: +44 (0) 20 7902 5500  
Fax: +44 (0) 20 7902 5511  
Email: [sally.lyon@memfund.org.uk](mailto:sally.lyon@memfund.org.uk)  
[www.theworkcontinues.org](http://www.theworkcontinues.org)  
Charity Registration Number: 1064238

Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation  
King's College London  
School of Medicine  
Bessemer Road  
London, SE5 9RJ, UK  
Tel: +44 (0) 207 848 5518  
Fax: +44 (0) 207 848 5517  
Email: [richard.harding@kcl.ac.uk](mailto:richard.harding@kcl.ac.uk)  
[www.kcl.ac.uk/palliative](http://www.kcl.ac.uk/palliative)

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## FOREWORD

In my role as the UN Secretary General's Special Envoy on AIDS in Africa I have interacted widely with people who provide care to people living with HIV including children. I have observed that, in most cases, palliative care for children is still underdeveloped in most centres in sub-Saharan Africa. Most health care practitioners do not treat children differently when it comes to life-limiting illness. They do not realise that children have special psychosocial needs which need to be understood and addressed appropriately. I recently met a 13-year-old boy with symptomatic HIV (AIDS), who was receiving anti-retroviral therapy (ART). However, he had not been told the details of his illness and his medication, only that he had an illness like asthma which needed long-term treatment.

If we believe that children with life-limiting diseases should get the best possible treatment and care, then access to palliative care from diagnosis onwards is essential. The holistic approach of palliative care ensures that the child's developmental and emotional, as well as their medical needs, are met.

In sub-Saharan Africa, where the challenge of the HIV/AIDS epidemic has placed such a burden on the health systems, the need for wider access to palliative care is even more urgent. For the many children who do not have access to treatment for HIV/AIDS, cancer or other diseases, palliation and symptom relief is the only realistic treatment option.

There are good examples of innovative children's palliative care that have responded to the challenges of the HIV/AIDS epidemic and the particular cultural needs in the region, producing many examples of good practice. These examples should be replicated.

This timely report provides a thorough and systematic appraisal of the evidence of the need for, and reported evidence on, palliative care for children in sub-Saharan Africa, and makes a comprehensive series of recommendations for researchers, care providers, donors and policy-makers. I hope that these recommendations will be taken up, so that we can ensure that all those children who need it have access to palliative care and can live with their illnesses, free from pain, supported with their families, and with the best quality of life possible.



Elizabeth N Mataka, *UN Secretary General's Special Envoy on AIDS in Africa*

## PROJECT ADVISORY GROUP MEMBERS

**Dr Richard Harding** (Principal Investigator) is Reader in Palliative Care at the Cicely Saunders Institute at King's College London and has published widely on the topic of African palliative care. He works extensively with African universities, clinical settings and advocacy associations in African palliative care. He has taught, mentored, and supervised a number of African clinical students and researchers in eastern and southern Africa. Dr Harding is involved in a number of public health, as well as clinical audit, descriptive and evaluative studies in African palliative care. His broader research interests are non-cancer palliative care (particularly heart failure and HIV), informal caregivers, and interventional studies.

**Professor Lorraine Sherr** (co Principal Investigator) is Professor of Clinical and Health Psychology at the Royal Free and University College Medical School with a specific expertise in HIV in mothers and babies and in death, dying and bereavement, and a wide-ranging portfolio of research in Africa and with children. She has been involved in projects in South Africa, Zimbabwe, Mozambique, Swaziland and other countries. She has published widely in the field of HIV/AIDS, as well as on the psychological wellbeing of children. She is the editor of three international journals (*AIDS Care*, *Psychology Health and Medicine*, and *Vulnerable Children and Youth Studies*). She sat on the World Health Organisation (WHO) Strategic Advisory Committee for HIV/AIDS and has written textbooks on end-of-life care.

**Dr Rene Albertyn** is a medical social worker on the pain team at the Red Cross War Memorial Children's Hospital in Cape Town. She has been involved in a number of clinical studies, as well as being clinically active in paediatric palliative care. Her PhD studies focused on the development of a paediatric palliative care tool for children.

**Dr Julia Downing** has been working in palliative care for 20 years. For the last ten of these, she has been in Uganda, first as the Director of the Mildmay International Study Centre, then moving into her current role as Deputy Executive Director of the African Palliative Care Association (APCA). Dr Downing is an experienced palliative care nurse and educationalist with a PhD evaluating the impact of palliative care education in Uganda. Since working in Uganda, she has been involved in the care and treatment of children with HIV/AIDS and in training health professionals in caring for children with HIV/AIDS through her work at the Mildmay Centre, one of the main centres for treating children with HIV/AIDS in Uganda. She also headed up the paediatric portfolio for APCA and led a study to develop a palliative care outcome scale (POS) for children. She is on the steering committee of the International

Children's Palliative Care Network (ICPCN) and is vice chair of the ICPCN research committee.

[Eunice Garanganga](#) is a registered nurse with more than 22 years of experience in palliative care. She is Palliative Care Standards and Technical Adviser with the Hospice and Palliative Care Association of Zimbabwe (HOSPAZ), team member for the WHO Palliative Care Initiative in Zimbabwe, on the board of Directors for the African Palliative Care Association (APCA) where she is also a member of the Monitoring and Evaluation Working Group for the development of the African POS for children, and a member of the Working Group for the development of a Children's Palliative Care Manual in Africa.

[Dr Liz Gwyther](#) is a palliative care physician with many years of clinical experience in South Africa. She is currently both the CEO of the Hospice Palliative Care Association of South Africa (HPCA) and Head of the Palliative Care Academic Unit with the Department of Family Medicine at the University of Cape Town. Dr Gwyther also heads teaching in palliative care at the Red Cross War Memorial Children's Hospital in Cape Town.

[Professor Irene J Higginson](#) is Professor of Palliative Care and Head of the Department of Palliative Care, Policy and Rehabilitation at King's College London. With a background in medicine and public health, she is still active in medicine alongside her academic roles, and was a co-author of the original appraisal of African palliative care by Dr Harding et al (6). Professor Higginson has authored a number of systematic evidence reviews, including National Institute for Clinical Excellence (NICE) Guidance, and presented international data synthesis before the UK parliament and the United States National Institute of Health.

[Joan Marston](#) is a paediatric palliative care nurse with 19 years of paediatric palliative care experience. She established the St Nicholas Children's Hospice in Bloemfontein, South Africa, initiated the development of paediatric palliative care training courses for professionals and community caregivers in South African hospices, and is currently portfolio manager for paediatric palliative care at the Hospice Palliative Care Association of South Africa (HPCA). She is chair of the International Children's Palliative Care Network (ICPCN) and its representative for sub-Saharan Africa.

[Dr Michelle Meiring](#) is a palliative care paediatrician working for the Hospice Palliative Care Association of South Africa (HPCA), the University of Cape Town (UCT) and The Bigshoes Foundation. Her role at HPCA includes training, mentorship and advocacy in paediatric palliative care, and at UCT she lectures in the paediatric elective of the postgraduate diploma in Palliative Medicine. In her Bigshoes capacity, Dr Meiring does clinical palliative care consults for

hospitalised patients in Cape Town state paediatric wards (including the Red Cross War Memorial Children's Hospital) and mentors Bigshoes hospital-based paediatric palliative care teams in Johannesburg and Durban.

[Dr Jennifer Ssenigooba](#) is a medical doctor currently working with Hospice Africa Uganda as its director of clinical services. She has worked with children affected by incurable disease, including HIV/AIDS and cancer, and their families for eight years. She has also been involved in the development of paediatric palliative care curricula, including training modules such as for the palliative care degree at Makerere University. She has also participated in the development of treatment policies and guidelines for paediatric palliative care, for example on the nutritional rehabilitation of HIV-infected children for the Mildmay Centre in Uganda, and on the use of ART and adjuvant care for children and adolescents infected with HIV and home-based care for children and adults, both for the Ugandan Ministry of Health.

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## 1. EXECUTIVE SUMMARY

### 1.1. RATIONALE AND AIM

The high rate of infant/child mortality in sub-Saharan Africa demands a public health approach for children affected by progressive, incurable and life-limiting disease who may benefit from effective and humane palliative care.

The previous appraisal by Dr Harding et al (2004) reviewing the status of adult palliative care within sub-Saharan Africa identified a wealth of experience, yet a dearth of evidence. That appraisal successfully catalysed the expansion of palliative care research within sub-Saharan Africa, building capacity and an evidence base on which appropriate and effective evidence-based care for adults is now being built. An appraisal of paediatric palliative care was beyond the remit of that review, but a further paediatric-specific appraisal was one of its recommendations.

Children and their families in sub-Saharan Africa facing progressive incurable and life-limiting disease should have the same right to the evidence-based and effective care that is now being achieved for adults. In order to respond to their care and treatment needs, it is important that we identify and synthesise evidence for best practice, use our research to inform innovation and replicate existing successful models of intervention.

This study aimed to systematically identify and appraise the evidence for paediatric palliative care in sub-Saharan Africa, in order to identify best practice and effective models of care, and to inform the development of the discipline.

### 1.2. STUDY OBJECTIVES

1. To describe the sub-Saharan African context for paediatric palliative care with respect to epidemiological need, cultural understandings and responses to health and sickness, and structural challenges.
2. To examine the interface and potential for paediatric palliative care to improve patient outcomes in sub-Saharan Africa in cancer and HIV/AIDS with reference to anti-retroviral therapy.
3. To identify and appraise existing descriptions and evaluations of paediatric palliative care projects in sub-Saharan Africa, with an emphasis on evidence for activity, outcomes and models of care, isolating the factors that lead to sustainability, local ownership and coverage.

4. To identify any evaluations of advocacy initiatives.

### 1.3. METHODS

For Objectives 1, 2 and 4, brief non-systematic reviews of electronic databases and grey literature were conducted to identify and scope existing information, as directed by the expert Project Advisory Group.

For Objective 3, two systematic search strategies in biomedical databases were undertaken.

### 1.4. MAIN FINDINGS

- In its 2008 report (reporting prevalence estimates from the year 2007), UNAIDS estimates that 1.8 million 0- to 14-year-olds in sub-Saharan Africa are living with HIV infection, and there are 15 million orphans as a result of AIDS.
- Roll-out of paediatric anti-retroviral therapy (ART) is limited; Immune Reconstitution Inflammatory Syndrome (IRIS – a serious condition whereby an immune response to pre-existing infections occurs as the immune system begins to recover as treatment takes effect) is experienced in up to one-fifth of children initiating therapy; and evidence is emerging of treatment resistance and failure among children.
- Although cancer incidence is rising in low and middle income countries, very little data is available on childhood cancers in Africa. However, available data does show that there has been a significant rise in paediatric malignancies due to the HIV epidemic.
- There is a body of literature describing the diverse cultural meanings in Africa attributed to the aetiology, meaning and management of terminal illness in children.
- To date, the evidence base in Africa has not progressed for paediatric as it has for adult palliative care. A fundamental reason for this is the lack of locally relevant, validated tools to measure outcomes for children.
- Very few models of palliative care have been described in either grey or peer-review literature (see Table 1).
- The models described cover a range of acute, hospice and network care models with a range of points of delivery. This range of models is important as it demonstrates the feasibility of delivering children's

palliative care at the point of need. Further process, outcomes and health economic evaluations are now vital to ensure that these models are replicated and adopted as effective models of essential care.

- Despite the prevalence of HIV in African children, and growing cancer incidence, only five peer-reviewed papers were identified. The papers report on two countries recognised as leading palliative care provision: South Africa (one service being reported in two papers) and Uganda. Of the five papers, only one reports on quantitative outcomes for children; the others report evaluation of activity and process, or describe service aims and components of care offered.

## 1.5. RECOMMENDATIONS

### 1.5.1. Our key recommendations are:

1. Researchers urgently need to provide evidence in paediatric palliative care across the fields of intervention/service development, activity, outcomes and costs.
2. Funding bodies should support the conduct of research in order to establish a body of evidence to support, and advocate for, paediatric palliative care.
3. Practitioners should ensure that paediatric palliative care needs are assessed and interventions delivered as an essential integrated component of HIV (alongside ART as necessary) and cancer care throughout the disease trajectory.
4. Policy-makers should ensure that the role of palliative care research in improving care, and how to conduct research in this population, should be taught as part of paediatric palliative care curricula.

### 1.5.2. Other important recommendations

#### For researchers

5. The clinical and public health paediatric palliative care research agendas for sub-Saharan Africa need to be scoped.
6. The epidemiology and needs of children with non-malignant, life-threatening and life-limiting conditions should be identified.

7. In order to begin to measure and improve the care of children, multidimensional tools that capture the needs and priorities of African children and their families, and approaches to scoring using appropriate methods, are urgently required for development and full validation.
8. Evidence of appropriate models and their effectiveness are required across settings, especially in acute inpatient and home-based care settings. Evaluative studies are needed to build on the papers that report interventions.
9. Models for clinical audit of paediatric palliative care, with simple guidance for their conduct, are needed.
10. Existing symptom measures should be revalidated in this population to determine whether the items and scoring methods used are appropriate.
11. Differing needs according to diagnosis, stage of disease and developmental stage should be determined in order to inform appropriate clinical practice.
12. Interventions to support the emotional and psychological needs of children appropriate to an African setting must be developed and evaluated.
13. The needs of family members of a dying child need to be determined in order to maintain informal care and avoid crisis intervention.
14. The bereavement needs of families are not yet understood and should be investigated to inform models of intervention.
15. High-quality evidence is urgently required to determine the added benefit of palliative care for those children accessing ART.
16. Advocacy strategies to improve the coverage and quality of paediatric palliative care should be evaluated and disseminated.

#### For funders

17. Individuals and organisations should be given appropriate support to develop an African academic discipline of paediatric palliative care with strong research, education and clinical links, and support from existing experts in adult palliative care research.

18. Practitioners must be given the resources to capture their innovation and successes and support to write up and appraise their existing services.
19. High-quality holistic assessment and interventions using the palliative care 'total care' model should be integrated into existing paediatric care services.

#### For practitioners

20. Sensitivity to cultural beliefs and practices must inform care delivery, and may differ within and between countries.
21. Services should offer interventions and transitions appropriate to age groups and developmental stage.
22. Acute pain services that are currently providing palliation to children should be supported to work within the broader dimensions of palliative care.
23. Appropriate methods of child participation to help plan and research palliative care should be developed.
24. Holistic assessment and care should ensure that the needs of the wider family unit are understood and met where possible.
25. In order to manage the anxiety of a dying adult, the needs of their children must also be adequately assessed and managed.
26. Appropriate models of bereavement care need to be designed and evaluated.
27. Using audit methods, appropriate outcome tools should be incorporated into routine practice in order to measure and improve care.
28. Healthcare providers urgently need training in communication skills and the expert guidance of palliative care practitioners.
29. Advocacy agents should capture and disseminate successful advocacy strategies to enhance the coverage and practice of paediatric palliative care.

### For policy-makers

30. Cancer registries should be supported to ensure comprehensive data collection that can determine the epidemiology of progressive cancer among children.
31. The existing evidence on the cost effectiveness of adult palliative care should be taken into account when planning care for children.
32. The existing published palliative care protocols should be advocated within all care facilities that provide care to children with life-limiting illnesses.
33. Clinical academic partnerships should be fostered to deliver truly translational research that is informed by clinical experts, and directly improves outcomes for children and their families.
34. Care facilities should be encouraged to measure their activity.

## 2. INTRODUCTION

The provision of high-quality, appropriate and effective palliative care for children is a global concern (1). Poor recognition and under-treatment of paediatric AIDS pain has been identified in industrialised countries (2), and the high prevalence of moderate pain for paediatric HIV/AIDS patients has been identified as a clinical challenge due to a perceived lack of paediatric pain management strategies (3).

As 41% of the Africa's population is under the age of 15 years (4) (compared to 28% globally), and the infant/child mortality rate is extremely high (5), the humane and effective care of children affected by progressive, incurable and life-limiting disease in sub-Saharan Africa is a pressing public health matter.

The previous appraisal by Dr Harding et al (2004) reviewing the status of palliative care in sub-Saharan Africa identified a wealth of experience yet a dearth of evidence (6). That appraisal successfully catalysed the expansion of palliative care research within sub-Saharan Africa, building capacity and an evidence base on which appropriate and effective evidence-based care now flourishes. The appraisal led directly to the development and validation of an African patient outcome tool for adults (7;8), and subsequent evaluation and research with a focus on quality measurement and improvement (9-19), although there are still very few funding streams to support palliative care research in Africa (particularly for children). However, the inclusion of paediatric palliative care was beyond the remit of the appraisal, and a further paediatric-specific appraisal was a recommendation of that report.

Children (from infancy, through childhood and into adolescence) and their families in Africa who are facing progressive incurable and life-limiting disease should have the same right to evidence-based and effective care that is now being achieved for adults. In order to respond appropriately to their care and treatment needs, it is important that we identify and synthesise evidence for best practice, use our research to inform innovation and replicate existing successful models of intervention.

This report appraises the evidence base from multiple perspectives including epidemiology, health services research and outcome evaluation.

### 3. BACKGROUND

#### 3.1. WHAT IS PALLIATIVE CARE?

Since its beginnings in the UK's modern hospice movement during the 1960s, palliative care has grown to be a medical specialty and multidisciplinary team service for patients and their families. It is now present in all continents of the world, but is only in its infancy in many countries, and entirely absent in others.

Palliative care is a clinical speciality concerned with the management of the physical, emotional, social and spiritual manifestations of pain among those living with a life-limiting, incurable disease. Provided from the point of diagnosis, right up until the end of life and into bereavement, it can be provided in any setting (at home, in outpatient settings, hospital inpatient wards, hospices, primary care) and by generalist as well as specialist multidisciplinary healthcare providers.

Through the high-quality assessment and management of the multiple aspects of 'total pain' (ie. its physical, psychological, social and spiritual manifestations) which is experienced in relation to a diagnosis of a progressive, incurable and life-limiting disease, and in conjunction with therapeutic strategies where appropriate (such as chemotherapy, radiotherapy, anti-retrovirals), palliative care aims to maximise the quality of remaining life. It also aims to provide the best possible death (or a 'good death') when it comes, although patients may live a long time in a chronic disease model (eg. those patients with HIV infection accessing anti-retroviral therapy).

Integrated palliative and curative approaches offer the potential to hope for the best whilst preparing for the worst. All palliative care activity should take the choices and views of the patient into account. Palliative care aims to achieve what the patient sees as most important and to enable them to live with their disease in the best way they can.

#### 3.2. WHO CAN PROVIDE EFFECTIVE PALLIATIVE CARE, AND WHEN?

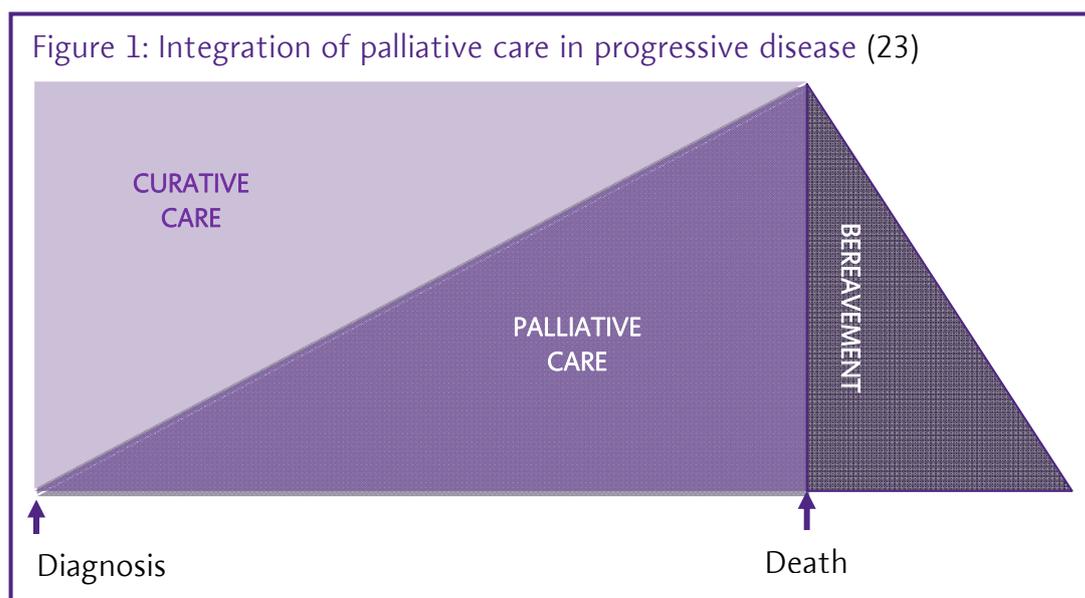
Basic palliative care can be provided by all members of the healthcare team at any point in the continuum of care from the point of diagnosis onwards.

Palliative care is delivered by a multidisciplinary team, which may include doctors, nurses, social workers, occupational/physical therapists, counsellors, psychologists, spiritual care providers and also others, such as music/art therapists.

Trained, multi-professional palliative care teams have been shown to improve outcomes for patients with advanced disease, and there is strong evidence that palliative care improves pain and other symptoms (20-22). It is essential to any public health strategy, and can no longer be viewed as an add-on to existing services. Indeed, modern palliative care protocols, training resources and inexpensive provision of oral morphine in developing countries have made palliative care an affordable and feasible component of care.

However, although palliative care is a recognised speciality or sub-specialty in some countries, not all providers need to be palliative care specialists. Providers can be trained in general palliative care skills. There are a number of simple protocols offering guidance in the assessment and management of physical, spiritual and psychological pain aimed at different levels of healthcare provider (medical doctors, spiritual care providers, community health workers, nurses, social workers etc), which offer simple routes to the affordable provision of palliative care within existing facilities. Through the use of care protocols, a facility should be able to detect/assess problems, manage simple problems, and have routes for referral to specialist providers (either within the team or in local services) for co-management.

In recent years, the traditional view of palliative care as a specialty that is introduced solely at the end of life has been modified, and the emphasis is increasingly on providing palliation from the point of diagnosis. This reflects the understanding that good management of physical and psychological pain can be required at many points when living with a life-limiting illness. Figure 1 demonstrates this shift in emphasis, from palliative care as end-of-life care to palliative care from diagnosis, with it being the major model of care towards the end of life.



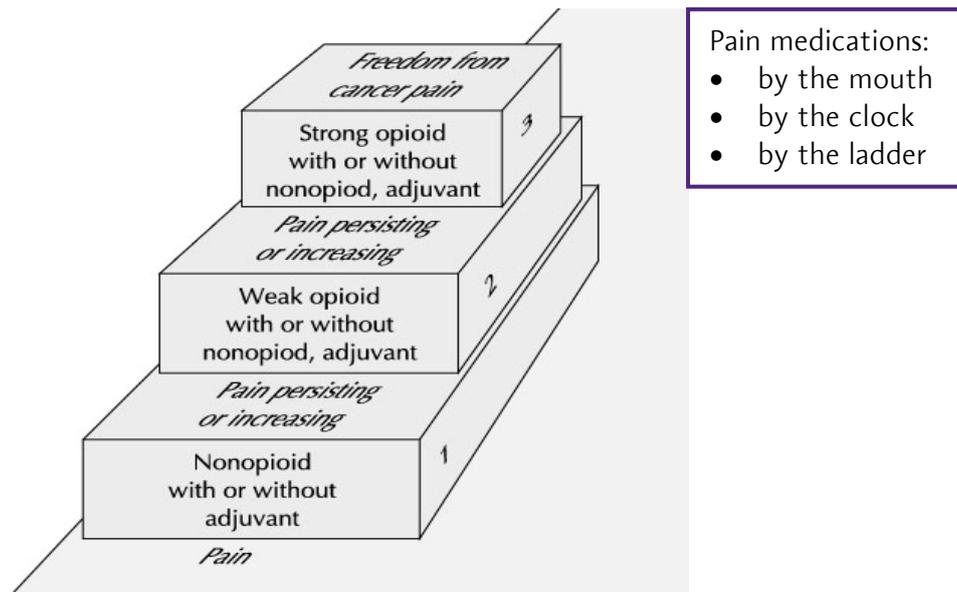
### 3.3. PAIN RELIEF AND PALLIATIVE CARE

While palliative care addresses the ‘total care’ needs of patients and their families, its hallmark (which distinguishes it from supportive care) is the expertise in pain and symptom control.

Good quality pain control should be seen as a basic human right (24), but without the involvement of healthcare staff with palliative care skills, patients often endure very distressing pain that could be managed.

The recommended means to achieve adequate pain control is through adherence to the WHO Pain Ladder (see Figure 2). In order to avoid unnecessary pain, analgesics should be given by the mouth (ie. oral analgesia), by the clock (ie. regularly, to avoid the emergence of pain) and by the (WHO) Pain Ladder.

Figure 2: The WHO Pain Ladder



Source: [www.who.int/cancer/palliative/painladder/en](http://www.who.int/cancer/palliative/painladder/en)

Palliative care also focuses on the provision of care and support for the patient’s informal caregivers and family members. The breadth of support and intervention addresses the needs of patients (physical, psychological, social and spiritual manifestations of pain) as well the psychological, social and spiritual needs of those significant others affected during the course of the disease and into bereavement.

### 3.4. PALLIATIVE CARE AND HIV/AIDS

Palliative care was developed in response to the needs of patients with advanced cancer, but is also now an essential component of care for non-malignant, progressive disease. Palliative care has a central role in the management and support of those affected by other conditions such as neurological disease, cardiac failure and dementia.

The scale-up of anti-retroviral therapy (ART) for HIV has had a huge impact on palliative care, and ART is also an important aspect of palliation. ART does not take away the need for palliative care, with the evidence suggesting that treatment-related problems may be burdensome (19;25). Palliative care can support adherence to ART and help to manage symptoms for those on anti-retrovirals (ARVs) from the point of diagnosis to the end of life. However, the lack of global coverage of ART means that palliative care for both treated and untreated HIV infection needs to be available according to treatment status. Clearly, universal access to ART treatment is a core component of palliative care provision as well.

The WHO has defined palliative care as an essential component of care provision in any context where HIV/AIDS care is delivered (see Figure 3). This standpoint has been supported by a systematic appraisal of the evidence, which demonstrated that palliative care improves multiple domains including anxiety, pain, symptom control, spiritual wellbeing and disease insight (26).

#### Figure 3: WHO definition of HIV palliative care

Palliative care is an essential component of a comprehensive package of care for people living with HIV/AIDS because of the variety of symptoms they can experience – such as pain, diarrhoea, cough, shortness of breath, nausea, weakness, fatigue, fever and confusion... At the community level, lack of palliative care places an unnecessary burden on hospital or clinic resources. (27)

### 3.5. PALLIATIVE CARE FOR CHILDREN

Palliative care for children is seen to be ‘unique and specific; it requires skills, organisation and resources which are different from those for adults’ (28).

Palliative care for children (or paediatric palliative care) represents a special, albeit closely related field to adult palliative care. The WHO’s additional definition of palliative care appropriate for children and their families is shown in Figure 4, and has a notably greater focus (compared to the adult definition)

on active and community-based care for children with life-limiting and life-threatening conditions.

Figure 4: WHO definition of paediatric palliative care (29)

The WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders.

- 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.

A further complementary definition of paediatric palliative care has been proposed by the Association for Children's Palliative Care (ACT) (see Figure 5).

Figure 5: ACT definition of paediatric palliative care (30)

Children's palliative care is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite, and care from diagnosis through death and bereavement.

This definition reflects the necessity for palliative care to 'address more than pain control and symptom management... and encompass attention to the child's relationships, hopes, fears and wishes' (31).

The WHO definition of palliative care for children stresses the developmental and psychological aspects of children's needs (32). Children are likely to have additional developmental needs in the presence of a significant illness, and may

therefore have worse outcomes across a range of domains. Therefore palliative care is well placed to apply a multidimensional person-centred approach to reduce this additional disadvantage.

Paediatric palliative care remains a discipline that requires formal training and significant experience to bring clinical confidence (33). A detailed description of the aims, activities and appropriate interventions for children's palliative care has been published in a full medical review (34).

Although there is evidence that palliative care can effectively improve the outcomes of people with HIV (including pain and symptom control, anxiety and insight into the disease), this evidence has been largely generated among adult populations living in resource-rich settings (26).

The lack of strategies for pain management and lack of experience in young patient populations are obstacles to the receipt of HIV paediatric palliative care (35). Data suggests a high incidence of error in analgesic dosing for children, and although innovation has attempted to address this with resources such as the paediatric analgesia wheel (36), this has not been tested in Africa where the more basic issue of drug availability is often a problem (37). The complexities of accurate dosing may also be compounded in the African context by the differential between the child's age and their expected weight resulting from poverty and malnutrition.

Furthermore, HIV is associated with wasting, and weight loss in the presence of illness may also affect the dose efficacy and potency for HIV-positive and ill children.

Clinical practice guidelines (authored from a high-income country) for the recognition and assessment of pain in children have been published and are freely downloadable (38). A clinical update on pain in children has been published by the International Association for the Study of Pain (39), and a further review of the assessment and management of acute pain in infants, children and adolescents has been published jointly by the American Academy of Pediatrics and the American Pain Society (40).

A number of clinical palliative care guides have been developed in sub-Saharan Africa. Some are general palliative care guides that focus mainly on adults but include some reference to the care of children (41-43). However, there are two guides which focus specifically on the practice of paediatric palliative care and are recommended as offering feasible approaches that are appropriate to local need (44;45), and specific guidance on paediatric care within a larger clinical guide to HIV/AIDS supportive and palliative care in Africa has also been published (46).

## 4. THE APPRAISAL: AIMS AND METHODS

This study aimed to systematically identify and appraise the evidence for paediatric palliative care in sub-Saharan Africa, in order to identify best practice and effective models of care, and to inform the development of the discipline.

### 4.1. OBJECTIVES

The objectives of this appraisal were as follows:

1. To describe the sub-Saharan African context for paediatric palliative care with respect to epidemiological need, cultural understandings and responses to health and sickness, and structural challenges.
2. To examine the interface and potential for paediatric palliative care to improve patient outcomes in sub-Saharan Africa in cancer and HIV/AIDS with reference to anti-retroviral therapy.
3. To identify and appraise existing descriptions and evaluations of paediatric palliative care projects in sub-Saharan Africa, with an emphasis on evidence for activity, outcomes and models of care, isolating the factors that lead to sustainability, local ownership and coverage.
4. To identify any evaluations of paediatric advocacy initiatives.

### 4.2. METHODS

#### 4.2.1. Design overview

The appraisal methods replicate those of the original adult palliative care appraisal (6), with a specific focus on paediatrics.

#### 4.2.2. Definitions

The Project Advisory Group recognises that paediatric palliative care is often termed 'children's palliative care' as the preferred lay option. It accepts and endorses both the WHO and ACT definitions of paediatric palliative care (27;29;43). In addition, the Project Advisory Group proposed that the definition

of paediatric palliative care should also include a clause that palliative care should be provided 'in the child's own environment'.

We note that different age ranges are offered to define a paediatric patient. For example, UNAIDS defines an adult as 15 years and above, and a young woman/man as aged 15-24, whereas for UNICEF, the definition of child is a person under 18 years. In this appraisal we use a working definition of paediatric as 0-17 years inclusive.

Although this appraisal focuses on life-limiting and life-threatening, chronic disease (primarily HIV and cancer), we recognise that other patient groups may benefit from palliative care (eg. burns, neurological disease, renal, accidents, injuries, severely premature alive births, severe malnutrition, congenital abnormalities, sickle cell, malaria, tuberculosis (TB), and cardiac disease).

In this appraisal a palliative care service is understood to be:

- in line with the WHO definition
- providing care to children with incurable, life-limiting disease or life-threatening illness
- providing holistic, supportive care and pain relief
- providing pain and symptom assessment and response
- providing terminal care where needed.

When identifying providers, we also recognised that acute pain services do sometimes provide palliative care in sub-Saharan Africa (although pain services are often purely medical and lack the other aspects of multidimensional care that constitute palliative care).

#### 4.2.3. Objectives 1, 2 and 4 (context, clinical interface, advocacy)

For Objectives 1, 2 and 4, brief non-systematic reviews of electronic databases and grey literature (ie. primarily reports of non-governmental organisations (NGOs) on websites such as UNAIDS and WHO) were conducted to identify and scope existing information, as directed by the expert Project Advisory Group.

#### 4.2.4. Objective 3 (existing evidence for effectiveness)

For Objective 3, two systematic review search strategies were undertaken.

#### 4.2.4.1. Search strategy A: peer-review literature

##### Databases

The following electronic biomedical, social science and nursing databases were searched and reference lists were subsequently hand searched:

- 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:

A) (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:

B) (sub-Saharan, 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:

C) (Minors, Paediatric, Pediatric, Infant, Child\*, Paed\*, Ped\*, Youth, Adolescent, Baby, Newborn, Neonates, Teen\*)

##### Inclusion/exclusion criteria

The searches were restricted to papers reporting human subjects in the English language.

Data on services were included that were:

- paediatric-only palliative care services
- palliative care services that serve children and adults
- paediatric services that provide palliative care.

Papers reporting data on any one or more of the design, delivery, organisation, content, or outcomes of paediatric palliative care in sub-Saharan Africa were included.

Papers reporting non-clinical data/data not reporting on human subjects, or reports not in English were excluded.

Case studies and reviews were not included in the analysis.

#### 4.2.4.2. Search strategy B: grey literature

The grey literature search strategy identified and contacted funders, non-governmental organisations (NGOs), associations and practitioners involved in palliative care in sub-Saharan African countries, who were requested to provide existing prepared reports on their activities. Specific advocacy initiatives were sought in the grey literature.

#### 4.2.5. Information sources and contacts

In order to obtain as many relevant reports as possible, advocates, associations, funders and NGOs associated with palliative care in sub-Saharan Africa were approached to assist in obtaining materials for this appraisal. Requests for information were posted on electronic mailing lists and websites.

Emails requesting information were re-sent one month later to any non-responding agency, and contact details were verified where possible.

#### 4.2.6. Data extraction and analysis

The data from papers and reports were extracted into themes, each of which sought to answer the primary aims of the appraisal. In addition, common tables were designed and piloted into which key variables from service reports and evaluations were inserted. This enabled models, the types of data reported, and apparent strengths and weaknesses to be presented and potentially compared, and to make recommendations for greater consistency in future data collection.

The common data extraction headings were as follows: country, aims, methods, sample description, service description, findings, lessons and comments. We were unable to apply study quality criteria in light of the type of evidence retrieved.

#### 4.2.7. Date of research activities

Email requests, re-requests and contact verifications were undertaken in January-March 2009. The literature database searches were undertaken in May 2009.

## 5. FINDINGS

### 5.1. OBJECTIVES 1 AND 2

- *To describe the sub-Saharan African context for paediatric palliative care with respect to epidemiological need, cultural understandings and responses to health and sickness, and structural challenges.*
- *To examine the interface and potential for paediatric palliative care to improve patient outcomes in sub-Saharan Africa in cancer and HIV/AIDS with reference to anti-retroviral therapy.*

The primary progressive and incurable diagnoses in sub-Saharan Africa are HIV and cancer, which are examined in turn below.

#### 5.1.1. HIV/AIDS

##### 5.1.1.1. Epidemiology

The magnitude of the problem is far greater in sub-Saharan Africa than in developed countries where research and evidence relating to palliative care in children are most likely to have been generated. Most children in the world living with HIV – around 9 out in 10 – live in sub-Saharan Africa (47). UNAIDS' 2008 report (reporting prevalence estimates from the year 2007) estimates that 1.8 million 0-14 year olds in sub-Saharan Africa are living with HIV infection, that there are 15 million orphans as a result of AIDS. In Uganda, 10% of people with HIV disease are thought to be under 15 years old (48). A prospective study to determine cause of death in children aged under 5 years in a regional health system in South Africa over a 12-month period attributed 21.3% of deaths to AIDS.

Paediatric HIV infection can be largely avoided by a number of strategies including: anti-retroviral treatment of the mother during pregnancy, anti-retroviral treatment of the mother during breastfeeding, avoidance of breast feeding and use of the exclusive breast feeding paradigm. However, reported data shows that as few as 10% of pregnant women in sub-Saharan African with known HIV infection received such intervention (49). It should be noted that these figures reflect only the level of intervention for those women already established as pregnant and HIV positive. The number of women not tested for HIV during pregnancy is unknown and child illness may only become apparent much later in the disease course.

Without access to life-saving drugs, including anti-retroviral therapy and preventive interventions such as cotrimoxazole prophylaxis, about one-third of

HIV-infected infants will die by the age of one year, and 50% by the age of two (50;51).

#### 5.1.1.2.Children and anti-retroviral therapy (ART)

A systematic review and meta-analysis of pooled data in published reports of HIV outcomes for treatment-naive children aged 0- to 17-years-old in developing countries found the virologic and immunologic benefits after 12 months of ART to be comparable with those observed among children in developed settings (52).

However, the roll-out of ART to children is a source of concern. The availability of paediatric formulations has been low, and is only beginning to be addressed. The cost of paediatric formulations has been higher than adult formulations (even for the same compound) and roll-out to children is far from reaching universal coverage.

Where roll-out has succeeded for children in Africa, evidence of treatment resistance and failure has recently started to emerge, which underlines the continued need for HIV palliative care (53). Good family-based care is needed for children in Africa to achieve the levels of adherence required for virological suppression (54).

Children also have other complex problems which need to be managed, such as the multidimensional and apparently refractory problems associated with Immune Reconstitution Inflammatory Syndrome (IRIS – a serious condition whereby an immune response to pre-existing infections occurs as the immune system begins to recover as treatment takes effect), which was found to affect 21% of children within a median of 16 days after starting therapy in South Africa (55). The unmasking of underlying tuberculosis (TB) infection is not uncommon when initiating ART in African children (56).

Despite the indisputable improvements in mortality rates with the advent of ART, a systematic review of quality of life outcomes found very little data on outcomes for children (57).

Thus in the context of poverty and poor treatment roll-out, HIV infection in very young children is a growing problem in sub-Saharan Africa. Their palliative care needs are, it seems, essentially uncharted, particularly for the aging cohort of infected older children with specific clinical needs (51).

#### 5.1.1.3.Psychosocial dimensions

The significant number of HIV-positive orphans in sub-Saharan Africa with palliative care needs has presented practitioners with a set of complex

management issues, and has led to the establishment of AIDS hospices and orphanages for these children (58).

HIV, by its very nature, clusters in families so palliative care needs have to be focused on multiple recipients. For those children who do have living parents, there is a considerable likelihood that the parents are ill themselves, again adding to the complexity of children's support and care needs. There is also an argument that provision of adult treatment is in the best interest of the child, so that they can be cared for and nurtured by a well parent. Need is heightened in the case of single parent death, where the survival of the remaining parent is of paramount importance to the wellbeing of the child. However, at the same time, the very fact that one parent has died makes it more likely that the second parent will also die.

A study of children with HIV infection in Nigerian Yoruba communities found that, compared to children in concordant families, those children with serodiscordant parents were more likely to be refused care by their HIV-negative father because of fears of infection and a sense that resources were being wasted on a dying child (59).

#### 5.1.1.4. Palliative care needs

The need for palliative care in achieving quality of life has been well described throughout the HIV disease trajectory from the point of diagnosis, through treatment initiation and adherence, into the chronic disease stage, alongside emerging co-morbidities such as liver failure and cerebrovascular events, and into the end of life (26;60-62). The evidence has also shown that there is inadequate access to HIV palliative care, particularly for children (35). Both appraisals have also found the evidence to be focused almost exclusively based on adult patients in resource-rich settings.

The palliative care needs of adults with HIV disease (even among those accessing ART) have been shown to be huge. One study reported that 50% of adult outpatients at an HIV clinic in Tanzania would benefit from palliative care (irrespective of treatment use) (63). Unfortunately, similar studies have not been conducted among children, although there is no reason to believe that their multidimensional problems (physical, social, psychological, spiritual) would be fewer. A systematic review of studies investigating cognitive status among HIV-infected children reported that 81% of studies showed some form of decline or deterioration, which would have an impact on their care needs (64).

There is a small body of evidence on the palliative care needs of children living with HIV in Africa. A study of adherence among children in Togo concluded that better preparation of children and carers with respect to side effects and their management is needed (65). A review of care and treatment of children in

Africa lamented the lack of research evidence into the treatment of pain in children with HIV disease (66), and also the lack of palliative care integrated throughout the disease trajectory alongside other care strategies. With respect to ART and terminal care, high rates of early mortality after initiating therapy were found in a study of under 15s in Malawi (67), with 12% dying within six months of initiating therapy. A pooled analysis of multiple African paediatric cohorts initiating therapy reported a 7% death rate within two years (68). A Malawian study reported that, among paediatric inpatients, the prevalence of HIV infection was 18.9%, with common clinically identified symptoms being fever, cough and diarrhoea (69).

### 5.1.2. Cancer

Each year approximately 166,000 children under the age of 15 are diagnosed with cancer worldwide (70). By 2030, the developing world is expected to bear 70% of the global cancer burden (71). Poverty continues to be linked to cancer in the developing world (72), with cancers having already progressed to an incurable stage in 80% of patients by the time of detection and diagnosis (73). The available registry data in Tanzania has revealed that 11.5% of all malignant tumours recorded in the cancer registry were in children aged 0–14 years (75).

The lack of developed cancer registries in Africa hampers the collection of robust surveillance data and reporting. A study reviewing the global cancer registration literature 2006-2008 found that less than 1% of abstracts originated from Africa (74).

Around 36% of cancers in Africa are infection related, which is twice the global average (76). This reflects the challenge of infectious disease (particularly of HIV), and that many cancer patients have underlying HIV infection. A study of childhood cancers in Zambia found a significant rise in paediatric malignancies due to the HIV epidemic, with the authors reporting the most common presentations as lymphoma (36.9%), retinoblastoma (12.5%) and Kaposi's sarcoma (12.7%) (77). Similar findings from Malawi in a retrospective audit identified increases for all cases due to the HIV epidemic, but particularly for Kaposi's sarcoma (with Burkett's Lymphoma being the most common childhood tumour in Malawi) (78). Burkett's Lymphoma is the most prevalent cancer among children across tropical Africa, and although usually treatable, evidence from Nigeria shows that children with a diagnosis of Burkett's Lymphoma will often need end-of-life care due to late presentation and their family's inability to afford curative options (79).

A study of the impact of the costs of care on the family and patient found that the additional costs of transport to the care facility, food and the family carer's inability to work while attending the child in hospital, can lead to the

abandonment of the child (80). A lack of family-based, informal carers may place greater responsibility on palliative care teams to provide for the child's needs, both physical and emotional.

A review of childhood cancer treatment in developing countries predicted that the high cure rates seen in developed countries will not be possible, due to a lack of resources and locally adapted treatment protocols, late presentation, and poor treatment compliance (81). These factors present significant challenges to the achievement of the Millennium Development Goals, although investment in research may improve outcomes for childhood malignancies (82).

### 5.1.3. Other causes of death

Although HIV is a leading cause of death for children in sub-Saharan Africa, and cancer incidence appears to be rising, less is known about the prevalence of other progressive conditions.

Evidence shows that for the years 2000-2003, six causes accounted for 73% of the 10.6 million yearly deaths in children under five years old: pneumonia (19%), diarrhoea (18%), malaria (8%), neonatal pneumonia or sepsis (10%), preterm delivery (10%), and asphyxia at birth (8%), with undernutrition as an underlying cause of 53% of all deaths in children under five (83). Clearly palliative care is not appropriate for all illnesses (ie. for those that are not progressive, incurable life-limiting diseases), although even for preventable and treatable illnesses, in the absence of curative resources a 'good death' (ie. with adequate levels of comfort) should be considered.

### 5.1.4. Estimating paediatric palliative care needs

In terms of the public health need for paediatric palliative care, some extrapolations have been made from available data in South Africa.

Estimates of the need for palliative care in an area are traditionally based on mortality and morbidity statistics for chronic, incurable illnesses. In the Cape Town Metro area an estimated 2,951 children died in 2006 (84). The greatest number of childhood deaths in the Cape Town Metro area occurred in children aged 1-4 years (135/100,000). Of these deaths, 105,231 (44%) were from chronic communicable (HIV, TB) and non-communicable (eg. cancers, organ failure, congenital conditions etc) illnesses. Mortality statistics only give an estimate of the need for improved end-of-life care (including bereavement) and do not reflect the whole spectrum of palliative care which ideally should begin with diagnosis.

The estimated prevalence of chronic illness among children in South Africa (ie. expected to last at least a year) is 20% (85). Approximately one-fifth of these children will have a life-limiting or life-threatening condition requiring palliative care. An approximation of the number of children living with a chronic illness in the Western Cape based on the mid-year (2009) population census for the Western Cape is 397,580 (20% of the 1,987,900 children living there). Approximately 79,516 of these children (20%) would require palliative care.

Chronic non-communicable diseases (eg. liver, renal and neurological conditions, genetic diseases and congenital abnormalities) are the predominant reason for admission to paediatric palliative care programmes in the developed world, but are also important in developing countries. Developing countries, however, additionally carry a high burden of chronic communicable disorders such as HIV and TB.

This work is novel, and offers a useful example of calculating the estimated need for paediatric palliative care provision. Such work is required across the sub-Saharan region.

#### 5.1.5. Cultural dimensions of serious illness for children and families

Person-centred palliative care should take account of the diversity of cultural beliefs, behaviours and traditions within, as well as between, African countries. A number of examples of cultural beliefs in relation to children and life-threatening illness were identified in the literature.

The meaning attached to a dying child may affect a family's willingness to access end-of-life care. For example in Ghana it may be seen as a result of the child's own 'evil' actions (86).

Cultural rules and expectations on the breaking of bad news should also guide clinical practice. For example, in Ethiopia the 'staging' of information giving, such as the timing within the day and avoidance of what can be seen as news that may shock in terms of poor prognosis of a child, all inform recommendations for working with Ethiopian patients (87).

Medical care of life-threatening illness may also 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' (88).

When looking at the provision of palliative care for children affected by progressive disease (and particularly at end-of-life care), it is important that clinical services providing care for adults can respond to the adult's care

planning needs in relation to their children (or the children they are responsible for, who may not necessarily be their biological children).

A study of what constitutes a 'good death' among the rural town inhabitants of Kwahu Tafo in Ghana identified components of a parent's good death in relation to their children (86). For example, the study found that a dying adult needs to know that their child's education has been provided for if they are to die well without anxiety.

The study by Morgan (2000) identifies children in infected households, who carry the burden of caring for their dying parents, as a group with very pressing needs, and concludes that they must be meaningfully and centrally placed in service planning activities (89).

When attempting to describe and incorporate cultural beliefs and practices within clinical care, we should recognise that culture is dynamic and not fixed. For example, evidence suggests that community practices in relation to the care of orphans have shifted. Previously, for example, Ugandan concepts of clanship and lineage meant that an orphaned child would be taken in by extended family members, but child-headed households are now common (90). This is understood to be due to the overwhelming impact of HIV on poverty, HIV-related stigma and the reduced availability of older adults now able to provide care. Another study in Mozambique found that terminally ill mothers assumed that their extended family would take care of their child following their death, although none had actually formulated a plan for this to happen (91). Interestingly, the mothers' preference was for their child to be placed in an orphanage, as they perceived this to offer better care in terms of food and education. Their concern has an evidence base in the literature, with several studies identifying reduced access to schooling as one of the effects of AIDS mortality and orphanhood in Uganda (92;93).

The controversy over childcare arrangements and the different outcomes according to health, nutrition and development is examined in depth in a recent report by the Joint Learning Initiative on Children and HIV/AIDS (94), which underlines the importance of family, and notes that institutional care is not in the best interest of the child's long term development and adjustment.

While dying adults need to have their children's needs taken into account when preparing care plans, the parents of a dying child should also be considered as part of the unit of care, and hospices have strived to develop good care for parents of children dying of AIDS (95).

### 5.1.6. Current focus of paediatric services

A 2002 review of paediatric HIV care and support activities in Africa concluded that generally the aims and interventions focused on primary prevention among youth, prevention of mother-to-child transmission (PMTCT) and orphan support. Very few paediatric treatment guidelines were found at that point in time and training was rare, particularly in the field of pain and symptom control and palliative care (96).

Appropriate high-quality orphan care has been hypothesised to impact on primary HIV prevention, which may provide good health economic arguments for the care of AIDS orphans (97). However, where orphan care services do exist, they have been found to focus on children's physical needs to the exclusion of their psychosocial needs (98). The social support and communication needs of HIV-infected and affected children have been demonstrated to be essential for children living long-term with HIV infection (99). While there are examples of interventions for HIV-affected children (such as the 'Kids Express' programme which aims to prevent psychological morbidity for children who are aware of their loved one's diagnosis)(100), there are currently no such interventions described within the context of palliative care services.

There is a substantial body of research on needs and interventions in relation to orphanhood which is beyond the remit of this appraisal. However, it is important that this evidence is recognised, as palliative care services will often need to respond to issues of orphanhood in relation to the care of parents and children affected by progressive disease. Orphans have been shown to be at elevated risk of sexual abuse, homelessness, higher mortality, worse healthcare access and poorer education (101), creating a cohort of children with additional needs which palliative care with its philosophy of 'total care' is able to address. Further complications have been evidenced in a systematic review of concepts and definitions of AIDS orphanhood (102). This burden of need among orphans presents a potential challenge to paediatric palliative care services with their focus on the management of problems of children presenting with life-limiting and life-threatening illness.

There is a large and robust body of evidence generated in a number of countries that demonstrates the high psychological burden and morbidity associated with bereavement and orphanhood among children in Africa (103-105). Palliative care services are well placed, and skilled, to provide emotional support pre- and post-death of the child's significant adult. While it is not feasible for palliative care services to take responsibility for the full range of needs of orphaned children, advance care planning and referrals to other agencies are essential where possible.

Although the issues of orphanhood and bereavement cut across diseases, almost no papers or reports focused on care beyond HIV.

#### 5.1.7. Ensuring quality: assessment and measurement to improve outcomes for children and their families

The palliative care research agenda for Africa has advanced significantly, and there is now a recognition of the central role of clinical and public health research to determine what constitutes appropriate and responsive palliative care, how to manage problems in progressive disease, and of the importance of undertaking outcome evaluation to determine what works.

To date, the science has not progressed for children as it has for adult palliative care, and as a result the evidence base appears even smaller than it is in the growing field of adult palliative care. One of the challenges contributing to this lack of evidence is that the conduct of ethical, robust and rigorous research among children must address problems that are specific to the population. While some issues are common (37), specific research questions remain. These include the identification of the specific needs of children across diverse care settings, diagnoses and age groups, the ethical and valid collection of data, the design of appropriate measures, and the configuration and evaluation of paediatric interventions and services responsive to the various age groups.

A study conducted in Malawi measured the signs and symptoms of children referred for palliative care (106). This study of inpatients up to the age of 16 sampled HIV/AIDS (n=73) and cancer (n=16) patients. Collecting self-report data with carer support, the study systematically asked about a series of symptoms, and found that the two most prevalent problems the children experienced in the previous seven days were pain (83.9%) and mouth sores (33.3%). This study is unusual in that it measured problems among paediatric palliative patients in Africa, and so offers a first step towards the important and immediate task of developing, validating and implementing tools to measure the multidimensional problems of children.

The need for well designed and validated tools to measure children's problems is underlined by the Rose and Amery's statement that assessment is the most important aspect of delivering children's palliative care in Africa (107). Their research outlines the core domains to be included in the assessment of children: health, education, emotional and behavioural development, identity, family and social relationships, social presentation, family history and functioning, housing, employment and income, family's social integration, and community resources. These domains are indicative of the complexity and breadth of outcomes of

interest, and should be taken into consideration in the development of the science of assessment and outcome measurement for children in Africa.

The assessment and measurement of pain and symptoms must be conducted using methods which recognise that children's experiences and expression of pain and symptoms will be mediated by age, experience, family and culture (108). While systematic assessment underpins good palliative care, and self report is the most accurate source of information, the child may not be able to communicate well. Children should not be seen as 'little adults', and existing tools developed in adult populations may not be appropriate, either in terms of their domains/items and response methods, or because they are unvalidated in African populations. Furthermore, although the needs of family/carers are taken into account in palliative care in general, the needs of parents of dying children may be specific, and they may need assistance in accepting the diagnosis and prognosis of their child.

It has been noted that the assessment and management of symptoms and suffering in children are challenging, and that few reliable, valid and developmentally appropriate methods are available (109). There are a small number of validated outcome tools for children, although to date none have been validated in Africa. These include the Memorial Symptom Assessment Scale (MSAS) paediatric version for children aged 7–12 years (110), and the faces pain scale which is a well validated and used visual scale for children who may not be able to work well with verbal ratings (111;112). Indeed, a study carried out among palliative care health professionals in Uganda identified skills to communicate with children to be the greatest training need (113).

There are other tools available for the assessment of pain in children (Ullrich and Wolfe, 2009)(114), but none that are multidimensional (ie. that address physical, psychological, social and spiritual domains) and validated for children in Africa. The African Palliative Care Association (APCA) is however currently developing a paediatric palliative outcome scale (POS) for Africa.

It is also recognised that medical staff in Africa need pain management models for children (115). Even if the necessary drugs (such as opioids) are made available for pain relief and training is delivered, data has shown that clinicians experience refusal by colleagues to prescribe opioids for children (37).

While there is almost no data on the care of children with progressive disease and on their end-of-life care, there is some data on death during acute care admissions. A study in Niger found that among children aged two and under, 138/461 admitted to a national hospital died over a period of two months. 47% of deaths were within the first 24 hours of hospitalisation, which is a challenge for appropriate palliative care intervention (116). A study of child deaths

following hospital admission in Mali found that 345/1,644 children admitted from the community died during their admission, and 40% of these died within 24 hours of admission (117). Another study of childhood mortality in an urban setting in Guinea Bissau found that 24% of all deaths occurred in hospital (118). A description of experiences on a paediatric unit in a Ugandan hospital underlined the lack of priority attached to, and availability of, adequate pain control (119). Therefore, while the emphasis continues to be on the provision of palliative care for children in the community, good paediatric palliative care is demonstrably essential in acute inpatient settings. This is supported by a study from Kenya in which the care of children who died in hospital was investigated, and the median length of illness following a visit to hospital before death was only 17 days (120). However, the data on acute care and mortality must be interpreted with caution as many will have died from the leading causes of child death in sub-Saharan Africa, eg. pneumonia, diarrhoea, measles, malnutrition and malaria, many of which are acute, curable diseases and not the progressive conditions addressed under palliative care.

While little data exists on the needs of children in relation to palliative care, no data was identified on the needs and assessment of their parents and caregivers.

## 5.2. OBJECTIVE 3

- *To identify and appraise existing descriptions and evaluations of paediatric palliative care projects in sub-Saharan Africa, with an emphasis on evidence for activity, outcomes and models of care, isolating the factors that lead to sustainability, local ownership and coverage.*

The identified papers, reports and abstracts are reported in Table 1 below.

Table 1: Studies reporting data from palliative/end-of-life interventions/services for children in Africa

Author, year, country, ref type	Intervention	Evaluation aim, methods, sample	Findings	Conclusions
<i>Evaluation of services within settings not exclusively palliative or paediatric</i>				
Henley 2002 (121) South Africa Journal	Secondary and tertiary teaching children's hospital	<ul style="list-style-type: none"> <li>→ To evaluate terminal care among hospitalised children who died of HIV/AIDS</li> <li>→ Retrospective chart review</li> <li>→ 165 inpatient deaths, mean age 10 months (median 4 months)</li> </ul>	<ul style="list-style-type: none"> <li>→ 84% had DNR orders, although written simultaneously in medical AND nursing notes 41% of time</li> <li>→ 44% had comfort care plans</li> <li>→ Pain and distress in final 48hrs recorded for 55%</li> <li>→ Half with pain/distress received analgesia</li> </ul>	Assistance is needed to transition to palliative care and to ensure comfort care plans are appropriate
Uys 2003 (122) South Africa Journal	Model of HIV home-based care, linking hospitals, clinics, and home-based care	<ul style="list-style-type: none"> <li>→ To explore the realisation of counselling, palliative care, and terminal care in seven settings</li> <li>→ Descriptive study</li> </ul>	<ul style="list-style-type: none"> <li>→ Staff identified counselling skills training needs for working with children</li> <li>→ No other data differentiated between adults/children</li> </ul>	<ul style="list-style-type: none"> <li>→ Counselling training is needed for staff working with children</li> <li>→ Additional palliative care trained staff are needed across</li> </ul>

		including infected adults and children, their caretakers, health careworkers, and community members using semi-structured interviews, observation, taping of onsite meetings, and questionnaires		settings
<i>Evaluation of paediatric palliative care</i>				
Amery et al 2009 (123) Uganda Journal	Focused children's service and training programme within existing hospice. Nurse-led with medical back-up, across acute, home and outpatient settings	<ul style="list-style-type: none"> <li>→ To evaluate a new paediatric palliative care service</li> <li>→ Mixed methods: Retrospective chart and activity (n=362) with pre-service historical controls (n=243) Qualitative interviews with 11 children, 12 informal caregivers</li> </ul>	<p><i>Quantitative:</i></p> <ul style="list-style-type: none"> <li>→ Increases in: Referrals = 129%</li> <li>Proportion of children on program = 49%</li> <li>Morphine prescriptions = 175%</li> <li>Chemotherapy prescriptions = 118%</li> <li>Chemo compliance = 282%</li> <li>→ Cost of \$100 per child</li> </ul>	<ul style="list-style-type: none"> <li>→ Affordable, nurse-led, volunteer-supported children's palliative care services are both achievable and effective in sub-Saharan Africa</li> <li>→ Palliative care units should provide a specialised service focused on children</li> </ul>

		and 10 professional staff	<i>Qualitative:</i> → Most valued service strengths were free drugs, food, play, learning, and staff attitude	
Harding et al 2009 (124) South Africa Journal	Specialist children's hospice providing inpatient care, home-based care and day care. The hospice piloted ART for children referred with advanced disease care and/or poor prognosis	<ul style="list-style-type: none"> <li>→ To evaluate outcomes for children with advanced HIV disease initiated on anti-retroviral therapy under multi-professional specialist paediatric hospice care</li> <li>→ Retrospective cohort file review with 6 month follow-up</li> <li>→ 37 children, mean age of 5.5 years</li> </ul>	<ul style="list-style-type: none"> <li>→ 31/37 children survived at six months</li> <li>→ From mean body weight of 13.3kg, average of 3.2kg increase (<math>p &lt; 0.001</math>)</li> <li>→ Mean CD4 counts more than doubled (<math>p &lt; 0.001</math>), with a mean increase of 467 cells per <math>\text{mm}^3</math> blood</li> <li>→ Mean CD4 percentages increased from 13.6% to 19.4% (<math>p &lt; 0.001</math>)</li> <li>→ Viral load decreased significantly from a median 271,000 copies per <math>\text{mm}^3</math> blood to a median of 25 (imputed value for undetectable viral load) (<math>p &lt; 0.001</math>)</li> </ul>	Hospice palliative care can successfully improve outcomes for children least expected to benefit from new therapeutics

			→ 23 children had an undetectable viral load	
Mwangi 1994 (125) Kenya Conference abstract	Total care for HIV-infected orphans within a hospice setting	Not known	→ Only 4/60 died over 1.5 years → 'Evident' stigma reduction: 5 orphans rejoined their family and 13 were adopted	Good nursing and prompt treatment of physical problems and focus on normal development with anti-stigma approaches can return children to family settings
<i>Descriptive papers and reports</i>				
Knapp et al 2009 (126) South Africa Journal	St Nicholas Children's Hospice, offering inpatient beds, home-based care, family bereavement care, day care, respite, counselling, orphan care, child/grandmother-headed household support, co-ordinated care with hospital services	-	-	-
Umodzi Palliative Care Clinic for Children Malawi	Paediatric palliative care service		→ 129 referrals July-Dec 2009 → 47 discharged into home	

Bi-annual report to The Diana, Princess of Wales Memorial Fund, 2009			<p>palliative care (twice-weekly visits)</p> <ul style="list-style-type: none"> <li>→ In 6 months, paediatric morphine use increased from 4250 to 11,195mg</li> <li>→ 'Play staff', and speech/language/swallowing rehabilitation integral to team</li> </ul>	
<p>Gauteng Palliative Care Centre of Excellence Paediatric Palliative Care Department/Bigshoes Foundation July – November 2006</p> <p>South Africa</p> <p>Report</p>	Paediatric palliative care service, providing consultancy to hospital and hospice sites		<ul style="list-style-type: none"> <li>→ 38 active cases during this period</li> <li>→ In 39% of the cases, the child died before or very soon after placement outside of the hospital</li> <li>→ Outcomes for closed cases: 13 returned to family, 11 died, 4 placed in step-down hospice</li> </ul>	
<p>Gauteng Palliative Care Centre of Excellence Paediatric Palliative Care Department/Bigshoes Foundation</p>	Paediatric palliative care service, providing consultancy to hospital and hospice sites		<ul style="list-style-type: none"> <li>→ 112 new patients in this period</li> <li>→ 164 follow-up visits</li> <li>→ Mean 1.5 staff visits, principally due to late</li> </ul>	

<p>Quarterly report January – March 2008</p> <p>South Africa</p> <p>Report</p>			<p>referral</p> <ul style="list-style-type: none"> <li>→ Majority of children seen (61%) were ACT Class 2 (ie. with conditions where premature death is inevitable, although long periods of relative wellness possible with intensive treatment aimed at prolonging life eg. HIV/AIDS.)</li> <li>→ Over a one-year period, the percentage of children receiving analgesia increased from 53% to 62%</li> <li>→ Mortality rate stable at 30%</li> </ul>	
<p>Bigshoes Foundation Activity Report October 2007 – November 2008</p> <p>South Africa</p> <p>Report</p>	<p>Not-for-profit organisation providing HIV testing, ART, palliative care for OVC, child health focused training. Active in advocacy for the healthcare of OVC.</p>		<ul style="list-style-type: none"> <li>→ 149 children received support from emergency fund</li> </ul>	

Bigshoes Foundation Activity November 2008 – April 2009  South Africa  Report	Not-for-profit organisation providing HIV testing, ART, palliative care for OVC, child health focused training. Active in advocacy for the healthcare of OVC.		<ul style="list-style-type: none"> <li>→ 72 children cared for in conjunction with Soweto Hospice in this period, a 31% increase on previous period</li> <li>→ 264 patients hospitalised (158 new admissions/106 re-admissions)</li> <li>→ 1,107 medical follow-up visits conducted</li> </ul>	
Bigshoes Foundation Activity May – October 2009  South Africa  Report	Not-for-profit organisation providing HIV testing, ART, palliative care for OVC, child health focused training. Active in advocacy for the healthcare of OVC.		<ul style="list-style-type: none"> <li>→ 505 hospitalised patients seen: 241 new, 264 re-admissions</li> <li>→ 957 psychosocial sessions delivered</li> </ul>	

### 5.2.1. Models of care, activity and outcomes

Very few models of palliative care have been described in either grey or peer-literature (see Table 1).

Only five peer-reviewed papers were identified. This is a very small number in relation to the epidemiology of progressive disease among children in the region. The papers report on two countries recognised as leading palliative care provision: South Africa (one service is reported in 2 papers) and Uganda. Of the five papers, only one reports on quantitative outcomes for children (124); the others report evaluation of activity and process (127-129) or provide a description of the service aims and services offered (126).

The evaluations of activity are very important in progressing the field, as both operational and process evaluations are essential alongside outcome evaluation. The models of care described address a range of acute, hospice and network care models with a range of points of delivery. The range of models is important as it demonstrates the feasibility of delivering children's palliative care at the point of need. Further process, outcomes and health economic evaluations are now vital to ensure that these models are replicated and adopted as effective models of essential care.

In terms of the grey literature, the activity reports from the Bigshoes Foundation describe a model of palliative care consultancy across multiple sites, (in which palliative care doctors offer an expert outreach service to hospitals), which provides a useful further model, in addition to the acute and hospice models.

### 5.2.2. Sustainability and coverage

The reported studies did not examine factors that lead to sustainability, local ownership and coverage. However, it is possible to extrapolate some potential lessons for replication from the small body of published evidence.

The only published paper to report on sustainability was the descriptive international comparative paper by Knapp et al (126), which noted that a relationship with health departments provides much needed sustainability for paediatric palliative care.

Several of the models described in the literature offer examples of how the integration of paediatric palliative care can offer routes to sustainability. The hospital care study (Henley 2002) is important as, with the large numbers of children with advanced illness, hospitals are likely to be feasible (and sustainable) places in which need is presented and can be appropriately managed. In high-income countries, palliative care has expanded coverage by integrating itself into tertiary and acute settings. In the light of HIV epidemiology, this is likely to achieve greatest possible coverage in Africa.

The study by Uys (2003) offers a model of integration that may enhance sustainability through the establishment of effective referral networks, achieving a model of care that aims to deliver palliative care across diverse healthcare settings and delivering at the geographical point of need. This model of flexibility and responsiveness is also likely to be successful in terms of coverage.

Lastly, 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 (2009) offers an effective route of ART delivery via hospices. Although much more evaluative data is needed on the supporting role of palliative care in ART provision and outcomes, such rigorous data could prove to be a route to successfully integrated and sustained palliative care (and improved outcomes) for people with HIV.

With respect to the complexities of managing children across physical, emotional, social, spiritual and developmental domains, hospice and palliative care may yet prove to offer a set of skills and experience highly appropriate to children's needs.

### 5.3. OBJECTIVE 4

→ *To identify any evaluations of advocacy initiatives.*

Advocacy activities, essential to the advancement of paediatric palliative care, were solely reported in the grey literature (usually within reports to funders).

Successful strategies (although evaluative data is not available) included:

- gaining access to existing advocacy bodies to advance the specific topic of paediatric palliative care
- ensuring that the issue of paediatric palliative care is included in draft national policy and strategic plans

- lobbying with the full range of relevant government departments (eg. not only health but also those concerned with social development).

Innovative strategic advocacy appears to be underpinning the expansion of care provision (and policy). However, in order that this expertise can be understood and shared, and that successes to date can be replicated, a greater understanding of strategic advocacy is needed. Clear descriptions of advocacy frameworks and activities already implemented, together with evaluation of advocacy initiatives, will both be highly valuable to those wanting to replicate the apparent successes in expanding paediatric palliative care in sub-Saharan Africa.

## 6. DISCUSSION

### 6.1. THE AVAILABLE EVIDENCE

The available body of data was small. The study by Henley et al (2002) is useful in that (using a simple retrospective file review), it identified current gaps in clinical care, which included a lack of comfort care plans in patient notes, poor recording of pain and distress in the final hours of life, and poor prescribing of adequate analgesia (121).

Although palliative care is expanding across many sub-Saharan African countries, some are more advanced in a public health and integrated approach than others. The evaluative evidence for paediatric palliative care identified in this report was focused on South Africa and Uganda, which are two countries commonly recognised as having achieved significant advancements. If a research active field of paediatric palliative care is to be developed, it is likely that investment in areas with markers of success may facilitate replicable models of paediatric care. One conference abstract (Mwangi, 1994) described a model in Kenya that has since shifted away from hospice care, but suggested that social aspects of hospice care, such as initiatives to reduce HIV stigma, can increase the numbers of children who return to their families from institutional care (125).

The study by Uys (2003) is a useful mixed-methods study that, while it did not report separately on adult and paediatric care, usefully identified the training needs of staff in delivering counselling to children, together with wider palliative care training needs across diverse settings, through its examination of a model of integrated home-based care (122).

Only two papers were found that reported studies of paediatric palliative care services. The study by Amery et al (2009) is an important study as it is the first to examine the impact of a children's palliative care service and identifies important service developments, including referrals, proportion of service users that are children, drug interventions and compliance (123). Its valuable description of the service development offers evidence that can inform replication, and the next step will be to develop methods and tools to begin to measure outcomes at the patient level. The study by Harding et al (2009) informs the interface between palliative care and ART, an area often understood to be a new and essential direction for palliative care but lacking research attention (124). This study demonstrates that

palliative care (in this case in a hospice setting) is an appropriate place to initiate children with advanced disease on to anti-retroviral therapy and enable them to maintain and respond to their regimen. Much more clinical research attention is required in this field.

Palliative care is often termed a ‘complex intervention’, ie. it is multidisciplinary and multidimensional and delivered according to need across a variety of settings. As often found in papers 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 reduces opportunities for replication. More detailed reports (and longer online publication of journal papers) should be encouraged. The lack of available data may also be a reflection of the lack of disaggregation between adult and children’s outcomes, although it should be noted that the previous appraisal identified very little evidence of adult outcomes for palliative care interventions.

The wealth of experience but dearth of evidence reported in the appraisal of adult palliative care is even more strongly evident here. Despite a body of experts highly active in the field, the lack of time, resources, expertise and appropriate methods/measures has precluded good documentation of activity and outcomes.

## 6.2. STUDY LIMITATIONS

It is important to clarify that lack of evidence does not equate to lack of good practice in clinical care; simply that there is no reported evidence to support and develop what is currently being achieved. We conducted an exhaustive search using a very large contact list and searches of grey and peer review literature, but found very little. As so little was found in the adult appraisal, the small body of papers identified here is perhaps not surprising.

## 6.3. CAPTURING CURRENT KNOWLEDGE AND GENERATING EVIDENCE

Although very little grey or peer review data was identified, the protocols that are available for children suggest that there is both a large body of NGOs working in the field and expertise in clinical care, and that there are innovative models currently not captured by the literature. Without investment in time and resources to capture this expertise, and without the description of care models, others are unlikely to be able to learn from and replicate the existing work.

Another, and fundamental, challenge a lack of evidence produces is that, in the absence of evidence of effectiveness, it is difficult to attract funds, educational input, service development and policy change.

Simkiss (2003) identified the challenges to paediatric palliative care to be developing provision beyond centres of excellence, furthering understanding of children's perception of pain and illness and focusing on effectiveness in community based programmes (130). The study goes on to conclude that addressing these challenges will require a focused research effort on African children's understanding of pain and illness and on children's wants and preferences with respect to their illness and treatment. This approach, in which research activity leads the development of paediatric palliative care, is essential.

This appraisal of the evidence has identified the current gaps in the peer-reviewed scientific research base. As the base is so underdeveloped with so little published evidence, and because there is also a need for improved methodology to enhance the robustness and reliability of the existing evidence, the immediate priorities must now be identified.

Consultation with multidisciplinary palliative care practitioners is advocated as a mechanism to generate an agenda of priorities that reflects current clinical challenges. There are existing examples of this approach being used in palliative care to identify medical research priorities using international survey methods (131); in the field of children's hospice care across a wide range of stakeholders using Delphi approaches (132); and in paediatric palliative care, using Delphi techniques across multidisciplinary practitioners and researchers (133).

As the previous appraisal concluded (6), the challenge is to expand coverage of palliative care for children while maintaining the quality of existing services. However, the additional challenge in the field of paediatric palliative care is that there is even less evidence available, and that coverage appears to be even narrower. A systematic review of the measurement and outcomes of health-related quality of life of children with HIV infection in Africa (under 18 years of age) found no measures or data (134). However, we anticipate that the publication of a fully validated African palliative outcome scale by the African Palliative Care Association that has been developed in a number of African settings will facilitate the development of an evidence base.

A further paper, which describes an African cancer palliative care team's responses to dying to children and their families in comparison to the experiences shared with colleagues from Europe, demonstrated that much can be done that is responsive, cheap and effective in the face of overwhelming numbers of child deaths (135). This brief paper gives a strong message that palliative care can achieve much in Africa without necessarily replicating what is done in high-income countries.

Although we have identified a lack of an evidence base, we also recognise the specific methodological challenges of conducting palliative care research in sub-Saharan Africa (136), and the additional challenges of paediatric palliative care research (137). Models of care that are developed within African settings and appropriate to local needs and resources are essential. Service development should use good research-based approaches, and be evaluated in terms of costs, activity and outcomes, if they are to influence policy, funding and practice.

## 7. RECOMMENDATIONS

### 7.1. OUR KEY RECOMMENDATIONS ARE:

1. Researchers urgently need to provide evidence in paediatric palliative care across the fields of intervention/service development, activity, outcomes and costs.
2. Funding bodies should support the conduct of research in order to establish a body of evidence to support, and advocate for, paediatric palliative care.
3. Practitioners should ensure that paediatric palliative care needs are assessed and interventions delivered as an essential integrated component of HIV (alongside ART as necessary) and cancer care throughout the disease trajectory.
4. Policy-makers should ensure that the role of palliative care research in improving care, and how to conduct research in this population, should be taught as part of paediatric palliative care curricula.

### 7.2. OTHER IMPORTANT RECOMMENDATIONS

#### For researchers

5. The clinical and public health paediatric palliative care research agendas for sub-Saharan Africa need to be scoped.
6. The epidemiology and needs of children with non-malignant, life-threatening and life-limiting conditions should be identified.
7. In order to begin to measure and improve the care of children, multidimensional tools that capture the needs and priorities of African children and their families, and approaches to scoring using appropriate methods, are urgently required for development and full validation.
8. Evidence of appropriate models and their effectiveness are required across settings, especially in acute inpatient and home-based care

settings. Evaluative studies are needed to build on the papers that report interventions.

9. Models for clinical audit of paediatric palliative care, with simple guidance for their conduct, are needed.
10. Existing symptom measures should be revalidated in this population to determine whether the items and scoring methods used are appropriate.
11. Differing needs according to diagnosis, stage of disease and developmental stage should be determined in order to inform appropriate clinical practice.
12. Interventions to support the emotional and psychological needs of children appropriate to an African setting must be developed and evaluated.
13. The needs of family members of a dying child need to be determined in order to maintain informal care and avoid crisis intervention.
14. The bereavement needs of families are not yet understood and should be investigated to inform models of intervention.
15. High-quality evidence is urgently required to determine the added benefit of palliative care for those children accessing ART.
16. Advocacy strategies to improve the coverage and quality of paediatric palliative care should be evaluated and disseminated.

#### For funders

17. Individuals and organisations should be given appropriate support to develop an African academic discipline of paediatric palliative care with strong research, education and clinical links, and support from existing experts in adult palliative care research.
18. Practitioners must be given the resources to capture their innovation and successes and support to write up and appraise their existing services.

19. High-quality holistic assessment and intervention using the palliative care ‘total care’ model should be integrated into existing paediatric care services.

#### For practitioners

20. Sensitivity to cultural beliefs and practices must inform care delivery, and may differ within and between countries.

21. Services should offer interventions and transitions appropriate to age groups and developmental stage.

22. Acute pain services that are currently providing palliation to children should be supported to work within the broader dimensions of palliative care.

23. Appropriate methods of child participation to help plan and research palliative care should be developed.

24. Holistic assessment and care should ensure that the needs of the wider family unit are understood and met where possible.

25. In order to manage the anxiety of a dying adult, the needs of their children must also be adequately assessed and managed.

26. Appropriate models of bereavement care need to be designed and evaluated.

27. Using audit methods, appropriate outcome tools should be incorporated into routine practice in order to measure and improve care using audit methods.

28. Healthcare providers urgently need training in communication skills and the expert guidance of palliative care practitioners.

29. Advocacy agents should capture and disseminate successful advocacy strategies to enhance the coverage and practice of paediatric palliative care.

### For policy-makers

30. Cancer registries should be supported to ensure comprehensive data collection that can determine the epidemiology of progressive cancer among children.
31. The existing evidence on the cost effectiveness of adult palliative care should be taken into account when planning care for children.
32. The existing published palliative care protocols should be advocated within all care facilities that provide care to children with life-limiting illnesses.
33. Clinical academic partnerships should be fostered to deliver truly translational research that is informed by clinical experts, and directly improves outcomes for children and their families.
34. Care facilities should be encouraged to measure their activity.

## 8. ACKNOWLEDGEMENTS

We are grateful to The Diana, Princess of Wales Memorial Fund for supporting this study, and to all the respondents who took the time to provide information.

## 9. USEFUL RESOURCES

### 9.1 WEBSITES

The following websites have a range of information and useful resources about paediatric palliative care.

#### ACT

ACT works across the UK to achieve the best possible quality of life and care for every child who has a life-limiting or life-threatening condition and their family.

[www.act.org.uk](http://www.act.org.uk)

#### Coalition on Children Affected by AIDS

The Coalition on Children Affected by AIDS is a collective of private and public foundations and re-granting organisations in the global North and South. It works to improve the lives of children infected by and affected by HIV/AIDS, aided by key technical experts.

[www.ccaba.org](http://www.ccaba.org)

#### International Children's Palliative Care Network (ICPCN)

A worldwide network of individuals and agencies working with children and young people with life-limiting conditions.

[www.icpcn.org.uk](http://www.icpcn.org.uk)

#### Baobab Paediatric Palliative Care Virtual Resource Centre

A South African web-based virtual resource centre developed by the Hospice Palliative Care Association of South Africa (HPCA) for professionals caring for children with life-limiting and life-threatening illnesses in South Africa.

[www.baobabppc.org.za](http://www.baobabppc.org.za)

### 9.2 FURTHER READING

Basic Symptom Control in Paediatric Palliative Care: the Rainbow Children's Hospice Guidelines. Dr. Satbir Singh Jassal et al (2008) provides comprehensive guidelines for treating a wide range of symptoms experienced by children with life-limiting or complex health conditions.

Children's Palliative Care in Africa. Edited by Justin Amery et al, Oxford University Press (2009) Written by a group with wide experience of caring for children with life-limiting illnesses in Africa, this textbook addresses key palliative care themes, which are crucial to expanding the provision of children's palliative care in Africa.

Available to download free of charge from [www.icpcn.org.uk](http://www.icpcn.org.uk) or for purchase from Oxford University Press.

Hospice Care for Children. Edited by Ann Armstrong-Dailey and Sarah Zarbock, Oxford University Press USA (2008) is a comprehensive resource emphasising practical topics and covering the range of issues related to the hospice environment. It describes several different models of care, the developmental stages of children's understanding of death, the crucial aspects of pain and symptom management including psychological distress and also discusses the special circumstances of neonatal and AIDS-related deaths. It also offers practical advice for providing emotional and spiritual support to staff, grieving parents, and surviving siblings, as well as tips for teachers and classmates who interact with these children.

Oxford Textbook of Palliative Care for Children. Ann Goldman, Richard Hain, Stephen Liben, Oxford University Press (2006) explores both the clinical aspects and the multidimensional and holistic nature of care for the dying child, covering ways of providing support in all of these areas both for the child, families and carers and recognising the importance of teamwork and taking an evidence-based approach.

Palliative Care for Children and Families: An Interdisciplinary Approach. Edited by Jayne Price and Patricia McNeilly, Palgrave Macmillan (2009) provides an in-depth look at the issues surrounding the palliative care of children, considering both malignant and non-malignant cases, and the specialist treatment required.

Perspectives on Palliative Care for Children and Young People: A Global Discourse. Edited by Rita Pfund and Susan Fowler-Kerry, Radcliffe Publishing (2010) A global discussion of caring for children with life-limiting illnesses in a world where some children survive and live out a normal life expectancy, some have a life-limiting/life-threatening diagnosis where death may come early, and others live on well past projected life trajectories into adulthood.

Promoting Early Childhood Development within Paediatric Palliative Care. Compiled and written by Sue Boucher, Hospice Palliative Care Association of South Africa (HPCA) (2007) is a practical resource handbook to assist those working with children, focusing on promoting early childhood development.

Contact the HPCA for further information at [www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za)

Toolkit for Children's Palliative Care Programmes in Africa. Compiled by Joan Marston, Maraliza Robbertze and Sue Boucher, Hospice Palliative Care Association of South Africa (HPCA) (2008) aims to assist sites both within South Africa and across the African continent to begin or to develop palliative care programmes for children.

Contact the HPCA for further information at [www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za)

When Children Die: Improving Palliative and End-of-life Care for Children and their Families. Edited by Marilyn J Field and Richard E Behrman, National Academies Press (2003) examines what is known about the needs of children with life-limiting illnesses and their families, the extent to which such needs are and are not being met, and what can be done to provide more competent, compassionate and consistent care. The book offers recommendations for involving child patients in treatment decisions, communicating with parents, strengthening the organisation and delivery of services, developing support programs for bereaved families, improving public and private insurance, training health professionals and more.

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## THE DIANA, PRINCESS OF WALES MEMORIAL FUND

The Diana, Princess of Wales Memorial Fund continues the Princess' humanitarian work in the UK and overseas. By giving grants to organisations, championing charitable causes, advocacy, campaigning and awareness raising, the Fund works to secure sustainable improvements in the lives of the most vulnerable people in the UK and around the world.

The Fund's [Palliative Care Initiative](#) aims to ensure that palliative care is integrated into the care and treatment of people with HIV/AIDS, cancer and other life-limiting illnesses in sub-Saharan Africa.

Over the past two years, the Fund has stepped up its investment in the development of palliative care for children, and is currently engaged in a range of activities designed to increase understanding about and widen access to high-quality children's palliative care, and to expand the capacity of countries in sub-Saharan Africa to provide it.

The Fund's work includes [scaling up services](#), [developing training](#), [advocacy](#) and [research](#), and is carried out through effective and dynamic partnerships in its seven countries of focus (Kenya, Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe) and through collaborations with others in the UK and the United States.

### EDUCATION AND TRAINING

- In 2003, the Fund supported the development of a curriculum for paediatric palliative care at the Hospice and Palliative Care Association of South Africa (HPCA).
- In 2005, the Fund gave a series of grants to South African palliative care organisations to develop and run paediatric training courses as part of a joint funding initiative with the Nelson Mandela Children's Fund and the Open Society Institute's International Palliative Care Initiative.
- The Fund published a toolkit for developing children's palliative care programmes in African settings in 2008 and funded *Children's Palliative Care in Africa*, a seminal textbook for health professionals in 2009 (Oxford University Press).
- The Fund is supporting the development of three beacon training centres for children's palliative care in South Africa, Tanzania and Uganda. This is the major investment and includes the development of several curricula.

- The Fund is supporting the development of a training package on home-based palliative care for children under 7 infected with HIV and their primary caregivers, which will be published in 2010.

#### ADVOCACY

The Fund is currently funding the salary of a children's palliative care expert employed by the Hospice and Palliative Care Association of South Africa (HPCA) for four years. The post-holder's brief is to develop children's palliative care in South Africa and regionally.

#### RESEARCH

The Fund is currently supporting research on a children's palliative care training analysis and an assessment of a children's palliative care course.

The Fund is also a member of the [Funders' Collaborative for Children: Malawi \(FCFC\)](#), a major collaboration with three other donors to model the provision of a complete package (education, health social care and livelihoods) to children infected and affected by AIDS.

An evaluation of the Fund's children's palliative care portfolio will be published in 2012.