THE STATUS OF PAEDIATRIC PALLIATIVE CARE IN SUB-SAHaran AFRICA - AN APPRAISAL
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EXECUTIVE SUMMARY
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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
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EXECUTIVE SUMMARY

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.

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.

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.
**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.

- Rollout of paediatric 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.

- 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-review 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.
RECOMMENDATIONS

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.
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.

Electronic copies of the full report are available to download from:
- the CD on the inside back cover of this report or
- www.theworkcontinues.org or www.kcl.ac.uk/palliative.
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 disadvantaged 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 it 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.

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