Palliative Care in Sub-Saharan Africa: An Appraisal
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“HIV/AIDS has made medicine understand that if it is only focused on cure and ignores suffering it is not doing its job. It has made the call for what palliative care is all about imperative, and the role of palliative care in fighting HIV/AIDS inevitable. The amount of suffering is simply too great, and the promise of cure, for many, too distant. Palliative care provides an effective model for integrating many aspects of care that are essential in the fight against HIV/AIDS. Obviously the model will be quite different in Windhoek than Washington.

This report offers an overview of existing palliative care models in Sub-Saharan Africa and provides an excellent foundation for donors, policy makers and practitioners wishing to scale-up palliative care provision in Sub-Saharan Africa.”

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FOREWORD

Despite lack of access to effective treatment for people in the developing world affected by HIV/AIDS and other life-limiting illnesses, the availability of palliative care continues to be extremely limited. Millions of people and their families suffer unnecessary pain and distress for want of access to palliative care, a simple and affordable approach which could so readily be incorporated into the work of every doctor, nurse, family member or volunteer. While there is hope that treatment for HIV/AIDS with Highly Active Anti-retroviral Therapy (HAART) will become much more widely distributed, it is not a cure and palliative care is still needed to support people accessing HAART.

Diana, Princess of Wales had an enduring commitment to people facing life-limiting illnesses. With her genius for making human connections, she was intuitively at ease with others’ impending death while focusing her attention on life in the present and on how to make it the very best it can be. She understood that the needs of sick people, as well as of their loved ones, are not only medical and physical, but also mental and emotional - the need for relief from physical pain, but also the need for love, resolution and peace of mind. It is therefore appropriate that her Memorial Fund should take up the challenge of promoting palliative care in the developing world through the work of its Palliative Care Initiative, established in 2001.

This programme of grants and advocacy, focusing at present on sub-Saharan Africa, aims to influence policy and raise public awareness in support of palliative care. Our goal is to ensure that palliative care becomes an integral and properly funded part of public health policy in every country in the region. This is being achieved through supporting local ‘champions’ who provide palliative care, promoting training for doctors, nurses, health workers, carers and volunteers, and advocating for the availability of drugs for pain relief and symptom control.

There is now a wealth of experience in sub-Saharan Africa about the ways in which palliative care can be delivered both affordably and effectively. However, as this excellent report shows, there remains lack of properly documented evidence and research to demonstrate the importance of this work and promote its development. If palliative care is to grow as a widely available specialty delivered to a high standard, then it is vital that the evidence base is increased. We hope that the report, with other mapping work commissioned by The Diana, Princess of Wales Memorial Fund, makes a useful contribution to this effort, as well as providing a source of reference for policy makers, practitioners, donors and researchers interested in this vital issue.

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Chair
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1. Executive summary

Rationale

Palliative care aims to maximise quality of life and relieve the suffering of patients with life-limiting incurable disease, and to support their families and carers. It is provided through specialist services such as hospices and palliative care teams and in general settings. The HIV/AIDS pandemic and rising cancer rates in Africa have increased the need for well-developed and integrated palliative care services. In sub-Saharan Africa, the concept of palliative care is not well developed and palliative care is largely confined to isolated specialist centres. Services have developed, but in very varied ways. In order to inform future developments, this review aimed to identify and appraise activities, opportunities and evidence of the status of palliative care in Africa.

The World Health Organisation (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Methods

Two key sources of information were investigated: firstly, electronic biomedical databases, and secondly prepared reports from funders, non-governmental organisations (NGOs), associations and practitioners. The evidence was analysed according to various headings: context, potential role, current models, and opportunities in relation to sustainability and quality of palliative care.

Main findings

The sub-Saharan African context of palliative care

In 2003 there were 26.6 million people in sub-Saharan Africa living with HIV, 3.2 million new infections and 2.3 million AIDS-related deaths. In addition, there are more than 0.5 million annual cancer deaths, and cancer rates in Africa are expected to grow by 400% over the next 50 years. 80% of cancer patients present with advanced incurable disease.

Although the definition of palliative care is globally relevant, what constitutes palliative care needs and services in sub-Saharan Africa is continent-specific, particularly in the light of poverty and HIV disease. Necessary components include practical care, pain and symptom...
control, counselling/emotional/psychological support, income generation, financial support for food, shelter, funeral costs and school fees, respite, spiritual support and orphan care.

5 Within Africa there are diverse attitudes towards death and dying informed by multiple meanings and traditions. This has important implications for the identification of appropriate models and places for end-of-life care. Traditional healers are often the first place where help is sought in both cancer and HIV/AIDS.

6 There are significant structural and resource challenges to establishing sustainable palliative care: resource limitations and poor infrastructure, poor access and regulatory limitations on drug procurement (particularly opioids), funding uncertainty and patient inability to pay, high rates of healthcare, staff mortality, and lack of clinical skills training.

7 Patients and families need emotional and psychological support, but these are rarely identified. Few such interventions for sub-Saharan African clients have been described.

The role of palliative care in HIV management, including antiretroviral therapy

8 Palliative care should be integrated into the management of HIV disease throughout the disease trajectory, from diagnosis to the end of life. The necessity for palliative care throughout the disease course is evidenced by both Western and sub-Saharan African data, with a high prevalence of pain and manageable symptoms from the point of diagnosis. Although the terminal management skills of palliative care are still necessary, patients who access palliative care need not be at the end-of-life.

9 Although pain prevalence is high throughout the HIV/AIDS disease trajectory, HIV/AIDS care has historically relied on home-based care without adequate pain and symptom control. Home care providers have recognised this inadequacy, and termed it “home-based neglect”.

10 Palliative care is necessary to support current and planned antiretroviral therapy funding initiatives. The clinical data is clear: poor adherence/toxicity/side effects/drug resistance, virologic failure, adverse reactions, and peripheral neuropathy. Some HIV-associated cancers have not reduced greatly in incidence, and the psychological and spiritual needs of people with HIV persist. Even in those countries with universal access to antiretroviral therapy, people with HIV disease continue to die at a higher rate than the uninfected. Palliative care can promote adherence and manage tolerance and also provide end-of-life care for this for whom treatment is unavailable or fails.
Current models of care

11 The core steps to service development are advocacy (national policies and guidelines), integration of palliative care into the continuum of care, education and training, drug access and data systems, and the need for opioids is fundamental to palliation. However, it is not yet clear how these steps translate into specific feasible, acceptable accessible and effective models of care at the service level. Although innovation has led to a diversity of models, the need for accessible quality services remains a crucial issue.

12 Where available, palliative care appears to be provided by highly trained individuals, but unfortunately does not reach many people who need it.

13 Grafting palliative care onto existing networks of home-based care that currently offer inadequate pain and symptom control is feasible. Other systems include referral to specialist services, nurse prescribing of morphine, and lay/professional protocol-led patient management manuals.

14 Home-based care is by far the most common model of palliative care provision, a resource-led decision in response to high numbers of patients and modest resources, thereby maximising coverage and sustainability. The home-based care offers flexibility and increased potential for culturally appropriate care, but is limited by the suitability and availability of a home and family care network, and by the geographic area that can be feasibly covered by palliative care providers.

15 Innovation has led to specialist and integrated palliative care being delivered by diverse models of care across settings, and in several cases has been developed in the absence of additional resources. Specialist palliative care centres are a focus for interested practitioners, advocacy, policy, resources and education, and have an important role in developing countries.

16 Referral networks and coverage maximisation are primary concerns in connecting patients with palliative care needs to quality services. In rural areas where doctors are rare, training at all levels is required. In urban areas, specialist palliative care hospital consultancy as well as the mainstreaming of clinical education are required.

17 Although there are many potential models of delivery, the palliative care approach can be employed by every doctor, nurse and volunteer, it can be simple, and protocol driven. The use of simple palliative care manuals is an excellent example of maximising skills at the appropriate levels.
Community involvement, particularly the use of volunteers to identify those in need, appears to be successful. However, the capacity and methods of volunteer recruitment and retention are still unclear. The diverse and innovative methods of incentives, training and support require further evaluation to ascertain how replicable they are.

Quality assurance

Community-based TB care has been shown to be more effective than institutionalised care, and palliative care services may benefit from the systems and operational research undertaken in TB care. Integration of HIV care, antiretroviral provision, TB care and palliative care may offer economies of scale as well as access to palliation at those points in time when patients could benefit from the approach.

Factors for success in community care include: realistic aims in the light of apparent limitations; political will and support; long-term goal setting and adequate time allocation for success; optimal referral systems.

Palliative care services clearly need to be scaled up in the light of low coverage and high need. Significant resources are needed to ensure that educational and training gains are employed in the workplace and that momentum is retained. Currently, although advocates for palliative care have achieved much, evaluations of advocacy activities are not undertaken.

Providers report a need for technical support in measuring and auditing quality of care. This is reflected in the general absence of evidence for development, outputs and outcomes, although some services have described measurement and assessment activities in annual reports. The poor recording of data was frequently reported.
Recommendations

For practitioners

1 Models and place of care must take into account local understandings of health and illness, and replication of models must consider feasibility and acceptability. Traditional healers form an important element of health services, and should be included in care provision through training and co-management of some symptoms and side effects.

2 The Western-originated palliative care model must be adapted to the needs and context of sub-Saharan Africa, and what constitutes a holistic total palliative care service in Africa should be designed at the outset of provision.

3 Pain and symptom management, and support, must be provided throughout the disease trajectory from diagnosis to end-of-life. In particular, enormous need and opportunity reside in the many HIV home-based care providers who should be encouraged and enabled to incorporate palliative care.

4 Efficient referral systems must be established to connect those in need to palliative care services. These services may be professional or lay, and can operate between various settings, e.g. hospital/specialist consultancy, generic/specialist co-management, community volunteer/specialist. Resources must be anticipated to address the likely increased uptake. Palliative care does not need to be provided in all care settings. If effective referral systems are in place generalist providers who do not wish to meet opioid storage regulations can ensure their patients receive palliation when required.

5 Emotional and support needs, particularly of families and carers, should not be overlooked. Further understanding and service responses are needed to meet these poorly explored needs.

6 A simple method to increase palliative care skills and coverage is the use of protocol-led care manuals identifying steps for the assessment and management of pain and symptoms. Widespread use of such manuals should be encouraged to disseminate the view that palliative care can be simple, protocol led and employed by all health care staff.

For funders

7 Clinical training must be mainstreamed in order to maximise coverage by placing palliation skills in all health settings. However, following training, resources must be allocated to enable continuity and application of skills learned.
8 It is not feasible for a single funder or provider to take responsibility for the resources and skills required to meet total need in the sub-Saharan African context. Co-ordination and multisectoral responses must be pursued to meet patient and family needs.

9 Antiretroviral programmes require palliative care integration in order to maximise adherence and clinical benefit through the management of toxicities and side effects. Also, funding for ethical health services requires palliation for those whom the treatment fails, who continue to develop life threatening advanced disease, or are unable to access therapy.

10 Funders should support advocacy activities to promote and sustain palliative care in sub-Saharan activities. Advocacy programmes must be subjected to evaluation to measure their success in reaching stated objectives.

For policy makers

11 Palliative care must be a public health priority in the light of current and projected need particularly in response to the HIV epidemic and increasing cancer incidence. The absence of palliative care is associated with unacceptable levels of poorly managed pain and symptoms.

12 The availability of opioids is fundamental to adequate pain relief, and must be guaranteed through legislative efforts and efficient drug supply services where necessary.

13 Diversity and innovation are key features of palliative care development in the diverse resource-poor settings of sub-Saharan Africa. However, a strategic approach is necessary to achieve palliative care delivery, incorporating advocacy (national policies and guidelines), integration of palliative care into the continuum of care, education and training, drug access and establishing data systems.

14 Explicit strategic approaches are needed to harness the twin approaches of advocacy for palliative care and community-level delivery. With respect to advocacy, the significant gains to date have been largely achieved through the advocacy goals of individuals not strategy. Further investment in developing sub-Saharan African “champions” of palliative care, within national and international strategies, may harness gains to date for longer-term sustainable growth. Advocacy activities should be evaluated.
For researchers

15 Systematic attention must be given to feasibility, acceptability, accessibility, effectiveness and designing specific models of care at the service level. The need for innovative, quality, accessible services remains a crucial issue.

16 Community-based care projects offer feasibility, optimal coverage, and active referral networks. However, replication of successful demonstration projects would benefit from further process evaluation and description of resources and potential weaknesses, as well as further understanding of the clinical support and community capacity to care.

17 In order to generate evidence for effectiveness grounded in the African context, funders must support research and technical assistance for their services across policy, advocacy, development and care objectives. An evaluative programme is required with respect to domains of process, feasibility, acceptability, accessibility and outcomes. To achieve this, technical expertise in measurement design, service goals setting and development, client assessment, quality measurement, audit and outcome research are required.
2. **Background**

2.1 What are the aims of palliative care?

Palliative care aims to maximise the quality of life and relieve the suffering of patients with life-limiting incurable disease. It also focuses on the provision of care and support for their carers and families. The breadth of support and intervention addresses the clinical needs of patients such as pain and symptoms as well the psychosocial, social and spiritual needs of those affected during the disease trajectory.

The World Health Organisation (WHO) defines palliative care as (1)

> “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

In recent years, the traditional view of palliative care as a specialism that is introduced into patient management solely at the end of life has been modified, and the emphasis is now 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. For people in sub-Saharan Africa with a terminal illness, there is need for the introduction of a greater component of palliative care earlier in the disease course. This is due to the lack of access to antiretroviral therapy for people with HIV disease, and the late presentation, inadequate diagnostic facilities and assessment skills, poor chemotherapy and radiotherapy availability for people with cancer.
3. **The review: aims and methods**

There is a wide body of literature established on palliative care in developed countries. This review sought to be a thorough appraisal of the sub-Saharan African context. It has taken a broad approach including the cultural context, epidemiology, practice and research issues, and has, therefore, sought to address the main issues of palliative care in sub-Saharan Africa and to be a source for current literature and resources.

This study aimed to:

1. Describe the sub-Saharan African context for palliative care with respect to epidemiological need, cultural understandings and responses to health and sickness, and structural challenges.

2. Explore the interface and potential for palliative care to improve patient outcomes in HIV/AIDS particularly with reference to antiretroviral therapy in sub-Saharan Africa.

3. Identify and appraise existing descriptions and evaluations of palliative care projects in sub-Saharan Africa, with an emphasis on isolating the factors that lead to sustainability, local ownership and coverage.

4. Identify and appraise evaluations of other primary health based care projects (principally in Malawi and Kenya, which are two of the 8 countries where the Fund currently supports work and are countries with comparatively different levels of resources) that could provide lessons and opportunities for the implementation of palliative care.

5. Identify models of TB care that may offer parallel opportunities for the delivery of palliative care.

6. Explore principles of scaling up and sustainability with respect to palliative care in sub-Saharan Africa.

7. Identify any evaluations of advocacy initiatives.

**3.1 Methods**

Two key sources of information were investigated. Firstly, the electronic biomedical databases were searched and reference lists subsequently hand searched (see appendices). Secondly, funders, non-governmental organisations (NGOs), associations and practitioners involved in palliative care in African countries were identified and contacted, and were requested to provide prepared reports on their activities.
3.1.2 Obtaining prepared reports

In order to obtain as many relevant reports as possible, advocates and associations related to palliative care in Africa were approached to assist in obtaining materials for this review. A high level of co-operation was achieved, and subsequent requests for information were posted on electronic mailing lists and websites by the Worldwide Hospice and Palliative Care Online, The International Association for Hospice and Palliative Care, PROCAARE, The Foundation for Hospices in Sub-Saharan Africa, the Hospice and Palliative Care Association of Southern Africa, and the Hospice Association of Zimbabwe. In addition, approaches were made to identify relevant contacts from funders, NGO's, health care organisations, trainers, providers, researchers and key advocates. Respondents to a recent survey of HIV end-of-life care providers in sub-Saharan Africa (4) were re-contacted.

3.1.3 Data extraction from service reports and evaluation data

The data from papers and reports were extracted into themes, each of which sought to answer the review primary questions. In addition, common tables were designed 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 compared, and to encourage and facilitate greater consistency in future data collection.

Table 1 presents service descriptions, and data are extracted into country, service type, service description, care statistics, service development issues and lessons learned. Table 2 presents research findings under the headings of study aim, sample, findings and comments. Tables are reproduced in the appendices.

3.1.4 Report structure

A summary of findings is provided at the end of each of the chapters.

Firstly, the report aims and findings are contextualised, using sub-Saharan African data with respect to epidemiology, cultural dimensions to end-of-life, the role of traditional health providers, structural and resource implications, definitions of palliative care with respect to the “total care” needs of patients in sub-Saharan Africa, and the need for paediatric palliative care.

Secondly, the palliative care and HIV interface in sub-Saharan Africa is explored, with an emphasis on the role of palliative care in both home-based care and the coming era of antiretroviral therapy in sub-Saharan Africa.

Thirdly, models of palliative care relevant to sub-Saharan Africa are explored with respect to the debate on integration throughout the disease trajectory versus end-of-life care, systems of referral and levels of coverage, and the primacy of home and community care.
Fourthly, the obtained service reports and evaluation data are presented in tabulated format.

Fifthly, care systems for people with TB are explored and the potential for palliative care to parallel these methods are explored.

Sixth, health care projects that have articulated concepts of primary and community care and empowerment are identified and explored with regard to similarities and potential for palliative care.

Seventh, the key tasks in expanding palliative care are explored: policy, strategy, national regulations and advocacy.

Eighth, the need for evaluation is presented, with recommendations for an ethical approach to evaluation audit and quality care measurement.

Lastly, conclusions and recommendations are drawn from the body of the report.
4. What are the contextual variables of palliative care specific to sub-Saharan Africa?

Although quality of care at the end of life is a global public health problem, it is focused in the main on developed countries (5). The fundamental question has been posed of whether palliative care is appropriate or possible in developing countries (6). Although this question is certainly appropriate, acceptability has been proven in both expanding uptake and provision across sub-Saharan African. However, the question of what constitutes feasible, accessible and effective diverse models for African countries remains.

These questions can only be explored and understood by first addressing the context of palliative care in sub-Saharan Africa. The HIV epidemic in sub-Saharan Africa is the first and most obvious difference between the epidemiology of terminal disease in sub-Saharan Africa and the developed world, and is compounded by the high levels of poverty and resource scarcity. The cultural beliefs that underpin health, sickness and societal responses, the structural limitations with respect to health care systems, and what constitutes the broad range of needs under palliative “total care” also need to be identified in order to ground palliative care in the sub-Saharan African context.

4.1 The epidemiology of terminal illness in sub-Saharan Africa

UNAIDS estimates that in 2003 there were 26.6 million people in Sub-Saharan Africa living with HIV, and that there were 3.2 million new infections and 2.3 million AIDS-related deaths (7). In addition to high HIV-related Tuberculosis (TB) incidence in sub-Saharan Africa (8), a study of Zambian AIDS patients with cryptococcal meningitis found 100% mortality at 6 months, with 43% having received only palliation without curative intervention (9).

Cancer rates in Africa are expected to grow by 400% over the next 50 years (10). This relates to HIV-related cancers (11) (such as non-Hodgkin’s lymphoma, cervical carcinoma and Kaposi’s sarcoma) and to those specific to Africa such as squamous cell neoplasia of the conjunctiva (12). The need for palliative cancer care grows with increasing cancer incidence due to industrialisation (13). The WHO estimates that there are more than 0.5 million annual deaths from cancer in Africa (2) and that by 2020 70% of new cancer cases will be in the developing world (14). The late presentation of cancer patients (it is estimated that 80% of cancer patients have advanced incurable disease at first presentation), inadequate diagnostic facilities, poor availability of chemotherapy and radiotherapy, and absence of the WHO stepladder approach, all increase the need for improved adequacy of cancer pain control in Africa (15). A study of cancer patients in Tanzania in the early 1990’s found that delayed presentation and advanced nature of cancers underlined the importance of palliative care, and stressed the importance of pursuing satisfactory palliation (16).
4.2 Cultural dimensions to end-of-life and palliative care

The “good death” varies both culturally and historically, and interplays with notions of religion, community, and (pertinent to modern debates on the role of palliative care) the length of time from diagnosis to the end of life (17).

Although there is an increasing awareness that patients should be informed of a terminal prognosis in Western medicine, African nations may offer different and varying understandings, a case example being Nigeria, where the clinician’s responsibility is for cure and not conveying “bad news” (18) (19). A survey of Nigerian nurses and physicians’ attitudes and experiences of terminal care found that 73% of doctors and 89% of nurses did not inform patients of their prognosis, despite well over half of those surveyed (55% and 69% respectively) believing that they should do so (18). However, the respondents’ reasons proposed for the benefits of disclosing terminal prognoses were in line with the goals of palliative care: to make peace with the self and family, address spiritual needs, adjust clinical goals, and attend to will writing. The study concluded that cultural beliefs and behavioural practices are difficult but not impossible to modify, and identified education as the key tool for change. Such terminal care education has been achieved in isolated cases for some considerable time (for example as early as 1983 at Island Hospice Zimbabwe), and more recently there have been great achievements in education at professional levels (20), although again this is undertaken in the complexity of cultural belief that may identify the bearer of bad news as the cause of a terminal illness (21).

A discussion paper on traditional African attitudes towards death and dying described many multiple meanings and traditions which carry implications for the identification of appropriate models and places for end-of-life care (22). For example, sick people may be removed from the village to avoid “risk” to the community, or removed from hospital and returned to the community in order to avoid the dangers of crowded wards and toxic Western drugs. A study of Zulu patients’ experience of terminal illness concluded that despite enormous cultural variation in the experience and needs of those with terminal illness, the universal unifying need is for clinicians’ disclosure of their prognosis in an appropriate way (23). The task of providing culturally appropriate end-of-life care has been identified for ethnically diverse populations in Western settings (24). This should remain an element of service design when funding and developing care in sub-Saharan Africa, and underlines the importance of indigenous control over services and also the recognition of cultural diversity within countries.

4.3 Traditional healers

Traditional healers are often the first place where help is sought in both cancer (19) and HIV/AIDS (25), and it is reported that patients with HIV/AIDS use traditional healers in terminal illness proportionately more than those dying of other diseases (26).
An interesting exploration of Malawian curative v. palliative beliefs regarding epilepsy treatment in relation to traditional and medical attributions of cause found that traditional approaches to treatment were rooted in the palliative model, whilst knowledge of and belief in Western models of care were aligned with curative approaches (27). This study demonstrates the potential alliance between traditional and palliative care, and an evaluation of an educational programme for traditional healers found positive gains in knowledge regarding HIV support (28).

The South African government has proposed national registration and training to incorporate traditional healers into mainstream medicine, a model that has been achieved in their national AIDS programme which enlisted healers' services (29). However, a number of acute poisoning cases have been audited from patient hospital admissions following administering of traditional medicines (30). These instances would, it appears, underline the importance of working alongside healers rather than excluding them from training opportunities, and practitioners of modern medicine report a useful co-existence of modern and traditional care of patients. It has been hypothesised that health services have a better chance of being sustainable if they incorporate indigenous health systems, and that traditional healing may have low costs and a community base, both of which contribute to sustainability (31). Working alongside traditional practice is seen to be crucial to patient retention and adherence to pain relief medications (32).

4.4 Structural and resource challenges to care delivery

A comprehensive review of drug supply in sub-Saharan Africa estimated that only a third of the population of sub-Saharan Africa had access to essential drugs (33). The review of systems of drug supply (private, non-profit, commercial and public sectors) identified significant opportunities for improving efficiency and reducing waste through careful selection and quantification, local production, and significant savings in procurement methods, storage and distribution wastage reduction, improving prescription, and rational use of drugs. The study concluded that funding difficulties need not be the main reason for drug shortages, and that systemic changes can improve supply. The lack of pharmacists is also a key factor in drug availability, with the model palliative care country of Uganda reporting that 87% of pharmacists were in the NGO and private sector in 2002, and only 12 in public service, with the majority of hospitals and health centres having no pharmacist (34).

Health care structures vary across cultures, and recognition of varying opportunities and challenges between countries is essential when identifying feasible systems of palliative care delivery (35). The burden of HIV has placed African health systems under particular stress, pushing up public health costs (36), and hospitals experience impossible strain on bed numbers that necessitate community-based palliative care (37). In general, the economic consequences of AIDS (using Namibia as a case study for economic
modelling) are felt across hospital, public health, private and community resources (38).

The structural and resource challenges facing palliative care services emphasise the need to address issues of sustainability, with the associated need to attend to difficult issues such as patient ability to pay and the effects of aid withdrawal (31). The challenges of funding are constant and unsurprising, and resolution requires considerable effort and commitment on the part of services. The example of Arusha Tanzania is of a hospice begun without any resources except existing staff and hospital facilities, and offer an example of reorganisation and role defining to achieve palliative care (39).

Human capital must be taken into account when considering resources for the management of chronic diseases in developing countries (40), and the issue of human resource availability is crucial to establishing ongoing palliative care services. A study of death rates in hospital health care workers in Malawi found an annual death rate of 2% (mainly due to TB and AIDS), and allowing for under-reporting the study predicted that steady death rates would lead to 25% of the current workforce dying over 10 years (41). A study of loss of TB officers from the Malawi national TB programme found 10-15% loss per annum 1993-1997, with Government recalling staff to other/general duties and staff deaths being key reasons (42). In addition, health care workers with HIV disease are expected, in some places, to refrain from providing patient care (43). Further human resources pressure is experienced through the large-scale exposure of palliative care staff to patient loss in the HIV/AIDS epidemic, and some sub-Saharan African hospices are attempting to respond with supportive interventions for their staff (44).

Poor social conditions, criminality and urban violence have been identified as further contextual barriers in effective cancer pain relief in developing countries (45). Examples are given as living in areas inaccessible to clinical staff, or as unsuitable for discharge, and where theft of drugs or medical equipment is common.

As suggested in the section on cultural issues, less than optimal clinical skills and attitudes may be detrimental to quality care, and a survey of West African consultants found limited assessment methods, an absence of psychological assessment, lack of opioids and dosing knowledge and an overall urgent need for clinical training in the management of cancer pain (46).

4.5 What are the palliative “total care” and family needs of patients in sub-Saharan Africa?

Managing disease-related pain in a patient with extreme hunger pains, or teaching a starving and exhausted family to provide care, are pointless exercises that highlight the importance of adapting Western palliative care models (47). A further significant difference is the magnitude of the associated orphan problem, which palliative care staff must plan for when attending the death of a parent/carer. In a rural Western Kenyan community 1 in 3 children
were found to have lost at least 1 parent, and 1 in 9 had lost both (48). The orphan crisis requires care planning to ensure that the burden of death does not impact on future life opportunities for orphaned children (49).

<table>
<thead>
<tr>
<th>Patient and family needs are many:</th>
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<tbody>
<tr>
<td>- Practical care</td>
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<tr>
<td>- Pain &amp; symptom control</td>
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<tr>
<td>- Counselling/emotional/psychological support</td>
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<tr>
<td>- Income generation</td>
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<tr>
<td>- Financial support for food, shelter, funeral costs and school fees</td>
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<tr>
<td>- Respite</td>
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<tr>
<td>- Spiritual support</td>
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<td>- Orphan care</td>
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A survey of the needs for palliative care among terminally ill people in urban Uganda identified key needs as home care, pain and symptom control, counselling and financial assistance for basic needs such as food, shelter and school fees (50). These priorities are corroborated by a study of Kenyan terminal cancer patients who identified physical pain and financial worries as key concerns (51). A review of HIV palliative care in South Africa identified the broad range of domains that a palliative care service must seek to address: practical care, legal help, food and respite facilities and group support (52). A study of household costs during terminal AIDS found comparatively high disease-related expenditure due to longer disease duration, and that funeral costs exceeded annual household income (26).

The WHO 5-country African palliative care project has assessed the needs of terminal patients as the first phase of its community, public health approach to palliative care (2). These multi-country data clearly show that beyond primary clinical need for pain and symptom control, patients’ main self-reported needs are social support, financial difficulties, emotional concerns, spiritual need, and food security.

The WHO study is important in that it identifies a second key set of needs, i.e. those of families and informal carers, who are often under-researched. Family members were found to provide the majority of care, and these carers

A palliative care service in sub-Saharan Africa should offer:
- Pain and symptom control
- Food
- Family support
- Income-generating activities
- Carer-specific training

WHO (2)
reported emotional strain as a result of caring as well as the loss of their own economic productivity. The identification of psychological needs of families in Africa is an original contribution, as it has been postulated that psychological needs are not pressing for patients receiving palliative care in sub-Saharan African. The authors make an important conclusion, stating that a palliative care package should include pain and symptom control, food, family support, and income-generating activities as well as carer-specific training. Also, it is important to remember that reliance on home and community-based care may mean that the carer has to give up work and income is lost. The services in sub-Saharan African often rely on volunteers (e.g. increased referrals by 200% in first 4 months using vigilantes at Hospice Africa Uganda (HAU) (53), and projects should demonstrate good networking success in meeting total care needs of those referred.

An example of the recognition of total care needs in an African palliative care service is that of Island Hospice Zimbabwe which quickly increased its social work staff numbers to achieve parity with nurses in response to the evident needs of patients and families (32). These staff have developed ongoing bereavement services, a further example of the need for psychological services in sub-Saharan Africa. There is a strong need to explore the bereavement process, which is largely missing in service descriptions, with some notable exceptions including the Island Hospice model and HAU where a bereavement service visit is offered with a one-off payment to the hospice.

There is a clear need to focus on holistic palliative care in sub-Saharan Africa: despite the evidence that pain is the primary need, psychological spiritual and social care are crucial (54). Also, beyond the basic need for drugs, finance to address food provision is crucial, as patients refuse medications when they are hungry (55).

When considering psychosocial needs, which are even less clear than clinical needs in sub-Saharan Africa, a model of counselling has been contextualised in a training manual in Southern Africa (56). However, basic lay education and training should not be overlooked, as reported by a survey in Botswana of lay carers of relatives with terminal illness, which found a lack of knowledge particularly in relation to symptom control (57). The importance of exploring patient, family and community priorities is emphasised by a study of the potential for palliative care in Kenya, which suggested that needs and priorities must be locally determined (58). Although family and carer needs are sometimes recognised at funder and policy level (e.g. a USAID discussion paper on palliative care for HIV/AIDS in less developed countries identified the medical elements to be pain control, nutritional support, prevention/treatment of opportunistic infections, medical treatment for symptom management, alternative/traditional healing, and counselling/psychosocial support, home health assistance and care of families (59)), the funding pressure on services addressing needs beyond the patient requires particular recognition.
4.6 Paediatric palliative care

The improvement of palliative care for children is a global concern (60). Poor recognition and under-treatment of paediatric AIDS pain has been identified in industrialised countries (61), and the high prevalence of moderate pain for paediatric HIV/AIDS patients has been attributed to the lack of paediatric treatment strategies (62).

In sub-Saharan Africa, the magnitude of the problem is far greater than in the developed countries where any research and evidence are most likely to have been generated. The significant number of HIV positive orphans in sub-Saharan Africa with palliative care needs have presented a set of complex management issues to practitioners, and have led to the provision of AIDS hospices and orphanages for these children (63). The development of paediatric palliative care services has been described as an enormous challenge, requiring both palliative care expertise with community outreach, and fostering/adoption opportunities for children known to be infected with HIV. The WHO definition of palliative care for children stresses the developmental and psychological aspects of children's needs (35). Few specialist services are described, although Mildmay's holistic model has promoted paediatric care (64), and some rare and useful research work has been undertaken by Child Advocacy International (65).

4.7 Summary of contextual variables

- The epidemiological evidence of the need for palliative care is clear and centres on the HIV epidemic and increasing cancer incidence.
- The resource limitations in diagnosis and treatment are compounded by late stage presentation.
- Responses to need must take account of “African” notions of end-of-life which vary greatly within, and between, countries and over time.
- There is enormous potential for education, change and appropriate end-of-life care throughout settings.
- Strong alliances with traditional healers are necessary for improved care, community engagement and sustainability.
- Structural and resource challenges centre on drug availability, clinical skills and human resources.
- Palliative “total care” needs are self-reported but as yet under-defined in the African context. They are broader than Western models, and psychological needs in particular are under-explored.
- Multisectoral collaborative responses are needed to meet the range of palliative care needs among patients and families. A single provider is unlikely to hold the skills or funding to be able to meet all needs. Paediatric palliative care is a high priority, although palliative medicine may lack treatment strategies.
5. What role should palliative care take in HIV/AIDS patient management in sub-Saharan Africa?

The HIV/AIDS pandemic has severely affected sub-Saharan Africa. The large numbers of people currently living with and dying from HIV disease, the affected communities, and the approaching large-scale introduction of highly active antiretroviral therapy (HAART) offer diverse roles for palliative care in sub-Saharan Africa.

It is suggested that the historical emphasis on HIV prevention in sub-Saharan Africa has been to the detriment of the necessary comprehensive package of HIV care, and that prevention and care (including palliative care) must be seen as intrinsically linked and of equal value (66). The needs of patients with HIV disease cannot be ignored in palliative care; although Hospice Africa began with a stated mission to assist cancer patients, the remit soon changed in the face of the HIV epidemic (67). The epidemic in sub-Saharan Africa has led to a profile of hospice patients that is different to that in other continents (68), necessitating a different set of clinical skills and knowledge. Although the relationship between palliative care and HIV has changed in developed countries, clinicians and health services researchers in both sub-Saharan Africa and developed nations are recognising the “untapped potential of palliative care for AIDS” (69).

The spectrum of HIV/AIDS palliative care needs includes voluntary testing and counselling, early support for living with HIV, effective treatment for opportunistic infections at primary clinic and district hospital levels, management of co-infections (TB, Hepatitis B & C), prophylaxis, management of AIDS-related cancers, rehabilitative care, long-term chronic care e.g. brain impairment, pain and symptom management including palliative and terminal care, home and community-based care and support, and family care (64). HIV/AIDS palliative management should include highly active antiretroviral therapy (HAART), management of opportunistic infections, support in healthy living and rehabilitation within the natural progress of the disease, and pain and symptom control. Active management of the disease is a distinguishing feature, and the funding goals and implications for palliative care here are very different to terminal pain and symptom management, and hospice and palliative care in sub-Saharan Africa is challenged by many competing priorities for health budgets.

5.1 Clinical and epidemiological dimensions

Very little original research evidence has been compiled with respect to clinical palliative care needs among African populations beyond the clear epidemiological basis for care being necessary. Patients with HIV disease who access palliative care are not necessarily at the end of life, and this need for intervention is evidenced by an audit of 85 HIV positive clients at the Mildmay Centre Uganda which found that 77.6% presented with pain, 61% with skin problems, 60% weight loss, 40% respiratory problems, 35.5%
diarrhoea, 24.7% nausea & vomiting, and 20% fevers (64). Sixty-six patients presented with 123 painful conditions, with an average of 1.9 painful conditions per patient. Therefore, integration of palliative care can be seen as appropriate for a full-disease spectrum service population.

<table>
<thead>
<tr>
<th>Palliative care is necessary for quality HIV care</th>
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<tr>
<td>“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” (1).</td>
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5.2 Reducing suffering: the overdue need to include palliative care for people with HIV

Models of HIV care in sub-Saharan Africa have historically not included palliative care, even if the elements that constitute palliative care (e.g. pain and symptom control) are searched as proxies for the specialism (70). Home-based care has been heavily promoted as the means to address the strain imposed by the HIV epidemic, but has sometimes selected elements of palliative care such as pastoral, basic nursing, counselling and family-based home patient care in the face of opposition to donor-proposed funding for hospice care (71). An evaluation of the hypothetical “continuum of HIV care”, using Zambia as an example, singled out palliative and terminal care as missed opportunities in strengthening care (72), and HIV home-based care without palliative care in sub-Saharan Africa has been accused of being “home-based neglect” (73). Even where the description of the elements that constitute comprehensive care in relation to HIV disease has included palliative care (74), its role has been poorly defined.

The need to identify what type of “terminal care” is needed for people dying of AIDS in sub-Saharan Africa, and how best to provide it, has been discussed at health policy and research levels since the early 1990’s (75). However, a review of challenges to providing effective HIV care in sub-Saharan Africa postulated that responses have been modelled on Western systems rather than being tailored to the African environment (76). The role of palliative care may best be locally determined, although consensus may not be achieved. For example, the South African Palliative Medicine Institute (PMI) expanded definition of palliative care aims specifically to provide an integrated approach to the management of HIV/AIDS patients (77), with the aim of offering good quality of life throughout the disease trajectory, although conversely a set of South African-originated guidelines that direct clinicians when to institute palliative care for AIDS patients focuses very much on terminal disease stages (78).

It appears highly likely that there is huge scope to work with HIV/AIDS NGO’s and care providers. A description of who should provide palliative care
identified: health workers provide basic medical and psychological support; family and community caregivers can be trained by health workers to provide prescribed medications and other support and can ensure that the patient is comfortable (1). In addition, home visits and access to health workers should be available when necessary, and carers require support after patients’ death.

An example of a model of home-based HIV palliative care is the Gambian Department of Health guide for HIV Care/Hands on Care Manual (79). The manual describes the necessary continuum of care from symptomatic disease to palliative and terminal care, with a specific section on the terminal patient and pain and symptom management, identifying palliative care as a core element of home-based care. The home-based care team is particularly well described in the manual, with the number of health professionals at each tier recommended per number of patients. Morphine is stated in the drug list as a drug that may be required for patients and would need a clinician for prescribing. The palliative care model is described in detail in home-based care, offering the “rectangles” model of integrated care, with the important statement

“REMEMBER: There is never nothing we can do! We can always give: pain relief and symptom relief, good nursing care, emotional support and spiritual support.”

Steps for pain and symptom management as well as guidelines for terminal care are given in detail. All drugs in the essential drug list are coded according to whether they can be prescribed at the primary, secondary or home care level. The Hands On Care home-based care manual clearly identifies palliative care and directly observed therapy (DOTS) as an essential of home-based care, with the referral flow chart identifying palliative care as deliverable in both primary clinical care and home-based care (80). Family and community skills training as well as care for the carers are integral elements of home-based care projects. Monitoring and evaluation are also included, although clinical palliative care outcomes are not suggested. This project offers a strong contribution to reducing the historical inadequacy of pain and symptom control in HIV/AIDS home-based care.

5.3 Antiretroviral therapy requires palliative care

The forthcoming expansion of highly active antiretroviral therapy (HAART) provision presents a significant opportunity for the promotion of palliative care. The clinical perspectives and data to support the integration of palliative care into HAART provision is clear (11): 40-50% of patients experience virologic failure within 12-24 months of initiating HAART due to poor adherence/toxicity/side effects/drug resistance, and around 40% of patients experience adverse reactions as well the ongoing problems of peripheral neuropathy; the cancers associated with HIV have in many cases not reduced greatly in incidence, and the psychological and spiritual needs of people with HIV persist. Treatment-related hepatotoxicity is common (81), and there is an increased risk of heart disease (82). Importantly, even in developed countries with universal access to HAART, people with HIV disease continue to die at a higher rate than the uninfected
Indeed, it is proposed that the era of HAART has only increased the need and possibilities for palliative care, due to the new range of co-morbidities and end-stage diseases being presented, as terminal stages are reached with less diagnostic certainty, and the burden of pain continues (84). A systematic review of patient outcomes in HIV/AIDS palliative care has found improved outcomes across disease stages and care domains (current authors, manuscript in review). The monitoring of long-term toxicities of HIV treatments is an under-researched area and methods and priorities have been proposed (85); such attention is also crucial to the African setting.

An example of the palliative care needs of sub-Saharan Africans accessing HAART was identified during a site visit in preparation for this report. A number of patients at an HIV full disease spectrum care project were accessing HAART from a clinical research centre, but as part of the feasibility research were not offered pain and symptom control, which was being assessed and provided by the original HIV non-palliative care service. HAART and symptom/pain control, with specialist palliative care referrals, were offered as components of comprehensive HIV care that “not only complement but also mutually enforce each other.”

Palliative medicine in sub-Saharan Africa has yet to engage fully with HAART, which may change HIV epidemiology but does not obviate the need for palliative care. The logistical reasons for this to date may be clear, as a recent review of maternal and child health in relation to HIV/AIDS in sub-Saharan Africa reported that HAART programmes in 13 countries reached less than 3% of HIV-infected women (86). The paper is in line with current global funding goals in that it calls for a rapid scaling-up and comprehensive continuum of care including HAART access, which will require palliative care practitioners in sub-Saharan Africa to learn new clinical knowledge and skills and to integrate their services to meet the needs of patients accessing HAART. Even with broad funding goals to provide HAART, both the clinical evidence and the weak public health infrastructure will continue the need for palliation in quality care (87).

The definition of palliative care which sees it as active total care clearly demonstrates that sustainable HAART programmes need palliative care to ensure adherence, maximum clinical benefit, reduced potential for the emergence of resistant strains and to offer care to those for whom treatment fails. A large amount of resources are planned, including the US President’s Emergency Plan for AIDS Relief as well as the WHO 3X5 programme (i.e. 3 million sub-Saharan African patients accessing HAART by the year 2005). However, this still leaves many without access, and even in developed countries efforts are required to expand access among marginalized populations (88).

Palliative care offers great opportunity for improved patient management in the coming HAART era, not least because surveillance systems need to be put in place, i.e. lab services and monitoring for CD4 and viral load monitoring, offering potential for improved health infrastructure. Polypharmacy is also a well-promoted approach to patient management, i.e. simultaneous
active and palliative care. Although it may be argued that a threat may be a focus on HIV and lack of attention to cancer patients, expansion into HAART care may promote palliative care on the public health services agenda, and for the large INGO’s who are or will be interested in HAART procurement and distribution, an increase in the number of health providers with palliation exposure and experience.

The International HIV/AIDS Alliance HAART toolkit

A public health approach to scaling up HAART treatment - i.e. providing HAART for as many as possible while aiming for universal access. This approach fits well with, and requires, public health approaches to palliative care. The toolkit requires standardised treatment protocols, based on WHO’s Scaling Up Anti-Retroviral Therapy in Resource Limited Settings, Guidelines for a Public Health Approach (2002), a standardised protocol-driven approach, which could offer excellent opportunities for including strategies for palliative therapy.

The toolkit, developed by the Alliance with UNAIDS, WHO, The Lighthouse Malawi and several African Health Ministries, aims to situate HAART provision within existing health care systems. A reading of the Toolkit shows the approach to HAART scaling-up to mirror current activities in palliative care expansion:

- Planning
- Enabling public policy environment
- Involving and mobilising stakeholders
- Supply management of commodities
- Service delivery
- Human resources
- Infrastructure
- Costing and financing
- Management systems
- Information management and communication
- Monitoring and evaluation

HAART will not be available to everyone that needs it, therefore it is necessary to ensure appropriate palliative care for those who do and do not receive HAART. The link between palliative care and HAART has been made by few NGO’s. An example of palliative care recognition is offered by the Horizons/USAID report “Access to treatment for HIV/AIDS: report from a meeting of International Experts” 2001 (89). Although it was not discussed as an adjunct to HAART, palliative care is mentioned in the opening remarks as pertinent to HAART delivery. Interestingly, palliative care is initially separated from end-of-life care, offering an integrated perspective for palliative care in the HIV disease trajectory, although it is later categorised as an end-of-life concern. Although Horizons ultimately discusses palliative and end-of-life care
as necessary for those who do not access HAART, those whose therapy is ceased, or for whom resistance develops, they are correct in their observation that “little is known about how to best provide palliative and end-of-life care and the needs of professional and lay caregivers to provide such care.” They also note that in the face of huge demand, it may be best to offer HAART as an integrated service in existing health care, although “an integrated approach will in many cases require a concerted effort to strengthen the health care system beyond the narrowly defined needs of an antiretroviral treatment programme.” A further important contribution of the report is that when considering access to treatment, the community perspective is highlighted with regard to palliative care. This underlines the importance of informing patients of the range of treatments available, and in promoting NGO roles in providing palliative care, although detail is lacking on how this mechanism would maximise public health palliative care in practice. The report also notes the problems with HAART mirroring TB treatment models, as TB drugs are concerned with observed treatment, whereas in palliative care observed therapy is not necessary (as motivation is clear) or feasible in the dosing periods of opioids.

The report concludes with a crucial set of research questions that are equally pertinent to palliative care:

- What is the most appropriate mix of care interventions?
- How to best identify the needs of particular groups?
- What factors and characteristics make for successful service delivery programmes?
- What are the benefits of centralised v. decentralised providers?
- Where and at what level of the health care system can HAART therapy be provided?
- What are the minimum requirements to provide a basic standard of care? How can quality of service be ensured?
- How equitable is provision of treatment?
- What is the effect of involving communities in designing and delivering treatment and care programmes?
- What is the role of communities in care provision?
- What is the effect of comprehensive programmes that treat families rather than individuals?
- What is the implication of user fees on the financial well-being of families?
5.4 Summary of the HIV/palliative care interface

- Palliative care is increasingly recognised as necessary throughout the HIV/AIDS disease trajectory, particularly for complex pain and symptom management.
- HIV/AIDS home-based care has been emphasised across sub-Saharan Africa, although adequate pain and symptom control are largely absent.
- Enormous scope is, therefore, presented through the active network of NGO’s and providers.
- Several manuals have been developed within Africa that describe protocol-led HIV/AIDS palliative care.
- HAART provides perhaps the greatest opportunity for palliative care expansion in sub-Saharan Africa. Although HIV disease changes in the era of HAART, palliative care is more necessary than ever.
- Funding input to HAART is enormous and growing: palliative care is crucial in order to obtain maximum clinical benefit by managing side effects and promoting adherence to HAART, and is also necessary for quality care for those who will experience virologic failure or the continuing terminal cancers and end-stage liver disease.
6. Which models of palliative care have been delivered in Africa, how, by whom and to which patients?

Innovation for palliative care delivery in sub-Saharan Africa has led to several working models being delivered. The variables that need to be considered when developing a model are the stages of disease addressed, the service design, which effective systems of referral will be put into place, how coverage can be maximised and, particularly relevant to sub-Saharan Africa, how best to operate community-based care.

6.1 Reported services and evaluations

The search methods identified 26 service organisations, which were described in 38 reports/papers. Research findings from 15 studies were reported by 8 organisations.

Table 1 presents service descriptions, and data are extracted into country, service type, service description, care statistics, service development issues and lessons learned. Table 2 presents research findings under the headings of study aim, sample, findings and comments. Tables are presented in the appendices.

6.2 When is palliative care provided in sub-Saharan Africa?

While modern palliative care was pioneered by Dame Cicely Saunders as end-of-life care in the Hospice movement, recent developments have viewed palliative care as a necessary component of quality care throughout the disease trajectory. Within sub-Saharan Africa, the view that palliative care should be available to all with life-threatening incurable illness has been espoused by the Palliative Medicine Institute (PMI) in South Africa (90), is integrated into total care service by the Mildmay Uganda (91), and is currently being incorporated by The AIDS Support Organisation (TASO) a care NGO that has traditionally focused on non-palliative HIV/AIDS community care. A perceived gain from the broader definition (e.g. in South Africa) has been the integration of palliative care into basic training courses for all nurses and for some medical students. The integration of palliative care throughout the disease trajectory has gained broad support: the WHO 5-country palliative care initiative has worked from the principle that palliative care “in the framework of continuum of care from the time the incurable disease is diagnosed until the end of life” (92).

Several different approaches are taken to palliative care, for example the Kenyan Ministry home-based care guidelines clearly distinguish between palliative (health maintenance during the disease) and terminal (pending death) care (93), and the need for networking with hospices for drug availability is stressed. The integration of palliative care is offered in many different ways and is best illustrated using the Ugandan centres, where HIV
care is a subset of specialist terminal care at Hospice Africa Uganda, and palliative care is offered as a subset of HIV total care at the Mildmay Centre.

6.3 How are services in sub-Saharan African developed?

The key areas required to develop a successful basis for palliative care services are advocacy (national policies and guidelines), integration of palliative care into the continuum of care, education and training, drug access and data systems. However, although the literature clearly demonstrates the importance of these steps, it is not yet clear how they translate into specific feasible, acceptable, accessible and effective models of care at the service level. The need for quality services, and how to make them available, remains a crucial issue, and may be met in many settings across home, day, and institutional care (94). Innovation is crucial and needs to be encouraged but documented- “All hospices have had to ‘make do’ with limited resources, and much innovation has been occurring under the circumstances” (95).

The specific service components required for services in sub-Saharan African are as yet undetermined, although it is suggested that a fully developed programme offers home care, informal carer support, consultation service, day care, outpatient clinic, inpatient care, and bereavement support (96). In addition, despite heavily reliance of volunteering, there is a lack of clear definitions and provision of rewards with respect to community volunteers.

In considering lessons learned for an affordable and accessible service for pain control and palliative care, Dr Merriman states that “pain control must be put in place before it can be called a palliative care service” (97). Oral morphine availability is fundamental; where doctors are few, nurses should be allowed to prescribe with specialist palliative care training, comparable to the concessions for midwives to prescribe pethidine in pregnancy. Even palliative care providers may interpret palliative care in unexpected ways, stating that their service has provided “palliative care without the pain control”.

The problems of identifying efficient models of delivery are demonstrated by a description of the Kenyan situation, whereby palliative care is being delivered to a high standard in hospices but they may be operating as tertiary centres for pain and symptom management, and therefore marginal to the majority of people that need them. The large number of agencies providing home-based care are, according to their professional staff, inadequately trained in clinical skills and lack access to essential drugs (58).

A lesson learned from an attempt to found a hospice in Tanzania has resonance for all countries, “opportunities accompany the problems. Hospice care doesn’t have to fit any particular model” (39). Home care is seen as most acceptable to the family and patient (98), and inpatient care is usually seen as “unthinkable” (32), and is rare in practice as it is expensive per patient, thereby offering low potential for sustainability and coverage. All countries need “hospice” that meets the cultural, spiritual and economic needs of its people (67), but may be offered in forms not recognised as a traditional
“hospice” model. Home-based care can offer comparatively low cost care that respects cultural practice and removes the need for family attendance at hospital (99). There are elements of the HIV epidemic and resource constraints that direct the site of care; with 80% of beds in South African hospitals occupied by patients with HIV disease, alternatives to hospital and institution-based care have been unavoidable (73).

It is suggested that home is often not appropriate for care, although it appears that the alternative options are few, and a strong argument is made that homecare is indeed feasible (44). However, the limitations of existing home-based care are recognised. St Francis Health Care Services, Uganda (personal communication) is an example of a service that provides HIV care and face many patients with palliative care needs but are very aware of their lack of palliative provision, which they wish to provide. The service reports having 3000 clients with around 60 new patients per month as at February 2003, and in a 12 month period to August 2002 reported 242 terminal patients who they had to refer to hospital for terminal care. The only two palliative care centres are 100km away. Therefore they conclude that these 242 patients died in “excruciating pain”. However, there are clinical staff available at the project, and they wish to provide palliative care.

The identification of opportunities as well as creating large-scale capacity and Government endorsement is important, as evidenced by Hospice Arusha (Tanzania). A small service was grafted onto existing cancer services using post-operative pain control drugs (pethidine) for the community, and proposed a combination of small rural projects and hospital-based services (39).

In addition to specialist palliative care centres offering intervention for referred patients from centres that are unable to provide palliation particularly for complex cases, specialist palliative care centres are a focus for interested practitioners, advocacy, policy, resources and education. Therefore they have an important role particularly in developing countries and such “beacon centres” should continue. Although there are many potential models of delivery, the central issue is that the palliative care approach can be employed by every doctor, nurse and volunteer, it can be simple and protocol driven (100).

6.4 How can patients be connected to palliative care services?

Referral systems can only be efficient when there is an appropriate and accessible care system with trained staff to whom referrals can be made. Coverage can only be achieved when issues of sustainability are addressed to guarantee continuity of that which is in place. Potential coverage is limited by the fact that many geographical areas where potential patients live are inaccessible for staff (101). Many models of provision and integration are needed: across disease trajectories, specialist advice, HAART, terminal care, education and advocacy, inpatient (e.g. hospital) and home/community. Donors are less keen on new ideas than existing projects; goals for spread and coverage must be realistic in the face of donor mistrust and reluctance to
work with economic and political instability and the need to work with existing success and interest (99).

Hospice Africa Uganda reports 80% of referrals coming from hospital in the urban setting, but have also made considerable gains in connecting those in need to rural palliative care through the use of community volunteers (“vigilantes”) (98). This may change when skills are extended and integrated into hospital care, but in the light of the morphine roll-out evaluations there are clear challenges. An evaluation of referrals in South Africa to palliative care delivered in a model of Integrated Community-based Home Care (ICHC) found the system to be sub-optimal. This was attributed to a series of issues: inappropriate referrals, poor documentation and communication with the hospital, and lack of clarity of the ICHC role (102). The audit and subsequent changes ensured that standards of referral were met, and the study demonstrates the importance of audit and evaluation initiatives to facilitate access to appropriate care. HIV stigma at the community-level has been found to prevent patients with high level needs referring themselves to hospice, and a service response has been the training of community volunteers to identify and link access to hospice care (44).

Coverage of palliative care in sub-Saharan Africa appears to be achieved through dialogue with the public, communities and villages to encourage people to enter clinics. Services need to consider their local setting, e.g. in rural areas doctors are irrelevant to referrals, local volunteers are the primary source. In primary care one needs to empower health care workers and patients as staff are usually attached to a building and often do not travel to communities.

Coverage may be best achieved through training across levels from public health institutions down to the village level (98), thereby rolling out the service into rural models. Although training is important, without health care sector/governmental support to make morphine available, trained staff are unable to achieve intended outcomes (98). The provision of palliative care training may be achieved during existing nursing and clinical training courses, as this may avoid the feelings of “overload” at gaining new skills and care paradigms. Education issues are particularly pertinent to referral and coverage themes, and by extension to the themes of the report as a whole. However, a review of education in palliative care across sub-Saharan Africa is beyond the scope of this report, and such a review is currently underway by the Hospice and Palliative Care Association of South Africa.
Case Study 1: Reach Out Mbuya, Uganda
Do all care services need to be providers of palliative care?

“Reach-Out”- Mbuya Parish HIV/AIDS Initiative Kampala (103) (104) is an example of a successful HIV/AIDS total care project in a poor parish that does not provide palliative care, but works well with the local Hospice which takes referrals and offers joint patient management and training. Mbuya provides home-care with a team of paid volunteers, a daytime clinic, income generation (e.g. a sewing room) and micro loans for generation projects, food provision through the World Food Programme, and school fees. It has 525 active care clients (increased from 109 patients over a one year period) for the free care project. It provides TB care, has an open access clinic 3 days per week, and performs HIV testing. Those admitted to local hospital are visited twice weekly. There were 81 deaths in 2002, and the majority of those who died were being treated for TB. 10% of deaths were within 2 weeks of patients first attending clinic, and 59% in first 3 months. These data clearly demonstrate that this community-based full disease spectrum service sees patients nearing terminal stages, and the referral process and inter-agency working ensures specialist palliative care is offered to those who need it. Patients with palliative care needs are referred to Hospice Africa Uganda. Reach Out staff have been trained by hospice to recognise and understand palliative care needs. Patients continue to be co-managed, and both parties are happy with the working system of patient referral and care.

Interestingly, a team of 14 HIV+ Reach Out patients who have undergone successful TB treatment (which has daily 8-month adherence requirements), support other patients in TB treatment adherence and help staff identify those who may have problems. This appears to offer great potential here for HAART adherence work (HAART is currently provided for around 80 Reach Out patients through collaboration with the Joint Centre for Clinical Research HAART trials).

Emergency food aid was also being provided for 203 patients by Dec 2002, with twice as many on the waiting list, a clear role for total needs care. There are other projects working with palliative care referrals, but this service is offered as an example of a working system of referrals to a specialist service (Hospice Africa Uganda). Most importantly Reach Out has no ambition to provide morphine to its patients due to the constraints it would place on the service in terms of drug storage and regulation, and are very satisfied with the existing work with Hospice.

6.5 Are the home and community the best places to care?

The data in Table 1 clearly demonstrates that palliative care in sub-Saharan Africa is mainly provided through home-based care. However, expansion of
home-based care may have been favoured even where “availability of opiate analgesia is extremely limited and unlikely to improve” (58) despite the availability of opioids being crucial to a working definition of palliative care, and this cannot be compromised. A further criticism of community-based care is that the cost per visit of community-based health care cannot be justified in rural areas, and that clinic based care should be promoted except in the case of “humanitarian, unavoidably high-cost, provision of needed health care” (105). This certainly seems an appropriate caveat when considering palliative care. Home HIV care is similar to palliative care in that it is conducted across levels of health care and is usually delivered with total care in mind, i.e. nutrition, psycho-social and family care concerns are addressed, but sadly lacks the palliative element.

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<th>Does home-based care need palliation?</th>
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<td>Case study 2: Home-based HIV care in Malawi</td>
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An evaluation of a Malawian home-based AIDS care project undertook a 5 district assessment, and 50 patients and 47 volunteers were interviewed (106). Although home-based care has been prioritised by the Government, it is found to have significant weaknesses. Chronic hunger, pain, diarrhoea and depression were inadequately treated, and the very frank report stated serious concerns about quality and of hospitals using home-based care as a dumping ground. An employee said “home-based care is an abuse of human rights because it’s just a way of sending patients from the hospital without treatment. Patients in home-based care die quickly because they know that the hospital has given up on them.” Very interestingly the volunteers interviewed were matched to the patients who agreed to participate, and their assessment of patient need was almost identical. However, when those needs were investigated and comparison made between what patients and carers think is being delivered, they only agreed on bedding: otherwise carers thought they were providing more than they actually were, especially medical care and medications. In particular, medications for pain and symptoms were chronically lacking.

The TASO project, when considering how best to graft palliative care onto existing services and enhancing quality, has noted that often the patient who needs palliative care is the one who is unable to attend a clinic, and TASO has therefore looked at new systems in existing care centres (107). The potential for home-based palliative care is strongly promoted in most situations, as exemplified by the WHO approach, “Some countries have already developed strong home-based care networks in coordination with the primary health care system to respond to the HIV epidemic. Palliative care, as part of the continuum of care of HIV/AIDS, cancer and other chronic conditions can relatively easily be integrated into this existing network” (92). However, we still lack a range of good descriptions of successful developments to achieve this. An example of a successful initiative to ensure that systems can offer palliative care is the Ugandan pioneering of nurses being authorised to prescribe morphine, which opens up far greater
opportunity for the community as an appropriate place for patient care. The community-based approach to patient care is consistently championed as the most useful method to pursue, as "thousands of terminal patients can be relieved from their pain and suffering by using low cost approaches and mainly community-based strategies that guarantee ownership and seek sustainability" (92).

Where is the most feasible place of care?
Case study 3: Place of HIV care in Zimbabwe

A Zimbabwean review of HIV/AIDS care investigated the case for residential AIDS care. It suggested that although home care is a cornerstone of HIV care, there is an argument that coverage is low and often patient needs are higher than home care can provide, and that hospital admission is not viable, and so patients may need forms of respite or hospice community centre to provide residential care (108). Also, coverage calculations may ignore those in need. Extended periods of time may be spent by healthcare workers travelling from home to home, a patient may not have a home, their home may be inadequate, the family may be busy thereby leaving the patient alone, basic drugs are often not available, and poverty may be overwhelming: “how can this need can be addressed without embarking on an unsustainable escalation of welfare provision?” The review of health care services in Zimbabwe concluded that hospice daycare had not succeeded due to high care and transport costs and low patient ability to pay. Residential hospice care had not been taken up as the costs would be unsustainable, thereby disallowing greater home care coverage. Further, the problem with community care centres is that they would quickly fill with the chronically ill and not have room for emergencies. Residential community care centres should be managed by home care to ensure that they do not undermine home care, and would need strict admission criteria. They should not replicate hospital care but provide simple palliative care, and should offer non-HIV related services.

Significant successes have been reported by Hospice Africa Uganda and Lighthouse, who both report great increases in referrals to palliative care when community volunteers are recruited. These successes are interesting in the light of data that suggest previous unwillingness for the community to provide care; an assessment of Kenyan community attitudes towards home-based HIV care found great ambivalence, a lack of information and some rejection, with a preference for institutionalised care (109); further, an investigation of the assumption that Ugandan families would care found that 27/30 HIV/AIDS patients reported limited care, often because of lack of food and money for medications and other family responsibilities. Half of those who died were refused care by some family members due to poverty and other commitments (110); a survey in Ethiopia found that only 55% of a community would be willing to give home care, and 90% felt that hospital was the best
place for HIV care (111); finally, even as late as 2001 Nigerian research suggested a great reluctance to provide AIDS home care despite clinical skills deficit and reluctance to provide AIDS-care in rural health facilities, thereby emphasising the home as the required place for care (112). Therefore, although enormous achievements have been made it is important to take account of initial reluctance and community resource limitations.

6.5.1 How can home and community-based care be strengthened?

There are considerable opportunities for care and support for patients and families (particularly through the use of step 3 analgesics) through palliative home and community-based care. The question remains how best to do this: if there are lay providers then where will adequate skills and drugs reside, and where are the potential improvements and challenges in the current successes of home-based palliative care?

Models must be developed to country settings, addressing economic spiritual and cultural needs. When noting the inadequacies of community and home-based care, it is important to also highlight achievements such as the framework for action in community home-based care in resource-limited settings (113). Palliative care is an element of provision of care, and involves pain relief, (inadequate at low levels, to be provided by community/home team members who must be familiar with national drug policy and guidelines, and there should be a member of the team who can prescribe and one who can administer), spiritual and emotional support, anticipatory guidance, attention to inheritance rights, psychosocial support, bereavement counselling, spiritual support, mobilised community support, care for the caregiver, confidentiality and autonomy.

A further interesting example of an initiative to provide community-based palliative care is the WHO IMAI (Integrated Management of Adolescent Illness) palliative care guidelines for first-level facility health workers in low resource settings (114). It offers protocol led teaching, care and symptom management instructions for assessment, treatment, prevention and care and very usefully offers protocols for HAART side effects, paediatric medical intervention, and distinguishes between potential responses for clinical/medical intervention and lay home care. It begins from the premise that family and community carers will provide most care at home with back-up by health workers. The flexible set of interventions simplifies and integrates guidelines, aims to need little laboratory support for use where resources are scarce, and is designed for adaptation to local and country-specific settings (115). Another important publication is the Hospice Africa Uganda “Blue Book”, which offers clinical guidance for clinicians working in Uganda and other African countries (116). The strength of this text is not only that it has been adapted for local usage, but that it offers clear clinical guidance for both HIV and cancer patients separately and also offers information on HAART use. A further example is the previously mentioned Home-based HIV palliative care manual by the Gambian Dept of Health guide for HIV care/Hands on Care manual (79), which describes the continuum to palliative and terminal
care, with a specific section on the terminal patient and pain and symptom management with palliative care as a core element of Home-based Care.

There is currently inadequate knowledge of community-based emotional and psychological needs in relation to caring and coping. We know that informal palliative care is enormously problematic for caregivers, and that interventions are few even in developed countries (117). Counselling is an important contribution to home-based care in Zambia and has been integrated into home-based and hospital care, although counselling carries high resource costs in terms of time, and as care becomes palliative the counselling becomes more important not least to support burnt out carers (118). The question of what models of counselling are appropriate is answered by the TASO service which sees a more systemic model of intervention, i.e. seeking permission to provide a culturally appropriate model and providing counselling to the whole family unit (119). A further question when considering the community potential is that although it is clear that community volunteers have increased referrals, how much trained professional input is needed per given number of patients to ensure quality care? How much is needed (if any) to make the difference between supportive/HBC and palliative care?

Despite palliative care being offered as a feasible and cost worthy way to manage patients, the Alliance/Glaxo Wellcome "Community lessons, global learning" project focused on community care and support (120), and identified palliative care as a high cost and complex type of care that can serve relatively few people. The working definition of care and support focused on a continuum of care that includes both curative and palliative care, psychological help, and material support. When assessing what constitutes a basic care package, local resources dictated elements, and relied on unadapted algorithms, lack of pharmacy skills, and problems in setting boundaries to support. Challenges included good medical records, systems for ensuring follow-up, cost recovery systems, efficient drug stock systems, and adequate support systems for volunteers, and a concluding observation was that community care requires adequate referral systems.

Lastly, in relation to the often cited interface between HIV prevention, treatment and care, and the claim that palliative care relates strongly to

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**Palliative care manuals: increasing access to palliation**

Manuals offer multilevel simple guidance to patient management. They prescribe:

- specialist palliative care, i.e. Hospice Africa Uganda Blue Book (*Palliative Medicine: pain and symptom control in the cancer and/or AIDS patient in Uganda and other countries*)
- home-based HIV care from diagnosis to end-of-life, i.e. Hands on Care
- first-level health facility guidance including HAART side-effect management, i.e. WHO “Extending essential care. Integrated management of adolescent & adult illness IMAI manual”
improved prevention outcomes, it appears that home and community-based care may maximise community participation in prevention. The inter-agency opportunities that may arise are worthy of investigation (121).

### 6.6 Summary of models of care: what works?

- Palliative care in sub-Saharan Africa has engaged with a progressive view that advocates integration throughout the disease trajectory.
- The arenas for action required to implement palliative care are clearly defined: advocacy, integration, education and training.
- Steps to service development are still unclear.
- Definition of components for quality service are needed.
- Efficient referral systems and maximum coverage must be primary goals.
- The debate on care settings is somewhat predetermined by the acute resource limitations.
- Community and home-based care have offered maximum potential to achieve access and delivery, and many successful examples are offered.
- It is important to address potential challenges to home and community care, and to note developmental questions in service configuration.
- Grafting palliative care onto existing networks of home-based care that currently offer inadequate pain and symptom control is feasible. Other systems include referral to specialist services, nurse prescribing of morphine, and lay/professional protocol-led patient management manuals.
- The use of simple palliative care manuals is an excellent example of maximising skills at the appropriate level.
- Volunteers are key to care: however, their role, capacity and methods of recruitment and retention are still despite high reported success in harnessing their potential.
- Specialist care and referral systems offer a diversity of models that can ensure palliation is offered at all stages including a highly specialist level for complex cases.
- What “works” will be determined by initial issues of drug procurement and regulation being resolved, as coverage and quality cannot exist without access to the necessary drugs for pain and symptom control.
7. **Tuberculosis care: are there parallel opportunities?**

An evaluation of home-based palliative care suggested that future research look at the potential for involving existing health care community workers providing directly observed therapy (DOTS) to provide palliative care (122). Home and community-based care have been often favoured in TB care, and lessons from these programmes may carry significance for effective sustained delivery of palliative care. However, to date, the possible synergy has not been explored in detail. This chapter seeks to identify information relevant and potentially beneficial to the provision of palliative care, and whether reciprocal benefits can be identified.

7.1 **What is the TB/HIV/palliative care interface?**

The WHO is calling for improved standards of TB care and for free TB drugs alongside HAART to be available for people with HIV, "We need to increase our efforts to address the deadly synergy between the two diseases, each of which is fuelling the other’s impact" (123). It is estimated that 1/3 of the world’s people living with HIV are TB co-infected, and that 90% of people living with HIV will die months after becoming sick with TB if they do not receive proper treatment. With respect to treatment, a review of the evidence suggests that enthusiasm for HIV directly-observed therapy programmes is premature and not supported (124). In the WHO African region, 31% of new TB cases were attributable to HIV infection (125). An investigation of TB mortality in Malawi found that of patients registered in 1997, 23% died and 40% of these died in the first month of treatment (126). In Ivory Coast, in nearly half of patients dying with severe wasting (AIDS), TB was the dominant pathological finding (127). These studies demonstrate that palliative and end-of-life care has a role in the management of patients with TB. A study of TB care in Malawi found a lack of cross-training in hospital staff, i.e. poor HIV management of TB patients (128), which suggests that TB/HIV care is not currently well integrated.

A further important opportunity to access palliative care rests with traditional healers; a study of TB patients in Malawi found that 37% had visited a traditional healer before seeking medical advice. None of the traditional healers referred the patient to medical services, and six claimed to have healed a total of 116 patients (129).

7.2 **Care programmes**

The provision of TB care is strongly based in community care models. An evaluation of a community-based treatment regime for new TB cases using guardian-based supervision in Malawi aimed to determine whether DOTS during the initial phase of treatment supervised either in hospital, at health centres or by guardians in the community, was associated with 1) satisfactory 2-month and 8-month treatment outcomes, and 2) with a reduction of in-patient hospital-bed days (130). At 2 months, mortality rates
were significantly higher in hospitalised patients. Decentralised DOTS resulted in a 25% reduction in hospital-bed days in patients alive at 2 months compared with that predicted using the old regimen. Decentralising DOTS to health centres and to guardians during the intensive phase was therefore associated with satisfactory treatment outcomes. Most interestingly, suitable guardians were defined as a member of the extended family entrusted to supervise treatment at home and able to record on DOTS monitoring forms.

Community-based TB care offers access for those who are far from healthcare institutions. A study of whether the distance a patient lives from hospital is a risk factor for TB mortality in South Africa started from the realisation that TB programmes that rely on district hospitals for diagnosis and initiation of treatment may disadvantage those living furthest away (131). The study found that the rate of death was high across all groups, but those who lived over 60km from the hospital had significantly higher odds of dying. This is significant for palliative care services, which currently offer low coverage but must respond to high levels of need.

Non-compliance is a key problem of TB, and in response to this an evaluation of community TB clubs in Ethiopia, compared to controls, showed a significantly better completion rate, lower defaulter rate, understandings of the disease and treatment compliance, and belief in modern health care (132). The clubs consisted of 3-10 people from the same village who attended the clinic on the same day, with a literate elected leader. Members also met weekly outside of clinic for 1-2 hours, and supported each other in adherence and shared information. Club leaders were provided with Department of Health materials, sought support from village leaders and religious persons, and identified and helped to refer others with TB.

7.3 How have TB programmes sought to develop and improve patient outcomes?

TB control at the district level in Malawi had a reportedly low cure rate during 1990-1991 of 24%. The problems identified were fragmented programmes, inadequate training and supervision, poor recording of patients’ addresses, and non-adherence to national treatment protocols (133). These issues were addressed in the district level, and 1992-93 cure rate rose to 68%. The study concluded that simple, inexpensive local programmatic interventions can dramatically improve TB case-holding with evaluation, training, and supervision at all levels of care.

A particular strength of TB care systems that has been achieved, and would be of benefit to palliative care services, is the introduction of operations research in Malawi, which has seriously improved recording and management of TB patients across public hospitals particularly with respect to incorrect registrations (134). An evaluation found that incorrect registrations at follow-up had considerably improved, as had appropriate treatment regimens.

Community responses have been a central response to improving TB care. A Kenyan study of a multi-sectoral approach to DOTS sought how to deal with
DOTS in response to a 500% increase in case load and a 60% decline in real per capita expenditure over 20 years (135). A major problem was the nomadic population, and the solution was the construction of TB treatment villages, where patients are accommodated and given 4 months of supervised TB treatment. A review of the role of the community in the control of TB made the following recommendations: (1) extend TB care to the community to improve access; (2) identify suitable community TB treatment supporters in consultation with the community; (3) ensure that effective systems extend into the community for recording and reporting, and for supply of anti-TB drugs; (4) monitor community contribution to TB care using standard indicators; (5) develop costed plans for expansion of the community approach. Ministries of Health should: (1) ensure adequate financing; (2) coordinate the efforts of national treatment programmes (NTPs), donors and NGOs to ensure sustainability; (3) consider opportunities for collaboration between NTPs and HIV/AIDS programmes (136).

A review of 14 community care organizations in Uganda, Zambia, South Africa and Malawi evaluated current TB care (137). The community care organizations assessed mainly provided care for HIV/AIDS, and received funding from non-governmental organizations. Shortcomings in tuberculosis care included delays in diagnosis, drug shortages, low completion rates, high default rates, inadequate recording, little interaction with government tuberculosis programmes, and inadequate training of staff. However, one organization that provided primarily tuberculosis care and collaborated closely with the district tuberculosis programme and hospital attained a high treatment completion rate. The strong points of the community care organizations that favour a potential role of community participation in tuberculosis care were accessibility and staff motivation. Despite most community care organizations’ shortcomings, they do have the potential to improve care, thus reducing the load on overstretched health facilities, although their potential impact on TB control depends on their population coverage and sustainability. HIV/AIDS community care organizations with strengthened management of tuberculosis care could serve as a model for expanded community participation in tuberculosis control, although operational research is needed to assess the feasibility and cost-effectiveness of community-based TB care.

Factors identified as contributing to a successful TB control programme in Malawi were the absence of TB-specific facilities, community participation in case-finding and treatment activities, and regional seminars to raise awareness among clinic staff (138). A further study of DOTS and TB control examined how policy is transferred between counties, with reference to the “branding” of DOTS as a means to achieving policy focus and improving care (139). While drastic difference can be achieved through branding and marketing, the study warns that simplifying policy to “one size fits all” carries risks, and can harm locally appropriate programmes. Top-down internationally-driven policy changes may lead to apparent policy transfer but not necessarily to successfully implemented programmes.
A review of attempts to integrate leprosy and TB in general health care in Kenya and Tanzania found benefits for a nationwide programme replacing efforts of independent isolated schemes, community-based care reducing isolation and stigma, and improved access as an incentive for stabilization of attendance patterns (140). General health staff were given extra training for these patients. Organizational problems were the greatest: clear job descriptions from the Ministry are crucial, general medical training required more substantial training on these diseases (3 years after training and integration 2/3 of staff felt they know too little to diagnose or treat with confidence), careful attention to drug distribution is necessary, and those who worked in single disease-specific care were not easily placed in jobs in integrated services.

7.4 Summary: Where does the synergy lay?

- The epidemiological evidence shows high mortality and a strong association with HIV infection
- TB care delivery systems offer innovation at all levels
- Community-based TB care is favoured and has been shown to be more effective than tertiary care
- Operations research in TB care has greatly improved quality and outcomes, and the steps and factors associated with achieving success may offer lessons to palliative care
- Further parallel opportunities and synergies are identified in programme development steps and specialist training requirements
- The primary factor that may offer success across the linked domains of HIV/HAART, TB and palliative care appears to be integration, i.e. ensuring that skills and treatment are available within, or via, single settings for patients in need
8. Empowerment, primary and community care: replicable goals?

The data on models of palliative care and TB care both highlight the community as the primary site of care in sub-Saharan Africa. The demonstration palliative care projects have mainly been home and community-based, but there are also unanswered questions with respect to the lay and community capacity to care. In particular, relevant but under-explored areas identified in this report are the drain on community resources and the capacity to care, the quality and level of care that lay carers can provide, the level of clinical support needed, the motivations, resources and incentives required to operate volunteer projects, and the needs of carers. Although demonstration projects are running with success, unless these questions are answered it is unclear how replicable they are outside the specific circumstances of existing work. The thrust for community and home care has not been supported by explicit policies and supporting strategic approaches to achieve them.

8.1 Defining community care and participation

A review of home and community care in Zambia found the common aim to be developed from “a concern for the increasing number of patients and the need to care for them in the simplest and most effective way given the resources available” (141). However, when considering the application of the report to community models to palliative care it is important to note the pressures in a total care scenario, “Most of the care programmes are able to supply foods or other materials for patient use in the home. It is important to achieve an acceptable balance between what is needed and what the patient wants. It would be unfortunate if the responsibility for care and provision for the sick relative were removed from the family”. The term “Human Capacity Development for response”, coined by the Salvation Army, affirms local community capacity to respond, and organisational capacity to adjust to that competence for response (142). This is an important consideration when considering the sources and capacities to provide care in sub-Saharan Africa in the face of limited resources. To address this, the Salvation Army proposes a “working culture of facilitation” (143). Health professionals involved in palliative and home care learn that the burden is too great if a provision culture is projected, and that family and community must be part of the process as contributors to care. In the context of HIV, burden sharing happens effectively when the belief that families and communities can respond is matched within support organizations by a working practice of facilitation.

The WHO defines community participation as “community involvement or partnership between individual groups, organisations and health professionals in health and health activities”, and an advantage is that utilisation and support of services are facilitated, and services become more appropriate (144). Empowerment is defined as “giving power to the communities by
enhancing their capacities in order that they realise their freedom and assume greater responsibility for their own lives or health” (144). The WHO states that programmes must decide at which of the many levels a community participates.

8.2 Community health programmes

An initiative to “empower communities” in Malawi sought to involve the population as participants not recipients in identifying health problems and identifying solutions (145). This was achieved by: 1) Identifying communities in need, 2) establishing a community health committee, 3) training, 4) community assessment (inc non-health needs for which you assist in making contact with relevant sector), 5) development of an action plan, 6) implementation and monitoring, 7) evaluation. The authors note that reluctance to participate may be due to previous unsuccessful efforts of healthcare workers to provide all required resources, i.e. having a negative experience, and lack of essential drugs was a significant problem.

A review of an anti-epileptic drug primary health care programme in Kenya found that key informants in the community alerted health care workers who assessed, and treatment was supervised by primary health care workers (146). As a common recommendation for working in an inadequate health care system is to use trained health workers to treat patients at primary health care level, the paper concludes that a successful approach is to teach them to identify cases, apply simple treatment protocols, and monitor therapy; the identification of patients by community volunteers is an ideal method. Community approaches to health may take several strategic forms; a comparison of Zambian and Ugandan approaches to health sector reform found that Uganda had decentralised all of Government with powers devolved to the districts, while Zambia has decentralised only the health sector, and concludes that neither has led to improved health services (147).

Potential for community-based health programmes care may be great, an example being the improvement of outcomes for children suffering from life-threatening conditions in East Africa when community resources are enhanced (148). A model for managing epilepsy in a rural community in sub-Saharan Africa reported that 3000 patients were eventually registered and receiving regular treatment at 45 units throughout Malawi, due to publicity being spread through an area action committee organised by the area chief (149).

8.3 What are the challenges to community health and participation?

A review of strategies for empowering community participation in developing countries found it to be seen as a “panacea” particularly in the light of the promotion of primary health care models. Participation is seen as a good thing not least because it allows reflection of geographical and cultural local factors.
However, the question remains of how to achieve sustained community participation (150).

The vast majority of community-based health programme papers report on health promotion and family planning (151;152). A Kenyan Study aiming to develop a replicable community-based health care programme, again based on health promotion, family planning and curative care, reported that community sensitisation can take 1-2 years, and that it takes some time and effort for the community to support community health workers (153).

The WHO sees also community participation as a slow time-consuming process, and reports that poverty militates against success, calling for realism with respect to the communities’ resources and its willingness to cooperate. A review of projects found resistance on the part of health workers to promote situations where they did not hold initiative and authority. In Zimbabwe it was questioned whether initiative and momentum could be maintained longer than funding lasts, with socio-economic factors being the biggest challenge. The South African experience shows that political support is crucial. Evaluations show that certain preconditions are necessary for sustainable community participation: it needs to be initiated from within, and evaluation should focus on the involvement of the community (144). In Tanzania, the push for primary and community services has been hard to initiate and sustain (154).

An historical overview of the Kenyan expansion from hospital outreach to community-based healthcare found inequitable access between socio-economic groups, low levels of community participation in health care provision, planning and funding, and that the cost of mobile clinics was rapidly increasing (155). Therefore, a thorough rethink aimed to increase community responsibility, introduce community leaders across socio-economic groups, and to take part in developing community health improvements. This constituted a programme of community development and community-based health care, using an area health committee, village health volunteers identified as already well-regarded women in the village who subsequently undertook unpaid sensitisation one-to-one work, follow-up on patients’ clinic appointments, and integration of income generation. The factors identified as favouring success of community-based primary care were: church involvement, co-option of the existing outreach infrastructure, movement from hospital to community-based care being seen as one streamlined service by the population, cost savings through integration of prevention and care, and improved role of equality and autonomy between hospital and community teams.

Estimating coverage of community-based care is an important area of investigation, and such a study in Zimbabwe noted that “it is important that all home care programmes think in terms of coverage and do not simply strive to provide high quality services to a few patients…although it is worthwhile to provide quality services to individual clients it is important that any service which claims to be community-based caters for as many of those needing the service as possible…coverage is an essential indicator of any community-based, public health programme” (156).
It is worthwhile to note here that the WHO 5-country palliative care initiative has made an important contribution to measuring population needs to develop a community-health approach to care (92) (50). Such local understanding and locally-produced knowledge is crucial to success for community care, as described in Kenya, “True, it must be conceded that in many cases corruption and inefficiency of third world officials hamper success of the projects; yet it would be foolish to ignore the irrelevance of the wrong solutions that are propounded by the experts, whose understanding of the problems of our poor nations is often vague, and many times wrong” (157). Contextual variables are key to success; an historical exploration of primary care in developing countries concluded that “improved health is not primarily a matter of medical systems, but rather a broader question requiring better understanding of the nature of underdevelopment itself. As a consequence, all activities concerned with health must begin with the specifics of underdevelopment in particular circumstances” (158).

A study of referral patterns in Namibia found a well-functioning referral system is a key element of a health system based on primary health care (159). Barriers to referral included finances of the patient, degree of differentiation of clinical skills and services between levels and providers, unwillingness to use lower-level entry points, and a danger that lower level services become underused and higher overloaded.

The most evident aspect of primary health care in sub-Saharan Africa is the recruitment and training of village health workers, who are often extensions of organised government health services, but who may be too limiting in the context of primary care (160). Communities should identify their own problems, prioritising and finding solutions within their resources. However, when considering the application of such an analysis to the field of palliative care, it remains to be seen whether a community would make it a priority in the face of many complex health and social needs.

Consideration of approaches to African health systems expansion identified both vertical growth (attacking one or a few health problems) or horizontal growth (multi-problem such as primary health care), stating that in this debate, cost effectiveness must be a crucial consideration (161). Vertical growth is unlikely to achieve the required palliative care coverage, and horizontal growth will require significant resources in terms of sustained availability of trained staff and essential drugs.

Finally, issues of proximity to health facilities and consultation with traditional healers have been identified as relevant factors in accessing community care. A study of factors influencing admission to hospital during childhood illnesses in Kenya found that those who died without admission had shorter duration of symptoms, lived further away from the bus stop, and had made greater use of traditional healers (162). The study concluded that education is required to improve earlier recognition of clinical signs, and that traditional healers need to be included in this education.
8.4 Summary: The need for a strategic approach to community palliative care

- The community is the main site of care in sub-Saharan Africa, and is largely seen as the only feasible setting.
- Empowerment of communities seeks to achieve communities that set their own health goals and priorities. Palliative care would need to be promoted to raise awareness if the community are to prioritise it.
- Community involvement is a key feature of services, but strong links with primary care (with the exception of ICHC) or stated aims of community empowerment in models of palliative care have not been identified.
- The thrust for community and home care has not been supported by explicit policies and supporting strategic approaches to achieve them.
- Several strategic approaches may be taken, although supervised primary care workers are always needed to assist lay effort.
- Factors for success include: realistic aims in the light of apparent limitations; political will and support; long-term goal setting and adequate time allocation for success; optimal referral systems.
9. The set of inter-related tasks: policy, strategy, national regulations and advocacy

In order to achieve quality palliative and end-of-life care in developing countries, a set of common tasks have been identified: development of indicators for quality and health measurement, establishment of locally-determined and culturally-based efforts to improve end-of-life care that are developed in-country, a mainstreaming of end-of-life care into global public health discourse and priorities, and strengthening local capacity to care (163). The WHO foundation measures recommended for the achievement of cancer pain relief are: drug availability, government policy and education, all achieved in harmony and pursued concurrently with a foundation of the establishment of process measures (164).

9.1 Strategic goals and successes in sub-Saharan Africa

Similar priorities to those above were identified using original data from HIV end-of-life care priorities in sub-Saharan Africa, and were identified as pain control and “good death” achieved through advocacy, an expansion of coverage with regard to maintaining quality services, technical assistance for monitoring and evaluation, collaboration networking and information sharing between agencies, and resource security for sustained improvements in care (4). National policies and strategies need to be established in order to achieve adequate coverage, and restrictive regulations need to be revised (2). The legislative tasks have been shown to be fundamental to success, and involving an indigenous well-respected professional is beneficial (165). Governmental collaboration and lobbying have been key to achievements such as access to morphine (39) and inclusion of palliative care as an essential service in the National Health Policy Plan and Strategy, and target-setting such as 25% of districts using the analgesic ladder for 20% of those in need by a specified date (98).

The need for, and necessary steps to achieving, quality palliative care coverage were enshrined by the Cape Town Declaration, which proposed home-grown solutions for Sub-Saharan Africa (166). While the elements of the declaration echo the necessary steps previously identified above, the declaration makes an important distinction in expressing the importance of developing local programmes in-country by those who understand potential and challenges. This echoes the importance of locally identifying needs and priorities.

The aims of hospice care have been carried forward by an array of individuals and associations, and may be demonstrated in the aims of Hospice Africa Uganda which began in 1993 with a set of aims that have remained, namely to provide palliative care and education, and to encourage initiation across the continent. However, earlier successes in hospice care are notable in Zimbabwe and Kenya, and much progress has been made in South Africa in terms of health policy recommendations, inclusion of morphine and codeine as essential drugs in primary care and the development of national standards of care in relation to cancer pain management (167) (168).
The WHO 5-country initiative has offered an important model by developing and testing instruments and designing methods for situation and needs assessments with respect to palliative care, compiling a country-specific set of data on health sector capacity and performance, establishing in-country group of key stakeholders and Government endorsements, drafting national action plans and identifying resources (92).

9.2 The tool of advocacy

The goal of the Open Society Institute Palliative Care Initiative in South Africa is to be a catalyst to advance programmes in palliative care education, training, and service delivery and to advocate for their full integration into international HIV/AIDS “treatment and care” programmes (169). However, advocacy is rarely mentioned as a specific activity within care organisations with the notable exceptions of Hospice Africa Uganda and the Palliative Medicine Institute (170). The Hospice Africa Uganda approach to advocacy has been, in part, the promotion of successful demonstration projects - visiting other African countries and using Uganda as an example of how palliative care delivery can work, using an African advocate to disseminate, to show that morphine and palliative care are safe and low-cost, and that funds are not diverted. A significant problem identified with successful advocacy activities is that greater visibility of hospice has led to an enormous drain on resources (122). If funders wish to promote advocacy work and encourage successful projects to showcase their work and welcome visitors, then they may consider making appropriate funds available for such activities.

The PMI closely relates advocacy to the concept of total care in palliative care, arguing that medical or nursing needs cannot be separated from poverty alleviation, clean water, grants, occupation and skills training. Palliative care is described as more than pain and symptom management, and awareness of the palliative approach to health professionals and the public is seen as a core task achieved through networking or partnering and enlisting peer educators. Therefore, advocacy goals are greater than advocacy for morphine and symptom control.

Advocacy is defined (in the context of access to HAART) as “a process of action that entails working towards changes in attitudes, policies and practices”, and needs to be undertaken at all levels: individual/community levels, at health system and national levels, and at the global level (171). The policy-advocacy link is highlighted by the Diana Fund Palliative Care Initiative view that palliative care can only be successful and sustainable where it is part of the country’s national health policy (96). The PCI approach to advocacy is as follows: “Advocacy is the effort to influence change through various forms of persuasive communication. The change could be geared towards public policy, change in personal behaviour, and attitude, change in political and public debate, and legal change” (172). Information, education and communication are seen as precursors of advocacy. The general aim in palliative care is that of creating enablement for the discipline. The final step to advocacy is defined as monitoring and evaluation, although the identified...
output variables are process rather than outcome-oriented, and the Fund recognises that outcome variables may be difficult, but not impossible, to measure (e.g. documented examples of positive changes in legislation or policy, amount of positive coverage in mass media, verbal or written feedback on an annual report or briefing pack, incorporation of the message into public statements and speeches, and whether a target audience has moved closer to your viewpoint).

In the context of world-wide palliative care “advocacy can play a role in preparing the way for improved services delivery” (173). Although advocacy can be seen as facilitating quality care, the lack of evaluation data in the context of palliative care in Sub-Saharan Africa does not allow us to measure the success of the approach. This statement by the UK Forum for Hospice and Palliative Care Worldwide goes on to say that “the factors determining practice change are more complex than for policy change…practice change is therefore harder to achieve than policy change, and should not be neglected in your planning.” It calls for advocacy objectives that are SMART: specific, measurable, achievable, relevant and timed. Cultural and organisational issues need to be addressed, and there are a series of barriers to advocating palliative care at the individual, societal and organisational levels.

9.3 Summary: making advocacy a transferable activity

- The foundation tasks to establishing palliative care are common across proposed agendas. National approaches and strategies are cornerstones to achieving palliative care.
- A key approach is the local determination and development of services.
- Advocacy is a common aim and approach but is variously defined and rarely measured. Evaluation of advocacy activities should be prioritised.
- Advocacy is often an output of “charismatic individuals”, i.e. is isolated to a few people.
- In order to ensure continuity of the successes achieved by pioneers, future advocates or “champions of palliative care” must be fostered from the African population to encourage continuity of successes to date.
- Greater visibility through advocacy also places greater stress on the resources of beacon centres.
10. Scaling up and sustainability

The complexity of balancing coverage and quality within the palliative care sector for sub-Saharan Africa has been explored, and relates strongly to further issues of scaling up coverage and securing sustainable quality care.

10.1 Sustainability

In the context of family-based AIDS care as a sustainable community alternative in Malawi, sustainability is defined as "the extent to which the family is likely to remain a credible source of persuasion long enough to justify any time and resources seriously invested in it" (174). A further definition in a similar context relates sustainability to community mobilisation, seeing sustainability as being achieved in the following circumstance: "when a particular group of people become aware of a shared concern or common need, and decide together to take action in order to create shared benefits" (175). Further, sustainability must be linked to quality, as service existence and continuity are not sufficient measures in themselves, and the role of conferences and workshops, international exposure and international recognition should be recognised in motivating and sustaining community AIDS workers in sub-Saharan Africa.

The resource implications for achieving sustainable change and ongoing services should not be overlooked, and are key to success. For example, hospital staff may attend specialist palliative care training then return to their care setting to a situation where they have no resources to begin practising. To address this challenge, palliative care education and training initiatives in sub-Saharan Africa often place great emphasis on follow-up to ensure that momentum and opportunities do not wane over time. Selection of individuals for training also relates strongly to sustainability, with institutions selecting those applicants who they believe are most likely to be able to implement change and act as pioneers to affect their care structure. Motivation for volunteers to ensure sustained care programmes remains a currently under-explored question. For example, how do services select volunteers, and what counts as incentives and reward, what level of training is required, and what resources are necessary to recruit, manage, and retain volunteer projects?

It is hypothesised that health services have a better chance of being sustainable if they incorporate indigenous traditional healers, who may have potentially low costs and a community base, both of which contribute to sustainability (31). Working alongside traditional practice is seen to be crucial to patient retention and adherence to pain relief medications (32).

Despite greater availability of opioids, policy change and purchasing do not guarantee sustained prescribing and administering of pain relief. Although liquid morphine had been available for 9 years in one region, it had not been requested beyond the two specialist palliative care providers (176). Anecdotally, hospitals often run out of drugs, pharmacies do not receive the
drugs they have ordered, drugs expire, and unexpected increases in demand happen (e.g. malaria outbreaks).

During data collection for this review, it was suggested that sustainability may be challenged and even inappropriate as a goal in sub-Saharan African health programmes as war, safety and instability force the project view to be only day-to-day. Instability, funds not being allocated as intended and becoming untraceable, and donor mistrust often reduce the question to “what can I do today?” Further, the issues of human resources return as pertinent in the light of the earlier data estimating a 25% loss of health care staff to HIV and TB over a 10 year period (41). Sustainability is also threatened by salary pressures - NGO pay rates often do not reflect local salaries and therefore staff are lost. Sustainability is often reduced to the simple factor of financial resources, or as “balancing the books” (177). This is unsurprising, due to the economic consequences of AIDS in sub-Saharan Africa (38). The structural and resource challenges facing palliative care services emphasise the need to address issues of sustainability, with the associated need to attend to difficult issues such as patient ability to pay and the effects of aid withdrawal (31). The challenges of funding are constant and unsurprising, and resolution requires considerable effort and commitment on the part of services. The example of Arusha Tanzania is of a hospice begun without any resources except existing staff and hospital facilities, and offer an example of reorganisation and role defining to achieve palliative care (39).

10.2 Scaling-up

Outputs of scaling up include reaching more people, expanding geographical areas reached, reaching other target groups, increasing the volume of outputs, and increasing intensity of impact within given geographic areas and social groups (178), which are exactly the current challenges facing palliative care in sub-Saharan Africa. Sustainability is a central dimension of scaling up, “a programme must be built with sufficient financial, technical, social and political support so that it lasts over time.” Although costs are the primarily quoted feature of sustainability, a broader understanding includes the fundamentals of whether a programme has accumulated sufficient programme experience and momentum to operate at a larger scale. Increasing the scale of activity may indeed stretch resources to the point of reducing sustainability. Strategies to scale-up include organisational expansion, catalysing other organisations, diffusion, and influencing policy and legislation.

Sustainability may also be defined as creating both demand and expectation with a view to quality and best use of resources, or as continuity over time. Sustainability requires community acceptance of the intervention, involving new generations when start-up is over, management level continuity and finance. It is important to avoid false economy in sustainability, e.g. fee charging for those experiencing health incidents who may then be exposed to destitution.
A further enduring problem for donors with respect to scaling up and continuity are issues of physical security, and national economic problems (67). Safety issues mean that some regions may not be safe for health personnel. Poor social conditions, criminality and urban violence have been identified as further contextual barriers in effective cancer pain relief in developing countries (45). Examples are given as patients living in areas inaccessible to clinical staff, or as unsuitable for discharge, and where theft of drugs or medical equipment is common.

As described in the section on structural and resource challenges, scaling up in sub-Saharan Africa faces further challenges in the problems posed of healthcare staff (40), particularly high death rates (41), reluctance to provide care to those dying of HIV disease (43), large-scale exposure of palliative care staff to patient loss in the HIV/AIDS epidemic (44) and poor clinical skills and attitudes in cancer pain management (179).

A review of scaling up HIV/AIDS and TB care in Zambia (2001) investigated the issue of low coverage (180). The principal reason appeared to be the low involvement and poor support of Governments, “research and development is needed for affordable, feasible and sustainable home care programmes that can be implemented by staff working in government, NGO and missionary health facilities with limited donor funding …sustainability appears to be determined by the ability to sustain funding from donors”. Motivation is key for sustainability, and will vary by community and region, therefore it is not possible to prescribe a formula for success.

Scaling up is linked to equity and access of coverage, and with respect to palliative care in sub-Saharan Africa “the danger is that islands of excellence, with unsustainable external funding, will be established and that these will be outside the public health system” (96). This has to some extent been addressed by the WHO 5-country project, which has taken a public health approach (92). A key WHO concern has been the integration of palliative care services into the continuum of care and ensuring sustainability of the initiatives.
### 10.3 Summary

- The current status of palliative care in sub-Saharan Africa is that of a specialist service available in a few centres, with low levels of integration but seemingly high (though unevaluated) standards of care.
- Sustainability is a key consideration in securing both quality and coverage.
- The community and home-based approach that has been favoured may offer the greatest potential for sustainability.
- Palliative care requires sustainable approaches to education and training and to the volunteer components of care delivery, and also to drug availability.
- Traditional healers enhance the sustainability of palliative care services.
- Political instability and short term funding threaten sustainability.
- Any efforts at scaling-up require initial attention to be paid to sustainability.
- Both scaling-up and sustainability are threatened by human resource and economic limitations.
- Enormous effort and resources are required to maintain the gains made in palliative care coverage.
11. How to ensure quality?

Research into palliative care in sub-Saharan Africa is embedded into a nexus of challenges: clinical, logistical, financial, social, political, and research: “Clinical and health service audit and research is desperately needed so that we can establish how best to deliver palliative care in the resource-poor setting, and to establish an information base relevant to the developing world” (181).

11.1 A dearth of evidence

Monitoring, evaluation, and audit across domains and activities relevant to palliative care tasks have been consistently flagged up throughout this report as key to establishing quality palliative care in sub-Saharan Africa, but also have been highlighted as largely lacking. There are significant weaknesses in the current body of evidence, and an evaluative programme is required. Evaluation is lacking not just with respect to outcomes and effectiveness but also process, feasibility, acceptability and accessibility.

Research approaches are needed to ensure that funding, policy, advocacy, development and care objectives are achieved. Although research must take place in collaboration with in-country organisations and institutions, the technical expertise in palliative care research currently resides in developed countries. A body of methodological expertise has been established in palliative care, and in this field more than most evaluations have failed, and it is important to learn from this. Funders must support research technical assistance for their services.

Research is a fundamental necessity in this resource poor context, therefore it is important to use them to best effect. Learning from what is being done now can inform the future, and it is important to understand what changes are needed and what works to convince funders (100). The challenges are that resources are limited, funders and services are caught up in the need to do something now, measures are complex, and inputs, processes and outcomes are locally determined. It is also important to consider the timing of initiating research and setting standards (96) when encouraging start-up: should standards be established but expected to be met after a initial period of establishment and growth? Even if outcome evaluation is postponed, process data are crucial.

The lack of research grounded in the sub-Saharan African context also limits the potential for the discipline, particularly as the tasks for increasing palliative care rest on research knowledge: “Training in palliative care which incorporates all the modern research and methods practical to the country, should be taught to all health professionals, commencing in undergraduate training schools and extending into post graduate education” and “Each hospice should be seen as a centre of teaching and research, as this is a relatively new speciality for developing countries. Cultural, spiritual, social and
even metabolic differences need to be researched in order to give the best comfort to patients and families” (97).

A fundamental problem is that a large proportion of the reported findings and “evaluation” data are not backed up, i.e. they rest on the authors’ attitudes, perceptions and beliefs that cannot be easily appraised or transferred. That is not to suggest that this data is not useful or accurate, but exemplifies the problem that the large body of knowledge and experience gained in bringing African palliative care to its current level of success has not been independently, rigorously or thoroughly captured, and useful evidence for success is lost. The WHO 5-country palliative care project offers the promise of evaluation of its objectives (92), but the approach, domains and methodology are not currently in the public domain. It will be useful to establish knowledge of a set of tested methods – both successful and unsuccessful - in researching palliative care in sub-Saharan African.

It may be that the pressurised services need greater emphasis and associated resource allocation to evaluating and writing up their services, not only outcome data but process and audit data. Although palliative care is deemed necessary and appears to be effective, there are still many questions to answer and the full research agenda to inform the broader field is as yet unaddressed.

11.2 The need for an ethical approach

When building research systems and activity in sub-Saharan Africa, it is important to note the importance of ethical issues (182). Ethics review committees are absent and often ineffective, and participants in studies need to be protected. Even when ethics committees exist in useful forms, the imbalance of power may impede their effective operation. They may have difficulties in being objective when projects offer collaboration with prestigious research institutions, where engagement may offer training opportunities, equipment, and publications. Also, power imbalance may invalidate the consent giving process at the patient level.

11.3 Evaluation, audit and quality care measurement

Although the principles of palliative care are consistent around the world, the socio-economic environments, prevailing diseases, health care systems, technology and drug availability differ enormously, meaning that palliative care has different characteristics in different regions (183). Higginson & Bruera’s consideration of palliative care audit in relation to developing countries describes the many measures that have been developed relating to the palliative care philosophy: physical and psychosocial symptoms, family needs and support, functional status, and prognostic factors. These measures make a fundamental contribution to decision making in relation to service development, identify successes and failures, and to the setting and monitoring of standards of care. In considering the application of measures and processes to developing countries, the principles remain the same and
may be even more important to identify failure and identify success as palliative care is in a rapid growth stage.

As discussed under “palliative total care in sub-Saharan Africa”, we need to understand what are appropriate outcomes and goals, and what quality of life means in a variety of settings: it is far from clear, although some current activity has been reported to inform the very scant quality of life literature (181).

Reporting of pain measurement research and practice in sub-Saharan African countries is rare. There is some data available, e.g. the Hospice Association of South Africa Annual Statistics 2001-2002 (184) which gives good coverage of resources and patients seen; the Hospice Africa Uganda (185) and Mildmay (64) clinical data; the ICHC South African research on costs, referrals and other operational research (95) (122); and several other studies of cancer palliation mainly focused on South Africa (68;186-189). South Africa is often perceived as being a resource-rich country with advanced health care systems including hospice availability in comparison to other African countries. However, pain management among cancer patients in South Africa was still found to be poor with black people experiencing greater unresolved pain and of greater severity than their white counterparts, and low overall pain relief (188). This study makes two important contributions: firstly, it presents the use of validated pain measurement and secondly identifies the need for collaboration to achieve pain management.

The Hospice and Palliative Care Association of South Africa (HPCA) audit tool is an example of standard setting, and although it is not the only case, it does attempt to achieve quality through networks of providers to standardise care across services (190). It addresses training, resources, policy and guidelines, team components, and records. The tool’s strength is to identify all the necessary components, although the endpoint of patient needs and care may require much greater attention.

11.4 Summary

- Impressive innovation has helped to establish palliative care in sub-Saharan Africa. Without setting a research agenda the opportunities for continuity and expansion of quality and large-scale care will be lost
- A wide range of issues are to be evaluated: development, access, process, and outcomes in many settings
- We must ensure that resources are used to best effect
- Research efforts must focus on assisting local evaluation through the provision of technical assistance and the experience of palliative care health services research
- Ethical research protocols are the right of all services, patients and their families
- It is not yet clear which measures and domains are appropriate for research; the local development of measures is crucial
12. Limitations

A primary problem in answering the original aim of this study - i.e. identifying and isolating factors associated with success - has been firstly the lack of research, secondly the lack of written experience, and thirdly the potential bias in reports being written mainly for an audience of funders. The risk in the latter issue is that services (understandably) wish to present the service in a positive light and lessons of challenges and even failures may not be fully shared. The lack of commonality in approaches to report writing and resulting service descriptions and tendency to underreporting of process data also limits the consistency across tables in extracting data. Such desk-based reviews are limited by the level of reporting activity, and original data collection was beyond the scope of this study. Assumptions could not be, and were not, made on any service and the contents of this report rely entirely on the current body of literature. Therefore service descriptions may not be whole or fully representative of the work undertaken by any programme.

Further, the electronic database literature searching was restricted to the English language, which may have implications for papers originating in West Africa. However, no service reports were ever encountered in French, suggesting that a minimal number of omissions were likely.

When conducting such an assessment it is not possible to know if all relevant reports have been obtained, however it is unlikely that any key players were omitted due to the collaboration with associations and key advocates and networks. When looking beyond palliative care to search for potential lessons to be learned from other fields, such an exercise must be tightly delineated and restricted as such a large number of NGOs are operating in the health sector across the African continent. Lastly, the field of palliative care in sub-Saharan Africa is developing quickly and is an emerging discipline, and successful advocacy aims to speed up this process. We hope that the current education and training and funding initiatives are increasing the number of palliative care providers, and so although this report is current to the point of publication, we would expect further providers to emerge.
13. Conclusions

The service review data presented in this report demonstrate the encouraging response to the need for palliative care in sub-Saharan Africa. The epidemiology of cancer and HIV demonstrate the overwhelming and increasing need for palliative care. In particular, the approaching expansion of HAART provision will require further palliative care intervention. The weaknesses of much current home-based care are very clearly described, and this shows great reflective willingness to take on board the benefits of palliative care. However, the severe resource limitations and weak infrastructure, drug access restriction particularly for opioids crucial to palliative care, and significant loss of healthcare staff to terminal disease, place enormous challenges on achieving development goals. They also underline the importance of a co-ordinated approach in achieving growth and meeting multi-sectoral palliative care needs in sub-Saharan Africa. A fundamental activity is that of “advocacy” and offering successful demonstration projects.

In the absence of outcome measures and evaluations, this review cannot explicitly endorse particular models with respect to effectiveness, but can use the small amount of descriptive, developmental and audit data as an indicator of lessons learned. There are several notable exceptions, which have demonstrated improvement in pain and symptoms following admissions. Community and home-based care are by far the most common models of care, and offer descriptive evidence of success. However, the selection of the model is resource (and feasibility) led and the challenges, weaknesses and operational requirements of the model are largely unreported.

In the light of the fears regarding opioid prescribing, it is helpful to have clear dissemination of working systems to hold up as a successful template, e.g. Hospice Africa Uganda. However, even if the advocacy goals of integration, drug access, funding, formation of working committees, carer support, capacity building for advocates and implementation of existing policies are successfully pursued, it is still necessary to establish exactly what a palliative care service should offer and how, what it should achieve and to know whether it is achieving it. Audit, research and evaluation must guide service development.

This appraisal is limited by the availability of information. When considering what “works” in palliative care, if we take the endpoint to be a patient receiving quality care then a set of chained events are under scrutiny. There are many issues to be addressed, e.g. defining components of palliative care for the continent, selecting appropriate outcomes, developing models, investing in clinical expertise and competencies, identifying partners, building measures, testing methods, and sharing technical skills and experience. The current paradox is that there is a chronic dearth of evidence and a wealth of experience and knowledge. Technical skills and opportunities need to be provided for those under resource and time pressure; a limitation for this appraisal is that those engaged in the field need to be further encouraged to
research and write. This requires donor recognition for the provision of resources and technical assistance.

When considering potential for providing palliative care, the fundamental message should be that palliative care can be simple, protocol-driven and practised by all, as has been exemplified by the cited sub-Saharan African palliative care manuals. Also, enormous potential exists in innovation and service variation, including home and hospital provision, specialist services with efficient referral systems and co-management of patients, or integration into existing care services. However, with respect to the site of care and access, the contextual limitations on feasibility must be borne in mind, including the need for clinical supervision and guidelines for carers, and the unsuitability or lack of some patients’ homes as the site of care.

Palliative care is at a rapid growth stage, and would benefit from audit and quality assessment. To date, those involved in palliative care in sub-Saharan Africa have been extremely successful in establishing the specialism, and those services involved deserve recognition for their achievements. Now that the initial innovation has taken place, it is timely to move on to another phase of consolidation and evaluation to prevent jeopardising the long-term future.
14.  Acknowledgements

We are very grateful to all those individuals and associations who assisted us in our endeavours to identify and locate reports related to palliative care in Africa. Their assistance and goodwill was invaluable in achieving our goal. Thanks also go to those individuals and organisations that took the time to furnish us with their reports.
15. Appendices

15.1 Biomedical database searches

The following databases were searched:

PREMED & MEDLINE 1966-2003
CINAHL 1982-2003
AMED 1985-2003
CancerLit 1975-2003
PsychInfo 1974-2003
EMBASE 1980-2003
Sciences Citation Index (SSI) 1981-2003
Social Sciences Citation Index (SSCI) 1981-2003

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

The search strategies were as follows:

Search 1: palliative care in Sub-Saharan African countries

The initial search for peer reviewed journal palliative care papers describing work originating in Africa was undertaken in July 2003. The search terms were the union of (hospice, terminal care, terminally ill, palliat*, hospice*, dying, end of life, advanced disease) intersected with the union of (Africa, Angola, Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote d'Ivoire, Djibouti, Eritrea, Ethiopia, Gabon, Gambia, Ghana, Guinea, 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, Zambia, Zimbabwe).

Search 2: Primary health care projects

The search for primary health care projects and parallel systems of acute health care was undertaken in August 2003. The search terms were the union of (primary care, TB, tuberculosis, community health, sustainability, coverage) intersected with (Malawi, Kenya).
### 15.2 Table 1 Service descriptions from published papers and reports

<table>
<thead>
<tr>
<th>Ref/Service/Country</th>
<th>Service description</th>
<th>Care statistics and service development issues</th>
<th>Lessons learned</th>
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<tbody>
<tr>
<td>(73;102) (191) (192) (193) South Coast Hospice, South Africa</td>
<td>Integrated HIV home care. Comprehensive package of HIV/AIDS care with a network of partners. Clinical (e.g. pain and symptom control) nursing (e.g. hygiene and nutrition, family skills teaching, medication supervision), psycho-spiritual support (counselling, stress reduction), social support (e.g. poverty alleviation and bereavement care) Home-based care covering 2,500 square km. Hospice staff provide weekly home visits. Interim care is given by supervised volunteers. Emergency food relief, gloves, food, bedding and toys available to poor homes; networking partners are important here. Specific children’s team.</td>
<td>The emphasis on HBC is a response to the enormous epidemic strain on hospitals, and home carers must be professionally supervised and include quality pain and symptom control. The expertise from the hospice is most useful to the formal health sector. A good set of guidelines to ensure caring for the caregiver is in place.</td>
<td>“Accurate documentation is one of the greatest challenges associated with community-based home care” Note this is from a large research study with established systems. Has established clinical standards of care and attends to community feedback as well as external evaluation. Research grants and activity cover many areas, although patient palliative care outcomes are not part of the comprehensive range of activities. Early lessons learned: high standards of caregiving, and associated training needs, are crucial. Those in rural areas are seen less often and so need even higher levels of quality assistance. Selection and ongoing support for community caregivers is crucial. Leadership in care is achieved through high credibility among clinics and hospitals. Their willingness to play their role is crucial and things would collapse without them.</td>
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<tr>
<td>(95) Integrated Community Home</td>
<td>The ICHC model (supported by hospice) emphasises a continuum managed by an NGO that is</td>
<td>ICHC has benefit of being managed by an NGO that is</td>
<td>“The sustainability and success of any model is dependent upon, amongst other</td>
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65
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<tr>
<th>Ref/ Service /Country</th>
<th>Service description</th>
<th>Care statistics and service development issues</th>
<th>Lessons learned</th>
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<td>Care programme, South Africa.</td>
<td>of care between all sectors of the health care system, and emphasises palliative care. Main characteristics: shift from professional to community carers, from institutions to home, focus on the family and patient, also on prevention. Free or pro-rata charging. Supervising nurse drops off caregivers who visit patients then call nurse with necessary visit info. Inpatient facilities for respite for short-term management of pain. Informal caregivers are paid and contracted for 1 year. Full patient load discussions by the team with doctors and nurses. Volunteers are paid a stipend and expenses and live in the community providing support to caregivers. Home visits address holistic needs. Usually caregivers visit patients once weekly. NOTE: some hospices do not have medication access and so the patients must attend hospitals, whereas others have poor access to the hospice but</td>
<td>already well-established and self-supporting. Hospital nurses generally lack palliative care knowledge and skills and so releasing patients into HBC projects offers an important alternative. NOTE: some hospices have geographical and historical reasons for specific areas of expertise, e.g. nutrition or paediatric care. Sustainability: two issues of funding and caregiver pay.</td>
<td>things, the availability of resources, the level of community participation and the level of ongoing commitment and organisational capacity of the coordinating body. If the coordinating body is already well-established in the community, there is an added degree of certainty about the capacity and sustainability of programmes it implements.” Referrals are dependent on good relationships with health care sector, and this is crucial and staff may not understand what palliative care is, and sometimes staff are competitive over their patients. Primary health care clinics often have fixed ways of working that have not included the hospice system.</td>
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<tr>
<td>Ref/ Service /Country</td>
<td>Service description</td>
<td>Care statistics and service development issues</td>
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<tr>
<td>Island Hospice, Zimbabwe</td>
<td>Caregivers have access to morphine. <strong>Referral info:</strong> Caregivers visit patient in hospital before discharge, and hospice transports patient home. Can have community or self-referral. This model does not provide medications from hospice but refers out. Only late stage patients are referred, preventing a “continuum of care” approach.</td>
<td>Parity between nurses and social workers quickly established due to working with deprivation. Satellite project was initiated with community meetings and community needs assessment and mapping. Skills training: provide follow-up and mentoring.</td>
<td>Also a satellite but unfortunately depletes staff at base. An enormous success has been working with hospitals and families to carefully care plan and reduce the number of readmissions that were blocking beds. Problem that community teams caseload has increased from 30 patients per month in care to 500. Carers are caring for 20 patients each from an original identified capacity of 10, child bereavement requests have gone up from 22 to 100 in one district per month, and enormous numbers of community groups are requesting training, e.g. 25 groups in 1</td>
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<td>Ref/ Service /Country</td>
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<td>(39) Arusha, Tanzania</td>
<td>Community-based care from hospital based team</td>
<td>No funding, created from existing cancer centre</td>
<td>Recommend the encouragement of many small projects based in hospitals where (limited) pain control drugs such as pethidine are used post-operatively and educational expertise is in place. Encourage small projects for rural areas.</td>
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<tr>
<td>(91) Mildmay Centre, Uganda</td>
<td>HIV care: Outpatients, support groups, children’s centre, education, children’s hospice, day care, home care, hospital consultations. The palliative focus is rehabilitative. 12,000 holistic care attendances (NOT all palliative). 6,500 grants from treatment and welfare fund. All HIV disease stages addressed.</td>
<td>£3 for initial consultation, £2 for subsequent. Assistance available and free care for children. HAART available to those who can afford it.</td>
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<tr>
<td>(195) Children’s support</td>
<td>Service for bereaved and terminal children. Palliative care, across</td>
<td>Aim of sustainability: designed with target groups</td>
<td>Problems: underestimated time for initial communication with groups, networking</td>
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<td>project @ Island Hospice, Zimbabwe</td>
<td>community, children’s homes and hospital wards, training, provision of medical supplies and drugs.</td>
<td>to meet perceived needs. Avoidance of problems associated with training by focusing on follow-up and support, supervision and consultation. Participation by invited community groups. Focus on teaching full understanding of need for palliative care. Grief and loss also central tasks. 90 children attended group work sessions, 432 counselled, 181 family member contacts. 372 palliative nursing contacts. Evaluation of groups: 9 Caring for the Carer workshops. 311 hospital contacts in Govt hospital critical children’s ward.</td>
<td>and decision making. Telephone communication a particular problem. Hard to achieve goals due to inappropriate data systems and inadequate staff. Need more allocation of time and resources to group supervision and debriefing. Have lowered expectations: time and achievements, “small is better”. Problem in understanding why low numbers of children are referred for palliative care. To meet goals identified a need for programme monitoring and evaluation assistance. Need monitoring and evaluation of staff to ensure skills transfer to the community remains of a high standard.</td>
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<td>(196) Cotlands child care, South Africa</td>
<td>Inpatient hospice and home care as part of range of HIV/AIDS child services. Hospice offers care for up to 20 children from birth to 6 years with terminal AIDS who can’t be cared for by their family or have been abandoned. Home care also Hospice aims to avoid children dying in hospital. “High turnover”, at full capacity in inpatient hospice.</td>
<td>High emotional pressure on staff. High financial costs for end-of-life care.</td>
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<td>offered with services of 2 nurses and 8 trained home</td>
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<td>carers, particularly for orphans and child/grandparent</td>
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<td>headed households. Daycare and educational facilities</td>
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<td>offered to all including hospice residents. Further</td>
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<td>home care project attached in Soweto offering care to</td>
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<td>120 children and their families.</td>
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<td>(197) Kara Counselling</td>
<td>Hospice inpatient care and collaboration with HBC</td>
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<td>and Training Trust @</td>
<td>projects, partnerships with other institutions providing</td>
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<tr>
<td>Jon Hospice, Zambia</td>
<td>similar care. Clinical, family, pastoral, emotional/psych,</td>
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<td>nutrition, education.</td>
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<td>Encouraged HBC projects to initiate palliative care early</td>
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<td>alongside active care as it can rehabilitate patients</td>
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<td>and return them home. Educating that palliative care is</td>
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<td>not for only those approaching death. Free care and</td>
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<td>income generation projects. 49 patients referred per</td>
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<td>month, 74% discharged. Home follow-up for all discharged</td>
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<td>patients. 22% death rate. 592 per annum, only 20</td>
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<td>children. 498 volunteer caregivers.</td>
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<td>Unpredictable and varying levels of participation by the</td>
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<td>5 HBC projects and their 1800 registered patients.</td>
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<td>Problems with security, break-ins &amp; stealing goods.</td>
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<td>Community and business organisation involvement and</td>
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<td>assistance with hospice has greatly assisted</td>
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<td>stakeholders' involvement.</td>
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<tr>
<td>(198) Nsambya Home Care, Zambia</td>
<td>Home palliative care, training, counselling, family support, social fund to purchase basics.</td>
<td>447 patients; 11 deaths. 78 patients access oral morphine. Rehabilitation success returns patients to work.</td>
<td>Problems are increasing number of clients. Too many patients come to project wanting HAART and need to be informed of palliative care. Poor manual data management system makes information sharing very hard. Believe that good palliative care depends on time spent with patients, a great challenge.</td>
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| (199) (200) (201) Kitovu Home palliative care and orphan care, Uganda | Health centre and home care, counselling, HIV testing, TB treatment, peer support. NOT a palliative care service in totality (see stats). Patients choose locations of care centres for visits every 2 weeks. Visit 5-6 centres per day. Basic supplies (food, blankets, soap) available for those in need. 180 patients seen each day. Community and hospital referrals. Initiate morphine in hospital then visit at home. Remote area patients are still served and may involve 200km round trips. Take TASO referrals and also HAU patients who leave Kampala. | Palliative care and oral morphine were integrated in 2000, and have registered 246 patients. Each centre is visited every 2 weeks-In 1 year 1353 new referrals, 1797 old patients, inc 396 children and 596 deaths. 3150 reg patients, 18,910 visits. See 1318 orphans. 88 new patients on morphine, total 117. 64 deaths. Average 5 months on treatment. 207 doctor and 209 nurse home visits. 480 community volunteers trained. Also train district health workers and Kitovu home care | Reasons for increasing referrals: NGOs offering free HIV tests, word of mouth through communities, poverty means those attending private clinics cease those services. Also Catholic Relief Services supplying food. Challenges: Burden of staff deaths and patient deaths increasing orphan need. Poverty-related needs also seem to be increasing. Men seem to be far less happy to attend or to allow female relatives to attend. Staff training in hospital; regularly changing staff means need to deliver every 6 months. "We need to become more skilled in treating the total pain of the patient and the family, not only physical but psychological, social and material. Often
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<td>(170) The Palliative Medicine Institute, South Africa.</td>
<td>Education, care and support (home and hospital based). Volunteer HBC teams Hospital teams rotate with home care teams and act in advisory role. Hardship fund available. Also hospital team work with the Hospital AIDS clinic.</td>
<td>MUST have nursing backup to enable diagnosis and treatment: suffering without clinical backup is chronic.</td>
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<td>(177) Highway Hospice Association, South Africa.</td>
<td>Palliative care (8 inpatient beds, 4 day centres, and home), family support (including bereavement), education and training. Care for those with a terminal illness. No charge.</td>
<td>Covers 1,366km2. 1000 inpatient new patients per year. 700 home visits per month.</td>
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<td>(53;202) (203) (204) (205) Hospice Africa Uganda</td>
<td>Incorporates Mobile Hospice Mbarara and Little Hospice Hoima. Aims to promote palliative care across the continent as well as provide home and hospital care and education in palliative medicine.</td>
<td><strong>Little Hospice Hoima</strong> is a demonstration project aiming to show affordable service at the village level for encouragement to other resource-constrained</td>
<td>With respect to Little Hospice Hoima, education in the form of community education on utilisation of palliative care services has helped to sensitise communities and increase referrals and uptake.</td>
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nurses. Programme of mobile home care started in 1987, now have 3,600 active patients, 15 nurses in 3 teams visiting 124 centres. our patient suffering is magnified by the extreme poverty in which they live. Our funding limits what we can do to relieve these problems. We are challenged to find new resources to benefit these patients” (201). They note the benefits to carers of oral morphine i.e. not seeing patients in pain.
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<td>Offers <em>terminal</em> care (often HIV-related) including pain and symptom control and counselling and spiritual support. AIDS care in cases of uncontrolled pain. 252, 205, 147 patients respectively currently on programme. Although £2 is charged per week (inclusive of all care and drugs), 70% receive assistance.</td>
<td>settings. Offers a weekly clinic and hospital visits three times weekly. Daily home care. Monthly sensitisation outreach. Monthly day care. Volunteer referrals and carers. <em>Mobile Hospice Mbarara</em> has seen 380 new patients per year since 1998. Offers outreach mobile home care, twice-monthly mobile clinics, roadside and 3 weekly hospital referral visits. Patients can be met at roadside points to be assessed and renew prescriptions. <em>Hospice Kampala</em> offers 20 km radius care of Kampala: daily home &amp; hospital visits and weekly day care, with a weekend emergency service. Can attend during day at Hospice for consultation if needed.</td>
<td>Key successes of HAU have been Government partnership ensuring palliative care is part of the National Health Strategy with specific targets, and the oral morphine roll-out to 14 of 56 districts.</td>
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<td>Referrals: 80% hospital, 20% self-referral, relatives, private sector. 20 k radius. Has cared for 4,000 patients in Kampala, 1700 Mbarara, 450 in Hoima (09/2003).</td>
<td>PR forum provides advocacy activities. And are instrumental in developing national policies. Sustainability is seen in terms of funding.</td>
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<tr>
<td>St Lukes Hospice, South Africa</td>
<td>Patient and family service for physical, emotional social and spiritual needs in non-curative end-of-life care. Technical demonstrations and promote values. Home care is reached most with specific trained lay carer with nurse support. 12 community branches each with a weekly day hospice service. Home-based carers also trained in TB treatment supervision. Have 2 wards for short-stay (max 14 days) stay for symptom control, family respite or terminal care.</td>
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<td>Sizanani Village Trust, St Joseph's Care Centre, South Africa. <em>(Leaflet information)</em>.</td>
<td>Hospice care for terminal illness with emotional and spiritual support, primary focus on HIV/AIDS. Palliative care inpatient services will not offer long term nursing care. Beds for 16 adults and 8 children.</td>
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<td>Family care also offered. Community-based orphan care across food and counselling to school costs. Home-based care for terminal HIV/AIDS patients primarily. Community caregivers are trained in palliative and counselling skills. These carers are supervised by co-ordinators.</td>
<td>The basis for setting up palliative care was: patients unable to pay for curative care leading to advanced disease, lack of HAART, chronic poverty and lack of pain relief drugs in routine care.</td>
<td>Interesting tension: the services are incorporated into the hospital mainstream due to lack of funding and the aim of raising awareness across all staff. However, they wish to at some point offer an independent service.</td>
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<td>Abeokuta Hospice and Palliative Care Project, Nigeria</td>
<td>Service integrated with the hospital: the palliative care services interfaces with patients in the emergency room, through routine ward admissions, day care, and offers specialist palliative home care and a pain clinic run by anaesthetists. Social work is a central role.</td>
<td>Can’t obtain funds for the clinic and so doctor is only seconded for 7 hours per week from the hospital. Community carers are necessary due to overload on nurses being unable to spend long with patients, they supervise community volunteers who are able to</td>
<td>The provision of basic poverty-mitigating parcels is inadequate and needs further resource allocation. Networking is crucial to meeting need; offers staff a broader resource base.</td>
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<td>Grahamstown Hospice, South Africa</td>
<td>Nursing home care, bi-weekly clinic at hospice (reducing hospital overload; transport provided as ambulances have no capacity and patients can’t afford public transport), training community workers, social and emotional support for patients and families, poverty relief, bereavement follow-up, networking to meet multiple</td>
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<td>(207) (208) Lighthouse Centre, Malawi</td>
<td>Community Home-based Care, Voluntary Counselling and Testing, Clinical Day Care. All based in district hospital. Offers care to the infected/affected in HIV, and to other terminally ill people. HIV paediatrician on staff.</td>
<td>Nurses provide direct home care, assist family cares, work with community volunteers to identify and care in the community. A “circle of care” from diagnosis to terminal stages. Taking a lead in both morphine and HAART (currently 900 patients). Clinic services also emphasise care. Morphine is being shared with other clinicians in other places. However, the report states that “we do not have large numbers of patients on morphine under Lighthouse supervision”. Offers some insight into</td>
<td>Major problem is keeping resources in line with expanding demand. Clinic visits went from 400 in January to 1200 in December. While CHBC team went from 150 to 300 visits per month. Palliative Care has been a new addition to services. Have been strengthening support to HBC to ensure quality and palliative care are addressed. Strong referral links to the Lighthouse Clinic. Morphine now introduced to the 3000 terminal home visits and evaluation systems in place. Logistics are key - need to have vehicles etc to keep things moving. Identified funders to pay for nutrition supplements/food for those who need it. A Log Frame for Palliative Care exists in Report to June 2003 p 26-29.</td>
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<td>(101) Nyeri Hospice, Kenya</td>
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<td>The small home care team and transport difficulties make things very difficult. Most areas are inaccessible; sometimes teams walk 2-3 km. Chronic lack of resources for holistic care and drug shortage. Haven’t been able to help emergency cases, not open at weekends and there is little telephone access. Lack of funds for minimal charges, though try to help using the ‘comfort fund’.</td>
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<td>(209) Joy Hospice, Mbale Uganda</td>
<td>5 bedded hospice in response to obvious additional need in existing medical service. Patients seen as outpatients with brief admissions for symptom control.</td>
<td>Home visiting programme delayed by: patients sometimes living over 50km from Hospice, and vehicle being written off in accident and not having funds to replace.</td>
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<td>(210) Joint Clinical Research Centre, Uganda</td>
<td>A centre for HIV care and research. 5-day outpatient clinic and 16-bed ward for the very sick. 80 outpatients per day.</td>
<td>Most present with advanced disease, 74% WHO clinical stages 3 or 4. Holistic palliative care is integrated.</td>
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<td>(211) Hospice Association of Zimbabwe</td>
<td>Strong belief in palliative care being taken to rural settings. Aim to strengthen the continuum of care</td>
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<td>Zimbabwe</td>
<td>between the formal health system and hospice. Stress on discharge planning and active referral systems.</td>
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<td>(212) Meru Hospice, Kenya</td>
<td>Started with donations of building in hospital grounds and equipment.</td>
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<td>Major challenges in Meru culture, government bureaucracy and funding. Very few home visits due to lack of vehicle, though staff try to attend on public transport and on foot.</td>
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<td>(213) Malawi Palliative Care Programme</td>
<td>Lighthouse is now providing morphine to 4 key hospitals.</td>
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<td>This is a response to the enduring problem that the Malawian Government does not financially support palliative care and hospices struggle to find medications. The essential palliative care drug list has been compiled but is not yet generally available.</td>
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<td>(214) Association Francois-Xavier Bagnoud (AFXB), Uganda</td>
<td>AIDS care using home-based community approaches. Since Jan 2003, have set up a palliative care component with MoH and Mildmay support, and have registered 30 patients. Community volunteers assist. Also offer supportive programmes of income generation and education to orphans.</td>
<td>Mobile team for over 300 patients to date from 1990.</td>
<td>Despite the palliative care programme, “PLWAs were experiencing a lot of pain especially in the late stages.”</td>
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<td>(215) Good Shepherd Hospice,</td>
<td>Home-based palliative care programme for those with a terminal illness: pain and symptom control,</td>
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<td>South Africa</td>
<td>family instruction, and holistic support. Nursing staff on 24-hour call. As disease progresses, and is advanced and progressive and death is foreseeable, they move on to hospice programme, 6 bedded. For short-term admissions, max 14 day respite care. Satellite day- and home-based care centres now exist in 6 centres. Volunteer caregivers and hospice staff provide services.</td>
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### Table 2 Research findings from published papers and reports

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<th>Findings</th>
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<td>(64) Mildmay, Uganda</td>
<td>Change in pain and symptoms from referral to 4 follow-up visits.</td>
<td>Of the pain (77%) and other symptoms (20-61%) reported at presentation, 70% reported significant improvements.</td>
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<td>(65) Mildmay, Uganda</td>
<td>Paediatric pain, symptom and mortality audit in HIV care (all disease stages service, offers palliation). 172 enrolled in 10-month period</td>
<td>Children recruited from hospital outpatient clinic and provided with total holistic home family-based care. 850 home visits in first year. At first assessment: 67% had cough, SOB 15%, skin problems 60%, diarrhoea 19%, abdominal pain 10%, fever 32%, night sweats 15%. 20% on active TB treatment during the year, and a further 16% had previous treatment. 19% had delayed development. 26% died. Care cost of $10 per month.</td>
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| (216) Mildmay, Uganda | Patient audit: 200 patients over 2.5 month period were audited in this total care service from diagnosis to terminal stages. Only 43% returned for 4 follow-up appts, 11% attended for one 14% did not return following 4th appointment.  | Using a scale of symptoms outcomes scoring 1 = recovered completely 2 = sig improvement 3 = mild improvement 4 = no improvement 5 = worse 6 = improved but recurred  
**Outcomes of the 8 most painful conditions after 1st and 4 follow-up visits:**  
Significant improvements: Herpetic ulcers 19/27  
Abdominal pains 18/23 | Notes that these are advanced stage patients and intervention can be successful, although these were less well controlled than painful conditions. The service sees itself as very much having restored patients to a functional role as they were advanced but not terminal. |
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| 1st appointment.     | N=85 had 4 follow up visits, 10.6% died before 4th follow-up visit. | Headaches 11/12  
Peripheral neuropathy 8/11  
Chest pains 7/9  
Joint pains 8/8  
Dysphagia/ odynophagia 8/8  
Back pain 5/6  
Postherapeutic neuralgia 6/6  
Other symptoms sig improvements  
Nausea/vomiting 12/21  
Skin rashes 8/21  
Itching 8/21  
Anorexia 7/12  
Fevers 7/15  
Cough 13/51 | |
| (44) Grahamstown Hospice, South Africa | “Quality of Life Project” Annual activity audit for 911 patients on caseload | 75 new per month, 5715 home visits, 764 seen at clinic, 596 bereavement visits, 110 poverty relief interventions.  
Total care needs: poverty increasing therefore even burials have to be negotiated. | “Have to empower communities to care because the professional service burden is overwhelming. Hospice clinic doctors are crucial: if you offer assessment and pharmacy services at hospital the queues are too long for the sick to attend. There are many community services, and district home care services, but they lack integration."
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<td>(34) Hospice Africa, Uganda</td>
<td>Operational research on morphine and pharmacy systems</td>
<td>In Uganda beacon programme there are only 12 pharmacists in the public service with most health care facilities having none; the majority are in the private sector. Only 4-month shelf life, studies underway to increase that to 1 year. $1.143 USD per 500ml bottle. Difficulties: lack of technical expertise, transport for distribution, monitoring and support supervision resources lacking, lack of appropriate storage facilities.</td>
<td>Meeting poverty needs is the most difficult drain on resources. HIV stigma prevents access to hospice care, therefore community volunteers have been recruited and are working well as referral agents.</td>
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<td>(217;218) Hospice Africa, Uganda</td>
<td>Report on Morphine start-up programme</td>
<td>Trained health professionals, consulted with agencies to decide best way to deliver morphine and evaluation tools developed. Tools were tested using a team (Kitovu) that currently used oral morphine. Collaborative team between WHO, Ministry of Health, and inter-agency palliative care providers. Ministry pharmacy liaised with clinicians to determine methods of making up solution, dispense and transporting. Generally very</td>
<td>Recommend that health facilities should be chosen according to those who can provide maximum benefit to patients. Follow-up visits are also crucial to ensure proper prescribing, evidence has been found of poor practice. Follow-up visits need 2 technical experts and should last 5 days.</td>
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<td>(185) Hospice Africa, Uganda</td>
<td>Review, including pain and symptom control audit</td>
<td>Directors of local hospital very impressed with the impact of Hospice care, and requested earlier disease stage intervention to improve psychosocial care and pain/symptom control. Patient self-report data on how hospice has made a difference (n=37) the key areas were pain control (n=27), symptom control (n=7) and psychological support (n=8). Pre-post measures (time period not specified) using 0-4 Likert scale: Pain control 3.3, 1.8 Symptom control: 2.9, 1.4 Patient anxiety 2.9, 1.3</td>
<td>The report recommends an audit of action taken on hospice advice with regard to patient care. Notes that Mildmay and HAU work very differently and asks how do patients understand the difference? Working with other charities and NGOs to meet needs is crucial particularly needed in poverty mitigation.</td>
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<td><em>Patient insight</em> 1.6, 0.2</td>
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<td>Consecutive sample of 20 sets of notes to establish effectiveness of pain control. VAS 0-5 no pain to very worst pain. From first to second visit this had dropped from 3.43 to 1.9. Lack of routine referrals to charity poverty mitigation providers. Patient payment over 1 month at main hospice site: 108/436 visits gave payment.</td>
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<td>(219) Malawi</td>
<td>12 site visits to review rural drug availability.</td>
<td>Access found to be unreliable, restricted and unpredictable with exception of morphine aid programme. Main restraints were cost (intrinsic, admin charges and logistical/financial collection problems in rural areas), availability (out of stock, erratic donations and delays), management issues (small rural settings, lack of input into what is required, staff reluctance to administer opioids), other cost implications (patients unable to pay and therefore recover costs, inflation eroding buying power, lack of assured income creating cash flow problems, rural setting disallowing “shopping around” for best prices).</td>
<td>Author concluded that the only thing preventing use of morphine was <em>knowledge of its availability</em>.</td>
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<td>(220) Uganda</td>
<td>Evaluation of morphine use</td>
<td>Aim 1 Evaluate safe use of oral morphine in the community</td>
<td>A broader range of morphine strengths is needed. Need to</td>
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<td>Aim 2 Evaluate patient and relative satisfaction with symptom relief Aim 3 Describe resource implications or prescribing in the community. Audit of 50 clinical notes showed: Morphine dose written clearly 84% Laxative prescribed 76% Method of obtaining morphine clear 16% HIV scale marked 30% Payment recorded 20% Assessment of total pain 28% 2\textsuperscript{nd} visit within 5 days in 50% of cases. How often was VAS used? Pain 1 40% pain 2 30% pain 3 20% pain 4 3% Observations of nurse visit: Severity of pain discussed: 81% Pain scale used 24% Duration of pain noted 85% Patient views on morphine sought 28% Instructions clear 90% Side effects discussed 66% Laxative given 66% Patient fully examined 61% Qualitative data: many don’t come to hospice and get pain relief because can’t afford it; lack of follow-up for hospital patients beyond the 20km range; late referrals mean patients die before</td>
<td>improve measures use, assessment improvements, referral communication with hospital needs to be improved, need better linkage with TB programmes.</td>
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<td>(221) Mulago hospital and TASO HIV/AIDS clinics</td>
<td>Pain prevalence in a non-palliative sample.</td>
<td>Cross-sectional study of those who freely reported pain. Confirmed status of those over 18, clinical examination and brief pain inventory administered and effect of pain on QOL. Nov 2000- Feb 2001 1,200 patients evaluated. 21% reported pain (n=206). Of these, 59% reported severe forms of pain. Severity was linked with reduced quality of life.</td>
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<td>(222) Evaluation of traditional healers input to AIDS care</td>
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<td>Health workers try to unduly influence traditional healers to practice like mainstream health sector professionals. Some healers do not wish to discuss death as it implies failure on their part. Traditional healers know their community norms and concerns. However, sometimes lack disclosure.</td>
<td>Research lessons: research efforts often not well understood. Doctors showed scepticism, while healers were suspicious of scientists and researchers. Strong TH feeling of losing patients and their secrets when asked to collaborate with hospitals.</td>
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<td>(95) (122) Integrated Community Based Home Care Model, South Africa.</td>
<td>Hospital admission days</td>
<td>Murchison Hospital reports that the average time spent in hospital has decreased from at least 14 days to 3.5 days for patients who are referred to integrated hospice and home-based care.</td>
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<td>(122) As above</td>
<td>Caregivers’ problems, interagency working and referrals, place of death, pain treatment.</td>
<td>Community caregivers started seeing an average of 4 clients per day and ten months later were seeing 85 clients per month. Community caregivers’ main problems are poverty and orphan care. High levels of satisfaction. Although partnership between health agencies is crucial to this model succeeding, the report states “this was a major problem in some sites, and in no site was this easy.” Hospitals may be too far or not community-involved. Hospitals may resent NGO suggestions for patient management. Hospital refusal to give medications to anyone except for the patient prevented care. The sustainability angle is described as the “bottomless pit”, i.e. as you meet a need a new one comes into focus. When presenting types of care given, pain control is not listed as a community caregiver task, at any WHO ladder step. There is close co-operation with DOT services with</td>
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<td>good understanding among CCGs. They supervise patients’ medication. Only 52% of patients died at home: it became too difficult for families; families believe that doing everything for the patient means taking them to hospital; family carers couldn’t control all symptoms. However, the study goes on to identify chronic under-treatment of pain.</td>
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