



## EVALUATION OF THREE FUNDED PROGRAMMES IN AFRICA

### IMPACT ON INDIVIDUALS, THEIR FAMILIES AND THE LOCAL COMMUNITIES

UGANDA: Kitovu Mobile Palliative Care Service, Masaka  
KENYA: Maua Hospital Community Based Palliative Care Programme, Meru  
MALAWI: Malawi Home Based Palliative Care Charitable Trust, Blantyre



Makerere University, Uganda



*Diana*

Princess of Wales Memorial Fund  
THE WORK CONTINUES

Evaluation conducted under the auspices of the Primary Palliative Care Research Group, University of Edinburgh, UK, and the Palliative Care Department, Makerere University, Kampala, Uganda, on behalf of the Palliative Care Initiative of The Diana, Princess of Wales Memorial Fund.

Individual country reports are also available for each of the three programmes covered in this report.

[www.homepages.ed.ac.uk/smurray1](http://www.homepages.ed.ac.uk/smurray1)

[www.mak.ac.ug](http://www.mak.ac.ug)

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## 1. EXECUTIVE SUMMARY

### 1.1 Aims and methods

We aimed to assess the impact of three projects funded by The Diana, Princess of Wales Memorial Fund's Palliative Care Initiative, one in Uganda, one in Kenya and one in Malawi. We focused on the differences that the palliative care programmes are making in the lives of patients, their families and their communities. At each site, a multidisciplinary team spent a week using rapid evaluation field techniques (REM), gaining data from three distinct sources – direct observations of the context of care, and clinical encounters; individual and group interviews; and document reviews. The team also gathered many moving first-person stories and photographs from patients, their caregivers and programme staff.

### 1.2 Local context

All three palliative care programmes are home- and community-based, and involve large numbers of volunteers, as well as paid staff. They operate in areas with high HIV/AIDS prevalence, and many of their patients have AIDS-related (Kaposi's sarcoma, cancer of the cervix, lymphoma), or other cancers.

In Uganda, the Kitovu Mobile Palliative Care Service is based in Masaka town and covers four districts with a combined population of 1.5 million, and is reached after a two-hour journey along the main southwest highway from the capital Kampala. Kitovu Mobile Palliative Care Service is part of a larger programme of HIV and AIDS support which focuses on community home-based care, orphans and family support, and counselling and training for children. Masaka town and its surrounding districts was one of the areas hardest hit by the HIV and AIDS pandemic, especially the fishing communities on the shores of Lake Victoria. Poverty is endemic, with individuals and communities facing daily challenges to meet their basic needs. The success of the wider HIV programme in increasing the availability of ART has meant that the majority of patients now in the programme are patients with cancers rather than HIV. The Kitovu Mobile palliative care team visits patients and their families in their homes and liaises closely with the wider HIV and AIDS programme to ensure ongoing availability of medications, including oral morphine.

In Kenya, the palliative care programme is based at Maua Hospital, which is a large, well-established rural Methodist institution in the Eastern Province of Kenya, about a five-hour drive from Nairobi, and is the main hospital in Igembe District of 700,000 residents. Since 2004, the Maua Hospital palliative care programme has treated many people with HIV (local prevalence estimated at 12-15%), as well as many patients with advanced cancers who are seen and reviewed in the hospital wards, at the weekly cancer clinic at the hospital, in the three weekly mobile clinics, or by home visits. Maua residents are generally poor, except for those in the *miraa (khat)* trade. *Miraa* brings to the community the additional challenges of a drug culture, including indiscriminate violence, especially to women and children, and poverty. Funding from the Palliative Care Initiative is especially vital to help cancer patients, as well as those living and dying from HIV/AIDS.

The Malawi Home-Based Palliative Care Charitable Trust programme is an NGO home- and community-based programme, and involves large numbers of volunteers, as well as paid nursing staff. The programme operates in the Bangwe and Limbe districts of Malawi's capital,

Blantyre, and is based at the district health centres of both areas. It works in areas of high HIV/AIDS prevalence, and many of the patients have AIDS-related cancers (Kaposi's sarcoma, lymphoma), or severe pain due to cryptococcal meningitis and neuropathies.

### 1.3 The impact of palliative activities on patients

We found that in all programmes patients received whole person care, and they spoke of being treated with courtesy, dignity and respect. Patients appreciated staff being concerned for all their dimensions of need. Physical suffering was dramatically relieved by oral morphine, and other medication. Patients felt greatly helped to address and solve many problems whether medical, or cultural, such as dealing with traditional healers and stigma about cancer. Some told us how they spent spending much money on lengthy trips and for treatments with limited or no benefit, before they met the palliative care team. Others spoke of giving up hope, feeling that there was nothing that could be done for them, until the team intervened and changed their circumstances. Patients received continuity of care, and this was frequently helped by the connectivity provided by mobile phones. Patients valued the spiritual and emotional support given by staff who took the time to listen, and for many, affirmed their common belief in a god who cared. All spoke of the sense of hope and reassurance given by the teams.

### 1.4 The impact of activities on family carers

Family carers felt greatly helped to care for their loved one. They appreciated receiving social, financial and practical support, such as food and soap, and instruction in feeding and bathing patients, and in administering morphine. They valued guidance and real help, having spent much time in futile and expensive searches for a cure. Carers valued good communication and counselling support, home visits with time to talk, and the sense of caring. Practical advice about terminal care and even preparing the body for burial (in Kenya) resulted in many good deaths at home. Regular visits from volunteers were greatly appreciated, especially in Uganda and Malawi.

### 1.5 The impact of activities on local communities

While members of the communities around these three programmes have been well sensitised and educated about HIV and AIDS in recent years, they were not as knowledgeable about cancer or palliative care services. All programmes were actively addressing this, and some community leaders had come to accept palliative care, and were inspired both to talk about it and to help identify those in need. In Malawi for example, the presence of the home-based care programme encouraged families to care for their members in their home, rather than send them back to their family villages and farms outside Blantyre, where there were almost no treatment options or palliative care services available. Community volunteers were well trained and exceptionally supportive to patients and carers. Many patients, carers and professionals spoke highly of the volunteers as people who cared and gave what they could to help others.

### 1.6 Integration of programme with other health services

In Uganda, there was evidence that the Kitovu Mobile Palliative Care Service was integrated at local, regional and national levels. For example, we talked with a doctor who signed all

morphine procurement processes in the district and highly commended the programme for its integration.

In Kenya, the Maua Hospital palliative care programme was well integrated into primary care and secondary care, and with the local church and schools, because it is based in a community health department in a large, well-respected church hospital. Many staff practising palliative care undertook other duties, and as part of their roles, taught and updated general community and hospital staff about palliative care.

The leadership of the programme run by the Malawi Home Based Palliative Care Trust recognised the need for better, and more effective and timely, service integration with the local government health services. The housing of the programme in the local health centres for the two districts has helped in creating networks, but the national system for HIV care and the hospital structures still mean that patients can spend a lot of their time travelling from different care providers for specific components of their care. The Palliative Care Association of Malawi (PACAM) is trying to help create a more co-ordinated and supported network, and everywhere, project staff members do their best to collaborate, while serving their patients.

### 1.7 Staff members of all programmes are dedicated to their work

In all three programmes, staff and volunteers spend long hours each week planning and doing home visits, some such as those in Kenya and Uganda in areas far from their base. Families and patients spoke movingly of their appreciation for the care offered. The work is demanding and draining and significant stress was expressed by some. However, it is also rewarding, and resilience is fostered by being able to give effective medication



which changes the lives of patients. Staff and volunteers struggle when they recognise that what they can offer in terms of social and practical support, eg. food, school fees, soap etc is limited, and could not meet the full needs of patients and their carers who lived in poverty. Supportive debriefing enables staff to cope with the pressures they face on a daily basis. Volunteers need encouragement and support to aid retention.

### 1.8 Analysis and discussion

These programmes offer vital pain relief, demonstrable psychological support, sensitive spiritual support within the community and social contact to patients and families. Several key issues emerged from our findings. These included the questions of how to provide effective palliative care in the face of poverty; how best to identify beneficiaries (which illnesses, which people and age group, and especially when in the course of illness was care required); how to manage patients, especially those with HIV, when their disease moved from a terminal to a more chronic disease; how to integrate palliative care into health and social care and the community in general; and how best to involve the local community in accepting and



working for the programme. Volunteer training, engagement and ongoing motivation in particular are further challenges, particularly when programmes have paid and volunteer staff working side by side. The growing use of mobile phones to facilitate access to, and the delivery of, palliative care was a noted facilitator that has further potential. There were innovative uses of the mobile phone, such as “flashing” (ringing a number through, but not connecting so no money is spent, but a signal is given to the team to call back). All these issues are discussed in the body of this combined report, and also in more detail in each of the individual country reports.

## 1.9 Country specific challenges to the programmes

All staff of the Kitovu Mobile Palliative Care Service in Uganda were very aware of challenges and opportunities and had a forward-looking perspective. Cultural resistance remains a problem, particularly with regard to traditional medicine and women’s empowerment. Resources continue to be insufficient to meet needs, meaning that difficult decisions about priorities need to be made and that the service is stretched too thinly over a wide geographical area. Volunteers remain an important backbone of the palliative care service and the excellent training and retention levels need continued support, as does ongoing community engagement.

In Kenya, the Maua Hospital palliative care programme faced cultural challenges that included a traditional fear that cancer would mean death “that day”, fear that dying at home would be interpreted by neighbours as neglecting the patient, and “prophets”/traditional healers offering to cure cancer with traditional medicines at a great expense. Many families gave long stories of patients who had visited dispensaries, herbalists, spiritual healers (“prophets”), spending a great deal of money on fees and transport. Other challenges included funding constraints within the programme, volunteer training and retention, and scaling the programme up to meet wider needs (probably 90% of cancer cases within the catchment area are not accessing palliative care).

For the Malawi Home Based Palliative Care Charitable Trust, challenges remain around how best to prioritise patient need, and how to manage patients who, with the increased availability of ART, are improving and moving from being non-ambulatory and expectant of death in the next 6-12 months, to being well enough to be able to move around independently. Integration with other local health services remains an ongoing challenge. There is also a need for further sensitisation and advocacy in local communities about palliative care. The nature of the work means that demand always exceeds supply and the programme, with limited funding, has to make decisions about the multiple needs (especially social and financial), that patients have.

## 1.10 Overview of this report

After an overview of each of the three programmes, this report gives many details and direct quotations



about the impact of the palliative care activities on patients, carers, communities and staff. We also report the extent to which the programmes are integrated into local health provision, and the effect on staff of working in complex health systems, as these were important emerging themes. The last sections consider key issues raised and make recommendations. In the course of their field visits, evaluation team members heard many moving personal stories of illness, recovery, death, despair and hope. Fifteen of those stories are attached to this report.

## 2. AIMS AND OBJECTIVES

To evaluate the impact of The Diana, Princess of Wales Memorial Fund's Palliative Care Initiative funded interventions in Uganda, Kenya and Malawi and assess the difference that these interventions are making in the lives of local people, their families and their communities.

Objectives:

- To put the Palliative Care Initiative funded interventions in context by summarising each project's purpose, challenges, development and perceived achievements against the backdrop of previous provision for people with life-limiting illnesses;
- To construct an evidence base that highlights the differences made by the interventions in the lives of those living with life-limiting conditions, their families and their communities.

## 3. METHODS OF EVALUATION



We used rapid evaluation methodology in order to speedily gain a range of qualitative and quantitative information on the impact of the programmes on the lives of patients, families and communities (Anker *et al*, 1991). The rapid evaluation method (REM) was developed by the World Health Organisation (WHO) in order to assess the performance and quality of healthcare services, identify operational problems, and assist in taking action. As a tool,

REM provides a useful system to bring prompt and relevant information together, and to elicit, across a raft of sources and different types of data, relevant and contextually useful knowledge to provide a comprehensive picture of activity. Data were derived from the following three sources.

### 3.1 Review of routine local information relevant to end-of-life care

Published materials are shown in Appendix 3. We noted especially articles relating to the three countries under the study (Kikule 2003, Katabira *et al.* 1998, Harding *et al.* 2003). Project documents and reports are listed in Appendix 1. Team members read and summarised these before field work began.

### 3.2 Interviews with patients, family members, staff and community leaders

The interviews focused on patient and carer identified needs, wishes, experiences and perceptions of the impact of the programme, and encouraged patients and carers to give their individual stories. Interviews were conducted in patients' homes, hospital wards or during mobile clinics held in the communities. We carried out individual interviews and focus group discussions (of 4-12 participants) at each field site, assisted by translators independent of each project to avoid reporter bias. Appendix 2 shows details of the people interviewed, a total of 150 in the three sites.

### 3.3 Direct observations by the researchers of the general environment within the project areas, as well as provision of services in the communities

Using the clinical evaluation skills of the researchers, we assessed the quality of palliative care provided. Observations were supported by photographs of the physical and socio-economic environment of care.

We deployed a field team (two researchers, a photographer and a local translator) to one project site in each country - Uganda, Kenya, and Malawi. The teams carried out data collection, working together for one week in each site between March and July 2009.

Each country report was drafted within a few days of leaving the field. They included key statistics, observations, lists of people interviewed, key findings and direct quotations. The country reports were then combined into the present overall report. During the site visits, we collected detailed case studies of many individual patients and their families. Fifteen of their stories appear and are an important part of this report.



## 4. FINDINGS

### 4.1 Overview of the three programmes in Uganda, Kenya and Malawi

#### 4.1.1 Uganda, Kitovu Mobile Palliative Care Service, Masaka

##### History and context

In the 1980s the HIV and AIDS pandemic swept Uganda, and communities were devastated and struggled to cope. In response to this challenge, Sister Ursula shared her vision for empowerment and support in the districts surrounding Masaka, one of the neediest areas. Backed

by the Medical Missionaries of Mary, Kitovu Mobile programme began in 1987, with a vision to 'see an empowered community with the ability to cope with HIV and AIDS and its impacts.' Handed over to the Masaka Catholic Diocese in 2007, the overall programme focuses on three areas:

- community home-based care, which includes pre-ART, ART and palliative care
- orphans and family support, which includes mobile farm schools for teenage school dropouts, "grannies" support and economic empowerment for women
- counselling and training for traumatised children

### Overview of the programme

The community home-based care programme covers four districts (Masaka, Ssembabule, Rakai and Lyantonde), 27 sub-counties and 111 centres, and is available to a population of around 1.5 million. There has been a steady increase in clients, with 27,698 registered in 2008. Services include HIV testing (2899 tested in 2008, with 37% HIV-positive), social support, home visits and CD4 testing (since January 2008). In practice, this means a patient can be counselled, assessed, have relevant investigations, start treatment, be monitored and have appropriate referrals such as for chemotherapy or palliative care. Significantly, haemoglobin tests can also be done, ensuring that patients do not travel a long distance for chemotherapy when they are too anaemic. Thirty "expert clients" have also been trained and are actively involved in ART (anti-retroviral treatment) support. In all, it is a very impressive programme.

One of the strengths of the Kitovu Mobile Palliative Care Service is its integration within such a longstanding and comprehensive home-based care programme. Patients receive core palliative care, such as pain assessment and moderately strong analgesia (such as paracetamol and codeine), from the pre-ART and ART teams. They are referred, if necessary, for morphine and specialist help to the dedicated palliative care service. Patients and families can also use the centres to pick up prescriptions and medications, including morphine.

This shared care was demonstrated elegantly by a recent review of all patients in the community home-based care programme who had been prescribed codeine. The review aimed to assess the need for referral for further pain assessment and the need for oral morphine; only one patient was identified and referred.



Since its beginning in 2000, the Kitovu Mobile Palliative Care Service has received a steady increase in referrals. It draws from the same area as the larger HIV and AIDS programme, but is not restricted to access at the 111 centres. This means that anyone living in the four districts can be referred and receive palliative care at home, with the result that a home visit to a patient may be as far as 100km each way, even as far as the Tanzanian border. This means that the palliative care team travels on average a total of 1,500 km per month. It also means some patients live too far from centres supported by the wider programme and cannot use them to get their medications, including morphine. Team home visits are carried out three days a week (two to four visits per day) based on need, availability and

geography. Visits may also be prolonged, as patients need time to ask questions, as well as have their needs assessed and a treatment plan agreed. Mobile phones are now more and more common, even in rural areas, and are used to monitor progress and arrange visits.

The palliative care team comprises two nurses, one doctor, one driver and a number of trained community volunteers, many of whom also work within the larger programme. It is straightforward to share skills across the whole community home-based care programme, so social support, counselling and training are available to the palliative care team, while core palliative care skills are available to the wider community team. There are formal monthly meetings in addition to daily prayers, staff lunch and information sharing.

### Beneficiaries

In 2008, a total of 321 patients were registered in the palliative care service, with 113 deaths, 728 home visits and 538 follow-up attendances at the home-based care centres. It is significant that the dominant patient diagnosis is no longer HIV and AIDS. During 2008, 69% (221) of patients had non-HIV related cancer, while 30% (96) had HIV- and AIDS-related conditions, and a small number had other diagnoses, including burns and sickle cell disease.

The 69% non-HIV cancer patients show the expected Uganda distribution: 21% breast, 12% cervix, 9% prostate, 8% liver, 7% sarcoma, 7% oesophagus, and smaller percentages of ENT, ovary, stomach, and rectum. Breast cancer numbers are said to be increasing.

The HIV/AIDS related patients with cancer mostly had a diagnosis of Kaposi's sarcoma (60 out of 96 patients), significantly these patients can also be supported on ART and offered chemotherapy at Kitovu Hospital. Other HIV and AIDS problems were related cancers such as cervix and lymphoma, as well as pain problems due to cryptococcal meningitis and neuropathies.

Patients are referred to Kitovu Mobile Palliative Care Service by staff at the nearby Kitovu and Masaka hospitals, by other NGOs such as TASO, Rakai Project, MRC and Uganda Cares, as well as from further afield. Referrals are also accepted from patients and families themselves and are often facilitated by a sensitised community. The majority come from Kitovu Hospital, which is not surprising as this was the original base for the community home-based programme. The second largest source of referrals is by church leaders, reflecting the successful sensitisation of the community. Palliative care workshops for the community volunteers have also meant an increase in referrals. The palliative care team has taken part in local media events with radio coverage and visiting dignitaries.

The palliative care service maintains an uninterrupted supply of oral morphine in two strengths which is obtained from Mulago Hospital pharmacy in Kampala, the national referral hospital which supplies most of the morphine for the country. It is notable that the palliative care service has coped with the many challenges and bureaucratic idiosyncrasies of this supply in contrast to the reports from other areas. This is due to the planning and diligence of the team, and in practice may mean a personal visit to Kampala to ensure the paperwork is completed and supplies collected in a timely way. The District Medical Officer for Masaka has to countersign all morphine requisition orders and notes it is only Kitovu Mobile Palliative Care Service that regularly requests morphine in his district. Oral morphine and other essential medications are prescribed and dispensed by the team, with relatives and patients also able to

collect prescriptions from the 111 centres covered by the overall programme. Medications are provided free of cost to patients and families.

The palliative care team are committed to staff training and development, and both nurses are graduates of the Diploma in Palliative Care offered by Makerere University, run by Hospice Africa Uganda (HAU). Ongoing training is frequently accessed, often via HAU or PCAU (Palliative Care Association of Uganda). The volunteers come from a pool of more than 700 trained community workers in 15 different parishes who are part of the overall community home-based care programme. The range of training offered to volunteers is impressive and contributes to their strong cohesion and high retention.



Training is offered to others via regular continuing medical education sessions run by the Uganda Medical Association, Kitovu Hospital and Masaka Regional Referral Hospital. The team was also influential in helping Masaka Hospital access oral morphine, though this is still not consistently available. Kitovu Mobile Palliative Care Service is also a clinical placement site for health professionals training at Hospice Africa Uganda and has a new palliative care library.

The Kitovu Mobile palliative care team works with other palliative care colleagues, particularly Hospice Africa Uganda via both the Kampala site and the Mbarara site, where there is some shared care for Rakai district. It is well integrated into the national networks, with Dr Carla both an office bearer in PCAU and a member of the country lead team chaired by the Ministry of Health. Members of the team regularly attend the PCAU updates in Kampala, which has a regional branch in Buddu. The team also attended the African Palliative Care Association (APCA) conference in Nairobi in 2007. Visitors from countries such as Botswana have come to explore Ugandan models of palliative care.

The palliative care team is close knit, with clear roles and close working relationships. Support is given at both a professional and personal level, though there are significant stresses, a theme further developed through the evaluation below.

#### 4.1.2 Kenya, Maua Hospital Community Based Palliative Care Programme, Meru

##### History and context

Maua Hospital is a large rural Methodist institution in the Eastern Province of Kenya, about a five-hour drive from Nairobi. It has developed over the last 50 years, together with a network of Methodist schools and churches, so is well embedded in the local community. Maua is the main hospital in the Igembe District of 700,000 residents, which used to be part of the Meru District. There are also two smaller hospitals in Igembe District, but Maua has the only palliative care unit. It has three mobile clinics that serve patients weekly. They offer integrated curative and preventive care, including anti-retroviral therapy (ART) and monitoring,

and the palliative care trained staff take part in these. On the day the evaluators visited one of these clinics, we found and met a group of 66 people coming for a group Voluntary Counselling and Testing (VCT) session. This illustrates good integration of VCT, the ARV clinic, and the palliative care team, with volunteers helping at all stages, prevention, treatment and palliation.

### Overview of the programme



Palliative care at Maua Methodist Hospital began more than a decade ago. As the Kenyan palliative in-charge said on our first day:

*We have people at our hospital who have worked in palliative care for 15 years, and they have stories to tell.*

We were privileged to hear some of those stories, and also stories from their patients and family caregivers, told in the colourful Meru language and translated into equally colourful English.

Links with Chogoria Hospital's palliative care programme, and a visit and report by an Australian palliative care specialist in 2002, stimulated the development of palliative care at Maua. Since 2004, the palliative care programme has treated many people with HIV, as well as over 200 patients with cancers. At Maua Hospital, palliative care appears to be associated with two

categories of patients: those with advanced cancers and those with HIV/AIDS (from the time of diagnosis). Oral morphine is prepared in the hospital pharmacy, at a concentration of 10 mg/ml. This and other drugs are purchased economically through large-scale purchasing from MEDS, the national church-related drug warehouse and distribution system. These are brought from Nairobi regularly, and are reliably available for prescription.

Cancer patients are seen and reviewed in the hospital wards, at the weekly cancer clinic at the hospital, in the three weekly mobile clinics, or by home visits. Radiotherapy is rarely considered, as it is available only in Nairobi, and travel is too costly. Chemotherapy is useful for Kaposi's sarcoma, but little else is feasible in Meru. The at-cost gastroscopy service at the Presbyterian Hospital at Chogoria, to the south, is helpful at diagnosing stomach cancer, and permits an appropriate care plan to be set up by the patient, carer and team. Usually about 5-15 cancer patients are being seen at any one time, either in the mobile clinics or at home. The funding from the Palliative Care Initiative (PCI) is vital in making treatment available for cancer patients.



### Beneficiaries

Maua residents are generally poor, except for those in the *miraa (khat)* trade. *Miraa* brings to the community the additional challenges of a drug culture, including indiscriminate violence, especially to women and children, and a high HIV infection rate. Problems of poverty and hunger are common, especially in the dry, lower areas far from the hospital. Caring for patients with cancer is financially very challenging for hospitals in rural Africa and none more so than Maua. The current HIV prevalence rate in Kenya stands at 7.4% (Kenya AIDS Indicator Survey, 2007), although the Meru North District Strategic Plan estimates the local prevalence to be between 12 and 15%.

Funding from the PCI is largely used to help patients with cancers, some of which are related to HIV/AIDS. The most common cancers are Kaposi's sarcoma, hepato-cellular carcinoma, oral cancer, and cancers of the breast, cervix, stomach, oesophagus and rectum. Oral cancer appears exceptionally common locally. The PCI pays several staff salaries, costs of palliative care training, and 70% of the price of medications used by cancer patients (the remaining 30% is paid by patients or written off by the hospital).

#### 4.1.3 Malawi Home-Based Palliative Care and Support Programme, Blantyre

##### History and context

In 2002, Community Health students from the University of Malawi's College of Medicine (COM) conducted a palliative care needs assessment in the Bangwe area, where a Salvation Army HIV/AIDS home-based care programme was being run through community volunteers. The assessment identified many sick people needing clinical care as well as social support, who were too ill to travel even to the local Bangwe Health Centre (inconveniently located at the top of a steep hill). The COM Community Health Department formed a small team of nurses to accompany the Salvation Army volunteers in the villages (the local district sections) of Bangwe. The nurses offered pain relief, antibiotics and wound care according to the national home-based care guidelines.

Home-based and palliative care activities were later expanded to parts of the neighbouring Limbe District. The programme set out its initial aims as:

- To establish home-based care services in the southern half of Limbe township, linking a volunteer scheme with the local health services
- To treat 400 new patients needing home-based palliative care
- To train 24 community nurses in home-based care involving a four-week training programme (to help scale up palliative care in Blantyre and Malawi)
- To collect data, compute and analyse it for publication in peer-reviewed journals





### Overview of the programme

A new three-year phase of the palliative care programme run by the Home Based Palliative Care Trust in Bangwe and Limbe began in July 2009. The programme staff currently includes two nurse-directors, four nurses, six home-based care assistants, a data manager and a cleaner. Over the years, a total of about 130 volunteers have received training and training updates, and 90 of them are currently active. New volunteers are chosen by the village in which they reside, through a community process facilitated by the local chiefs. Daily work is structured around a planned visiting routine and nurses have allocated groups of villages which they visit on agreed days each week. Volunteers usually work two days a week, and support the nurse who visits their area. Volunteers check in with ongoing patients and visit new patients to assess whether a nurse's visit is necessary. On the morning of the weekly visit by the nurse to their village, the volunteers meet the nurse, discuss each of the cases requiring a nursing consultation, and lead the nurse to the homes. Volunteers are thus supervised on-the-job by the nurses.

A few years after the formation of the programme, the senior programme nurses recognised the need for a new cadre of health worker – the Home-Based Care (HBC) Assistant. Job descriptions, special training modules, and appropriate pay scales were developed within the programme. As the patient enrolment numbers increased, the Assistant's role became increasingly useful in enabling the team to provide more extensive coverage. The peak of patient activity probably occurred in 2007.

The home-based care team see their distinctive role as providing a clinical service, with a focus on the patients' physical health. A clinical check list is used by nurses on every visit, and visit findings are recorded in the patient's official Health Passport. Alongside physical needs, social and material needs abound as patients and their families struggle to find enough money for daily basics such as food, or essential house repairs such as leaking roofs. Nurses and volunteers often refer families to other organisations such as the Salvation Army for social support needs. Volunteers sometimes provide support services such as cleaning and washing, and carry small foodstuffs.



Access to morphine and other medicines is increasing. Nurses carry prescription drugs, and can carry morphine if a hospital doctor has prescribed it for a patient. The number of patients on morphine has varied between three and five over the year. Prescription drugs are available to the programme via two routes, through private purchase from local business and as free drugs from the district health centre. Volunteers carry drugs and supplies that do not require prescriptions such as aspirin, paracetamol, vaseline, body oils, bandages, gloves and a local antiseptic to clean cuts and small wounds.

### Beneficiaries

Since 2003, the home-based care teams in the two areas (Bangwe and Limbe) have enrolled a total of 3,000 patients, who fall into two main categories. A small number of patients have

suffered strokes, diabetes, and cancers which are life-shortening, with death probable within the next months or year. The large majority of the patients have HIV/AIDS. Many of them, especially in the early days of the programme, came to medical care very late, already having serious AIDS-related illnesses such as tuberculosis, peripheral neuropathy, Kaposi's sarcoma and other cancers.

Thus the focus of the programme in Malawi is primarily HIV patients. The staff and volunteers can provide HIV testing and appropriate medical care for patients at home. They work closely with the two government health centres and community groups to see that HIV patients qualify and receive a full range of care and treatment, including advanced medical care, anti-retroviral medicines (ARVs), food supplements as appropriate, patient support groups, and help for families, orphans and vulnerable children.

Being based in the health centre has facilitated referrals from the health centre staff, although the majority of referrals are still via the community – through the volunteers themselves who have a case finding role. Alongside finding new patients, volunteers are central in ensuring ongoing clinical care, by identifying emerging physical health problems of their patients and referring on to the nurses.



The programme supports staff in ongoing training and has sought to hold regular in-service training and volunteer training opportunities. Through the initiative of the programme a local community based organisation (CBO) *Tigwirane Manja* was established to take forward palliative care in the community and create support networks for volunteers. The CBO, after a difficult start, has regenerated itself and with new leadership is aiming to deliver a stronger palliative care support network.

#### 4.2 Impact of programmes on patients

**Summary:** We found that in all programmes patients received whole person care, and they spoke of being treated with courtesy, dignity and respect, and appreciated staff being concerned for all their dimensions of need. Physical suffering was dramatically relieved by oral morphine. Patients felt greatly helped to address and solve many problems whether medical or cultural, such as dealing with traditional healers and stigma about cancer. Some told us how they had spent a lot of money on lengthy trips and treatments with limited or no benefit before they met the palliative care team. Patients received continuity of care frequently helped by mobile phones. They valued spiritual and emotional support, with staff taking time to listen and affirming their common belief in a god, and spoke of the sense of hope and reassurance given by the teams.

#### 4.2.1 Patients received whole person care in a dignified way

In each of the three countries, the evaluation team observed that in every house they entered, patients greeted the team as welcome guests. Patients were treated as people leading their own lives, among their children, families, and household activities. Being cared for in the privacy and comfort of their homes was important, and there was a relaxed, positive attitude in all the visits. Statements from people in each country indicate remarkably similar positive attitudes and outlooks:

*I feel good, because when the volunteers come into my home, they treat me with ulemu (“due respect”, “happiness”, and “politeness”).* (FG patient, Malawi)

*Before this programme started, patients used to die in pain.... Now patients die with dignity.* (Volunteer, Uganda)

*I really appreciate the Maua team, even the love they showed to my mother, talking, praying, comforting her. They helped the whole family. What they did was not to just “gucera” (to visit casually at their own leisure); it was to “kuraitha” (to comfort and support).* (Sarah, Rachel’s daughter, Kenya)

#### 4.2.2 Physical suffering was greatly relieved

In all countries the evaluators noted that access to analgesia and thus relief of suffering is significant and reported as an immediate benefit. This was particularly so when patients were suffering from advanced cancers.

*Now we are observing that something can happen to let people die in peace.... People died in agony before, and now we realise importance of controlling pain.* (Rose, nurse, Uganda)



*Pain was overwhelming. When the morphine was finished, he started feeling a lot of pain. The medicine helps him a lot because before that he was in much pain.* (Wife of Edmund, Uganda)

*The morphine brought back my happiness. I have no words to express my gratitude.* (Jess, Uganda)

*Jess couldn’t sleep day or night and could not be left alone, until God brought these people to see her.* (Jess’ mother)

*What helped the most was the drugs – now she has no pain.* (David, son of Maria, Kenya)

*Home-based care can be done by volunteers, but palliative care needs specialised medical care.* (Nurse, Christine, Malawi)

In Malawi, patients, volunteers, home-based care staff, and community members told us of the historical background of the programme. Before clinically-supported home-based care was introduced, many patients remained in their homes suffering pain, too weak to walk to the health centres and unable to afford transport. Patients and their carers struggled to manage severe pain and sickness, especially vomiting and diarrhoea. Patients lacked access to effective pain relief, antibiotics and vitamins. Before the widespread availability of anti-retroviral (ARV) medicines, people with AIDS remained in their homes or returned to the villages of their fathers to die.

*The neighbours believed I would never leave this bed. They thought I was dead, but with the help of the team I am walking again. It is a miracle. Jesus heals.* (Simon)

*People would die if this project ended. Instead, many of our patients now are no longer bedridden.* (Bangwe FG staff)

#### 4.2.3 Patients felt helped to identify problems and make decisions



In Uganda, patients who were referred to the programme often needed immediate help in stopping their futile and expensive search for treatments, and some needed support in making decisions about the next stages in their care. All those involved in the evaluation spoke of the money they had spent on treatments with limited or no benefit, and of the tremendous and ongoing family burden that this represented.

*I took him to over 20 traditional healers, travelling as far as Rakai.... I spent over a million shillings (GBP 335) on medical care that failed to heal him. I took my own children out of school and sold their inheritance. I sold land, cows, goats, chicken.* (Doreen, talking of her futile and expensive search for treatment for her nephew)

*He wasted so much money, around 600,000 US\$ (GBP 170), on traditional healers.* (Wife of Edmund)

For everyone social support was essential when financial pressures are so significant. Holistic assessment was given with clear explanations, plans for treatment and reassurance, backed up in practice, that patients would not be abandoned, even if the problems were difficult to solve.

In Kenya, the Maua Hospital palliative care team helped patients to address and solve many problems when they needed information or advice about medical and cultural issues, including inappropriate treatments. Staff were good at trying to help the patient receive decent, culturally appropriate care, responding to their ideas and commenting and advising as appropriate.

In Malawi, patients, staff and volunteers talked about the multiple barriers to accessing health care, including lack of knowledge that care was available, and failure of services to deliver what was required at the right time and in the right place. As the first on-the-scene health provider, the home-based care team frequently identify illness and put in place a referral process to ensure that the patient is seen appropriately. Patients and carers recognised that the interventions of the home-based care team improved their health, and in many cases saved their lives. Patients described the role of the volunteers in bridging the gap between need and care. A key step was finding who needed help and helping them understand what assistance was available.



*The volunteers are the most important persons, because they are the first ones to see us. Volunteers hear that someone is sick, and they come tapping at the door. They are the first to find our problems.* (FG patient)

*I felt tired for months and was not able to do the housework. I had no energy. The HBC team took me to Limbe Health Centre to be tested. The HIV result was positive, and once I started on ART I felt better.* (Jean FG patient)

#### 4.2.4 Patients received continuity of care and did not feel abandoned



In Kenya, the Maua Hospital palliative care team provided continuity of care by holding regular mobile clinics in sites far from the hospital, by visiting home-bound patients, and by encouraging the community volunteers to visit. In addition, they keep in touch with volunteers and patients alike, through the innovative use of mobile phones, which are now common and inexpensive in rural Kenya. The team offer information and practical support, up to death and beyond.

*We try to make sure that no one dies alone and neglected in the village.* (FG volunteer)

In Malawi, the home-based care staff recognise that, with early diagnosis and care, HIV/AIDS is now a long-term, chronic illness. They pointed out, however, that patients, although they are getting better still need constant watching and require good follow-up. Without timely intervention, patients with evolving opportunistic infections can quickly become very sick.

*We manage their opportunistic infections, encourage adherence to ART, and refer them in a timely fashion for advanced medical care...Some HIV patients get better and*

*“discharge themselves”, but never completely. They will come back to us when they need us, so we keep their records in the files.* (Bangwe and Limbe staff members)

In Uganda, we met some patients wanting the assurance that help would be available over the longer term. Jessica had her amputation four years ago. She is now pain-free, no longer requiring morphine and able to dig her garden (which, more than any other activity, has restored her sense of worth and the feeling of being a normal part of her community again).

#### 4.2.5 Patients received and valued spiritual and emotional support



During this kind of long-term caring, staff form deep bonds with patients, and through doing so, often impart to patients a sense of self-value, dignity and respect.

*Kitovu Mobile made me feel alive.* (Ronnie, patient, Uganda)

*We instil a sense of hope.... Before, that hope was lost in pain.* (Staff, Uganda)

*I must say the word ‘touch’. We make these people smile.... There was a patient who had a wound that smelled very bad. The patient said, “Nurse, you don’t want to touch it.” But we do touch and treat their wounds.... This touching helps put a smile on people’s faces.* (FG staff, Uganda)

In Uganda, staff told of one old man with prostate cancer who said he expected to get little help from young nurses. After they listened to his problems however, he shared his past experiences and then said:

*You people are my daughters.* (FG, staff)

Other patients spoke of their appreciation for support received:

*The nurse (from the programme) was there for my daughter, and even if Lillian could just see her, she would smile.* (Mother of patient Lillian, Uganda)

*The nurse told me, “It will be okay, because we are together, even if your husband is going to die.”* (Joyce, widow, Kenya)

In Uganda and Kenya, the two palliative care programmes are carried out by faith-based organisations, and various types of spiritual support were observed and mentioned often by patients, families and staff. Staff meetings often included prayers for strength and understanding. Many patients, when asked about the future, vocalised that God would care for them, despite their difficult situations. During home visits, patients or families sometimes requested staff or volunteers to pray with them. We neither observed nor suspected any instances of religious pressure or proselytising by palliative care staff or volunteers. Staff

encouraged patients and families to draw strength and help from their own faith and faith communities, and offered spiritual support as part of holistic palliative care.

In Malawi, the home-based care team used a clinical checklist at every patient encounter. This checklist did not include a spiritual needs assessment section. While none of the patients cared for by the Malawi team directly mentioned receiving spiritual care and support from the team, the overarching values of respect and dignity and care were embedded in all practice.

A number of the patients in Malawi spoke about the importance of spiritual support and help that they received from others, especially when members of their churches came to pray and sing with them. Others told us that at the time of death, church members came to spend the whole night with the bereaved. One patient said that the intervention of the home-based care team was the answer to his own prayers:

*I prayed that Jesus would come and heal me, as Jesus is the only one who can heal our diseases. One week later a volunteer arrived. I knew it was an answer to my prayer. God had heard me calling him and he sent the volunteer. Why else would she have come at that time? (Simon)*

### 4.3 Impact of programmes on carers and families

**Summary:** Family carers felt greatly helped to care for their loved one. They greatly appreciated receiving social, financial and practical support, such as food and soap, and instruction in feeding and bathing patients, and in administering morphine. They valued guidance and real help, having already spent much time in futile and expensive searches for a cure. Carers valued good communication and counselling support, home visits which give time to talk, and the sense of caring. Practical advice about terminal care, and even preparing the body for burial (in Kenya), resulted in patients being able to die with dignity in their homes. Regular visits from volunteers were greatly appreciated, especially in Uganda and Malawi.

#### 4.3.1 Carers felt greatly helped to care for their loved one

In Malawi, programme staff told us that before the programme started, families had to provide care for their patients themselves, some guardians were not willing to care for patients, others who were willing did not know how to care, and patients did not feel free to discuss their illnesses or to disclose their HIV status.

A key role of the home-based care team is to support family carers in their caring role. Support to relatives involved education, confidence building, and affirmation of the work they were doing as carers:

*Towards the end of her life, my daughter was unable to go to the toilet or feed herself. Her major problems were vomiting and severe headache. She had frequent attacks of fever on and off, and even her eyes were jaundiced. The home-based care people all came together to help. They even provided me with gloves so that I could use them to lift the soiled linen. They talked to me about my daughter. (Aya, bereaved mother)*

Being part of a community of carers was important. For example, the wife of one new patient explained that she knew what to expect:

*The home-based care team has helped many of our neighbours. Some were very sick, some even passed away, and the team saw them right up to the last day. They even attended the burial. I know the team will visit me, and I will be very happy because they will counsel me on how to take care of him.* (Wife of Moffat)

In Kenya and Uganda, the palliative care teams showed families many ways to make their patients comfortable at home during their final months and days.

*As my husband's mouth cancer got worse, he and I went to a seminar at Maua Hospital, where I learned how to measure his medicine and give it to him. In fact, I almost turned into a doctor! When our medicine was finished, the team would drive me to the hospital to get more. The medicine gave me very nice nights. My husband was never in hospital. He died at home, not in pain.* (Harriet, widow, Kenya)

The Maua Hospital palliative care team in Kenya helped family carers prepare very practically for the terminal stage of the illness, by explaining how the patient might become very weak or confused, or might stop eating or drinking and become cold. They explained that this should be expected and allowed to happen, and that the patient will eventually simply stop breathing. This reassurance and increased understanding of the journey towards death enabled many patients to die at home. In Malawi, the home-based care team also offered support and reassurance.

*Many people died at home, and many in hospital. It's best to die at home!* (FG patients, Malawi)

The period of death and burial is often extremely stressful for poor rural African families. They must notify the local chief and numerous relatives, many of them living in distant cities. Then, because they often have to wait several days for everyone to arrive for the funeral, families need to arrange to preserve the body. The Maua Hospital palliative care team in Kenya explained how to lay out and preserve the body in the home. (Put two sacks on the floor, cover them with charcoal, smash the charcoal, and soak it with water. Place the body on the charcoal and keep the charcoal wet; the evaporating water will keep the body cool.) Some carers told us of the great satisfaction they felt in having cared for and buried their loved one at home in their *shamba* (family land), with support from the palliative care team, who sometimes attended the burial.

The Kenyan team has also helped to increase the community's understanding that not taking a patient to the hospital does not indicate neglect, a view commonly held by many community members. Nevertheless, some still fear death in the community, so not all families agree that death at home is best. Furthermore, a plan for the patient to die at home may be thwarted by an acute, unexpected event, such as sudden vomiting, and family members may then hurriedly take a dying patient to the hospital, thus incurring further debts.



#### 4.3.2 Carers received social, financial and practical support

In all countries extended family members tried to care for their patients' basic needs. Caring is costly, and frequently considerable money is spent in vain. Inherited family land is sometimes sold or children are removed from secondary school in order to use the money for medical care or healing by "prophets" or traditional healers. Most patients struggled with poverty, especially as illness drained family resources, and all teams acknowledged this. Volunteers often try to support people, even though they often have limited resources themselves. Some enthusiastic volunteers not only connect residents with the palliative care team, but visited the patients frequently, washing and cooking for them, accompanying them to hospital, often using their own money. In Kenya, one volunteer had both positive and negative stories to tell:

*One lady refused to take her ARV medicines, but with my encouragement she became strong and able to lead a normal life.... But I also remember a man who came back to his home place, sick with AIDS. I sometimes gave him food, but he refused to eat and even threw away his medicines, so I could not do anything to help. (Helen, health volunteer)*



In Uganda, the financial pressures of caring for very ill family members are significant. The wider Kitovu Mobile HIV and AIDS programme facilitates access to appropriate treatment, thus saving unnecessary expense of searching for cures or travelling for services. Palliative care patients are given care at the community centres without charge, and morphine is provided free of charge by the government. Often the needs of patients' children are dominant in their minds, and help for children is a programme priority in Uganda, offering much needed support for school fees. Other programmes were unable to provide this level of support. The attempt to provide holistic care seems to distinguish the Kitovu Mobile HIV and AIDS programme from other services in Uganda.

*By the time people get to this programme they have used up all their money on transport, medical treatment and witch doctors. After we care for them, the people say "You are a god, you have saved us." (Staff)*

*The most important role the team has played is giving food for her children and giving her medications. (Staff)*

*The palliative care had really helped me by bringing morphine and talking to me, bringing food and blankets for the children and paying to go to Kitovu Hospital for the chemotherapy. (Chris)*

*Medicine is of little value when patients are hungry. (From a programme report.)*

*When they come, they give him medicine, soap and sugar. They also give him a blanket. They have given him morphine and metro (metronidazole and antibiotic). It has helped the pain to subside. (Grace, family carer)*

In Malawi, all the homes we visited lacked at least some of the basic essentials (food, essential furniture, warm bedclothes). Few had running water. The home-based care programme does not have funds to support the many needs of patients, carers and families in any sustainable way. Occasionally, other donors or programmes provide some help, but only temporarily, and often sporadically. In such a poor setting, staff felt that no amount of help would meet all the needs. However, volunteers described how difficult it was to go into the house of a family with several hungry children, where the one healthy adult was spending much time looking after the patient and was therefore not generating any income, and the volunteers often showed their concern for carers as well as the patients by offering practical help.

*We could not leave the house without doing something, so we put our hands in our pockets and gave some small thing that we had. (Volunteer)*

*Before the health volunteers started, we had to organise somehow among ourselves to get sick people to the hospital. (FG patients)*

*The volunteer comes twice a week, but she never brings anything. (John)*

*After some time, the volunteers gave me soap, and soya flour for porridge. (Limbe FG patient)*

*When we are sick, they come to our house, bring food, wash the clothes, clean the house, mop, and when we are unable to go to the toilet, they help us, and they wash the bedridden clothes. They assist us in visiting the hospital. They give us drugs, even money for transport from their own pockets. (FG patient)*

*The HBC team mostly deal with the medical part, but I am lacking some other requirements. If I could be assisted to be doing small-scale business that would help me. (Ali)*



*My house leaks when it rains, and the bedding is not enough, I am very cold in the evenings, especially this month. I wish the HBC team could help mend the house. (Ira)*

#### 4.3.3 Carers valued good communication and counselling support

In Uganda, family structures are close but often complicated, especially when men have more than one wife or partner. Roles such as decision maker, carer and financial supporter may all belong to different family members. In addition, the stigma surrounding both cancer and HIV/AIDS sometimes results in poor communication and misunderstandings. All these factors

demand skilled and careful negotiation and counselling. Family carers appreciate having someone visit at the home, with time to talk, and a heart for caring.

*One patient did not want to talk of his HIV status in front of his 14-year-old daughter but was happy to discuss it privately. He had been referred only a few weeks before our visit yet seemed to have established real trust with the team. While they were attending to his dressing, the nurse spoke to him about communicating with his family, and he asked sensitive questions about how to safely make love to his wife (who is HIV-negative). Outside the house, his family members were asking very similar questions, saying they had not had anyone come to their home to discuss this before – despite the patient being diagnosed one year ago and having counselling from another service. (From evaluation team field notes)*

*The counselling helps a lot. To know someone is caring for you is most encouraging. (Wife of Benson)*

*When Charles' partner realised he could no longer be the breadwinner, she became frightened and ran off. "Things were in a mess," she told us. With little support from family, the visits of Kitovu Mobile were crucial for Charles. At the time of our visit, his partner had come back, and she expressed her wish to get married, so the Kitovu team discussed with her practical action to facilitate this. (From evaluation team field notes.)*

In Malawi, Simon's wife was no longer able to cope with his illness, as he physically deteriorated. She ran away leaving Simon looking after his youngest son who is seven. Without the aid of the home-based care team Simon explained that he would not have been able to pull through, but with their support, the family is now back together again.

In Malawi and Kenya, many family carers said they were much helped by the teams coming frequently. Encouraging patients to believe that healing was possible was a role that a number of volunteers took on:

*I was very weak, I couldn't walk, not even to go to the toilet, and my face was swollen. Someone submitted my name to the volunteer and the volunteer came with a nurse to see me. She saw I was very sick. I said, "Better that I die." The volunteer said, "No, we have seen others like you and they get better." I felt happy, because up to then I had no way of help. (William, Malawi)*

*There was a volunteer called J and one called E who used to care. They came once a week with the other people every Thursday, and sometimes they came just by themselves to find out how we were doing. (Bereaved mother, Malawi)*

*Yes, I know my mother might not be healed, but I still hope. We leave it to what God wants. We are expecting God to work miracles and we rely on the hospital. (David, son of Maria, Kenya)*

Staff did not destroy such hope, but affirmed the family and helped them in planning for the worst, as well as hoping for the best:

*The Maua Hospital people showed real concern (“kwolia”), by looking seriously at my late husband, comforting and giving help if possible. They showed kindness (“kiao”).*  
(Joyce, widow of Jacob, Kenya)

#### 4.4 Impact of programmes on the community

**Summary:** While members of the communities around these three programmes have been well sensitised and educated about HIV and AIDS in recent years, they were not as knowledgeable about cancer. Knowledge about palliative care services has increased but there remains more work to be done. All programmes were actively addressing this, working with community leaders to inspire them to accept and talk about palliative care and to help identify those in need. Community volunteers were well trained and exceptionally supportive to patients and carers. Many patients, carers and professionals spoke highly of the volunteers as people who cared and gave what they could to help others.

##### 4.4.1 Communities are now aware of the concept of palliative care

In Kenya, the palliative care team leader told us he was shunned in the community when he started this work nearly 15 years ago, but now the concept of palliative care is more accepted:

*Even the men are now (finally) coming around.*

We found health volunteers and several health committee members (but not all of them) to be knowledgeable about morphine and other aspects of palliative care.

Communities have been sensitised much less to cancer than to AIDS. In one community focus group in Kenya, AIDS seemed to be an old and much discussed topic, but when cancer was mentioned, the participants quickly warmed to the subject and began to ask many questions:

*People still think cancer means death that very day.*

They wanted to know all about identification of cancers, as well as treatment and prognosis. Thus, information about other illnesses can and should accompany AIDS work, especially as co-morbidities are now common.

In Uganda, sensitisation of the community has been a means of recruiting committed volunteers, who then further educate and support their own communities. Volunteers often first hear about Kitovu Mobile Palliative Care Service in church. At a local Catholic centre, a sister told of a sensitisation session after mass, when a large number of people stayed behind to hear about palliative care and volunteers.



*Kitovu Mobile made a very, very, very big difference. Before they used to look for patients, but now patients look for them. (Volunteer)*

One local community leader told us about trained community volunteers and how he discovered that palliative care was about helping people in pain, even in the dying stage when there is no hope of surviving:

*The community volunteers were sensitised by Kitovu Mobile and they then moved on to do sensitisation themselves. The community now identify patients, alert the volunteer, who then alerts Kitovu Mobile. They give painkillers, financial support, help keep children in school, give medical things such as gloves and plastic sheeting. They offer counselling, and spiritual support. Once a palliative care patient is identified, the team come immediately.*

In Malawi, when we asked a group of AIDS patients whether the community made things difficult for them, only one patient could remember one neighbour who had teased her. The majority felt supported, as they explained, home-based care had been in the community for some time:

*We were doing this (care) before, as part of church groups. The volunteers came first, and the nurses came later. (FG Volunteer)*

The volunteers told how they used community meetings to increase awareness of the concept of caring for an ill person within the home and the roles that different people have to play in providing this care. Patients also mentioned the importance of such meetings:



*We first learned about home-based care several years ago. The different chiefs held meetings and introduced the health volunteers. So we knew them as people, as neighbours. Then later, when we got sick, we already knew about the volunteers and we called for them. (Limbe FG patients)*

*The volunteers try to sell themselves to you, if you are willing. They often persuade the patient to have a nurse come visit. (FG patient)*

Nevertheless, the home-based care assistants of the programme run by the Malawi Home Based Palliative Care Charitable Trust explained that the concept of caring for those who were dying was not well embedded in all families. Some believed that serious illness was the effect of either witchcraft or the will of God, or the consequence of misdemeanours which could no longer be rectified. Therefore nothing could be done and the patient would have to accept what was coming to him/her. The assistants also said that some families sent their patients to the family village, where there was no possibility of any curative care, palliative or analgesic

support. This is now changing in the community, although it does still happen. Later, a patient told us this himself:

*My relatives wanted me to go to the home village to die, but there are no injections available in the village and I would have died had I gone there. (William)*

The home-based care staff noted that their work in the community had helped shift the practice of sending people away to die, but more needed to be done.

#### 4.4.2 Volunteers are now an increasingly accepted part of end-of-life care in the community

Repeatedly, in all three countries, the importance of community volunteers was emphasised, their training, their activities and their faithfulness.

In Uganda, the roles of volunteers are varied, and they have access to a variety of training opportunities: palliative care, family planning, STDs, counselling, advocacy, making wills, use of traditional herbal medicines and self help. Volunteers visit patients, give health education talks, and encourage those who need it to come for care. Some volunteers do regular counselling. Volunteers also find bedridden patients who cannot help themselves, then educate family caregivers on how to care for the patients. Previously, when someone fell sick, both men and women wanted a female caregiver, so sometimes families would take girls out of school to take care of patients. Now, however, volunteers educate patients that caregivers can be male or female. They provide holistic - spiritual and physical - care.

*Palliative care has given me so much knowledge, and it encourages us to find patients. We also teach the carers and tell them how to care for the patient. We check on the patient and refer them back to the nurses if need be. (Volunteer)*



In Malawi, we asked the home-based care nurses who people in the community say are the most important members of the healthcare team. They replied:

*The community knows all are important, but the volunteers are very important to them and to us. They are there at every stage – identifying people who need help, calling us and following up. (Nurses)*

*We volunteers attend the burials of our former patients. We organise ourselves to contribute a little, and we register at the funeral that we are members of the community organisation Tigwirane Manja and have come to pay our respects. Sometimes the nurses also come, but most times they are not available. (Limbe FG Volunteer)*

#### 4.4.3 Communities are inspired to talk about and accept palliative care

In Kenya, some community leaders we met, such as a local chief, a pastor and members of the health committee, appeared genuinely inspired about palliative care. They suggested that many seminars will be needed to inform and motivate the “*man in the shamba*” (the common people on their farms).

In Malawi, all the home-based care staff and a number of volunteers voiced their opinion that the number of patients dying of AIDS is now much lower than before. Although people recognised the power of antiretroviral drugs in changing the lives of those who were ill with AIDS, many also believed that it was because of the presence of the home-based care team in the communities that people were getting better more quickly and were not confined to their homes.

In Uganda, a volunteer expressed this well:

*The confidence the patients have in me gives me courage.*

#### 4.5 Integration of palliative care programmes with other health and social services

**Summary:** In Uganda, there was evidence that the Kitovu Mobile Palliative Care Service was integrated at local, regional and national levels. For example, we talked with a doctor there who signed all morphine procurement processes in Kitovu district and highly commended the programme for its integration. In Kenya, the Maua Hospital palliative care programme was well integrated into primary care and secondary care, and with the local church and schools, because it was based in the community health department of a large, well-respected church hospital. Many staff practising palliative care also undertook other duties and, as part of their roles, taught and updated general community and hospital staff about palliative care. The leadership of the Malawi Home Based Palliative Care Charitable Trust programme recognised the need for better service integration with the local government health services. While they now successfully run the programme from the local health centres for the two districts, they still feel that there needs to be better referral processes between mainstream services and palliative care. The particular national structure of the HIV/AIDS service in Malawi has meant that integration and co-ordination of on-the-ground services is more difficult to achieve. The Palliative Care Association of Malawi (PACAM) is trying to help create a more co-ordinated and supported network. Everywhere, project staff members do their best to collaborate, while serving their patients.

##### 4.5.1 Examples of integration: Kenya

In Kenya, Maua Hospital’s health volunteers are sensitised to many health-related problems and are trained to recognise needs and connect people with a variety of help and resources. They know about various programmes and donor agencies, their purposes and how they can help the community. One volunteer told us in some detail about her own training:

*My husband died 14 years ago, leaving me with three small children. I was chased away from my house and had to come back here to live near my parents. I became very ill and then learned that I was HIV-positive. I got better but kept secret my HIV status. In 2004, I began to talk publicly about being HIV-positive, and the next year I received my first health training through the provincial AIDS programme. Then I was*

*trained to teach youth about HIV prevention, in a project under Samaritan's Purse. Maua Methodist Hospital trained me about anti-retroviral medicines and positive living with HIV. Last year I attended training at Nairobi Hospice about end-of-life care, cancer, writing wills, etc. (Helen, volunteer, Muriri)*

#### 4.5.2 Examples of integration: Uganda

In Uganda, a government official described the services offered by the Kitovu Mobile Palliative Care Service and the way they fit into the big picture:

*They gave some training for other health workers in the region. They have a very long history of service and a lot of experience. Before even the government came in to take care of the patients with AIDS, they were taking care of these patients. There is quite a lot of integration between Kitovu Mobile and government services. The purpose is not for health workers to go out and start providing the services, but that they know what the patients need and where to refer patients in terms of palliative care. (District Medical Officer)*

#### 4.5.3 In Malawi there are challenges to integration with local health services

In Malawi, however, the situation is much more complicated, and thus reported in greater depth. The home-based care team there works in peri-urban deprived neighbourhoods, trying to collaborate effectively with overcrowded government health services, but often hampered by a complicated web of government procedures and regulations.

The home-based care nurses receive approximately half their medications (including morphine, amitriptyline, and loperamide) from the government health centres, and the other half they buy independently. Morphine must be prescribed for a patient by a Medical Officer at a health centre, in order for the home-based care nurses to administer it, as we witnessed during one of our home visits.

The home-based care teams are sometimes frustrated that patient services are split in what appears to be, from the perspective of the patient and their family, an illogical way. Almost all the patients we visited had multiple health providers, with the home-based care team being just one among many, including hospitals, clinics and traditional healers. Patients appeared to spend a lot of their time being patients. When we asked one AIDS patient who her main health provider was, she explained that she goes to a mission hospital for drugs for her skin rashes, collects her ARV drugs from the local health centre, and goes to Queen Elizabeth Hospital because of her peripheral neuropathy. She then said:

*The HBC team is good with my minor problems. They listen and they understand. But they can't take care of my major problem - getting ARVs that work for me. (Tess)*

#### Multiple providers and duplication of services

Having multiple providers sometimes resulted in duplication of services, as illustrated by one Malawian patient we visited. According to his patient held records, on 23 July, he had his three-month review at the ARV clinic of Queen Elizabeth Hospital. Just five days later, the home-based care nurse did a home visit for her fortnightly review. She checked his weight, temperature and chest, examined his legs and gave him four medicines (ointment, clear cough,



multivitamins, and paracetamol). On this visit she did not write in his Health Passport, saying, *“because I have not prescribed any strong medication.”*

### Service delays

Patients in Malawi who had been prescribed a new clinical intervention often experienced long delays in starting it. Patients who needed *Plumpynut* (a fortified food supplement) had to go to the government health centre to register and collect it. Even then, they did not get it right away but sometimes had to wait for days or weeks because of high demand, stock-outs, etc. Home-based care staff felt that many patients would benefit if they could carry the food supplements, rather than having to send patients to the health centres.

### Regulations and limitations

The Malawi Ministry of Health procedures require a doctor’s review and a prescription for HIV patients to start taking anti-retroviral (ARV) medicines. The patient’s name is then placed on a waiting list to receive counselling and the first supply of medicines. The waiting list is centrally controlled to manage the number of new patients that every clinic registers every month. At the local health centres in Bangwe and Limbe the waiting time is approximately two to four months, and at the more distant Queen Elizabeth Hospital it is one month. Home-based care teams are not currently authorised to counsel and start their patients on ARV medicines, or even to carry ARVs to renew a patient’s stock.

One home-based clinician noted how illogical these restrictions are, since ARV clinics in government health centres, being short of staff, frequently use low-level trained health assistants to distribute ARV medication, with no true clinical encounter taking place. The home-based care nurses in interviews and focus group discussions also spoke of the regulations and their own frustrations:

*Currently many patients are on the government waiting lists and must wait months to begin ARVs. But we have been trained to counsel patients on ARVs and adherence. We could get them started ourselves!* (Bangwe FG staff)

*We are the ones who manage the patient’s opportunistic infections and side effects. For example, when a patient feels tingling, the hospital will say that it’s a side effect of ARV medicines, but they don’t do anything about it. We are left to do something. We manage patients ARV adherence, and many have started the ARVs because of us. We are a bridge between the hospital and the community.* (Limbe FG nurse)

### Referring patients

The Bangwe and Limbe districts have no local government district hospital where patients can be referred for secondary level care, such as for more tests, consultation for STIs, a skin clinic etc. Instead patients must go to Queen Elizabeth (QE) Hospital, a large and severely crowded tertiary care hospital. The bus fare per person (approx 100 kwacha = GBP 44 pence) is more than a day’s minimum wage. Private transportation for a very sick or weak patient ranges from 500 to 3,000 kwacha. Fortunately, once they arrive, the hospital staff often recognise the home-based care team’s referrals. As one patient explained:

*The home-based care team sends a note with us to the doctor at the QE Hospital, so we get better access to ARV services than other patients.* (John)

## 4.6 Impact of programmes on palliative care team, including volunteers

**Summary:** In all programmes staff and volunteers spend long hours each week planning and doing home visits in areas far from their base. Patients and their families spoke movingly of their appreciation for the care offered. Despite this, the work can be demanding and draining and significant stress was expressed. However, it was also rewarding and resilience is fostered by having effective medication to help people and through supportive debriefing. Volunteers needed encouragement and support to aid retention.

### 4.6.1 Such work is stressful: “it hurts to lose a patient”

In Kenya, working in palliative care is stressful and very demanding, but staff members say it also can be rewarding:

*For the past year, I have been a health volunteer right here in this town. I have followed five cancer patients who have all passed away. Now I have nearly 32 HIV patients. I work two days a week and try to reach three or four people each day, some patients think I am on salary and expect me to bring them food. Some patients are smelling bad. Some do not want to come for their treatment. We volunteers ask ourselves so many questions: Will I catch something from these people? What about me – am I HIV-positive? Will I ever be paid for doing this kind of work? (Patricia, health volunteer)*

*It's a lot of work and pressure, and I need more time to talk with patients... but it really feels good when you see a patient improve, or when he dies free of pain. (Elly, nurse)*

*The staff would really like to spend more quality time with patients. And we need staff retreats, for team-building and to avoid burnout. (Stephen, palliative in-charge)*

In Uganda, it was clear this kind of caring comes with significant stress. Distances covered by the Kitovu Mobile palliative care team are vast, with often long, hot tiring days in the field - sometimes only to find the patients had died. A key member of this team is the driver, who was clearly able to offer support and skill in several ways. Staff spoke movingly of relieving the pain in patients, but bearing the pain themselves in their own bodies.

*I realise that palliative care is a good service, but it is so stressful. Most of our patients come to us with advanced disease. After a few months, you have to lose that patient, and it is very hard. It's painful. It helps that you are able to help them die in peace. (Nurse)*

*One woman has cancer of the cervix, and we have to advise her to take oral morphine prior to sex with her husband. Sex was very painful for her, but he would not desist. It hurts us when we see this, but we have to try and help the woman and talk to the husband. (Nurse)*

*It's so stressful. Most patients we get do not live... some children, some parents. It hurts to lose a patient...we are happy when they die with no pain, but it is painful to lose a patient (FG, Staff)*

4.6.2 Such work is rewarding and resilience is fostered/helped by having effective medication and financial support to give patients

In Uganda, the compassionate and skilled care observed and reported has significant impact on palliative care staff. Resilience is built by having something important and concrete to offer:

*The work is difficult, but it was so much harder before anti-retroviral medicine – the patients used to die and we felt as if there was nothing we could do. Because we have morphine we can give help. (Dr Carla)*



*I get a lot of strength from talking to the other nurses. We depend and lean on each other and are able to counsel each other. It also helps a lot to pray together. (Resti)*

Team members share patient and personal stresses, as well as a sense of spiritual value and celebration. Mass is offered every month, and each day prayers are shared by the whole team, accompanied by music and drumming. This is followed by

information sharing and opportunities to celebrate, such as chocolates for a returning team member, or a great cheer at the announcement of a colleague's wedding plans.

The Kitovu Mobile palliative care team is committed to staff training and development: both nurses have the Diploma in Palliative Care offered by Makerere University, and staff attend continuing medical education sessions run by the Uganda Medical Association, Kitovu Hospital, Masaka Regional Referral Hospital, and the Palliative Care Association of Uganda.

In Uganda and Kenya, we met team members who have palliative care needs in their own families and are supported by the team.

*It touches my own family, I have spoken about my uncle, I think he probably has cancer, and the doctor said they will see him. (Volunteer, Uganda)*

Team field notes described how Gordon, age 60, had long served his farming community as a health volunteer. Several years ago his wife Vashi, developed oral cancer. A week ago, the palliative nurses visited and promised to bring pain medicines to the home every week, so the family would not need to bring her to the hospital. On the day of our visit, the nurses found Vashi weak and drowsy, and it seemed a good time to discuss with Gordon and other



relatives what to do if Vashi should progress toward death. Gordon assured them that he was prepared to stay here and take care of her in the compound, and that he would inform them when the hour comes.

#### 4.6.3 Volunteers need ongoing support to aid retention

In Uganda, the volunteers of the Kitovu Palliative Care Service appeared to be integrated and valued members of the palliative care team. Training is available on an ongoing basis, and volunteers spoke of having attended so many trainings they could not remember them all. Attrition rates are low – one interviewee has worked as a volunteer since 1987.

*Volunteers all stay for a long time, and even when they are old they continue working.*  
(Volunteer)

Working as a trained volunteer has a tremendous impact on the individuals themselves. Key motivations for the community volunteers seemed to be non-financial (though the practical support was appreciated). One man spoke movingly about the credibility and respect the volunteer role has given him – despite his own lack of formal education:

*I went to church and heard from Kitovu Mobile that you could go and care for others, so I decided to see if volunteers really do care for other people. I started volunteering, identifying patients and helping them with their disease. The patients told others that I was caring for them, and more patients came to see me. I felt good, because I was popular and helping people, even though I am not an educated man. When I give good advice to patients, they sometimes call me “Doctor”, because I have gotten lots of training. I feel very good, because I know more from trainings than many other educated people know. What inspires me is that Kitovu Mobile gives volunteers transport and bicycles. When patients come here, they give the patients sugar and soap, and the patients appreciate it so much.* (Volunteer)

In Malawi too, volunteers in the home-based care programme appeared to remain active for long periods. Of 130 volunteers trained since 2003, 90 were still active in 2009. They were eager to tell of their experiences:

*I felt good when I saw others do this volunteer work. I myself decided to join.* (FG volunteer)

*When I visit patients and they get better, it’s one of the greatest feelings for me.* (FG volunteer)

*I feel honoured when I visit patients and accompany them to hospital, and they thank me.* (FG volunteer)

*Most of the patients were bedridden but are now getting better. Patients come back to say “Thank you”, which encourages us. Because they are getting better, we see them prospering and doing business, going back to previous jobs. Some of our patients come to send messages through us to the nurses that this type of people and work should continue.* (Limbe FG volunteer)

The home-based care staff had hoped that the formation of the local community-based organisation, *Tigwirane Manja*, would act as driver for introducing palliative care and inspiring volunteers. Though volunteers spoke positively about the organisation, the staff felt it had not yet achieved its potential. Furthermore, a few volunteers struggled with team tensions and lack of respect when working together:

*Home-based care assistants look on us volunteers as inferiors, as ordinary members of the village. One even addresses me as “lee” (“Hey, you!”) – the way you would call a child. But the volunteers came first, even before the nurses! (FG volunteer)*

Volunteers appreciated the training and technical support they receive:

*We meet with volunteers from other areas once a month. We help each other see how home-based care activities take place in different areas, and we share experiences. Nurses really help us volunteers when we call them. We flash them from our cell phones, and they ring us back, and if we need them, they come. (FG volunteer)*

However, volunteers wished for some kind of financial support as well:

*We volunteers all have other activities. The majority are not working but looking after their families and gardens, in church groups, taking care of others, and one is a chief’s advisor. ...Several of us are widows. We need some cash to survive, so if we could be invited to HBC trainings and meetings, they would give us something small (i.e. per diem or cash for transport) and that would help us. We would feel better if we got some form of incentives to appreciate the work we are doing. (FG Volunteer)*

*If you gave us identification badges, that would help when we accompany patients to the hospital. We visit some patients who live very far from us. Could the project give us bicycles? We also need things like rain gear. (FG Volunteer)*

Home-based care team leaders recognised that financial benefits could and did act as a useful incentive, though the programme was limited in what it could supply.

In Kenya, on the other hand, volunteer retention seems to be a real problem for the Maua Hospital palliative care programme. In two different areas, we were told that about 30 people were trained just a few years ago, but very few are still active. A staff member said this:



*Volunteers are difficult to train. They expect to get something – allowances or regular employment. If that doesn’t happen, they fall away. (Palliative nurse)*

Staff point out that many volunteers are quite poor themselves, and they drop out, hoping to find another way to earn money for clothes, school fees, and other cash items. Since these volunteers were apparently well trained in case

finding and follow up, their high attrition rate has probably contributed to the rather disappointing case finding, particularly of cancer patients (only about 50 new cases per year, of an estimated 700 in the Maua catchment area). Nevertheless, some volunteers are highly motivated and do persist. When we asked one active volunteer about her own background, she told us this:

*My husband died of AIDS and I myself am infected. But I am taking anti-retroviral medicines and am healthy and strong enough to do this work. I have been given a chance to live and raise my children. I want to help others do the same.* (Hannah, volunteer)

## 5. ANALYSIS AND DISCUSSION

**Summary:** All three of these programmes offer vital pain relief, demonstrable psychological support, sensitive spiritual support within the community and social contact to patients and families. Several key issues emerged from our findings. These included the questions of how to provide effective palliative care in the face of poverty; how best to identify beneficiaries (which illnesses, which people and age group, and especially when in the course of their illness people require care); how to manage patients, especially those with HIV, when their disease moved from a terminal to a more chronic disease; how to integrate palliative care into health and social care and the community in general; and how to best involve the local community in accepting and working for the programme. Volunteer training, engagement and especially ongoing motivation are other challenges, particularly when programmes have paid and volunteer staff working side by side. The growing use of mobile phones to facilitate access to, and the delivery of, palliative care was a noted facilitator that has further potential. There were innovative uses of the mobile phone, such as “flashing” (ringing a number through but not connecting so no money is spent, but a signal is given to the team to call back). These issues are discussed in the body of this summary report, and also in more detail in the individual country reports.

The three programmes in the three different countries were constructed differently and served different client groups, using different mechanisms and different staff investments. Yet all focussed on delivering optimal palliative care that was culturally and contextually appropriate to the conditions and to the resource constraints that the programmes found themselves working in.

### 5.1 Palliative care in poverty

The poverty of those requiring palliative care was both an underlying feature of all three programmes, and the overarching factor that influenced the shape of each programme. All programmes recognised the challenges of families whose priority needs were not simply pain relief, but also basic food and a safe, dry place to live. The



Kitovu Mobile Palliative Care Service, already embedded in the community through the overall HIV and AIDS programme, aimed to provide a comprehensive support basket, giving direct packages of items such as sugar, soap and flour, paying for school fees, and linking families into micro-enterprise and skills programmes run by the wider community home-based care service and other NGOs. The Maua Hospital palliative care programme in Kenya and the Home Based Palliative Care Charitable Trust programme in Malawi could not offer the wider basket of care that Kitovu had managed to develop through its long-term investment in the community. In both Malawi and Kenya, volunteers and staff tried to meet basic needs with small gifts of household essentials, but there was a frequent recognition, particularly from the volunteers, that patients required more than they were able to deliver. For all the programmes, patient needs constantly exceeded the resources available, and all programmes recognised that the more care they delivered the more demand they received.

Each of the programmes recognised the multi-dimensional nature of palliative care. The essential components of physical, social, psychological and spiritual care which constitute effective palliative care were delivered in different ways by the programmes. In the Kitovu Mobile Palliative Care Service and Maua Hospital's palliative care programme, with their strong Christian-oriented health service delivery, the package of palliative care was frequently wrapped in supportive religious and spiritual care. Psychological care was given by the Malawi team through the supportive visits of the volunteers, relieving patients' angst.

## 5.2 Client groups, referral and discharge systems

The Maua Hospital palliative care programme was established largely to provide ongoing palliative care for patients with cancers, a significantly neglected cadre in many sub-Saharan countries. The Kitovu Mobile Palliative Care Service has transitioned its care from serving a majority of patients with HIV to serving patients with cancer diagnoses unrelated to HIV and AIDS. These patients now represent the majority of referrals and the spread of diagnoses is very similar to known prevalence rates in Uganda. In Malawi, the majority of the patients who are registered with the home-based care team are patients with HIV and HIV-related cancers and there are very few non HIV patients. Neither the Maua Hospital palliative care programme nor the home-based care programme in Malawi had children as clients, although there were a number of children receiving ART and AIDS treatment in both Maua Hospital and at Queen Elizabeth Hospital in Blantyre. The Kitovu Mobile Palliative Care Service had few children either, although the number was consistent with the expected number of children with cancer in the region.

All programmes faced the problem of erratic referrals, late diagnosis and unclear patient care pathways. In Kenya, the Maua Hospital palliative care team were covering a vast geographical area, which meant that Maua Hospital was often not the nearest health service to the patient. The Kitovu Mobile palliative care team had effected excellent networking with other districts and especially with the Hospice Africa Uganda programme, and established referral systems. The Maua Hospital programme had immediate access to hospital services and could structure its services knowing that there was hospital back-up to implement clinical decision-making, whereas the Malawi home-based care programme was reliant on the fragile health service infrastructure for onward referral.

In Malawi, the home-based care team had, through the dedication of the programme staff, managed to position the team in the two government health centres which ensured

recognition of the work that the team was doing, and offered opportunity for more direct referrals of patients. Patients of the home-based care programme in Malawi in particular, struggled to easily access the national HIV programme, which was designed at a population level to tackle the rapid scale up of ART to a huge number of patients. Frequently the clinical decisions that the home-based care team made were frustrated by the lack of hospital staff to implement the decisions. For example, one patient with peripheral neuropathy who needed to be changed from first to second line ART treatment, lay in pain waiting for a hospital appointment.

None of the programmes had a formal discharge system. The Malawi home-based care team believed that given the nature of the client group, discharge should be a choice the patient made and not the team. The majority of the patients looked after by the Kitovu Mobile Palliative Care Service tended to have a prognosis of one year or less, and the Maua Hospital palliative care team in Kenya often continued to support patients as part of active rehabilitation, through their volunteer system.

### 5.3 Project engagement with the community

All programmes aimed to function in the community and with community support, encouraging grassroots buy-in to the programmes and using grassroots demands to shape the nature of the programmes. In all three programmes community engagement was a key strength. The Kitovu Mobile Palliative Care Service, in particular, accessed community champions, and community resource spaces and places, particularly by engaging church leaders. Churches, at the local grassroots level, became associated with palliative care, with local pastors allowing time during or after services for the team to present the principles of good palliative care to the community. The churches were also a base for recruitment of volunteers. Volunteers used the church support networks for their own emotional and spiritual support and the cycle of integration created strong commitment. In Malawi, using community-based volunteers was also effective. Volunteers were recruited through village chiefs and village events and functioned within their own local village area, which added to the strength of the community programme.



Profiling the work of the different programmes to their local communities and nationally was achieved in different ways. The Kitovu Mobile Palliative Care Service was particularly effective at using local media to inform the wider community of the opportunities that the programme provides, and of embedding a sense of responsibility for those who are facing death and living with terminal illnesses. In Malawi, the formation of a community-based organisation, *Tigwirane Manja*, which literally means *Lets hold hands together*, was designed to improve local knowledge as well as ensure local responsibility and ownership of the programme. This community organisation had struggled initially, but is now gaining strength again. The Malawi



home-based programme did not feel that they had been overly successful in accessing medical communities to engage with them. The Maua Hospital palliative care programme in Kenya, because it is part of a medical and nursing community, believed it had significant success. Starting just over 10 years ago, palliative care is now very much built into the Maua Hospital system, with regular meetings and all staff recognising the programme's responsibilities and remit.

#### 5.4 Volunteer engagement

In Kenya, the Maua Hospital palliative care programme saw a high turnover of volunteers, which may be related to the distance that volunteers had to travel. In Malawi, a large number of volunteers remained with the programme through its duration which was impressive. For all programmes the use of mobile technology has been one of the most innovative assets, which has changed the face of care. Being able to stay in touch, to "flash" a nurse (ring but not let the call go though thus not using any money), and then to have a nurse return the call so that advice, support, affirmation and confirmation could be given, was critical in enabling volunteers to do their work, in encouraging them, and in supporting patients and their carers to remain in the community.

#### 5.6 Communication and the use of mobile phones

These three programmes illustrated that those at the cutting edge of health in the community can and do adapt technology to meet real time needs, and this in turn can build up effective primary care. Mobile phones, almost unknown in all three countries 15 years ago, are now used by families, volunteers and programme staff to provide a sophisticated form of telehealth, with systems in place to override problems such as lack of money to make calls. "Flashing" (see above) was used consistently and ensured that volunteers were mentored, and access to care was available to everyone. Even where there was no running water or electricity, mobile phone networks permitted communication and support. Mobile phones saved time in visits especially when patients lived far away, and enabled more effective planning and prioritisation of work. Most importantly they ensured patients and particularly carers felt supported.

## 6. COMMON CHALLENGES FOR THE PROGRAMMES

**Summary:** The staff of the Kitovu Mobile Palliative Care Service in Uganda were very aware of challenges and opportunities and had a forward-looking perspective. Cultural resistance remains a problem, particularly with regard to traditional medicine and women's empowerment. Resources continue to be insufficient to meet needs, meaning that difficult decisions about priorities have to be made, and that the service is stretched too thinly over a wide geographical area. Volunteers remain an important backbone of the service, and the excellent training and retention levels need continued support, as does ongoing community engagement. In Kenya, cultural challenges faced by the Maua Hospital palliative care team included a traditional fear that cancer would mean death that day, fear that dying at home would be interpreted by neighbours as neglecting the patient, and spiritual healers ("prophets") and traditional healers offering to cure cancer with traditional medicines at a great price. Many families gave long stories of patients who had visited dispensaries, herbalists and "prophets", spending a great deal of money on fees and transport. Other

challenges included funding constraints within the programme, volunteer training and retention, and scaling up the programme to meet wider needs (probably 90% of cancer cases are not accessing care). In Malawi, challenges remain around how best to prioritise patient need, as well as how to manage patients who, with the increased availability of ART, are improving and moving from being non-ambulatory and expectant of death in the next 6-12 months, to being well enough to be able to move around independently. Integration with other local health services in Malawi remains an ongoing challenge. There is also a need for further sensitisation and advocacy in local communities about palliative care. The nature of the work means that demand exceeds supply and the programme, with limited funding, has to make decisions about the multiple needs (especially social and financial) that patients have.

The programmes successfully meet their aims and objectives, and do make a great difference in the lives of their beneficiaries, and increasingly in the local communities. However challenges remain, especially with respect to:

- increasing coverage to meet unmet medical needs at the end-of-life
- sensitisation and advocacy in the communities, and
- multiple physical and social needs in beneficiaries in the context of limited funding.

### 6.1 Need to increase coverage, scaling up and training

In Kenya, the Maua Hospital palliative care team has established weekly mobile clinics in public buildings in several parts of their large catchment area. These clinics seem efficient and effective in treating and supplying large numbers of AIDS patients within reasonable distance from their homes. However, the case finding of cancer patients (for whom the PCI project funds are mainly targeted) remains quite low. Using international statistics, one can estimate the number of people in the Maua area who have a cancer and compare it with the number currently being reached:

700 = Expected cancer deaths per year in Maua's catchment area of 700,000

50 = Cancer deaths seen per year by Maua staff

Thus the Maua palliative care team is probably reaching fewer than 10% of the people with cancer in their area. Finding these people and extending care to them are clear priorities for the coming years.



In Malawi, the directors of the programme run by the Home Based Palliative Care Charitable Trust, and also the nursing staff themselves, worry about maximising the effectiveness of home-based care nurses. Repeated home visits, even within this limited urban area, are very time-consuming. One attempt to use the nurses' time more efficiently is a "static clinic" now being held monthly in a community building. About 12-16 patients are seen

in one day (a number which would require two to four days of home visits). Other such sites are planned.

As noted above, the Malawi home-based care programme has also developed, trained and mobilised a new cadre of health worker, the home-based care assistant. These paid team employees live in the community, are authorised to refill patients' stocks of certain medicines, and assist the nurses in the community and the office. This cadre is seen by the team leadership as promising, but not universally accepted, and is still under review by the Ministry of Health.

The majority of patients seen in the Malawi home-based care programme had an AIDS-related illness. Few of the patients had cancers, and cancers were said by the home-based care team not to be common. However, the cancer clinic at the major tertiary hospital of the area, the Malawi National Cancer Registry and the Malawi Medical Journal all report significant rates of cancer, including paediatric cancer, in Blantyre and its environs. Thus cancer case finding and care may deserve added attention in the future.

In Uganda, the distances travelled by the Kitovu Mobile palliative care team are enormous. A government doctor expressed admiration for the programme, as well as frustration about how it can ever be expanded:

*The services are really required but they are not able to cater for everyone who needs those services because of manpower and because they are the only ones who provide. I don't know why other people do not want to provide these services. With other government providers, we would like to provide such services but there are limitations.... We have a problem of staffing. Kitovu Mobile go out and find patients, but as for the public centres, how do you reach patients there? And what will happen in a few years when Kitovu Mobile runs out of funding? We need to think of the future and how government services can be extended.*

## 6.2 Sensitisation and advocacy within the community

In Kenya, as in many countries, younger people give little consideration to death and dying, while older people often retain old attitudes or lack current information:

*Young people have no time for this. (Stephen, nurse)*

*Patients still think illness is caused by witchcraft, herbal medicine and disease. There's also a massive use of herbal treatment. One patient sold his land for KShs 50,000 (GBP 400) and paid for herbal treatment, then died.... Sometimes relatives refuse to let the palliative team disclose the diagnosis and prognosis to the patients, especially very old patients. (Faith, nurse)*

*This week has been a real experience for me, learning about cancer and palliative care. I knew very little about it, since I spent most of my life in a school classroom with children. I knew very little about it. (Joel, retired teacher, translator for the evaluation team.)*

Many Kenyan families told us long stories of patient visits to dispensaries, herbalists, spiritual healers (“prophets”) and possibly three or four hospitals, spending a great deal of money on fees and transport, before they finally came to the attention of the Maua Hospital palliative care team. Some of these patients might have been cured of their cancers early on, or at least could have been made comfortable at home. Why does it take so long for them to access appropriate care?



*Some people fear to say the word cancer. There’s no local word for it, but even the old people and small children know that cancer kills. They think the patient will lose hope and die tomorrow. There’s a lot of ignorance about it. Patients go from one place to another, to charismatic sects, or to healers who take their money and give them useless things, but there’s no improvement. As for education about cancer, the churches usually leave it to the hospital. (Pastor, Maua town)*

*Some physicians do not understand palliative care and want to do surgery. In advanced cancer they want to open up and see what’s happening. (Faith, nurse)*

In Malawi, a number of patients and their families described using parallel health systems, traditional medicine and witchcraft, alongside hospital medicine.

In Uganda, sensitisation of the community has been a key success, but there is still a need to continue with advocacy and education about palliative care and the services offered by Kitovu Mobile Palliative Care Service. For example, the nurse in a local clinic was aware of palliative care and the benefits of morphine, but did not realise there were palliative care services so close by.

Thus community empowerment is key to the identification of those in need. When asked about giving advice to other areas about the benefits of having a service such as Kitovu Mobile Palliative Care Service, the district councillor said:

*People needing palliative care are there, but how to expose and fish them out?*

Community awareness must also continue to address issues of traditional beliefs and treatments. Stigma and seeking futile treatments remain a problem:

*Traditional beliefs – people do not easily accept medical treatment, and this has yet to change. (A community leader)*

### 6.3 Limited funding, but unlimited needs (especially social and financial)

In Kenya, funding from the Palliative Care Initiative (PCI) is vital to Maua Hospital's palliative care activities, particularly for patients with cancers (AIDS-related or not), but the funding is never enough to meet all the needs:

*Caring for cancer is expensive for a hospital. Our palliative care activities cannot be sustained without the Diana funds. Patients simply cannot pay for it.* (Dr CS, hospital deputy CEO)

*Poverty is a problem. For example, if a patient is told to come for a biopsy (which costs KShs 5000 or GBP 40), she waits a long time, or she simply never comes.* (Faith, nurse)

*When we visit homes, the families say to us, "Yes, you have brought drugs, but what about food?"* (Ellykhana, nurse)

In Malawi, many staff and volunteers of the home-based care programme mentioned the hidden costs of being ill, the problem of transport costs to the health centre or hospital, the costs of getting foods for the patient, and their wish that more financial support (or even a vehicle) could be dedicated to patients' needs.

In Uganda, despite the significant support offered by Kitovu Mobile Palliative Care Service, finances remain a major expressed need of many families:

*Her husband was helping, but the house was almost collapsing. She was grateful for the small amounts of aid they had received but in this life no one is ever satisfied.* (Jess's mother)

The need for help with school fees was most frequently mentioned, followed by housing problems such as leaking roofs. The school fee issue is particularly difficult, as support may be needed for many years. Income generation support (such as buying a sewing machine) can be of help, but perhaps there is a need for more linking with other income support or micro-enterprise programmes. The needs here are enormous, so targeting and prioritising are crucial.

## 7. ILLUSTRATED PATIENT AND CARER STORIES

### 7.1 Uganda

#### 7.1.1 Difficult decisions

Peter, aged 13, has osteosarcoma, an aggressive bone tumour. As we arrived to speak with him about his experiences, the entire family gathered in the living room, and various people interjected periodically. Peter is cared for mainly by his maternal aunt, Doreen, and other relatives also help. His parents live on an island in Lake Victoria and for some time he has been cared for by his aunt. Their experiences underline the economic and psycho-social benefits that Kitovu Mobile Palliative Care Service can bring.

Peter's illness started six months previously, with a small swelling on his right leg. After a week, the swelling increased, and he had a fever. Doreen took him to a private clinic, where he was given an injection, but it brought no relief, and his pain increased, until he could not walk. Doreen then took him to Mulago Hospital, the national referral hospital, two hours away in Kampala. There Peter was seen by an orthopaedic doctor. According to the family, the doctor claimed that Peter had a broken bone, and demanded 30,000 shillings (GBP 10) before putting Peter's leg in a cast. The family managed to meet the costs but the swelling and pain increased. Peter began to lose hope. He missed school and was unable to distract himself from his pain.

Peter began to worry. His leg smelled bad, and he was concerned that the swelling would move to his heart. He knew the leg was useless. As he was lying in bed all day in pain, Peter was traumatised by the other children in the house who teased him.

After failing to get help at Mulago, Doreen became desperate. She began to take Peter to various traditional healers, even travelling as far as Rakai. Doreen estimates that she took Peter to over 20 healers, all of whom claimed that Peter would be healed, if she only gave them money. As Peter's condition worsened and Doreen sold more land and took her own children out of secondary school to conserve funds, the family became increasingly worried about Peter's declining health.

Finally, Doreen took Peter to Kitovu Hospital, where he was referred to the palliative care team. Doreen was surprised when the team showed up at her house. After their first visit, she saw Peter's pain decrease. In January 2009, the team advised Peter and Doreen that he could become mobile and pain free only if his leg were amputated.



After counselling from the team, Peter and Doreen were convinced that the amputation would help. Other family members, including Peter's paternal uncle, whose consent was legally required for the amputation, remained unconvinced. The team spent time counselling family members, and talking on the phone to the paternal uncle, who was persuaded to visit Peter and see the leg himself. Upon seeing Peter unable to walk and in pain, the uncle finally consented to the amputation, which took place three months ago.

Since the amputation, both Peter and Doreen are greatly relieved. The pain has almost disappeared, and family members have returned to their normal activities. Peter is grateful to his family and the team for their support during his trying ordeal. Family members helped while he was bedridden, bathing and feeding him. The team treated him, took him to the hospital and supported and encouraged him during their visits. Doreen is also grateful to the team, and hopes their care for Peter will continue.

Note: A few months after our visit, we learned that Peter had died.

### 7.1.2 Support for the long term

Michael is a 76-year-old community health volunteer (CHV). We met him at the small home of Robert, a 55-year-old man with HIV/AIDS and Kaposi's sarcoma, a cancerous swelling that is common in HIV patients in Africa. We talked with both men and also with Robert's main carer, his 11-year-old son Joseph.

Michael has known Robert since 2003, when he began trying to convince him to get an HIV test. After two years of intermittent ill health, Robert, a police officer at the time, finally went for a test and learned of his HIV infection. Michael then referred him to Kitovu Mobile Palliative Care Service and briefed the nurses on Robert's status. Visits began in January 2006. The palliative care team diagnosed Robert with Kaposi's sarcoma and arranged chemotherapy, while treating his pain with morphine. Michael took him to the hospital and remained with him during his three-day stay. After treatment, Robert recovered briefly, then again became bedridden with cancer in his legs.

Robert is grateful for the counselling that the palliative care team has given him. They have continued to encourage him throughout his illness, helping him feel strong and positive, through various emotional and financial struggles. Michael often accompanies Robert to the health centre to get treatment.

In addition to the palliative care team's counselling and home visits, Robert receives support from his religious community. A nun had visited Robert just that morning to pray with him and give him a few necessities. Robert is also helped by his son, Joseph, who helps him wash and apply cream to his feet. Joseph is supported by Robert's parents, who live in a larger house next door. Joseph told us he finds it difficult to care for his father, and he misses his mother who left when Robert became ill.

Michael, the volunteer, then told us his own story. He began working with Kitovu Mobile Palliative Care Service in 1987, a time when many myths surrounded HIV, and people often turned him away. Since most patients had presented very late for medical care, Michael's home visits began to be associated with death, because several people died after only a few visits. In order to gain acceptance in the community, Michael often used his own money to bring small gifts to his patients.

Michael has received continuous training throughout his 20-year volunteer service. Courses have covered topics such as counselling, tuberculosis, gender awareness, palliative care and behaviour change. The courses have been helpful to Michael, both personally and in his role as health volunteer. All his grandchildren have degrees, and he has counselled them on the importance of protecting themselves against HIV.

Michael is not paid for his work, but he feels morally supported by Kitovu Mobile Palliative Care Service. They gave him money to repair his house after a devastating storm, as well as seeds to grow a garden. Michael feels that he plays an integral role in the work of the service. People in the community know him, and now approach him for counselling and testing.

### 7.1.3 Strength to go on



Leah is a 38-year-old single mother of three, whose breast cancer is now in remission. She received the evaluation team in her very clean, partitioned, rented one-room house. Leah runs a business out of the second room of the house, selling food that she has cooked on a charcoal burner outside. Her story illustrates continuing stigma against cancer in the community, as well as integration of the Kitovu Mobile Palliative Care Service with the broader healthcare system.

*Before I met Kitovu Mobile, I thought I was going to die. I had so little hope, I made a will.*

When Leah was pregnant with her second child, her left breast began to swell. She was worried, but people in the village told her it was normal because she was pregnant. After giving birth to her child, the breast continued to swell, so she went to Masaka Hospital, where they drained pus from her breast. Although smaller, the breast still had a hard lump that was “itching and eating me.”

At this time, Leah sought the services of a traditional healer, who gave her a cream to treat the lump. After using the cream, her skin broke out in blisters. Shaking her head vehemently, Leah told us she never again went to a traditional healer.

During her third pregnancy, Leah’s husband and his other wife kicked her and her two children out of the house. They believed she was going to die of her breast illness, and since she was contributing nothing to the household, they wanted her to leave. Pregnant and sick, Leah managed to rent a modest two-bedroom flat to share with her children and operate her business. Around the same time, a neighbour started spreading rumours about Leah, telling people in the village that Leah had a horrible-smelling wound, and they should not buy her food as it would poison them. Leah “informed the authorities” about this woman, who went away and never returned.

*Before I went to Kitovu Hospital, I never received any medical advice or information about my illness.*

After giving birth to her third child, Leah referred herself to Kitovu Hospital Palliative Care Service. Only then did she learn that her fungating wound was breast cancer and that she needed radiotherapy and chemotherapy. The Kitovu





Mobile palliative care team took her to Mulago Hospital in Kampala and provided a place for her to stay during the three weeks of radiotherapy. Leah then went home for three weeks, after which the palliative care team provided transport every two weeks to Kampala for chemotherapy.



Now Leah's breast cancer is in remission, and her wound has healed completely. The palliative care team initially gave her liquid oral morphine, but she is now feeling less pain and takes a less strong painkiller when she needs it. The team continue to visit Leah every two to four weeks. She said the most important role that the team has played for her is giving food for her children and giving her medication.

Leah says there is a *"big difference"* in the care she receives from Kitovu Mobile Palliative Care Service and the care she received before. Previously she had little hope and thought she was going to die. Now she is not worried about the future, because she doesn't feel any pain. She is so confident in the care she receives from the team that when we asked if she had any questions, she replied:

*No, all my questions have been answered by Kitovu Mobile.*

#### 7.1.4 Becoming normal again

Lillian is a 26-year-old village woman, who had her left leg amputated four years ago due to bone cancer. Reaching her house required a rough 20 minute drive, after which we were ushered into a small dark front room where Lillian was sitting next to her sewing machine. Her mother, in a smart red dress, sat nearby, and five small children occasionally popped out from behind a ragged curtain. Her mother and Lillian told us their story.

Lillian spoke slowly in the local language, as nurse Resti translated. She began by telling how her husband used to beat her and once hit her on her leg. The pain gradually got worse, and she used to buy ibuprofen at a local store for the pain. While digging in the fields one day, she collapsed and her knee became very swollen. She was taken to a government health centre and treated for three months with painkillers until she was eventually referred to Masaka Hospital. She had also tried traditional and local medical help to no avail. At this stage she was not walking or sleeping due to the pain. A physician's note stated that Lillian's bone cancer in fact was not related to her being struck in the leg, just an unfortunate coincidence.

She first met the Kitovu Mobile palliative care team at Masaka Hospital. She vividly remembers her pain being relieved with the first dose of morphine that she received:

*The morphine brought back my happiness. I have no words to express my gratitude.*

Lillian spoke fondly of her relationship with Resti, that she was there for her and that even if she could just see her she would smile. She had appreciated the sugar, maize meal, oil and soap brought during the visits. She also had had help from the service to pay for the hospital bill.



Lillian said her main current problem related to her husband's relatives. They had accused her of causing her husband's mental illness and were very unsupportive.

Lillian was supported through her local church, with members visiting and praying for her. She had recently given a testimony at a church meeting about God's goodness to her and the good work of the palliative care team. Over the last few years, she had found a

friend who had a similar problem and she had referred her to the team. When asked how the team could help her more, she talked about her children – whether they could get more support for school fees, as the in-laws don't bother. The sewing machine had been a previous source of income, but was not currently being used.

Lillian mentioned pain in her left groin. We examined this area and found a fungal infection, but no recurrence of tumour. The full-length crutches were giving her some pain, so elbow crutches were recommended instead.

Lillian's mother Paula was the person who had been caring for her and also had to search for money to support two families, buying food and medicine. When we asked how the team had helped her as a carer, Paula first mentioned help with Lillian's pain:

*My daughter couldn't sleep, day or night, and could not be left alone, until God brought these people to see her.*

Now they could both sleep. She was very genuinely appreciative of having regular drugs supplied, whether brought to the house, or left for her to pick up at a shop we had passed on the road.

Paula's main ongoing problem was help with the children, as Lillian was lame, her husband was not helping, and the house was almost collapsing. Paula was grateful for the small amounts of aid they had received, but added *"in this life no one is ever satisfied."*

After the interviews, we went outside to see the kitchen. Lillian showed that she still managed to do some hoeing in the garden, and that even with one leg she was still "normal".

### 7.1.5 Getting married

Benson, a 37-year-old lorry driver, was taking treatment for AIDS. He was referred to the Kitovu Mobile team by a local NGO when he developed Kaposi's sarcoma, a large heavy tumour on his foot. We were ushered into a very dark room with cracked walls. Benson hobbled in with a large fungating mass covering most of his right foot. His wife Prisca came and sat nearby, and their little girl, about 3-years-old, came in and out of the room. We spoke with both Benson and Prisca.

Benson told us how he had gone to various local stores for medicines for his leg, and he also had tried traditional healers. He had recently been told it was cancer. He then asked Sister Karla if the injections (chemotherapy) could cure it; she replied that they might not cure it, but they could keep it from getting worse.

Benson had been greatly relieved of the pain by the morphine, but the tumour was still enlarging. Speaking of the home care team, he said that he really trusted them:



*They are caring very hard for what they are doing. I know I'll get some improvement by what they are doing.*

Benson's main problem was that he could no longer work and could not raise money for the family. His brothers and sisters were helping, but they also had problems. He and his wife had never officially married, as he had nothing to give as the customary gifts to her family.

When we asked if there were people who were not helpful to him, he mentioned those who "said that I was going to die". Benson just doesn't listen to them now. He said the Kitovu Mobile team had really helped him by talking to him, by bringing the morphine and also food and blankets for the children, and by paying for him to go to Kitovu Hospital for chemotherapy.

They had told him to be patient and to accept the disease, and he said he was starting to do this. He used metronidazole solution to try to clean the tumour, which made it very yellow. When Benson mentioned that he was now helping himself to walk, using a large stick, the team doctor offered to bring crutches for him to try. The team left some soap and maize.

Benson's young wife said her main problem was the stress of seeing the breadwinner of the family ill and not able to work, when there was need everywhere:

*The children were no longer in school and things were in a mess.*

Initially she was scared, but now she was trying to cope (she had run off for a time, but then came back). Her parents were not supportive. Prisca said her main problem was that she would like to get officially married but doesn't know where to start. At this point in our visit, a sensitive counselling session developed, with Resti, the palliative care nurse displaying tremendous compassion and counselling skills.

A final word from Kitovu Mobile palliative care staff:

*Let us continue bringing to fullness the lives of those entrusted to us, and their caregivers. Our motto is 'We care'.*

## 7.2 Kenya

### 7.2.1 A volunteer health worker making a difference

We drove up a very dry and dusty road, and entered a small, poor homestead. Tabitha was kneeling, attending to her maize and millet. Behind was a traditional kitchen with maize cobs drying outside. She shared her living and sleeping area with her adopted daughter and her cow and chickens. There was an old outside toilet with an unstable base about 20 metres into the nearest field.

Tabitha, aged 70, was the second wife of her husband and had had no children. Five years ago she had developed a large tumour on her right foot which made it impossible for her to work. It had been moist, smelly, bled easily when she tried to walk, and gave her constant pain. The local clinic sent her to Isiolo District Hospital for a biopsy. Sometime later, frail and weak, she was brought hobbling to Maua Hospital mobile clinic in her community by a volunteer, Hannah.



Hannah told us:

*I knew her when I was a child. She was a business woman, like my own mother. I married and left, then later came back to this area, as a widow, with my three children. One day, I saw her limping on her bad leg, and I began visiting her, using my own money. Then the Maua people began to visit her.*

Tabitha was counselled about her condition and was given analgesia, antibiotic tablets to crush up and apply to the smelly tumour, and crutches to help her move around her home. The pain was controlled, but despite bags tied with string over her foot, the tumour remained very offensive and infected. Tabitha was distressed but remained courageous and determined to beat her condition. Eventually, she herself brought up the possibility of amputation, which she felt she had "not deserved". She was prepared to take the risk of surgery. This was only possible through the help of her community volunteer, as she required several visits for consultation prior to surgery. These visits involved long and uncomfortable travelling in local transport, and Hannah accompanied her on each of these visits. At last, the palliative care

team arranged for the amputation by surgeons at Meru District Hospital. Hannah wanted to accompany her to Meru, 50 miles away.

Hannah continued:

*I went to her house that morning, then walked very, very slowly with her to the bus stop. It took us about seven hours. The Maua people had given me money for our bus fare. After the operation, she stayed in the Meru Hospital for two months. After she came home from the hospital, I went to her house every Friday with the palliative nurse.*

Tabitha referred to the palliative care staff as her children and she described her appreciation for the medication (which included ibuprofen capsules, antibiotics and morphine), and the help and support given by the palliative care team:

*Anyone taking care of me is my child! I could not move well before getting that medicine. Finally I drank [the oral morphine], I slept and there was no panic. They brought maize and beans.... I tell them my problems and they listen.*

She had thought that her illness would kill her but now, one year after the operation, Tabitha is hopeful that she might be cured. Her main current problems were a neighbour who had beaten her and taken a cow, and her constant lack of money. She is especially concerned about secondary school fees next year for her adopted daughter, who lives with her and helps her when she is not in school. They also get occasional food packages from the local chief.

Hannah, the volunteer, assured Tabitha she would continue to visit from time to time. Tabitha prayed with the team before they left. She was so obviously thankful for all the assistance she had gained from the palliative care nurses and especially from Hannah as a volunteer.

### 7.2.2 A good death in rural Kenya

We trundled along a narrow dusty road, then walked a further 200 yards uphill, past maize fields, and entered a small homestead of three wooden huts and a stake where animals are tied. Gladys was sitting with a friend, relaxing after working with her machete in the garden.

Her husband Henry had died 11 months previously. Gladys recalled that his problem had begun with swellings all over the body, and he developed an abscess on the chest. He was operated on at Maua Hospital, where staff reassured him that they would continue to help, although they could not cure him. He had attended private clinics, herbalists and small shops to buy medicines to no avail. Henry's wound healed but recurred on his back, and he realised that he was seriously ill. They then learnt it was cancer. They were referred to a larger hospital, where staff



confirmed that his illness could not be cured and that he should get help at home from the palliative care team at Maua.

Gladys's main problem in caring for her husband had been that he was unable to eat and that she hated *"staying with him and just looking at him get sick."* He would ask for various foods, but sometimes was unable to eat them. He received medicines from the Maua home-based care programme, including *"drops into his mouth"* (oral morphine). She had been very reassured to have the mobile phone number of Faith, the palliative care nurse, whom she could call at any time.

The hardest days had been when Henry couldn't get out to urinate. He got very constipated and was catheterised. Faith and the staff came and helped with everything. Gladys said:



*I missed no help that I needed. My husband also got all the help he needed.*

In Henry's last week, he became confused and talked inconsistently. The family had discussed where he should die. Henry, Gladys and their son had agreed that home was best. Gladys said:

*I looked at him and saw he was going to die and that he accepted to die at home. Even if he went to hospital, nothing would be done. From my own heart I knew he would die.*

When asked how the home-based care could have been improved, Gladys said:

*Just continue to do what you are doing. The one who is advised must have his own knowledge.*

Then Gladys used a local proverb to query her visitors:

*When someone comes carrying a kiondo (woven basket), they are either bringing something, or taking something away. Which are you doing?*

We replied that we were taking away her story in order to help others.

Did Henry have "a good death"? He certainly died where he wanted, at home with his family in attendance, with pain well controlled, and with little apparent psychological or spiritual distress, although terminally confused. This happened, despite urinary and faecal incontinence, and no running water or electricity or indoor toilet. Henry's wife had been counselled and supported throughout the illness, including on practical aspects of the last hours of life and what to do at the very end. He had been buried four days later, in his own compound, with a palliative care team member present to support the family.

This, surely, was a good death. No running water, no electricity, but the technology which did really help Gladys was having a mobile phone to keep in touch with relatives and the palliative care team.

### 7.2.3 The grand matriarch

Far from Maua Hospital, again along a dusty road, the palliative care nurse led us into the large family compound. The nurse had been called by Susanah's son on her mobile phone, requesting a visit. She had recently been discharged from hospital after a blood transfusion for anaemia due to stomach cancer.

Susanah, a woman in her eighties, came out of her hut and began telling us about herself. She said it was old age that was disturbing her, but she was now eating well. As various relatives came out of nearby huts to meet us, Susanah dug out an old 200 shilling note and sent someone to a local market to buy peas to give us as a present. Susanah was the first of five wives of her deceased husband. She had had eight children – many of whom lived nearby. Many of her grandchildren were playing close at hand and, as we talked, she also surveyed the goats, chickens and cows which surrounded her hut. She was very much the head of the compound and seemed to enjoy her responsibilities and role as matriarch.



Her son Jacob, a teacher at a nearby school, recounted that his mother had been to a hospital where they *“passed down a tube”*. The diagnosis of stomach cancer had been made nine months previously by gastroscopy. Susanah said that the blood transfusions had given her great strength, and if she got weak again she would want another. On admission to hospital, she had thought she might die, although she had not discussed that with anyone.



Jacob was very happy with the palliative care she was receiving. His main problem was that he had spent a lot of money on her care and had debts and other obligations, especially school fees for his own children – two at university, one in college, and one in secondary school. The family, he said, all appreciated the wide-ranging support that the team were giving his mother, and their visits to bring her morphine.

Her son confirmed that Susanah had been told in hospital that she had cancer but she chose to consider her current illness as *“murimu wa miaka meingi”*, literally “a problem of many years”, rather than cancer.

The role of the hospital for her in terms of palliative care was offering blood transfusions. The blood transfusions were successful palliative care treatments, as they improved her strength and quality of life. This and morphine were treating her physical symptoms; the counselling of nurses offered psychological support, whilst her family and extended family provided her with social and spiritual support.

When it was time for her to die, Susanah would do this at home, in the midst of her extended family. It should be a good death, where she wants, surrounded by her family and community, supported by the palliative care team. She is indeed fortunate that this project is in place.

#### 7.2.4 Squalor

Jenifa, aged 50, had no children, and she had been brought back by her husband to her family homestead five years ago. Three years ago a tumour, which her brother said was like “protruding teeth”, appeared on her right cheek. It had been removed at a hospital but had returned.

We entered Jenifa’s small run down shack with crumbling mud walls and holes in the roof. There was a strong offensive smell from her large facial tumour. She had taken only some tea leaves that day, and her sparse grey hair reflected her malnutrition. When asked if she had opened her bowels that day, she motioned to faeces in the corner of her room, next to the bananas. In another corner were three stones and ashes, where she had been cooking previously. There was no running water or electricity nearby.

The palliative care nurse asked Jenifa to remove the rag which bound her tumour, but she hesitated to do this, saying that would make it bleed. She said she took 4mls of her morphine mixture every four hours, which greatly relieved her pain. However without food, the medicine made her feel dizzy, so she rarely took it. The nurse suggested reducing the dose to prevent dizziness.



Nobody visited Jenifa, not even from her church. She had no way to tell the time – so we wondered how she could tell when her morphine was due. She said that God gave her strength. The nurse dispensed more morphine, encouraged her to trust in God, and handed over some rice and greens.



Fifteen yards away from her hovel, we spoke to Jenifa's brother and his wife. They claimed that they were cleaning her and giving her food every morning. However the nurse, who had been visiting her weekly, felt that was unlikely. Indeed, Jenifa had denied receiving any food or help from her family.

As we left, we pondered over what we had just seen. Most other people with serious illnesses in Kenya were living in extended families and appeared to be very well-supported socially. How unusual is Jenifa? Was it a cultural disgrace to have a barren woman dying in their compound? Was this why the family seemed to be refusing to care for their sister? What was really going on here?

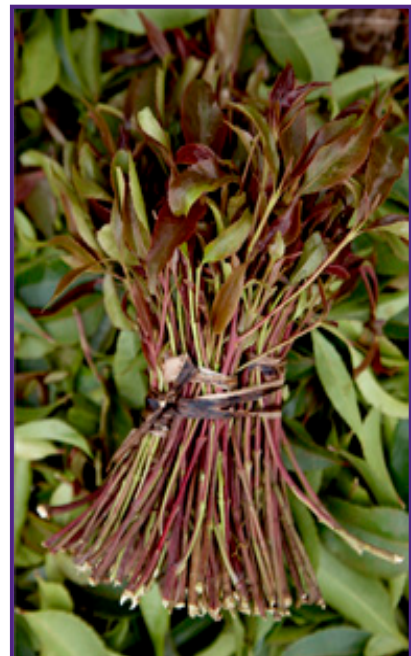


### 7.2.5 Dying among the *miraa* trees

We walked through a homestead with cows and goats tied up, then between tall dry maize plants and *miraa* trees. We passed a dozen men bundling up *miraa* stalks in banana leaves to take to the local market, where the narcotic would earn them vital cash. At the next homestead we noticed a fresh grave, fenced off and with a simple wooden cross. This was the resting place of Maria.

She had died two weeks before from cervical cancer. We talked with Ruth, a niece, who had been her main carer at the end, and with Stefan, Maria's son. Both were aged 22. Ruth mentioned that Maria had gone to various clinics and dispensaries, then Meru District Hospital for a scan, and then to Chogoria Mission Hospital where "*her womb was found to be full of holes*". They told her to return home and find the palliative care team at Maua Hospital. Thus many tortuous and expensive journeys had led to diagnosis and culminated with a sad retreat home.

The Maua palliative care team had helped by visiting every week, bringing medicine and showing Ruth how to give it to Maria. Ruth acted out drawing up morphine in a syringe, as she had been taught. The morphine had allowed Maria to sleep and had taken away all the pain. Both women had also really appreciated the comfort (*kuraitha*) provided by the visiting palliative care nurses. The women of the church also visited, bringing firewood and water, and supporting her with prayers. (Maria's husband drank a lot and had not been of much support.)



We asked how Maria had died. Ruth said that she knew her patient was dying when her hands and her forehead were cold and she stopped breathing. Faith, the palliative care nurse, had

mentioned to Ruth to look out for these signs, but not to worry, and to let death occur. Maria's last words had been:

*If I have sins, forgive me and bless my children.*

Ruth then put wool in the nostrils and lit a small charcoal fire in the room. The next day Ruth used her mobile phone to call Faith, who consoled her so much and said:

*Please go ahead and send Maria to the grave.*

Family members soon gathered, and Maria was buried the next day, with the pastor from the local Catholic church presiding. He took a collection, which he gave to Maria's husband. We asked whether the family was in agreement that death in the family compound was the right thing. They agreed it had been best, and that things had gone well.

## 7.3 Malawi

### 7.3.1 A father and a little boy caring for each other

The living room window had the best view in the whole neighbourhood, across the other rooftops to the distant green hills. The room had one soft chair, some dining chairs and a table. On the wall were two pictures, one with the words "Trust in God". The other was an African village road scene with a very poignant comment: "When problems come, friends run away."

Poverty had its stamp everywhere in the room – in the small cracked dishes with some left over greens, in the broken table, in the soft chair with its newspaper lining, in the ragged net hanging across the window. But somehow the house felt happy. Simon, a 39-year-old man with a shy smile, greeted us with a firm handshake.

Simon was first brought to the attention of the home-based care team through his Seventh Day Adventist church. A church member spoke about Simon's condition with a member of a community group taking care of orphans. This person knew about the health volunteers, whose role was to find sick people in their homes; she called the local volunteer who then visited Simon and immediately referred him to the home-based care team.

Simon is married and has three children. Two of them live here with him and his wife – Michael, aged 11 and Benedict, aged 5. The oldest child, aged 16, lives with Simon's sister in the family village. Simon used to work at temporary jobs, but for several years he has been too sick to find or hold any employment.

Simon's illness started early in 2002, with leg pains and skin lesions near his groin. He went to Queen Elizabeth Hospital and was referred for physiotherapy, but it did not ease the pain he felt. A neighbour saw Simon's lesion and said:



*No, this is not a cancer that we know. This is something vicious. This is something like witchcraft.*

This neighbour recommended that he go to the compound of a traditional healer who lived on the outskirts of Blantyre. For six months Simon and his wife stayed with that traditional healer. During this time his grandmother visited him, and *“she was caught doing witchcraft”*. The traditional healer accused the grandmother of having poured a *“black medicine”* on Simon’s leg, and it was this that had started his illness. The grandmother, when confronted by the healer, confessed that this was indeed the case. The healer assured Simon that, now that the witchcraft had been revealed, his illness would go away.

Simon returned home, but the illness became increasingly severe. The infection spread from his foot to his knee, with open wounds. The weight and pain of his swollen leg made it impossible for Simon to walk, even to the latrine just behind his house.



One day, Simon heard on the radio about PMTCT (Preventing Mother-To-Child Transmission of HIV), and the need for all HIV-infected pregnant women to take nevirapine tablets to reduce the chance of passing HIV to the baby at the time of delivery. Simon remembered that he had seen two white pills belonging to his wife, shortly before the birth of their youngest son. He confronted his wife, who admitted that, yes, those were nevirapine tablets. She had tested positive for HIV, but had not had the courage to tell him. Simon realised that his own illnesses were probably caused by AIDS:

*I lay here on my bed for three years without going out. My leg became bigger and bigger, and worms started to come out. Every morning when I took off the covering that was over the foot, I picked out the worms, but the next day they were there again.*

During this period, Simon’s wife left him. She was unable to cope any longer with his wounds, the smell, the increasing illness. She left the youngest son with him, and for months the little boy and the father cared for each other. Neighbours occasionally sent food.

During what Simon described as a *“desperate time”*, he lay on his bed:

*I prayed that Jesus would come and heal, as Jesus is the only one who can heal our diseases.*

A week after he prayed this prayer, the health volunteer arrived:

*I knew it was an answer to my prayer, Simon told us. God had heard me calling him, and he sent the volunteer, for why else would she have come just at that time?*

Soon after that, the home-based care nurse visited, then arranged for a car to take Simon to the Queen Elizabeth Hospital cancer clinic:

*They made a stretcher, he said, and carried me from this house, up that hill to the road, and there they put me in the car.*

Simon was admitted to the hospital, where he received treatment for his Kaposi's sarcoma. Since his discharge, the cancer centre has liaised with the home-based care team to provide almost all his care at home. Volunteers began coming on a weekly basis to look after Simon, clean the house, and do small tasks. A nurse and home-based care assistant come weekly to check his swollen foot and ensure that he is comfortable and without pain. However, the delivery of anti-retroviral medicines has not been delegated to the home-based care system, so Simon must travel to the Queen Elizabeth Hospital every one to three months for those drugs.

Over the past six months Simon's health has improved markedly. Neighbours who thought three years ago that he was dying see his recovery as a miracle. His wife has returned.

Simon spoke with passion about the problem of HIV denial and stigma within the community. Like his wife, he said, many people are frightened to talk about their HIV status, and it's during this silence that their illnesses develop:

*If only my wife had told me when she knew she was HIV-positive, my cancer might never have happened. We would have known what to do. My leg would never have swollen so big. I would never have lain for three years in pain, thinking I was dying. If only my wife had told me.*

### 7.3.2 First the sister, now the brother

A family of 17 lived in the stone house. Though well constructed, the main room was barren, with multiple pieces of assorted broken furniture piled in corners. We sat on small stools, and Ali sat on an empty, uncovered bed frame, probably the work of his carpenter father, the only person in the household working. Ali's mother sat on the floor.

The home-based care team has been involved with this family for three or four years. Initially they supported Ali's mother to look after Ali's younger sister. She was HIV-positive and died in 2006. Recently the team have re-engaged with the family to provide support for Ali.

Ali started his story:

*I was working as a painter in Lilongwe, where I was married and lived with my wife and two children. I was feeling very weak and was having problems breathing. I went to an HIV clinic where I was tested and found positive. After two weeks they booked me for a CD4 check. When I went to the hospital for the test they discovered that there was a black notch on my wrist. The doctors said I should be started on ARV very quickly because of this as the notch was a cancer. I decided because of the cancer and HIV that I should return back to my mother's home. That was in 2007."*

Ali explained that he was not frightened to tell his mother what was wrong:

*To me there was no problem to disclose, because she is my mother.*

His mother added:

*I accepted that my son had come back, it was okay.*

Ali continued:

*My wife and my children stayed in Lilongwe. Up to now, I have never gone back to Lilongwe due to financial problems, and my family have never come here. In the past I used to call them but I don't anymore.*

We asked Ali's mother if she had met her grandchildren:

*No, she said, I have only seen their photos.*

When Ali arrived home, his mother took him to St Joseph's Hospital where he was admitted with a diagnosis of TB. He was started on TB treatment and after finishing the course felt much better and remained free of illness for about 12 months.

Ali's illness became more severe in 2008. His mother explained that it was the palliative care team who encouraged the family to take him to Queen Elizabeth Hospital. He was admitted and discovered to have a second infection of TB. He received TB and ARV treatment and also attended the cancer centre.

Over the past year, Ali had a series of appointments at the hospital for review. He travels on a public minibus, accompanied by his father. The journey is difficult because of the pain in his chest and his shortness of breath. The family struggle to afford the transport, almost 500 kwacha (GBP 2) for each journey.



Ali was readmitted to hospital earlier this month.

*I am still feeling very weak, he said, because I was discharged just two weeks ago. I still have chest pain and problems breathing, and I am not strong enough.*

Ali's mother, who looks after all 17 people in the household, explained:

*My biggest problem has been finding the food for Ali.*

Ali also said food was the major problem, but for a different reason:

*I used to buy food for myself, but now I am given food by my parents, and I don't have a choice, I am given what is available.*

He was grateful, though, that he was being cared for at home, and he knew he was an added cost to a family already struggling to cope.

Ali explained that the family were of the Muslim faith, but members of the local mosque do not know of his illness and do not come to visit. Only relatives come, and of course the volunteers:

*Back when my sister was sick, she got treatment from the HBC team and food supplements from the team. The volunteers visit us every Wednesday. In the past they came on their own, or maybe two together, but now they always come with the nurses and assistants. They encourage me, give me drugs, help when I have a problem, and they counsel me. What is still missing, though, is food attached to the medical care that we get.*

Ali explain that earlier that morning he had at last received from the health centre, via the home-based care team, 30 small containers of Chiponde (fortified peanut butter). He went on:

*I get my ARV medicines from the health centre and my drugs for Kaposi's sarcoma from Queen Elizabeth Hospital.*

We asked if Ali was part of a patient support group.

*No, he said, I have never been with other people who have the same illness as I have.*

Then Ali told us of his bigger needs and plans:

*The HBC team mostly deal with the medical parts of looking after a patient, but I am lacking some other requirements. If I could be assisted in doing a small-scale business when I get better.*

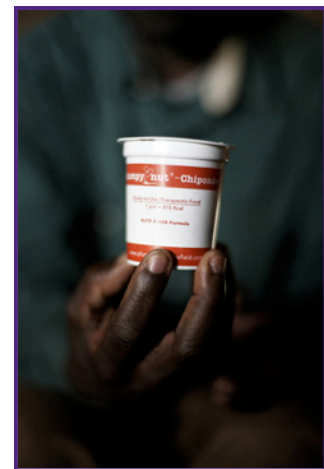
### 7.3.3 If only she had told me

On Thursday morning Aya was waiting for us outside her stone-built home. She welcomed us into a room with only four chairs and stools, a small table, and a cupboard with a clock. Calendars of previous years provided colour on the wall. Cell phone numbers were written across one. Off this main room were a few other rooms; in one of them her daughter had stayed until she died a few weeks ago.

Aya began her story:

*I was caring for her. I was the one taking care of my girl who passed away. Her name was Lucy, and she was 30 years old. She and her children lived just down the hill below my house, but after she began to feel unwell I brought her from her home to mine so we could be close.*

*My daughter did not tell me ahead of time that she had HIV. She was discovered to have HIV when she went for antenatal care before the last baby was born, but she did*



*not tell anyone. If only she had told me very early that she was HIV positive, maybe I could have helped. I know a lot about HIV, through village meetings and the radio. I could have taken some measures. But my daughter did not say anything. Perhaps she was shy or afraid to talk about it. I don't know.*

After the birth of this child, Lucy struggled to regain her strength:

*She was very ill. We visited a traditional healer who gave us a concoction of medicines. But after Lucy took the medicine, she started having frequent diarrhoea. It was found that the diarrhoea was associated with cholera and she was admitted to the clinic. After she got discharged, she felt well, but after some time she started suffering again from chronic fevers and possibly malaria. This time she was admitted to Queen Elizabeth Hospital, and it was then that I came to know that my daughter was HIV positive.*

As Lucy's health deteriorated, the home-based care team started to visit her. They brought vitamins and medicines to ease her pain and nausea, and they treated her oral thrush. They referred Lucy to the Health Centre for nutritional supplement.

During the last few months of her illness Lucy was unable to go to the toilet herself, or feed herself. Aya told how the team engaged with her and taught her the best way to care for Lucy:

*The nurses and volunteers all came together. The major problems were vomiting and severe headache, and she had frequent attacks of fever on and off, and even her eyes were jaundiced. I remember at times that they even provided me with gloves so that I could use them to lift the soiled linens.*

Aya told us how much she appreciated the company of the volunteers:

*They talked to me about my daughter. There was a volunteer called J and one called E who used to care. They came every Thursday with the other people, and sometimes they came just by themselves to find out how we were doing.*

The team organised transport to the health centre. Lucy and her mother travelled there and met with a clinical officer who told them again that she was at Stage 3 of her illness and needed ARVs. A date was set for Lucy to collect her first dose of ARVs:

*I was waiting, Aya said, for the date for her appointment, to be started on different drugs, but she never was started. She died even before the booked date. The illness was just getting worse and worse. It never improved. I did not take her to the hospital. I was relying on the care that the HBC team gave.*

Aya spoke softly:

*My daughter passed away on Sunday, in the afternoon at 3pm. There was a lot of shouting on Saturday evening, but on the whole of Sunday she was very quiet.*

When we asked if Aya had been scared or unsure by her daughter's shouting, she explained that she was not unfamiliar with death. She had cared for her brother, who died over 15 years ago, so she knew what would happen. She explained that she had not called the volunteers that Saturday evening, as it was so late:

*When Lucy passed away peacefully, said Aya, I called the relatives around to come and assist me to prepare for the burial on Monday. I am a member of the Abraham Church, and the church members came and spent the whole night singing songs. They also came to the burial on Monday.*

Aya is resilient. Her husband is currently employed, but the amount he earns is small. They now have Lucy's three children living with her, and their father, who lives close by, remains engaged with the family.

*We belong to a programme that gets us some food and help from the health centre. I don't know about the children's HIV status. I took the baby to the clinic and was told that after 18 months he can be tested for HIV. He is strong and happy. The other children are in school and they are fine.*

Aya is hopeful that all the children will do well.

#### 7.3.4 Almost unbearable

Zora at least had a bed, with a thin mattress and a couple of blankets. On the sunny afternoon that we visited her, the air and the cement walls had warmed to a comfortable temperature, but she told us she suffered from the cold at night.

*She is one of our earliest patients, the nurse had said. When we first knew her in 2003, it was difficult for us to get people tested anywhere for HIV. Finally, two or three years later, when she had a severe skin rash, she was tested and found to be HIV-infected. She was referred urgently for anti-retroviral therapy (ART) and finally in 2007 began taking the medicines. She had various other rashes since then and went to the dermatology clinic, but no thorough assessment was done. Finally, last month she was hospitalised, and I presented her case to a clinical ART meeting. The group concluded that she probably had a nevirapine-induced rash, so her drug regimen was changed three weeks ago, and she is responding well.*



Zora's palm was rough when I shook her hand in greeting. Her face was blotched, and the soles of her feet were deep purple from medicine. As we talked with her through an interpreter, we learned that she had been living elsewhere, but had been brought here to live near her relatives, so they could take care of her. One by one, Zora mentioned the people important in her life:

→ Mary, 18, her younger sister, who lives nearby and takes care of her on a daily basis



- Her son Daniel, 9, who lives with her in this two-room house
- Her older brother, her “guardian”, who goes every month to distant Mulanji Mission Hospital to collect her ARV medicines
- The priest and elders from her Catholic church, who visit every month or two (or when she calls for them), sometimes bringing groceries or money, sometimes bringing the Mass
- Volunteers from the palliative care programme, who come every Wednesday with the nurse and home-based care assistant. The volunteers often return another day of the week on their own, bringing a few groceries, and staying to sweep and mop and clear the bushes around the house.

*I feel very good after their visits, because they do the jobs I can't.*

We asked Zora what she needed to make things better. She answered:

*My house leaks when it is raining. The beddings are not enough. I get very cold in the evenings, especially this month of July.*

The interview seemed to be at an end. As an afterthought, we happened to ask, “Do you have any other children besides your son Daniel?”

*Not now, she said. I had daughter named Blessing. She was 14 years old, but she died in April. She was visiting in the village and she started vomiting, and she suddenly died.*

Zora’s eyes filled with tears.

*I loved her so much.*

We all wept together for awhile. Such suffering was almost unbearable. Then we grasped Zora’s rough hands, said our farewells and went out into the afternoon sunshine.



### 7.3.5 A comfortable death at home

The account of an home-based care volunteer:

*One chilly morning in Blantyre, I was waiting for a ride with Rose, a trained HBC assistant. Together we had seen several patients, some very ill, some not likely to live long. When I asked Rose about deaths in this community, how they happened, and how the palliative care team could help, she told this story.*

*Our patient Anna had a painful cancer, Kaposi's sarcoma, in front of her right ear. At Queen Elizabeth Hospital, they had told her that her disease was deadly and she would never get better. Anna understood that, but her family was in denial. Also*

*people from her church were trying to encourage her by praying that she would be healed.*

*One Monday we visited her and gave her the regular supply of morphine. Then on Wednesday, Anna used her cell phone to “flash” me (signal me she needed to talk). When I called back, she told me she was vomiting. I called the nurse and together we*



*went to Anna’s house and gave her medicine to stop the vomiting. We advised her to eat only small amounts of food at a time, to prevent more vomiting. We went again that Friday. Anna’s vomiting had stopped and she was more comfortable.*

*She died on Sunday, free of pain.*

## APPENDIX 1

### PROJECT DOCUMENTS CONSULTED

#### UGANDA: Kitovu Mobile Palliative Care Service, Masaka

- Evaluation covering the period 2000-2005
- Kitovu 20 years of care. Kitovu Mobile AIDS organisation, Nov 2007
- Kitovu Mobile AIDS Organisation: Annual Report 2007
- Kitovu Mobile AIDS Organisation: Annual Report 2008
- One sheet description, designed by the Palliative Care Initiative, 2008
- Kitovu Mobile Palliative Care Programme; 5 month report, Oct 2008 – Feb 2009
- Kitovu Mobile Homecare Programme: Palliative care services (information leaflet)
- Kitovu AIDS Organisation: The Diana, Princess of Wales Memorial Fund Proposal 2010 – 2012

#### KENYA: Maua Hospital Community Based Palliative Care Programme, Meru

- Maua Project Proposal, August 2002
- Maua Annual Report, 2005
- Maua update and the way forward, June 2006
- Maua Annual Report, 2006
- Maua Annual Report, 2007
- One sheet description, produced by the Palliative Care Initiative, 2008
- Maua Report, April 2009

#### MALAWI: Home Based Palliative Care Charitable Trust, Blantyre

- Bangwe Project Report, January 2004
- Bangwe Project Report, January 2005
- Limbe Programme Report, December 2006

- Report of training for Home-Based Care Assistants, January 2007
- Limbe Programme Report, June 2007
- Visit to Malawi by London based Palliative Care Initiative staff, October 2007
- Limbe Programme Report, December 2007
- Limbe Programme Report, June 2008
- One sheet description, produced by the Palliative Care Initiative, 2008
- Malawi teaching palliative care Joint Cross Party Group Meeting, Paper 6, 8 October 2008. [www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

## APPENDIX 2

### TABLE OF PEOPLE INTERVIEWED

	UGANDA	KENYA	MALAWI	TOTAL
	Kitovu Mobile	Maua Hospital	Bangwe and Limbe areas	
<b>Date of evaluation</b>	20–21 March and 21–24 June 2009	19–24 July 2009	26–31 July 2009	-
<b>Evaluators</b>	S Murray and S Leng	S Murray and J Brown	J Brown and E Grant	-
<b>Patients</b>	8 patients at home	6 patients at home (4 clinical encounters observed) 3 patients in hospital	7 patients at home (4 clinical encounters observed) 9 patients in 2 focus groups	<b>33</b>
<b>Current home caregivers</b>	7 (carer, mother, wife, carer, sister, daughter, wife)	5 (son, son, husband and daughter, sister-in-law)	5 (daughter, wife, mother, sister, wife)	<b>17</b>
<b>Bereaved caregivers</b>	n/a	5 seen at home (wife, wife, daughter, wife, wife, niece and son) 2 in hospital (son and daughter)	1 (mother)	<b>10</b>
<b>Volunteer (community) caregivers</b>	3 volunteers in individual interviews	4 volunteers in individual interviews 8 volunteers in a focus group	10 volunteers in 2 focus groups	<b>25</b>
<b>Staff members of palliative care project</b>	5 individual interviews 10 staff in focus group	1 project in-charge 2 clinical officers 4 nurses	2 project in-charges 4 nurses 5 HBC Assistants 2 support staff	<b>36</b>
<b>Project overseers</b>	n/a	7 members of hospital administration	1 project director, College of Medicine	<b>8</b>
<b>Community leaders</b>	3 (district councillor, district medical officer, community leader)	17 in two focus groups	1 head of related community organisation	<b>21</b>
<b>TOTALS</b>	<b>37 people</b>	<b>64 people</b>	<b>47 people</b>	<b>150</b>

## APPENDIX 3

### REFERENCES

#### Palliative Care in Africa

Grant E, Murray SA, Grant A and Brown J, A good death in rural Africa? Listening to patients and their families talk about care needs at the end of life. *J Pall Care* 19:3159-67 (2003)

Grant E, Logie D, Masura M, Gorman D and Murray SA, Factors facilitating and challenging access and adherence to antiretroviral therapy in a township in the Zambian Copperbelt: a qualitative study. *AIDS Care* 20(10):1155-1160 (2008)

Harding R, Stewart K, Marconi K, O'Neill JF and Higginson IJ, Current HIV/AIDS end-of-life care in Sub-Saharan Africa: a survey of models, services, challenges and priorities. *BMC Public Health* 3:33 (2003)  
<http://www.biomedcentral.com/1471-2458/3/33>

Katabira E, Mubiru F and Van Praag E, Care for people living with HIV/AIDS. *World Health* No 6: 16-7 (1998)

Kikule E, A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 327(7408): 192–194 (2003)

Murray SA, Grant E, Grant A and Kendall M, Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carer. *BMJ* 326: 368 (2003)

#### Methodology for Evaluation

Anker M, Epidemiological and statistical methods for rapid health assessment introduction. *World Health Statistics Quarterly* 44:94-97 (1991)

Anker M, Guidotti RJ, Orzeszyna S, Sapirie SA and Thuriaux MC, Rapid evaluation methods (REM) of health services performance: methodological observations. *Bull World Health Organ*.71(1):15-21(1993)  
[http://whqlibdoc.who.int/bulletin/1993/Vol71-No1/bulletin\\_1993\\_71\(1\)\\_15-21.pdf](http://whqlibdoc.who.int/bulletin/1993/Vol71-No1/bulletin_1993_71(1)_15-21.pdf)

Brown C, Lloyd S and Murray SA, Using consecutive Rapid Participatory Appraisal studies to assess, facilitate and evaluate health and social change in community settings. *BMC Public Health* 6:68 (2006)

Kendall M and Murray SA, Tales of the Unexpected: Patients' poetic accounts of the journey to a diagnosis of lung cancer: A prospective serial qualitative interview study. *Qualitative Inquiry* 11, 5, 733-751 (2005),

- McPake B, Blaauw D and Sheaff R. Recognising patterns: health systems research beyond controlled trials. HSD working paper, HSD/WP/10/06 (2006)  
[http://www.hsd.lshtm.ac.uk/publications/hsd\\_working\\_papers/recognising\\_patterns\\_web\\_version.pdf](http://www.hsd.lshtm.ac.uk/publications/hsd_working_papers/recognising_patterns_web_version.pdf)
- Murray SA, J Tapson, L Turnbull, J McCallum and A Little, Listening to local voices: adapting rapid appraisal to assess health and social needs in general practice. *BMJ* 308:698-700 (1994)  
<http://www.bmj.com/cgi/content/full/308/6930/698>
- Murray SA, Experiences with "rapid appraisal" in primary care: involving the public in assessing health needs, orientating staff, and educating medical students. *BMJ* 318;440-444 (1999)  
<http://www.bmj.com/cgi/content/full/318/7181/440>