



EVALUATION OF THE MALAWI HOME BASED PALLIATIVE CARE CHARITABLE TRUST, BLANTYRE, MALAWI

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 Malawi Home Based Palliative Care Charitable Trust 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 Kitovu Mobile Palliative Care Service, Masaka, Uganda. Reports from these evaluations and a summary report covering all three evaluations are also available.

Evaluators: Dr Elizabeth Grant*, Senior Lecturer in International Studies, University of Edinburgh
Dr Judith E Brown*, Lecturer in anthropology and global health, Eastern Virginia Medical School, USA
Professor Scott A Murray, St Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh
Dr Mhoira Leng, Head of Palliative Care, Mulago Hospital and Makerere University; Medical Director, Cairdeas International Palliative Care Trust

Photographer: Nadia Bettega*, <http://www.nadiabettega.com>

* Conducted fieldwork in Malawi

www.homepages.ed.ac.uk/smurray1

www.mak.ac.ug

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1. EXECUTIVE SUMMARY

1.1 Aims and methods

We aimed to assess the impact of the Malawi Home Based Care Charitable Trust programme on patients, carers, community and formal and volunteer staff. A multidisciplinary team spent a week using rapid evaluation field techniques – direct observations, individual and group interviews, and document reviews. The team focused on the differences that the Trust’s palliative care programme had made in the lives of patients, their families and their communities.



The team also gathered many moving first-person stories and photographs from patients, their caregivers, and staff.

1.2 Local context

The Malawi Home Based Palliative Care Charitable Trust programme is a home- and community-based programme, and involves large numbers of volunteers, as well as paid nursing staff. The programme operates in the Bangwe and Limbe region of Blantyre, in areas of high HIV/AIDS prevalence, and many of their patients have AIDS-related cancers (Kaposi’s sarcoma, cancer of the cervix, lymphoma), or severe pain due to cryptococcal meningitis and neuropathies.

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 travel to the local health centres or hospitals, while their carers struggled to manage the patient’s severe pain, vomiting and diarrhoea. Some patients described spending money they had borrowed for lengthy trips and treatments with traditional healers which had limited or no benefit, until they met the home-based care team. Patients said they received pain relief, the assurance of continuity of care, some social and practical support in the house, and a sense of being valued and respected as a person. Some patients have recovered enough to lead near-normal lives again.

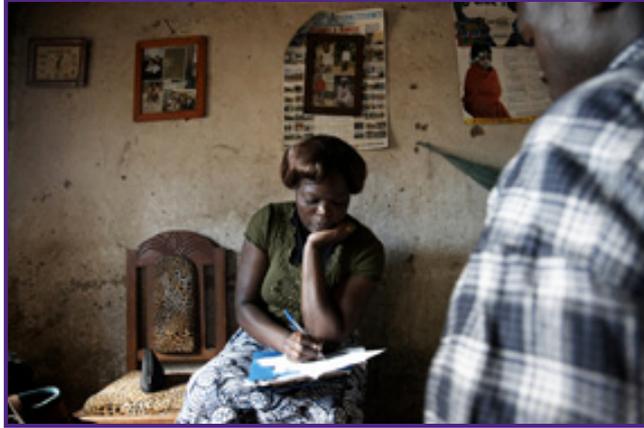


1.4 The impact of activities on family carers

Carers within the palliative care programme told of receiving useful practical instructions on feeding and bathing patients, administering medicines, and feeding components. They also spoke of receiving regular visits from the

volunteers to aid with housework, and to bring occasional food and soap. A number felt that the counselling support they received was useful, and appreciated the sense of togetherness that the programme gave them.

1.5 The impact of activities on local communities



There has been substantial input into the communities from a number of different HIV agencies, alongside a widespread national HIV prevention programme, leaving the community relatively well sensitised and educated about HIV and AIDS in recent years. However the knowledge of cancer and of palliative care services was low. The programme therefore invested significantly in helping people understand the concepts behind palliative care and in encouraging those in

need of additional support to register with the programme. The community volunteers who are jointly trained by this programme and the Salvation Army are well trained and exceptionally supportive to patients and carers. They live in the community in which they provide service, and they feel very much a part of their community and proud to be working within it. Everyone spoke highly of the volunteers, as people who cared and gave what they could to help others.

1.6 Integration of programme with other health services

The leadership of the programme recognised the need for service integration with the local government health services and now successfully run the programme from the vicinity of the two local health centres for the two districts. In general however, palliative care in Malawi exists in a complex web of health programmes and providers (many focussed on HIV), with rules and procedures that often seem to conflict or overlap, although the Palliative Care Association of Malawi (PACAM) is trying to create a much more co-ordinated and supported network. Everywhere, project staff members do their best to collaborate, while serving their patients.



1.7 Staff members from the programme are dedicated to their work

All staff were committed to the programme work, which is demanding and draining. Staff serve beyond the time that they are paid to provide service and often care beyond the expectations of their role. Staff developed supportive relationships with patients, which is essential to the ethos of good palliative care.

1.8 Analysis and discussion

Several important themes emerged in our findings: how to deliver palliative care in the context of poverty; how to identify patients and which patient management and follow-up systems to use; issues around programme coherency and integration; volunteer training, engagement and sustaining volunteer activity; and the growing use of mobile phones to facilitate access to, and the delivery of palliative care.



1.9 Challenges to the programme

The programme has a substantial number of clients and is certainly achieving its aims and objectives, and in doing so, is making an effective difference to the lives of its beneficiaries, and increasingly, the local communities as well. Challenges remain around how best to prioritise patient need, and how to manage patients who, through the availability of ART, are improving and moving from being non-ambulatory and expectant of death in the next 6-12 months to being well enough to be able to move around independently. There is also a need for further sensitisation and advocacy in local communities about palliative care. The nature of the work means that demand exceeds supply and the programme with limited funding has to make decisions about the multiple needs (especially social and financial), that patients have. Integration with other local health services in Malawi remains an ongoing challenge.

2. AIMS AND OBJECTIVES

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

Objectives:

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



3. METHOD OF EVALUATION

We used rapid evaluation methodology 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). The rapid evaluation method (REM) was developed by the World Health Organisation (WHO) in order to assess the performance and quality of healthcare services, identify operational problems, and lead to appropriate actions. 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 three countries 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) at each field site, assisted by translators independent of each project to avoid reporter bias. Appendix 2 shows details of the people interviewed, a total of 47.

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

Using the clinical evaluation skills of the researchers, we assessed the quality of palliative care provided. Observations were supported by the professional photographer who documented the physical and socio-economic environment of care. We deployed a field team consisting of two researchers, a photographer and a local translator. The team carried out data collection over one week in July 2009.

A site report was drafted within a few days after 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 many individual patients and their families. Five of their stories appear and are an important part of this report.

4. FINDINGS

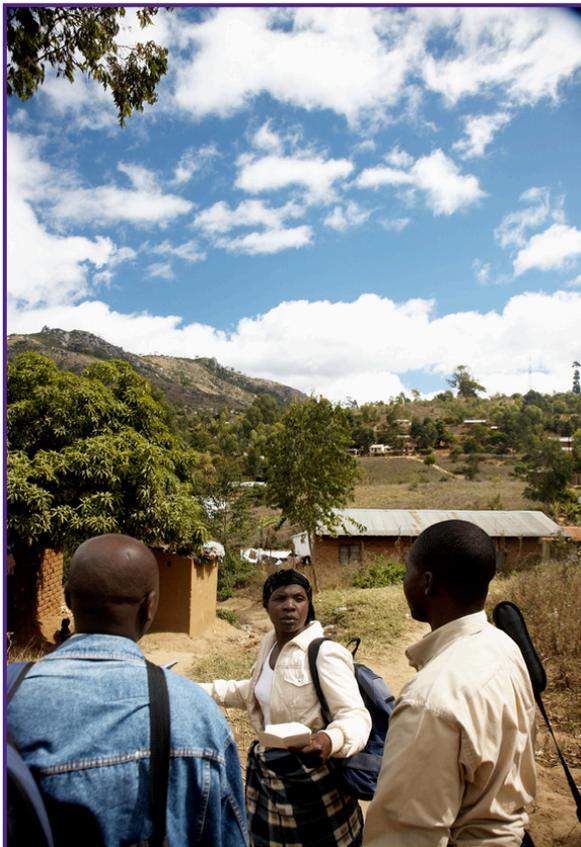
4.1 Context and description of the palliative care programme activities funded

The Malawi Home Based Care Charitable Trust programme presently delivers clinically-led home-based care to the residents of two districts of Blantyre city, with a combined

population of 157,000. The districts are of medium to high density, with most houses within a few metres of each other. The area has an HIV prevalence of 27% (2007 surveillance data from Limbe ante-natal clinic), which is 13% above the estimated national prevalence.

4.1.1 History and context

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



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

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

Home-based and palliative care activities were later expanded to parts of the neighbouring Limbe District.

4.1.2 Overview of the programme

A new three-year phase of the palliative care programme run by the Malawi Home Based Palliative Care Charitable Trust in Bangwe and Limbe began in July 2009, just a few weeks before our visit. The programme's staff currently includes two nurse-directors, four nurses, six home-based care assistants, a data manager and a cleaner. It is funded by the PCI via the Malawi Home Based Palliative Care Charitable Trust.

Over the years, a total of about 130 volunteers have received training and training updates, and 90 of them are currently active. New volunteers are chosen by the village in which they reside, through a community process facilitated by the local chiefs. Volunteers usually work two days a week. They check in with ongoing patients and visit new patients to assess whether a nurse's visit is necessary. On the morning of the weekly visit by the nurse to their village, the volunteers meet the nurse, discuss each of the cases requiring a nursing consultation, and lead the nurse to the homes. Volunteers are thus supervised on-the-job by the nurses.

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

The home-based care (HBC) teams see their distinctive role as providing a clinical service, with a focus on the patients' physical health. Volunteers are encouraged to identify physical health problems for referral to the nurses, and carry drugs that do not require prescriptions such as aspirin and paracetamol, as well as vaseline, body oils, bandages, gloves and a local antiseptic to clean cuts and small wounds. Volunteers may refer families to other organisations such as the Salvation Army for social support needs. Volunteers sometimes provide support services, such as cleaning, washing dirty linens, carrying small foodstuffs etc.

4.1.3 Beneficiaries

Since 2003, the HBC teams in the two areas (Bangwe and Limbe) have enrolled a total of 3,000 patients, who fall into two main categories. A smaller number of patients have suffered strokes, have diabetes and cancers which are life-shortening, with death probable within the next few months or year. The large majority of the patients are infected with HIV/AIDS. Many of them, especially in the early days of the programme, came to medical care very late, already having serious AIDS-related illnesses such as tuberculosis, peripheral neuropathy, Kaposi's sarcoma and other cancers.



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

4.2 Impact of programme on patients

Summary: The programme benefits patients in a number of different ways. Patients felt respected, and cared for, and described feeling important and valued as people. This was in contrast to how they felt they were being treated in busy clinics and hospitals as just another number with a disease. All staff carried a useful assortment of non-prescription drugs and treatments, such as vaseline, and nursing staff carried a small number of essential prescription drugs including pain relief. Patients constantly expressed gratitude that because of the team's intervention, they no longer had to suffer with uncontrolled pain, or live with poorly managed side effects or associated illnesses. Patients also noted that

alongside the value of treatment being made available in their own home, reducing the emotionally and physically painful and economically costly travel to health centres, the programme provided considerable value in meeting patients where they were, with their families around them. Patients felt they had time to discuss their issues more fully and get guidance on next steps. The HBC team were in a position of also being able to identify other physical and social needs within the family that both directly and indirectly impacted on the patient's wellbeing.

4.2.1 Patients received whole person care in a dignified way

In each house we entered, patients greeted the team as known and welcome guests. Patients were treated as people leading their lives among their children, families, and household activities, rather than as people with diseases. Being cared for in the privacy and comfort of their homes was important to patients, and there was a relaxed, positive attitude in all the visits we shared.



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

While many patients appreciated the care provided at the hospital and health centres, they explained that the atmosphere generated by the HBC team was different:



Hospital people were negligent and had a negative attitude. The home-based care people did not treat me that way. (John)

The home-based care team spend time with me at home, but the hospital people are always in a hurry. Sometimes at the hospital they don't give me everything written on my prescription, like chiponde (fortified peanut butter), saying they have run out. (Zora)

I arrived at the hospital at 6 in the evening, feeling very ill. We waited. We were told that we had missed the day staff and would have to wait for the night staff. The night staff came at 9. I had travelled there, because I was so sick and thought that when I got to hospital I would be helped with the pain and the illness. The home-based care team is different – they come to my house, and they treat me well when they meet me here. (William, KS and TB)

4.2.2 Physical suffering was greatly relieved

The historical background of home care was explained in similar terms by patients, volunteers, nurses, and HBC assistants. Before clinically-supported home-based care was introduced in the area, many patients remained in their homes suffering pain, physically too weak to travel to the health centres and economically unable to afford the cost of such travel. Patients and their carers struggled to manage severe pain and sickness, especially vomiting, and diarrhoea when patients became bedridden. Patients lacked access to effective pain relief, antibiotics and vitamins. Before the widespread availability of anti-retroviral medicines (ARVs), people with AIDS remained in their homes or returned to the villages of their fathers to die.

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

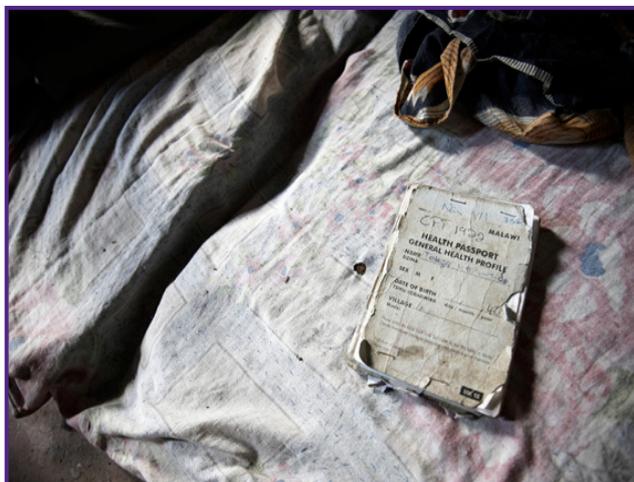
Effective pain relief delivered in a timely manner was noted by patients, volunteers and staff as one of the most important contributions of the programme.

I was bedridden, and I couldn't move. I sent my sister to call the volunteer, and she came and gave me drugs – painkillers and smaller drugs.
(Limbe FG patients)

All of the HBC team, including the volunteers, carry mild painkillers, and nurses carry prescription palliation, but are unable to prescribe morphine. Bangwe staff emphasised the importance of the programme's steady supply of medicines, noting that the government health centre frequently had stock-outs.



The availability of ARV medicines has revolutionised the lives of many residents who are HIV positive. With ongoing care, patients who were expected to die are now up and walking about. A constant refrain from patients, volunteers and the healthcare team was that patients steadily improved when they were receiving the right treatment.



I could not breathe (because of the pleural effusions), so I thought I would be better to die, but then the team came to help me. Without home-based care some people would certainly die as they would not have the strength to get to the hospital or health centre. (William)

We like seeing the improvement of the patients – from being very ill to getting better. Most patients were bedridden, and now they are doing great. (Limbe FG Volunteers)

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

The church, the CCAP people came to pray when I was very sick, they are now amazed. I'm thankful to God. (William)

A number of the patients we spoke to were accepting of their illness and of the future, especially after the HBC team became involved.

I was found with TB and at the same time the HIV test was positive. When I knew I was ill I was not shocked, I only said I would accept whatever they told me. (Zora)

Only God knows the future. (William)

4.2.3 Patients felt helped to identify problems and make decisions

Patients, staff, and volunteers talked about multiple barriers to accessing healthcare, ranging from a lack of knowledge that care was available to failure of services to deliver what was required at the right time and in the right place. The Malawi Home Based Palliative Care Charitable Trust programme was established to tackle some of these barriers to care and to enable patients to find assistance quickly.



Patients described the role of the volunteers in bridging the gap between need and care. A key step was finding who needed help and telling them what assistance was available.

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

As the first on-the-scene health provider, the HBC team frequently identify illness and put in place a referral process to ensure that the patient is seen appropriately. Patients and carers recognised that these interventions of the team improved their health, and in many cases saved their lives.

Several years ago as the HBC programme was starting, a volunteer visiting a patient in their home noticed a sickly boy in the household and called a nurse to talk to the boy's mother, a neighbour. Both mother and son went for counselling and HIV testing, and both were HIV positive. The son was started on ARVs at the beginning, and now he is doing very well and is finishing school. The mother became ill last year, and the HBC team referred her to Queen Elizabeth Hospital. She has now started taking ARVs. (Ida, FG patient)

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

There are advantages of being in the HBC programme. We are seen quicker at the hospital when we tell the doctor that we are part of the programme. (FG patients)

The home-based care team saw that my daughter had oral thrush. They also discovered that she was due for nutrition supplement, but before it was supplied she died. (Aya, bereaved mother)



4.2.4 Patients received continuity of care, including social and practical help and did not feel abandoned

Both Bangwe and Limbe HBC nurses identified that the value of the programme lay in its consistency. Without such care, they noted that some patients would not survive. The value of this consistent and constant care was further demonstrated in the case of a young man with severe burns. An example of this is the case of Bernard, which we learned about while examining records in the office of the Malawi Home Based Palliative Care Charitable Trust.

During an epileptic seizure in 2006, Bernard fell into the fire and spilled a pot of boiling water over his leg and foot. He was initially treated at the Queen Elizabeth Hospital but later refused hospital care and chose to remain at home. The HBC team first met him in February 2007, through referral by a volunteer. The nurse and HBC assistant dressed his burns each week and reported a significant improvement initially, but unfortunately the wounds reopened, and he became increasingly unwell. The team regularly changed bandages, provided pain relief, and ensured that Bernard and his family understood the importance of his anti-epileptic medication. Throughout 2007 the team kept in regular contact with Bernard and his father, who was his principal carer. In January 2008, Bernard re-injured the foot that had been burned, and his wounds became re-infected. He retreated to bed as the infection spread. He lost his appetite, developed oral thrush, headaches and oedema, and became incontinent.

The HBC team facilitated an outpatient referral to the hospital for further treatment. Over the next eight months, they continued their home visits once or twice a week to debride the wound (which had a foul odour) and attend to the burns and bedsores. Bernard improved gradually, and his father requested that he be taught to change the dressings so he could do it more often. The team taught him and provided gloves, bandages and dressings. Bernard's wounds and pressure sores are now healed, and he is able to move about again. The team stays in touch with him and his father.

The programme has highlighted the changing nature of illness in the community. The staff recognise that with early diagnosis and care, HIV is becoming, at least for some, a long-term, chronic illness. They point out, however, that patients need constant watching and require good follow-up. Without timely intervention, patients with evolving opportunistic infections can quickly become very sick.

We manage their opportunistic infections, encourage adherence to ARVs, and refer them in a timely fashion for advanced medical care. (Bangwe FG staff)

Some HIV patients get better and discharge themselves, but never completely. They come back to us when they need us. We keep their records in the files. (Bangwe nurse)

4.2.4 Patients received and valued spiritual and emotional support

Patients appreciated the social and practical help that volunteers gave them. Volunteers from the HBC programme come every Wednesday with the nurse and HBC assistant, and often return another day of the week on their own, bringing a few groceries, and staying to sweep and mop and clear the bushes around the house. As one bed bound patient, Zora, explained:

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



A number of patients spoke about the importance of spiritual support and described the help they received as members of their churches came to pray and sing with them. Others told us that at the time of death, church members spend the whole night with the bereaved.

Though asked, none of the patients spoke of the HBC team offering spiritual care to them, and the team did not discuss spiritual or psychosocial issues during the visits we observed. Although the team recognise that spiritual care is much wider than either Christian or Islamic rituals or traditions, we did not see any staff or volunteers praying or reading the Qur'an or Bible with patients. The HBC team assessment form does not have any questions on spiritual or psychological need. One patient, however, said that he believed that the intervention of the team was the answer to his own prayers:

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

4.3 Impact of programme on carers and families

Summary: Visiting patients in their homes also had a significant impact on carers and families. Carers felt that their work of looking after their patients was being supported and that others were able to see and acknowledge the difficulties that they experienced in carrying out their tasks of caring. Carers welcomed the encouragement that the team gave them. The programme reduced the isolation that carers often experience, alongside relieving anxieties and doubts about what to do next in the caring process. Nurses and volunteers coming into homes provided an opportunity to carry out an ongoing needs analysis of both the patient's and the family's capacity and capability to cope with the illness. The programme was able to suggest interventions and provide supportive systems to enable better care for both patients and carers.

4.3.1 Carers felt greatly helped to care for their loved one

Before the palliative care programme, according to programme staff (Bangwe FG staff):

- families had to provide care for their patients themselves
- some guardians were not willing to care for patients
- those who were willing did not know how to care
- patients did not feel free to discuss their illnesses or to disclose their HIV status.

A key role of the HBC team was to support family carers in their caring role. Some relatives had the duty of care placed upon them, even without their consent.

I was brought here so that my relatives could care for me. (Selia)

Support to relatives involved education, confidence building, and affirmation of the work that carers were doing.

When they visit, they teach me to bathe, feed her if necessary, and be close to her. (Carolyn, daughter of Tess)

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



Being part of a community of carers (though not described in such terms) was important. For example, the wife of a new patient explained:

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

4.3.2 Home visits reduced the social, financial and practical costs in supporting patients

The greatest burden on funds are the transport costs to hospital, and that is especially so when patients are bedridden and have to make their journeys by private car rather than by the minibus. Almost all the patients we met required a carer to accompany them to the clinic or hospital. Thus patients and carers were very grateful for the visits to the patients at home.

If there were no volunteers, we would have to go very often to the hospital, and that takes a lot of time and money. (FG patients)

Our volunteers come to the house, not like the hospital. (Limbe FG patients)

Before the health volunteers started, we had to organise somehow among ourselves to get sick people to the hospital. Many people died at home, and many in hospital. It's best to die at home! (FG patients)



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

But health centre and hospital visits were also necessary, especially for ART follow-up, and carers were appreciative when the HBC team gave them some transport money. With limited or negligible incomes, a constant refrain from all patients was the lack of food, and the lack of money to buy food.

The drugs we are getting are very good, but they make us very hungry, and that is not good. Can someone provide us with food? (FG patients)

Our biggest problem is food – when the patient demands something and we don't have the money, for example, she sometimes asks for white maize flour or a soft drink. (Carolyn, carer to Tess)

In all homes we visited, other essentials were also missing. The HBC programme does not have funds to support in any sustainable way the many needs of patients, carers and families. Volunteers described how difficult it was to go into the house of a family with several hungry children, where the healthy adult was spending much time looking after the patient and was therefore not generating any income. Sometimes they felt they could not leave the house without doing something, so *“put our hands in our pockets and gave some small thing that we had”*. There was a strong message from the volunteers that they had to pay for the cost of small essential goods out of their own money, and there was no opportunity for reimbursement.

HBC volunteers occasionally carried small items such as soap and sugar, supplied through other organisations, especially the Salvation Army, working in the area. Patients appreciated receiving these items, in addition to the regular social and psychological support, but some wished there could be something more:



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

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

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

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

4.3.3 Carers valued good communication and psychological and counselling support

For HIV-positive patients in the Bangwe area, the home-based care programme, along with the Salvation Army, facilitates a weekly support group with over 80 members registered.

The roles of the HBC team are clearly demarcated and purposively focused on a bio-medical model of illness. For all patient encounters, nurses and HBC assistants use a clinical check list. This list does not ask any questions about psychosocial or spiritual needs. However, the supportive care given by the whole team was appreciated and identified as more than just physical care. Volunteers particularly were singled out for giving social and emotional care.

Meeting patients where they were and encouraging them to believe that healing was possible was a role that a number of volunteers took on.

I was very weak, I couldn't walk, not even to go to the toilet, and my face was swollen. Someone submitted my name to the volunteer and the volunteer came with a nurse to see me. She saw I was very sick, I said "Better that I die," the volunteer said, "No,

we have seen others like you and they get better". I felt happy because up to then I had no way of help. (William)

Few family carers put into words how the programme helped them to cope emotionally, but almost all said that they were much helped by the team coming frequently. One carer spoke of how she appreciated the concern that the visits expressed.

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

The HBC team offers both palliative and rehabilitation care in the home, with the hope that the patient will remain well enough not to need constant nursing input. We did not have the opportunity to witness the team counselling a patient or carer about the proximity of death.

She might get better, but she might get worse and die. The neighbours say when a person comes near to death they should go to hospital. (Carolyn, carer to Tess)

The home-based team did not mention death to me, only encouraging me that my daughter would get better. (Aya, bereaved mother)

The death of patients is not very common, but for other patients that die, we think that maybe it's according to God's plan that they die. (FG volunteer)

4.4 Impact of programme on the community

Summary: The presence of the palliative care programme in the communities of Bangwe and Limbe has had a significant impact on how people understand the concept of palliation and how the community treat those who are living with a life-limiting illness. Programme staff and volunteers spoke of how before the programme commenced many families would send their sick relative up country to the family homeland, often to villages where there was no access to any pain medication or treatment, and where the patient was left to die without any care interventions. The programme, by investing resources (such as time, medication, and clinical care) in patients, provided a strong message to the whole community that supporting patients to die well was as important as supporting patients to live well.

4.4.1 Communities are now aware of the concept of palliative care

The community-based organisation (CBO), *Tigwirane Manja (Let's hold hands together)*, was formed by the College of Medicine programme and community members to foster a strong sense of ownership of home-based care in the Limbe area. Though the HBC team described problems with the CBO's early phases, the principle of community empowerment is critical. The CBO is committed to helping residents understand and accept their role and responsibility in making home-based and palliative care work for everyone.

Even when families have struggled alone to find enough money to care for their sick, the time of death and burial is not an isolated event. Relatives come to help prepare the body. Community and members of the family's church or mosque come to the house and to the

graveside to be with the family and show concern. The HBC volunteers spoke specifically of the importance of being part of this communal grieving process, and being identified by the community as an organisation that offers care right to the end.

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

We asked the Bangwe staff, “Who would people in the community say are the most important members of the healthcare team?” Their reply:

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

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

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

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

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

During a focus group discussion, HBC assistants explained that the concept of caring for those who were dying was not well embedded in a number of families, particularly the families where neither the father nor mother could read or write. They said it was not uncommon for such a family to reject their patient, believing there was nothing more that could be done, as the illness was the effect of witchcraft, the will of God or the consequence of misdemeanours which could no longer be rectified. Therefore the patient would have to accept what was coming to him or her. The HBC assistants also described how some families, feeling that nothing could be done, would send their patient to the village of their fathers, where there was no possibility of any curative care, palliative or analgesic support.

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

When we asked a group of AIDS patients whether the community made things difficult for them, only one patient could remember one neighbour who had “teased” her (FG patients). Others explained that because of the team’s presence they were accepted and supported in their illness.

4.4.3 Communities are inspired to talk about and accept palliative care

All the staff and a number of volunteers voiced their opinion that the numbers of patients dying now are fewer than before. There were mixed views on how and why this change had happened. Some explained it was because of the presence of the HBC team in the communities, while others spoke of the fact that there was now treatment available and the treatment enabled people to get better more quickly and meant patients were no longer confined to their homes. With anti-retroviral treatment, many AIDS patients were able to live their normal lives again.

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

Summary: The palliative care programme aimed to act as a conduit between the different services and between their patients and the services. All agencies, and especially government services, are constrained by lack of time and resources, and often the communication pathways between agencies are not as good as needed. Patients, and the HBC team, noted with frustration the frequent to-ing and fro-ing from hospital and health centre for different components of their care. As a staff member noted, *“It is a full time job being a patient.”* Patients explained that the quality of service at government health centres and main hospitals was particularly compromised because of lack of staff. Systems established primarily to ensure best and safe practice, such as the limit placed on the number of patients able to register to receive ART each month, and the need for these patients to attend the hospital for registration and regular monitoring, created huge problems for patients. As in most other countries, morphine must be prescribed for a patient by a doctor at a health centre, but the HBC nurses can administer it, as we witnessed during a home visit.

4.5.1 Co-operation

The HBC teams aim to work as closely as possible with the various government and non-government health and community services in the local area of Bangwe and Limbe. The HBC nurses receive approximately half their medications (including morphine, amitriptyline, and loperamide) from the government health centres, at no cost, as the team are seen to be delivering critical health services. But with so many different agencies all with a remit to provide parts of services, tensions were inevitable. Nurses sometimes felt disempowered, and unable to take appropriate clinical action, because a patient’s main clinical providers (at Queen Elizabeth Hospital) were making the decisions.

Yes, there are two systems at work. The HBC team knows what is wrong with Tessa (peripheral neuropathy), and we tell the ARV clinic what is wrong, but they want to do all the medical tests (including MRI scan) to prove what is wrong. They despise us and think we are just community people, who don’t know what we are talking about.
(Nurse)

4.5.2 Service quality standards

Various patients interviewed during the week explained that the quality of service that they received from different health facilities and service providers varied immensely, and was often poor. The quality of service that they felt they received from the HBC nurses and assistants was seen as high. For every patient-nurse visit, a checklist is used to conduct a

comprehensive health assessment. This information is recorded in a patient case file, and a review date set.

The HBC team described being frequently frustrated, however, by the complicated web of procedures and regulations in which they had to work, particularly those that split patient services illogically. Almost all the patients we visited had multiple health providers, with the HBC team being just one among many, including hospitals, clinics, other NGOs and traditional healers. Patients appeared to spend a lot of their time ‘being patients’. When we asked one patient with AIDS who her main health provider was, she explained that she goes to a mission hospital for drugs for her skin rashes, collects her ARV drugs from the local health centre, and goes to Queen Elizabeth (QE) Hospital because of her peripheral neuropathy. She then said:

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

Having multiple providers sometimes resulted in duplication of services, as illustrated by one patient we visited. According to his Health Passport, (a document containing the health record of a patient, instigated as part of Malawi's national health service), he had his three month review at the ARV clinic at Queen Elizabeth Hospital on 23 July. Just five days later, the palliative care nurse did a home visit for his fortnightly review. She checked his weight, temperature and chest, examined his legs and gave him four medicines (ointment, clear cough, multivitamins, and paracetamol). On this visit the nurse did not write in his Health Passport, explaining that this was because she had *“not prescribed any strong medication”*.

4.5.3 Service delays

Patients who had been prescribed a new service or treatment, from either hospital or clinic, often experienced long delays in starting. Even patients who needed ‘Plumpynut’ (a fortified food supplement for severe malnutrition) did not get it right away but had to wait for days or weeks, because of high demand, strict criteria for access, limited distribution centres, or stock-outs. Moreover, they had to go to the government health centre to pick up Plumpynut, and those most in need of it were physically or financially least able to make the journey to pick it up. The home-based care programme staff felt that many patients would benefit if they could carry the food supplements, rather than having to send patients to the health centres. The HBC team do not have access to the Plumpynut to prescribe, and have to negotiate with the health centre in order to collect it after prescription and bring it to the patients, a service which they felt was a priority in delivering comprehensive palliative care.

4.5.4 Regulations and limitations

HBC teams are not currently authorised to counsel and start their patients on ARV medicines, or even to carry ARVs to renew the patients' stock. One HBC team clinician noted how illogical the restriction was, since ARV clinics in government health centres, being short of staff, often use low-level health assistants to distribute ARV medication, with no true clinical encounter taking place.

The Ministry of Health's national HIV procedures require a doctor's review and a doctor's prescription to enable a patient to enrol into the anti-retroviral therapy (ART) programme. We were told that, once a doctor has prescribed ARVs, the patient's name is placed on a waiting list to receive the first supply of medicines. The waiting list at both Bangwe and

Limbe Health Centres is two to four months; at the more distant Queen Elizabeth Hospital it is one month. (Waiting times are related to national restrictions on the number of new patients each centre can register each week and were established in an attempt to support the appropriate management of patients.) For a patient on ART to change to an alternative first line or to second line treatment, the decision has to be made by a senior clinician and the HBC team reported long delays in transferring treatment regimes linked to personnel shortages. The HBC team were in a position to review patients and identify sometimes severe complications with their treatment regime, but not to make any changes.

The HBC nurses in interviews and focus group discussions spoke of those regulations and their own frustrations:

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

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

4.5.5 Referring patients back and forth

Unfortunately, the neither Bangwe nor Limbe have a government district referral hospital where patients can be referred for secondary care – more tests, consultation for STIs, a skin clinic, etc. Instead patients must go to Queen Elizabeth Hospital, a large and severely crowded tertiary care teaching facility. The bus fare per person (100 kwacha = GBP 44p) is more than a day's minimum wage; private transportation for a very sick or weak patient ranges from 500 to 3,000 kwacha. Ali, a patient whose sister had also been cared for by the team until she died, explained how frustrating it was to be always seeking for healthcare:



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

Fortunately, Queen Elizabeth Hospital staff seem to recognise and respect the HBC team's referrals. As one patient explained:

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

4.6 Impact of programme on palliative care team, including volunteers

Summary: All the staff described their commitment to offering quality palliative care. Staff described how the programme gave them an important identity. They recognised that it was they who had responsibility for developing their role and ensuring that their role was accepted and respected by delivering good practice at all times. Patients described the difference in attitude between the HBC nurses and healthcare staff they met in busy hospital wards, and much of this difference focussed on the quality of care that staff gave in patients' homes and their empathy. It is hard to underestimate the significant emotional investment of staff and volunteers to this programme. Patients are needy in multiple ways and look to the whole team for a wide range of help and support. Coping with not being able to meet all of the patients' demands, particularly when the demands are so very necessary, such as for food or money, was hard for all staff, and particularly for volunteers, as they lived in the community in which they provided care. Volunteers appreciated the training that they received from the programme, noting that it gave them more understanding and more authority to carry out their tasks, and it also supplemented their income, as training time was reimbursed.

4.6.1 Providing palliative care is a rewarding and fulfilling vocation

All staff, including volunteers, described how the work was rewarding. They noted that resilience is fostered and helped by having a strong team working together and also by having the tools to do the job well, such as effective medication.

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

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

I feel honoured when I visit patients and accompany them to hospital, and the patient thanks me. (FG volunteer)

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

But alongside the vocational nature of the work, there was also recognition that it was hard and emotionally draining.

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

While recognising the value of their work, there were also times when nurses felt frustrated and disempowered, and unable to take appropriate clinical action, because a patient's main clinical providers (at the Queen Elizabeth Hospital) were making the decisions.

Yes, there are two systems at work. The HBC team knows what is wrong with Tessa (peripheral neuropathy), and we tell the ARV clinic what is wrong, but they want to do

all the medical tests (including MRI scan) to prove what is wrong. They despise us and think we are just community people, who don't know what we are talking about. (Nurse)

A few volunteers reported negative community reactions to them.

People tease us. They say we are HIV positive and that is why we volunteer. They mock us for doing a volunteering job and getting no pay. (FG volunteers)

4.6.3 For the volunteers working without resources was difficult

A common stress factor, often mentioned by the volunteers, was their inability to meet the financial needs of their patients.

Some patients and families have a problem with food, and they ask us, but we don't have the money for food. (Limbe FG Volunteer)

Sometimes when patients die, we volunteers contribute a little to assist the bereaved families, but it is not enough to cover their needs. (Limbe FG Volunteer)

When our patients die and have left young ones, the children sometimes come to ask assistance from us. (Limbe FG Volunteer)

We volunteers have our own problems, as well as the patients. We don't have the resources to help ourselves and the patients. (Limbe FG Volunteer)

We volunteers all have other activities. The majority are not working but looking after families, kitchen gardens, church groups, taking care of others, and one is a chief's advisor. ...Several of us are widows. (Limbe FG Volunteer)

4.6.4 Volunteers need ongoing support from nurses, and from peer support and the team recognises that this does aid retention

Nurses really help us volunteers when we call them. We flash them from our cell phones, and they ring us back, and if we need them, they come. (Limbe FG Volunteer)

We meet with volunteers from other areas once a month. We help each other see how home-based care activities take place in different areas, and we share experiences. (Limbe FG Volunteer)

The programme staff agreed that volunteers need and deserve incentives to show appreciation and encourage them to remain active in the programme. Project leaders recognise the importance of staff and



volunteer development and retention to ensure the sustainability of the programme. Training was appreciated, particularly by volunteers, both as a means of improving their capability to do their jobs and as a source of some additional income. And volunteers themselves frequently expressed their pride and mentioned intangible rewards:

Four of us volunteers had training, but one person who started six months ago did not. We all need training to update our knowledge. (FG volunteer)

We need some cash to survive, so if we could be invited to HBC trainings and meetings, they would give us something small (eg. cash for transport or per diem) that would help us. We would feel better if we got some form of incentives to appreciate the work we are doing. (FG volunteer)

5. ANALYSIS AND DISCUSSION

5.1 Palliative care in poverty

For all patients in the Bangwe and Limbe areas, illness comes as an addition to poverty. Few, if any, patients have any additional resources and their illness soaks up what little funding they have. Without the programme run by the Malawi Home Based Palliative Care Charitable Trust in the Limbe and Bangwe areas of Blantyre, many patients would live and die in severe pain, and their families would suffer. At the patient level the programme's intervention changes the way a patient experiences their illness. Patients are encouraged to believe that things can be done to make their illness more bearable; they are supported to take action to improve outcomes, such as keeping wounds clean, using antiseptic creams to reduce infections; they receive information about the nature of their illness; and they can through the regular visits begin to chart the progress of their illness. At a family level the programme provides a support mechanism, emphasising to families that the work that they are doing caring every day and night for their patient is important and valuable work and work that is valued by others. With the small resources that the programme can give in the form of financial and food aid, families and patients feel encouraged. At a community level the presence of the programme reaffirms the importance of caring for people at this stage of life, and asserts that, counter to assumed thinking, things can be done to improve the life of those who are dying. With the rapid scale-up of ART in the community, there has been a much wider acceptance of the possibility of improvement and a recognition that treatment can bring people back from almost inevitable death.



All home-based care team members including volunteers, and all patients and families, spoke of the need for further investment to deal with the determinants of health and illness, as well as the physical needs. Often the most pressing problem was not the illness but the lack of

food and money in the home. Some families had no resources at all to meet their very basic needs, and volunteers in particular felt the burden of caring for patients, frequently giving their own money, a sign of just how committed the volunteer team are to their task.

5.2 Patient identification, management and referral systems

The programme does recognise that the client group is split and, while some of those with HIV have a hope of recovery (though not complete healing) because of the availability of ART, those who have aggressive HIV or AIDS, or those who have cancers, do not have such hope. They also recognise the difficulty in supporting these two different groups, which have overlapping, but also very different, needs. Staff in the programme spoke of their frustration about the failure of the national health system to manage the community demand for treatment and services. Patients often were left suffering and deteriorating because of delays – delays in getting onto ART, delays in assessments for peripheral neuropathy and other side effects of ART, and delays in getting referrals for second line treatment, and these problems were visible in the programme. The programme is not in a position to make radical changes or improvements, but its very presence provides a continuous statement of the need for better palliative care in Malawi. This awareness of the weakness of the national health system has led to the HBC team ensuring that they keep all patients who register in the programme within the programme. Discharge is not a team choice but a patient choice. As the staff say, *“we never discharge as people will be back again at some point in the future”*. The client book contains different categories of patients, those requiring palliative care, and those who will probably require such care again in the future but who are at present ambulatory and coping well. The challenge for the team is to ensure that their resources are targeted to those who require home-based palliative care, with a different (and less resource intensive) type of support being given to those who are able to access care services themselves.

5.3 Programme coherency and integration

To achieve the greatest community impact there is a need to join up programmes in a much more integrated and transparent way. A number of programmes and services working in the Limbe/Bangwe area have a similar client base, though they are delivering different components of care. The next stage to embedding palliative care into the community will be to marry these different components of care together so that the patient, rather than the disease or their separate needs, becomes the central focus of care. Referral systems that are patient focused and patient centred, and that recognise the nature of disease progression, are



desperately needed but probably still a long way off, especially with national hospitals so overstretched and poorly resourced. Yet the money spent by patients desperately and painfully trying to attend different appointments for different components of their care at different clinics and hospital outpatient departments is a tragedy that the home-based care team are trying to respond to.

5.4 Project engagement with the community

Close links with the community chiefs and leaders, especially through community meetings, was central to the success of the programme. People knew of the programme through the presence of volunteers at numerous local meetings, events and funerals.

5.5 Volunteer engagement

With a high proportion of volunteers still attached to the programme, the Malawi team have clearly been successful in their non-formalised retention strategy. Volunteers are chosen by the local communities of which they themselves are members, and they feel proud to be engaged with a programme that is needed and has a clear clinical-led agenda. Volunteers recognised that it was helpful to be in a position to bring nurses into the community who could physically make a difference to the patient outcomes. However, like all programmes the tension between voluntary work because of vocation and altruism and the need for volunteers to make ends meet in their own family homes was a real issue. Also, as noted above, the lack of social support that volunteers could offer had a bearing on their commitment.

5.6 Communication and the use of mobile phones

Mobile phones have greatly aided access to and the delivery of timely palliative care services and advice in the community, and contributed to continuity of care and improved reassurance and support for patients and their relatives. Patients and their carers could phone or text to request a house visit or ask for information about what they needed to do, and this helped them to cope better at home with their patients. Volunteers could 'flash' their nurses (start a call ringing but not carry it through so that it did not cost anything) and they were reassured that the nurses would ring back as soon as they were able. Visits were arranged this way, instructions given and new patients identified.

6. CHALLENGES AND RECOMMENDATIONS

Summary: Resource constraints were one of the major challenges that the Malawi Home Based Palliative Care Charitable Trust programme faced. Staff and volunteers generously gave of their time and even their own money to care for patients. Volunteers provide the backbone of the programme and the programme faces the challenge of how best to care for, and recognise this essential group of workers, while also managing the new cadre of worker, the HBC assistant. Additional challenges included how to meet the needs of the wider community, particularly the number of children who require home-based care.

6.1 Cultural resistance

Seeking help from traditional healers was common and costly. When hospital curative services were unable to offer any further help, many families made use of traditional herbs and sought services from healers, often far afield. Palliative care, with its new approach to patients that does not see physical healing as the end point, but sees total care as the priority, is challenged by traditional beliefs about health and illness, and the approaches to healing advocated by traditional healers.

A number of patients and their families, as well as staff, talked about a commonly held view that illnesses were the result of witchcraft, the will of God or the consequence of behaviours for which there needed to be recompense. Working against this cultural belief was challenging and often exacerbated by the economic pressure that many families felt in caring for sick relatives.

6.2 Funding constraints

Many staff and volunteers mentioned the problem of transport for sick patients to the health centre or hospital. The programme currently provides only minimal funds for occasional public transport. However, seriously ill patients cannot reach public transport, but have to hire expensive private vehicles. The HBC team members hope that more financial support (or even an ambulance or other vehicle) can be dedicated to these needs. Alongside



transport problems, there is also a lack of funds for social support, particularly food gifts, and an abiding frustration, felt most acutely by volunteers, that they had to go empty handed into patients' homes. With the additional three-year grant received in July 2009, the programme has a steady source of income for the short term, although all staff recognise the difficulty of sustaining work and investing in long-term training and capacity-building solutions within the community when the long-term future of the programme remains uncertain.



6.3 Volunteer recognition

There was some tension between volunteers and paid staff, and volunteers wished that they could receive some monetary recognition for what they do. Patients were always grateful to see volunteers in their own homes. Volunteers were frustrated when their roles were not recognised by staff.

If you gave us identification badges, that would help when we accompany patients to the hospital. (FG volunteer)

We visit some patients who live very far from us. Could the project give us bicycles? We also need things like rain gear. (Limbe FG volunteer)

6.4 Coverage, personnel and training

Interviews with other government health professionals indicated that there were a large number of cancer patients who attended the Tianjani cancer clinic, who would have benefited from an effective home-based palliative care programme but who were not in receipt of it, although some patients were successfully referred.

A staff member at Limbe Health Centre explained that the Centre's team regularly saw children in need of additional home-based care support and no one was available to support these children in their own homes. The long lines of mothers and children attending the baby and child clinic were a major constituent of the queues in the morning. A community nurse also explained that the work of the clinic was frequently repetitive and involved fire fighting: feeding malnourished (frequently HIV-positive) children, who returned to their homes in the community only to be re-admitted a few weeks later with the same problems. There was no one looking after these children in the community.

A community nurse attached to the Limbe Health Centre suggested that there might be value in changing the order of how the HBC team delivered their services, arguing that the majority of those who attended the Limbe Health Centre and who would require additional follow-up from the team attended the clinic in the morning. This, however, was when the HBC team were on their home visits. In the afternoon when the team were in the office doing paperwork etc, there were very few people attending the clinics. We saw this at both Limbe and Bangwe when we had afternoon appointments and the clinics were reasonably quiet, in contrast to when we arrived at 8am to start work and the clinics were packed full of people.

Like all programmes there is a need to be constantly responsive to the often rapidly changing healthcare scene. The availability of ART within the community has significantly changed how HIV is understood, but also the patient trajectory. While ART has transformed the lives of many, there are multitudes more whose illness has not responded or who are not in receipt of therapy, and whose prognosis is death. The difficulty that the programme faced was identifying and managing the increasingly diverse client group.

Home visits by nurses are very valuable, although very time-consuming, and the programme staff are searching for other models of care. One attempt to use the nurses' time more efficiently is the very recent introduction of a 'static clinic', now starting to be held once a month in a community building in one area of Limbe. About 12-16 patients are seen in one day (a number which would require two to four days of home visits). The project staff feel the static clinic is working well so far, although it is only running for a small area. Bangwe staff said the majority of their patients are no longer bedridden, and almost all can walk a short distance. They would like to establish more static clinics, such as the one in a Limbe community building, to save staff time and allow them to cover new and unserved areas.



A new category of health worker, the Home Based Care (HBC) Assistant, was conceived and developed largely by The Malawi Home Based Palliative Care Charitable Trust programme. Several promising, young, English-literate community members have been trained to fill a niche between the nurses and the volunteers. The HBC assistants are paid employees, most of them living in the Bangwe or Limbe communities. Volunteers say they can phone the assistants (or flash them by cell phone) for advice or in emergencies.

The HBC assistants are trained and authorised to provide patients with top-up supplies of about 25 common medicines, none requiring prescriptions. They accompany nurses on home visits and sometimes complete visits or procedures after the nurse has left. In the project office, they work on records, stock up the nurse bags with drugs for the following day, and check the motorcycles. Some of the assistants also do counselling and testing for HIV (which none of the nurses are trained to do).

At the time of our field work (July 2009), this new cadre of health workers had not yet been recognised officially by the Ministry of Health. The Bangwe-Limbe programme directors believe that this cadre provides an excellent model of how to initiate and sustain clinical home-based care in the community. The assistants themselves felt that to improve the programme:

We need more assistants to extend to other areas.

The assistants described their role as multiple:

Carrying the nurses' bags, getting the motorbikes ready for the team, doing the paperwork, accompanying the nurses on their visits.

At the peak of the period of AIDS deaths at home, before ART became more freely available, the assistants travelled with the nurses to designated areas each day, and then saw patients separately as the patient load in each area was so huge. The assistants said that now they did not often see patients on their own but with the nurses.

The assistants spoke of the need for more opportunities. They wanted to go for nurse training and felt that this was an excellent stepping stone and preparation.

Not all comments, however, were positive toward the HBC assistants and their role. Some of the nursing staff explained that, if salary funds were limited, the role of assistant was less important than others. Community members remarked:

The assistants? They don't stay close to us. They just come once a week.
(Tess's carer)

Some HBC assistants look on us volunteers as inferiors, as ordinary members of the village. One even addresses me as "Hey, you!" – the way you would call a child. But the volunteers started this work first, even before the nurses! (FG volunteer)

On the basis of our short visit in Malawi, the evaluators do not presume to judge the effectiveness or appropriateness of the HBC assistants' role and performance. We simply note that varying opinions exist within the Bangwe and Limbe areas.

Everyone recognised the need and the value of training. Ongoing training was requested by all the volunteers, especially if the training was supported by a per diem, a small reimbursement or incentive to support the volunteers in their work. Retention of staff did not appear to be an issue, and staff spoke of being dedicated to their work and committed to the people whom they visited.

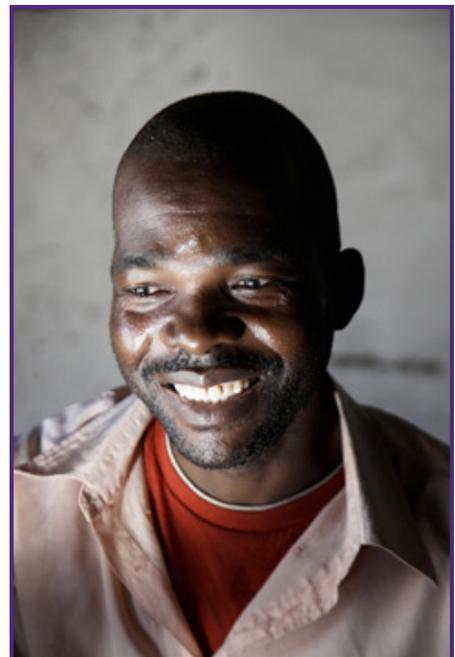
The skills of all staff were exceptional, given the circumstances that they worked in and the range of issues they addressed on a daily basis.

7. ILLUSTRATED PATIENT AND CARER STORIES

7.1 A father and a little boy caring for each other

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

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



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

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

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

If only my wife had told me when she knew she was HIV positive, my cancer might never have happened. We would have known what to do. My leg would never have swollen so big. I would never have lain for 3 years in pain, thinking I was dying. If only my wife had told me.



7.2 First the sister, now the brother

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

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

Ali started his story:

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

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

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

His mother added:

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

Ali continued:

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

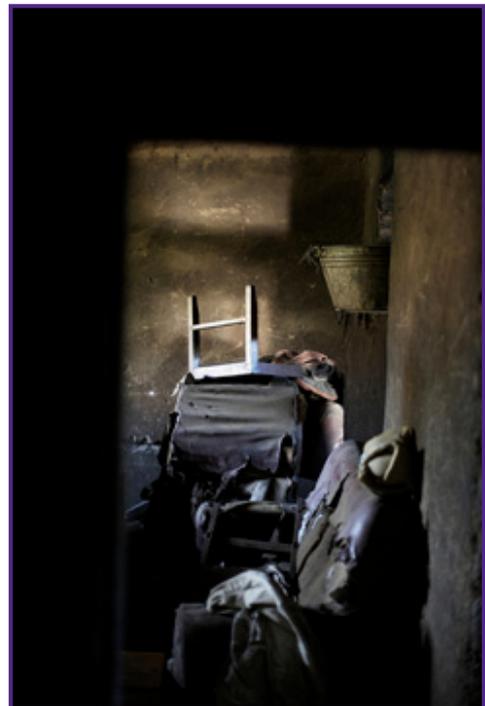
We asked Ali's mother if she had met her grandchildren:

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

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

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

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



Ali was readmitted to hospital earlier this month.

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

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

My biggest problem has been finding the food for Ali.

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

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

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

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

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

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

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

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

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

Then Ali told us of his bigger needs and plans:

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

7.3 If only she had told me

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

Aya began her story:

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



My daughter did not tell me ahead of time that she had HIV. She was discovered to have HIV when she went for antenatal care before the last baby was born, but she did not tell anyone. If only she had told me very early that she was HIV positive, maybe I could have helped. I know a lot about HIV, through village meetings and the radio. I could have taken some measures. But my daughter did not say anything. Perhaps she was shy or afraid to talk about it. I don't know.

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

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

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

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

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

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

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

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

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

Aya spoke softly:

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

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

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

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

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

Aya is hopeful that all the children will do well.

7.4 Almost unbearable

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



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

Zora's palm was rough when I shook her hand in greeting. Her face was blotched, and the soles of her feet were deep purple from medicine. As we talked with her through an interpreter, we learned that she had been living elsewhere, but had been brought here to live

near her relatives, so they could take care of her. One by one, Zora mentioned the people important in her life:

- Mary, 18, her younger sister, who lives nearby and takes care of her on a daily basis
- Her son Daniel, 9, who lives with her in this two-room house
- Her older brother, her “guardian”, who goes every month to distant Mulanji Mission Hospital to collect her ARV medicines
- The priest and elders from her Catholic church, who visit every month or two (or when she calls for them), sometimes bringing groceries or money, sometimes bringing the Mass
- Volunteers from the palliative care programme, who come every Wednesday with the nurse and HBC assistant. The volunteers often return another day of the week on their own, bringing a few groceries, and staying to sweep and mop and clear the bushes around the house.

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

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

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

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

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

Zora's eyes filled with tears.

I loved her so much.

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



7.5 A comfortable death at home

The account of an HBC volunteer:

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

Our patient Anna had a painful cancer, Kaposi's sarcoma, in front of her right ear. At Queen Elizabeth Hospital, they had told her that her disease was deadly and she would never get better. Anna understood that, but her family was in denial. Also people from her church were trying to encourage her by praying that she would be healed.

One Monday we visited her and gave her the regular supply of morphine. Then on Wednesday, Anna used her cell phone to "flash" me (signal me she needed to talk). When I called back, she told me she was vomiting. I called the nurse and together we went to Anna's house and gave her medicine to stop the vomiting. We advised her to eat only small amounts of food at a time, to prevent more vomiting. We went again that Friday. Anna's vomiting had stopped and she was more comfortable.



She died on Sunday, free of pain.

APPENDIX 1

PROJECT DOCUMENTS CONSULTED

- Bangwe Project Report, January 2004
- Bangwe Project Report, January 2005
- Limbe Programme Report, December 2006
- Report of training for Home-Based Care Assistants, January 2007
- Limbe Programme Report, June 2007
- Visit to Malawi by London based Palliative Care Initiative staff, October 2007
- Limbe Programme Report, December 2007
- Limbe Programme Report, June 2008
- One sheet description, produced by the Palliative Care Initiative, 2008
- Malawi teaching palliative care Joint Cross Party Group Meeting, Paper 6, 8 October 2008. www.palliativecarescotland.org.uk

APPENDIX 2

TABLE OF PERSONS INTERVIEWED

| People seen & interviewed | MALAWI Bangwe & Limbe peri-urban areas |
|--|---|
| Patients | 7 patients at home (observed 4 clinical encounters) 9 patients in 2 focus groups |
| Current home caregivers | 5 (daughter, wife, mother, sister, wife) |
| Bereaved caregivers | 1 (mother) |
| Volunteer (community) caregivers | 10 volunteers in 2 focus groups |
| Staff members of palliative care programme | Programme manager Programme advisor 4 nurses 5 Home-Based Care Assistants 2 support staff |
| Community leaders | Chair of community organisation Tigwirane Manja |
| Programme director | College of Medicine |
| Total | 47 people |

Independent translator for evaluation team: Yotam Kasakula, trained nurse

APPENDIX 3

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