

EVALUATION OF THE MAUA HOSPITAL COMMUNITY
BASED PALLIATIVE CARE PROGRAMME, KENYA

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 Maua Hospital Community Based Palliative Care Programme, Kenya was conducted alongside evaluations of two other projects funded by The Diana, Princess of Wales Memorial Fund: The Kitovu Mobile Palliative Care Service, Masaka, Uganda 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 – direct observations, 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

Maua Methodist Hospital 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 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 vital to help cancer patients especially, as well as people living and dying from HIV/AIDS.



1.3 The impact of palliative activities on patients

We found that patients received whole person care and that they 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 even cultural such as dealing with traditional healers and stigma about cancer. Patients received continuity of care through regular mobile clinics and mobile phones. They valued spiritual and emotional support with staff taking time to listen and affirming their common belief in a god who is in control and will care for them.



1.4 The impact of activities on family carers

Carers felt greatly helped in providing personal care to make their loved one comfortable at home during their final days. Practical advice in feeding and bathing, administering morphine, terminal care and preparing the body for burial resulted in many good deaths at home. Carers received social,

financial and practical support sometimes by volunteers visiting and cooking for them. Carers valued the real concern (*kwolia*) shown by staff to themselves and the patients, and helpful counselling.

1.5 The impact of activities on local communities

The community was sensitised with health volunteers and health committee members knowledgeable about morphine, but such awareness did not reach distant rural areas where we interviewed teachers. AIDS was much more known about than cancer which to many meant death that day. Some community leaders were inspired to lead seminars. A number of community volunteers were very dedicated to their work, while some were less active.

1.6 Integration of programme with other health services

Being based in a community health department in a large well respected church hospital meant that the programme was well integrated in primary care and secondary care, and with the local church and schools. Many of the staff practising palliative care undertook other duties and as part of their role taught and updated general community and hospital staff about palliative care. Co-operation



with other neighbouring hospitals such as Meru District and Chogoria was good, with an effective referral system in place helped by the district health team.

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

Staff spend long hours doing home visits or holding mobile clinics in areas far from their base. All staff were appreciated by colleagues, volunteers, patients and families. Such work was stressful and demanding – *“It hurts to lose a patient.”* However, it was also rewarding with resilience fostered by having effective medication to really help people and through supportive debriefing. Volunteers, although their work included other aspects of care as well as palliative care, also needed support to aid retention.

1.8 Analysis and discussion

Issues included how to provide effective palliative care in the face of poverty, how best to identify beneficiaries, (which illnesses and especially when in the course of their illness), 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.

1.9 Challenges to the programme

Cultural challenges included a traditional fear that cancer would mean death “that day”, fear of dying at home being interpreted as neglecting the patient, and “prophets”/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, 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 less than 10% of cancer cases are accessing care).

2. AIMS AND OBJECTIVES

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

Objectives:

- To put the intervention into 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 Kenya.

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

We noted published materials relating to East Africa (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 or during field work.

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 4-16 participants, assisted by independent 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 within the project area, 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 the professional photographer who documented the physical and socio-economic environment of care. We deployed a field team (Dr Leng, Prof Murray, Ms Betttega and a local translator). The teams carried out data collection and analysis, working together for one week in each site between March and July 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 collected detailed case studies of five individual patients and their families (see Section 7).

4. FINDINGS

4.1 Context and description of the palliative care programme activities funded

4.1.1 History and context

Maua Methodist 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, and is well embedded in the local community. Maua is the main hospital in Igembe District of 700,000 residents, which used to part of 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 services, the ARV clinic and the palliative care team, with volunteers helping at all stages – prevention, treatment and palliation.



4.1.2 Overview of the palliative care 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.



A visit and report by Dr Albrook in 2002 stimulated the development of palliative care. 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 between 5 and 15 cancer patients are being seen by the palliative care team at any one time, either in the mobile clinics or at home. The funding from the Palliative Care Initiative (PCI) is vital to make treatment available for cancer patients.

4.1.3 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).

4.2 Impact of programme on patients

Summary: Patients received whole person care and appreciated staff being concerned for all their dimensions of need. Physical suffering was greatly relieved and many patients spontaneously said that morphine was the most important difference that the team had brought. Patients felt greatly helped to address and solve many problems whether medical or cultural, such as dealing with traditional healers and stigma about cancer. Patients received continuity of care through regular mobile clinics and mobile phones. They valued spiritual and emotional support with staff taking time to listen and affirming their common belief in a god who is in control and will care for them.

4.2.1 Patients received whole person care in a dignified way

Patients appreciated how the palliative care staff were truly concerned for them in all their dimensions of need. One patient's daughter, having mentioned the great benefit of morphine in relieving pain, also highlighted the real care and concern the team showed for her mother:

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 just "gucera" (visiting casually at their own leisure); it was "kuraita" (comfort and support). (Susanne, Rebecca's daughter)

4.2.2 Physical suffering was greatly relieved

Most patients spontaneously said that making morphine available was the most important difference that the palliative care team brought to them. One home carer, when asked which painkiller her patient used, acted out drawing up a syringe to measure the dose, then dropping it in the patient's mouth.



Others had these comments:

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. (Sabina, widow)

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

As we drove toward the farm of Mary (aged 60), the nurse explained:

She has cancer of the face and mouth. She came to Maua three months ago, in distress and much pain, especially during the day. We have been visiting her at home every week, but up to now we have never got the pain under control.

Later that day, after our visit, the physician evaluator was able to report:

A good clinical encounter. Now no pain during the day.

Maua Hospital palliative care staff made every effort to get medicines to patients, including sometimes delivering them or dropping them off at a nearby shop (*kitovu*).

Appropriate drugs were available for constipation and nausea, and in one case the palliative care nurse, Faith, had catheterised and provided bowel care (as a district nurse might for a terminal illness in the UK). (See the story “A good death in rural Kenya”.)

In a number of cases, the team assessed when blood transfusions were needed (in the relatively common situation of bleeding gastric cancer with no surgical intervention. See the story “The grand matriarch”).

4.2.3 Patients felt helped to identify problems and make decisions

The palliative care staff helped patients address and solve many problems when they needed information or advice about medical or even cultural issues, including inappropriate treatments. Staff were good at trying to help the patient receive ‘decent care’, responding to their ideas and commenting and advising as appropriate.



4.2.4 Patients received continuity of care and did not feel abandoned



The team provide continuity of care by holding regular mobile clinics in sites far from the hospital, visiting home-bound patients, and 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. In summary, the team offer information and practical support, up to the moment of death and beyond:



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

4.2.5 Patients received and valued spiritual and emotional support

The staff provided spiritual support by valuing the patient as a person, taking time with them, and affirming their belief in a god who is in control and will care for them. Most patients, when asked about the future, vocalised that God would care for them, despite their difficult situations. They also found strength in the people around them:

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

Now I am in the Warigiro (Hope) Group of widows – we have over 400 members. (Sabina)

4.3 Impact of programme on carers and families

Summary: Carers felt greatly helped to provide personal care to make their loved one comfortable at home during their final days. Practical advice in terminal care and caring for the body resulted in many good deaths at home. Carers received social, financial and practical support sometimes by volunteers visiting and cooking for them. Carers valued the real concern (*kwolia*) shown by staff to themselves and the patients.

4.3.1 Carers felt greatly helped to care for their loved one

The palliative care team show families many ways to make their patients comfortable at home during their final months and days. They help 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 explain that this should be expected and allowed to happen, and that the patient will eventually simply stop breathing.

The period of death and burial is often extremely stressful for poor rural Kenyan families. They must notify the local chief and numerous relatives, many of them living in distant cities. Then, as they wait several days for everyone to arrive, they must arrange to preserve the body. The palliative care team, when appropriate, explain how to lay out and preserve the body in the home. (Put two sacks



The palliative care team, when appropriate, explain 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. Then 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. The palliative care team often attend the burials.

The palliative care team has helped some people realise that not taking a patient to the hospital does not indicate neglect. Nevertheless, some still fear death in the community, so not all families agree that death at home is best. Sometimes a plan for the patient to die at home may be thwarted by an acute, unexpected event, such as sudden vomiting.

Mary's family knew she was dying, but they spent over KShs 50,000 elsewhere for care and promises. Finally they brought her to Maua Hospital, and she died peacefully yesterday. (Jane, cancer nurse)

Here are two narratives about the last day in the life of Jacob, a man living with AIDS and cancer of the jaw: They illustrate that occasionally the family find it unacceptable for the actual death to occur at home, although they had cared for him at home until then.

As told by Jacob's widow, Joyce:

My late husband had HIV and cancer of the jaw. He took ARV medicines until he was unable to swallow. On the last day, we phoned the Maua people, and they came with the vehicle and took him to hospital. (Why to hospital?) It was our last resort – what else would you do? (Was your husband willing to go?) Yes, he was willing. I followed the next morning, and when I arrived, I learned he had already died.

As told by palliative care nurse, Faith:

Our doctor decided to stop Jacob's ARVs, because they were no longer adding to his quality of life. He was taking liquid morphine, and we visited him weekly. On his last day, the family called us to come, so I went to the house with the cancer nurse and the team driver. We spent about one hour at the home. The family wanted to send him to the hospital, but Jacob refused. We asked if he could be allowed to die at home. Then Jacob's brothers arrived and carried him forcefully to the vehicle. What could we do but drive him to the hospital? He died before being admitted to the ward. A few days later, the driver and I attended the burial.

4.3.2 Carers received social, financial and practical support

Most patients had great needs in these areas, and the team acknowledged this and tried to support people in these problems. The best volunteers not only connect residents with the Maua palliative care team, but they themselves visit patients, wash and cook for them, accompany them to hospital, often using their own money. One of the most active volunteers told us some of her experiences:

One lady refused to take ARVs, but with my encouragement she became strong and able to lead a normal life.... A man 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)

Extended families usually care for patients' basic needs, but in one exceptional case the team supplied a little food where the patient was starving and living in squalor. Frequently considerable family money has been spent in vain on healing by "prophets" or healers following traditional beliefs. Inherited land is sometimes sold, or children are removed from secondary school, in order to use the money for medical care.



4.3.3 Carers valued good communication and counselling support

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)

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)

The palliative care team did not destroy such hope, but affirmed the family and helped them in planning for the worst, as well as hoping for the best.

4.4 Impact of programme on the community

Summary: The community was sensitised with health volunteers and health committee members knowledgeable about morphine, but such awareness did not seem to be widespread among, for example, teachers in rural areas. AIDS was much more widely known about than cancer, which to many meant death that day. Some community leaders were inspired by palliative care to lead seminars.

4.4.1 Communities are increasingly aware of the concept of palliative care

The palliative in-charge told us he was shunned in the community when he started this work nearly 15 years ago, but that he and the palliative concept are now better accepted. He said:

Even the men are now (finally) coming around.

Indeed, we found health volunteers and several health committee members knowledgeable about morphine and other aspects of palliative care. However, such awareness did not yet seem to be widespread: two teachers and community leaders in a focus group at Machungulu mobile clinic had never heard of morphine.

Cancer still means “death that day”, one focus group member said, and others agreed. Communities have been sensitised much less to cancer than to AIDS. In one community focus group, AIDS seemed to be an old topic, but when cancer was mentioned, the participants quickly warmed to the subject and began to ask many questions. They wanted to know all about identification, treatment and prognosis. Thus, information about other illnesses can and should accompany AIDS work, especially as co-morbidities are now common.

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

A small number of volunteers are active in the community, but many challenges need to be overcome to aid their continuing work and increase their impact in the community (see Section 6.4).

4.4.3 Communities are inspired to talk about and accept palliative care

Some community leaders we met, such as one 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*”.

Palliative care is not yet well known in Kenya, but some beginnings have been made. A schoolteacher mentioned



that AIDS education, now a routine part of the school curriculum, does include some teaching on home-based care and also end-of-life issues.

Maua's 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, Hannah, 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 program. 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. (Hannah, volunteer at Muriri)

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

Summary: Being based in a community health department in a large well respected church hospital meant that the programme was well integrated in primary care and secondary care generally. 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. Co-operation was good with other neighbouring hospitals such as Meru District and Chogoria, with an effective referral system in place helped by the efficient Meru district health team.

The palliative care team at Maua Methodist Hospital has had numerous opportunities to work with local churches, as well as the national co-ordinating bodies of church-related health facilities. The team also offers practical palliative care training for health workers from other parts of Kenya.

4.6 Impact of the programme on palliative care team, including volunteers

Summary: Such work is stressful and demanding and *"it hurts to lose a patient"*. However, it is also rewarding and resilience is fostered by having effective medication to really help people and through supportive debriefing. Volunteers, although their work included aspects of care other than palliative care, also needed support to aid retention.



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

Working in palliative care is stressful and very demanding, but according to the Maua staff, it also had big rewards:

It feels good when you see a patient improve, or when he dies free of pain. (Ellykhana, nurse)

For the past year, I have been a health volunteer right here in Maua 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.
(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)



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

The work was stressful and demanding but supportive debriefing and effective painkillers helped the nurses to realise their work was effective.

4.6.3 Volunteers need ongoing support to aid retention

The Maua policy is clear that volunteers receive no pay, but the hospital does provide umbrellas, jackets, gumboots, and transport costs to meetings (but not for home visits). Key volunteers have received bicycles.

Some of the trained volunteers have palliative care needs within their own families.



Gordon, aged 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.

5. ANALYSIS AND DISCUSSION

5.1 Palliative care in poverty

Dealing with patients who also have basic needs, such as for food, brought obvious extra challenges when there was no funding available to provide these essentials. However staff sometimes managed to provide token amounts or advocate their case to local administration.

5.2 Patient identification, management and referral systems

Identifying patients who would benefit from the programme was challenging as many were far from the hospital and clinics and did not perceive a need of the service. Stigma of death and dying stopped people presenting. Referral systems around Maua however were excellent for people who presented for treatment. Some patients improved and withdrawing support was challenging in some instances when a relationship had been built up. Continued support from a volunteer, but not the nursing staff, was a good solution in some cases. In economically developed countries, futile disease-modifying treatment by medical staff, such as chemotherapy, often gets in the way of starting palliative care earlier. Delays caused by other hospital treatment are still rare in Africa, so there is great opportunity to begin appropriate palliative care, right from the time of diagnosis.

5.3 Programme coherency and integration

Duplication of services was not an important issue in Maua due to its central position in Igembe and a well-functioning district health team.

5.4 Project engagement with the community

Project engagement in the community was excellent with respect to the Methodist and other churches, many secondary and primary schools, as well as local administration. However, programme staff felt that they could engage better, especially with people with advanced illnesses other than HIV/AIDS, and in particular with those who have cancer.

5.5 Volunteer engagement

Volunteer engagement programmes had been successful although only a few very motivated individuals were very active. The poverty in the area possibly meant that people were busy growing food and had little time to volunteer.

5.6 Communication and the use of mobile phones

Mobile phones facilitated care in the community. Patients and their carers could phone or text to request a home visit, giving them greater confidence to receive terminal care at home. Patients could also seek advice from the staff at any time and contact relatives, for example to arrange a funeral, and bodies could therefore be buried with less delay than before.

6. CHALLENGES AND RECOMMENDATIONS

Summary: Cultural challenges included a traditional fear that cancer would mean death “that day”, fear of dying at home being interpreted as neglecting the patient, and “prophets”/traditional healers offering to cure cancer with traditional medicines at 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 less than 10% of cancer cases are accessing care).

6.1 Cultural resistance

Cultural challenges included a traditional fear that cancer would mean death “that day”. 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)

As in economically developed countries, younger people in Kenya 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 and paid for herbal treatment, then died. (Faith, nurse)



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, 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.)

In the rocky hills around Maua, with their widespread homesteads and villages, home visits by hospital palliative care staff are, of course, quite costly in time, salaries, and vehicle fuel and maintenance. Nevertheless, the home visits are vital to the life and wellbeing of patients and families during the most difficult times of their illnesses. Patients who are recovering are encouraged to come themselves to the palliative care team – either at the hospital or at the weekly mobile clinic site, or are visited by a volunteer. One patient had a leg amputation several months ago because of cancer and she manages fairly well on crutches. She is now being visited occasionally by a local volunteer, rather than by hospital staff, which seems appropriate.

6.2 Funding constraints

While the PCI funding is vital to Maua's palliative care activities, particularly for cancer patients (AIDS-related or not), 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 5,000), 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)



6.3 Coverage, training and scaling up

A key activity at Maua has been training more health workers in palliative care. At least some nurses from every hospital department have been trained.

At first, staff didn't want to hear any mention of morphine, because to them it meant that their patient was dying. We

trained many staff members, and now they understand and help us. (Palliative care in-charge)

In addition, Maua Hospital is trying to scale up and enrol more HIV/AIDS and cancer patients by holding weekly mobile clinics in different parts of the catchment area. Government problems, however, have caused delays.

It is possible, using international statistics, to estimate the number of people living within the Maua area who have a cancer, and to compare the number currently being reached by palliative care services:

700 = Expected cancer deaths per year in a catchment area of 700,000

50 = Cancer deaths seen per year by Maua staff

The Maua team is therefore reaching less than 10% of the people with cancer in the area. Finding cases and extending coverage are clear priorities for the coming years.

6.4 Volunteers

In the Muriri area, one health volunteer said she had been trained two years ago in a group of 30, but only two or three are still active. Volunteers at Kimathi told the same story: 30 were trained, but only two are still active. Why do so many drop out? Many volunteers are themselves quite poor, and they need to earn money for clothes, school fees, and other cash items.

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

Since these volunteers were apparently well trained in case finding and follow-up for both HIV and cancer, their high attrition rate has contributed to the rather meagre results in case finding, particularly of cancer patients. 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, Muriri volunteer)

7. ILLUSTRATED PATIENT AND CARER STORIES

7.1 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 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 up. 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.

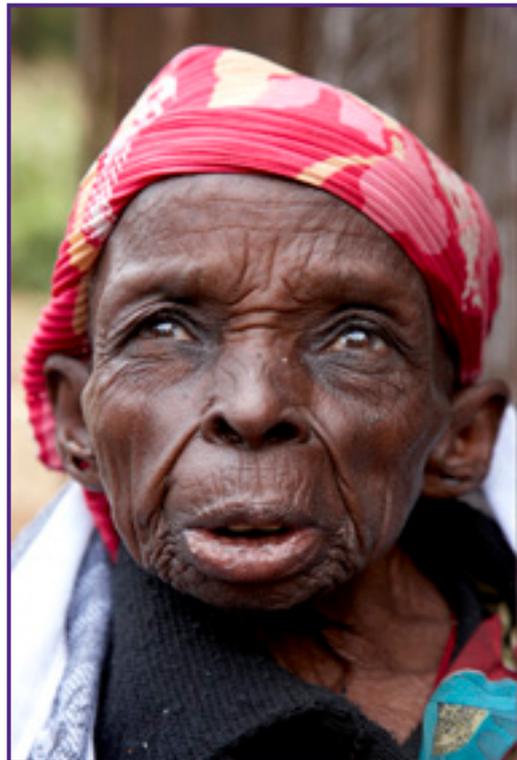
Did Henry have “a good death”? He certainly died where he wanted, at home with his family in attendance, with pain well controlled, and with little apparent psychological or spiritual distress, although terminally confused. This happened, despite urinary and faecal incontinence, and no running water 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.

7.3 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.



7.4 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 4 mls 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?



7.5 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.

APPENDIX 1

PROJECT DOCUMENTS CONSULTED

- 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

APPENDIX 2

TABLE OF PEOPLE INTERVIEWED

People seen & interviewed	Around Maua
Patients	3 patients in hospital 6 patients at home (observed 4 clinical encounters with nurses)
Current home caregivers	5 (son, son, husband & daughter, sister-in-law)
Bereaved caregivers	5 seen at home 2 seen in hospital
Volunteer (community) caregivers	4 volunteers in individual interviews 8 volunteers in a focus group
Staff members of palliative care programme	1 programme in-charge 2 clinical officers 4 nurses
Programme overseers	7 hospital administration
Community leaders	17 in two focus groups
Total	64 people

Independent translator for evaluation team: Joel, retired teacher and community leader

Key informants at Maua Hospital Community Based Palliative Care Programme

Dr Claire Smithson	Deputy CEO, referral doctor for AIDS and cancer patients
Stanley Gitari	Director, Community Health Department
James Gikemi	CEO (since 2004)
Stanley Mungathi	Hospital Admin
Sr Eunice Ogori	Deputy Nursing Officer
Rev Alexander Mauta	Chaplain
Andrew Mauta	Financial controller
Mary Muakami	Internal auditor
Stephen Gitonga	Palliative in-charge
Jane Gray	RN Cancer Nurse (Methodist church UK)
Faith Ngore	KECN Palliative nurse
Safina Njege	Clinical Officer Palliative care
Mr Elylkahn	KRCHN Community Palliative work
Ms Penina	KECN Palliative nurse

APPENDIX 3

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