



EVALUATION OF KITOVU MOBILE PALLIATIVE CARE SERVICE, MASAKA, UGANDA

IMPACT ON INDIVIDUALS, THEIR FAMILIES AND THE LOCAL COMMUNITY



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.

The evaluation of the Kitovu Mobile Palliative Care Service, Masaka, Uganda was conducted alongside evaluations of two other projects funded by The Diana, Princess of Wales Memorial Fund: The Maua Hospital Community Based Palliative Care Programme, Kenya and The Malawi Home Based Palliative Care Charitable Trust. Reports from these evaluations and a summary report covering all three evaluations are also available.

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1. EXECUTIVE SUMMARY

1.1 Aims and methods

We aimed to assess the impact of this project on the lives of patients, their families and their communities. A multidisciplinary team spent a week using rapid evaluation field techniques gaining data from three sources – direct observations of clinical care and the area, individual and group interviews, and document reviews. The team also gathered many moving first-person stories and photographs from patients, their caregivers, and staff.

1.2 Local context

Kitovu Mobile Palliative Care Service is based in Masaka town and covers four districts (Masaka, Sembabule, Rakai and Lyantonde), a population of 1.5 million. Masaka is on the shores of Lake Victoria and is reached by the main southwest highway from the capital Kampala, a journey of around two hours. 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. However, the palliative care service takes referrals from a wide variety of sources and accepts patients with palliative care needs regardless of diagnosis. Masaka town and its surrounding districts was one of the areas hardest hit by the HIV and AIDS pandemic, and the fishing communities on the shores of Lake Victoria are still some of the most at risk in Uganda. Poverty is endemic with individuals and communities facing daily challenges to meet their basic needs. The prevalence of HIV and AIDS has now decreased to a national figure of 8.2%. The majority of palliative care patients now have non-HIV related cancers, although a significant number still have HIV- and AIDS-related conditions. The Kitovu Mobile palliative care team visits patients and their families in their homes and liaises closely with the wider community home-based programme to ensure ongoing availability to medications including oral morphine.



1.3 The impact of palliative activities on patients

Patients spoke of being treated with courtesy, dignity and respect. Previously, many patients had remained at home, too weak to walk to a health centre, while their carers struggled to manage severe pain, vomiting, and diarrhoea. Some told of uselessly spending much money on lengthy trips and treatments with limited or no

benefit, before they met the palliative care team. Patients said that physical suffering was greatly relieved as morphine was available. Patients felt helped to identify problems and make decisions about treatment. Patients received continuity of care and did not feel abandoned. Patients received and valued spiritual and emotional support and spoke of the sense of hope and reassurance given by the team.



1.4 The impact of activities on family carers

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 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.

1.5 The impact of activities on local communities

While members of the communities have been well sensitised to and educated about HIV and AIDS in recent years, they seem not to be as knowledgeable about cancer or palliative care services. Volunteers are an accepted part of end-of-life care in the community. Communities are inspired to talk about and accept palliative care and to help identify those in need.

1.6 Integration of programme with other health services

There is evidence of integration at local, regional and national levels. We talked with a doctor who was responsible for signing all morphine procurement processes in the district and was therefore well aware of the palliative care services available. He said:



They are the only ones getting morphine in my district. 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 with 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. (Dr SM)

1.7 Staff members from the programme are dedicated to their work

Staff spend long hours each week planning and doing home visits in areas far from their base. There is a strong team spirit and sense of common vision with support at professional and personal levels. Colleagues, families and patients spoke movingly of their appreciation for the care offered. Despite this, the work can be demanding and draining and significant stress was expressed.

1.8 Analysis and discussion

A well-balanced and holistic programme, Kitovu Mobile Palliative Care Service offers care with excellent clinical skills, demonstrable psychological support, sensitive spiritual support within the community and social contact to the patient and family. The service faces an ongoing struggle to offer holistic care to patients and families who lack even the most basic needs. This brings up the question of the role of palliative care services and emphasises the need for them to work closely with other agencies and the community to support schooling, housing, food and other needs. Identifying patients and accepting referrals works well because of local relationships and knowledge, although the difficulty of ensuring that those who are most in need reach the service still remains. A real strength of the Kitovu Palliative Care Service is in its community engagement, especially through the church and parish-based links. This in turn leads to active volunteers, who then increase the community involvement. The small palliative care team is cohesive, with a strong sense of shared vision and values and a commitment to training and quality. It is well integrated into local and national frameworks and committed to supporting increased coverage and scaling up. Patients and families are clearly the focus of care.

1.9 Challenges to the programme

Staff were very aware of both challenges and opportunities and had a forward-looking perspective. Cultural resistance remains a problem, particularly regarding 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 a geographical area.



Few other services are developing, but there is still a need to continue to disseminate knowledge and skills to the wider medical community. Volunteers remain an important backbone of the palliative care service, but the excellent training and retention levels need continued support, as does ongoing community engagement.

2. AIMS AND OBJECTIVES

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

Objectives:

- To put the Palliative Care Initiative funded intervention in context by summarising its 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 intervention in the lives of those living with life-limiting conditions, their families and their communities in Uganda.

3. METHODS OF EVALUATION

We used rapid evaluation methodology (REM) in order to gain a range of qualitative and quantitative information on the impact of the programme on the lives of patients, families and communities (Anker *et al.*, 1991). 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 silos, 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

Consulted documents providing background local and national context are shown in Appendix 1. We noted especially articles relating to the country under 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 all of them 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), assisted by translators where feasible to avoid reporter bias. Appendix 2 shows details of the people interviewed.

3.3 Direct observations by the researchers of the general environment and the clinical care provided

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

We deployed a field team (Dr Leng, Prof Murray, a data collector Ms Julie Limoges, a photographer and a local translator). The team carried out data collection over one week in Spring 2009.

This site report was drafted within a few days of leaving the field. It included key statistics, observations, lists of people interviewed, key findings and direct quotations. During the site visit, we also collected case studies of five individual patients and their families (Section 7).

4. FINDINGS

4.1 Context and description of the palliative care programme activities funded

4.1.1 History and context

In the 1980s, the HIV and AIDS pandemic swept Uganda, and communities were devastated and struggling 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 her religious order, 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.

4.1.2 Overview of the programme

The Kitovu Mobile Palliative Care Service 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 (2,899 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 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, if required, referred 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 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 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.

These vast distances mean the team averages a total of 1,500 km of travel per month along rough roads. 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.

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 HIV and AIDS programme. Medications are provided free of cost to patients and families.

Indeed, the palliative care team seems 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 the Palliative Care Association of Uganda (PCAU). 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.

Though the Kitovu Mobile Palliative Care Service does not have a clear research agenda, significant contributions have been made, including increasing referrals of patients with Kaposi's sarcoma, and collaborating with a Medical Research Council research study to make chemotherapy available in Kitovu Hospital.

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

4.1.3 Beneficiaries

In 2008, a total of 321 patients were registered with 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 the 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 team has taken part in local media events with radio coverage and visiting dignitaries.

4.2 Impact of programme on patients

Summary: Patients received whole person care in a dignified way. Physical suffering was greatly relieved as morphine was available. Patients felt helped to identify problems and make decisions about treatment. Patients received continuity of care and felt “not abandoned”. Patients received and valued spiritual and emotional support and spoke of the sense of hope and reassurance given by the team.

4.2.1 Patients received whole person care in a dignified way

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

This care definitely improves the quality of life you are living before you go and meet your maker. Even if you are going to die tomorrow, you can die a happy man or a happy woman without a lot of pain. For me that is the most important benefit. People should not suffer. That's why we have those painkillers, and of course the

counselling that they have during the care. The counselling helps you die not a miserable woman. (SM)

4.2.2 Physical suffering was greatly relieved

Access to analgesia and thus relief of suffering is significant and reported as an immediate benefit.

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)

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)

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

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

4.2.3 Patients felt helped to identify problems and make decisions

Patients referred to Kitovu Mobile Palliative Care Service may need immediate help in stopping futile and expensive searches for treatments, and they may need support in making decisions. All those involved in the evaluation spoke of the money spent on treatments with limited or no benefit, and of the tremendous and ongoing family burden that represented. Social support is essential when financial pressures are so significant.

The team helps in many practical ways from facilitating diagnosis and treatment. (Leah)

After Leah was told she had breast cancer, Kitovu Mobile palliative care team brought her to Mulago Hospital in Kampala for three weeks of radiotherapy. They provided her with a place to stay and took her to the international hospital (IHK) where she was given a course of chemotherapy. This involved visits to Kampala every two weeks and the transport costs were met by Kitovu Mobile Palliative Care Service.



When John needed an amputation of his leg because of an osteosarcoma which was now fungating, the team supported him in this decision and then helped to communicate and explain it to his uncle. During this time he began to despair:

"I wanted to keep my mind occupied, but I was not able to... I had lost hope of ever walking again." He missed school and was unable to distract himself from his pain. 'I was dying of pain.' After analgesia and the amputation, he says "I am comfortable now because the pain is less, and I can move." (John)

4.2.4 Patients received continuity of care and did not feel abandoned

Holistic assessment was given with clear explanation of plans for treatment and reassurance, which is backed up in practice, that patients would not be abandoned, even if the problems were difficult to solve:

They did give me some medicine for the saliva. Unfortunately it has not worked, but we have not stopped. We have increased the dosage each time. The other thing she did was give me something else, some drops. (Benson, patient)



For some patients help is more long term. Jess, now four years after her amputation, is pain free, no longer requiring morphine and able to dig her garden, showing she is now 'normal'.

4.2.5 Patients received and valued spiritual and emotional support

Patients and carers spoke of the sense of hope and reassurance given by the team:

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

Before I had no hope, but now I have hope because I am getting treatment and I am getting help. (Edward, patient)

Before I met them, I thought I was going to die. I had so little hope that I made a will. Now I am not worried about the future because I don't feel pain. (Leah)

When they come they examine her and find her problems, they give her medicine, soap, corn flour and sugar. The most important role that Kitovu Mobile has played has been giving her medicine and food. There is a big difference in the care that Kitovu Mobile gave her. (Leah's family carer)

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

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

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)

This kind of caring forms deep bonds with patients and is key to spiritual support, as well as giving a sense of value and dignity. Staff told of one old man who said he thought he would get little help from young nurses. After they listened to his problems however, he felt very differently, and then he said, “*You people are my daughters.*”

During another visit, the mother of patient Jess said about the palliative care nurse:

Resti was there for her, and even if Jess could just see her, she would smile.

On many occasions the compassion and counselling skills of the team members were displayed. We observed Resti talking with a carer who wanted advice regarding marriage. She listened skilfully and supported a young woman who was devastated by being abandoned by her husband, unable to see her children and told by the community that she was of no use as she was going to die.

4.3 Impact of programme on carers and families

Summary: Carers felt greatly helped to care for their loved one. They greatly appreciated receiving social, financial and practical support and guidance, 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.

4.3.1 Carers felt greatly helped to care for their loved ones

Families spoke of the difference the palliative care team has made and on occasion contrasted this with their experience of other services. It was clear to the observers that there was a trusting, supportive relationship which continued to make a real difference for families and carers. Comments are noted under the specific headings below.

4.3.2 Carers received social, financial and practical support

The financial pressures of caring for very ill family members are significant. Kitovu Mobile Palliative Care Service has a role in facilitating access to appropriate treatment and thus saving unnecessary expense.

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, chickens. (Doreen, talking of her futile and expensive search for treatment for her nephew)



He wasted so much money, around 600,000 USh (GBP 170), on traditional healers. (Wife of Edmond)

We try to teach the reality, but people expect cure and treatment. They expect miracles. (Staff)

If we were not there, the people would be very poor... Now we can educate people, and they stop selling their land, because they know not to expect a cure for their loved ones. (Staff)

By the time they 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 usual charge for patients to attend the community centres is 500 USh (GB 15p), but palliative care patients are given care without charge, and morphine is provided by the government. Thus often the needs of patients' children are dominant in their minds, and help for them is a priority.

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)



Medicines alone would be of limited help when patients have so many varied needs. As one programme report says, 'Medicine is of little value when patients are hungry.' The attempt to provide holistic care seems to distinguish Kitovu Mobile Palliative Care Service, and some contrast it with other services.

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)

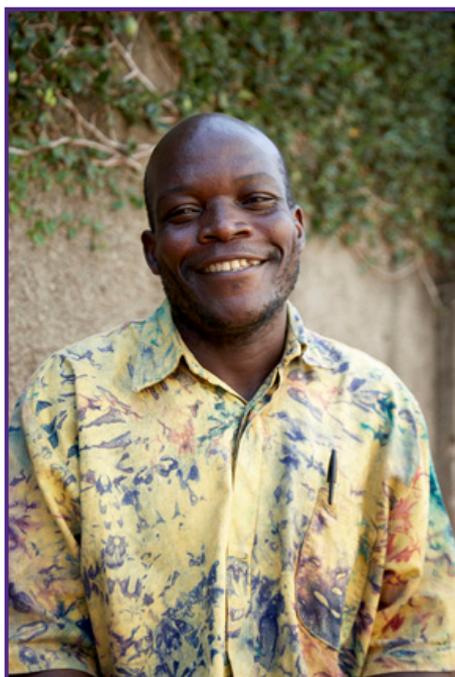
There is a big difference between now and before Kitovu – they made a bigger difference than the UC people. He has gained weight, he can eat food and he can move around. (Wife of Edward)

4.3.3 Carers valued good communication and counselling support

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 may result in poor communication and misunderstandings. All these factors demand skilled and careful counselling.



One patient did not want to talk about 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 palliative care 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 received counselling from another service.



Family carers appreciate having someone visit at the home, with time to talk, and the sense of caring:

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

One carer talked of her need for people to pray, and even the support from this evaluation team. We were then able to pray with this husband and wife. Such support may be crucial at the beginning, but it also continues into bereavement. When Chris's 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 palliative care team were crucial for him. At the time of our visit, his partner had come back, and she expressed her wish to get married, so there ensued a discussion of the practical action to facilitate this.

4.4 Impact of programme on the community

Summary: Communities are now aware of the concept of palliative care. Volunteers are an accepted part of end-of-life care in the community. Communities are inspired to talk about and accept palliative care.

4.4.1 Communities are now aware of concept of palliative care

The Kitovu Mobile Palliative Care Service has not only focused on care for individual patients and families but also on wider community empowerment.

Martin, a community volunteer, spoke of his efforts over two years to encourage Richard (patient) to agree to an HIV test and now supports him at home. He proudly spoke of the information he has shared with family and friends and ascribes to his training and advocacy the healthy choices his own daughters have made.

The roles of volunteers are varied, and they have access to a variety of training. This includes palliative care, family planning, STDs, counselling, advocacy, making wills, use of traditional herbal medicines and self help.

GB talked of his varied roles as a volunteer, describing how he visits patients, counsels them, gives health education talks, and refers those who need it to come for care. He does continuous counselling.



Volunteers also find bedridden patients who cannot help themselves, then educate the caregivers on how to care for the patients. Previously, when someone fell sick, both men and women said they wanted a female caregiver. Sometimes families would take girls out of school to take care of patients. Now, though, they educate patients that caregivers can be male or female. They give holistic 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)

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

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 the 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 the 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 spoke 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 had been sensitised by Kitovu Mobile and they then moved on to do sensitisation themselves. The community now identify patients, alert the

volunteer, who then alert Kitovu Mobile. They then give painkillers, financial support, help keep children in school, give medical things such as gloves and plastic sheeting. They offer counselling. Oh, they do offer spiritual support. Once a palliative care patient is identified, the team come immediately.

Community volunteers not only helped People Living with HIV and AIDS (PLHA) but also other people in the community, because they are seen as 'community consultants'. (From the 2008 Annual Report.)

The volunteers 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.

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

Many team members are also touched by palliative care needs in their own families: It touches my own family, I have spoken about my uncle, I think he probably has cancer, and Dr Carla said they will see him. (Volunteer)

4.4.3 Communities are inspired to talk about and accept palliative care

One patient spoke of giving testimony at her church about God's goodness to her and the good work of the palliative care team.

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 volunteer spoke movingly about the credibility and respect this 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)

Through helping I get what I want, so God blesses me with other things.... The confidence the patients have in me gives me courage. (Volunteer)

Volunteers need some motivation, maybe help with transport, but they should not get a salary. (Staff)

4.5 Integration of palliative care programme with other health and social services

Summary: Although a small staff team, the palliative care service is well integrated into local and national services and participates in national strategic planning. This includes defining minimum data sets and quality standards.

There is evidence of integration at local, regional and national levels, as outlined above in the overview of activities (4.1).

Locally there is close liaison with Kitovu Hospital, but also training sessions and liaison with other HIV and AIDS groups and medical colleagues in the Uganda Medical Association and Masaka Regional Referral Hospital. The clinical placements are open to students on the HAU clinical specialist course, as well as welcoming other visitors.

The lead of the palliative care team is an executive member of the Palliative Care Association of Uganda (PCAU) and is actively involved in planning national training, service audit and conferences. She is also a member of the country lead team which is chaired by the Ministry of Health and offers a strategic forum for palliative care planning and development.



We talked with a doctor in one district who is well aware of the palliative services available, as all morphine procurement processes need his signature. He said:

Kitovu Mobile is the one that is offering such care in the region. In order to scale up the services they did some training for other health workers in the region. You know Kitovu Mobile get their drugs from me. They are the only ones getting morphine in my district. 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 with 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)

4.6 Impact on palliative care team, including volunteers

Summary: The staff and volunteers found their work stressful: “it hurts to lose patients.” However they found such work rewarding and resilience is fostered by having effective medication available to give patients.

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

Despite this close and supportive environment, it was clear this kind of caring comes with significant stress. Distances covered 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 skills in different ways.

Staff spoke movingly of ‘receiving the pain’ from their patients:

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. (Staff member at focus group)

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)

Team members talked about the pain of women rejected or mistreated by men when they are ill with cancer of the cervix. Resti told of a woman whom they had to advise how to take oral morphine prior to sex with her husband; it 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.

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

The compassionate and skilled care observed and reported has significant impact on staff. There was clear sharing of 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.



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)

Resilience is also built by having something important and concrete to offer:

The work is difficult, but it used to be so much harder before ARVs, and the patients used to die and we felt as if there's nothing we could do. Because we have morphine we can give help. (Dr Carla)

4.6.3 Volunteers need ongoing support to aid retention

Motivation and financial support for volunteers is always a challenge. The Kitovu Mobile Palliative Care Service addresses this by providing bicycles and training but volunteers do not get a direct financial reward. Volunteers need to feel part of the team and valued for their contribution. When asked if she felt appreciated for her work one volunteer broke into a wide smile and said “*Yes, very much so.*” Another said “*Yes I think so*”, then broke into English with a huge smile, and said “*They thank me.*”

5. ANALYSIS AND DISCUSSION

5.1 Palliative care in poverty

Palliative care in resource-constrained environments is challenging. Where basic needs such as food, shelter, education and school fees, opportunities for employment are not met then holistic palliative care must address these. It is not enough to offer a clinical service when patients may be forced to sell any medications to fund basic needs. The Kitovu Mobile Palliative Care Service is highly attuned to these issues and seeks to meet basic needs in a number of ways. They give direct packages of food such as sugar, soap and flour. They have a school fees programme and links with the micro-enterprise and skills programmes run by the wider community home-based care service and other NGOs. They also seek via the volunteers to explore ways for the family and wider community to offer support; perhaps something as simple as ensuring good communication, so that prognosis needs and expectations are clearer. Despite this, need continues to exceed resources, and this ever present challenge makes it difficult to prioritise. It also makes it difficult to find a balance between dependency and empowerment. However, this can be achieved. For example, we met one patient, who was struggling with an open cancer wound. Unable to work, she was facing financial ruin and she was avoided by her family and neighbours who said she was unclean. However, with support from the Kitovu Mobile Palliative Care Service, she accessed the long treatment she needed in Kampala, her wound healed, and she now runs a small catering business supporting herself and her children.

5.2 Patient identification, management and referral systems

The Kitovu Mobile Palliative Care Service is an impressive grassroots service. It shows great strengths in its relationship to the wider community home-based care programme. This kind of seamless referral process has many advantages in terms of sharing skills and ensuring patients are the focus of care. Informal and formal referrals within this system appear to work very well. A bigger challenge is referrals from the wider medical community. Many patients present very late to medical services and then there is then a further delay in reaching the palliative care team. This is despite training and liaison within the regional Masaka Hospital and other local institutions. Referrals directly from the community appear to work more smoothly, largely as a result of the active community sensitisation work and advocacy. The type of patients being referred has steadily changed and this is a tribute to the palliative care team as they could have kept to the patient group of the overall HIV and AIDS programme.

However, a strength is that patients in the overall programme have access to core palliative care and are only referred when more specialist help is needed. Cancer diagnosis unrelated to HIV and AIDS now represents the majority of referrals and the spread of diagnoses is very similar to known prevalence rates in Uganda. This would suggest a balance in referral sources. Although there are not many children registered with Kitovu Mobile Palliative Care Service, the numbers registered are consistent with childhood cancer incidence rates globally. Networking with other districts is good particularly through the Hospice Africa Uganda programmes, although there is always the potential for patients to 'get lost' in the system as they travel between healthcare and community settings. There is no formal discharge policy as most of the patients are cared for until their death. This informal system works well, although more formal referral guidelines may be helpful.

5.3 Programme coherency and integration

There are few services offering palliative care and care for cancer patients, so there is little duplication. Potential duplication for HIV and AIDS patients receiving ART is more challenging.

5.4 Project engagement with the community

Community engagement is one of the Kitovu Mobile Palliative Care Service's key strengths. Close links with community leaders, especially churches, has been a real success. Local churches have allowed time within church services or just afterwards to talk about palliative care. Pastors have a lot of influence in this community. Churches have also been a base for recruitment of volunteers and in turn these volunteers are great local advocates. Media access has also been an area of success with good use of local radio and print media. Perhaps more challenging areas are the political and medical communities. There have been several good initiatives here, but there remains work to be done.

5.5 Volunteer engagement

It was very clear from the volunteers interviewed that they felt engaged, supported, appreciated and integrated into the team. They particularly mentioned the training opportunities in the wider programme which include counselling, traditional medicines, behaviour change, training of trainers, training of caregivers, making a will, gender awareness, ARVs as well as core palliative care. They spoke movingly about their motivation and this was often linked to their faith and sense of God's blessing and the desire to serve those in need. Volunteers also seemed to gain recognition and standing in their communities and feel able to communicate wider healthcare messages. Although financial motivation was mentioned and would be welcomed, it was not the key motivating factor. Retention is strong and much of this is due to common vision and values. The small number of clinical staff also means a 'family' atmosphere with celebration of important events and sharing of sorrows.

5.6 Communication and the use of mobile phones

Given the significant distances involved, managing communication has been a real challenge. As seen across sub-Saharan Africa, the widespread availability and use of mobile phones is a real help. The team can offer follow-up and plan visits, as well as direct families to where they need to go to collect medicines. Even if the family do not have their own mobile phones, there may be a shared phone in the village.

6. CHALLENGES AND RECOMMENDATIONS

Summary: These included cultural resistance, funding constraints, volunteer support and retention, coverage and scaling up.

6.1 Cultural resistance

Cultural issues in healthcare remain a major challenge. Many, many patients spent time and money accessing traditional remedies and there are many herbalists in the area. This was identified by one community leader as a major issue:

Traditional beliefs... People do not easily accept medical treatment, and this has yet to change.

Experience of healthcare becomes skewed as patients wait so long before seeking treatment that inevitably there is little that can be done to treat or cure. This is true across Uganda where most cancers present at a late stage when treatment options are limited.

Stigma and misunderstanding are commonplace, and may be even more prevalent in relation to cancer. One woman with cancer of the cervix told us it would be easier if she just had AIDS. Women's empowerment remains a challenge, particularly within marriage. It is distressing to the staff to see so many women faced with illnesses, such as cancer of the cervix, turned away from their homes and children. They become 'useless' as women and are seldom able to challenge these views.

6.2 Funding constraints

Despite the significant support offered by the 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)

Help with school fees was mentioned the most, 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.

6.3 Volunteer recognition

Sensitisation of the community has been a key success, but there is still a need to continue with advocacy and education. The team identified the need to continue to inform the community about what is meant by palliative care and the availability of the services offered by Kitovu Mobile Palliative Care Service.

One 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.

The district councillor we interviewed was very enthusiastic about what had been achieved thus far, but saw a continuing need and identified community leaders as key in this advocacy:

They should go to local gatherings, such as church and other religious gatherings and political meetings. Also get the attention of the leaders – use local leaders at the LCI (local council) level and use them to get attention of leaders at district levels. Other NGOs have used drama well, and that would be a good way to move.

This 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 palliative care service such as Kitovu, the district councillor said:

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

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

There is a woman who spread rumours and went around telling people that they should not buy food for one patient, because she had a bad smelling wound. This woman was a neighbour, but Sarah told the authorities about the woman and then she went away and has not come back. (Leah)

6.4 Coverage, training and scaling up

Distances covered by the palliative care team remain a big challenge, as well as the reduction in routine centre visits by the overall HIV and AIDS programme (from twice a month to once). Calendars have been given to patients to help them remember when a centre will be visited.

Another challenge is delays in referrals. Patients are sometimes told to come to Kitovu, but if the team is not notified, they are unable to facilitate early assessment. Dissemination of information and building further relationships with key referrers should remain a priority.

Improving access to palliative care by training other colleagues and supporting government sector provision remains a big challenge. Kitovu Mobile Palliative Care Service attempts close liaison with Masaka Hospital, especially since it offers palliative care and sometimes has oral morphine. However without a home care programme, Masaka patients may be lost to follow-up if referrals are not made. Pain assessment and management is often not seen as priority by healthcare staff outside Kitovu Palliative Care Service, said the District Medical Officer:

The Kitovu 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.

Continued training was requested by the volunteers, even though there seems to be significant support and training available. Areas such as advanced counselling were identified and also the need for more in-depth training on areas already covered. One volunteer also asked that the results of this evaluation be disseminated.

7. ILLUSTRATED PATIENT AND CARER STORIES

7.1 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.

7.2 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.

7.3 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 went to a traditional healer again.



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.

7.4 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'.

7.5 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'.

APPENDIX 1

PROJECT DOCUMENTS CONSULTED

- 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

APPENDIX 2

TABLE OF PEOPLE INTERVIEWED

People seen and interviewed	Around Kitovu
Patients and carers	8 patients at home
Current home caregivers	7 home caregivers
Bereaved caregivers	n/a
Community volunteers	3 volunteers in individual interviews
Staff	5 individual interviews; 10 staff in focus group
Community leaders	3 (district councillor, district medical officer, community leader)
Project overseers	n/a
Total	37

APPENDIX 3

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