MODELS OF DELIVERING PALLIATIVE CARE IN SUB-SAHARAN AFRICA

ADVOCACY SUMMARY

2012
The Palliative Care Initiative of The Diana, Princess of Wales Memorial Fund commissioned the University of Edinburgh and the University of Makerere, Uganda, to investigate different models for the delivery of palliative care in Kenya and Malawi. Data was analysed by the two universities.

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A full version of this report is also available on request from The Diana, Princess of Wales Memorial Fund. Please email memorial.fund@memfund.org.uk to request a copy.

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The Diana, Princess of Wales Memorial Fund continues the Princess’ humanitarian work in the UK and overseas. By giving grants to organisations, championing charitable causes, advocacy, campaigning and awareness raising, the Fund works to secure sustainable improvements in the lives of the most disadvantaged people in the UK and around the world.
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FOREWORD

The Diana, Princess of Wales Memorial Fund believes that palliative care should be an integral part of health care in Africa, accessible to all who need it. Much of the focus on improving healthcare in Africa is centred on strengthening national and community health systems and decentralising healthcare so that services are delivered close to the patient in their communities.

The approach of palliative care and the skills and experience of its practitioners can both strengthen and add value to national and local health systems. The case studies within this report provide specific examples of this and can be used to both inform discussions about the future role of palliative care within health systems and to provide evidence for advocacy.

The way palliative care is delivered exemplifies many of the skills, knowledge and attitudes necessary to improve and support health systems and patient care. The holistic, patient and family-centred approach of palliative care avoids the silo approach to disease treatment and ensures that all patient needs are captured and addressed. The skill of effectively managing pain and symptoms, combined with attention to psycho-social issues, improves the health status and well-being of patients across all domains.

Palliative care practitioners have specialist expertise in pain control and train healthcare staff at all levels in the identification and treatment of pain and related symptoms. This is not only crucial for the patient but enables them to be treated within their communities and helps avoid admissions and readmissions into hospital.

Palliative care in Africa is being developed as a public health, primary health care focused model. It has long experience of working within communities, utilises community capital through well-trained and incentivised volunteers and by empowering families to care for their sick relatives. Community palliative care models, where palliative care is integrated into home-based care programmes, demonstrate how through a holistic patient and family-centred approach, medical problems and related social issues are identified and addressed.

Palliative care has developed excellent referral systems to and from the community into health facilities that support a continuum of care. Furthermore, the way palliative care teams operate in multi-disciplinary teams, focusing on spreading skills and shared care, is increasingly acknowledged as an effective way of managing the care of patients.

The seven case studies in this report, all organisations funded by the Fund’s Palliative Care Initiative, show how palliative care is integrated into and relates to health systems in specialist, district hospital and community settings. As well as demonstrating how palliative care effectively strengthens and supports health systems, the report raises some of the challenges of integration. The examples are from Kenya and Malawi, but the approaches and skills demonstrated are common to palliative care in other African countries.

Olivia Dix
Head of the Palliative Care Initiative, The Diana, Princess of Wales Memorial Fund
INTRODUCTION

Palliative Care in Africa and The Diana, Princess of Wales Memorial Fund (the Fund)

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

Palliative care is part of the essential package of care for all people living with life limiting illnesses. In sub-Saharan Africa it has been developed with a specific remit for people living with HIV/AIDS and cancer, but is also needed for those with other chronic life-limiting illnesses such as end-stage organ failure.

Sub-Saharan Africa (SSA) is still the region worst affected globally by HIV/AIDS with increasing cancer rates and an increase in chronic conditions. Palliative care in sub-Saharan Africa has been increasing in profile over the past decade with 16 African countries having established national Palliative Care Associations (PCAs) as of April 2011, and a number of countries including palliative care in national plans and policies.

Seven case studies

This study was commissioned by the Fund to investigate different models for the delivery of palliative care in sub-Saharan Africa through a series of case studies. The objective of the study is to show how palliative care works with, adds value to and supports the health-care system by enhancing the care of people with life-limiting illnesses.

The term healthcare system refers to the way that a country organises people, institutions and resources to deliver healthcare services to meet the health needs of target populations. Healthcare systems in almost all African countries are fragile, under-resourced and have a tendency to focus on vertical health strands, which has channelled workforce skills and resources into disease silos.

This study considers seven different programmes in Kenya and Malawi. All these programmes are partner organisations of the Fund. The primary use of the study results will be for advocacy.

Models of palliative care delivery

To meet the challenge of providing palliative care in Kenya and Malawi, a variety of models for palliative care delivery have been developed, which include the following examples listed below.

All of these models can be found at specialist, district and primary care / community levels of the health system.

Specialist palliative care organisations
(eg. Umodzi, Queen Elizabeth Hospital, Malawi, Nairobi Hospice in Kenya, Ndi Moyo in Malawi)

Specialist services may be provided across the continuum of care at tertiary, secondary and primary levels of care. They also provide an element of leadership, training, mentorship and supervision.

Hospital-based palliative care teams
(eg. Kenyatta National Referral Hospital, Nairobi, Queen Elizabeth Central Hospital, Blantyre)

These teams provide specialist services within the hospital context and this is a model of palliative care delivery that is growing in the region. In Kenya, the Kenya Hospices and Palliative Care Association (KEHPCA) is working with the government to train teams in various regional hospitals and to increase access to palliative care services across the country. A network for hospital palliative care teams was set up at the APCA conference in Namibia in September 2010.
Inpatient services
(eg. St Gabriel’s Hospital, Malawi)
While the majority of palliative care in the region is provided in the home, or through hospital-based teams, inpatient services can provide care in particular for patients with difficult symptoms that cannot be brought under control in the home.

Home-based care
(eg. Chipini Palliative Care Programme, Malawi)
Much of palliative care provision in Kenya and Malawi occurs in the home. It may be provided through specialist palliative care teams that visit patients and support them in the home, or else through home-based care services provided by community volunteers and supported by palliative care staff. In Africa home-based care is a well established model of care provision within the context of HIV/AIDS.

Outreach services
Some palliative care providers have outreach services that support other organisations to provide palliative care, or provide roadside and mobile clinics. These services help to increase accessibility to palliative care service provision for those in rural and difficult to reach communities.

Methodology
This study employed the following methodology:

1. Desk review: a desk-based review and analysis of relevant documents was carried out for each country and for each model delivering palliative care.
2. Interviews and focus groups with stakeholders: Each of the seven programmes was visited. For each case study, programme staff, community, and local health leaders were interviewed. The interview schedule was based on the questions listed in the Terms of Reference (ToRs) for this study and included:
   a. How the model in question relates to the local health system.
   b. How well the model fits with, and adds value to the existing health system.
   c. The challenges of integrating palliative care in each setting.
   d. The advantages and disadvantages of providing palliative care in each setting.
   e. The types of adaptation team members made to ensure more effective operation of the programme.
   f. What can be learned / replicated from the programmes studied.
3. Data was also collected using a structured audit tool and through direct observations of service delivery.
4. A thematic data analysis was carried out responding to the study questions above (as listed in 2).

Purpose of this Advocacy Summary
This report is a summary version of the full report. It summarises and complements the full report which contains more detail under each of the thematic areas as well as study data in the appendices. The remainder of this report is structured as follows:

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<th>This section gives background to palliative care in Kenya and Malawi. It summarises some information from the desk review.</th>
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<td>This section includes a one-page summary on each of the seven programmes reviewed, highlighting how each is integrated into the health system.</td>
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BACKGROUND

This section contains a brief summary of palliative care provision in Kenya and Malawi.

Palliative care in Kenya

Kenya has a population of 38.8 million with an average life expectancy of 54 years. There are 80,000 AIDS-related and 22,000 cancer-related deaths in the country per annum. There is one doctor and 12 nurses per 10,000 of the population.

Palliative care services began in Kenya 20 years ago with the development of Nairobi Hospice. More hospices were established in the following years, and with the launch of the Kenya Hospice and Palliative Care Association (KEHPCA) in October 2004, service levels began to increase. The Government of Kenya is supportive of palliative care, and is working closely with KEHPCA to ensure that effective policies are in place and appropriate medicines and other resources are available. Training initiatives have included the development of a national palliative care training curriculum; the integration of palliative care into the medical and nursing curriculum; the provision of specialist training; and the use of essential medications, including morphine.

Despite these developments, coverage of palliative care provision remains stretched. However, as there is now strong leadership in palliative care, coupled with commitment from the Ministry of Health to support palliative care services, Kenya looks set to continue developing quality and access to palliative care services.

Palliative care services began in Malawi just over 10 years ago, through the provision of home based palliative care at the Lighthouse in Lilongwe. The Palliative Care Association of Malawi (PACAM) was formed in 2007. Since its launch there has been strong, dedicated leadership for palliative care in Malawi and strong support and leadership at the Ministry of Health through the office of home-based and palliative care. Oral morphine is listed as a vital drug in the Essential Health Package Medicines and Supplies List and has been provided free of charge since 2004. However, despite these developments, coverage for palliative care provision across the country remains poor in many parts, and access to essential medications can be challenging.

There has recently been an intensive sensitisation programme rolled out across Malawi with regards to pain management and the use of oral morphine in both adults and children. A five-day national palliative care accredited training curriculum has been used to train more than 700 health professionals since 2007 and palliative care has been incorporated into the undergraduate medical curriculum. More recently Malawi has published National Palliative Care Guidelines (Ministry of Health, March 2011).

Palliative Care in Malawi

Malawi has a population of 14.8 million with an average life expectancy of 53 years. There are 51,000 AIDS-related and 11,000 cancer-related deaths in the country per annum. There are less than 0.5 doctors and 3 nurses per 10,000 of the population.
CASE STUDY 1: UMODZI PAEDIATRIC PALLIATIVE CARE SERVICE

Model: SPECIALIST
Sector: GOVERNMENT

Staffing:
- 1 PART-TIME DOCTOR
- 1 TEAM LEADER/CLINICAL OFFICER
- 2 NURSES
- 1 PLAY LEADER

Approximate Caseload: 30 CHILDREN PER MONTH

Setting
Umodzi is located within Queen Elizabeth Hospital (QEH) in Blantyre, the national regional referral hospital in Malawi, and as such, it accepts referrals from all of Malawi. It is the only formal paediatric palliative care service in Malawi.

Service
Umodzi provides inpatient care and home-based care. It does not have allocated inpatient beds and contributes to a continuum of care rather than functioning as a stand-alone service. The team provide counselling and support for children and families, pain relief and symptom control, nutritional support and bereavement support.

How well does this model fit with, and add value to the existing health system?
Umodzi’s service has been designed to be fully integrated with the rest of the hospital. Specific features facilitating integration include:

- **Joint management of patients with other wards (normally oncology).**

- **Expert advice, clinical supervision, and role clarity:** Umodzi acts as the conduit for palliative care skills and knowledge at QEH. Umodzi staff have clearly identified work roles, and regular structured ward rounds and meetings through which they provide clinical supervision and support. Umodzi’s leadership have also identified the need to integrate clinical supervision and support into daily activities.

- **Structured referral process:** All ward staff are encouraged to refer patients to the Umodzi team using a referral form developed in-house. A clear and properly implemented referral process is regarded by the team as an essential component of care.

- **Organisational links:** Umodzi has built close links with other expert organisations such as the Palliative Care Association of Malawi (PACAM), and has provided input into national guidelines for children’s palliative care.

- **Multi-organisational integration:** Umodzi has a new integrated service between adult and children’s services through linking Umodzi with another adult palliative care programme called Tiyanjane. This type of linkage provides an excellent template for other programmes, demonstrating the importance of working together to maximise the voice of palliative care and of creating synergies which respond to patient need.

- **Training and capacity building:** Umodzi carries out a significant amount of training including for family members, other hospital staff, palliative care clinicians throughout Malawi and students, in collaboration with the Palliative Care Association of Malawi.

What are the key challenges of integrating palliative care in this setting?

**Burden of disease:** As a tertiary health centre, children are often very sick and unlikely to return alive after discharge. This creates a lot of pressure on health workers.

**Lack of professional network across Malawi:** The level of palliative care services available in most regions is negligible.

**Capacity:** There is a growing demand for services, but limited resources to provide them.
**CASE STUDY 2:** PALLIATIVE CARE UNIT, KENYATTA NATIONAL HOSPITAL, NAIROBI, KENYA

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<th>Model:</th>
<th>Sector:</th>
<th>Staffing:</th>
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| SPECIALIST | GOVERNMENT | ✓ 1 PART-TIME DOCTOR
✓ 3 NURSING STAFF |

**Setting**
The Palliative Care Unit is based within Kenyatta National Hospital, Kenya’s national tertiary referral hospital in Nairobi, and receives patients from across Kenya. The hospital also services the local Nairobi community.

**Service**
The unit provides palliative care services for all patients within the hospital and acts as a gateway for Nairobi Hospice, which is based in the vicinity of the hospital. Services provided by the unit include counselling and support, adherence support, pain relief and symptom control. It does not provide wound management, and bereavement support is limited. The unit is doctor led, although the majority of routine care is carried out by the nursing staff. The unit has no beds, so its patients are seen on other wards.

**How well does this model fit with, and add value to the existing health system?**
As a central unit spanning the whole hospital, the unit’s strategy has been to define the boundaries of palliative care clearly and work to ensure the most equitable coverage. Specific features facilitating integration include:

- **Shared responsibility for care:** Shared care provides a strong marker for the integration of the palliative service into the existing health service structure.
- **Provision of expert advice:** Regular weekly staff meetings are held for all staff to discuss the ongoing patient caseload and to advise other staff on care.
- **Structured referral processes:** Centralised referral forms have been developed so that all staff across the hospital can refer to or contact the Palliative Care Unit. The referral process includes patient discharge records to provide evidence of continuity of care, including a strategy for ongoing management of illness, as well as referral letters to healthcare facilities near patients’ homes.
- **Training and capacity building:** Training is embedded within the practice of the unit. Twice weekly continuing medical education is held for all hospital staff (based in the Radio-Oncology unit). Additionally the unit provides ‘Expert Training’ days on the general principles of palliative care. It also provides a rotation for University of Nairobi medical students and teaches components of the post graduate Masters in Medicine (MMEd) training thus helping to embed palliative care in the national medical curriculum.

**What are the key challenges of integrating palliative care in this setting?**

**Policy and culture within the hospital:**
There is a culture in the hospital of viewing the patient trajectory as linear. While the care load is initially shared, once patients have all their care consigned to the palliative care team it can be difficult to return care back to the staff on the admitting ward.

The current hospital policy is not to admit patients onto the clinical wards unless there is an active management issue, eg. a surgical intervention, which means that not all patients who require palliative care receive it.
CASE STUDY 3: PALLIATIVE CARE UNIT, ST. GABRIEL’S HOSPITAL, LILONGWE, MALAWI

Model: DISTRICT
Sector: FAITH-BASED HEALTHCARE PROVIDER

Staffing:
- ✓ 3 NURSES
- ✓ 2 DOCTORS
- ✓ 10 NURSING ASSISTANTS
- ✓ 1 PASTOR

Approximate Caseload:
SIX MONTH JUNE – DECEMBER 2010:
93 INPATIENT ADMISSIONS

Setting
St Gabriel’s Hospital is a small faith-based hospital, an hour from Lilongwe in Malawi near the border with Zambia and Mozambique. The hospital has 250 beds. The palliative care inpatient unit is located within the hospital and has 16 beds. The catchment area is largely home to poor subsistence farmers, and has high HIV prevalence.

Service
Patients are seen in both the outpatient department (OPD) and as inpatients. Patients are admitted to the inpatient unit through OPD assessments. The service includes patient and family counselling and support, and pain management. The hospital also operates a home-based care service.

How well does this model fit with, and add value to the existing health system?
Specific features facilitating integration include:

- **Provision of expert advice:** Team members visit patients on other wards who are being looked after by other clinicians and provide advice and guidance. The two medical doctors work across the palliative care department and the main hospital wards.

- **Joint management (for outpatients only):** While the palliative care inpatient unit functions as a stand-alone service, palliative care patients are seen in the regular hospital outpatient clinic system rather than in a separate palliative care outpatient clinic.

- **Structured referral processes:** St Gabriel’s Palliative Care Unit has connected the hospital and the community by putting in place clearly articulated patient pathways which patients, clinicians, other social and health services and families understand. The criteria for admission are based on principles which prioritise community care, but recognise the different stages in illness and the capacity of families and carers to manage illness in community settings.

- **Use of community volunteers:** St Gabriel’s palliative care team/unit has established a presence in the community by training and supporting around 140 volunteers who each see four to five patients weekly.

- **Use of tools and technology:** Community volunteers use a screening tool to divide patients into three categories depending on their stage of illness and mobility. Using this tool has provided volunteers with a structure for decision-making and patients with a more structured, purposeful care programme.

What are the key challenges of integrating palliative care in this setting?
**Management of staff time:** The team have identified the need to develop more effective and efficient time management systems. Currently, few staff members measure or chart their use of time against identifiable and measureable outputs.
CASE STUDY 4: NYAHURURU HOSPICE, NYAHURURU DISTRICT HOSPITAL, LAIKIPIA DISTRICT, CENTRAL KENYA

Model: DISTRICT
Sector: MINISTRY OF HEALTH / COMMUNITY (NGO)
Staffing: ✓ 1 NURSE

Approximate Caseload: 23 - 30 ACTIVE PATIENTS AT ANY ONE TIME

Setting
Nyahururu Hospice was set up as a satellite hospice to Nyeri Hospice approximately 100km away. It is situated in one room of Nyahururu District Hospital, a Ministry of Health facility. Its only staff member is a Ministry of Health nurse seconded from the hospital to deliver palliative care. It serves a population of 50-70,000, many of whom are poor and living in rural villages outside the main towns.

Service
The services that the hospice provides include pain relief and symptom control, nutritional support and bereavement support. The hospice is located within, and is an integral part of, the HIV Comprehensive Care Centre (CCC) and sees HIV patients from the CCC, cancer patients from other parts of the hospital, patients in the outpatient clinics and patients in the community on afternoon home visits.

How well does this model fit with, and add value to the existing health system?
The model, by being part of a hospital structure, serviced by Ministry of Health staff, allows for a level of integration while also keeping a separate identity. Despite being the only staff member, the hospice nurse has been able to embed palliative care skills into the healthcare system through informal skills sharing on a daily basis with other non-palliative care staff and with patients and their families. There is a spirit of reciprocity between the hospice nurse and the CCC staff, who support and provide cover for each other. Other features supporting integration include:

- Use of community volunteers: There is a planned and structured formal volunteer training for the 70 plus volunteers on a quarterly basis. This has strengthened the whole of the local health service provision, created a much more stable environment for patients, and provided valuable support for relatives, enabling them to carry out their tasks of caring with confidence.

- Use of tools and technology: Using mobile phones to keep in touch with volunteers and provide expert advice has maximised the hospice’s reach to patients.

What are the key challenges of integrating palliative care in this setting?
- Capacity levels: While limited staff resource is an issue, the hospice is addressing this by integrating the hospice within the health system and utilising the health system resources as described above.

- Historical association between HIV and palliative care: At Nyahururu Hospice there is a strong association between HIV and palliative care, because of the hospice’s proximity to the HIV Comprehensive Care Centre (CCC) and the ongoing efforts of the CCC to care for those dying with HIV. The hospice has identified a growing need to establish a more structured, inclusive system of care for all patients with chronic life threatening illnesses, and to embed this into the hospital system.
CASE STUDY 5: CHOGORIA PALLIATIVE CARE PROGRAMME, CHOGORIA MISSION HOSPITAL, EASTERN KENYA

**Model:** DISTRICT  
**Sector:** FAITH-BASED HEALTHCARE PROVIDER  
**Staffing:** ✓ 4 PLUS 1 DIRECTOR

**Approximate Caseload:**  
AS OF 12TH OCT 2010, 344 PATIENTS REGISTERED

**Setting**
Chogoria Palliative Care Programme (CPCP) is based at Chogoria Mission Hospital, approximately 180km north of Nairobi. The hospital has a catchment area of 500,000 people, many of whom live in severe poverty on the dry, barren Tharaka lands below the hospital or in the tiny villages on the slopes of Mount Kenya.

**Service**
Care is provided through a mix of services: inpatient, outpatients, home visits and quarterly on-site day care for community patients. The Chogoria Palliative Care Programme does not have any dedicated inpatient beds. The team consult across all wards, visiting registered patients and identifying new patients. Services include counselling and support for patients and their families, pain relief and symptom control, adherence support for treatment, nutritional support and bereavement support.

Unlike many other palliative care programmes only about 7% of patients in the programme have HIV. This reflects past practice and the current hospital structure where funding has supported a separate HIV unit.

**How well does this model fit with, and add value to the existing health system?**
The team is integrated within the hospital, and is regarded as owned by the hospital and not as a separate entity. Other features supporting integration are:

**Multi-organisational integration:** The programme has an established relationship with the local government hospital, Chuka Hospital, and the team make regular visits to provide palliative care services to inpatients there. The programme has recognised the huge value of the spiritual support that non-health organisations such as the church provide, and the importance of their contribution to a more holistic care package.

**Referral processes:** A nascent referral system is in place that allows staff from other wards to contact the team by phone to make referrals.

**Use of tools and technology:** Patients, families, volunteers, and staff all use mobile phones to share information, seek help and find support.

**Investing in the workforce:** Staff support is provided for the team through therapy sessions in Meru at the Kenya Institute of Psychology and Counselling, and at annual staff retreats. They also support each other informally as a team.

**Use of community volunteers:** The programme has successfully established its presence in the community through the engagement of community members. Approximately 600 volunteers have been trained to identify patients, provide basic care at home, and act as a link worker between the community and the team.

**What are the key challenges of integrating palliative care in this setting?**

**Lack of resources:** Access to resources in the hospital can be a challenge, in particular to hospital vehicles for transport to home visits.

**High volunteer turnover:** Volunteers do not receive any funding for providing care to patients in their homes. This has caused friction within the team and made the retention of volunteers difficult. Of the 600 volunteers trained, only 100 are still serving.

Separate funding streams for the HIV and palliative care work can make full integration difficult.
CASE STUDY 6: CHIPINI PALLIATIVE CARE PROGRAMME, CHIPINI HEALTH CENTRE, CHIPINI, MALAWI

Model: DISTRICT
Sector: FAITH-BASED HEALTHCARE PROVIDER

Staffing:
✓ DOCTOR
✓ 1 NURSE
✓ 140 VOLUNTEERS

Approximate Caseload:
114 PATIENTS REGISTERED ONTO HBC IN 2009

Setting
Chipini is a rural region in the southern part of Malawi, 55kms from Blantyre. The Chipini Health Centre (CHC) was opened in 1990 by the Medical Missionaries of Mary. The nearest government health facilities are about 15km away. CHC aims to increase access to quality health services for the community within the 76 villages of Chipini. Chipini Palliative Care Programme (CPCP) operates as part of CHC.

Service
CPCP is a community-based service with no inpatient beds. Patients are seen at home, or at the weekly on-site palliative care clinic. Patients include those with HIV, TB, cancer, the physically disabled, and the elderly and weak. Services offered include counselling and support for patients and their families, pain relief and symptom control, nutritional support (as part of a wider feeding programme for poor communities), bereavement support and herbal remedies.

How well does this model fit with, and add value to the existing health system?
Due to its remote location, Chipini is less integrated into the formal national and district health system than other programmes in this report. Where it has been particularly successful, however, is at linking into the local informal health systems in the community. Specific features supporting integration include the following:

Use of community volunteers: CPCP have an excellent model of using a network of community members to deliver care, underpinned by a governance structure which splits volunteers into seven groups, each with separate geographical coverage. In this structure, there is a system for clinical support and peer support at both cluster and overall levels. Volunteers feel involved, have responsibility and autonomy in their decision making, and have clear remits.

Training and capacity building: Community volunteers receive comprehensive training in palliative care with special emphasis on the assessment of pain. Volunteers also receive training on traditional herbal remedies. The palliative care team also meet regularly with the staff of the HIV/AIDS programme to share good practice, minimise duplication of work, and ensure good communication and care.

Advocacy: Through working so closely with the community, Chipini have been successful in emphasising the importance of continuity of care, and breaking down the traditional view that healthcare should take place in either the homestead or the hospital, but not both. In an under-resourced health system, this is a key feature for health systems strengthening.

What are the key challenges of integrating palliative care in this setting?
Geographical remoteness: Like many other community-based models, Chipini’s geographical remoteness and independence from other healthcare institutions has the potential to leave it isolated within the formal healthcare system with only fragile links to other services.
CASE STUDY 7: THE COLLEGE OF MEDICINE HOME BASED CARE PROJECT, BLANTYRE, MALAWI

Model: COMMUNITY
Sector: NON-GOVERNMENTAL ORGANISATION (NGO)

Staffing:
✓ 6 NURSES
✓ 6 HOME BASED CARE ASSISTANTS
✓ 1 DATA MANAGER
✓ 90 VOLUNTEERS

Approximate Caseload:
40 PATIENTS PER MONTH

Setting
The College of Medicine Home Based Care Project operates in the Bangwe and Limbe regions of Blantyre, Malawi, both areas of high HIV/AIDS prevalence. Many patients have AIDS-related cancers, or severe pain due to cryptococcal meningitis and neuropathies. The programme was established as a stand-alone service in response to need in the community, and now works out of two government health centres.

Service
The services provided include voluntary counselling and testing, anti-retroviral therapy (ART) adherence support, free basic medications, catheter care and wound care. The programme also accesses nutritional support and income generation support through links with other local organisations. Patients are seen in their own homes. Pain relief and symptom control, counselling and support are also provided.

How well does this model fit with, and add value to the existing health system?
The College of Medicine Home Based Care Project is integrated both within the formal and informal health systems. Built on the principles of primary healthcare, it is an excellent model, which works effectively with the government health system and in collaboration with the community.

Empowering families and carers: Considerable investment is made by the team to help patients understand the nature of their illnesses and to educate patients and their families on palliative treatment.

Creation of new cadre of health worker: In order to address its shortage of staff, the programme developed a new cadre of practitioner, the Home Based Care Nurse Assistant, whose clinical expertise was beyond that of volunteers, but not as advanced as that of the nursing staff. By task-sharing and shifting, the programme has been able to greatly extend its reach into the community.

Use of community volunteers: MHBCP operates using a network of community volunteers who support the nurses and the Home Based Care Nurse Assistants.

Structured referral process: Trained volunteers identify patients and jointly assess them at home with a nurse, using a structured assessment tool. The tool enables staff to identify those with complex problems, and facilitates patient referral to other organisations for social or nutritional support. The patient assessments are held within the MoH system used in the supporting clinics.

Investing in training: All staff receive training on a regular basis and training programmes are built around developing complementary strengths within the multi-disciplinary team. As the service functions out of two sites, the programme teams meet together once a month to discuss business and offer support to each other.

What are the key challenges of integrating palliative care in this setting?
Sustainability of the model: the role of Home-Based Care Assistants has not yet been recognised by the Ministry of Health.

Multiple health providers: Staff must manage patients who have multiple providers across the health sector.

Lack of capacity: The service covers a wide and often remote geographical area with limited staff, and staff have a heavy workload.

Endemic poverty: Patients’ non-clinical needs, especially relating to poverty and nutrition can place an extra burden on staff and the service.
This section of the report provides a summary of the key themes arising against each of the questions identified in the terms of reference for this study (see the methodology on page 4 for a brief synopsis).

Integration with health systems: model characteristics

Across the seven programmes studied, the following common features were identified as key to success in integrating palliative care services into wider public health systems.

• Structured referral process: All models had a process for referrals.

• Patient focus: All the models had a focus on the patient and family, the final layer in the health system and ultimate beneficiary.

• Training: Most models had invested in training and building the capacity of their own team, other health workers and community workers.

• Location: Many of the models were physically located within the local / national health system (eg. in a hospital building) and used Ministry of Health systems and resources.

• Joint management: Many models jointly managed patients with other organisations, or with other units within the same organisation.

• Expert advice: In many of the models, team members provided expert advice to others within the health system.

• Embedded in the community: Some models, particularly community-level models, were very well integrated with the informal health sector, ie. the carers and social structures within the community.

• Multi-disciplinary teams: Many of the models operated using a multi-disciplinary team of workers from across the health system.

The added value to health systems

How well does the model fit with, and add value to the existing health system?

All of the programmes studied for this report are adding value to the existing health system in various ways. The following key value-additions were identified in this study:

• Advocacy: Highly visible services, particularly the specialist services, function as national champions / exemplars of palliative care within the health system. The organisations operating at a community level strengthen community understanding of holistic care and send out a strong message that clinical care can be delivered at home as well as at a public health facility. All organisations which build relationships and establish collaborations provide important signposting through the health system of the value of palliative care.

• Access to essential medicines: Specialist hospital-based programmes are in a position to advocate for a regular supply of palliative medicines, and this in turn increases access throughout the system.

• Dignity and respect for the patient: The culture of dignity and respect for the patient, inherent in palliative care, is being spread through the health system by example.

• Improvements in referral processes: Most programmes are helping to improve their local health system’s referral processes. Specialist programmes have improved the patient pathway from hospitals to the community, and created documentation to streamline care, including referral forms, discharge planners and
patient reports. District level programmes have developed referral and discharge forms, which have added to existing health service procedures. The use by community programmes of volunteers for assessment and referral has created new patient pathways from the community into formal health services.

- **Expert advice:** Many of the programmes provided expert advice in palliative care to other health providers throughout the system.

- **Consistency of care:** Many programmes have built patient / public confidence in the health system. Palliative care patients understand that their care is ongoing, rather than a treatment / cure / discharge type of care. This is facilitated by process-driven care (e.g. regular ward rounds, home visits, phone calls).

- **Increased capacity:** Many of the programmes have used innovative methods to increase the capacity within the health system.

**Integration challenges**

*What are the key challenges of integrating palliative care in each setting?*

- **Capacity:** Virtually all teams are lack capacity. Specialist teams in particular are in demand to help at all levels, national, regional and district, for example to develop guidelines and provide training.

- **Balancing service delivery with capacity building:** Specialist and District models find it difficult to achieve a balance between advocacy, training and service development and their limited capacity to deliver existing services. Nyahururu Hospice, for example, already knows how it could fill gaps in service delivery at a district level through training and service development, but does not have the resources to implement this.

- **Working within existing systems:** While this is key to ensuring integration, it also brings challenges. These include: systems which view patient trajectories as linear; policies which make it difficult to access patients with palliative care needs, unless they require another intervention; government job descriptions, which lack sufficient flexibility to allow for the holistic nature of palliative care.

- **Late presentation:** Late presentation occurs due to lack of resources and knowledge at both community and health centre level.

- **Staff retention:** Retention of staff, particular of volunteers, is a problem in some models.

- **Natural crises:** Rural programmes are often affected severely by natural crises such as flooding. Specialist hospitals, as the final referral point, are also affected.

- **Rising fuel costs:** This is a challenge particularly for home-based care programmes, which rely on transport to visit patients.

- **Cultural traditions and beliefs:** These can often be stronger in rural settings for example the belief in spirits and witchcraft as causes of illness.

- **Power and authority of traditional leaders in the community:** While sometimes a challenge for community-based models, it can become a strength when community leaders are supportive of palliative care.

- **Multiple care providers:** This is a challenge especially at district level, and creates an additional incentive to co-ordinate with other providers to avoid gaps or duplication, and a perceived burden on patients and families to attend multiple centres for different components of care.
Adaptation and innovation strategies

What have team members done to make the programme work more effectively? What have team members seen patients and relatives do to make the programme work more effectively for them?

The programmes reviewed in this study demonstrate considerable skill in adapting to their local environment and developing innovative responses to overcome the challenges of delivering palliative care services in resource-stretched settings. Strategies include:

Training and building the capacity of healthcare professionals and allied professionals across the whole health system from government clinics to NGOs.

Working with partners whose remit is not health but rather faith, business, food or farming, has increased provision of holistic palliative care in many of the models studied.

Establishing flexible staffing so that staff can cover each other’s roles as needed, and establishing a team whose members have specific roles within the palliative care service, but who also have other roles within the wider hospital or clinic.

Training and maintaining community volunteers is a strategy used by District and Community models. Each programme varies, giving volunteers different levels of support and responsibilities.

Training relatives as caregivers was a strategy used across the models.

Creating a new cadre of health worker to bridge the gap between health professionals and community workers, and, through task shifting between cadres, creating capacity for delivery of care.

Creating opportunities for internships both for in-country and international trainees.

Introducing time management systems to facilitate prioritisation, task-shifting and most effective use of resources.

Use of mobile phones is increasingly becoming essential to ensure effective patient pathways and follow-up.

Use of motorbikes as transport is a strategy used in particular by community models to reach remote areas and significantly reduce transport costs.

Further learning points

What can be learned from these models and what programme features could be replicated more widely?

A number of lessons learned, and programme features that could be replicated in other models are identified on page 24 (The added value to health systems) and on page 27 (Adaptation and innovation strategies). Additional points which are not fully covered in those sections are listed below.

- Importance of national training: Many programmes highlighted the value of palliative care training at district level, noting that when district staff were supported to manage end stage illness, they were less likely to refer unnecessarily, or refer too late to make a difference, therefore saving the patient, families and hospitals unnecessary expense.

- Importance of health system: Specialist services noted that one of the constant dangers of all health services is to see individual services as stand-alone entities, failing to see that a service is only as strong as the system in which it sits.

- Need for regular supervision and support: Specialist models identified a need to provide regular supervision and support for generalist health professionals providing palliative care. District and community models identified a need to support volunteers to ensure retention.
• **Confidence building:** Staff in the specialist units noted the need to build confidence among community and district staff that although diseases may present differently, the palliative care needs of patients were often very similar and could be managed by generalist staff.

**Model advantages and disadvantages**

*What are the advantages and disadvantages of providing palliative care in each programme’s specific setting and site?*

**Specialist models**

**Advantages**

Palliative care services in specialist units are staffed by highly qualified health professionals who provide expert leadership for palliative care nationally. These programmes can offer an ongoing practical site for training and clinical placements, and contribute to policy development and national guidelines. They can also establish new areas of work at a national level. For example, the recognition of the need for more comprehensive children’s palliative care services in Malawi is as a result of the work of the specialist service at Umodzi.

**Disadvantages**

Specialist models are frequently working at the centre of their country’s health crises, responding to a heavy disease burden. By their nature, they are less able to tap into community resources than district or community models.

**District models**

**Advantages**

By marrying hospital-based inpatient care with home-based care visits, the district model cuts across the hospital / community divide, and creates more accessible pathways for patients to enter and leave the formal health system. By engaging with communities, the programmes strengthen the acceptance that holistic care, including clinical care, can be delivered outside of the hospital buildings by hospital and community staff working together.

**Disadvantages**

The multiple roles required of a district hospital palliative care team often means that staff find themselves working in isolation rather than as part of a larger team. They may not always have a multi-disciplinary team to work with, especially if the team must divide their time between home visits, static clinics, outpatient care and inpatient care. Many of the teams studied in this review have formed partnerships with non-palliative providers, or built up their volunteer network to help manage the disparity between workload and resources.

**Community models**

**Advantages**

Community models strengthen the evidence that holistic care can be delivered outside a clinic and create new pathways from the community into formal health services. They make use of a range of community resources to do this.

**Disadvantages**

The community models reviewed in this study had less access to specialist staff, drugs and equipment than either district or specialist models, and needed to find innovative ways to deal with this.